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Music-caring within the framework of early intervention

The lived experience of a group of mothers of young children with special needs, participating in a music therapy group

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Publication date:
2011

Document Version
Tidlig version også kaldet pre-print

[Link to publication from Aalborg University](#)

Citation for published version (APA):

Jonsdottir, V. (2011). *Music-caring within the framework of early intervention: The lived experience of a group of mothers of young children with special needs, participating in a music therapy group.*

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Music-caring within the framework of early intervention

**The lived experience of a group of mothers of young children with
special needs, participating in a music therapy group**

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Dissertation submitted for the degree of Doctor of Philosophy

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Professor Even Ruud PhD
Associate Professor Gro Trondalen PhD**

**Department of Communication and Psychology, Faculty of Humanities
Aalborg University, Denmark
2011**



The picture on the cover is of a music box that the mothers gave the therapist/researcher upon the completion of the music-caring sessions. For the therapist/researcher, this music box, which plays a traditional Icelandic lullaby, is symbolic in different ways. It is a symbol of the metaphorical braiding that took place during the research journey. It also represents the seven mothers who participated in the music-caring sessions and all the musicking they engaged in. Because the music box rotates, it is also symbolic of the interpretive phenomenological framework that anchored this research.

DECLARATION

I confirm that this thesis and the research it publicizes has not previously, in part or in its entirety, been submitted for examination at an academic institution of higher education in Denmark or abroad.

Valgerður Jónsdóttir

ABSTRACT

Despite developments in the field of early intervention, and an increase in the variety of available services and number of specialists equipped to assist, the needs of caretakers of children with disabilities in times of crisis have not received enough attention. It seems that too often caretakers themselves get lost in the role given to them as their infants' best specialists, and in the emphasis which is placed on their children's developmental milestones. The caretakers and the potential psychological distress they experience having a disabled child are more often than not the forgotten component in the existing support and treatment schemes.

This focused the author's attention on the idea that parents of disabled children could benefit from music therapy. Thus a hermeneutic phenomenological research was designed which focused on the lived experience of a group of mothers of young children with special needs participating in a music therapy group introduced as music-caring. Seven mothers participated in the research. The central music-caring phase encompassed ten 90-minute to two-hour consecutive weekly sessions. Songwriting was used as a process and a central method of musicking in the group. The notion of music-caring and the mothers' lived experience of it was the focus of this study. Music-caring was initially defined as an empathetic and emotionally supportive relationship that an act of musicking brings into existence.

The empirical material consisted of one semi-structured group interview, one individual semi-structured interview with each mother, participant observations and artefacts. The mothers related their experience in the music-caring group to eight core categories: the group, musicking, songwriting, the CD, the therapist, me and my time, process-change, and the diary. In the empirical explorations the different themes in the core categories were discussed from the following perspectives: Stern's motherhood constellation, group dynamics and processes, the concept of empathy, positive psychology, play, and the helping relationship, developmentally-informed theories, musicking as defined by Small, the concepts of affordance and appropriation as presented by DeNora, theories on quality of life, reflection on music and emotion, emotional creativity, Yalom's notion of a structured exercise, Csikszentmihalyi's theory on flow, some speculations on the personal and the social self and the formation of self-identity, empowerment, and a common factors approach.

The mothers' experiences in the group supports the idea that musicking in a caring context can build empathetic and supportive relationships, which facilitates and deepens emotional expression, conducive to other empowerment type benefits.

ACKNOWLEDGEMENTS

First and foremost I would like to thank my supervisors, Professor Even Ruud and Associate Professor Gro Trondalen, who encouraged me to pursue this learning experience. Always present when called upon, they supportively shared their knowledge and guided me onwards while allowing me the freedom to progress at my own pace and ability from start to finish.

I would also like to thank the most efficient music therapy faculty at Aalborg University. In particular, Professor Tony Wigram for organizing inspiring and exciting PhD courses that always managed to invigorate. Despite the enormous amount of work involved in organizing these courses, he expressed genuine interest in our diverse studies and in the most humane way oversaw that everything ran smoothly. Even the music was there in the early morning hours, setting the tone for the day. I thank all the lecturers in the programme for sharing their expertise, thoughts and ideas. I also thank my fellow students who encouraged and supported me in the friendliest way.

I thank my dear friend Dr. Lilja Ósk Úlfarsdóttir, a music therapist and a psychologist who read my thesis and asked some important clarifying questions. My clinical supervisor, psychologist Ragnheiður Indriðadóttir, who guided me, empathetically supported me and encouraged me. I thank Dr. Tryggvi Sigurðsson, who lent his name to the research as a guarantor of it. I thank the center Sjónarhóll, which gave me a letter of support. I also thank my physiotherapist, Ágúst Jørgensen, who caringly softened pain, allowing some more hours at the desk. I also thank my proofreader, Eliza Reid, and Ruth Bejder, my Danish translator, for their conscientious work.

I gratefully acknowledge all my former and current clients who have shared precious moments with me, taught me to appreciate my profession and how to use music in a caring way. I also thank the board members of Tónstofan's parent association: Gerður Steinþórsdóttir, Gunnhildur Gísladóttir, Rut Ríkey Tryggvadóttir, Sólborg Bjarnadóttir and Þorleifur Hauksson, who for the past ten years have in various ways faithfully supported me and the work carried out at Tónstofan.

Finally, with deep gratitude I thank the seven exceptional women who, with genuine interest and devotion, participated in this research. I consider myself very lucky to have been a participant observer in the first music-caring group, learning about their lived experience and how they defined music-caring.

DEDICATION

I dedicate this work to Erla Elíasdóttir and Jón Ragnar Einarsson, my dear parents who in so many caring ways have supported me throughout my life. I also dedicate this work to my dear children, Jón Emil Guðmundsson and Álfheiður Erla Guðmundsdóttir who have taught me what life is all about.

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PART I

INTRODUCTION OF THE CONTEXT OF THE RESEARCH STUDY

Part I of this thesis establishes the rationale of the research study by contextualizing it within both the researcher's personal experience and a professional framework. Part I also introduces the clinical population and situates the study within the context of early intervention and the disciplinary context of music therapy in Iceland, where the research was implemented. This context, as introduced in Part I, provided the researcher with her initial focus for the study, presented in this dissertation as problem formulation or research questions. Having formulated the research questions, the research methodology is presented, outlining the method of data collection and analysis, the stance of the researcher as a participant observer, and some ethical guidelines and considerations. Part I concludes with an overview of the thesis.

CHAPTER 1

A PRELIMINARY DESCRIPTION OF THE RESEARCH STUDY AND AN INTRODUCTION OF THE RESEARCH CONTEXT

In a speech at the Tenth World Congress of Music Therapy in Oxford, England in July 2002 the keynote speaker, Sir Michael Mayne, talked about the challenge we face when balancing our ‘outer journey landscape’ and our ‘inner journey landscape’, or the visible landmarks of our work and what we hope for and believe in. Sir Michael’s words made a deep impression on me and were thought provoking at a time in my life when I had been a music therapy clinician for more than fifteen years and was slowly approaching the unfamiliar world of music therapy research. I realized that I carried with me certain beliefs and needs and that I had certain hopes based on the landmarks of my past clinical work. I was interested in undertaking a research that would serve me as a music therapist, music therapy as a profession in Iceland, and, most importantly, the chosen clientele. My interest touched upon three different existential realities, three different life worlds that needed to be combined. The epistemology¹ and the ontology² of the whole project seemed very complicated and it remained to be seen whether it was at all possible to gain insight or an understanding of the combined personal and professional realities – the internal and external worlds – as they would present themselves in my proposed research.

1.1 A preliminary description of the research study

The focus of this research is the lived experience of a group of mothers having young children with special needs participating in a music therapy group introduced as music-caring within the framework of early intervention.

¹ Epistemological questions deal with what it is possible to know. They concern “how we gain access to reality, or what is the relation between reality and its representation in language and thought. Such issues may then lead into ontological questions” (Ruud, 2005, p. 33).

² Ontological questions focus on the nature of knowledge, reality itself and issues of existence and essence. Questions such as: what is real, what is music, what is music therapy, and what is music-caring, could be said to be ontological (Ruud, 2005, p. 33).

This qualitative research was anchored within an interpretive phenomenological frame (hermeneutic phenomenology) and sought to find answers to the following main research questions:

1. What is the experience of mothers of special needs infants participating in a music therapy group introduced as music-caring?
2. How do the mothers' experiences define music-caring?

Songwriting was used as a process and a central method for providing music-caring. In this context, songwriting was defined as "the process of creating, notating and/or recording lyrics and music by the client or clients and therapist within a therapeutic relationship to address psychosocial, emotional, cognitive and communication needs of the client" (Baker & Wigram, 2005, p. 16).

The researcher was a participant observer in a group of seven mothers who each had a child or children with various special needs. The children's age range was from eleven months to five years and four months. The children did not participate in the research.

The implementation of the research was divided into three phases:

- 1 The initial preparatory phase was launched in the spring of 2006. The main purpose of this preparatory phase was to recruit participants, prepare them for what was to come, prepare the therapist/researcher personally and professionally, and to design the music-caring sessions and the research design itself.
- 2 The central music-caring phase began 23 September, 2006 and included ten music-caring sessions which were run weekly on Saturday mornings for one and a half to two hours.
- 3 The reflection phase, or coda, involved one group interview/follow-up session (held 12 December, 2006), and one individual and semi-structured interview conducted with each of the seven participants. The last interview was conducted on 4 January, 2007. Interviews were the main data-gathering tool in this research.

Music-caring in the context of this research was preliminary defined as an empathetic and emotionally supportive relationship that an act of musicking brings into existence. The concept of 'lived experience' as used in this research is based on van Manen's explanation of it from a hermeneutic phenomenological perspective. Letting the mothers' experiences describe themselves (phenomenological) the study is interpretive from the stance that it holds that all lived phenomena is already

interpreted. This understanding claims that the specifics of lived experience have already been meaningfully experienced. Furthermore, lived experiences gather hermeneutic significance as, through interpretive acts, we attempt to determine the meaning embodied in them (van Manen, 1997).

1.2 The personal and the professional context of the researcher

The context of an inquiry includes all those personal, professional, interpersonal, and environmental factors or conditions that may be operating and affecting the research process. These factors and conditions may influence the focus or purpose of the study, the way the researcher interacts with participants and colleagues, the way the data are gathered and analyzed, and the way the findings are communicated (Bruscia, 1996, p. 97).

To be authentic is to continually bring these myriad contexts into awareness and to take responsibility for them as appropriate. Several contexts require special attention with regard to authenticity: the personal context of the researcher, the professional stance of the researcher, and the interpersonal environment. Put together, these contexts constitute “where I am coming from” as researcher (ibid.).

The opening quote by Bruscia is a reminder that undertaking this research and writing this thesis is necessarily from the stance of the researcher who is sharing a developmental process. This process, based on her genetic nature and nurture through life as well as conscious and unconscious motivations, reveals certain levels of development, insight and understanding that needs to be contextualized before the research process unfolds itself in the thesis. According to Bruscia, the personal context of the researcher, the professional stance of the researcher and the interpersonal environment all require special attention with regard to authenticity. This is also referred to as an *epoché* in phenomenology or *self-hermeneutic* in hermeneutic research; combined, these contexts constitute ‘where I am coming from’ as a researcher (Bruscia, 1996, p. 97).

Having become aware of issues/material that might influence the study, the researcher can either suspend or hold in abeyance this material to minimize its effect on the study. The researcher can also acknowledge and incorporate the material into the research study, an approach which is characteristically used in hermeneutic studies. Aigen (1995, p. 294) has listed ‘seven elements of the researcher’s biography’ which provide information relevant to this. These are: 1) Motivation for conducting the study. 2) Experiences and beliefs which have

shaped the area of inquiry which influence data collection and analysis. 3) Information such as the researcher's gender, ethnicity, socioeconomic status, position of employment, etc. allowing consideration of political and social issues which may have influenced the study. 4) Biases, shortcomings or personal difficulties that may distort the findings and render them incomplete. 5) The nature of the relationship between the researcher and the research participants. 6) Intuitions and expectations about research findings prior to its beginning. 7) How the research process changed the researcher.

Contextualizing acts like self-disclosure, it clarifies where one stands in relation to what one is doing or wishes to accomplish. To explore these contexts it is important to find answers to questions such as: who are you as a person, what motivates you, what are your personal and professional needs.

In the fall of 2000 when I began the master's study on which this research is based, I was confronted with my past professional work, which started in 1987 after I graduated from the University of Kansas and became a Registered Music Therapist. I started to ask myself some questions and one of them was: what had I been doing all these years? I had to find out what kind of music therapist I was, to realize if I wanted to continue on the same track or if I needed a change. If a change were needed, what kind of change would most benefit me as a music therapist? I had been self-employed working eclectically with individuals of different ages - individuals with mental retardation, learning disabilities, multiple disabilities, psychiatric disorders, social emotional and behavioural problems, sensory impairments, communication disorders, physical and orthopaedic disabilities, neurological impairments, and other disabling conditions. In an inward search for answers, individuals who had shared their music and memorable moments with me brought 'feelings to my mind'. These were feelings of warmth, joy, sympathy, empathy, caring, pride, excitement, tolerance, sorrow, irritability, immediacy and endurance.

These feelings were important and seemed far more pronounced than a feeling of proficiency or a lack thereof in the use of theories or methods. There were feelings evoked by the boy who, when playing the drum with arms fighting CP said: "This music doesn't fit into me." Or my friend who, when struggling with note reading, declared: "The keys are blocked." The little three-year-old who said: "When I feel sad and I hear this kind of music I want to cry. When I feel good and I hear this music it is like God is sending it to me." The beautiful girl with Rett syndrome who jumped up and down in wild excitement during her 'Hello song', the melody of which was borrowed from Mozart's Alla Turka. The

members of the bell choir, mourning the loss of their loved ones, who cried while playing Amazing Grace. The young metallophonist who said after his improvisation: “It felt like floating”. The young woman in her wheelchair, who cried and banged the drum fiercely, expressing deep sorrow and anger for the loss of her life’s possibilities. And there were many more.

The emotions I felt at this stage concerned the core of my professional work -why I had chosen music therapy as a profession, the way I had been doing things, for whom, for what purpose, and how effective or ineffective I had been in reaching therapeutic goals for the benefit of my clients. In her book *The Field of Play*, Kenny argued that hidden beneath the surface of the music therapy practice of every music therapy practitioner lies a unique theoretical foundation (1989, p. 8). She also said that every music therapist is endowed with an individuality in which the psyche and the soul of the work are contained. So perhaps I had been a good enough music therapist, despite lacking specialization and despite lacking words to describe theoretically what I had been doing. I discovered that interlacing theories I learned about (Gaston, 1968; Rogers 1990; Ruud 1980) had coloured and complemented one another, increased my knowledge and understanding of the elements operating at different stages of the music therapy process, benefited my clients and sustained my basic need to help.

Upon reflection, it was not the autism, Rett syndrome, Down syndrome, ADHD or all the other syndromes, disorders or diseases that came to mind, but the different people, and different characters who had brought with them their individuality, their uniqueness shaped by different life forces. I had truly experienced the human factor and I was certain that in music therapy, as in other helping relationships, it is the uniqueness of those involved, the uniqueness of the whole, that sets the foundation. It became clear to me that the therapist’s caring attitude, her need to help, her intuition, communication skills, attitudes, affection and respect for the client was as significant for the positive outcome of therapy as the underlying theories or methods. I also realized that the clients’ perception of the therapist’s attitude towards him or her as a whole being in the therapeutic relationship was equally important, if not at times more important, than the theoretical framework.

So perhaps I have been on some kind of pilgrimage that started in the fall of 2000 with the goal of discovering the essential elements upon which effective therapeutic relationships must reside. I believe these elements are essential for effective therapeutic relationships whether the techniques are derived from psychoanalysis or behaviourism. Expressed differently, these elements are what

helping interventions may have in common. They are both the general helper characteristics and facilitative traits. Furthermore, they colour the way music is used and influence its effectiveness in the therapeutic relationship; without them, the best methods and the most elaborate techniques become hollow and superficial, and there can be no music-caring. The research is based on this personal feeling, my need to help others, my belief that music can heal, my need to discover the psyche and the soul of my work, as well as my need for personal and professional growth and satisfaction.

In the preparation phase of this study I considered these points:

- My own needs may intrude upon the therapy process in the research.
- It is important to realize that the clinical needs of the clients always come before my needs as a researcher.
- It is important to separate the two roles of therapist and researcher.
- My ‘advanced level’ of work and understanding in one area may not transfer to a new clinical area.

According to Bruscia, authenticity is “an ongoing process of taking responsibility for what is in one’s own awareness regarding all aspects of the research” (1996, p. 82). As it relates to research, Bruscia writes:

When I am authentic as a researcher, I bring into my awareness whatever is possible for me to bring into it regarding my study; I act in a way that is consistent with what is in my awareness; and, I take appropriate responsibility not only for what is and is not in my awareness, but also for what I do and do not do in relation to it (1996, p. 82).

This definition has two features. It is intra-subjective, meaning that it governs the researcher’s relationship to herself, and it is an ongoing process that a researcher undergoes from the beginning of the research to its conclusion (ibid., p. 82).

1.3 Concluding remarks

Being aware of my own shortcomings, losses and aspirations, I realized that my personal needs would affect the research. Thus to the best of my ability I tried to be consciously aware of the different personal needs and feelings affecting my work at any given moment. These were issues such as accepting my own shortcomings, wanting to succeed, wanting to be liked as a music therapist,

wanting to feel and act self-assured despite experiencing fear and uncertainty in my role, wanting to experience the feeling of truly belonging to the group, and insecurity in balancing my role as a therapist and a researcher. I had not worked with this target group before and I had neither devised nor conducted research at this academic level before. From that perspective I was researching the work of a beginner rather than the work of an experienced therapist. Trying to see the light in my most fearful moments, I regarded myself as somewhat experienced in using music-caring, since by definition it should operate in a similar manner, regardless of the clients' needs. I carried with me the hope that music-caring, as an empathetic and a supportive relationship that an act of musicking brings into existence, would benefit my new client group, which in this study would be non-clinical adults.

CHAPTER 2

THE CLINICAL POPULATION AND EARLY INTERVENTION

In the past, an acquaintance with my clients' caretakers has revealed glimpses of feelings, needs, and struggles associated with having a child with a disability. As a listener and an observer I asked myself why a mother of a clever, handsome 20-year-old son with special needs weeps in front of a large audience when posing questions to specialists on disability? Why does a mother in her eighties, with a 45-year-old disabled daughter shed tears when talking about her daughter's future with the music therapist? Why does a mother of a delightful nine-year-old girl with special needs, who was born prematurely, cry when talking to the music therapist about her child's first two years? Why does a mother of a musically talented and a kind spirited 18-year-old son with special needs cry when she admits how tired and helpless she feels? These expressions are only minor in the lifespan of these mothers but they are indicative of how their children have influenced their lives and how their challenges have followed them through the passage of time. Like all parents, these mothers are different from each other but they share the need to express their distress or sorrow, their nonfinite loss³ of a perfect child. This has focused the attention on the idea that parents of disabled children could benefit from music therapy just as much as their children.

2.1 The clinical population

When the caretakers are informed that their child has a disability, the loss of the ideal child and the discrepancy between expectations and reality can precipitate a crisis reaction characterized by feelings of grief and loss. By reading personal accounts in magazines and books, one learns about the caretakers' feelings, their coping mechanisms, and how some of them survive (Ragnarsson, 1997; Rúnarsson, 2004). "Our insides are torn by such shock, grief, fear, and sense of loss that it feels like death" wrote Gill (as cited in Sorel, 2004, p. 23) when discussing the impact of finding out that one's child has a disability. The

³ In this context Bruce's & Schultz's (2001, p. 7) definition of nonfinite loss is used. It refers to "losses that are contingent on development; the passage of time; and on a lack of synchrony with hopes, wishes, ideals, and expectations."

parent's identity is forever changed and "the whole shape of ourselves and our lives is ... pulled into a new form" (ibid., p. 23). He continued:

The sorrow, although unwelcome, can be a pathway to an unconditional love that grows from a realization of the intrinsic beauty of each child's existence. We parents of children with disabilities can feel fine about ourselves when we grasp this and give up superficial achievement-based values. For Tariq, as for most children with disabilities, there has been no miracle, despite all my striving and wishes. I was powerless to change him, but he has changed me so much that I have no idea who I would be without him. ...Still, there are times that I won't deny wishing we could sit down and really talk (Klein & Schive, as cited in Sorel, 2004, p. 24).

Gunnarsson, a former president of *Landssamtökin Proskahjálp* (The National Federation for the Assistance of People with Learning Disabilities, an umbrella organization for various associations serving the disabled and the sick) in Iceland and a father of a daughter with autism, referred to the common experience of parents of special needs children in his keynote speech at the Federation's National Congress in October 2003:

To learn that your child has a disability is a trauma on which I do not have to elaborate, when normal expectations about your child's future change into worries and new and unforeseen tasks. What follows are examinations, assessments, treatments, a search for information about the nature of the disability and for supportive devices, days from work and a loss of income. Dealings with day-care centres and later with the school system become complicated and demanding. Often the biggest ordeal is to have to learn a new dance, which I prefer to call the System's Limbo. The rhythm is perplexing, the sound dissonant and the dance floor sticky. Often members of the orchestra are not even playing the same song. During the solo, the orchestra stops and the players point at each other (Gunnarsson, 2003, p. 7) (Author's translation).

To give birth to a disabled or ill child is an ordeal no one foresees. To use the words of a father who had a disabled son: "What were we supposed to do with the child who was not the one we had longed for or expected, a child so fragile and vulnerable that we could lose him at any moment. ...Living only in the moment, it felt like there had never been any past; the future was hidden in a haze and the present was almost unbearable" (Ragnarsson, 1997, p. 23).

(Author's translation). Ragnarsson's answer to the question: What it was like to have a disabled child, changed from day to day. His answers were coloured by how he felt, how he managed to work through his emotions and by his view of life and religion in general. He also recognized that society and culture were influential in shaping his answers.

Like so many in a similar position Ragnarsson was left to grieve, consciously or subconsciously, the loss of the perfect baby. He went through stages of denial, isolation, anger, bargaining and depression. He fought pain and sorrow, built defence mechanisms and fluctuated from a state of stupor to one of being constantly alert (Kubler Ross, 1970; Ragnarsson, 1997, p. 24). He neglected his own needs as he became consumed by the struggle of life and the different themes this new constellation had brought. He became co-dependent in an attempt to do everything he believed possible to compensate for his son's disability, he too became a victim of his situation. Yet a long list of specialists, including a music therapist, were at his disposal, to help his son.

Whatever the means and the resources of the caretakers, Ragnarsson's task, and that of other caretakers in a similar situation, is to come to terms with the fact that their child differs from other infants in some way, that their infant has a disability and needs special attention. Caretakers must accept the fact that it is possible to help but not to cure. Caretakers also have to integrate the child and the disability into their lives, to learn to endure their own shortcomings and to search for meaning in their loss. This is a difficult task, and in the process, dysfunctional patterns of parenting may develop, possibly eliciting behavioural and emotional problems in the children. The family must cope with a stressful situation affecting all individuals and their relationships with each other.

The parents themselves draw attention to all the striving and their wishes, as well as the importance of meeting other parents who have similar experience. They talk about their powerlessness, their nonfinite loss, and a grief that never perishes. They say that as parents, they speak the same language, that they understand and receive the most important information from one another. They also ask important questions: "What is the difference between accepting what cannot be changed and settling for less? How do I use anger to solve problems and not be overwhelmed by that anger? ...What issues are about me and what issues are about my child? ...How do I live today to its fullest?" (Gill, 1997, p. 87).

The parents also say that caretakers of children with special needs should not only be offered personal help but that such help should be mandatory. The fact

is, however, that within early intervention (EI) services, the parents themselves and the potential psychological distress they experience are more often than not the forgotten component in the overall support and treatment schemes. However, the emotional reactions are there and when not dealt with or even validated they invite additional feelings of guilt and inadequacy which may set off an escalating process leading to psychological or even physical ailments.

According to Skewes (2001, p. 17), the themes running through the grieving scenarios are the same; however, the experiences are distinctly different. According to Skewes' theory, each mother responds uniquely to her situation and potential gains from any help offered to her are related to the individual mother's responses, awareness, capacity, desire and current emotional state. The literature encourages creative expression as a modality for addressing grief issues. The mothers are the experts and their voices need to be heard. Storr (1997, p. 168) questions how it is possible that "an art which promulgates no doctrine, which preaches no gospel, which is often entirely dissociated from verbal meaning, can yet be experienced as making sense of life?" Providing mothers with an opportunity to work through issues of loss and grief in a safe and creative environment with other mothers may significantly alter their ability to cope with life. By contrast, inhibited grieving may lead to illness or psychological disorders, which negatively affect the child and the whole family.

To maximize the positive outcome of EI services it is of paramount importance to recognize the often enormous emotional strain that parents encounter and to provide something which addresses the resulting needs.

2.2 The clinical population and early intervention

In its narrowest sense the term 'early intervention' (EI) refers to what is done early in the life of a child to influence its developmental course. In a broader context, research within EI seeks to find answers to questions concerning which aspects of the environment have the most significant influence on early development and what might be needed to alter the course of development for the better. Although EI refers to children from birth to the age of six all the various definitions collectively emphasize the importance of influencing the developmental course of at-risk and disabled children with systematic interventions as early as possible. Forms of intervention include various educational, developmental and therapeutic activities as well as support networks of both a public and personal nature. That is support from family, friends, and professional relationships that help families maintain their central

role as caregivers and to develop new knowledge and skills (Innocenti, 2001, p. 2; Shonkof & Phillips, 2001, p. 21; Sigurðsson, 2001, p. 41). Traditionally, this parental role has been resource-oriented, focusing on the caretakers' awareness of available services. In some countries less emphasis is placed on positive qualities of interaction, and how to use these qualities to support the infant's development, learning, and interactive capabilities. Moreover the caretakers themselves receive very limited, if any, systematic help when faced with the nonfinite loss of having a special needs child.

Perhaps this overemphasis within EI on influencing the developmental course of children with disabilities through systematic intervention as early as possible, and the emphasis on the caretaker's role as the child's specialist constantly reminds parents of their failure to give birth to the perfect child. Mothers are usually the main caretakers and they share this nonfinite loss. This loss and the chronic sorrow it perpetuates are natural, but they still need to be accepted and dealt with. Meeting the mothers' needs for emotional and personal support is of paramount importance. They need to be with someone to whom they can ask questions, someone who listens to them, someone who hears what they are saying and not saying, and someone to whom they can surrender and be assertive. Mothers need to give their trauma a voice, to channel it and share it productively and without embarrassment. They need an opportunity to explore their creativity and potential for growth and self-awareness. They need a place where they can be heard and accepted in a non-judgmental and empathetic way.

For the future development of EI it is imperative to provide scientifically grounded portraits of the most important achievements of early childhood and the environmental conditions that either promote or impede them. It is also necessary to point to directions for both action and further studies toward those ends. Nevertheless, the use of knowledge to nurture, protect and ensure the health and well-being of all young children and their families is an important objective in its own right, regardless of whether measurable returns can be documented in the future (Shonkoff & Phillips, 2001, p. 36). This is a collaborative, interdisciplinary task that needs to be based on positive and healthy relationships between all involved.

2.3 Early intervention and the disciplinary context

On 8 November, 2003, *Sjónarhóll*, a new service organization in Iceland intended for children with special needs and their caretakers, collected money nationwide to

buy a house for its establishment. At Sjórnarhóll headquarters various associations⁴ that hitherto worked separately, or as umbrella associations, joined forces. Since its foundation, Sjórnarhóll's purpose has remained:

- To support parents in their role, to inform them about their rights, to assist them in getting support and the official services they are entitled to.
- To collect and store knowledge, to make accessible in one place the varied information caretakers need.
- To inform those who provide services to special-needs children.
- To connect families who face similar challenges.
- To form a team of all those specialists who are involved with the family of a special-needs child.⁵

There are between 4000 and 5000 families with special-needs children in Iceland. The mission of Sjórnarhóll is thus enormous and only time can tell how well it will manage its different tasks. It is my hope that Sjórnarhóll will bring different professionals and caretakers of special-needs children closer together and increase understanding, tolerance and respect among those faced with different disabilities as well as among different specialists. If successful in connecting families who face similar challenges, then I believe Sjórnarhóll will to some extent, meet the emotional needs of the caretakers. However, I hope that in the near future Sjórnarhóll will take a more direct approach to the emotional needs of those families, and advocate the use of creative therapies for that purpose. In harmony with my research interests, it will be my future goal to inform the directors of Sjórnarhóll about the possible beneficial effects of music for their clients and to offer music-caring groups as part of their services for caretakers of special-needs children.

The Icelandic Music Therapy Association was formed in 1997. For many years, it has tried to obtain governmental approval or official licensing for music therapists from the Ministry of Health. The association has been supported by members of parliament, but at the time of writing, whether our profession will be included or excluded in new by-laws set by the government concerning health practitioners remains to be seen. One of the ministry's arguments is that only

⁴ *Landssamtökin Proskahjálp*, The National Federation for the Assistance of People with Learning Disabilities, under which are 24 associations; *Umhyggja*, The National Society for the Support of Children with Chronic Illnesses, under which are 17 associations; *ADHD samtökin*, The National Society for the Assistance of People with ADHD; and *Styrktarfélag lamaðra og fatlaðra*, The Benefit Society of Children with Disabilities.

⁵ For further information see their homepage www.sjonarholl.net

those professions that work directly in healthcare should receive official approval or a licence from the Ministry of Health. Two music therapists working within the hospital setting lost their jobs at the beginning of 2009 due to the economic crisis in Iceland. One had been working for 22 years at the child psychiatric department and in the fall of 2008, the other had been requested to start a group music therapy programme for adult psychiatric patients attending an outpatient unit. I consider it of paramount importance for our campaign that music therapists try to work more closely with other health care professionals. Whether through including them in the referral system, by working alongside them, or informing healthcare professionals about our research findings in music therapy they must be encouraged to see the effectiveness of music therapy. Thus for the profession of music therapy in Iceland it is important to advance its use by exploring theoretically, clinically and empirically its possibilities as a treatment modality for clinical populations which have not received music therapy until now.

2.4 Concluding remarks

It is hoped that situating the present research within the framework of early intervention will draw the attention of healthcare professionals to the findings and to music therapy as a discipline. Hitherto no empirical work has been completed in Iceland by music therapists or music educators focusing on infants or their caretakers within the hospital setting (neonatal intensive care units) or the framework of early intervention. To the best of my knowledge neither a study examining the effects of music therapy on a group of mothers of infants with special needs nor a study examining the lived experience of the same population participating in a music group has been undertaken prior to this research. This is so despite scientific documentation of the power of music to arouse emotion, alter a person's mood and enhance and co-ordinate group feelings. Furthermore, clinical music therapy has provided patients of all ages with an effective means of exploring and communicating a wide range of emotions.

CHAPTER 3

PROBLEM FORMULATION AND METHODOLOGY

Experience in the degree in which it *is* experience is heightened vitality. Instead of signifying being shut up within one's own private feelings and sensations, it signifies active and alert commerce with the world; at its height it signifies complete interpenetration of self and the world of objects and events. Instead of signifying surrender to caprice and disorder, it affords our sole demonstration of a stability that is not stagnation but is rhythmic and developing. Because experience is the fulfillment of an organism in its struggles and achievements in a world of things, it is art in gem. Even in its rudimentary forms, it contains the promise of the delightful perception which is esthetic experience (Dewey, 1934/1958, p. 19).

According to Dewey, interaction with the world decreases isolation with own private feelings and emotions, increases experience/knowledge, including aesthetic experience, and leads to interpenetration of self and the world of objects and events. As previously noted, mothers of special-needs infants can become relatively isolated from the world. This can cause potential problems for themselves and their infants. They may lose their identity in the demanding role as mothers and opportunities for psychosocial and physical development may become limited. These problems can be decreased by giving the mothers the opportunity to interact with the world, specifically by participating in an emotional, aesthetic experience in the form of music-caring.

3.1 Problem formulation

It is the aim of this research to provide mothers of special-needs infants with an experience which '*is*' a music-caring experience intended as a channel for their individual and collective needs as expressed in the present. I am interested in sharing with the mothers and communicating with them when they exchange with the 'world' this study will present to them. I want to develop an understanding of the participants' lived experiences through the mothers' voices, their descriptions and interpretations. I want to develop an understanding of music-caring from the mothers' perspective and to discover whether the music-caring experience has an effect on the lives of the mothers and the way the mothers relate to their infants. I want to learn from these mothers about the music-caring processes at work, and through disseminating the findings inform

others working within the framework of EI of the effects of music-caring. Furthermore, I want to use this learning experience to develop my own clinical practice within the field of EI. Designed towards this end this study sought to find answers to the following research questions:

- 1 What is the experience of mothers of special-needs children participating in a music therapy group introduced as music-caring?
- 2 How does the mothers' experience define music-caring?

The focus was on the participants and their experience of the music-caring offered to them and intended as a channel for the mothers' individual and collective needs. The emphasis was not on the therapeutic method itself used for this purpose (songwriting) but on developing an understanding of music-caring from the mothers' perspectives. True to the research intent as stated in this introduction, all I needed to do was to be available for the mothers, recognize their uniqueness by listening and responding to them as valued members of the group and through individualized concern for them, aim to elicit positive feelings such as trust, comfort and security. Furthermore, through the applied method I needed to ensure that the mothers were given ample opportunity to express their personal needs, feelings and thoughts. All I could hope for was to provide the mothers with a rich and positive experience that would address their needs in some way and, by doing that, learn from them in various ways.

Music-caring in this context was defined preliminary as an empathetic and emotionally supportive relationship that an act of musicking brings into existence. Being of a humanistic origin, music-caring is perhaps not a new concept to practicing music therapists, but because it is somewhat intertwined in our tacit knowledge its importance is perhaps not realized and its meaning not elaborated on. One reason for choosing a helping profession as a career is the desire to help others. As music therapists we have chosen music as our medium to serve that purpose because we believe in its potential. Thus we need to become aware of what caring is all about, to elaborate on the meaning of caring and on how it relates to different theories and people's relations with music in various ways.

The primary research questions necessitate some additional questions. How is it possible to find answers to these questions? What kind of research method is applicable to this research interest? What beliefs, values and methods best frame the researcher's understanding of the research finding? "The personal encounter in therapy requires research methods appropriate to the situation." said

Langenberg (1996, p. 4). She was referring to the importance of a research method being able to sound different qualities such as those encountered in a relationship formed among the participants. These qualities include the exchange of thoughts and feelings and qualities in musical interaction. “We are interested in developing qualitative research approaches to obtain a better understanding of our clinical work, our patients, and ourselves, while placing a high priority on communicating what we learn to other professionals,” she wrote⁶ (ibid., p. 1).

Aigen also advocates the use of qualitative methods in disciplines such as music therapy where creativity, nonverbal expression and relationships all play important roles. In qualitative research, or naturalistic research as Lincoln and Guba prefer to call it, there are multiple, constructed realities. The focus is on dynamics and processes occurring in the lived world rather than on stimulus-response transactions in staged encounters. The emphasis is on qualities, nuances, details, and subtleties rather than on statistical regularities and tendencies; instead of being a distanced observer, the researcher can be actively and personally involved. The knower and the known interact, and “all entities are in a state of mutual simultaneous shaping” (Lincoln & Guba, 1985, as cited in Aigen, 1995, p. 286). Qualitative research allows for holistic insights through which idiosyncrasies, complexities and interdependencies can be traced.

The first account of research using qualitative methods appeared in the *Journal of Early Intervention* in 1989. A reported increase in the use of qualitative research methods within EI between 1990-1998 confirmed its importance and applicability with this population and supports this researcher’s choice. Within EI, parents are the main consumers of services and their contentment has become a primary measure of the quality of health care plans. Considering their voices and listening to them within the full context of their experiences is thus crucial (Conner, & Nelson, 1999, p. 347; Sandall, Smith, Mclean, & Ramsey, 2002, p. 135; Trivette, & Dunet, 2004, p. 18).

“Qualitative research is about exploring particularity and diversity and there is a plethora of qualitative research approaches around with rather different answers to basic ontological, epistemological, and methodological questions,” says Stige (2002a, p. 65). Qualitative research does not stand for a unitary body of commonly accepted principles. What distinguishes it are various philosophical foundations, methods for data analysis, and views on the role of the

⁶ The ‘we’ Langenberg refers to is a community of researchers who in 1994 began to define itself and hold dialogues about research, hoping that it would encourage the development of standards among qualitative researchers in music therapy.

researcher. The same labels may be used by different researchers but denote different things, or the researchers may use different labels to represent similar approaches (Aigen, 1995). In order to tackle this variability, Tesch identified 40 labels used by qualitative researchers, which she then distilled into 26 types of qualitative research. According to the research focus, each of these types fall into one of the following four main areas/groups: 1. Characteristics of Language, 2. Discovery of Regularities, 3. Elaboration of Meaning, 4. Reflection. Along a continuum, these four areas become less structured and more holistic, relying more on insight, intuition and scholarly reflection in their data analysis (Tesch, 1990, p. 59).

According to Aigen (1995), it is the absence of consensus on methodological issues that makes the domain of qualitative research a confusing one to enter. Aigen believes that it is the researcher's interests, beliefs, experiences, and knowledge that help define qualitative research. However, like Forinash and Gonzalez (1989, as cited in Aigen, 1995, p. 300) Aigen is of the opinion that the flexibility inherent in the qualitative approach makes it possible to frame one's research interest into a meaningful research question, and furthermore to adapt one's approach to the specifics of one's situation. This allows findings to be produced which are congruent with one's experience and useful for other practitioners hoping to gain an insight into the nature of music therapy with a certain type of clientele.

Concerning the lack of standard set of methods in qualitative research Kenny writes: "We cannot assume a common understanding of our approach. This is an ethical issue. We offer this information as we can, when we can, as much as we can, depending on our own level of development, insight, and understanding. It is a developmental process in articulation" (1996, p. 60).

The lack of consensus on methodological issues allows me as the researcher to be both flexible and creative. Within certain limits I can allow my interests, intuition, and experience to guide me as long as I state why I am doing what I am doing and what I hope to accomplish by doing it. Yet this freedom brings with it many uncertainties and a need for extending and deepening an understanding of the relevant knowledge base and guiding principles for conducting research. This will have to be done along the research continuum in order to make the 'correct' methodological and ethical decisions. The researcher wants the participants to experience the power music holds for care and cure. She wishes to engage the participants in some way to generate the data. And she wants to participate in their lived experience to which they bring their values,

meaning, hopes and feelings. She wants to gain an understanding of what happens when the participants engage with one another within given musical conditions. The researcher has decided that, qualitative discipline research or research which focuses upon the lived experience in a music-caring group designed for a group of mothers of special-needs children best serves the constraints of this research that is, the chosen clientele, music therapy in EI/Iceland, and the researcher as a professional and a person. The participants will be musically engaged in music-caring. The basic qualitative character of this research intent could be described as having an exploratory and descriptive focus (collecting descriptive data such as people's own written or spoken words and observable behaviour), evolving design "which allows the research to stay vital and creative", data collection in the natural setting, emphasis on 'human-as-instrument', qualitative methods of data collection, and early and ongoing inductive analysis (Kenny, 1996, p. 60).

3.2 Research methodology

The relationship between world and experience, text and reality, structure and action remains uncompromisingly problematic in a way that allows no given or traditional social theoretic solutions to impose order on what is not orderly' (Marcus, 1992, as cited in Alvesson & Sköldbberg, 2000, p. 191).

No traditional theoretical solution can impose order on what is not orderly, writes Marcus. Contradictory though they may appear, these words sounded rather comforting when searching for orderly thought processes and courage for action. Searching within the qualitative approach for a research method one is confronted with schemas, labels and categories. Having chosen to undertake a qualitative research project the next question, and a more difficult one for a novice researcher, emerged: What type of qualitative research best serves this research interest as stated in the research questions - biography, ethnography, case study, grounded theory, naturalistic inquiry, phenomenology, or hermeneutics?

In her continuum of research methods, Tesch states that although the dividing lines between them are not clear it is possible to differentiate them in a general sense. She articulated 40 different labels currently used by qualitative researchers in human sciences, and distilled this list into 26 types of qualitative research, each of which falls into one of four main areas: 1. Characteristics of Language, 2. Discovery of Regularities, 3. Elaboration of Meaning, 4. Reflection. Being interested in the lived

experience of the participants, hoping to provide insightful description of it and interpreting the meaning it holds for them the most suitable research methods would fall in groups 2 (Discovery of Regularities) and group 3 (Elaboration of Meaning), and their subgroups 2b (Discerning Patterns), 3a (Discerning Themes) and 3b (Interpreting) as these may point towards research approaches which tackle meaning and experience: naturalistic inquiry, phenomenology and hermeneutics (Aigen, 1995, pp. 288-290; Tesch, 1990, pp. 59-73).

Following the principles found in naturalistic inquiry the researcher acts as an instrument. Her whole self serves as a tool for data gathering and analysis, although her insight and flexibility as a human being are also important. Based on the belief that human processes gain meaning from their context, naturalistic inquiry also emphasizes the importance of studying events and interactions in their natural environment. Provided with general guidelines, criteria for evaluation and an overall perspective, this method also gives the researcher leeway to develop specific procedures for her study (Aigen, 1995, p. 291). The importance of the context, the researcher as an instrument and the flexibility all sounds supportive and reassuring while searching for an appropriate research method.

According to Aigen (1995), phenomenology like naturalistic inquiry is “more a complete paradigm than a narrowly defined method of research” (p. 291) which has “inspired music therapists to study experiences as they emerge through musical meetings with the clients” (Ruud, 2003a, p. 6). “A phenomenological perspective includes a focus on the life world, openness to the experiences of the subjects, a primacy of precise description, attempts to bracket foreknowledge, and a search for invariant essential meanings in the descriptions,” wrote Kvale (1996, p. 38). Within this paradigm I could focus on studying the nature of the mothers’ experiences free from preconceived notions as phenomenology emphasizes. For example, she could examine their expressions and feelings as they evolve in the present. Through discovering underlying themes emerging from comparison of various experiential accounts some essential components of the music-caring experience might be discovered.

The goal of a hermeneutic account is to “understand everyday skills, practices, and experiences; to find commonalities in meanings, skills, practices, and embodied experiences” (Benner, 1994, p. 56). In hermeneutics, accumulating data through direct observation is emphasized. The purpose is “to engage deeply in the circle of understanding in order to develop insightful and plausible interpretations of events”, as Aigen puts it (1995, p. 292). Although differences are to be found within the hermeneutic traditions (objectivist

hermeneutics and alethic hermeneutics) they both emphasize the importance of the whole, intuition, and empathy for true knowledge acquisition. Polarization between subject and object and between understanding and explanation is dissolved. Sometimes treated as one of several interpretative research methods, hermeneutics advocate a spiralling path through the research endeavour. This path which moves back and forth from the part to the whole, and from the whole to the part, according to the objectivist hermeneutics, and back and forth from pre-understanding to understanding according to the alethic hermeneutics (Alvesson & Sköldberg, 2000, p. 54). According to Stige (2002b, p. 332) hermeneutics is a basic discipline to research on health care when viewed as a process for understanding the existential conditions of human beings.

3.3 Hermeneutic phenomenology

There is More Light Here.

A man saw Nasrudin searching for something on the ground, “What have you lost, Mulla?” he asked. “My key,” said the Mulla. So the man went down on his knees too, and they both looked for it. After a time, the other man asked: “Where exactly did you drop it?” “In my own house.” “Then why are you looking here?” “There is more light here than inside my own house.” (Shah, 1966/1999, p. 9)

Following Bruscia’s levels of decision making and Tesch’s continuum of qualitative research approaches (Aigen, 1995; Bruscia, 1995a; Tesch, 1990), reading literature on research methods as well as dissertations related to my research interests, I have been searching for a relevant knowledge base prior to making an informed decision regarding the most appropriate qualitative research method for this undertaking. Finding myself lost at times in the stream of words and with no prior research experience guiding the decision-making, no well-lit and paved path to travel has been found. Possibilities stay open and I have to adapt my approach to the specifics of my research.

The story of Nasrudin above emphasizes the importance of balancing both worlds - the external environment and our internal processes, also known as the phenomenon occurring “within our own house,” in the dark. Instead of looking for the key outside oneself in the daylight like Nasrudin did, the story encourages one to bring the whole self into consciousness, to shift the focus inwards to our emotions, our insights, and other subtleties of our being. To be

aware of how others influence us and how we can influence others. To be aware of the spontaneous empathetic reactions basic to the need to help others. To be aware of the mothers not as objects but as physical, cognitive, cultural, social, emotional, and sensuous beings (Vetlesen & Nortvedt, 1997).

The focus on the lived experience of the mothers anchors this research within phenomenology, which tries to elucidate that which appears and the manner in which it appears while searching for an ontological meaning in the descriptions. According to van Manen (1997) in phenomenological research it is vital not to lose sight of that which sparked the interest and to define that as a phenomenon. For this researcher, the motivating phenomenon is music-caring. Caring resides in a thinking-feeling (thoughtful in its fullest sense) mode of being that gives rise to activity, said Dunlop (1994, p. 38). In Heidegger's sense 'care' is having our being be an issue for us. Existentially we exist in terms of the things that we care about or in terms of what matters to us. What matters now is to describe, develop interpretations/explanations and understanding which are based on concern, commitment, experience, and research.

"Understanding human action always involves an interpretation, by the researcher, of the interpretations being made by those persons being studied," said Benner (1994, p. 55). For this researcher to learn is to understand, and to understand is to search for a meaning which goes beyond layered description of the phenomenon. An understanding and a meaning developed from this research will be influenced by foreknowledge originating from 'fore experience' or a lack thereof. The word 'care' itself brings the researcher into the study as an instrument where her insight and flexibility as a human being is valued, where the whole self serves as a tool for data gathering and analysis in a search for meaning, meaning which goes beyond the immediately 'experienced one' in order to articulate the pre-reflective level of lived meanings where the invisible becomes visible. This stance expands phenomenology to include interpretation. All entities will be in a state of mutual, simultaneous shaping where every encounter is an interpretation. Furthermore the importance of the whole, intuition and empathy will be valued.

What counts as an answer in hermeneutic phenomenology? How can the essential themes which characterize the phenomenon be found? From a hermeneutic phenomenological perspective the meaning of music-caring needs to be found in the experience of music-caring itself, because the lived experience of music-caring is all that remains if presuppositions are suspended. Yet, one needs to realize that experiential accounts or lived-experience descriptions, whether oral or written, are never identical to the lived experience itself. All recollections of experiences,

reflections of experiences, descriptions of experiences, taped interviews about experiences or transcribed conversations about experiences are already transformations of those experiences. Even life captured on video is already transformed at the moment it is captured (van Manen, 1997, p. 54).

In this study, the researcher, the mothers and the situation were in a dialogical relationship, allowing caring alterations if called for. The researcher was carefully listening, hearing the voices and concerns expressed while the mothers were experiencing the music-caring process. The researcher herself was also experiencing it as a participant observer. Through data triangulation⁷ made possible from rich data, the researcher hopes to give the fullest possible account without indulging in over-interpretations, speculations, or an over-reliance on personal opinions and personal experiences (van Manen 2001, p. 67 as cited in Vist, 2005, p. 11). It is hoped that the interpretive account will illuminate the worlds of the participants, their experiences, meanings, values and concerns. The researcher designed the research with some anticipation and understanding but with the intention of staying open to the experience and allowing the text to reveal blind spots, mysteries and distinctiveness while constructing meaning. As Bateson describes it (1994):

Ways of understanding are integrated works of art created by many minds, like cathedrals, as much masterpieces of the human spirit as the Greek tragedies or the paintings of the Renaissance. Human beings construct meaning as spiders make webs – or as appropriate enzymes make proteins (as cited in Ely et al, 1997, p. 63).

The following data sources provided rich data which allowed for the triangulation mentioned above:

- A questionnaire (which provided general information about the participants) completed in writing by each mother during her first visit to the research site.
- A questionnaire completed in writing by each mother prior to the first group session.
- Written diaries. A diary with some guidelines was given to each mother at her first visit to the research site.

⁷ “Triangulation is the use of multiple sources, methods, investigators, and theories” (Lincoln & Guba, 1985, p. 305). “The rationale is that when we find a convergence of results generated in different ways and by different individuals, those results become more credible” (Aigen, 2005, p. 359). “Triangulation ...helps ensure that resulting constructions are grounded in the sense of being as well-informed and holistic as possible” (Abrams, 2005, p. 249).

- Transcriptions of the first to tenth sessions.
- Transcription of an open group interview in the 11th session (narrative text).
- Transcriptions of semi-structured interviews with each mother in individual sessions numbered as session 12.
- The researcher's memos.⁸

Central to this research were the mothers' worlds, their lived experiences and how their experiences defined music-caring. From a phenomenological viewpoint a person is 'having a world'. This world "is the meaningful set of relationships, practices, and language that we have by virtue of being born into a culture" (Benner, 1994, p. 46). It is our world that sets up possibilities for who a person can become and who she cannot become.

Secondly, a person is a being for whom things have significance and value and also qualitatively different concerns based on their culture, language, and individual situation. "To understand a person's behaviour or expressions one has to study the person in context. For it is only in context that what a person values and finds significant shows up" (ibid., 51).

Heideggerian phenomenology differs from other approaches in that it posits that the very act of perception is a grasp of meaning and an interpretation. From this viewpoint human action always involves an interpretation, by the researcher, of the interpretations being made by those persons being studied. Interpretation of meaning is the central theme in hermeneutical understanding with an emphasis on the interpreter's foreknowledge of a text's subject matter. Nothing can be encountered independent of our background understanding and every encounter is an interpretation.

An anchor for the three-fold purpose of this research endeavour was found within interpretive, phenomenological frame (hermeneutic phenomenology). Being closely connected, both phenomenology and hermeneutics require a deep reflexivity on the part of the researcher. Both practices are process oriented and seek understanding circling back and forth, revisiting the subject of the study and re-analyzing and re-interpreting data until essences (phenomenology) have been discovered or meaning assigned (hermeneutics) (Kenny, Jahn-Langenber, & Loewy, 2005). Hermeneutic phenomenology involves a "phenomenological sensitivity to lived experience" and a "hermeneutic ability to make interpretive

⁸Memos (the researcher's reflections) are post-session thoughts and impressions written down the first time the researcher listens to and transcribes the taped sessions and the interviews. Memos are written down in short notes and in free-associative, unstructured writing style (Wengraf, 2001, p. 211).

sense of the phenomena of the life world” (van Manen, 2001, p. 2 as cited in Vist, 2005, p. 9). The mothers in this research are the ones to describe their experience, and their self-interpretation is fundamental to any understanding gained. “These human experiences happen relationally, in a shared reality, a shared subjectivity” (Kenny, 1996, p. 64) experienced by both the mothers and the researcher. Prior to being studied this experience already has a meaning for the participants and as such has already been interpreted. Furthermore, expression or presentation through writing is in itself an interpretation, or as van Manen (1997) puts it: “The aim of phenomenology is to transform lived experience into a textual expression of its essence – in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience” (p. 36).

3.4 The researcher as a participant observer

My intention was to study the lived experience of a group of mothers of young children with special needs, participating in a music therapy group introduced as music-caring within the framework of early intervention. Figuratively speaking, I removed myself from my current clinical practice and the caretakers of my past and present clientele which I had become acquainted with, people who could have become subjects for this research. These people suggested the idea that is now being studied. Instead of inviting them to participate in the proposed research I brought my old clinician’s self and my notion of music-caring into a new therapeutic relationship with new and unknown clientele.

Seen from a more pragmatic stance it could also be argued that my contextual situation was such that I alone was able to carry it out. I was a novice researcher and had not worked with these clients before, despite having over 20 years of clinical experience. Other music therapists in Iceland were also novice researchers who had never worked with these clients and who had limited clinical experience. If this research was to be undertaken in Iceland, then the best and perhaps the only choice seemed to be the dual role of a therapist and a researcher. My motivation was to discover essential elements upon which effective therapeutic relationships must reside and the individuality in which the psyche and the soul of my clinical work was contained. I, as a therapist and a researcher, had to take on the role of being a participant observer. This involved being a member of the group with an active and established role as a group leader and facilitator yet at the same time establishing

and keeping some distance to observe and to analyze. According to Manis and Meltzer it can be argued that:

When working with people, scientific aims can be pursued by explaining the meaning of the experiences of the observed through the experiences of the observer. This arises from a perspective that the social world involves subjective meanings and experiences constructed by participants in social situations. The task of interpreting these meanings and experiences can only be achieved through participation with those involved” (1967, as cited in Robson, 1993/2005, p. 314).

Bruscia states that authenticity of intent is in jeopardy when researchers study their own clinical work (1996, p. 83). He also says that “qualitative research is enhanced when the researcher is the subject’s therapist or when the researcher actively engages and interacts with the subject” (1995c, p. 75). Smeijsters (1996, p. 186), on the other hand, is of the opinion that treatment and research can be of benefit for the client but that when the therapist and the researcher are the same person then a problem of ‘inauthenticity’ (when someone is not aware of his own perspective) may arise. To be authentic in the role of a researcher and a clinician simultaneously one needs to be aware that it may be impossible to pursue both roles with equal devotion. It may become necessary to emphasize one at the expense of the other. To acknowledge this possibility and take responsibility for the choice one makes is an act of authenticity, according to Bruscia (1996, p. 83). When studying one’s work with clients through research, the primary intent must be scholarly, seeking insight for other clients, other therapists, and other researchers (ibid., p. 84). However, a scholarly intent can never be at the expense of clients in their role as research participants. So rather than abandoning the idea of studying one’s own work, one should develop procedures and relationships to address any difficulties that emerge and be aware of not only possible disadvantages but also possible advantages for the client to participate in therapy which is being researched (Aigen, 1996).

Wanting to study one’s own clinical practice as a participant observer brings forth important ethical and methodological concerns writes Aigen “In terms of ethics, it is essential for researchers to disclose any information that bears on their having a vested interest in obtaining certain research results” (1996, p. 15). An ongoing investigation or awareness of the researcher’s emotions in relation to her study is thus important for “bringing the potential for a deeper degree of understanding to ourselves and to our readers”, as Aigen words it. So instead of putting aside or suppressing my subjectivity, I acknowledge it and reflexively incorporate it into the study. I openly admit to using

my own perspectives and biases to colour and shape all aspects of the study, including the findings (Bruscia, 2005a, p. 131).

Not having access to a research support group as Ely et al. (1991) advises, since the autumn of 2006 when the music-caring phase of the research began, I have attended weekly or fortnightly supervision from a psychologist experienced in group work. Analytic memos⁹ were written during the implementation phase of the research. Through these means and some private focusing work¹⁰, feelings were explored in order to avoid projecting them onto the research participants to minimize negative effect on both the therapeutic and the research process itself.

Being “fellow travellers” and of service to one another as Yalom words it (2001/2008) both therapy and research is dynamic and ever-evolving with a continuous sequence of experiencing and then examining the process. As a participant observer, I gained a lot of important information from the inside of the group, information necessary for analytical reflections about therapeutic processes and other aspects of the group’s functioning as well as information about their understanding and experience of music-caring. These observations could be regarded as an auxiliary method supplementing the main data-gathering tool of this research, which was interviewing.

As a participant observer in the dual role of being both the participants’ therapist and this study’s researcher, the usage of the first person ‘I’ will be abandoned from now on and the third person ‘she’ will be used interchangeably with the ‘therapist’, the ‘researcher’ and the ‘therapist/researcher’. The therapist/researcher did all the translation from Icelandic to English needed in this dissertation except for translating the poems and the mothers’ validation. The poems were translated by Bernard Scudder and the mothers’ validations were translated by Dr. Lilja Ósk Úlfarsdóttir.

3.5 Ethics

“Ethical stances are expressions of caring rather than the products of abstract rationality” wrote van Hooft (1995, p. 138). As a professional member of the American Music Therapy Association, Inc. (AMTA) and the Icelandic Music

⁹ The researcher’s record of analysis, thoughts, interpretations, questions and directions for further data collection. Analytic memos can include a variety of topics, including both personal and professional difficulties that the researcher is encountering (Strauss & Corbin 1998, p. 110; Wheeler, 1995, p. 549).

¹⁰ Focusing is a method developed by Professor Eugene Gendlin who in the early 1960s, began research into the question: “Why is psychotherapy helpful for some people, but not others?” Focusing is a body-oriented process of self-awareness and emotional healing (Cornell, 1996, pp. 2-3).

Therapy Association the therapist/researcher rigidly adheres to the following ethical conducts.

[To] recognize and publicly accept the proposition that the fundamental purposes of the profession are the progressive development of the use of music to accomplish therapeutic aims and the advancement of training, education, and research in music therapy. Our objectives are to determine and utilize music therapy approaches that effectively aid in the restoration, maintenance, and improvement in mental and physical health. To that end, we believe in the dignity and worth of every person. We promote the use of music in therapy, establish and maintain high standards in public service, and require of ourselves the utmost in ethical conduct. Therefore, we collectively and individually affirm the following declarations of professional conduct.¹¹

These conducts relate to professional competence and responsibilities, general standards, relationships with clients/students/research subjects, relationships with colleagues, relationships with employers, responsibility to community/public, responsibility to the profession/association, research, and more. The AMTA ethical research conducts are the following:

8.1 The MT establishes a precise agreement with research subjects prior to their participation in the study. In this agreement, the responsibilities and rights of all parties are explained, and written consent is obtained. The MT explains all aspects of the research that might influence the subject's willingness to participate, including all possible risks and benefits. The MT will avoid any deception in research.

8.2 Participation of subjects in music therapy research will be voluntary. To ensure ethical research practices, appropriate authorization will be obtained from the subjects involved (or specified and/or legal guardians) and the facility's Institutional Review Board or other similar consulting agency. The subject is free to refuse to participate or to withdraw from the research at any time without penalty or loss of services.

8.3 The MT is ultimately responsible for protecting the welfare of the research subjects, both during and after the study, in the event of after-effects, and will take all precautions to avoid injurious psychological, physical, or social effects to the subjects.

¹¹ <http://www.musictherapy.org/ethics.html>

8.4 The MT will store data, including written, audio, video, digital, or artistic media, in a secure location accessible to the researcher and authorized members of the research team. The researcher and authorized members of the research team will determine a set period of time after completion of the study by which all research data must be shredded or erased. The researcher or the research team may apply for a waiver allowing creation of a database given informed consent of participants.

8.5 The MT will be competent in his/her research efforts, being cognizant of his/her limits.

8.6 The MT will present his/her findings without distortion and in a manner that will not be misleading.

8.7 Publication Credit.

8.7.1 Credit is assigned only to those who have contributed to a publication, in proportion to their contribution.

8.7.2 Major contributions of a professional nature made by several persons to a common project will be recognized by joint authorship.

8.7.3 Minor contributions such as editing or advising, will be recognized in footnotes or in an introductory statement.

8.7.4 Acknowledgment through specific citations will be made for unpublished as well as published material that has directly influenced the research or writing.

8.7.5 The MT who compiles and edits for publication the contribution of others will publish the symposium or report under the title of the committee or symposium, with the therapist's name appearing as chairperson or editor among those of the other contributors or committee members.

In accordance with Icelandic research regulation, the research project was approved by the National Bioethics Committee on 7 March 2006, receiving the file number 06-020-S1 (Appendix A). The research was also presented to the data protection authority receiving the file number S2847 (Appendix B). Procedures were followed to ensure that the participants could not be identified in any material related to this work such as material presented orally and in writing or material kept in various formats.

The research participants received information about the research project through written and oral presentations. They had access to web pages, a brochure (Appendix C) in which the research was introduced and in their first meeting with the therapist/researcher they were given a folder with various material that introduced the research and could be used throughout the sessions. The material included instructions for filling out questionnaires and the use of a diary, questionnaires, a diary, song texts, a notepad and an informed consent form (Appendix D). Informed consent in a research context is defined as:

a legal term which refers to the decision a person makes freely and independently to participate as a subject in a research project after having been fully informed of all pertinent information, as well as all potential risks and benefits to him or her. Informed consent is based on the core ethical principle of autonomy, and requires that the person be provided information prior to his or her participation in the research (Beach, 1996, as cited in Dileo, 2000, p. 176).

The mothers were informed both in writing and orally about the purpose of the study, procedures to be used, expectations of the participants, the time commitment involved and duration of the study, the nature of the risks involved, possible benefits that might result from the study, procedures used in protecting the confidentiality and privacy of the participants and their data, who would have access to the data, how it would be kept, used and disposed of, and how the results of the research would be disseminated. The mothers were told they could withdraw their consent to participate in the research at any time without any consequences. The mothers were told that if they decided to participate in the research they would have to sign the informed consent form and bring it to the first music-caring session. All the mothers signed the informed consent form in the presence of the therapist/researcher at this introductory meeting. The consent forms were kept by the researcher along with other written material such as the participants' answers to the questionnaires and the transcribed interviews. The mothers chose their own pseudonyms which were used when presenting data from the research orally and in writing. The interview transcriptions saved on a computer included no person identifiable material. All person identifiable recorded material on minidisks and video recordings were kept in a safety box in a bank to be destroyed after the completion of this study. The CD that accompanies the dissertation and includes a compilation of the participants'

musicking in the music-caring sessions is presented with a written permission from the mothers (Appendix E) as it may contain voice recognizable material.

According to Bruscia (2005a) two ethical issues are of particular concern in qualitative research: the evolving and often changing nature of its design, and dual relationships of various natures. As discussed in the previous section (3.4), being a participant observer in one's own research poses various ethical dilemmas. Some of these dilemmas were known beforehand, while others revealed themselves as the research progressed and were dealt with throughout the different stages of the research. Awareness of the therapist's/researcher's subjective feelings at any given time during the study was very important as well as acknowledging the fact that as research undertaken in a clinical situation it might never be at the cost of the therapeutic process. According to Corey et al. (1998, as cited in Dileo, 2000, p. 43) unethical practice can result when therapists use techniques with which they are not familiar or skilled. In this case the therapist/researcher had a limited knowledge of and experience with the songwriting approach used and limited clinical awareness of the music therapy group process. Weekly supervision from a psychologist experienced in working with groups provided necessary guidance and reflexivity and supported the therapist's/researcher's self-awareness. In these sessions, issues related to therapy, research and the therapist's/researcher's own personal and professional developments were brought up and dealt with. When stating that it is just as ethically imperative to be competent in how one 'is' with clients as being competent in what one 'does' with them Dileo (2000, p. 44) stresses that self-awareness is one of the key characteristics of effective therapists. A continuous process evaluating one's beliefs, values, biases, self-perception and needs is thus imperative. Otherwise destructive types of countertransference issues might become ethical issues and present themselves in a number of ways (Nolan, 1998).

From the standpoint of the therapist the following ethical guidelines regarding responsible use of therapeutic approach /techniques were followed: 1) The therapeutic approach/techniques were theoretically grounded and had a particular therapeutic goal. 2) The approach/techniques were selected according to the needs of the clients and supported the clients' self-exploration and awareness. 3) The approach/techniques were adapted according to the clients' needs and diversity. 4) The approach/techniques were used to enhance group process. 5) Techniques were implemented sensitively and carefully according to the group process. 6) The therapist/researcher invited participation of the group members, but they were free to contribute or not.

Ethical codes seldom provide a definite answer, says Kvale “They are more like texts to be interpreted than rules to be followed: They provide guidelines that must be judged according to their relevance to specific situations” (1996, p. 110). Conducting music therapy research requires adequate professional and personal competence, just like doing music therapy. As an academic undertaking, this study was learning and a developmental process for the therapist/researcher calling for answers to different questions at each stage. To ensure ethical conduct, conceptual soundness, appropriate design and analysis and adequate competence, the therapist/researcher received supervisory guidance and consultation. The evolving nature of this undertaking allowed a continuous evaluation of every step in the research process so as to affirm or revise the overall direction of the research according to whatever was discovered during each step of the process. This helped to ensure the welfare of the participants and both the therapeutic and the research’s ethical soundness in the best way possible throughout all phases of the research.

CHAPTER 4

THESIS GUIDE

The thesis is organised into six parts:

- I. Introduction of the context of the research study.
- II. Theoretical frames and related perspectives.
- III. The research participants and the research design.
- IV. The music-caring sessions.
- V. Data collection, interpretive phenomenological analysis and empirical explorations.
- VI. Concluding discussions.

Part I is in four chapters. Chapter 1 provides the focus for the study and establishes its rationale by contextualizing it within the therapist/researcher's personal experience and her professional framework. Chapter 2 introduces the clinical population, early intervention and its disciplinary context. Chapter 3 presents the research focus and its hermeneutic phenomenological methodology. It also discusses some ethical issues related to the research participants and the conduct of the therapist/researcher, as relevant for this undertaking. Chapter 4 is this short thesis guide.

Part II, Theoretical frames and related perspectives, explores the disciplinary context for this research in six chapters. This part focuses on how different theories, practices and research encourage, inform and support this study. Chapter 5 discusses key factors in the implementation of early intervention (EI), the population it serves and its defining features. Chapter 6 explores the concept of motherhood constellation developed by Daniel Stern and its associated themes, relationship disturbances specific to children (from birth to six) and their caretakers, and possible interventions. Chapter 7 examines the various factors that can contribute to parenting stress and emotional reactions to having a disabled child described as chronic sorrow or non-finite loss. This chapter also discusses coping-styles and the benefits of supportive social networks such as found in parent-to-parent groups. In chapter 8, music therapy research and practice as related to early intervention and music-caring is introduced. The limited empirical work available relevant to this area of study, emphasizes the importance of context and relationships between participants for the formation of meaning in music. Chapter 9 explores theories of care defined by health care practitioners and the helping relationship. The reciprocal

nature of helping is discussed, as well as the concepts of empathy and intuition. Chapter 10 explores the question of ‘why music-caring?’ by discussing music and emotion, and introducing the concept of musicking and how music-caring could be accomplished through its use. A brief introduction to how quality of life from a salutogenetic perspective can contribute to maintenance of health is also included in this chapter. This part finishes with a concluding assumption about information, relevant to the notion of music-caring, which this research might provide.

Part III, The research participants and the research design, is divided into three chapters. It introduces what is referred to as the preparation phase of this research. Chapter 11 presents the research participants through some factual information, a character sketch and a self-portrait. Their recruitment and an individual preparation session conducted with each one of them are also described. Chapter 12 provides an overview of the setting and the equipment used. Chapter 13 outlines the research and the session format as well as the central music therapeutic approach, namely songwriting.

Part IV, The music-caring sessions, referred to as the implementation phase, consists of chapter 14. It outlines the music therapeutic approach used in the ten music-caring sessions. It is intended as a broad overview of how the session structure and the longitudinal guidelines for the ‘improvisational songwriting’ approach were realized. From a therapeutic point of view, the overview is limited in scope but may nevertheless provide a general framework that can be adapted to new therapeutic and research contexts.

Part V is titled Data collection, interpretive phenomenological analysis and empirical explorations. This is the reflection phase and it consists of three chapters. Chapter 15 presents the data collection that started in the initial preparatory phase and extended through the reflection phase. One semi-structured group interview and a semi-structured individual interview with each mother was the main data gathering tool in this qualitative research. Chapter 16 describes the thematic analysis of the interview text. The purpose of the interviews was to have the mothers objectively and subjectively describe their experiences and define music-caring in their own words. Chapter 17, the empirical explorations, focuses on the lived experiences of the seven mothers participating in the research. From a hermeneutic phenomenological perspective, the process of empirical explorations is described as an interactive and an abductive one, travelling back and forth on a spiralling path, with and ‘within’ the mothers own voices, the researcher’s thematic analysis, published theory, and the process of writing as a construction of meaning. Following the

subsection 17.1, which introduces the process of validation, a separate section is devoted to each of the eight core categories and their related themes as revealed through the analysis. The core categories are: the group, musicking, songwriting, the CD, the therapist, me and my time, process-change, the diary. The categories with 18 related themes are discussed in relation to the theoretical framework presented in Part II, as well as to other theoretical perspectives informative and supportive in the analysis.

The final Part VI, Concluding discussions, includes two chapters. Chapter 18 addresses the research questions that provide the focus for this study by synthesizing relevant theoretical framework presented in Part II, the empirical explorations presented in Part V, and other related research and theoretical perspectives that informed the study after the completion of data collection and its analysis. Chapter 19 addresses the limitation of this research from the informants' as well as the therapist/researcher's perspectives. For that purpose, it uses the agenda EPICURE and discusses aspects related to engagement, processing, interpretation, critique, usefulness, and relevance. Issues related to ethics were discussed in section 3.5. The subjects of groundedness, reflexivity and comprehensibility are also addressed. Chapter 19 concludes with a summary and an epilogue.

References, an English summary, a Danish summary and Appendices complete this dissertation.

PART II THEORETICAL FRAMES AND RELATED PERSPECTIVES

According to Bruscia to contextualize is to “identify and take into account the many different frameworks, systems, environments, and conditions operating within a research study and potentially affecting the participants, the researcher, and implementation of the study itself” (2005a, p. 134).

In section 1.2, the personal and the professional context of the researcher was introduced. In this section the disciplinary context for this research is explored specifically how theory, practice and research in music therapy, as well as early intervention and other relevant areas, encourages, informs and supports this study. Theories on loss and grief, stress and coping, quality of life, care defined by health care practitioners, music and emotion, as well as Stern’s motherhood constellation, maternal representations, developmentally informed theory, working models for parent-support groups, and Small’s definition of musicking will all lend their support to this study. Part II ends with a summary and a concluding assumption.

Contexts are interrelated and to contextualize should be an ongoing concern in any evolving research study (Bruscia, 1995b, p. 405). As this research progresses, it can thus be expected that new theories, practices and research will inform the study.

CHAPTER 5

EARLY INTERVENTION

Developments in neurobiological, behavioural, developmental and social sciences in the last three decades led to major advances in understanding the conditions that influence how well children fare in the world, advancing today's early intervention, known as the second generation of Early Intervention (EI) (Shonkoff & Phillips, 2001; Sigurdsson, 2000; 2001).

In its narrowest sense, the term 'early intervention' refers to what is done early in the life of a child to influence its developmental course. In a broader framework research within EI seeks to find what aspects of the environment have the most significant influence on early development and what is needed to alter the course of development for the better. Although EI refers to children from birth to the age of six, all the various definitions collectively emphasize the importance of influencing the developmental course of at-risk and disabled children with systematic interventions as early as possible. Interventions include various educational, developmental and therapeutic activities as well as support networks of both a public and personal nature. These network include support from family, friends, and other professional relationships that help families maintain their central role as caregivers and to develop new knowledge and skills (Innocenti, 2001; Shonkoff & Phillips, 2001; Sigurdsson, 2000; 2001).

5.1 Key factors in the implementation of early intervention

Cultural differences, the variety of available resources, implementation strategies, theoretical models, and EI's extensive and multidisciplinary research base all make the scope of EI extensive and complex. However, major milestones of development, certain assumptions regarding services, and goals and principles of early intervention are shared where EI is successfully implemented. The following core concepts reflect the prevailing views of researchers, theorists and clinicians who study young children and their families and frame our understanding of the nature of human development during early childhood (Innocenti, 2001, p. 6-16; Shonkoff & Phillips 2001, p. 22-32)

Premises of development:

- Relationships and the effects of relationships on relationships are the building blocks of healthy development.

- Human development is shaped by a continuous interaction between biology and experience.
- The first few years of life are critical to subsequent development.
- Regulation is an essential property of all living organisms, including physiological and behavioural regulations as well as those that influence complex behaviours involved in the expression of feelings, the capacity to pay attention and control impulses.
- Children are active learners, influencing their environment as well as being influenced by it. This reflects the intrinsic human drive to explore and master one's environment.
- Intervention is more effective when begun as early as possible, but the child remains vulnerable to risks and open to protective influences throughout the early years of life and into adulthood.
- Family life, culture, health and other external circumstances influence development.
- Individual differences among young children can make it difficult to distinguish normal variations and maturational delays from fleeting disorders and persistent impairments.
- Development is shaped by the ongoing interaction among internal and external risk factors that increase the probability of a poor outcome and protective factors that increase the probability of positive outcome.
- Children develop along an individual pathway whose course is characterized by continuities and discontinuities, as well as by a series of significant transitions.
- Effective intervention that changes the balance between risk and protection can alter developmental course in early childhood.

Four assumptions regarding services:

- Children at risk or with established disabilities have the right to specialized services to maximize their development and their possibility for success.
- Families of children with disabilities often experience special needs and stresses.
- The provision of earlier services might mean the achievement of the most favourable outcomes for children and their families.
- Because of the unique characteristics, needs, and resources of each family, an individualized approach to service planning and delivery is essential.

Goals and principles of early intervention:

- The quality of a child's physical and social environment has a significant influence on the child's behaviour and long-term development.
- EI is effective in reducing the impact of disabling conditions.
- Parent involvement is essential in EI.
- EI is most effective when professionals work together as an interdisciplinary team.
- Professionals should focus on the child's strengths rather than its deficits.
- Intervention needs to be developmentally based.
- Individualized assessment is a necessary prerequisite to effective intervention.
- Skills taught to children with disabilities may not generalize to other settings unless specific planning and training is designed towards that end.

These key factors conducive to the child's maximum growth and development concern elements in interpersonal relationships such as sensitivity, reciprocity, affective warmth, non-intrusive patterns of interaction, and discourse-based social exchanges as well as experiences organized by the family that involve social networks adapted for the special needs and talents of the child.

5.2 Nature through nurture

The debate about nature versus nurture no longer exists. Research in developmental neurobiology and developmental psychobiology now emphasizes their inseparability and complementary forms. Nature *and* nurture, or nature *through* nurture, is now believed to be a source of stability and flexibility in human growth, their interaction resulting in human development (Shonkoff & Phillips, 2001, p. 41). An infant's responsiveness to its surroundings hinges significantly on genetically-based ways of feeling, interpreting, and responding to environmental events. This emphasizes the importance of considering each infant's individuality and caring conditions that can counteract the expression of inherited vulnerabilities.

Developmental neurobiologists make a distinction between the so-called "experience-expectant" and the "experience-dependent" processes influencing the architecture of the human brain. The "experience-expectant" processes are based on the expectation that certain experiences will occur that organize and structure essential behavioural systems. These include early visual and auditory

stimulation the lack of which can cause life-long detriments in behavioural functioning. The “experience-dependent” processes are based on new experiences that help to trigger new brain growth and refine existing brain structures. They rely on the unique life experiences that contribute to individual differences in brain growth and are the source of the human brain’s adaptability and lifelong plasticity (Shonkoff & Phillips, 2001, p. 54).

Neuroscientific research indicates that brain development which begins well before birth is characterized by remarkably rapid brain development in early childhood. Research also indicates that the brain has a lifelong capacity for growth and change. Animal studies have revealed that younger brains react more rapidly and to a greater degree to environmental variation. These studies also suggest that removal from complex environments results in decreasing benefits over time. As mentioned above, certain brain systems, such as the auditory and visual systems, need early environmental inputs to develop normally, while others, for example those involved in cognitive, emotional, and social development, are now thought to be less sensitive to critical periods.

Animal studies have also shown that early or sustained stressful experiences such as disrupted caregiving can cause detrimental effects by over-activating neural pathways that regulate fear-stress responses. Behavioural data on young children exposed to adverse experiences and the physiology of traumatized or deprived children are consistent with the animal studies (Shonkoff & Phillips, 2001, p. 217). Secure infant attachment increases the prospect of future mental health and has been shown to positively influence motivation, cognitive development, social skills and peer interaction.

Mothers who are grieving or experiencing depressive states may be less sensitive to their infants’ needs. Their emotional state may interfere with the maternal sensitivity necessary to promote secure attachment (Niccols & Mohamed, 2000). Thus early stimulation matters, especially for those who are born with conditions that affect their capacity to access and incorporate the stimulation needed to organize the developing nervous system. It is also important to be sensitive to the emotional needs of the mothers to counteract potential danger of dysfunctional mother-child interaction due to distress.

5.3 Population served

Early intervention is aimed at families and young children (0-6 years old) who are either defined as at-risk, or with established disabilities. At-risk conditions are grouped as either environmental risk conditions or biological risk conditions.

The scope of possible environmental risk conditions varies between societies. The following are the most common ones: caretakers unable to perform essential parenting functions due to a disease, young age or a disability; upbringing in a shelter or a foster care environment; violent, neglecting or abusive caretakers; upbringing in an unstable home environment; legal guardian not established. Infants with biological risk conditions are those born prematurely, children who fight life threatening or chronic diseases, and children who become injured or exposed to drugs or other intoxicants (Innocenti, 2001, pp. 3-4).

Children with established risk conditions are those born with chromosomal abnormalities, neurological impairments, atypical developmental disorders, very low birth weight (less than 1000 grams), and a delay in cognition, physical/motor, speech and language, psychosocial, or self-help skills (Zervigon-Hakes, as cited in Innocenti, 2001, p. 5). In the United States and many other western countries the type of risk conditions affects to some degree the type of services offered. What works best for each one of the three categories mentioned above is still unanswered.

The families of these children are also being served within the framework of early intervention. And they are as varied as they are many. The caretakers', the siblings' and even the grandparents' life situation with regard to upbringing, education, experience, social and work status, and external support, are interwoven with culture and everything else that shapes a person, including his or her needs, dreams, hopes, and personality.

Within EI a tapestry of multi-various relationships are thus formed. There are relationships between the infant and the parent (the mother or the father), between parents and the infant, between siblings, between grandparents and the infant, between the therapist and the caretakers, the therapist and the infant, between the different therapists and health professionals. With regard to all the different relationships formed, both personal and professional, the clinical picture can become extremely complicated, even to the extent that it hinders effective intervention. New relationships are formed, and reciprocal interpersonal relationships coloured by different interactive patterns, affective qualities and needs at any given moment (Hougaard, 1996/1997, p. 132).

5.4 Early intervention research and services

In its early years, research on the influence of EI focused on the promotion of intelligence. Often this research showed a short-term impact on standardized IQ test performance, with a subsequent fade-out of effects during middle childhood.

As the number of those who criticized conventional intelligence testing increased over the years, investigators within EI shifted their focus. An approach to evaluation and intervention embedded within the child's natural environment and conducted in an ongoing information-gathering manner became advocated. Also, interest in measuring programme effects shifted towards different target areas. Self-regulation, interpersonal skills and relationships, knowledge acquisition skills and problem-solving abilities became the focus of research. Emotional and social development, and the underlying functional capacities that lead to cognitive gains are today considered a better indicator of how well the child will fare in life than a measure of IQ (Shonkoff & Phillips, 2001, p. 348; Sigurdsson, 2000, p. 55).

Ainsworth, Blehar, Waters, and Wall (1978); Bell (1974); Broussard and Hartner (1970); Goodman and Cameron (1978); Holmes and Masuda (1974); Moos (1974); and Rahe (1974) (as cited in Abidin, 1983/1995, p. 2) encouraged the examination of human behaviour in context. They recognized existing reciprocities between parent and children coloured by certain qualities and temperamental dispositions.

Rye (2001, p. 7) refers to classical studies by Spitz (1946), Harlow (1962), Bowlby (1969, 1980, 1988), Vygotsky (1978) and Bronfenbrenner (1979) as well as studies by Antonovsky (1987) and Rutter (1985), which demonstrated the importance of opportunities for human contact, care and learning in the early years of a child's development. In the interplay of various factors important for the infant's health, psychosocial development and learning, the quality of human relationship and the care experienced by the children seemed to serve a principal role. Attachment security became a central feature of early relationships and concepts like *attachment* and *bonding* the framework for studies in child-caregiver interaction. Research on clinically depressed mothers noted significantly elevated proportions of insecure attachments manifested as a child's disrupted exploratory play, display of distress and anger upon reunion, and not being easily comforted. In the 1980s, Trevarthen and Stern also described an incredibly fine-tuned reciprocal communication between infants and their mothers through the mutual use of sounds, mimicking and movement (Stern, 1985; Trevarthen, 1986).

Empirically described qualities of caretakers-infant's communication, recognition of certain parent characteristics and family context variables, and different clinical theories launched the modern era of early intervention. Various private and public programmes were developed to implement governmental laws and regulations. Examples include the Head Start programme and the Disabled

Children's Early Education in the United States, the "Marte Meo" programme in the Netherlands and the "More Intelligent Sensitive Child" programme (MISC) developed by Professor Pnina Klein in Israel (Abidin, 1983/1995; Rye, 2001, p. 11; Shonkoff & Phillips, 2001, p. 35).

5.5 Defining features of today's early intervention

The prior emphasis of EI practices on the child and related medical issues shifted about 15 years ago towards becoming more family-centred. Family variables such as family characteristics, family interactions, potential stressors for the family related to the child's disability, as well as the impact of social support, were studied empirically. Key concepts were revised and new approaches developed (Dunst, 2000; Hooste & Maes, 2003, p. 296).

Dunst and associates (2000) adopted three important principles as a way of reversing pathological thinking about families and intervention practices. The acronym PEP or "Proactive Empowerment through Partnerships" stands for these principles. The first principle – proactive – emphasized strengths rather than weaknesses as the focus of intervention practices. The empowerment principle emphasized family control and access to desired resources instead of dependency-forming and competency-impeding supports. The third principle – partnership – emphasized collaboration between families and practitioners instead of professionally centred approaches as a primary means of support. Based on an extensive review of health care literature, Dunst et al. (1990, as cited in Dunst, 2000) differentiated between treatment, prevention, and promotion models and the outcome of interventions based on each model. Their findings led them to conclude that treating or preventing problems or poor functioning was not the same as enhancing or strengthening capacity. Recognizing that building on strengths, interests and preferences were more conducive for positive behavioural change than merely correcting weaknesses or alleviating deficits encouraged the development of empowerment-, strength- and asset-based models. Research has confirmed that practices based on these models are more effective than traditional practices in influencing developmental outcomes and the quality of life for all concerned. Furthermore, Dunst stresses that instead of focusing on partnership per se, one should emphasize programme and practitioner factors conducive for positive outcomes. Thus partnership could be thought of as a particular kind of participatory helping experience contributing to empowerment-type consequences.

According to Karuza, Rabinowitz, and Zevon, (1986, as cited in Dunst, 2000) research indicates that how assistance is given often matters more for favourable benefits than what is done. Relational elements such as active listening and empathy are of paramount importance, as well as positive beliefs about the family's competence and capability. The caregiver's responsiveness to and support of family's decisions and the encouragement of actions based on choice is also vital. Summarized, the new emphasis, based on a salutogenic way of thinking is as follows:

- Instead of focusing on disorder, problem or disease and its consequence the focus is on *strength* and optimization of *competence*.
- Instead of depending on *professional* expertise for problem solving the focus is on *empowerment practices*, which create *opportunities* for development of *new competencies*.
- Instead of correcting people's weaknesses or problems, *assets and talents* are recognized and used to *strengthen functioning*.
- Instead of relying primarily on professional services, a broad range of *community experiences* becomes a valuable resource.
- Instead of expert professionals who base their interventions on their own perspectives, professionals become *sensitive* to a *family's desires* and concerns and serve as families' *agents*.

Today's EI (third generation) acknowledges that a family's social network such as a mix of intra-family, informal, community, and formal social network members, provides the support and resources needed for everyday living, carrying out parenting responsibilities, and supporting child learning and development. These networks and the supportive exchanges that occur within them provide a context for a broad range of experiences. These experiences are recognized as supportive exchanges, strengthening existing competence and promoting new capabilities (Bronfenbrenner, 1992, as cited in Dunst, 2000). As environmental variable, informal supportive experiences can and do work as early intervention, whether deliberately manipulated or not. Their influence can be either direct or indirect on the child, the parents or the family as a whole. According to this model, social support directly influences the health and well-being of the recipients, health and well-being influences parenting styles, and well-being and parenting styles directly and indirectly influence child behaviour and development.

How children react to the events and people around them and what they expect from themselves and others is deeply affected by the relationship with their parents, the behaviour of parents and their home environment. The concept of parenting and parental influence is complex and takes into consideration adjustment to various needs and characteristics of their children, the conditions in which they live, and the circumstances of their own lives. Contemporary researchers take into account the network of contexts in which parenting is embedded. Parenting intersects with the child's inherited strengths and vulnerabilities to affect the pathways that are followed to adulthood. If, for example, depression in the mother goes unrecognized paediatricians' treatment of the child's clinical problems may not be successful. Research has shown that shifting parental behaviour in ways that shift the odds of favourable outcomes for children is often remarkably difficult (Hooste & Maes, 2003; Shonkoff & Phillips, 2001, p. 226). Plausible reasons for this include inadequate time for counselling and inadequate training and knowledge of health care providers about symptoms of depression and diagnostic criteria. Some paediatricians do not perceive themselves as responsible for recognizing depression in mothers. Screening or diagnostic assessment is usually not carried out at an early age to measure the relative magnitude of stress in the parent-child system. All too often children do not come to the attention of mental health professionals until they begin school (Abidin, 1983/1995; Olson, Kemper, Kelleher, Hammond, Zukerman, & Dietrich, 2002).

5.6 Early Intervention in Iceland

The institutions in Iceland serving special-needs children and their families within the framework of EI are: Landspítalinn Háskólasjúkrahús in Reykjavík (*Landspítalinn - University Hospital*) and other paediatric hospital departments and neonatal units around the country; Mæðravernd/ungbarnaeftirlitið (*Community child health/care services*) situated in various health care clinics in the capital, its suburbs and major towns around the country; Svæðisskrifstofur um Málefni Fatlaðra (*the different regional offices concerning affairs of the disabled, ROAH*); day-care systems; pre-schools; various parent- and service-related associations which now have combined their forces as Sjórnarhóll (an institution situated in Reykjavík); and Greiningar- og Ráðgjafarstöð Ríkisins (*The State Diagnostic and Counselling Centre*) situated in one of the suburbs of Reykjavík.

The last mentioned institution is the main evaluation and rehabilitation centre in Iceland for children and adolescents with various types of

developmental disabilities. Its main goal is to evaluate children and adolescents with various types of developmental disabilities and to provide subsequent counselling to parents, caregivers, teachers and therapists serving the family. The children who are referred to the centre are evaluated by an interdisciplinary team which works towards a consensus on the child's condition and prognosis. The needs of the child and its family for special services are defined, counselling offered and necessary referrals are made. An important part of the centre's work is to organize congresses, workshops and lectures on various topics of interest to parents of disabled children and others working with and for this clientele. Two popular workshops include "Owning a Disabled Grandchild" and "A Parent Workshop". The State Diagnostic and Counselling Centre also has a parent association/group which organizes social gatherings and formal meetings where experts are invited to speak on a wide variety of topics and parents share experiences. The association is developing a new homepage where information parents feel is important and relevant, will be made accessible. The homepage will also be an avenue for questions and the sharing of life stories.¹²

If an infant born prematurely or diagnosed with a disease or a disability does not need intensive medical care it is discharged from the hospital. While still in a state of initial shock, the infant's caretakers are informed by medical staff (doctors, nurses, social workers, physiotherapists) of future procedures, prognosis, available services, their rights, etc. How well caretakers are informed and how much of the information they find useful at this point in time varies. Many parental accounts depict how little of the initial information they received was remembered and proved useful. From the parental accounts it can be assumed that giving support and information is a very delicate and difficult task. How successfully it is achieved depends partly on the professional's empathetic understanding of the family's emotional state and emotional needs at the time of discharge.

At this point in time, the emphasis is not on taking care of the parents but on completing the medical task and discharging. The parents go home with the new family member, and in the months that follow they are visited on regular basis by a nurse. Without doubt, many nurses provide families with quality care and empathy in their home visits. Some children need physiotherapy while in infancy and some are seen regularly by various medical doctors. During those visits, the focus is on the child's needs and neither directly on the caretaker's worries nor their non-finite loss, which could develop into post traumatic stress

¹² <http://www.greining.is/>.

disorder if left untreated. In general, the care parents of special-needs infants receive is not different from the care parents of “normal” children receive.

When special-needs children go to day-care centres or kindergartens they are provided with the extra support they need and, according to the initiative of their parents or the day-care directors, meetings are held with the team of specialists working with the child. The purpose of these meetings is to share information, solve problems, and to set new goals and objectives for the child.

For the past few years, one or two people at a time have been running music groups for infants and young children in Iceland. For two years a music teacher from Estonia, worked with about 20 children and their caretakers in Tónstofan a private music therapy studio. In the context of this research it is interesting to note that no special-needs child was enrolled in her groups and not a single parent of a special-needs child requested information about the groups. This is so despite an interesting newspaper article introducing these groups and stating that a music school for children with special needs is run in Tónstofan. Is this because parents of infants/children with special needs feel discouraged, insecure, disconnected, alone, afraid, distressed, bitter, or angry? Are they protecting themselves by avoiding places, people or feelings? Or as Austin words it (2002, p. 234) are they forfeiting their own voice to survive? Do they need individual encouragement?

In January 2005, four researchers (a psychiatrist, two psychologists and a nurse) employed by the Landspítalinn University Hospital received a research grant from *Rannís Research Fund* to study pregnancy and postpartum depression in Icelandic women, their social circumstances, their use of psychoactive drugs and the inter-connectedness of these factors to their children’s developmental stage at the age of one. The purpose was to find predictive variables/profiles to target those in need of intervention. Information from this research will be used to develop check lists and assessment tools which may lay the foundation for systematic screening and intervention for depressed mothers offered by the health services.¹³ This research may be indicative of a shifting focus and an increased awareness of the caretakers’ needs within early intervention services.

Within the framework of early intervention and in the rapidly growing field of infant health, varied therapeutic concepts and clinical theories are borrowed and applied and new services are being developed. Behavioural theories focus on teaching various skills, developmental theories focus on enhancing the

¹³ <http://en.scientificcommons.org/49043685>

natural growth process, cognitive theories focus on experience and action that help to build thinking skills, family system theory focuses on the child within the family and psychodynamic and interaction theories focus on the relationships between family members. In practice theories are combined, and they undergo modification to meet the needs of a new clinical population.

To establish a need for services is an important undertaking, but it is also important to identify aspects of care that are pertinent to parents and integrate it within the framework of EI services. Towards this end it is important to offer parental care accounting for their heterogeneity which influences both expectations and perception of care to assess the significance to parents at specific points along the continuum of care and to target improvement efforts and judge the quality of care as measured by parent satisfaction with EI services. Gradually it will be possible to map out the important components as measured by parent satisfaction within each phase of the care process (Dempsey, 2008; Harrison, Henderson & Leonard, 2007; Kingston, 2007).

CHAPTER 6

THE MOTHERHOOD CONSTELLATION

Similar to the unique 'psychic organization' formed with the birth of a baby (dubbed the 'motherhood constellation' by Stern), so must a unique psychic organization or a constellation be formed with the birth of a disabled baby. According to Stern, this 'constellation' can last for months or years and it determines a new set of action tendencies, sensibilities, fantasies, fears, and wishes. Yet the period the caretakers of a disabled infant enter is not as transient as the motherhood constellation, and it involves subjective themes that may need a different therapeutic partnership (Stern, 1995, pp. 171-172).

6.1 The motherhood constellation and associated themes

In most normal situations, pregnancy is a time of anticipation. Caretakers form mental worlds of the baby and of themselves as parents. This representational world which is made up of real objective and imagined subjective situations includes among other things, the caretakers' fantasies, hopes, dreams, memories and prophecies for the infant's future, and plays an important role in determining the nature of the caretakers' relationship with the baby (Flagg-Williams, 1991, p. 238; Stern, 1995, pp. 12-18). This relationship begins prior to birth, forming a schema of being with the present and the future baby. Between the fourth and seventh months of gestation (at a time when the foetus is capable of hearing, although thresholds are high (around 100 dB)) the richness, quantity and specificity of the schema about the infant-to-be grows. Between the seventh and ninth months, however, the positive representations are believed to be intuitively undone in order to protect the infant-to-be and the caretakers from becoming disappointed, should there be a discrepancy between the real infant and the one who dwells in their mind (Stern, 1995, p. 23). Both positive and negative representations, such as fear of deformity, are thus undone, although they may flourish subconsciously. Some of the themes that emerge when a child is born include groups of ideas, wishes, fears, memories and motives that influence the caretaker's actions, feelings, interpretations, interpersonal relations, and other adaptive behaviours. These themes may not be specific to the motherhood constellation but to all those concerned for the well-being of their newborn infant (Stern, 1995, p. 173).

The life growth theme is concerned with one's capability to maintain the life and growth of the baby. Concerns about the ability to feed the infant and make it grow

physically are manifestations of the mother's worries about whether she is a good enough mother; they also reflect a worry about the infant's ability to stay alive despite perhaps a profound disability or a disease.

The primary relatedness theme concerns the caretakers' concern over their ability to emotionally engage with the baby. Will I be able to love that disabled infant? Will I be able to respond to all its needs? Can I relate to the infant in a nonverbal, pre-symbolic, spontaneous, intuitive manner?

The supporting matrix theme evolves around how the caretakers create and permit the necessary support systems to fulfil their obligations. In time of crisis, for example when giving birth to a disabled infant, the available support system is limited. Relatives and friends do not know how to behave. They do not know if it is proper or improper to congratulate the parents. The parents may feel abandoned in the failure to maintain a supporting matrix. In a state of shock they cannot make necessary use of the first information or initial support they receive. They may find themselves wanting as parents or judged inadequate and even destructive. Their earlier parental experience doesn't suffice. Their pain, self-accusations, or other feelings may compromise their parental capabilities. They may become co-dependent, and fused with the baby in their parental role. They do not have any role-models with whom to identify. For years to come, the struggle for their child's rights will remain a source of anger and sorrow.

The identity re-organization theme relates to the caretakers' ability to transform their self-identity to permit and facilitate their parental functions. The model needed for identification only partially exists, due to the special needs of this unexpected constellation. Identifying with the caretakers' own parents doesn't provide the right model to feel secure in the new and difficult role (Stern, 1995, p. 180).

6.2 Relationship disturbances and intervention

As previously mentioned, in early intervention the population is comprised of infants and children from 0 to 6 years of age and their caretakers. According to Stern, pathologies of the aforementioned may consist of relationship disturbances that can be manifested as eating and sleeping disorders, attachment disturbances, early conduct disorders in the infant, or as parental anxieties, disturbances in parenting, and other forms of parent-infant disharmonies. Developmental lag, disabilities and other disabling conditions not originating in the parent-infant relationship are also included as possible causes of pathologies (Stern, 1995, p. 2).

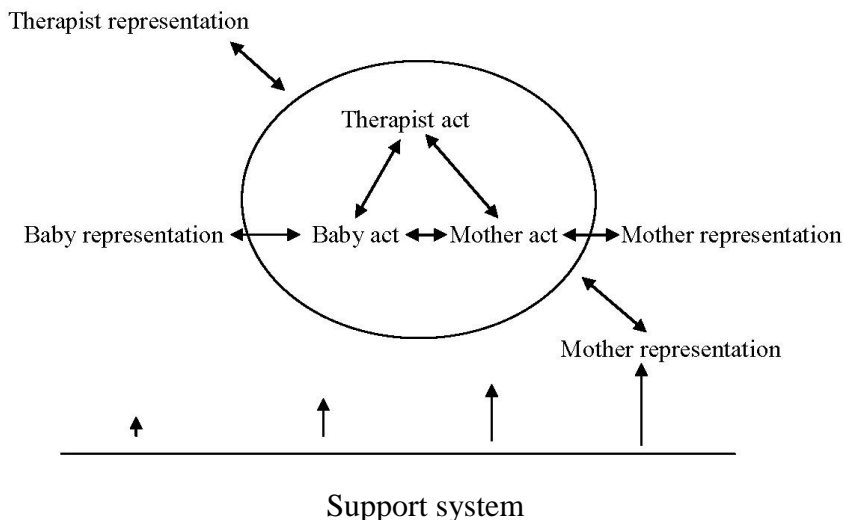
Discussing the often broad and vague definitions of music therapy as well as the elusive criteria of success in therapy, Horden writes:

How can the personal contribution of the therapist be distinguished from that of the music, or indeed from other kinds of ‘treatment’ which the musical one may complement, such as art therapy? ...How can the outcomes of therapy be categorized and assessed in ways that give weight to parental instincts as much as to clinical calibrations, to the psychosomatic as much as to the organic - above all, to the evolving *meaning* for both therapist and client, of the problems being addressed? (Horden, 2000/2001, p. 15).

Like Horden, Stern advocates (1995, pp. 2-4) that various parent-infant therapies work equally well and that it may be difficult to find differences in outcome between different therapies. What the different therapies share seems thus to account for more of the beneficial effects than the differences do. This notion explains why multidisciplinary teamwork can function, i.e. when the same client (caretakers-infant) is perhaps assessed and treated by different therapies without the therapists ever consulting each another, as sometimes is the case.

According to Stern’s belief the following can be assumed:

- In all the different therapies there are common features (always present and always acting) that are non-specific to any one of the therapeutic approaches.
- The different therapies have roughly equal outcomes, but they arrive there by different mechanisms of therapeutic action.
- Therapies can be combined to get better results than any single therapy alone.
- If there are commonalities used by all the various parent-infant approaches different from those used in other domains one can perhaps talk about unique and coherent features belonging to parent-infant therapy.



This graphic model by Stern (1995, p. 15) shows how a support system (therapy) can act as a continuous maintaining force or as an episodic influence on different elements of the mother-infant-therapist interaction. If the support system or intervention is directed towards the mother, this model holds that it will have its greatest effects on the mother's representations affecting how she regards herself as a mother and a person, and consequently affecting what she does behaviourally with the baby. All the elements in this model are however always:

- Present and acting
- Interdependent
- Dynamically and mutually influencing each other
- Reciprocal

If music therapy interventions are successful in changing the primary caretakers' feelings (representations) then they will also, according to Stern, have direct or indirect effects on all the other elements in the relationship. They will change how the mother subjectively experiences herself as a mother, thus changing her interaction with the infant. This in turn may alter the infant's behaviour as it adjusts to the new interactive reality and adjusts its representation of current and future interactions.

This model allows the different therapies to use different ports of entry into this single dynamically interdependent system. The interrelated nature of the system itself transforms specific clinical interventions into general clinical outcomes. The nature of the system also makes it difficult to restrict therapeutic intervention to one port of entry alone. It constantly crosses boundaries between the interpersonal and the intrapersonal, the individual and the shared (Stern, 1995, pp. 16-17).

When compared to established therapeutic approaches the caretaker-infant relationship presents several unique aspects. These aspects must be considered when designing treatment for this clinical population (Stern, 1995, pp. 2-4). They are:

- The patient is not a person but a relationship between an infant and its caretakers. It is influenced by the past history on the caretakers' part but by an evolving one on the infant's part. In this context, the term 'relationship disturbance' is not clear.
- To what extent the infant's psychological nature is the construct of the caretakers' imagination is not known.

- Based on classification systems such as DSM or ICD, the infant is not diagnosed as having psychopathologies.
- The caretakers see themselves as having a problem rather than an illness.
- The caretakers, especially mothers, have a ‘psychic organization’ referred to as the motherhood constellation - a mental life adapted to the reality of having an infant to care for. This reality cannot be viewed through the lens of a therapy intended for other sorts of clientele.
- Therapy takes place within a phase which prime function is to effect change, maturation, development and growth.
- To identify the problem may be difficult. Caretakers often feel responsible for the infant’s state affecting normal responsibilities and defences of the target “patient”.
- The mode of interaction is primarily nonverbal and pre-symbolic (a paralinguage or a gestural language of biological communication (Small 1998, p. 58)). Pathology or difficulties dealt with are seen as the result of these preverbal interactions.

If one abandons the pure behaviouristic approach focusing treatment/therapy solely on what the caretakers and the infant do while interacting and bring instead into focus the different relationships and the representation of the interaction, the clinical picture becomes more complicated. Representation refers to the amalgam of remembered history, personal interpretation of relationship and interaction as perceived through the many lenses of fantasies, hopes, fears, family traditions, myths, important personal experiences, and current pressures. It is the caretakers’ representations that are enacted in the interaction that influences the infant. The interaction between the caretaker and the infant is also the ground for the enactment of the infant’s representations, which in turn may influence the caretakers respectively.

CHAPTER 7

PARENTING STRESS AND THE NONFINITE LOSS

Research shows that families with special needs children have higher stress levels than other families and the stress levels of the mother tend to be higher than those of the father. Stressors are multi-dimensional in source and kind. Sources of stress and potential dysfunction of the parent-child system may be related to child characteristics, dimensions of the parent's functioning, or to what Abidin (1983/1995) calls situational/demographic life stress. Due to the heterogeneity of families with special-needs children, some conflicting evidence has been found with regard to stress and its relationship with the severity of the child's disability or the type of disability and also with regard to the child's age. In one study, younger mothers reported higher stress levels (Breslay, Staruch & Mortimer, 1982, as cited in Webster, 1992, p. 4) while Whittick found that having a child with special needs had a reverberating effect on the whole family and the relationships within it. It has been estimated that the enormous pressure a child with special needs often puts on the marital relationship results in a divorce rate twice as high as for the general population. Mothers and fathers are affected differently by parenting a child with a disability and use different defences against stress. Fathers are protected more by aspects of the family environment than are mothers. Research also indicates that mothers derive more benefit from their social support networks than do fathers (Whittick, 1988, as cited in Webster, 1992, p. 3).

Research has also revealed that high levels of parenting stress are associated with dysfunctional parenting behaviour and negative interactions between parents and their child. Parenting stress has been associated with abnormal child development and the presence of a diagnosed psychopathology. Parenting stress during the first three years of life is thought to be especially critical in relation to the child's emotional and behavioural development and to the developing parent-child relationship. Research data indicates that it is possible to make gross predictions about the course of developing parent-child's relationships and the child's later adjustment (Abidin, 1983/1995, p. 1; Niccols & Mohamed, 2000, p. 138).

Emotional strain, social isolation, and the burden of caretaking are described as family stressors in several studies examining distress associated with rearing infants with Down syndrome. Guralnick (1998/1999, as cited in Hooste & Maes,

2003, p. 300) distinguishes between four types of stressors related to child's disability and its effect upon the family and thus the child's development. These stressors are: information needs concerning current and anticipated health and development; interpersonal and family distress manifested as a process of grieving with feelings of uncertainty, guilt, disappointment and ambivalence; the provision of services for the child; and confidence threats or the caretakers' perceived ability to provide adequate education and care for their child.

In the caretaker-infant constellation there are various factors that can contribute to the parenting stress. The infant may display qualities that make it difficult for the caretakers to fulfil their parenting roles. Behavioural symptoms like restlessness, short attention span, distractibility, oversensitivity to sensory stimulation, or an inability to adjust to changes in the physical or social environment can make the parenting task more strenuous and hinder the development of a positive relationship with the child. The interactions between the caretakers and the child fail to produce good feelings in the caretakers about themselves and they may even feel rejected by the child. This can be due to the fact that the child is defective in his or her response capability, the caretakers misinterpret or are unable to understand the child correctly, or the caretakers are depressed and project negative responses onto the child. The caretakers may feel that the child places many demands upon them. The child seems unhappy; it cries a lot or displays other signs of unhappiness. If the child is not as attractive, intelligent or pleasant as the caretakers had hoped, i.e. the child does not match the caretakers' expectations, poor attachment and even a rejection may become an issue in the caretaker-child's relationship (Abidin, 1983/1995, pp. 8-10; Hooste & Maes, 2003, pp. 299-301; Ziolkko, 1991). Stresses related to the parent functioning can be listed as follows:

- Lack of competence.
- Feelings of inadequacy.
- Social isolation from peers, relatives and other emotional support systems.
- The absence of emotional bonding.
- Difficulties understanding the child's feelings and or needs.
- Deterioration in parental health as a result of parenting.
- Parenting role restricts and frustrates in an attempt to maintain identity.
- Feelings of being controlled and dominated by the child's needs.
- Depression due to dissatisfaction with self and life circumstances.
- Lack of physical or psychological strength to fulfil responsibilities.
- Inability to be assertive or authoritative enough.
- Lack of emotional and active support from the other parent.

Guðlaugsdóttir's findings (2002), as well as inferences drawn from informal interviews with caretakers of disabled children, suggest that despite a number of available services and specialists in the field of early intervention, the needs of the caretakers in time of crisis have not received enough attention. It seems that too often the caretakers themselves get lost in the role given to them as their infants' best specialists, and in the emphasis which is placed on the children's developmental milestones. In spite of an adherence to Stern's reciprocal and dynamically interdependent system, various parent organisations and successful treatment programmes need to shift the focus of early intervention strategies more towards the caretakers' wants. Acting in response to their needs is of no less importance than attending to the needs of the infant, or as Trevarthen words it:

Emotional disorders can weaken or destroy relationships between any two persons at any age. If one is too excited or depressed, or too fearful or aggressive, their mutual contact takes a form that reduces the chances of cooperation in awareness and action. This is true for exchanges between young infants and their mothers, and the 'play' of protoconversation with a 2-month-old fails if either is in a disturbed or withdrawn state (Trevarthen, 1993, p. 69).

7.1 The nonfinite loss - chronic sorrow

In grief, nothing 'stays put.' One keeps on emerging from a phase, but it always recurs. Round and round. Everything repeats. Am I going in circles, or dare I hope I am on a spiral? ...But if a spiral, am I going up or down it? (Lewis, 1961, p. 46, as cited in Bruce & Schultz, 2001, p. 149).

Olshansky (1962) described parents' emotional reactions to having a disabled child as a chronic sorrow. His psychoanalytic perspective emphasized that the family carried the grief over the loss of the ideal child throughout life (as cited in Flagg-Williams, 1991). The constant burden of the child's dependency reminded parents of their loss of the expected perfect child. Olshansky's perspective emphasized increasing the parents' comfort in living with and managing the disabled child. Chronic sorrow was regarded as natural, and professionals were advised to help parents deal with the emotional state of grief rather than spend time helping them reach an arbitrary level of acceptance of their situation. Years later, Bruce and Schultz (2001, p. 7) used the term 'nonfinite loss' to describe losses that are contingent on development, the passage of time, and the lack of synchrony with hopes, wishes, ideals, and expectations.

In discussing premises influencing therapeutic approaches in helping individuals deal with nonfinite loss and grief, Bruce and Schultz (2001, p. 170) stress that the grieving process involves cyclical themes of yearning and searching, protest/demand, defiance, despair/resignation, and integration as well as anger, bitterness, and sadness. Guðlaugsdóttir (2002, p. 40) found sorrow to be a significant component in the lives of mothers of autistic children. Experiencing an initial sorrow at the time of diagnosis it recurred at almost every milestone and change in the child's life.

Although debated, chronic sorrow is a valid concept. Like Guðlaugsdóttir's study showed, Wikler, Wasow, and Hatfield (1981, as cited in Flagg-Williams, 1991) and Konanc and Warren (1984, as cited in Ziolkó, 1991) found that parents experienced grief at transitional periods, such as the child's entry into school and at the onset of puberty. Professionals therefore need to understand sorrow and accept it as a normal response for parents, especially at significant life transitions; their parental responsibility never ends. An ability to channel and share negative and positive emotions productively can be a major factor in family success over the disabled persons' lifetime. A chronic sorrow need thus not to be seen only from a negative perspective, but as one aspect of the emotional challenges facing families with disabled children. It should also be mentioned that although milestones may become a hindrance, families can experience great joys and triumphs over things, for that parents of non-disabled children, might pass unnoticed. All milestones gain greater significance (Dempsey, 2008; Harrison, Henderson & Leonard, 2007; Kingston, 2007).

Chronic grief caused by a life event can lead to depression if not dealt with adequately. When sadness lasts a long time, alters one's normal routines or becomes inhibiting in one way or another it may lead to depression. To assess one's emotional state a simple test can be taken which provides yes or no answers to statements indicative to symptoms of depression:

- You often feel sad, lonely, and angry or lack motivation.
- You avoid people and activities previously enjoyed.
- You have difficulties concentrating and making decisions.
- You feel restless and extremely tired.
- You don't trust your skills/talents anymore.
- You torture yourself with self-criticism and guilt.
- You constantly think about the future and see no hope.
- You cry often and sometimes for no reason.

- Your sleeping habits change. Either you sleep too much or you are unable to sleep even when you are tired.
- You have unexplained aches and pains.
- You have little or no appetite or experience other changes in eating habits.
- You have lost your interest in sex.
- You feel devastated and thoughts of death, suicide or harming yourself or others may appear.¹⁴

According to Beckman, Newcomb, Frank, Brown and Filer (1993) movement towards more family-centred interventions have been difficult to implement. This may be because services were designed to provide child rather than family-centred services, the appropriate balance between child and family outcome may be hard to find, or because most programmes/services do not address parents' potential psychological distress and its related long-term effects (Barry & Singer, 2001). Procedures/programmes in use may also lack a clear articulation. To provide information about group structure, processes and strategies could thus clarify why some support groups in EI are effective in addressing what they are intended for and others are not.

7.2 Coping styles

According to Bruce and Schultz (2001, p. 171) the overall goals of therapy for those who suffer from a nonfinite loss are:

- To achieve a sense of mastery over grief or an adaptation that encompasses the preservation of identity.
- To restore control over emotions, cognitions, and behavior.
- To facilitate attachment of meaning to the emerging reality.

Psychoanalysts Solnit and Stark (1961, as cited in Flagg-Williams 1991) were of the opinion that the grief over the loss of the expected ideal child should be resolved. The time for mourning is not available to parents when faced with new responsibilities and feelings for which they were not prepared. Based on Solnit's and Stark's conceptual framework the following suggestions for family treatment interventions have been made: temporary period of maternal separation from a special-needs infant allowing the caretakers an uninterrupted mourning period; crisis intervention focusing on the parents' grief, helping them move on toward positive

¹⁴ www.thunglyndi.landlaeknir.is; www.vh.org/pediatric/patient/pediatrics/cqqa/depression

coping mechanisms; and a group counselling process for parents of disabled infants based on Kubler-Ross's stages of death and dying (1970).

Although actively debated, like the idea about chronic sorrow, stage theories introduced around the 1950s are still an accepted perspective for understanding the parents of special-needs children. The different stage theories share the notion that adjustment is accomplished by moving through predictable and sequential emotional states. Blacher (1984, as cited in Flagg-Williams, 1991, p. 240) reviewed 24 different stage theories and found that they could be summarized using a three-phase model:

1. Initial phase of shock and denial regarded by some as a necessary aspect of the process of moving on.
2. Disorganization following the initial shock. Characterized by a wide range of feelings such as shame, ambivalence, anger, disappointment, guilt, and hopelessness. Disorganized emotional state in siblings is characterized by feelings of resentment, jealousy, and over-compensation.
3. Resolution into a state of acceptance or adjustment.

Huber (1979, as cited in Ziolk, 1991, p. 5) gives the following suggestions to those working with parents of special-needs children: "a) feelings of loss should be recognized as normal and even encouraged; b) it should be recognized that denial or anger may be the best coping mechanism available to parents who are not able to progress to acceptance stage; c) parents should be allowed to proceed through the stages at their own pace; d) the parents' feelings should be accepted and may be constructively channelled into activities; e) parents may need help in seeing that there is some value in being, even when no overt progress is being made; and f) parents' back and forth movement between the stages should be accepted."

Opponents of stage theories say that although it may explain some aspects of family life some of the time, this approach alone does not take into consideration many factors in the lives of families that can moderate, channel or help when coping with crises. Exactly how we cope in a crisis situation may depend on how we perceive stress, the parent and the child characteristics, available formal and informal resources, and environmental factors such as family, neighbourhood, schools and work situation. Thus the broader context of family life needs to be considered in research dealing with the coping mechanisms of parents of special-needs children.

The concepts positive reappraisal, confronting coping, escape avoidance and distancing have been used to explain how people react in painful situations (Dunn et al., 2001; Lazarus & Folkman, 1991). Positive reappraisal involves personal growth, which can be accomplished through being creative and finding new and important concerns in life. Confrontive coping involves fighting for the child's rights, taking changes, and finding ways to express feelings such as anger. Positive reappraisal and confronting coping can lead to increased well-being. On the other hand, escape avoidance, such as hoping for miracles, using food or drugs, and avoiding others is a negative coping mechanism which may lead to increased depression and spousal difficulties. Distancing oneself from difficult life events by behaving like nothing has happened or by trying to forget has also been associated with increased depression.

The theory of inhibition, developed by Pennebaker (1985, as cited in Barry & Singer, 2001), relates confiding traumatic events to negative health outcomes. Not sharing traumatic events (like that of losing the ideal child) is a type of inhibition requiring physiological work, which may become detrimental to one's psychological and physical health. Complex interventions are not always needed for restoring. Methods as simple as brief journal writing can provide temporal organization, increased understanding and sequencing thoughts and feelings, and has been associated with reduced psychological distress, decreased intrusive thoughts, decreased physical stress, and decreased long-term stress-related illness (Barry & Singer, 2001).

Ziolko (1991) encourages grieving parents to express their feelings through talking, crying, exercising, or engaging in creative work. She also recommends that reassurance and support be received from other grieving people.

7.3 Parent-to-parent groups

Parent to Parent has been my lifeline. When I first heard the diagnosis, I was devastated. Well-meaning doctors and nurses, as well as friends and families simply did not understand. It was only when I finally connected with another parent through the Parent to Parent program that I could begin to hope for a future for us all. My veteran parent was gently there for me whenever I needed her (Santelli, Turnbull, Marquis & Lerner, 1997, p. 75).

In this parent match a common bond facilitated intimate emotional sharing which was instrumental in acknowledging feelings and in planning for the future. In a study by Hodapp (1995, as cited in Hooste & Maes, 2003, p. 302),

the presence of supportive social networks was found to enhance the ability of mothers to cope. Parent-to-parent programmes are one form of such network. In parent-to-parent programmes, parents of children with special needs receive emotional and informational support from another parent who is experiencing or has experienced similar life events. The parents are carefully matched with a parent who has been trained as a helper. In the US, the first parent-to-parent programme began 30 years ago. According to Guralnick (1998, 1999, as cited in Hooste & Maes, 2003, p. 302) “parent-to-parent support groups are a unique source of information capable of strengthening families by giving social and emotional support.” They can also assist caretakers in mobilizing friends, extended family, and other community-based natural supports to establish an informal social network influential in minimizing stressors. In a national survey of local parent-to-parent programmes conducted between 1989 to 1993, more than 60% of participating parents felt the following most important in the programme: the emotional support of having someone who shares their experiences listen and understand and getting information on disability and everyday living concerns. The following quotes give insight into the emotional depth and caring empathy often found in parent-to-parent programmes.

My husband and I were so numb with shock that we didn't know which way to turn, and we needed someone to give us some direction. She cried with us - - real tears that only another parent can generate - - and then helped us to see our way through some major decisions. ...When my son was born, there was no local Parent to Parent program, and I felt very alone and scared. There was simply no one who could possibly understand what I was feeling. For that first year until I finally connected with another parent in our new Parent to Parent program, I kept all of my feelings tightly inside. Meeting another parent whose child also had Down syndrome helped me to reconnect with life. So when I was trained as a veteran parent and first walked into that hospital room to meet my referred parent, so many memories filled my heart – both painful ones and joyful ones. I so wanted to help her stay connected with life (Santelli, Turnbull, Marquis & Lerner, 1997, p. 78).

Parent-to-parent programmes can also benefit early intervention professionals when fulfilling needs for families they themselves cannot satisfy.

Thoit's theory of social support (1986, as cited in Singer, Marquis, Powers, Blanchard, Divenere, Santelli, et al., 1999), which many self-help programmes are based on, has also lent itself well to parent-to-parent programmes. This theoretical

framework explains the effectiveness of these programmes by the perceived sameness of experience that members share, serving as an extension of individual coping efforts and enhanced and promoted through modelling and practical advice offered by other members. In these groups, a special kind of intersubjectivity develops based on commonality of experiences. The person being helped senses that his or her feelings are understood and respected. In a quantitative and qualitative study, Singer, Mardquis, Powers, Blanchard, Divenere, Santelli, et al. (1999) found that parents benefit from contacts with other parents by feeling better able to cope with their child and family situation, being able to view their family and personal circumstances more positively, and being able to help others make progress on personal and shared goals. Contrary to many parent-to-parent accounts this study revealed no increase in sensed empowerment.

Dunst et al. (1997, as cited in Hooste & Maes, 2003, p. 301) found that social support has direct, mediating and moderating influences on family functioning and on the behaviour and development of children. Social support provides emotional support which affects parental attitudes, perceptions of children, family functioning, the quality of parenting style and parental well-being. Informal support showed the strongest relationship to several behavioural and developmental outcomes. The researchers hypothesized that psychological closeness and mutual caring among personal network members could have competency-enhancing effects.

Mitchell-DiCenso (1996, as cited in Conner & Nelson, 1999) recognized a caring personality as an important domain in parent satisfaction. Parents themselves report that caring, sympathetic, emotional, physical and spiritual support; an opportunity to talk and to be heard, an opportunity to show feelings, an effort to make parents feel better and to feel accepted, and being given enough time are all favourable approaches to care that influence perceived satisfaction (Able-Boone, Dokecki, & Smith, 1989; Baas, 1991; Blackington, & McLauchlan, 1995; Jacano, Hicks, Antonioni, et al., 1990; Kenner, 1990, as cited in Conner, & Nelson, 1999).

Cunningham (1996, as cited in Hooste & Maes, 2003, p. 301) found that problem-solving strategies were effective in coping with child problems. These strategies were associated with caretakers increased well-being and better functioning for the child. In general, social support is believed to have important influences on parent, family and child functioning. Family counselling services have been helpful for caretakers when having to cope with negative feelings and reactions, and subsequently contribute to a reduction in interpersonal and family distress.

Shonkkoff et al., (1992, as cited in Hooste & Maes, 2003, p. 302) found a correlation between participation in parent groups and changes in the subjective evaluation of being helped. Parents who received help that encouraged or required interactions with other parents evaluated the help more positively than families who got individual help.

According to Krauss, Upshur, Shonkoff and Hauser-Cram (1993) investigations of the benefits of parent group participation have yielded inconsistent findings. Some empirical studies show evidence of benefits for those participants who feel in need of support and who are skilled in interpersonal communication. Other studies show evidence that parent groups may have adverse effects on those who have limited needs for additional support. An example of this could be mothers who feel compelled to listen to the complaints of others or obligated to share their feelings before they are ready to do so (Affleck et al, 1989, as cited in Krauss et al, 1993). Krauss and associates examined the outcomes of participation in professionally organized parent groups for 150 mothers receiving EI services. Parent groups were found to enhance maternal perception of the amount of support received and the quality of available support from peers. Participants who benefited from their participation stated that the groups reduced their sense of social isolation, provided a forum for sharing their pride in their child's progress, allowed them to share resources and ideas, and gave them an opportunity to make friends.

Participation was not found to alter mothers' interactions with their children, their feelings about their children's behaviour, their feelings about the personal consequences of parenting, or their appraisals of the adverse impacts of a child with a disability on family life. Some mothers commented negatively on the group experience and felt that they were pushed into a relationship, and that they felt uncomfortable listening to other parents who had different or more severe problems than their own. Some participants questioned the competence of the group leaders and were concerned about the dominance of the group by a few.

These findings reveal a complex and multi-dimensional impact of parent groups on participants during the first year of intervention. Krauss & al. (1993) recommend that explicit goals of parent groups, their content and process of group formation, the professional training of group facilitators, and the criteria for individual parent participation should be studied further (Krauss & al., 1993).

According to Niccols and Mohamed (2000) the advantages of group-based interventions over individual interventions are: 1) The group provides social networking with other parents, and social support is an important factor for family

and child outcomes. 2) The therapeutic group processes or group dynamics. 3) Parental empowerment enabled through the act of helping others. According to Dunst, Trivette and Deal (1994, as cited in Niccols & Mohamed, 2000, p. 135) individual interventions run the risk of disempowering parents. Also, individual treatment programmes are usually more expensive than group interventions and may also have more psychological barriers (Cunningham, 1995, as cited in Niccols & Mohamed, 2000).

CHAPTER 8

MUSIC THERAPY RESEARCH AND PRACTICE AS RELATED TO EARLY INTERVENTION AND MUSIC-CARING

8.1 Music therapy research

A literature search in databases reveals that empirical work done by music therapists or music educators evaluating the use of music in EI is relatively scarce. Early quantitative research studies focus mainly on the infant's physical responsiveness to musical stimuli. Chapman (1975) examined the effects of lullabies on weight gain and movements of newborns. He found a 16% reduction in the total time it took premature infants to reach weight criterion for discharge. Owens (1979) conducted a similar study with term infants from birth to three days old. In her study no significant differences in variables were found. Falb (1982) investigated the effects of music versus recorded heartbeat as a reinforcer for conditioned vasoconstriction in three multiply-disabled, nonresponsive, profoundly mentally disabled infants. Both heartbeat and music were found to elicit response in these infants as manifested by overt signs of sucking at the end of the experimental period.

Witt and Steele (1984) assisted the mother of a fourteen-month-old multiply-disabled child over a period of 16 weeks to use music and music-related activities and objects in her interaction with the child. Behavioural observation was conducted of eye contact, purposeful reaching for objects, and response to own name; it revealed a significant improvement. According to the mother, a more important achievement was that the family felt improvement in its ability to relate to the child in a helpful and a meaningful way.

More recent research conducted with premature infants in neonatal intensive care units (NICU) has advanced the application of music therapy with this fragile population. Besides using behavioural observation to measure physical gains affecting, for example, the length of hospital stay (Caine, 1992; Kaminski & Hall, 1996; Schwartz & Ritchie, 1999) researchers are also interested in examining interaction, communication and bonding between the infant and the parents (Nocker-Ribaupierre, 1998; Shoemark, 2004; Standley, 1991). According to Shoemark:

We do not have a music therapy literature base for the inclusion of music therapy as early intervention for the long term development of hospitalized infants. More specifically, there is a need for research and documentation of the role of music therapy in supporting the family as the intervention unit, rather than the infant alone (2004, p. 141).

While the above studies describe, for example, the parents' helplessness in handling their babies and their difficulties in engaging them, only one study has been found which focuses solely on how music was used in therapy for mothers of older disabled children. This study as well as two Norwegian research projects done in 1997, will be described below as they hold relevance for this research.

Trolldalen (1997) did a qualitative music therapy project called Music Therapy and Interplay: A Music Therapy Project with Mothers and Children Elucidated through the Concept of "Appreciative Recognition". Working at a childcare institution, Trolldalen's participants were a voluntary group of single parents/mothers. Three mothers and child pairs (aged 2-4 years) attended regularly and two pairs occasionally. The group consisted of ten 35-60 minute recorded sessions over a period of four months. The study examined how mutual recognition and appreciation can promote interplay between mothers and children and how can musical interplay can function as potential for change and shed light upon musical processes in the music therapy group. In her study, Trolldalen used a qualitatively oriented method focusing on events. The approach was abductive or a combination of both inductive and deductive methods. Theoretical understanding was based on empirical work, where alternation between theory and empiric work was used when searching for an understanding. An element of hermeneutics could also be found in her study, where parts were interpreted in light of its entity and vice versa, and the researcher's pre-understanding or pre-assumptions played a role.

Trolldalen found that mutual recognition, meaning 'I am me' and 'you are you', and 'we understand each other and share a relationship', is fundamental to processes of change. She also found that mutual 'recognition' in a musical dialogue can promote a positive development (Trolldalen, 1997, p. 109; Trolldalen, 2000, p. 74).

Another master's study focusing on interaction between parents and their disabled child was conducted in 1997 by Frisk - *Sang i kommunikasjon med det svaktfungerende spebarn. Hva skjer når mor synger til sitt svaktfungerende spebarn?* (Song in communication with a disabled infant. What happens when a

mother sings for her disabled child?) Working with parents/a mother and a Down syndrome child, the purpose of Frisk's study was to portray how parents' singing might influence the special-needs infant's attention span and how song might influence positive interaction and the development of 'safe communication' in early contact formation. Furthermore, she wanted to depict how music therapists might provide support for parents facing a difficult life situation and to inspire other music therapists interested in the subject. Like Trollalden, Frisk used a qualitatively oriented method focusing on events within the hermeneutics tradition. Moreover, she defined her project as an experiment or a pilot study, using action research as a method, whereby the intention was to learn by doing.

Frisk was interested in encouraging people to use their inborn musicality. She wanted to make music a part of everyday life and not an activity framed by certain places or used by professionals only. She wanted to encourage the transference of song to the child's home environment. She was also interested in meeting the needs of the caretakers and, in that context, examined the importance singing and music might hold for them. Frisk drew attention to the fact that parents often need help to understand their children and that perhaps due to their role as primary caretakers, and the common emphasis on the children's needs, the parents' needs are overlooked (Davis, 1995, as cited in Frisk, 1997, p. 3).

Frisk's study showed that the mother's conscious use of her voice and her singing elicited more focused eye contact from the child, which in return motivated further interaction. Her study also revealed how important and beneficial supervision and early support can be for the caretakers of disabled infants. What happens spontaneously and intuitively needs to be encouraged. According to Frisk it is not the selection of 'correct songs' but the mother's own repertoire, kindled by her own feelings at the spur of the moment, which holds the meaning.

Webster (1992) presents three short case studies in a paper called *Caring for the carers. Communication and support in music for parents of children with special needs*. Webster had planned to conduct one group session and three individual sessions with the ten parents who originally expressed an interest in the project. However, due to different reasons only two mothers remained in the study. Instead of working with them as a group she offered to work with them on a one-to-one basis. Only one of them had two individual sessions after the first group session and the other one dropped out before she got started. Her son was continually ill and she gave the reason that it was not the right time for her. Difficulties in getting people to participate brought up questions. Was the thought of music therapy too intimidating?

Did the mothers think it would be too threatening to their coping mechanisms? Was the offer seen as therapy, support or neither?

Of the three single case studies Webster presents, one mother referred herself to music therapy because she was “keen to experience it for herself.” Her daughter, now 15 years old, had had two years of music therapy. Jane, the mother, was feeling lost and withdrawn and wanted a creative outlet. She was also hoping that what she would learn could be transferred to her home situation, “making our sessions livelier and more appropriate to our abilities.”

A citation from session seven:

She cried, as I continued playing in the same style. Jane said that she did not feel she had the strength to face all the things she had to deal with. She felt inadequate. I suggested that Jane played the soprano glockenspiel and that she tried to find that strength in the music. In the improvisation that followed, Jane started by playing “Swing low, Sweet Chariot” and I added an increasingly dissonant accompaniment. Her playing grew in dynamic and strength, and she then improvised out of the song. The high-pitched metal bars took on a piercing quality as Jane hit harsh dissonances, and the music became hard and gritty. It was very expressive and it was obvious that Jane was completely involved in it (Webster, 1992, p. 12).

In the final improvisation, Jane played three drums and a large cymbal almost continually, leaving very little space in the music for me. There had been little quiet during this session and it seemed as if Jane needed to off-load difficult emotions, requiring merely my support as she did so. I also felt, however, that she needed to feel she had the strength to cope with her life and the demands it made of her. She would only be able to find that strength from within herself. The sessions could offer her immediate support. Could it also offer her an opportunity to grow as a person and realize her own inner strength? (ibid., p. 12).

In her final, tenth session, Jane talked about being sad to finish. Her playing had little energy and sounded empty and lethargic. Her daughter was ill and Jane felt it was impossible to do anything purely for herself. The last improvisation on the soprano glockenspiel was child-like. Jane cried towards the end, still playing in her simple style and the therapist provided a support by playing warm, strong romantic chords. The session lasted an hour, and Jane seemed reluctant to finish. She talked about the long summer holiday ahead and her fears of coping with it.

A minute account from a case study gives only a glimpse into the feeling world brought into, provoked by and expressed through the music. And it tells neither something of the therapeutic process nor the therapist's thoughts and reasons for her actions. The therapist tells us that Jane was able to release some of her feelings in a positive and creative way, which perhaps balanced her life a little. Jane herself tells us that she had been reminded of her own strength, that she had felt renewed hope shared in a relationship with another human being, and that she had been reminded of the fact that she did not have to be or feel alone. She could use her own initiative to find new possibilities. She felt she could enjoy her daughter and enjoy being with her daughter through the music they shared (Webster, 1992, p. 14).

The three women Webster presents in her case studies all have children who need extensive care. Their lifestyles revolve around their children and the mothers' personal needs and wants become suppressed. "There was a strong sense of a very powerful amount of energy which lay just underneath the surface, and which had been suppressed for a long time" (Webster, 1992, p. 19). In order to manage, they take one day at a time, and allow themselves little time for their own personal needs. The coping mechanisms of the mothers are reflected in their playing. This was reflected in Nora's playing as short melodic or rhythmic fragments, and limited sense of overall shape or direction. Her music was tightly controlled and it seemed difficult for her to let go. Hannah's music mirrored separation from her own feelings. She showed some musicality and was capable of playing in different styles, yet it seemed like her own music was meaningless to her. To endure, these women neither allowed worries about the future nor personal dreams to throw them into turmoil.

Hanna had hoped that the music therapy would relieve some of her stress and anger, and she thought music therapy might be fun. Nora thought she would get some "mental relaxation." She wanted to do something for herself. She loved music and to play instruments and told her therapist that music always made her relax. Jane was keen to experience for herself what her daughter might have experienced when in therapy. She felt lost and withdrawn and was lacking creative outlet. She hoped that what she would gain in music therapy could be transferred to their home situation.

Webster's suggestions for further work in this area concern the outer framework. She feels that parents should be informed about the availability of music therapy for themselves. If interested, they could come forward and commit themselves for a trial period. Based on experience they are in a better

position to decide if they are interested in music therapy for themselves, sessions with their children, or therapy for their children.

The three research studies described above disclose a vulnerable population and intense therapeutic moments. They reveal how musicking and music therapy can address the various needs of both caretakers and their special-needs infants dealing with issues such as relationships, development, change, sensitivity, emotions and context.

Reflecting on Frisk's and Trollalden's studies, among others, Ruud stresses the importance of the context of the musical interactions or the relation between the people involved in musical communication for the formation of meaning in music. Ruud says that if we examine why music is effective as a therapeutic medium by saying that it is because music creates meaning, then we have to ask how and why music is meaningful in therapy (1998, p. 15). The answer is that music is meaningful not only because of the expectations aroused in us when we relate to music or because we make explicit some hidden meaning embodied in the musical structure, but because of the dialogical nature of the musical interaction. It is meaningful when the client experiences moments of presence or a real authentic relationship with the therapist - moments where the therapist is really present or caring (Ruud, 1998).

Hitherto no empirical work has been done in Iceland by music therapists or music educators focusing on infants and their caretakers within the hospital setting (NICU) or the framework of early intervention.

8.2 Music therapy practice

The Head Start and the Disabled Children's Early Education programmes in the United States, the Marte Meo programme in the Netherlands, and the More Intelligent Sensitive Child programme (MISC), developed by professor Pnina Klein in Israel, are examples of early intervention programmes/institutions serving special-needs infants and their caretakers available in many countries today. These programmes/institutions have developed different perspectives and approaches in an attempt to meet the various needs and varying challenges of these families, but to the best of knowledge they do not in particular encourage the use of music, musicking or music therapy in their treatment schemas. According to Frisk (1997) an exception to this is a programme launched by a Norwegian psychologist, Anne Marie Rostad, in Nord-Trøndelag in 1993. Following the principles of EI it is interesting to note that Rostad advocates the

use of children's songs, rhymes and poetry to support and stimulate communication between children and caretakers.

Music groups for infants/young children and their caretakers have been available in many countries for some years now. These groups are either run privately, by different organizations or by official health care institutions. An example of this is the Norwegian national organization *Musikk fra livets begynnelse*,¹⁵ founded in 1990. This organization focuses on music with children from birth to six years old and their caretakers. Currently *Musikk fra livets begynnelse* has around 500 members, most of whom are specialists in working with young children. The organization focuses on developing its members' skills through participation in workshops and sharing written information. Sometimes different professionals, like music teachers/music therapists, nurses, physiotherapists, and play therapists, run music groups together. The structure and the outer framework of these groups/programmes vary, i.e. the number of participants, duration of sessions, the length of the programmes and the goals of the groups.

“Introducing a child and his or her parents to music can be like opening a curtain to let some sunlight pour in” says Gascho-White (1991, p. 61), who began running music therapy circles for babies at Plan and Learn Nursery in 1986. In her opinion, the music sessions were as important, if not more so, for the parents as they were for the infants. According to her, there are two important considerations in this type of work; how is music used to make contact with a child under the age of two and how can a meaningful contact be made with the child's parents?

Kari Aftret, a Norwegian music therapist, delivered a lecture on music courses for parents and their babies at the Nordic Music Therapy Conference in Bergen in May 2003. She has for some years now run four to five music courses a year for this population. The groups are run together by three professionals – a community nurse, a physiotherapist and a music therapist. In home visits after a child is born the community nurse invites parents to attend these groups. Vulnerable families, i.e. families with a disabled infant, a premature baby, young parents, single parents, immigrant parents, parents with mental and learning difficulties, and families with a small social network are specifically encouraged to come. These courses are run for eight weeks and last one to one and a half hours each time. In those groups, music is used in the work of health promotion as a source of joy and vitality, cultural activity, a

¹⁵ <http://www.musikkfralivetsbegynnelse.no>

tool to elicit interaction between parents and babies, and a bridge-builder between families and social networks.

The above mentioned music therapeutic research and practices strongly suggest that music therapy within early intervention services could in various ways benefit its clientele.

CHAPTER 9

THEORIES OF CARE DEFINED BY HEALTHCARE PRACTITIONERS

Bearing in mind the emphasis EI places on researching what environmental factors have the most significant influence on early development and the use of knowledge to nurture, protect and ensure the health and well-being of young children and their families, questions arise. What defines caring? Is it possible to provide care through the use of music? What does helping mean and what does it mean to be a helper?

9.1 The helping relationship

Helping can mean different things to different people in different situations. The various definitions of help make it difficult to describe. Furthermore, just like music, it is possible to define helping as both science and art. Like science, helping involves research and theory on helping. It is concerned with descriptive data, predictions and generalizations about behaviour. On the other hand, helping as art refers to intuitive and feeling elements of interpersonal relationships that are rooted in the humanities and the creative arts (Brammer, 1979, p. 11). Each helping session is then a product of creation (art) and science where integrated theories within an eclectic and holistic framework are required to fulfil a basic premise which is helping another human being to sense his or her wholeness and reach his or her unique potential. According to Bruscia, music therapy provides a specific kind of help:

[M]usic and the therapist combine their resources to provide clients with opportunities for receiving empathy, understanding, validation, and redress; for verbal and nonverbal self-expression, interaction and communication; for feedback on themselves and insights about their lives; for motivation and self-transformation; and for direct assistance and intervention (Bruscia, 1998a, p. 21).

Aldridge said that we could disable our clients further within their own disability by the way in which we respond to them (1996, p. 15). Having observed the same clients interact with different music therapists has made it clear that the personality of the therapist, his or her intuition, communication

skills, attitudes, affection and respect for the client may be as significant for a positive outcome of therapy as the underlying theories or methods. It is the expressed affection for and playfulness with the child, the humour and admiration with the teenager, the warmth and respect for the grown-ups, which the client senses to often surprising depths, despite a disability or disease. It is the client's perception of the therapist's attitude towards him or her as a whole being, which, in the therapeutic process, may be as important, if not more important, than the theoretical framework.

Based on experience as a music therapy clinician, it is the therapist/researcher's opinion that there is no one way of doing it right with regard to theories and methods, although there are some essential elements upon which effective therapeutic relationships must reside. These elements are essential whether the techniques are derived from psychoanalysis or behaviourism. In other words, these elements are what helping interventions may have in common. They are both the general helper characteristics and also facilitative traits. Furthermore, they colour the way music is used and influence its effectiveness in the relationship; without them, the best methods and the most elaborate techniques become hollow and superficial. Also, without them there can be no music-caring. This is perhaps our tacit knowledge, which loses its vitality and depth when put into words, the knowledge that allows us to be persons and not only professionals in the relationship, and which also changes in depth and scope throughout our professional lives.

Although diffuse, these elements could be grouped under the concept of caring or care. It is because one cares for the well-being of the client that a therapist behaves and reacts in a certain way. It is not only the dying or the newborn baby who need our care, as a literary research in music therapy and caring might suggest. All humans need care and it is not only within family or friendship relations that care can be provided. Music therapy is a helping relationship that provides professional care at its best. It is because one is a professional striving for competence that one integrates theories, and it is because one is a person that one communicates care in an intra- and interpersonal helping relationship.

Theories of caring have been developed in helping professions such as nursing. These theories strengthen the conviction that along with integrated theories and a holism, a caring attitude needs to be developed in music therapy practice. Parenting techniques will not work unless a basic level of attachment and caring exist. Similarly, mere techniques and knowledge are not enough in

therapy. It is the person's sense of being cared for which is therapeutic. This is what sustains the relationship and adds depth and life to it. It is the caring attitude with all its elements, which in many helping relationships may be the single most important factor. The basic concepts are: Caring is central to human expertise. Caring is a basic way of being in the world. Caring is central to curing and to healing. Caring creates possibility (Benner & Wrubel, 1989).

“Caring sets up what matters to a person, it also sets up what counts as stressful, and what options are available for coping” (Benner & Wrubel, 1989, p. 1). It is our caring that may cause experience of loss and pain, and also make joy and fulfilment possible. It is the caring concern about people, projects, things, and events which provides motivation and direction for action. If, for some reason, we stop caring for our loved ones, worries about their well-being diminish. Moreover, if a parent does not care for his or her child, if the parent is not engaged by its cries, its laughter, or its milestones, finding ways to manage in extreme conditions may be extremely difficult. As a source of the stressful experience itself, maintaining the caring relationship may thus be overlooked too often (Benner & Wrubel, 1989, pp. 1-4).

Although the therapist–client relationship is not at the same level as the parent–infant relationship, what is done to, for or with the client has different effects in a caring context than in a non-caring one. Thus ‘professional caring’ allows the therapist to notice the subtlest signs consciously or unconsciously expressed by the client. It also builds trust, which enables the one cared for to accept the help given and to feel cared for. A caring relationship occurs in a context and this context is central. It is the client's feeling of uniqueness that he or she identifies as caring. It is also the therapist's involvement in the situation here and now, which cannot be transferred to another situation. The therapist has to ‘presence herself’. She has to be accessible, to instruct, to be available, to understand and to be with her client, in contrast to standing outside the situation or being inattentive while being physically present (Benner & Wrubel, 1989, p. 6).

According to Riemen (as cited in Halldórsdóttir, 1996, p. 11) three themes identify a caring therapist–client interaction. They are: 1. An ‘existential presence’ or being available for the client. 2. A recognition of the client's uniqueness by listening and responding to the client as a valued individual and a human being of value. 3. The consequences when the therapist's individualized concern for the client results in the client feeling comfortable, secure, at peace and relaxed.

Conversely, a non-caring interaction can be recognized by: 1. A physical presence available briefly to ‘get the job done’. 2. An attitude that does not

recognize the client's uniqueness. The therapist does not really listen. He or she appears too busy to pay attention to the client as an individual. 3. Consequences manifested by the client feeling frustrated, angry, frightened, upset or depressed.

Professional care is not a unidirectional relationship but rather reciprocal or circular. Both the helper and the helped influence and are influenced by the other. The client's reaction gives the therapist feedback that modulates her actions accordingly. The therapist's response communicates to the client an array of messages, some of which are interpreted and responded to. There is a constant flow of intra- and interpersonal messages to affect the behaviour of the other in such a way as to produce mutual satisfaction of needs. One's knowledge of the person one is working with, one's relationship, and one's observation of gestures, all affect one's actions as a therapist while also affecting the client. Who is the initiator? There are multiple, simultaneous cause and effect relationships between events at all times in the ongoing interaction. If one cares about the client's well-being, one allows him the feeling of being in control. Being in control is an important factor in the perception of health. If the client's sense of control is diminished, whether knowingly or unknowingly, by ignoring causes and effects between events, one diminishes the client's sense of health and well-being and thus works contrary to the proclaimed aim of therapy, which is to manipulate our world in such a way that one can make one's environment more conducive to survival and well-being.

In the music therapeutic relationship, the therapist also meets her own needs to help others and her own needs for personal and professional growth and satisfaction. In its broadest sense, counter-transference takes place because both conscious and unconscious predispositions and responses of the therapist to the client have their origin in the therapist's personality and experience (Brammer, 1979). So long as the unconscious needs of the therapist, his/her need to help and his/her caring attitude do not interfere with effective intervention strategies this circular cause and effect relationship may prove beneficial. Evaluating one's values and being in touch with oneself guides against the misuse of counter-transference and allows for an empathetic understanding, despite possible differences in values and opinions from that of the client. To that end, questions like: Who am I as a therapist? What is it that makes me react the way I do in a helping relationship? and What is important to me? may prove helpful. Supervision or counselling as well as reflection and meditation are also possible means for the helper to analyze and stay in touch with his or her own feelings (Benson, 2001; Brammer, 1979; Bruscia, 1998b; 1998c).

Bruscia states that empathy is the basis for all helping interventions and music, with its adaptability and its multiplicity, is an excellent medium for empathy (1998a, p. 61). Empathy is a facilitative trait that enables the therapist to understand the client and enables the client to feel he is understood. The therapist makes an effort to identify with or experience the world as the client experiences it, i.e. from the client's internal frame of reference without losing his own identity or objectivity. When we sing or play with the client we become united within the experience. Music unites participants in the same activity which can be both active and receptive and which exists in space and time. Through this inter-subjective music experience where the client's music is being responded to as expressively and communicatively meaningful, the client has a sense that the therapist knows how he/she feels and the therapist gets a clear sense of how the client experiences himself (Pavlicevic, 1997, p. 117).

But it is not enough to be skilful in empathic techniques such as imitating, synchronizing, reflecting and incorporating; the client must be able to use the therapist's empathetic understanding for his own self-understanding. Too much empathy from the therapist could perpetuate a dependent immaturity in the client. Too little empathy, on the other hand, limits the therapist's understanding of the client's needs and prevents the building of trust in the helping relationship. Exactly how much empathy and what kind of empathy the therapeutic situation requires must be negotiated between the 'horse' and the 'waggoner' or the 'rational mind' and 'feelings', respectively. It is a role played by our intuition and one can agree with Aldridge when he states: "Somehow that which is intuitively sought is lost in the process of description" (1996, p. 24).

According to Stige creativity and intuition are overlapping concepts that are difficult to define (1991, p. 68). A dictionary definition of intuition is: "the act or faculty of knowing without the use of rational processes; immediate cognition" (The American Heritage Dictionary of the English Language, 1980, p. 88). To this definition one could add the 'faculty of knowing without' the conscious use of rational processes. Guided by our intuition, or 'faculty of knowing' helpers are truly present, spontaneous and flexible in the helping relationship. It is because they care that they bring their best selves and everything they know to be conducive to the client's growth, development and well-being. To a certain extent one could compare the therapeutic relationship to the relationship parents have with a newborn when its care is entrusted to them. There is presence, acceptance, closeness, understanding, feelings, warmth, structure and freedom in the relationship. Caring parents sing for and with the child. They sing the songs of others long before the child understands cognitively what they are singing about but the child is nurtured by the warmth, closeness and feelings

expressed through this communicative act. Parents make up their own songs for and about the child affected by its being and simultaneously encoding and decoding communication cues. Furthermore, parents are guided by the experience and knowledge of others. Most importantly, however, it is our own intuition, creativity and immediacy that play a central role. Intuition is not an innate talent says Stige, but one that can be developed, and through which one comes to realize interconnectedness and wholeness (1991, p. 74). Whether partly innate or not, intuition is a part of tacit knowledge and its importance becomes apparent as professional experience increases. One comes to realize that one's intuition does not exclude knowledge -it only makes better use of it.

CHAPTER 10

WHY MUSIC-CARING?

10.1 Music and emotion

The motherhood constellation as described by Stern (1995) is a basic and normal psychic organization in response to getting pregnant and having a baby. Maternal depression, on the other hand, is a clinical situation “a large concept made up of many smaller criteria that are present over a period of time” (Stern, 1995, p. 62). Maternal depression involves different types of depressive interactions on both macro (“a single traumatic event”) and micro (“way-of-being-with”) levels (Stern, 1995, p. 63).

According to Field (1998), depressed mothers have a distinct biochemical profile that can be used to target those in need of intervention. Field found mood-induction interventions, such as music therapy and massage therapy, to be extremely effective short-term interventions for depressed mothers as measured by electroencephalography (EEG) and urine analysis of the stress hormones cortisol, norepinephrine and serotonin. After listening for 20 minutes to rock music, ten of 12 depressed mothers showed attenuation in right frontal EEG activation towards symmetry between right and left activation. When the two mothers who didn't like rock music listened to their favourite classical music, their EEG measures also shifted toward symmetry. According to Field, brief interventions that alter the mother's mood (as measured by EEG and lower stress hormones (norepinephrine and cortisol) may reduce the infants' arousal, improve their interactions and make them more responsive to interaction coaching. From the perspective of biological functioning, music can have a positive effect upon neural functions and hormonal activity facilitating the healthy functioning of the body's own immune and regenerative processes.

Despite these findings, the field of music and emotion has developed slower than other domains of musical science. Emotions and emotional reactions to music are difficult to study in the laboratory. Cognitive science has hitherto dominated the field on music psychology, leading to a strong emphasis on cognitive aspects of musical behaviour. This field has been guided by information-processing approaches as a common paradigm but the study of music and emotion is not yet guided by any universal paradigm. According to Juslin and Sloboda (2002, p. 5) it is debated whether current theories of emotion are adequate for dealing with music.

Due to disagreement in the field, Juslin's and Sloboda's view is that it be best served by a multiplicity of approaches. Early studies on music and emotions (for example Kate Hevner in 1935 and others), focused on matching emotion labels to excerpts of music. These early attempts, which gave no directions towards further studies, were abandoned in the era of behaviourism in the 1940s and 1950s when the study of emotions was seen as non-scientific. To date there have been limited advancements in the field. Another contributing factor to the neglect or avoidance of studying music and its relationship with emotion is an emphasis on approaching music intellectually. One is taught to appreciate music silently and respectfully with minimum bodily movement and emotional expression. Where emotions are valued "they tend to be those rarefied (transcendent or spiritual) forms that are related to 'higher' abstract and aesthetic properties of works, rather than the everyday or full-blooded emotions" (Juslin & Sloboda, 2002, p. 5).

Seen through the eyes of a physicist a musical event is a collection of sounds with various pitches, durations, and other measurable qualities. The human mind endows these sounds with significance. They become symbols for something other than pure sound, something which enables us to laugh or cry, like or dislike, be moved or be indifferent. Besides some 'primitive responses' to music shared by the whole species (manifested for example when certain pitch ranges, timbres and repetitive rhythms attract infants or when loud and fast music arouses and slow music soothes) our emotional response to music has both cognitive and learned components.

According to Sloboda (2000) primitive tendencies can neither count for the subtle and multidimensional nature of the adult response to music, nor for the many significant cultural differences in response. Furthermore, our emotional responses cannot be explained simply by conditioning theory, which supposes that a piece of music acquires the emotional significance of the circumstances in which it happened to be heard. The context is important, but this theory is inadequate as a complete explanation for emotional responses, argues Sloboda. He gives the following reasons for this opinion:

- Listeners within a musical culture generally agree on the emotional character of a given piece of music, even though they may have never heard it before. Conditioning theory would predict wide individual differences according to circumstances of hearing.
- The emotional character of a piece of music is not unitary and unchanging. Experienced listeners to some types of music are able to identify a web of differing emotions which are evoked by the detailed

sequence of events, and which become more finely differentiated the better the music is known.

- Our emotional response to the very same music can vary considerably from hearing to hearing.

Langer (1979, as cited in Sekeles, 1996), who warned against baseless assumptions regarding music and emotional expression, mentions differing emotional interpretations that performers and audiences can apply to the very same work. Sekeles (1996, p. 32) draws attention to the fact that research has not been able to provide answers to the question of why music with characteristics such as low pitch, a moderate melodic range, a moderate tempo and a soothing dynamic arouse varying feelings such as sadness, longing, and tranquillity in different subjects.

Sloboda answered the question of why so many take part in musical activities of some kind by stating that music arouses deep and significant emotions. “These emotions can range from the ‘pure’ aesthetic delight in sound construction, through emotions like joy and sorrow which music sometimes evokes or enhances, to the simple relief from monotony, boredom or depression which everyday musical experiences can provide” (1985/2000, p. 7). Furthermore music’s emotional factor is transcultural. “It seems unlikely that music could have penetrated to the core of so many different cultures unless there was some fundamental human attraction to organized sound which transcended cultural boundaries” (Sloboda, 1985/2000, p. 7). Music also has a secondary social meaning, and gives social rewards to those who participate in it.

Still lacking scientific explanations for music’s emotional power, the therapist/researcher, concerned with the impact of music-caring for mothers of children with special needs asks herself: What kind of emotional/social meaning could music hold for these mothers? Could music and music-caring in some way have an effect on their quality of life?

10.2 Music-caring through musicking

Musicking is a term Small introduces in his book *Musicking: The Meanings of Performing and Listening* (1998). Small believes that one cannot ask the question: “What is the function of music in human life?” because there is no such thing as music. Music is an activity he says, something that people do. The object or thing termed ‘music’ is only an abstraction of the action. It is useful perhaps when conceptualizing our world but dangerous because one may come

to think of it as more real than the reality it represents (1998, p. 2). Small also believes that the fundamental nature and meaning of music lies in what people do with it. “It is only by understanding what people do as they take part in a musical act that we can hope to understand its nature and the function it fulfils in human life” (1998, p. 8).

To take part in a musical act is of central importance to our humanness. And ‘to music’ covers all participation in a musical performance, whether it is active or passive, sympathetic or antipathetic, constructive or destructive, interesting or boring (Small, 1998, p. 9). In Small’s opinion, every human being forms a kind of theory of musicking. That is, an idea of what musicking is and is not, and of the role it plays in our lives. As long as it remains unconscious and un-thought about, Small argues, it can be both controlling and limiting (1998, p. 13).

According to Dissanayake (2000, p. 73), infants are guided by their instincts to look to elders in a search for what is meaningful. Research has shown that parents use pre-verbal communication or musical elements intuitively with their newborn not knowing about the importance of humming, singing, rocking and playfulness. This musical interaction supports the acquisition of speech, affects behavioural or emotional states in infants, and supports the development of musical, interpersonal and emotional intelligence. Parents do this most often without formal knowledge of its importance. At its best, it is done lovingly, carrying with it emotional states, and it is also done playfully, encouraging creativity and perhaps humour in later life, says Papousek (1996, pp. 46-50).

It can be the role of the music therapist to inform caretakers about the importance of their intuitive musicking or the music stimulation in which they partake with their infants. It is their role to make caretakers of children with special needs aware of their theories of musicking in order to make better use of it for the benefit of themselves and their infants. To understand musicking is a part of understanding ourselves and our relationships with other people, be it our infants or other creatures with whom we share our planet, as Small stresses (1998, p. 13). If through musicking we can bring into existence relationships in our world as we wish them to be, as Small suggests, then it is possible for caretakers, with the guidance of a music therapist, to use music to learn about themselves, their infants, and their experiential world of relationships in all its complexity. By knowing their world they learn how to live well in it (1998, p. 50).

Small builds his theory of musicking on Bateson’s philosophy of mind – the ability to give and respond to information which is connected to the larger

network in which every living creature is united with the other ones. The mind relates to the environment by an active process of engagement with it. What holds the pattern together is the passing of information from the outside world to the inside world, from the external to the internal pathways and vice versa. Thus one can say that living things shape their environment as much as they are shaped by it (Small, 1998, p. 53).

If the ultimate goal of music-caring is to induce some kind of change, it is done through relationships. In early intervention the participants in various relationships are the music therapist, the caretakers, the infants, perhaps siblings and other relatives and preferably other therapists. The possible clinical applications are diverse, targeting areas such as:

- Physiology (for example heart rate, blood pressure, respiration electromyography, neurological functions and immune responses).
 - Psychophysiology (for example pain, levels of arousal and levels of consciousness).
 - Sensory motor development (for example reflexive responses and their co-ordination, sensory motor schemes, and fine and gross motor development).
 - Perception (for example comprehension of figure-ground, part-whole and same-different relationships and discrimination of differences).
 - Cognition (for example learning skills, knowledge, thought processes, and attitudes).
 - Behaviour (for example activity level, efficiency and morale).
 - Emotions (for example range of emotion, variability, appropriateness, and congruence of feelings, reactivity, expressivities, vitality, defences, anxiety, depression, motivation, and imagery).
 - Communication (for example receptive and expressive speech and language skills and other nonverbal communication modalities).
 - Interpersonal relationships (for example awareness, sensitivity, intimacy, tolerance of others, interaction skills, and role behaviours).
 - Creativity (for example inventiveness, and problem-solving skills).
- (Bruscia, 1998a, pp. 153-154).

What happens in the representational worlds of the expressive and receptive participants during their participation in one song? The cognitive sciences tell us that representations, memories, and motor programmes are composed or constructed anew each time an act is committed or a memory is retrieved. This means that what is happening now will employ the entire schema that is related

to the present ongoing activity, mentally or physically. The relationship formed around a song theme or an improvisation focuses on the moment-to-moment interaction to activate and make conscious different and perhaps latent representations. It is capable of eliciting change in implicit knowledge by influencing the 'moment of meeting' as well as eliciting change in explicit knowledge through interpretations (Stern, 1995, p. 58; Stern, 1998, p. 300).

Each family has unique characteristics, needs and resources and no one type of therapy or set of services can meet the needs of all of them. However, a positive change induced by a therapeutic intervention like music-caring/music therapy can have an extensive influence when generalizing to non-musical areas because of the interdependence in all areas of human functioning and the interdependence and reciprocal nature of the system at work (the clinical model).

In early intervention the emphasis is on supporting families in achieving their own goals. They may want to learn mediation qualities, conducive for emotional communication and attachment. Their focus can be to gain insight or to build a support system, which helps them to endure. Their focus may also be on the infant, encouraging developmental milestones to emerge. The incredible diversity of the clinical population within early intervention and the possible music therapeutic interventions are overwhelming. Through musicking alone, with other caretakers, with their infants, with their music therapist, or others, the focus could be to prevent, cure, reconstruct, support, habilitate, rehabilitate, or palliate. But whatever theoretical background the music therapist has and whatever his or her therapeutic aim, the emphasis should be to work within the caretakers' own frame of reference, helping them to discover their own resources, gain awareness of positive qualities of interaction, and how to use these qualities to form mediating relationships (Bruscia, 1998a, pp. 155-157; Klein, 2001, p. 32; Trollalden, 1997, p. 27).

10.3 Quality of life

Instead of focusing on why we become sick (pathogenetic research) we should concern ourselves with why and how we can maintain health (salutogenetic research), believes the sociologist Antonovsky (as cited in Ruud, 1998). In order to strengthen our resistance to disease we need to experience life as comprehensible, manageable and meaningful. Instead of focusing on the infant's disability or a disease (exercise the problem out) and instead of focusing on why parents of disabled infants become depressed, we should focus on general resources of resistance to disease, measures of prevention, and the subjective

feeling of a better quality of life. According to Ruud the term ‘quality of life’ refers to a subjective state of well-being, purpose and happiness rather than an objective set of criteria in the form of material conditions or competencies.

Hope, meaning, feelings of communality and identity are components that contribute to a good life says Rustoen (as cited in Ruud, 1998, p. 56). She suggests that being active, experiencing inter-subjectivity, having a feeling of self, and having a basic sense of joy, all make important contributions to the quality of life. It has already been noted in this dissertation that mothers of infants with special needs are in danger of losing their identity and becoming isolated. Their primary task is to take care of their infants, and they consciously or subconsciously get lost in their demanding role and isolate themselves from various community groups where mothers meet. It is important for these mothers to increase their sense of quality of life or their subjective feeling of well-being. Music is an ideal tool for encouraging participation, networking, and empowerment through developing identity (Ruud, 1998, p. 56; Stewart, 2002). In music groups, participants constitute a place in relation to themselves and form a personal narrative that is in accordance with how they experience reality. This in turn may elicit a feeling of group belonging (Ruud, 1998, p. 3; Richards & Davies, 2002).

Ruud identifies four categories that describe how music may be a potential resource for obtaining a better quality of life. These are: awareness of feelings, agency, belonging, and meaning. He emphasizes that a strong, flexible and coherent identity provides the most basic feeling of meaning in life. Ruud relates it to Antonovsky’s terms ‘coherence’ and ‘continuity’. A flexible identity composes and adjusts a personal narrative in accordance with how life is perceived and lived. Feelings of continuity and sameness support a coherent identity. A concept of self that entails awareness of feelings, agency, belonging and meaning creates a strong identity.

Næss also lists four components as the constituents of quality of life: “1. Activity, which contains the dimensions of engagement, energy, self-realization, and freedom; 2. Good interpersonal relations, which are realized through friendship and intimate relations; 3. Self-confidence, which has to do with self-esteem and self-acceptance; and 4. A basic sense of happiness, which is maintained through emotional experiences, safety and joy” (as cited in Ruud, 1998, p. 55).

10.4 Summary and a concluding assumption

In the context of this research, music-caring was defined (section 3.1) as an empathetic and emotionally supportive relationship that an act of musicking brings into existence. This definition was inspired by past experience as a music

therapist where caring encounters had mattered, assimilation of theories developed in helping professions such as nursing, Stern's interaction theory (1995) (presented in a graphic form in section 6.2), his model of psychopathology, and Small's definition (1998) of musicking. If successful, for example in changing the mother's negative feelings brought on by the nonfinite loss, then it would have direct or indirect effects on all the other elements in the relationship. It would change how the mother subjectively experienced herself both as an individual and a mother, and how she experienced her situation, thus changing her interaction with the infant. This might alter the infant's behavior, which would adjust to the new interactive reality and as well alter its representation of current and future interactions. By participating in a music-caring group, mothers might allow themselves to nurture through music and to be nurtured through music.

If the mothers experienced music-caring through means the therapist/researcher provided them with, then this research would possibly illuminate whether or not musicking in a caring context could be used:

- To address the needs of mothers who have infants with special needs.
- To encourage mothers to express themselves creatively.
- To give and receive reassurance and support.
- As a tool for positive reappraisal and confrontive coping (Dunn et al., 2001; Lazarus & Folkman, 1991).
- As a tool to channel and facilitate sharing of positive and negative emotions.
- To reduce social isolation.
- To develop understanding of feelings and needs.
- To maintain or improve identity.
- To fight depression.
- To increase assertiveness and feelings of competence.
- To achieve a sense of mastery over grief.
- To restore control over emotions, cognitions, and behaviour.
- To facilitate attachment of meaning to the emerging reality.
- To develop inter-subjectivity.
- To develop a feeling of acceptance.
- To develop a feeling of continuity and sameness.
- To develop self-realization and freedom.
- To develop friendship.
- To share resources and ideas.
- To affect positively the quality of life.
- To develop a sense of safety and joy.

- To develop self-confidence, self-esteem and self-acceptance.

If the mothers did not experience music-caring, that too would inform the research by suggesting an alternative methods, different way of musicking, a different framework, different therapeutic techniques, or different mode of interaction.

Boxill said (as cited in Bruscia, 1998a, p. 230) that music therapists must look to new ways and possibilities for bringing the essence of music therapy to people. Music-caring is perhaps not a new concept in use by practicing music therapists, but because it is intertwined in our tacit knowledge its importance is perhaps not realized and its meaning not elaborated. One reason for choosing a helping profession as a career must be the need or wish to help others. It is because one cares for the well-being of others that one wishes to help. Thus one needs to become aware of what caring is all about. Music therapists have chosen the means and ways to care for others which interests them the most as persons and professionals, namely music, and it is neither demoting nor unscientific about allowing oneself both as a person and a professional to elaborate on the meaning of caring and how it relates to different theories, music, and people's relations with music in various ways.

No amount of empathy can eradicate all the difficulties and sorrows that caretakers of disabled infants are confronted with. But caretakers need to express their grief and to share their grief and worries without embarrassment or fear. They must be given permission to communicate, through their chosen medium, their grief and their inconsolability. They need an opportunity for non-verbal/verbal self-expression, an opportunity to explore their creativity and potential for growth and self-awareness. Waisbren found that parents of special-needs children experience more feelings of uncertainty, helplessness, anger and rejection than other parents (as cited in Webster, 1992, p. 7). These feelings and various other emotions need to be worked through. An opportunity to express them in a creative way without guilt and judgments, and in a way which can enhance their feelings towards themselves and their life's situation, is healing. They need a place where they can be heard and accepted in a non-judgemental way and to feel accepted by an empathetic group. They need to cry with and to laugh with and to feel support and friendship from someone who has a similar experience. "A father of a child with a serious degenerative condition called his feelings 'disappointment'. It was only after therapy in a group of parents in similar circumstances that he felt permitted to choose the words 'gaping wound'

to describe the pain he felt both for his child and for himself” (Bruce & Schultz, 2001, p. 176).

It is of paramount importance to recognize the often enormous emotional strain that parents of children with special needs encounter. It is also important to provide something that addresses those needs. This could be accomplished through music-caring with a group of caretakers who laugh, cry, or otherwise share empathetic understanding in a musical relationship, or in a group where caretakers are informed about the importance of intuitive musicking for their children’s, as well as their own, well-being. Supporting parents emotionally, respecting them and their relationship with their children, identifying and working through problems can all be done through musicking or music-caring.

Like Ragnarsson (1997), Rúnarsson (2004) and the mothers referred to above, parents of children with special needs can be so heavily focused on the needs of their children that they ignore their own needs. The mere thought of therapy for themselves could be threatening and interfere with their day-to-day coping mechanisms. Each parent is different from the other and caretakers search for a philosophy that best fits what they experience. Both the route to acceptance and the final destination will look different. The caretakers themselves create the meaning of this event and they are the ones who decide how to weave this thread into the larger design. But by inviting them and even requesting their participation in music-caring groups they can find their sense of self, strengthen it, focus on emotional awareness, get a creative outlet for feelings such as sorrow and pain, positively channel their anger, and break their isolation. If this is accomplished, then EI has achieved its goal far better than it has managed hitherto.

Through the use of music and relationships music therapists are concerned with improving quality of life. Through engaging mothers of children with special needs in a music-caring group work where they are offered both structure and freedom, where they can form interpersonal relations with others who share similar experience, where they are encouraged to explore emotions and feelings in a creative and structured way, where their feelings are accepted and empathized with, they will develop a stronger, more flexible and coherent identity needed for their optimal well-being.

PART III THE RESEARCH PARTICIPANTS AND THE RESEARCH DESIGN

In Part I and Part II of this thesis the study is introduced and put into context. This section, Part III, presents the preparatory phase of the research, which was launched in the month of March 2006, when permission to conduct the research had been obtained from the National Bioethics Committee in Iceland. The main purpose of this preparatory phase was to recruit participants, prepare them for what was to come, and to design the music-caring sessions as well as the research itself. Part III thus introduces the research setting and the equipment used, the research and the session format as planned, songwriting as the central music therapeutic approach, and the research participants themselves.

CHAPTER 11

THE RESEARCH PARTICIPANTS

The intention of this thesis was to examine the lived experience of a group of mothers of young children with special needs, who were participating in a music therapy group introduced as music-caring within the framework of early intervention. Figuratively speaking, the therapist/researcher removed herself from her current clinical practice and the caretakers of her past and present clientele who were instrumental in creating the notion which was to be studied. Instead of inviting them to participate in the proposed research she brought her old clinician's self and her notion of music-caring into a new therapeutic relationship with a new clientele, namely non-clinical adults.

The caretakers of the therapist's past and present clientele to whom she had become acquainted with throughout the years were mostly mothers. The choice of working with mothers and not fathers (or other family members) in this research was based on this fact and also the reality that mothers remain the primary caregivers for children worldwide, including those with special needs. As stated earlier (Part II), research has shown that families with special-needs children have higher stress levels (greater psychological distress) than other families and the stress levels of the mothers tend to be higher than those of the fathers. Also, mothers and fathers are affected differently by parenting a child with a disability and use different defenses against stress. Research indicates that mothers derive more benefit from their social support networks than do fathers (Whittick, 1988, as cited in Webster, 1992, p. 3).

Running a music-caring group for non-clinical adults for the first time, the therapist admits that instrumental in the choice of subjects was the thought that she would feel more at ease around women than men. Nevertheless, she was aware that fathers of children with special needs might also suffer from health problems and social isolation because of a lack of social support networks and support from health care professionals within the EI services. The therapist/researcher hoped that if her intervention were successful in changing the mothers' feelings it would, according to Stern's reciprocal model, have a direct or indirect effect on every relationship the mothers were engaged in, including those with the fathers, possibly influencing the fathers' own well-being.

11.1 Recruiting participants

The process of recruiting participants began in January 2006. The first step in that direction was an application to the National Bioethics Committee of Iceland for permission to conduct the research. With some minor amendments, permission was obtained on 7 March 2006 (see Appendix A). The researcher was asked to encrypt personal information which was to be obtained in the first meeting with the participants. This was so, despite the fact that they themselves were to choose pseudonyms to be used in the research. The researcher was also required to find an Icelandic contact person, who would take a professional responsibility for the execution of the research project. This was required even though the study was conducted for the degree of Doctor of Philosophy, Institute for Psychology and Communication, Aalborg University, Denmark. Dr. Tryggvi Sigurðsson, the head psychologist at the State Diagnostic and Advisory Centre and a specialist in EI and children's disabilities, took on that task. Dr. Sigurðsson received his doctorate from Sorbonne, Paris. By lending his name to the research, the following statement appeared in writing when introducing the research (in a brochure, on websites, in the folder given to the participants): The guarantor of this research is Dr. Tryggvi Sigurðsson, a psychologist and a specialist in children's disabilities (Ábyrgðarmaður rannsóknarinnar er Dr. Tryggvi Sigurðsson, sálfræðingur og sérfræðingur í fötlun barna).

After having obtained permission from the National Bioethics Committee, a brochure (introductory leaflet, see Appendix C) was designed, printed and distributed. The brochure was intended to inform and attract prospective participants. The brochure was placed at the State Diagnostic and Advisory Centre, at Sjóðarhóll (an umbrella association serving families of children with special needs) which gave the researcher a letter of support referred to in the brochure (see Appendix F), at three different places at Barnaspítali Hringins (the Children's Hospital), including the NICU, and at three local health centres (Heilsugæslan í Kópavogi, Heilsugæslan á Seltjarnarnesi, Miðbæjarstöðin).

Since supporting parents and other relatives of children with special needs is one of the aims of Sjóðarhóll, gaining their support in the form of a statement of approval included in the leaflet was instrumental in sparking the interest of prospective participants. With the support of Sjóðarhóll, this study was introduced both on their website, and by having the brochure available at their headquarters. On 29 March 2006, a lecture introducing the research was delivered for the staff at Styrktarfélag Lamaðra og Fatlaðra (The Benefit Society of Children with

Disabilities (SLF))¹⁶. The research was also introduced in person to the faculty chairman at the Children's Hospital in Iceland, a professor in pediatrics at the University of Iceland who volunteered to distribute the brochure around Landspítali University Hospital. The brochure was also posted on four websites and circulated through the Down's syndrome association post list.

The core of the therapist/researcher's clinical work had been done in relative isolation from other health care practitioners and the general public. Thus, the support and encouragement she got from the specialists and the directors of the institutions mentioned above was instrumental for recruiting participants as well as encouraging her to pursue her research intentions.

On 4 April 2006, the therapist/researcher received a phone call from the first mother who expressed an interest in participating. She had a six-month old boy, who was missing both legs below the knees. As reflected in the therapist/researcher's memos, her heart pounded in excitement during this phone call, which evoked various feelings. Being a mother herself, the therapist/researcher formed some kind of emotive connection to the mother's voice, which sounded energetic and enthusiastic. Being aware of the therapist/researcher's countertransference issues, the mother's voice even sounded courageous, which was exactly what the researcher needed; somehow, she felt thankful. A physiotherapist who had attended the lecture that was delivered at SLF, had given the mother an introductory leaflet when working with her son.

Initial inclusion criteria for the mothers were that they were neither acquainted with one another nor the researcher and that they had children with special needs born in the years 2003 to 2006 (0-3 years old). In accordance with EI, children with special needs were defined as young children (0-6 years old) who were either defined as at-risk, or with established disabilities. It should be emphasized that this was an inclusion criteria for the mothers, but not the children, since they were not direct participants in the research (the children did not participate in the music-caring sessions). Thus there was neither an inclusion nor an exclusion criterion for the children as such. No additional exclusion criteria were included for the mothers.

The therapist/researcher believed that sensitivity to the way one related to the mothers was very important. The ones who expressed interests were those in need of support and an exclusion criterion would be insensitive to their vulnerability at this

¹⁶ The Benefit Society of Children with Disabilities is an organization established in 1952 to support and care for children and young people diagnosed with polio. The SLF's rehabilitation centre is a community-based organization offering Iceland's most extensive rehabilitation services and programmes, aimed at improving the abilities and participation of children with disabilities. Clients are mainly children of all ages with various physical or mental conditions.

time in their lives and in fact contradictory to the stated purpose of this research. It would be like stating that your diagnosis distorts or blurs your experience of music-caring or you are too depressed to be able to express yourself about your music-caring experience. If any problems were to arise during the music-caring phase, due to, for example, the emotional state of a participant, it would be dealt with, and the mother possibly referred to a specialist. Also, should the number of those interested in participating in the research exceed the needed number of participants the mothers would be invited to participate in another group beginning at a later date, or in a parent-infant group held at the same location.

The expertise of Beneson (1987/2006, p. 28) and Yalom (2005, p. 292) was used when speculating about the most efficient group size for this undertaking. They argue that the purposes and needs of the group should determine its size. According to them, opportunity to participate, intimacy, support and satisfaction tend to increase as the number of participants gets smaller. Depending on group function it can be anticipated that larger groups experience less harmony, more dissatisfaction, and less consensus than smaller groups. Where the emphasis is on self-disclosure, intimacy, involvement and support, the optimum size for a group is seven to eight members with an acceptable range of five to ten members.

While waiting for volunteers in the months of April to September 2006 a slight change was made in the inclusion criteria. The age limit of the participants' children was extended to the age of five. Still within the age framework of EI, this change made it possible for the researcher to accept more applicants of the relatively few who expressed interest in participating. Also the number of participants, which initially had been scheduled to be from four to six, was increased to seven to ten to compensate for possible dropouts.

Being a closed therapeutic group¹⁷ conducted for research purposes it was not the intention to compensate for a possible decrease in the number of participants during the implementation phase with new ones entering the group. However, according to Yalom dropouts were to be anticipated. Being a threatening problem for both a neophyte and experienced group work therapists, demographic research demonstrates that a substantial number of clients will leave a group prematurely regardless of what the therapist does. In order to minimize the dropout rate the following is recommended: proper selection of

¹⁷ Yalom describes a closed group in the following way (2005, p. 282): It accepts no new members except within the first three sessions and meets for a predetermined length of time. Usually closed groups are brief therapy groups meeting weekly for less than six months.

participants, working towards achieving a cohesive group, allowing an escape hatch and comprehensive pre-therapy preparation (Yalom, 2005, p. 332).

11.2 Individual sessions with each mother

Ten mothers in total contacted the researcher. Two of them had children who were too old to fall within the EI criterion and one mother felt that due an irregular work schedule she could not commit herself to the group. Thus seven participants were recruited for the research project. They responded to an informal invitation (through the means mentioned above) to join a research project, and contacted the researcher through phone calls and e-mails. As pre-therapy and pre-research preparation, they were invited to visit the research site, meet the researcher individually, have the opportunity to ask questions, and to receive further information. The following list (pseudonyms chosen by the mothers themselves at the first meeting) shows the dates of the initial meeting with each mother:

Esja 12 June 2006
Klambra 20 June 2006
Skonza 22 June 2006
Kristjana 9 July 2006
Hanna 17 July 2006
Góa 10 September 2006
Einræn 20 September 2006.

The last meeting with the seventh mother was on 20 September, three days before the music-caring sessions began. Serving the purpose to inform, get to know and prepare the mothers for the forthcoming group therapy experience, each meeting with a prospective participant was organized in the same way. Music from the disk *Madredeus Antologia* (a Portuguese Fado music) was played in the background. After a brief welcome, the mother was given a folder and its contents were explained. The folder contained the same information as in the leaflet and on the websites used to introduce the research. The folder also contained two questionnaires labelled A and S (see Appendix G), the consent form, instructions on how to use a diary (see Appendix G), a diary, a notepad, and some song texts (the songs are listed in Appendix H). After having gone through the folder, the mother was asked to complete form A to provide some basic personal information. She was informed about confidentiality issues and told that she could ignore any question if she wished. She was also told that if she decided to participate in the research she needed to answer nine questions on

form S in writing, fill out the consent form and bring it to the first music-caring session. In this initial meeting, questions were answered and in one instance a misunderstanding corrected when a mother thought that her child would also be participating. The mothers also engaged in some self-disclosure, revealing some personal information such as past and current life events, hopes, aspirations and current feelings. The researcher's self-disclosure at this stage concerned her motivations for conducting the research. The mothers were informed that although they could withdraw their participation due to some unforeseen circumstances it was important for all concerned that they be able to commit themselves to the music-caring group for its entire duration. The duration of the research was introduced in the leaflet, on the websites as well as in the preparatory meeting. Participation would involve ten weekly music-caring sessions, lasting for between 90 minutes and two hours each, as well as two interview sessions conducted within six weeks of the last music-caring session.

All seven mothers listed above chose to fill out the consent form at that meeting (instead of returning it in the first music-caring session) and participated throughout the research period. A list of their attendance can be seen in the Appendix I. One mother was pregnant when the research started. During session #7, on 4 November 2006, her water broke and a baby girl was born by Caesarean section later that day. The mother, Esja, skipped session #8 but brought her baby to all four remaining sessions.

11.3 Portraits of the mothers

In a sense, the seven mothers have been participants for more than four years as they have continued to meet and have shown a keen interest in the progress of the research. Thus, the therapist/researcher feels it important that they get the opportunity to introduce themselves as they choose through self-portraits created from collage pictures, some factual information and a character sketch. What follows are their answers to the questions on form A. The profiles below also include the mothers' written answers to question 7 on form S (see Appendix G): describe yourself as completely as you can in any way or form you feel like (in words, a poem, a story, a picture, etc.). Thirdly, they share with us a self-portrait (made with a collage technique, cutting or tearing pieces of colored crêpe paper which were glued on a sheet of paper taken from their diary). This was done in a group meeting the mothers had with the researcher on 27 January, 23 days after the last individual interview with them (the individual interview was labelled as session number 12 in the reflection phase). The mothers had expressed an

interest in staying in contact and in meeting again. Thus an informal group meeting was planned before bringing closure to their individual interview. The researcher asked them to bring pictures of their children to share with each other and she also told them that for a possible decoration purpose they could also make a self-portrait from coloured paper. Only Einræn was absent at this meeting. The mothers shared some photos of their children, created a self-portrait as described above, listened to music, talked about their children, their latest struggles, and had some refreshments. In what follows the mothers introduce themselves as described above. The forms were completed in Icelandic and translated by the therapist/researcher:

Participant 200608M1



Pseudonym: Hanna.

Date of birth:

Age: 31 years old.

Education: Bachelor of Education.

Work title/employment: Housewife.

Marital status: Married.

Special-needs child:

Age: 11 months old boy.

Diagnosis: Missing both feet below knee.

Other children: A girl born 2002, 4 years old.

Closest family: Mother, father, in-laws.

Physical health: Good.

Emotional health: Good.

Music education: None.

Instruments at home: None.

Musical interest (instrument, genre, group, include your favourite): I am musical. I like to dance. I sing relatively well and enjoy it. I like music that is tranquil, comfortable, old and beautiful.

Do you use music? I dance to music if I am sad or if I am happy.

Other comments or something you want to share:

Describe yourself as completely as you can in any way or form you feel like (i.e. in words, a poem, story, picture, etc.).

I am a good mother. I love my children more than anything else in this world. I am a good wife. I am generous, gentle, and have much to give. I am determined and conscientious. I am tidy. I sometimes try to be perfect (but try not to be). I let my family come before everything else. I like music, and I very much like to meet my girlfriends to discuss matters, my family, children and husband. I also like to discuss other matters, matters of the heart. I am open and talkative/communicative. I am forthright/forward. I am thorough. I have a tendency to worry. I am a creature of habit and it sometimes limits me. I often fear the unfamiliar. It is difficult for me to be divided/partitioned, for example if I had begun working now. It would be difficult for me because first and foremost I would like to take care of my children and my home. Work would be in the way but still I would like to do well at work. I have little tolerance for stress and strain. I want every day to pass pleasantly and I am always trying to create pleasant memories for my children and myself and the family. I have no inferiority complex for my limited education (teacher) and for not being employed. I am very happy with my fate, but I often feel it is very difficult to take care of two little children. It is very challenging and exhausting, but I take pleasure in it. Sometimes I am sentimental but I am sometimes tough I think. I have very good parents and I got a wonderful upbringing.

Participant 200608M2



Pseudonym: Skonza.

Date of birth:

Age: 27 years old.

Education: BSc in Business Administration.

Work title/employment: Accounting specialist.

Marital status: Common-law marriage.

Special-need child:

Age: 2.8 years old girl.

Diagnosis: Amniotic Band Syndrome.

Other children: None.

Closest family: In-laws, parents.

Physical health: Good, some digestion disturbances.

Emotional health: Good.

Music education: I learned to play the recorder and the organ from eight to ten years old.

Instruments at home: None.

Interest in music (instrument, genre, group, include your favourite): Easy listening, rock, pop.

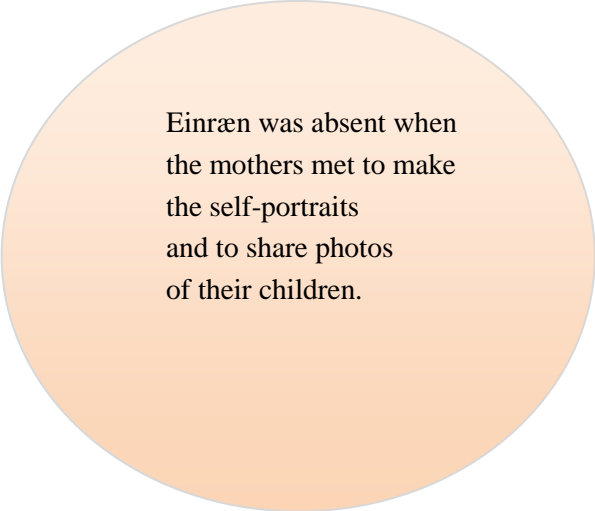
Do you use music? For entertainment and relaxation purposes.

Other comments or something you want to share:

Describe yourself as completely as you can in any way or form you feel like (i.e. in words, a poem, story, picture, etc.).

As a person I am rather easygoing and shy. I like attention, however, but I am not much seeking it. I am rather independent. Occasionally I have a tendency to become rather depressed, and then I want to do as little as possible. I like very much to read books, study and be with people. I enjoy very much outdoor life and dancing but due to lack of time I cannot pursue my interests. I like staying at home and I am self-sufficient (independent/self-reliant). I think it is important to go out and meet other people and to travel. I am rather sentimental or frail in a certain way. I feel that I can easily put myself in other people's shoes, be sympathetic, both in real life and when watching movies and it is difficult for me to stop the tears. But when I need to be strong for example for my husband, my child or another family member, then it is no problem.

Participant 200608M3



Einræn was absent when the mothers met to make the self-portraits and to share photos of their children.

Pseudonym: Einræn.

Date of birth:

Age: 44 years old.

Education: Piano teacher

Work title/employment: Piano teacher.

Marital status: Married.

Special-need child:

Age: 5.4 years old boy.

Diagnoses: Autism.

Other children: 21- and 16-year-old girls, a 14-year-old boy.

Closest family: My stepfather and his sister, ex mother-in-law.

Physical health: Bad.

Emotional health: Bad.

Music education: Piano teacher.

Instruments at home: Grand piano.

Interest in music (instrument, genre, group, include your favourite): Piano music.

Do you use music? For relaxation.

Other comments or something you want to share:

Describe yourself as completely as you can in any way or form you feel like (i.e. in words, a poem, story, picture, etc.).

I am conscientious, withdrawn, very tolerant and patient. I have difficulty expressing my feelings.

Participant 200608M4



Participant /pseudonym: Klambra.

Date of birth:

Age: 44 years old.

Education: Degree in Architecture.

Work title/employment: A housewife.

Marital status: Common-law marriage.

Special-need child:

Age: 3.2 years old boy.

Diagnosis: Autism.

Other children: A girl, 14, and a boy 5.

Closest family: Parents, two sisters, in-laws, two sisters-in-law.

Physical health: Very fine last year. I have had a weak immune system before.

Emotional health: Fine.

Music education: Some piano lessons as a child. I sing in a choir (completed first grade in voice).

Instruments at home: Piano, guitar, afro-drum.

Interest in music (instrument, genre, group, include your favourite): I sing in a choir. I like different music.

Do you use music? I sometimes use music for relaxation or to induce movement.

It is rewarding to sing in a choir.

Other comments or something you want to share:

Describe yourself as completely as you can in any way or form you feel like (i.e. in words, a poem, story, picture, etc.).

I am rather organized and accurate and perhaps rather conscientious but my need for perfection restricts me and is often the reason why I don't begin the task at hand. Perhaps I have performance anxiety. I tend to procrastinate when it comes to tasks that are extensive or important but get stuck in carrying out a million little things that I pretend I am going to clean up first. And then I can be very productive. By nature I am rather serious and much too insecure and shy and on guard against other people. I am actually a loner and I like being alone, but once out there I like to speculate about people and emotions. We have had a terrific group of friends for many years who meet regularly and whom I value a lot. I am too sentimental or frail and I wish I were tougher (even at the cost of losing my sensitivity and empathy). My family and its well-being is very important to me. I could definitely be carefree more often and know how better to enjoy life.

Participant 200608M5



Pseudonym: Esja.

Date of birth:

Age: 36 years old.

Education: Medical secretary.

Work title/employment: Part-time medical secretary in a hospital.

Marital status: Married.

Special-need child:

Age: 3.9 years old girl.

Diagnosis: Cerebral palsy.

Other children: 6 years old and a newborn girl.

Closest family: Spouse, grandmother, sister-in-law, girlfriends, mother-in-law.

Physical health: Good.

Emotional health: Good.

Music education: Recorder in childhood.

Instruments at home: A recorder, children's drums.

Interest in music (instrument, genre, group, include your favourite): Rock, classical, opera, vocal music, pop.

Do you use music? Yes, to make me feel better and to let emotions wear away.

Other comments or something you want to share:

Describe yourself as completely as you can in any way or form you feel like (i.e. in words, a poem, story, picture, etc.).

Caring and impatient! Adventurous, nature lover, a mother, a woman, a maiden, a lady who respects other people and nature.

Participant 200608M6



Pseudonym: Kristjana.

Date of birth:

Age: 36 years old.

Education: A nurse.

Work title/employment: A nurse.

Marital status: Common-law marriage.

Special-need child:

Age: 3.4 years old boy.

Diagnosis: Down's syndrome.

Other children: 9-year-old girl.

Closest family: Parents, in-laws, brothers and sisters, grandfather, grandmother, many friends.

Physical health: Good, asthma.

Emotional health: Good, excellent.

Music education: None.

Instruments at home: No.

Interest in music (instrument, genre, group, include your favourite): I listen to music a lot at home, easy-listening, pop, rock, children's music.

Do you use music? While doing housework, in the gym, sometimes in the evening.

Other comments or something you want to share:

Describe yourself as completely as you can in any way or form you feel like (i.e. in words, a poem, story, picture, etc.).

I am down-to-earth, casual (tranquil) and determined. It is rather easy for me to be around people and I take pleasure in being with my family, my parents and brothers and sisters. I have good friends for whom I have great affection. I am social. I trust myself the most and best and thus I have a tendency to do everything myself. Despite a down-to earth and a stable front I am extremely sensitive and can begin to cry at the slightest thing, but mostly when I am alone. I am ambitious for my children and myself.

Participant 200608M7



Pseudonym: Góa.

Date of birth:

Age: 40 years old.

Education: BA in English.

Work title/employment: A housewife.

Marital status: Married.

Special-need child:

Age: 3.0 years old boy.

Diagnosis: Cerebral palsy.

Other children: A twin girl to P, 3.0 years old, 7-year-old girl, and a 4.5-year-old boy.

Closest family: Four sisters, father-in-law (died March 2007).

Physical health: Fine.

Emotional health: Fine.

Music education: None (sang in choirs in schools).

Instruments at home: No (shakers and drums).

Interest in music (instrument, genre, group, include your favourite): Pop, rock, good melodies, folk music.

Do you use music? In the car, sing along with the children. To relax at home I listen to Channel One and the music there.

Other comments or something you want to share:

Describe yourself as completely as you can in any way or form you feel like (i.e. in words, a poem, story, picture, etc.).

Mother

Standing on the stairway with her breast expanded and
breathes in the morning coolness.

A new day emerging.

Mother.

Standing on the stairway with arms outstretched and
breathes deeply the evening air.

Prepares a good night.

CHAPTER 12

SETTING AND EQUIPMENT

12.1 Setting

The research took place in Tónstofa Valgerðar, a private music therapy studio and a music school for people with special needs, founded by this researcher. Its location is in central Reykjavík. Its available space is around 100 square metres, divided into an entrance (a waiting room) with chairs, a sofa, table and magazines; an office space with bookshelves, cupboards, chairs, a desk and a refrigerator; a small storage corridor, and two rooms (a big one and a smaller one), both well equipped with various instruments. The sessions were held in the bigger room, with eight chairs arranged in a circle and instruments arranged on shelves and tables along the walls. The rooms are well lit, with windows that can be opened to ensure fresh air, and with both blinds and curtains to diminish noise from outside and to guarantee privacy. The studio was not used for other purposes during the time the sessions were held. Except for occasional traffic noise, there were virtually no outside disturbances.

12.2 Equipment

The sessions were audio recorded using a Sony portable minidisk recorder MZ-R90 and a Sony stereo microphone ECM-MS907 with a selectable directive angle of 90-120 degrees. The sessions were also video recorded on a Sony digital video camera recorder (Handycam DCR-PC108E/PC109E).

A selection of various string, wind, and percussion instruments were available to the participants. These included:

- Acoustic guitars, electronic guitars, harps/dulcimers, violins, a cello
- Kazoos, reed horns, flutes, recorders
- Keyboard instruments
- Gongs, sound bowls, chimes, choir chimes
- Drums, various hand percussion instruments and melodic percussion instruments (Orff)
- Various ethnic instruments

CHAPTER 13

THE RESEARCH AND SESSION FORMAT

Being an adventure into the unknown both clinically and experimentally speaking every step in this expedition needed thoughtful consideration and careful preparation. As previously noted, the therapist/researcher had hardly any experience of working with the non-clinical population, her experience of working with therapeutic groups was close to none, and she had never done research at this academic level. Right from the start it was thus evident that careful planning was needed on various levels. The researcher needed to prepare herself as a person and a professional, as well as prepare the participants, the format of the music-caring sessions in a group setting, and the research design itself (including theoretical framework, method of data collection and analysis).

What follows is a description of the research format and the session structure used in the short-term, closed, therapeutic music-caring group, run weekly for up to two hours, over a period of ten consecutive weeks, followed by two interview sessions for each participant (one group interview and one individual interview) in this experimental research study.

13.1 The research format

Mainly for the researcher to prepare herself mentally for the journey ahead and to help her focus on each important step in this endeavour, the research period was structured into three phases: 1) the initial preparatory phase. 2) the central music-caring phase. 3) the reflection phase.

The preparatory phase was launched in March 2006 after having obtained permission from the National Bioethics Committee to conduct the research. The main purpose of this preparatory phase was to recruit participants, prepare them for what was to come and build a relationship with them, prepare the therapist/researcher personally and professionally to the best of her ability and to design the music-caring sessions. Since this phase, as it concerns the research participants, has already been described above, only an outline in point-form is presented here:

- An interest was sparked by distributing information on websites, through brochures, and a lecture.
- A mother called the researcher or sent her an e-mail.

- A verbal exchange via phone was conducted whereby some questions were answered.
- If the mother was interested then an appointment was scheduled at her convenience at the research site.
- The mother was welcomed to Tónstofan.
- She was shown around and handed some material organized in a folder.
- The material included: A form (A) to be filled out and given back at this meeting providing some basic personal information. Written information in an outline form about the purpose of the research, the research format, and data collection. An informed consent form to be signed and handed in if the mother decided to participate. A questionnaire (S) which needed to be answered in writing and brought back to the first music-caring meeting. A diary and some information about how to use it, a blank notebook and some song texts.
- Before leaving the mother was informed that she would be contacted when enough participants had been recruited, and that the music-caring group/research was scheduled to start in August/September of 2006.
- Each mother was also encouraged to start using the diary and to call the researcher at any time if need be prior to the beginning of the research.
- Each mother was asked to return the questionnaire and the signed consent form at the first music-caring session.
- The mother was informed that although she would be able to withdraw her participation due to some unforeseen circumstances it was important for all concerned that she be able to commit herself to the music-caring group for its entire duration.

Speaking from a clinical point of view, Yalom (2005, p. 294), talks about great variance regarding the number of individual sessions with clients prior to group therapy. After seeing the client once or twice in so called 'selection interviews' some group therapists do not meet with them individually again, whereas others continue individual sessions until the group begins. The purpose of this pre-group interview from the perspective of both the client and the therapist should be to build therapeutic alliances: clarify misconceptions, unrealistic fears and expectations; foresee and diminish the emergence of problems in the group's development; provide clients with a cognitive structure that facilitates effective group participation; and, generate realistic and positive expectations about the group therapy.

The researcher decided that as research participants, the mothers would only be seen once prior to the music-caring phase to avoid possibly skewing their

actual experience of it. Personally the researcher worried about that the long time that would pass from the first individual session held 12 June 2006, until the first music-caring session scheduled for late August or September, would cause the mothers to lose interest and withdraw their participation. As it turned out, the first music-caring session started 23 September, more than three months after the first preparation session. But the researcher's reasonable worries were unfounded, since all the mothers who came for an individual preparation session participated in the research. It is believed that the folder that was given to them and the diary which four of them began writing in prior to the first music-caring session (five out of seven used the diary altogether) was instrumental in sustaining the mothers throughout the waiting period.

Personally and professionally the therapist/researcher prepared herself through focusing activities, self-nurturing through music listening and piano playing. She also read literature that was believed helpful in making informed choices regarding different aspects in the next phase of this study, which was the central music-caring phase or implementation phase.

The structure, duration and frequency of therapy sessions have been the subject of experimentation both in individual and group therapy. Beneson (2001), who supports experimentation with the length of sessions, number and frequency of meetings to suit group needs, recommends six to twelve meetings for task-oriented group work. He also supports weekly meetings to build up a sense of belonging and commitment as well as stability and predictability, which is important to promote a healthy and productive group. Yalom (2005), who also recommends weekly sessions to maintain interactional focus, facilitated bereavement groups that met weekly for eight sessions. According to Yalom, groups that meet less than once a week have considerable difficulty maintaining an interactional focus.

The recommended length of session varies but most group therapists agree that, even in well established groups, at least sixty minutes is required for the warm-up, interval and for the unfolding and working through of the major themes of the session. There is also some consensus among therapists that after about two hours, the session reaches a point of diminishing returns and the group becomes weary, repetitive and inefficient (Yalom, 2005, p. 283).

It was decided that the central music-caring/implementation phase would encompass ten 90-minute to two-hour consecutive weekly sessions. This phase began on a Saturday, 23 September 2006 and concluded on 25 November 2006.

The sessions started at 10 o'clock and were scheduled to be finished within two hours. When planning at what date this phase of the research should begin it seemed easiest to structure consecutive sessions over a period of ten to twelve weeks in the fall rather than during, for example, the late winter months (October – February) or early spring (March – May) a time period interrupted by holidays and vacations. Since only ten music-caring sessions were scheduled it was believed important that they were continuous and uninterrupted by vacations to ensure stability and continuity.

As planned, the reflection phase consisted of:

- One group follow-up session, scheduled 11 December 2006, 17 days after the last music-caring session (25 November 2006).
- One individual meeting/session with each participant, scheduled by appointment within one month from the group follow-up session.

The reflection phase continued throughout the various steps of analysing and interpreting the data, the writing of the thesis and the formal completion of this study. Also, neither foreseen nor planned as being part of the research itself or the reflection phase of it, the group continued meeting informally after the music-caring sessions were over. These meetings were instigated by one of the participants through the use of e-mails. Their attendance was not registered, although it can be said that only twice all seven of them were present and at other times one to three mothers were absent (much like their attendance during the implementation phase of the research). No formal data was taken at these meetings. However, these meetings will be reflected upon in the discussion part of this thesis as they resulted from the participants' experience of the music-caring group/research. Actual dates and locations of these meetings can be seen in Appendix J.

These meetings were believed instrumental in sustaining the therapist/researcher through the completion of the study. The mothers were always curious about its progression and interested in knowing when it would be finished.

13.2 The session format and the central music therapeutic approach

In the preparation phase of this research the music therapeutic approach for providing the mothers with music-caring as well as the session format/structure was chosen.

Perhaps the most important reason for using programme is to provide a point of focus – a context for group members to come together. Context creates boundaries and boundaries create rules and structure, consistency and predictability. ...Without the consistency and predictability that comes from patterned interaction and context, human interaction tends to be weak, diffuse, and anarchic (Benson, 2001, p. 31).

According to Benson, the music therapeutic approach should provide context for members to engage in and interact, provide structured experience, influence both directly or indirectly the group and its individuals, aim at achieving particular results or desired objectives, be able to modify or control undesirable behaviour and facilitate the development and the growth of a group. The therapist should always be able to say why she is using a certain activity or engage the group in a particular project, but the programme chosen should never be an end in itself (*ibid.*).

No manual was available which told the researcher how to perform music-caring in this research context or what type of musicking would best support a music-caring experience. Should an instrumental improvisation be used, vocal improvisation, pre-composed songs, movement activities, receptive form of musicking, something else or a combination of the above? Going back to the research questions it was the lived experience of the mothers that was the focal point of this study and not the music-caring programme as such. It was about how they experienced this researcher's attempt to provide them with music-caring. Borrowing Kenny's words: "I could hope to communicate the essence of the experience to others, thus offering a template of the referential totality, looking not for facts or causes or effects or proof, but rather for experience and meaning in an aesthetic and philosophical approach" (1996, p. 62).

The researcher hoped to provide the mothers with rich and positive experience that addressed their needs. However, being true to the research intent, the researcher needed to bracket her fear and set aside worries about making wrong choices when choosing/designing the clinical method intended for providing music-caring. The researcher, being also the participants' music therapist, would through the clinical method and her caring interaction be available for the mothers, recognize their uniqueness by listening and responding to them as valued members of the group and, through her individualized concern for the mothers, aim at eliciting positive feelings such as trust, comfort, and security. Furthermore, through the applied therapeutic approach, she would

ensure that the mothers were given ample opportunity to express their personal needs, feelings and thoughts.

13.2.1 Songwriting

The choice was made to structure the session format around songwriting as a process and a central music therapeutic approach for providing music-caring. Guidelines were to be followed providing needed structure which would be allowed to sway ‘in rhythm’ with the needs and wishes of the mothers. In this context, songwriting was defined as: “The process of creating, notating and/or recording lyrics and music by the client or clients and therapist within a therapeutic relationship to address psychosocial, emotional, cognitive and communication needs of the client” (Baker & Wigram, 2005, p. 16). Songwriting has been described as ‘one of the most powerful methods in music therapy’ (Ruud, as cited in Baker & Wigram, 2005, p. 9):

It seems like the song gives the client a new context, a freedom and strength to bypass his or her own vulnerability. The song form not only *affords* a range of possibilities for self-expression, but it equally *allows* one to touch on and warm to themes and relationships which have been deeply-frozen for a long time. Songwriting provides an aesthetic context inviting clients to explore, within a new play-frame, their own life, their possibilities, their losses and their aspirations (ibid., p. 10).

According to Baker and Wigram, songs assist in developing group cohesiveness, encourage social interaction, provide group support, provide opportunities for one to experience joy, and facilitate development of therapeutic relationships (2005, p. 11).

13.2.2 A temporal (vertical) session structure

A temporal (vertical) session structure centred on songwriting as the primary therapeutic approach was planned as follows:

- A welcome.
A ‘welcome activity’ will provide an opening to what lies ahead and sets the tone. It will acknowledge each mother and the group as a whole. It will also give the researcher an opportunity to sense the atmosphere in the group and to evaluate the mood of each individual mother. A welcome activity may include a group rendition of a welcome song chosen by the researcher, a group rendition of a song chosen by a mother, a receptive listening to a song/music chosen by

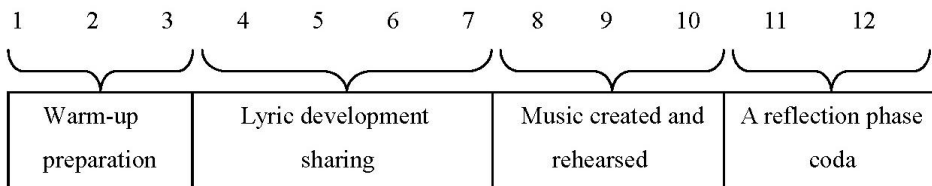
the researcher, a receptive listening to a song/music chosen by a mother, a relaxation/focusing activity, or something else.

- A warm-up.
A ‘warm-up activity’ will be designed to ‘break the ice’ and to encourage the mothers’ ‘musical selves’ to appear. A warm-up activity will also be used as a preparation for the songwriting activity used later in the same session or the following sessions. A warm-up activity will be a free or structured vocal, instrumental or movement improvisation (Wigram, 2004, p. 183).
- Songwriting.
A songwriting activity will be a step in the progression of the song-writing process. The technique for lyric creation will be allowed to develop in the group based on individual and collective needs and ability. It is anticipated, however, that the songwriting will advance in stages, moving from themes, to words, to sentences, to phrases, to verses. Similarly the technique of music creation in the songwriting process will be allowed to develop in the group based on individual and collective needs and ability.
- A pause.
A break for refreshments and an informal chat will be given after the songwriting activity when nearing the end of the session. The pause offers an opportunity for informal chats where information can be shared and friendship developed. It can also provide a needed distance from possible intense emotional material brought up in the songwriting process.
- A goodbye.
A ‘goodbye activity’ will be used to bring closure to the session. An activity will be chosen by the researcher which reflects the mood of the group or by the mothers, reflecting their individual or collective needs or wants.

13.2.3 A temporal (horizontal) structure of the songwriting process

A temporal (horizontal) structure of the development of the songwriting process used in the music-caring sessions to address the needs of the mothers was planned as follows:

The music-caring process centred around songwriting.



Sessions 1 – 3.

- Free group improvisation on instruments chosen by the mothers will be used to ‘paint’ words provided by the researcher and the mothers.
- One mother selects a word from a collection of words provided by the researcher and the mothers, and selects an instrument(s) and a player(s) to ‘paint’ that word.

Sessions 4 – 7.

- Brainstorming (sharing). The mothers are encouraged to speak freely about any topic, while the researcher transcribes words, ideas, and or thoughts and then draws out salient comments or remarks. If needed, open-ended and direct questions will be used to generate information about a theme.
- Sharing. Home-based lyric development. The mothers bring/share pictures, words, sentences, poems, verses, or anything else they have written in their ‘research diary’ between sessions.
- Structuring. A central theme(s) (issue) will be formulated/structured as the mothers decide what best fits the content (for example a free floating lyric, a verse/chorus, a structured poem, a story).

Sessions 8 – 10.

- Music is created and rehearsed. It could be a word painting technique where music is created that represents or describes the general mood, an emotion or an image of a word or a phrase.
- The music will be graphically notated by the mothers and the researcher.
- The ‘song creation’ will be performed and recorded.

The temporal (horizontal) structure of the music-caring process presented here provided a framework. It was assumed that the needs of the mothers, the group process itself and other unforeseen elements would be the actual controlling factors influencing how the songwriting process would evolve from one session to another.

Sessions 11 and 12 (belonging to the reflection phase of the research) were planned as follows:

Session 11.

- The song(s) is performed again and the mothers reflect on their experience in the songwriting process (the music-caring programme).

Session 12.

- In a meeting with one mother a recording of the song will be played and afterwards a semi-structured, in-depth interview will be conducted and recorded. The mother will be encouraged to reflect on her experience and to express spontaneously anything regarding her experience or anything else that she feels like sharing with the researcher. If the mother speaks of a need or an interest in continuing in individual/group work of a kind, she will be informed of the possibilities.

13.3 Summary

In the preparatory phase of this research the therapist/researcher prepared herself as well as possible for the central music-caring phase (the implementation phase). She gained permission from authorities to conduct the research. She gained support from professionals at institutions serving the clinical population. She recruited the research participants, became acquainted with them, and prepared them for their participation by informing them about the research intention, the structure of the research, their form of participation, and answered questions pertaining to the research brought up by the mothers in the preparation. The therapist/researcher prepared herself personally and professionally by structuring each session, and by writing it in an outline form as a manual which she could possibly follow (Appendix K). When everything the therapist/researcher could think of had been planned the music-caring could begin.

PART IV THE MUSIC-CARING SESSIONS THE IMPLEMENTATION PHASE

Part IV outlines the music therapeutic method used in the ten music-caring sessions. It is intended as a broad overview of how the session structure and the longitudinal guidelines for the ‘improvisational songwriting’ approach were realized.

CHAPTER 14 THE MUSIC-CARING SESSIONS

Experiment

All different
I think
Yet we have surely all been
Berry-picking!
Now we are stuck
In Valgerður's berry box.
She will try to make a tasty jam from
insecurity,
fear,
anxiety.
But housekeeping hints are of little avail
because the recipe
has never been tried before.

Góa

With a clear session structure in mind and broad guidelines in the toolbox about how songwriting might possibly be developed in this context, this 'experiment', as Góa names it in her poem above, or the central music-caring phase (the implementation phase of this study) began on 23 September 2006. It consisted of ten 90-minute to two-hour consecutive weekly sessions, held on Saturday mornings from ten to twelve o'clock. The tenth session was held 11 November 2006. Metaphorically speaking sailing with a sea chart (a program) on unknown waters felt safer. So the therapist/researcher embarked on the voyage with a lighthouse guiding her towards her goal. But like Góa wrote in her poem, housekeeping hints were of little avail because the recipe had never been tried before.

As reflected upon in Góa's diary prior to the first session and the researcher's analytic memos written after the first music-caring session various feelings and thoughts echoed in our minds while trying to anticipate what would happen.

Excerpts from Góa's music-caring diary (the therapist/researcher's translation).

Day one, Sunday 10. 09. 2006.

After my first meeting with Valgerður finished I could not contain myself. When I left, the tears trickled down my cheeks, and I could not hold it back any longer. I walked the street home without meeting anyone and dried my eyes continuously, opened the front door to my house and went silently into the bathroom where I sat down and cried it all out. I watched myself in the mirror in front of me and I was relieved that no one knocked on the door. I felt it was good to cry like this, but it did not concern anyone else. If someone had asked me why I cried I would not know how to answer.

I know Valgerður saw how I felt during the meeting or at least that I needed to cry. Often the tears pressed on my eyelids and demanded to fall, but I did not like the thought of crying in front of a strange woman in our first meeting. Not that I usually cry in front of people that I know or in front of friends. This act, crying, is personal in nature. I had not hurt my knee or fallen on the floor: the cry was an expression of an emotion that I had not realized that I needed to express. I felt a certain relief but also fear. I had signed up for a course – designed as research - which I did not know anything about. Despite this meeting with Valgerður the fear gnawed me. I knew, though, that I would not turn my back on this. Valgerður and I sat together for a while and discussed what awaited us in the ten weeks that the course would run for. I was none the wiser but learned that this was nothing like what I had expected. It was Þ's occupational therapist who informed me about this research. I do not know if V (the occupational therapist) herself knew what this was all about, but I at least had got the wrong idea. I had mentioned that Þ really enjoyed singing, both to listen and to sing himself. V said she knew of a research project that was in preparation where mothers would meet with their disabled children and sing together. She volunteered to send me some more information. I was very pleased and looked forward to the singing that was in store. It was no problem to get there as the research would take place at the end of my own street. Brilliant!

Later that same Sunday I met two of my sisters at the house of one of them. I told them how I had felt previously that day, and that I had cried all the way to my house. They looked at me and listened, I felt that the look on their face expressed a surprise like they had not realized that I was feeling bad and that they were perhaps not doing a good job in their role as sisters and soul mates. But I had not been feeling bad. This cry came out of the blue. It came

unexpectedly like a bomb. But I think it is so extraordinary that I have written a whole page about it in my diary!

Now that I have recovered I still worry that I will be sitting crying among six to eight unfamiliar women every Saturday between ten and twelve o'clock until Christmas. ... Different things bring forth my tears, among other things when I am approached with unexpected kindness and a gentle presence, and not least a beautiful singing which touches me somehow, also often when I sing myself. Even "Gamli Núi" if nicely sung could bring forth a little cry. I will remember to bring my tissue.

Day two, Monday 11. 09. 2006.

Now I am feeling better. I am excited. I have this feeling that this course can somehow transform my life. I realize that these are unrealistic expectation, but I feel the time has come to take a little risk, because this is a dangerous course. The ladies' feelings will be in the foreground. I think. That is auspicious, but also crying. I am all the same and perhaps from an old habit preparing myself to shut down strong feelings, just so that I will not be exhausted after the sessions. But I am going to participate. And I am excited!

Memos written by the therapist/researcher after the first music-caring session, 23 September 2006.

Everyone was present. Surprisingly my anxiety disappeared and I felt calm. I almost felt good in the group. The group took off somehow, like it did not need me. I speculated about my role. I had provided them with physical needs like light, heat, nourishment, instruments, chairs and candles. They had also been nourished intellectually, as much as I felt necessary, by telling them what sparked this research interest, what music therapy is, how the sessions would be structured, why I had chosen songwriting as a central therapeutic approach, and that we needed to honour the individuality of each mother, her personality, feelings and state of being.

I felt happy about how it went but when I listened to the recording I spoke hesitantly. My voice was in the background, and it was like I let the mothers take over. Perhaps it was okay. I did not know quite how to participate in their discussions, but I wanted to sound supporting, strengthening, and wise in order to deepen what they were talking about. It appeared that when they left the session they felt happier and more at ease than when they arrived. Their worry about not being able to play instruments seemed to be gone.

It is apparent that controlling time will be a difficult task for me. I had far too much material for this session and we did not manage to do the activity that was scheduled as a preparation for a songwriting activity. I also worry that one of the mothers will take up too much time and space but her presence seemed instrumental in moving the group forward. Her self-disclosure, sincerity and honesty seemed to do the group some good; it encouraged the others. Skonza seems the most introverted. She is the youngest and her voice is very quiet. Besides worrying about her own daughter and her own life she worries about... I worry somewhat, or I am curious, about how the group will be next week when Hanna is not there.

I think I can be pleased with this start. The preparation has taken a long time. These sessions are built on a deep need for so many things including to break from professional isolation, to get an opportunity to undertake new things, and to have the chance to do that with supervision and with such deliberation is priceless. What seemed in the far distance almost insurmountable seems to be transpiring. My hope is that the music-caring group will meet the needs of the mothers and that their experiences will bear witness to the importance of this idea.

Yalom (2005) explains how positively the therapist/researcher felt despite all her fear. The first group therapy session is invariably a success he says. "Clients as well as neophyte therapists generally anticipate it with such dread that they are always relieved by the actual event. Any actions therapists take to reduce client's anxiety and unease are generally useful" (p. 310).

Being a double novice, both as a researcher and as a therapist, in this situation the relief was understandable. Speculating about why the mothers' apprehension before and in the first session may have decreased, the following measures may have been instrumental: disclosing the motivation for conducting the research, defining music therapy, giving information on session and research structure, clarifying confidentiality issues, elaborating on the researcher's intention and the common group goal, emphasizing that our personality and individuality would be honoured and emphasizing that this was in no way a competition in music making.

Both structure and disclosure must be of the right amount to be effective, says Yalom (2005). The most potent way of providing structure is to build into each session a consistent, explicit sequence. It makes for the most efficient use of a limited number of sessions; it also ameliorates anxiety and confusion and supports efficiency. Leaders who provide excessive structure may be positively evaluated by their members, but their groups will fail to have positive outcomes.

An effective group takes maximum responsibility for its own functioning. If one structures the group tightly it will create a dependent group – if the therapist does everything for the members, they will do too little for themselves. Too much or too little leader structuring can thus be detrimental to growth. The same argument applies to self-disclosure. It facilitates group cohesiveness. Yet too much disclosure, on the other hand, can arouse anxiety in others rather than affection. So from the first moment the therapist/researcher was reminded of a delicate balance between various helping traits and facilitative behaviour in this formative stage of the group (Benson, 2001; Brammer, 1979, p. 47; Yalom, 2005, p. 497).

The main objectives in the first session were to introduce the participants, provide information about music therapy, the research and the group goal, promote self-disclosure and build trust and intimacy. Explaining to the mothers what music therapy was all about they were told that:

Music therapy is the structured use of music, sound and movement to obtain therapeutic goals aimed at the restoration, maintenance, and development of mental, physical, and emotional health. In a systematic manner, a specially trained individual uses the properties and unique potentials of music and sound, and the relationship that develops through musical experiences to alter human behaviour, to assist the individual to use his fullest potential, to communicate his uniqueness and to increase his well-being (Jónsdóttir, 1993, p. 280).

Introducing the therapeutic approach to the mothers in the first session they were told that along with improvisation, music listening, composing and performing, singing and songwriting are all much-valued tools in the music therapist's toolbox. The therapist/researcher also mentioned that research had shown that creative work in the form of singing, songwriting and music making is an effective approach in therapeutic work with different client groups, including cancer patients, trauma survivors and those in grief. She talked about music and singing as a cultural phenomena which may have developed from verbal language as an expression of emotions, and also mentioned the place singing holds in Icelandic culture. The majority of Iceland's population knows enormous numbers of folk songs and popular songs of various kinds and enjoys singing. People sing when they get together and songs and singing are connected to most, if not all, of people's most important moments in life. Very many are or have been a member of a choir, and very many have a favourite song or personal memories connected to a specific song and or a song lyric.

The therapist/researcher talked about how singing together in a group could develop group cohesiveness, encourage social interaction, provide group support and be a source of joy. She pointed out that singing facilitates expression, reduces isolation and loneliness, and gives one an opportunity to experience joy and happiness even during difficult times. To make one's own song would only be a small step away from singing the songs of others and one's creation could be performed again and again. One could share it with others and keep it. The influence from a songwriting process does not finish when the song has been created; the process carries on. The song is rehearsed; its life continues and is even performed for others. The therapeutic meaning and importance of the song is thus not only connected to the song itself as a specific means of expression, but also to connections which evolve in the process of its creation and during its use within therapy and beyond. For many who have tried songwriting it has proved to be a joyful experience and a witness to an important period in one's life.

The mothers were given an overview of what was called a temporal vertical structure of each session. There would be a tuneful welcome a warm-up through musicking together, a songwriting activity, and a break with some nourishment. To conclude the session there would be a tuneful goodbye. In the first session a timeline or a temporal structure of the research period or the process was introduced. The therapist/researcher showed the mothers how she intended to progress from a warm-up or preparation in sessions one to three, towards a lyric development in sessions four to seven and conclude with lyrics transformed into a melodic form to be rehearsed and performed in sessions eight to ten.

The therapist/researcher believed that introducing the research intentions to them in this manner and the rationale behind some of her choices was important and instrumental in engaging the mothers. This undertaking would be a common effort, "our creation" as they refer to in the interviews when talking about how lucky and grateful they felt being participants in this first group (Klambra, SP I 001; Góá, SP I 004).

14.1 The progression of the music-caring sessions

In order to demonstrate the development of the music-caring sessions and the central songwriting approach used, the activities carried out in the session have been listed in numerical order. To distinguish between musicking and the spoken word all musicking activities have been highlighted. Besides structured activities there was a lot of laughing, crying and spontaneous talking in each session. In fact, there was so

much talking that the therapist/researcher often felt her greatest challenge was to keep time and to direct the participants back to the music.

Whether in therapy or in research each situation is unique, thus it is impossible to generalize from one setting to another (Wheeler & Kenny, 2005, p. 67). However if described somewhat thoroughly, others interested in working with this population might be able to use this approach as a referential template to some extent. It should be stressed that the following outlines of the music-caring sessions are only intended as an overview showing the main structure of the musicking. Worded differently, it is a template of the music therapeutic approach used in the ten sessions but it does not provide the rationale for the choices made in the flow of each session and thus from a therapeutic point of view it is extremely limited in scope. The relative emphasis given to music experiences versus verbal experiences varied considerably from one session to another.

Session #1 23. 09. 2006

- 1 Madredus plays in the background.
- 2 The researcher introduces herself.
- 3 The mothers introduce themselves (their names, their child/children etc.).
- 4 Name song.
- 5 The research is introduced. What is music therapy? What sparked the research? The horizontal and vertical structure of the research period and the sessions. Why songwriting is used as a central approach. In no way is this a competition in music making. Honour different needs, different personalities. The importance of giving each voice an opportunity to sound itself in whichever way the mother prefers. Confidentiality issues.
- 6 We sing together “Ef þig langar að syngja þinn söng.”
- 7 What is this song about?
- 8 A pause for refreshment and informal chatting. Background music is playing.
- 9 The mothers explore available instruments.
- 10 The mothers choose instruments that appeal to them.
- 11 An instrument song. We play together as a group: “play the instruments and make a ____ sound.”
- 12 The song is repeated but now with solo versus group playing.
- 13 The mothers select a new instrument or keep the same. The sound of the group. Free instrumental improvisation.
- 14 How was it for you to play these instruments? How did the group sound? Can we describe the group sound?

- 15 How was it for you to come to this group? What do you take home with you? Remember your diary!
- 16 We sing again (6) “Ef þig langar að syngja þinn söng.”

A lot of laughing, crying and talking.

Session #2 30. 09. 2006

- 1 Background music is playing.
- 2 How was it for you to participate in the first session? Is there something you want to express concerning that experience – some thoughts, questions? Is there something in your diary you would like to share with us?
- 3 We sing again “Ef þig langar að syngja þinn söng” from session #1.
- 4 The mothers explore available instruments and choose one that appeals to them.
- 5 Free instrumental improvisation. Same activity as in session #1 but this time one mother begins the circle sound.
- 6 A drum circle.
- 7 How was it for you to play these drums? Can you tell if you feel in any way different now than before you started the drum playing?
- 8 The following words have been written on the whiteboard: quality/attribute, an individual, incident/happening/experience, a wish, an emotion. These words sprang from the mothers’ discussions in session #1.
- 9 The mothers are asked to stand up and write on the whiteboard, one or more words under one or more categories.
- 10 A break. Background music is playing during the break.
- 11 Grounding movement. Standing in a circle with eyes closed we let music from Secret Garden ‘move us’ at will.
- 12 We sing “Dagur er risinn” (Morning has Broken.)
- 13 How was it for you to sing this song? Did the song evoke any memories, thoughts or feelings?
- 14 How was it for you to participate today? Remember your diary!

A lot of laughing, crying and talking.

Session #3 07. 10. 2006

- 1 Background music is playing.
- 2 We sing together “Dagur er risinn” from session #2.

- 3 We return to what they spoke about in session #2 in connection with the lyric of this song.
- 4 Is there something you would like to share with us that could be connected to the song text? Is there something you would like to share with us that is related to your participation or the activities in session #2? You are reminded of the opportunity you have here to give and receive in the form of the spoken word, music, sounds and movements.
- 5 A drum circle.
- 6 How was it for you to play the drums?
- 7 Review task #9 from session #2. I encourage them to add more categories or words to categories on the whiteboard.
- 8 One mother chose *paranoia* as her word and a player/instrument (the researcher on the piano) to express it. Esja, referring to the paranoia, said “paranoia finishes and then you become free.”
- 9 The words *to live here and now* were sounded. A mother chose various instruments and players to sound her words. She says: “I think I am crying because I am happy.”
- 10 How was it for you to sound your words?
- 11 A break. Background music is playing (Secret Garden).
- 12 Relaxation with music. Alina by Arvo Pärt.
- 13 How was it for you to relax with this music? Can you share with us what you experienced on this ‘musical journey’?
- 14 How was it for you to be a participant today?
- 15 What is it that you take with you now? Remember your diary!
- 16 A farewell song: “Sitjum, við sitjum saman.”

A lot of laughing, crying and talking.

Session #4 14. 10. 2006

The attendance of the mothers varied (see Appendix I) and in session #4 only three were in attendance. Despite the researcher’s worries about what would happen in the session with only three of them there she felt afterwards that it had not been disastrous and that it had created a useful space for those present.

A new song was sung together, the lyrics were discussed and the reason for choosing the song. The group sound was played. Instruments were selected to sound words from the whiteboard: “being tired” and from the wish category the words “being positive”. The mothers had fun with kazoos, relaxed with music, and gave each other a musical farewell gift when sounding together optimism, hope and energy. A goodbye song was sung. The therapist/researcher also gave them

some questions for thought: Why am I here? What are my hopes or my fears with regard to the group? What is my aim for being in the group? What is the aim of the group? What do I like about the sessions? What do I dislike? How was it for me to participate in this session? Where do we go from here? What do we take with us today? What do we leave behind?

Sessions one to three had been intended as a warm-up and a preparation for the songwriting experience. Sessions four to seven were intended for lyric development and sharing. Until now the mothers had been looking at lyrics, singing them, talking about them, noticing how both the lyrics and the music affected them, and they had brought their own favourite songs. They had been choosing instruments to sound themselves, choosing instruments and players to sound different words/feelings and thoughts. They had been using receptive music for relaxation, imagery and focusing. So in many different ways, both structured and improvised, they had been weaving together music and words, and music and feelings.

Session #5 21. 10. 2006

- 1 Secret Garden is playing in the background.
- 2 The mothers chat informally about various things (music, a conference, a young man with a disability, etc.).
- 3 The mothers are told about the song “Barnagæla” which was sung in session #4 and how it was somehow felt reflected in what they had been discussing in session #3.
- 4 The song “Barnagæla” from session #4 is sung.
- 5 The lyric is discussed (any ideas, feelings, thoughts, etc. that it evokes) and the researcher’s reason for choosing it.
- 6 She asks them how it was for them to use the diaries this week and if there is something they want to share with the group.
- 7 The therapist reads her compilation of issues they had talked about in previous sessions.
- 8 She gives them a written summary of issues discussed in the previous sessions. The issues were related to the categories and the subcategories on the whiteboard.
- 9 A relaxation and a focusing activity. Is there something that calls my attention right now, an emotion, a feeling, a thought, an image, colour, sound or something else? Questions are asked: Who am I? What are my needs? How do I feel right now? What do we have in common? What feelings do we have in common? What needs do we have in common? How can we express individual and collective needs, feelings, and

- experience? What is our aim in this group? What is the aim of the group? Stay with what comes to your minds, or with what you find in your bodies. Pay attention to it like you were sitting beside it and observing it.
- 10 An induction and relaxation with music by Arvo Pärt.
 - 11 The mothers write down their experience. They are asked: What came to your mind? What did you hear? What did you see or pay attention to? You can also give a name to what you attended to.
 - 12 A pause for some refreshment. Background music is playing.
 - 13 Words are chosen from the blackboard and sounded with instruments of their choice. The words *empathy* and *to be able to listen to others* are chosen.
 - 14 How was it for you to sound your word?
 - 15 A mother brought a CD with Pink Floyd's song "Dark Site of the Moon" which was listened to.
 - 16 A kazoo activity (breathing in what we need and sounding through the kazoo what we want to get rid of.)
 - 17 How was it for you to be a participant today? In our last session you took with you energy, equanimity, and being positive. What do you need to take with you today? Remember your diary!
 - 18 A farewell song.

A lot of laughing, crying and talking.

After session #4 when only three mothers were present, the therapist/researcher began to worry about how she would kind of effortlessly bring the song creation forward. She had realized that the mothers used the music differently to express themselves and their personalities were reflected differently in the music. Although they had many things in common, they also had different needs and were at different places in their process of grieving. The therapist/researcher did not want to tell the mothers how to write their songs or tell them what to write about. However, she also felt the mothers had to focus somehow and collect their thoughts if the task to create a song was to be realized. Thus the therapist/researcher verbally summarized all the main issues the mothers had brought up in the sessions and produced a 13-page handout that she gave to them. The therapist/researcher listed in three columns her view of how the categories she had chosen following session #1 and put on the whiteboard and the related subcategories the mothers had put on the whiteboard in sessions #2 and #3 related to the main issues of their verbal discussions in the first four sessions (Appendix L).

Because of the fluctuation in the mothers' attendance it was predicted that giving them the summary in session #5 would be helpful. Possibly it would

emphasize the feeling of continuity that the therapist/researcher felt was so important. In the handout they should be able to recognize their own expressions, and she believed that this tapestry could somehow assist or encourage them in their songwriting process. Furthermore she reminded them of their collective task, i.e. to shape their expressions into a song or songs. They were told that it could be done in different ways, that they could do it as a group or as individuals. As an example, the therapist/researcher also gave them a few verses she had written using a collage technique grouping together their own words/issues from column number three in the handout (Appendix M).

Actually the therapist/researcher was worried. It was difficult to keep the session structure. There was always so much need for talking and she had difficulty controlling or containing that as much as she felt she should. On the surface nothing seemed to be happening in the way of songwriting, and she began wondering if keeping to her original songwriting intentions could possibly harm the evolving therapeutic process.

Session #6 28. 10. 2006

- 1 Background music is playing. (Secret Garden). A lot of talking while waiting for all the mothers to arrive.
- 2 The mothers are reminded about the kazoo activity from sessions #4 and #5. The kazoos are used to sound one verse from the song “Óskastund” and then it is sung.
- 3 How was it for you to sing this song? Did it evoke any feelings or thoughts? Is there something that you want to share with us that relates to the lyrics?
- 4 How was it for you to use the diary this week? Is there something in it you want to share with us?
- 5 A verbal review of the issues discussed in session #5 is distributed. Many things were brought up in our last session. Among other things, you discussed:
 - a. Stoicism – or to be able to face fearlessly the things you encounter.
 - b. Uncertainty in life and the costly experience you all have gained.
 - c. How to measure happiness and what defines the value of a person.
 - d. Changed identity (or the tendency to identify yourself from the perspective of the child) and the constant demand of doing well.

- e. Empathy and the importance of being able to put oneself into another's shoes.
 - f. How important it was to be listened to and to have the freedom to express oneself.
 - g. Einræn shared with us her agony and the horrendously difficult decision she is faced with. Her conditions and her emotions touched us deeply.
 - h. We also discussed how important it was to be able to stay in the silence, listen to one's heartbeat, become aware of our own thoughts, feelings and state of health, to stand by oneself and claim some space in this world so we could among other things, stand by the ones who needed us.
- 6 The mothers choose an instrument and play it the way they feel best describes how they feel in the moment or how they had felt last week.
- 7 First they sounded themselves all together and then one by one.
- 8 How was it for you to sound yourself?
- 9 A break for refreshments. Background music is playing.
- 10 The mothers are asked about their homework.
- 11 Klambra plays and sings her song.
- 12 Kristjana recites her poem.
- 13 Einræn recites her poem and also presents a lyric.
- 14 Hanna recites her poem.
- 15 A discussion about what is possible to do with the lyrics. You can read them, you can sound them, sing them and rehearse, and then they will be recorded. The poems/songs will stay with us after the group is finished.
- 16 What do you take with you today? Remember your diary!
- 17 A farewell song, "Sitjum, sitjum saman" is sung.

A lot of laughing and talking.

The urging on mode or the focusing stance in session #5 was fruitful because in session #6 four song lyrics were introduced. Klambra sang a fully formed song where she expressed both feelings and wishes using these words: anxiety, sorrow, worry, fatigue, standing up to challenges, enjoying life, exploring colours, learning new ways, finding peace, and letting positive thinking in.

Kristjana talked about endless strain, waiting and pain and the importance of having more time. She also talked about how difficult uncertainty can be, the importance of having an opportunity to express and name feelings, and to have someone who just listens without criticizing. Continuing is the only way out, she argued.

Rigning og ró

Rigningin er þung og dropar renna.
Ljósaskiptin leggjast yfir reit.
Áhyggjurnar vilja á mér brenna.
En af stjörnunum þarna uppi þó ég veit.

Hvernig get ég öðlast innri ró
sem í gamla daga Gandhi yfir bjó?
Setja sorgina í orð,
sett áhyggjur upp á borð.
Þá við verðum fær í flestan sjó.

Njótum lífsins litla barn í dag.
skoðum alla litina í kring.
Þú kennir mér nýtt tilbrigði við lag
með hljóðfæri í hönd ég með þér syng.

Hvernig get ég öðlast innri ró
sem í gamla daga Gandhi yfir bjó?
Hleypa jákvæðninni að
lagt þreytuna í bað.
Þá við verðum fær í flestan sjó.

Klambra

Óvissa

Ósýnilegt álag, endalaus bið og kvöl.
Nauðsynlegt að fá meiri tíma.
Að fara í gegnum sársaukann er eina
leiðin út.
Óvissan er svo erfið.
Að fá að tjá og nefna tilfinningar.
Og hafa einhvern sem bara hlustar
gagnrýnislaut.

Kristjana

Rain and peace

The rain is heavy and the drops pour down.
Twilight descends upon the land.
Burning anxieties gnaw at me.
But I know of the stars up there above.

How can I find the peace within,
that Gandhi possessed in days of old?
Put my sorrow into words,
bring my worries into the open.
Then we'll stand up to challenges.

Enjoy life, little child, today,
explore the colours all around.
You teach me variations on a tune,
instrument in hand I sing with you.

How can I find the peace within,
that Gandhi possessed in days of old?
Let positive thinking in,
bathe my fatigue away.
Then we'll stand up to challenges.

Klambra

Uncertainty

Invisible strain, endless waiting and
torment.
More time is necessary.
Experiencing pain is the only way out.
The uncertainty is so tough.
Being able to express and name
feelings. And having someone who
just listens without criticizing.

Kristjana

In her poem “Outer and inner autumn”, Einræn shared with us her sorrow and torment watching her child’s pain, which she was incapable of doing anything about.

Ytra og innra haust

Úti fyrir rignir.

Það haustar og blöðin falla af trjánnum.

Það haustar einnig innra með mér.

Sorgin er allsráðandi.

Tárin falla, og ég kvelst yfir því að horfa á sársauka barnsins míns.

En ég fæ engu um það breytt.

Einræn

Outer and inner autumn

Outside it is raining.

It is turning to autumn and the leaves fall from the trees.

It is turning to autumn within me as well.

Sorrow controls everything.

The tears fall, and I am tortured by watching my child's pain.

But I cannot change any of that.

Einræn

Hanna expressed how much she loved her children and how much she loved being a mother. But being a mother was a difficult role and her tiredness makes everything go astray.

Ég elska börnin mín svo heitt
að því er ekki hægt að lýsa með orðum.
Samt er ég stundum svo þreytt,
að hjá mér allt fer úr skorðum.

I love my children so warmly
that words cannot describe it.
Yet sometimes I am so tired
that everything goes astray.

Ég elska það að vera mamma.
Ég dýrka það og dái.
Samt er það stundum svo erfitt,
að mér finnst að stöðu mína þurfi að manna.

I love being a mother.
I worship it and adore it.
Yet sometimes it is so difficult
that I feel my job should be manned.

Hanna

Hanna

Session #7 04. 11. 2006

- 1 Music is playing in the background.
- 2 The song “Óskastund”, introduced in session #6, is sung and decorated with sounds.
- 3 Góa presents two poems. “When I wrote them I felt they were great, but now I feel they are stupid,” she says.
- 4 Esja presents her poem.
- 5 An additional summary of issues discussed in sessions #5 and #6 is given to the mothers.
- 6 Klambra presents a new poem.
- 7 Klambra sings the first poem from session #6.
- 8 Esja selects instruments and players to paint her poem.
- 9 How was it for you to hear your poem sounded in this way?
- 10 Klambra selects instruments and players to sound her poem.
- 11 How was it for you to hear your poem in this way?
- 12 A break for refreshment. Background music playing.
- 13 The mothers select drums and play together.
- 14 How was it for you to play the drums this time?
- 15 Relaxation with Samuel Barber’s Adagio.
- 16 Will you share with us how it was for you to relax with this music? Where you went, what you saw or how you felt?
- 17 The mothers are reminded of the summaries they have got, the diary, and the common task?
- 18 A farewell song is sung.

A lot of laughing and talking.

The poems Góa shared with us in this session discuss her intent to manage insecurity, fear and anxiety, and how the notes flow on their own, single but fuse hesitantly and boldly start to weave bandages for our souls.

Tilraun

Allar ólíkar
Held ég
Höfum samt örugglega allar farið á
Berjamó!
Núna erum við fastar
Í berjatínu Valgerðar.
Hún mun freista þess að gera braggóða
sultu úr
Óöryggi,
Ótta,
Kvíða.
Góð húsráð duga skammt
Því uppskriftin
Hefur aldrei verið reynd áður.

Góa

Líkn

Hikandi
renna tónarnir fram
einir
stakir
en blandast saman
hikandi.
Svo taka þeir galvaskir til við að
spinna
sárabindi
á sálirnar okkar,
Tökum á móti kvíða, ótta, óróa,
Guði
og Veru sem er bara köttur
svartur
og hvítur og
dauður
Gerum að særðum
forðumst þó
eitthvað
viljum halda lífi.

Góa

Experiment

All different
I think
Yet we have surely all been
Berry-picking!
Now we are stuck
In Valgerður's berry box.
She will try to make a tasty jam
from
insecurity,
fear,
anxiety.
But housekeeping hints are of little
avail
because the recipe
has never been tried before.

Góa

Care / charity

Hesitantly
the notes flow out
alone
single
but fuse
hesitantly.
Then they boldly start to weave
bandages
for our souls,
we take in anxiety, fear, unease,
God
and Vera who is just a cat
black
and white and
dead
we tend the wounded
yet avoid
something
want to stay alive.

Góa

Esja shares with the group what she wants for herself: to be able to trust, to be able to listen, to be able to express herself, to live here and now, to be able to adjust and to be all the good things. She believes that she is what she lives, sees, and says and she wishes for inner strength for herself.

Lausnir

Að geta treyst.
Að geta hlustað.
Að geta tjáð sig.
Að lifa í núinu.
Að geta aðlagast.
Ég vildi ég væri allt það góða
Guð, Gandhi, kærleikurinn.
En ég verð það sem ég lifi, sé og
segi
og get óskað mér innri styrks.

Freeing/liberation

Being able to trust.
Being able to listen.
Being able to express.
Living in the present.
Being able to adjust.
I wish I were all good things
God, Gandhi, love.
But I will be what I live, see and say
And can wish for inner strength.

Esja

Esja

Having voiced her worries after session # 4 about how she could potentially effortlessly bring the song creation forward, the therapist/researcher wrote analytic memos after session #7 (more than half way through the music-caring sessions), including:

I have received poems from everyone except Skonza. It appears that the mothers feel insecure about their lyrics/poems, perhaps Esja in particular. She also worried about giving birth to her baby. She is scheduled to have a Caesarean 14 November. She did not choose an instrument for me to participate in sounding her poem. It somehow troubled me. Why did she not choose an instrument for me to play? Then I wonder how my silence affects them – what they think about it. They talk so much themselves and I cannot share my experience, which is different from theirs, since I do not have a child with special needs. Their world is special and that is continually becoming clearer to me. They cannot even at times put themselves in each other's shoes.

Often it appears that Hanna is leading and perhaps somewhat dominant in the group. She is so spontaneous and giving and I think her way of being is very good, especially for Einræn. But then I feel somehow that she is somehow usurping my

role as a leader of the group. What is my role? Is it different from one session to another? Am I only a timekeeper? Do they feel that I am rushing them, for example at the end of this session when I introduced a relaxation activity but a long time passed until I felt I could start the music?

Hanna arrived fifteen minutes late. I went straight from the introductory song to their songs and did not give them any time for a warm-up. Sometimes I feel like the group is losing its drive. That is how I felt after the last session, but when I listened to it then lot of things seem to be happening, at least if their discussions are a measure of a normal group process. Different issues are brought up – difficulties from childhood, difficulties with their other children, difficulties in their marriages, losses and grieving. They also talked a lot about professionals and how unsympathetic and unprofessional they can be. The mothers said the pros are inconsiderate and do not follow up on how people are doing.

When I think about the research protocol, I realize I have not managed to bring them towards one central theme. Perhaps I can focus on it in our next session. What do we have in common? What bothers us the most? What do we want to express? Can we do that in a common narrative, in a joint song? In our next session we are supposed to rehearse notations of their song painting and also create music.

Session #8 11. 11. 2006

- 1 Background music is playing.
- 2 The song “Vetrarsól” is sung.
- 3 How was it for you to sing this song?
- 4 Discussions which took place in session #7 are summarized.
- 5 Other issues talked about are the song creation, the group closure and the function their songs can serve once the music-making is finished.
- 6 Klambra presents a new poem, “Superwoman”
- 7 Discussions about some issues from the handout given to the mothers in session # 7.
- 8 A break for refreshment. Background music is playing.
- 9 Góa selects instruments and players to sound her poems.
- 10 A discussion is sparked by one of Góa’s poems.
- 11 Einræn’s song is rehearsed.
- 12 Contrasting emotions are sounded: *being worried* versus *being carefree*.
- 13 How was it for you to sound these contrasting feelings?
- 14 A guided relaxation with music.
- 15 How was it for you to participate in this activity?

- 16 A farewell song is sung.
- 17 The therapist/researcher listens to the answering machine and shares good news from Esja with the mothers. Esja had a baby girl after session #7. Mother and child are doing very well. Esja plans to come to session #9.

A lot of laughing and talking.

Session #9 18. 11. 2006

- 1 Background music is playing “Húm”.
- 2 “Vetrarsól” is sung again.
- 3 Issues discussed in session #8 are reviewed. (“I must have been with you because I was writing the same things in my diary at home,” says Esja, the woman who gave birth earlier in the month).
- 4 Feelings associated with parting and the tasks ahead are discussed. The songs need to be rehearsed and made as we want them to sound on the CD. After the group interview (session #11), the mothers will each take a CD home with them.
- 5 Skonza is going to send her poem in an e-mail.
- 6 Klambra reads her new poems: “Ó” and “Valgerður”.
- 7 Klambra reads her text “Súperwoman”.
- 8 Klambra selects instruments to be used for sounding the one and only “Superwoman”.
- 9 Klambra reads her poem and “Superwoman” is sounded.
- 10 Klambra reads her poem “Rain and peace” and then the group sings it.
- 11 Hanna’s song is sung.
- 12 Hanna’s song is discussed.
- 13 Hanna’s song is sung again.
- 14 Esja’s song is sung and recorded.
- 15 Esja’s song is discussed.
- 16 Esja’s song is sung again and recorded.
- 17 Einræn’s song is sung.
- 18 Einræn’s song is discussed.
- 19 Einræn’s song is repeated.
- 20 Kristjana’s song is sung and repeated.
- 21 Góa reads her first poem and then it is sounded.
- 22 Góa reads her second poem and then it is sounded.
- 23 A break for refreshment. Background music playing.
- 24 One of Klambra’s favourite songs, “Vikivaki”, is sung.
- 25 What has this group done for me? What do we have in common?

- 26 The therapist/researcher tells the mothers how important they have been for this undertaking, and how grateful she is. A reference is made to Góa's poem, "Berry picking" and the mothers are told that if the therapist/researcher had handpicked the participants herself she would have wanted to pick exactly them and no one else. The mothers are reminded again of the fact that their next session will be their last music-caring session together.
- 27 A farewell song is sung.
- 28 The mothers remain seated.

A lot of laughing and talking.

The relative large amount of time allotted to Klambra in session #9 was because she was going to be absent in session #10. Her song and all her other poems therefore needed to be recorded in session #9.

In her diary Klambra, expresses herself about this:

Sorry to say I missed the tenth and last session in music-caring, but I felt I needed to go with my husband and his work colleagues on an adventure trip. I also had to cancel two song gigs with my choir, which the director rather disliked. I had in fact taken up a lot of space in session number nine, played and sang, read poems and a story. Far too much (although Valgerður made the best of it).

The girls may have thought: "sjúkkett, she won't be able to attend the poem-crazy one."

Well the adventure trip was very amusing and I did exceed to a great extent my own ability and courage and that was a marvellous feeling.

Session #10. 25. 11. 2006

- 1 Madredues plays in the background.
- 2 The mothers are welcomed and informed about those who are absent. A short introduction to this last session is given and it is compared to the changing nature of life itself. The therapist/researcher mentions contrasting feelings they might experience associated with the closure of the music-caring sessions, feelings such as happiness, anger, worries, ease, hope, or hopelessness.
- 3 The song "Fræ í frosti sefur" is sung.
- 4 How the music should be organized on the CD is discussed.
- 5 Some time is taken for the mothers to sort their handouts. Einræn and Kristjana are lost in all the papers.
- 6 Góa distributes instruments to be used to sound her first poem.

- 7 Góa reads her poem and then it is sounded.
- 8 Góa reads her second poem and it is sounded.
- 9 Einræn reads her poem.
- 10 Einræn's song is sung.
- 11 Einræn's song is repeated.
- 12 Marta reads her poem.
- 13 Marta's song is sung.
- 14 Marta's song is sung with the addition of percussion instruments.
- 15 How was it for you to sing your song with these instruments?
- 16 Skonza reads her poem.
- 17 Skonza's song is sung.
- 18 Skonza's song is decorated with bells and sung again.
- 19 How was it for you to sing your song with these instruments?
- 20 Skonza's song is repeated.
- 21 Hanna's song is sung.
- 22 A break for refreshments. "Húm" is playing in the background. A discussion about children placed on a waiting list for Tónstofan music school. Do students ever graduate?
- 23 Esja reads her poem.
- 24 Esja's song is sung.
- 25 Esja's song is repeated.
- 26 A musical self-portrait. The mothers choose an instrument(s) that they feel best describes the way they are feeling in the moment or the way they felt last week.
- 27 The six of us (five mothers and the therapist/researcher) sound ourselves one at a time.
- 28 How was it for you to sound yourself this time?
- 29 The group sound is played.
- 30 The mothers are provided with closure in the form of a brief overview of what they have been doing and what is still to be finished.
- 31 A discussion about when they could possibly meet for the group interview.
- 32 The song "Fræ í frosti sefur" is repeated.
- 33 They remain seated and discussions evolve around Esja's baby girl, who took part in the session.

In her poem, Skonza speaks of shifting emotions and of being tired, worried, fearful, guilty, stressed and lacking time. Kisses, hugs and soft strokes from small fingers push darkness away and all worries disappear. Happiness and love make fear, guilt and tiredness flee. Time takes her side but only for an instant.

Preyta	Fatigue
Áhyggjur	Worry
Ótti	Fear
Sektarkennd	Guilt
Álag og tímaleysi	Stress and lack of time
Liggur svo þungt yfir mér.	Weigh so heavily upon me.
Lítið bros	A little smile
Klístraður koss	A sticky kiss
Gott knús og blíðar strokur frá litlum fingrum	A nice cuddle and gentle strokes from little fingers.
Ýta myrkrinu frá.	Push the darkness away.
Allar áhyggjur hverfa á braut, Hamingja og ást leysa óttann og sektarkenndina af.	All worries vanish, Happiness and love take over from fear and guilt.
Preytan flýr og tíminn verður mér hliðhollur.	Fatigue flees and time takes my side.
En einungis í eitt andartak, í eitt augnablik.	But only for an instant, for an instant.

Skonza

Skonza

The last music-caring session came to an end and the last song was sung together. The final overview (the postlude below), given to the mothers in session #10, was intended as a review, a brief summing up but also as a preparation for the group interview to be held (see Appendix N for the Icelandic version).

Postlude

At the beginning of our first session together I spoke, among other things, about my hope that music-caring and the activities in the sessions would strengthen empathy, make you become aware of your feelings and state of being and encourage their expression in a creative way. I also mentioned that music-caring had not been carried out before in this way so that their individual experiences would provide important knowledge and become a guiding light for me, other music therapists and other mothers who in the future would participate in music-caring.

I also mentioned that it was important that every mother be allowed to shine and let her voice be heard in a way she herself would choose each time. In each session we would get an opportunity to express any pressing issues we have. We would travel together for a while, and give each other some insight into our lives, our emotions and our thoughts. We would give each other and receive from each other in the form of music and sounds, togetherness and the spoken word.

Everything has its ending. The sessions will soon be over and we realize that in a short while so will our music-caring. Then you will take with you all the good things you gave to each other with your presence and sincere expression. The sincerity, trust, empathy, support, sympathy and your friendship will sound on your CD and stay with you for times to come.

In our next session we will review this journey together. You will express yourselves about what you felt was noteworthy and what you disliked along the way. At the end of the road we will examine your expectations, your hopes and your fears regarding your participation in the group. We will examine how you felt in the group and how it was for you to participate in the activities. We will discuss if you missed something, what you found difficult, what you liked and what you enjoyed. We will speculate about the value of the activities, what role the music played and the merit of the songwriting. We will also look at what could be changed and what improved.

Think about what is involved in music-caring and also about the moment(s) you felt music-caring was at its height. You can also think about the following questions: How am I feeling now? What has participating in music-caring given me? Will this experience follow me onwards? Will it somehow influence the way I feel, my daily life, and the quality of life? What are the common threads/experiences/feelings that we have been braiding together? Were we successful in letting it all sound in our poems and our songs or haven't we yet accomplished that?

The therapist/researcher's analytic memos written after session #10:

Somehow I did not feel quite good enough after this last session. Hanna was not present and I did not know why. Klambra was on an adventure trip with her husband and Einræn had to leave early because her students were playing in a concert at the music school. I also felt that the agenda itself, lacking time to finish recording their songs and the postlude itself shifted the focus away from the mothers. The attention was moved away from them towards the project/task itself. I felt bad about that.

I also worried a lot about how the recording would turn out. I felt I played badly and too fast, that I sang the loudest and that their voices would not be heard in the recording. I would have needed at least two additional sessions to teach them the songs, to harmonize/arrange them better and to work more on the CD recordings so that one could be proud of it. Esja brought her baby girl and somehow there was a feeling of sadness around it. The child is adorable so delicate and beautiful. I was allowed to record her daughter too.

The week was devoted to selecting music excerpts and to arrange a time with Þórdís at the studio to make the CD. I would never have managed it myself in the time I had available. Þórdís has some connections to the group. She has a child with special needs and she was thinking about participating but did not have the time. I sat with her in the studio. I had edited the excerpts so she did not hear any of the conversation. Today it is 7 December and I still have not listened to the CD. It was finished Thursday 30 November, and copied for the group Monday 4 December.

I have tried a lot to find time for the group interview when they can all meet. That is important. Christmas is a busy time and all sorts of activities are taking place: Christmas concerts, Christmas dances, Christmas handicrafts, husbands abroad, mothers-in-law not in town, so for various reasons it was impossible to find a time within the frame I had set myself (within two weeks from the last music-caring session). Luckily 11 December they can all come. Hurray!

I have been worrying about Einræn. Her boy will be admitted to the Children's Psychiatric Hospital today. She is therefore not doing so well but she holds herself well. Hopefully nothing will happen that might hinder her participation. I have been in e-mail correspondence with all of them and that has kept the connection with them, but Einræn has not responded to my messages. So I decided to call her yesterday. It was good that I did because she told me that her computer connection was bad these days and always closing down so it is not clear if she saw the e-mails.

I have started to miss the group and I hope our session 11 December will go well. Our task is to look at this journey as a group. We will listen to the CD. I will offer them hot chocolate and cookies, and I think I will move the tables together and put candles and tablecloths on them. We will not sit in a circle around the "fire" as usual but along this table with a "long fire". It remains to be seen whether I manage to control the discussion in such a way as to discover the core of the matter and obtain answers to the burning questions.

In session #11 the mothers would get a second chance to say goodbye when in a semi-structured group interview they would reflect upon their work together. The group would attempt to evaluate what was accomplished in light of the set goals. The final meeting with each mother would then be one semi-structured individual interview in session #12.

14.2 Concluding remark

“Housekeeping hints are of little avail because the recipe has never been tried before,” wrote Góia in her poem *Experiment*. The reason for introducing the “recipe” which now has been tried out in this research context (giving a broad overview of how the music-caring sessions developed from one session to another) is to encourage music therapists interested in working with this population to adapt music-caring and songwriting to their own situations. As previously emphasized, the model of the music therapeutic approach used in the ten sessions does not provide a rationale for the therapeutic choices made in the flow of each session. It is thus from a therapeutic point of view limited in scope but may, however, provide a general idea or framework which can be adapted to new therapeutic and research contexts.

PART V DATA COLLECTION, INTERPRETIVE PHENOMENOLOGICAL ANALYSIS AND EMPIRICAL EXPLORATIONS THE REFLECTION PHASE

“Analysing qualitative data is an exciting process of discovery, although it can also be an adventure in the unknown.” says Arnason (2003, p. 127). Being an “emergent process,” as Bruscia describes it (2005b, p. 186) the researcher learns how to do a qualitative research while doing it, and to adapt to what is happening from moment to moment. Not following a particular manual, the feeling is like travelling alone in the unknown. Part V of this thesis shares the adventurous travelling through the process of data collection and analysis. The process is described as it evolved throughout the research journey, beginning in the initial preparatory phase, evolving during the implementation phase, and extending throughout the reflection phase.

Part V also presents the main findings of the study based on empirical explorations, which focused on the lived experience of the seven mothers participating in this qualitative research. The findings are the result of going back and forth between the researcher’s pre-understanding, the researcher’s identification of categories and themes, the mothers’ own words in quotes and a narrated form, and relevant theoretical literature which has informed this study.

CHAPTER 15

DATA COLLECTION

Researchers of more modest learning sometimes prove more creative than those who are too well read in a field. The risk with too much book-learning is to become over-dependent on earlier authorities and tangled up in all the old problems, so that it becomes difficult to see new possibilities. ...A general look through the broad outlines of the theoretical and empirical research field, followed as quickly as possible by a leap into one's own empirical material, can therefore be one possible strategy. However, too weak an insight into the research field also has its drawbacks, such as the possible reinvention of the wheel (Alveson & Sköldberg 2000, p. 17).

The hermeneutic phenomenological method does not offer a procedural system for data collection and analysis, and that was somewhat problematic. The researcher became tangled up in her own insecurity trying to find some guidelines to follow, and asking questions like: What is enough? How do themes come about? Do categories come before themes? The researcher does not know how creative she became in her search, but the time it took to gain enough security to proceed felt like reinventing the wheel. Proceeding with care and designing the study to the best of her ability, for the purpose of providing answers to the research questions, gave access to varied data throughout the different phases of the research.

15.1 Data collected from the initial preparatory phase

In the preparatory phase the following forms were used to gather data:

A form 'A' providing some basic personal information completed by each mother in the first individual meeting with the researcher (Appendix G). The mother was informed about confidentiality issues and instructed that she could omit answering a question if she wished.

Form 'S'. Questions to be answered in writing at the participant's own time and pace (see also Appendix G). The answers to these questions were to be returned when the music-caring group (the research) started. The mothers were informed about confidentiality issues and instructed that they could omit answering a question(s) if they wished to do so.

- 1 What sparked your interest in participating in this programme?
- 2 Have you previously been invited to participate in a support group of some kind?
- 3 Have you or are you presently participating in a support group of some kind? If, yes then please describe the group.
- 4 What kind of professional support/assistance are you receiving from health care professionals?
- 5 Is that assistance related to your child in any way?
- 6 What kind of support (emotional, assistance with daily tasks, assistance with taking care of the child, etc.) are you receiving from your family? (spouse, other children, relatives)?
- 7 Describe yourself as completely as you can in any way or form you feel like. (In words, poem, story, picture, etc.)
- 8 Describe your child as completely as you can in any way or form you feel like.
- 9 What are your hopes and your dreams for the future?

The reason for asking these questions was primarily to get to know the mothers and their situations to some extent from their own perspective prior to their participation in the music-caring group. The researcher was also interested in getting some information about their motivations for participating, the personal and professional support they had had or were currently receiving, and information about their previous experience in support group(s) of some kind. Furthermore, she wanted to know how they regarded themselves and their child(ren) prior to the beginning of their work together and what the mothers' outlook on life was. Also, in the back of the researcher's mind lurked the possibility of comparing their answers to questions seven, eight and nine before and after their experience in the group to see if their self-image or outlook on life had changed in some way.

The mothers' reasons for participating in this study and their previous experience of participating in a group work of some kind is revealed in their written answers to questions one to six from this questionnaire (Appendix R). Before proceeding with the empirical explorations it is of interest to review their answers. They might shed some light on their experience of participating in the music-caring group as revealed in the thematic analysis.

Two of the mothers said that the use of music sparked their interest in participating. Four of them mentioned both music and working with emotions as a reason for their interest. One mother became interested based on a

misunderstanding that this would be a sing-along with other mothers and children. She said later that she would not have registered if she had known the purpose of this study.

Five of the mothers said that they had never been invited to participate in a support group. Two of the mothers mentioned open parent groups that they had known about and attended and one mother talked about “a very good course” which was introduced to her at *Greiningarstöðin (the State Diagnostic and Counselling Centre)*. In this course she learned about the different disabilities and parents in small groups discussed among themselves issues related to having a disabled child and shared it then with the bigger group.

At the time this research was undertaken five of the mothers were not participating in a support group of any kind. Two of the mothers attended informal open meetings at their respective associations (The Downs Syndrome Association and Autism Society).

The mothers’ answers to question number four (what kind of professional support/assistance are you receiving from health care professionals) can be interpreted in such a way that only one of them was receiving assistance for herself (from a psychiatrist) during this time period.

According to answers to question number five all the help the mothers received was directly related to their children and not themselves. Understandably, even the help Einræn received she related to the difficulties her son had due to his extreme disabling conditions.

Six mothers said that they received support from a spouse and close relatives to a greater or lesser extent.

As seen above it was both the use of music and the idea of working with emotions that sparked the mothers’ interest in participating in this research. Only two of the seven mothers felt they had previously been invited formally to participate in a support group of any kind.

15.2 Data collected from the central music-caring phase

Data gathering in the central music-caring phase focused on material obtained from sound recordings of sessions and diary/journal entries. Videotapes of the sessions are also available, but they were not used to provide data. Videotaping the sessions was part of the novice researcher’s planning which was to prepare everything she could think of as thoroughly as possible. Interviews had also been planned as the main data-gathering tool. As soon as possible after each session

and prior to the next one, the sound recorded material was listened to. The main issues discussed in each session and the structure of it was written down using an Excel spreadsheet. In that same spreadsheet (see appendix O), the researcher recorded her analytic memos, which also were used as data.

Diaries were given to the mothers when they visited the research site in the preparatory phase. They received in writing the following instructions for its usage:

- You are encouraged to use the diary.
- Diary entries need to be dated.
- Use it freely to express anything you feel like.
- It can be a word, a sentence, a poem, a drawing, etc.
- It can be something about yourself, your participation, your family, your child, your dreams, your feelings, nature, an occurrence, an accomplishment, your fantasies, hopes, etc.
- It is fine if you do not want to use the diary.
- With your permission, something you have entered in the diary might be used anonymously in the research.
- The diary will be yours to keep after the research.

The mothers could begin using the diary in the time period between the first individual preparation meeting and the first music-caring session. At the end of each session the researcher verbally encouraged each mother to use the diary to privately reflect both subjectively and objectively on her experience. The researcher also asked them at the beginning of each session if there was something in their diary they wanted to share with the group. Five of the seven mothers used their diaries in the research period. After session #11 the researcher collected the diaries and returned them to the mothers in their individual interview in session #12.

15.3 Data from the reflection phase – the research interviews

According to Robson (2005, p. 270), interviews can easily be used in combination with other methods in a “multi-method” approach. The purposes of a research interview are to increase intellectual understanding, to understand themes of the lived daily world from the subjects’ own perspectives and, in this research, to understand the significance and the value music-caring has for these mothers. The qualitative interview is also interpretive as it allows the interviewer to use her knowledge about the topic and her sensitivity to obtain different nuances and depths of the themes of the interview. It allows the interviewer to

seek clarification of the meaning of what is said and in such a way interpret as she goes (Kvale, 1996, pp. 35-178).

The relationship between the interviewer and the interviewee is dialogical. The meaning and the contents of experience are thus not within but between individuals (Polkinghorne, 1989, p. 47). How the mothers answered the questions is also an interpretive work. Whether on a conscious or unconscious level, their responses depended on various ideas about the interviewer and the interview context (Alvesson & Sköldberg, 2000, p. 261). The interviewer was always in control, however. She selected the topics and she phrased and ordered the questions (Hollway & Jefferson, 2000, p. 31). What was said by the interviewee was addressed to a specific listener present, and in the moment was open to “horizon of possible meanings” (Kvale, 1996, p. 182) to be explored and developed further.

One group interview (session #11) and one semi-structured interview (session #12) with each mother were the main data-gathering tools in this research. The interviews were recorded on a minidisk and transcribed by the researcher. The protocol for transcribing the interviews was kept simple:

- Each five- to ten-minute segment on the minidisk was marked and labeled, the first as 001, the second as 002, etc. The researcher listened repeatedly to each segment until she felt nothing could be added or changed.
- In the transcription three dots ... signify talking which is impossible to grasp.
- Three slashes --- mean a long pause.
- Words in parenthesis () are an input from the interviewer or other participants, bodily actions, laughter, crying, coughing, etc.
- When words are emphasized with a certain tone of voice they are put in **bold**.

A short segment follows from the group interview in session #11 to demonstrate the use of this protocol.

Klambra: By the way, because I have so often gone through the songs you gave us. I do not know all these songs. I would want to, if we have time, to hear them. Could you play a little bit from them...

005

V: We could also do it in our individual session (yes) for those who are particularly interested in singing.

EI: Yes.

Klambra: Everything we have been singing is so terrific you see.

V: Yes.

Klambra: So one does not want to miss anything.

V: Yes, and I used the time to put together this year's Christmas CD.

EI: Yes, yes.

V: It has arrived. (Laughter)

Klambra: Yes, is that so.

The group interview was conducted 16 days after the last music-caring session. What went on in the session reflected a feeling of 'long time no seen'. The mothers shared facts and feelings, which the therapist/researcher could not so easily cut through. She felt it was difficult to keep the mothers focused on her objectives. The plan was to use an unstructured interview since the researcher's interest was to have the mothers in the focus group reflect on their music-caring experience (the group itself, the music, any material, important event(s), moment(s), the process, individuals, etc.) in a spontaneous and informal manner. As Robson puts it (2005, p. 270), "the interviewer has a general area of interest and concern, but lets the conversation develop within this area."

According to Kvale (1996, p. 101), group interaction reduces the interviewer's control of the interview situation. This may result in relatively chaotic data collection, and difficulties when systematically analysing the intermingling voices. Seen from a positive viewpoint it often leads to spontaneous and emotional statements about the topic being discussed.

As it turned out, the researcher felt that this group interview was in a way not successful, mainly because of the difficulties she felt when trying to focus the group to the task at hand. When transcribing it later, she also had enormous difficulty hearing the two soft speaking participants express themselves. So from time to time, the unstructured interview was directed en route by using questions from the semi-structured interview guide intended for session #12.

In session #12, which was an individual session carried out with each mother, a semi-structured¹⁸, in-depth interview was conducted and recorded. It was anticipated that the questions used in the semi-structured interview guide

¹⁸ A semi-structured interview has predetermined questions. Their order and wording can be changed, explanations can be given and, if appropriate, some questions can be omitted or new ones included (Robson, 2005, p. 270).

would be allowed to develop somewhat, both as the researcher's interview skills improved and as the mothers' needs changed. Of principal interest was each mother's experience; therefore Kvale's advice – to ask questions and give comments that deepened the conversation and encouraged the interviewee to reflect more – was followed (1996). It remained vital to keep one's orientation to the fundamental questions or notions, which in this research were:

- 1 What is the experience of mothers of special-needs children participating in a music therapy program introduced as music-caring?
- 2 How does the mothers' experience define music-caring?

The following questions provided the focus in the semi-structured individual interviews with the seven mothers Hanna, Esja, Góa, Klambra, Kristjana, Einræn and Skonza:

- 1 How would you describe your experience of belonging to the group?
- 2 What did you feel was particularly helpful?
- 3 What did you feel was particularly challenging?
- 4 What was it like being in the group at the beginning?
- 5 What was it like being in the group at the end?
- 6 How did you experience making music in the group?
- 7 Think about the musical activities the group did together. Is there anything that stands out for you?
- 8 What are your thoughts about the themes that developed for the songwriting?
- 9 What are your thoughts about the songwriting experience as such?
- 10 What are your thoughts about the overall structure of the music-caring programme?
- 11 Reflecting back on your experience is there anything in particular you would consider music-caring?
- 12 Could you describe in as much detail as possible a situation in which music-caring occurred for you?
- 13 How would you describe the music-caring process itself?
- 14 What has coming to the group been like for you?
- 15 Have you noticed any changes in your life since being part of the music-caring group?
- 16 Have you noticed any changes in the way you think or feel about yourself?

- 17 Have you noticed any changes in the way you think or feel about your child?
- 18 How would you describe yourself today?
- 19 How would you describe your child today?
- 20 What are your hopes and your dreams for the future?
- 21 Do you have any recommendation for a future music-caring group?
- 22 Could you compare a support group where there is no music to a support group in the form of music-caring where musicking is used?

The order of the questions as well as the actual wording of them varied somewhat in the interviews. The researcher wondered on occasion if her interview guide intended to focus her on themes relevant to the research questions turned the interviews into structured ones that at times also had therapeutic overtones. In other words, being a novice in the role the researcher did not at times feel secure enough to allow the interview to be shaped in the process. The dilemma is that the interview guide may have limited her, yet as a beginner interviewer she could not have gone into the situation without it.

According to Wengraf (2001, p. 5), semi-structured research interviews are “high-preparation, high-risk, high-gain, and high-analysis operations.” As in the case of the participant observer the interviewer is the instrument in use, and Kvale (1996, p. 105) stresses that the outcome of the interview depends on the knowledge, sensitivity and empathy of the interviewer. It is not a good idea to enter the field with questions that are too specific, too tight, or too slanted, argues Ely (1991/1998). According to her, a narrow focus from the beginning may well limit what and how we see, and both questions and answers must be discovered in the social situation being studied: “Learning about questioning, the rhythm, the form, the impact, is a task that never ends for qualitative researchers. It is particularly central to beginners. Sometimes what one learns is frustrating, poignant, and important to the research as well as other facets of life” (Ely, 1991/1998, p. 63).

The advantage of being the instrument in use as the interviewer as well as playing the role of participant observer is its directness, since the researcher watches what the mothers do and listens to any expression they make (Robson, 2005, p. 310). This observation provided a valuable insight and complemented and supplemented data obtained through the transcribed material, the diaries, the questionnaires and the interviews (data triangulation). Robson emphasizes that since the observer/researcher is the research instrument, great sensitivity and personal skills are needed if worthwhile data is to be collected. Lincoln and

Guba (1985, as cited in Robson 2005, p. 315) also stress that an extensive background of training and exposure is needed to function adequately as a 'human instrument'. This researcher was well aware of her lack of qualifications and shortcomings as a participant observer, transcriber and interviewer. She would have to proceed carefully, learn from her mistakes, and seek guidance from experienced supervisors. As Ely et al. word it (1997, p. 17), the transcribed material was "the written record of the data as shaped through the researcher's eyes, with all that this implies about the way individuals see the world, how they interpret what they see, both explicitly and implicitly, and why."

15.4 Concluding notes

The therapist/researcher's role was that of a participant observer as she was the music therapist in the group and an instrument of observation. In other words, in addition to the research, she had a job to do. Wolcott explains this position when distinguishing between three different participant-observer styles: the active participant (who this therapist/researcher was), the privileged observer, and the limited observer (1988, as cited in Ely et al. 1991/1998, p. 45). The privileged observer is someone who is known and trusted and given easy access to information about the context, and the limited observer, the role most often played, observes, asks questions, and builds trust over time, but doesn't have a public role other than that of researcher. This researcher was the music therapist in the group and an instrument of observation and as such a subject of the influence of her own personality and the personality of the mothers. Being a novice researcher, it was hoped that a relationship of trust established between the researcher/group leader and the mothers would be instrumental in eliciting honest and significant information from the interviewees.

The multi-dimensions and multi-layers of the therapist/researcher's phenomenon could have been shown in different ways. One way could have been to focus on one mother at a time. Each mother's personal story, experiences and therapeutic process through writing narrative accounts could have been based on what she told the therapist/researcher, about herself verbally in their first meeting and in writing by answering some questions prior to the first music-caring session. In her diary she wrote many things about how she experienced music caring and also things about her daily life. So her diary contained reflective accounts of experiences that are of phenomenological value. In her song texts she expressed feelings, thoughts, and ideas, giving shape to her lived experience in an artistic way. In the music-caring sessions the mother expressed

herself musically, commented on her experience and answered some questions from the participants and the researcher. In the group interview and in a semi-structured individual interview she answered many questions in depth concerning her experiences in the music-caring group. In this research, this data was available to the therapist/researcher for each of the seven mothers.

Analysing or interpreting the transcribed interviews within an interpretive phenomenological framework opens up many possibilities. Meaning condensation, narrative structuring, meaning interpretation and ad hoc methods can all be applied. What is most important is that the method sounds the participants' voices as honestly and holistically as possible. That means exploring in depth in order to sound the essence of the experience as truly as the researcher is capable of.

Using Kvale's analogy (1996, p.79) a therapeutic research voyage can be likened to Odysseus sailing the narrow strait between Charybdis and Scylla on his return from Troy. This research reflects knowledge that grew in depth and scope as the study progressed. Figuratively speaking a ship was built which took the researcher on a voyage. It could only be hoped that the attempt at avoiding Charybdis (a monster swallowing whole ships and their crews) would not take the researcher too close to the other side of the narrow strait where Scylla (the six-headed monster) awaited. But instead, this voyage ended with contentment, and once ashore, the therapist/researcher was able to reflect upon it calmly and with ease.

CHAPTER 16

INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

The text used for thematic analysis in this hermeneutic phenomenological study was the transcribed interviews. Kvale (1996, p. 80) emphasizes that the mode of interview analyses depends on the subject matter of the interview, on what is analysed and on the purpose of the interview. The purpose of the interviews in this research was to have the mothers in their own words objectively and subjectively describe their experience and define music-caring. The questions answered in writing prior to the commencement of the programme provided information about the mothers that could be used for substantiation and/or validation of meaning gained from analysing the interviews. The other data – the diaries and transcripts of the music-caring sessions – provided narrative stories supporting or questioning the interpretation through triangulation. The practice of working towards having a broad focus is referred to as triangulation (Bruscia 1995b, p. 408).

Triangulation allows for a wider perspective, multiple interpretations of reality and alternative interpretations throughout the study (Alvesson & Sköldbberg, 2000, p. 46; Strauss & Corbin, 1998, p. 44). In order to obtain a broad focus or a holistic picture of a phenomenon, researchers gather different types of data or data from different participants. According to Strauss and Corbin it is possible to combine methods and combine phenomena “for supplementary, complementary, informational, developmental or other reasons” (1998, p. 28). It was hoped that by combining data from various people, events, experiences, and materials, a deeper understanding of music-caring and the mothers in the group would be gained. Instead of narrowing the scope, triangulation opens up possibilities for gaining an in-depth understanding of the lived experience of the participants by travelling many different routes to the final but as yet unknown destination.

“Each case is unique and important in qualitative research,” argue Wheeler and Kenny (2005, p. 66) when advocating that researchers begin understanding the individual in their study. Comparisons between the individuals are made later, in an effort to form categories or draw conclusions, they point out. In her interpretative phenomenological analysis, the researcher began by focusing on

each mother. She read through each one's answers to the questions from the preparatory phase. She read each one's diary and she read through her transcribed interview at least three times using a combination of a detailed line-by-line¹⁹ approach and a selective or highlighting approach²⁰.

The first time the researcher read through the transcribed interviews she highlighted and numbered the research questions. She wrote memos on the left margin and on the right margin she wrote excerpts in English of the mother's answers. The second time she read through the interview the text was divided into meaning units marked by vertical lines and labelled or coded in the margins next to each unit (see Appendix Ó).

Various kinds of codes can be used, and they are named and defined differently by various authors. Essentially, to label or code a unit is to place a title on a unit of data that best describes or represents the unit. According to Miles and Huberman (1994, p. 183), a label can be a word, phrase, number, colour, design or musical symbol. In this research the labels were created inductively which means that they emanated directly from the transcripts and described or characterized the unit. This process of labelling is called open coding. When labelling meaning units the researcher used one word or as few words as possible and descriptive labels when possible as the labels for meaning units could be tentative titles for categories. She became aware that the same meaning units could be an example of more than one label/category and that labels/categories could overlap. In some cases the interview questions themselves defined meaning units.

The researcher's fellow PhD students participated in this process by labelling meaning units in the mothers' answers to interview questions number two and seven. The students received the following information: in this case the interview question itself has defined a meaning unit and you are asked to label the meaning units. That is, in the margin next to each unit label what that unit is about. Try to use one word or at least as few words as possible, and use your own labelling words, unless the label jumps out at you from the text. Sharing her

¹⁹ "In the detailed reading approach we look at every single sentence or sentence cluster and ask, what does this sentence or sentence cluster reveal about the phenomenon or experience being described?" (van Manen, 1997, p. 93).

²⁰ "In the selective or highlighting reading approach we listen to or read a text several times and ask, what statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described?" (van Manen, 1997, p. 93).

data was instrumental in validating and grounding the researcher's own process of defining meaning units and labels/categories.

What the researcher had done could be called a first level of abstraction. She had given each unit a descriptive label or labels that stayed close to the raw data. Her next level of abstraction would be about looking at relationships between the codes, combining them and to developing them into categories. This would allow the meaning units to grow more substantial, eventually evolving into thematic statements and themes.

In the researcher's third reading of the transcript she brought together what she had done before by creating an Excel spreadsheet for each mother. In this Excel spreadsheet she listed side by side:

- The question used in the interview.
- The mother's answer to it (in some cases a complete English translation of it and in others only a shortened or an extracted version.)
- In the next column the labelled meaning units were placed. (By organizing the information like this, the researcher had extracts and in some cases verbatim narratives that she could link directly to the labels, codes or categories.)
- In another pane, in the same spreadsheet all the labels (codes) for that mother were listed in one column.

Having studied each mother using this vertical analysis, a new Excel spreadsheet was created where the labels (codes) from each mother were placed in separate columns side by side. Then the labels (codes) were grouped together in a horizontal analysis and a category was found that would do for the entire group - namely a core category. The core categories that emerged in this way were:

- The group
- Musicking
- Songwriting
- The CD
- The therapist
- Me and my time
- Process-change
- The diary

Grounding herself in the data in this way while approaching thematic analysis was a circular process which went back and forth between the researcher's pre-

understanding, the empirical material and literature. In the midst of the process of finding categories the dilemma of when ‘enough is enough’ emerged. There is no escape, as Ely puts it (1991/1998, p. 145). Creating categories means reading, thinking, trying out tentative categories, changing them when others do a better job, checking them until the very last piece of meaningful information is categorized and even at that point, being open to revising the categories. Lincoln and Guba (1985, as cited in Ely) tell us that when the data repeats itself, when the researcher has confidence that themes and examples are repeating instead of extending, it may be time to leave the field. To find this confidence was hard for this researcher and until the very end it felt like the categories should be “revisited”, as Ely words it. What the researcher experienced could be compared to feelings sometimes expressed by ethnographers when having to leave the field and stop collecting data. They may experience sadness when leaving people who have been helpful and interesting. Another challenge could be the anticipation of the agonizing amount of work that still lies ahead. Another and more plausible truth being realized is perhaps the notion that “our appropriation of the meaning of lived experience is always of something past that can never be grasped in its full richness and depth since lived experience implicates the totality of life” (van Manen, 1997, p. 36).

Yet another task ahead of the researcher was to pull out the meaning of her findings as she considered the supporting evidence in each category and determined how evidence might be linked to form thematic statements and themes. Articulating a theme is not just a skill or a cognitive process that can be described and then learned or trained, says van Manen (1997) but in order to proceed, one needs to determine how themes come about. Ely (1991/1998) defines themes as a statement of meaning that runs through all or most of the important data or one in the minority that carries heavy emotional or factual impact. So a theme is like a tool used for getting at the meaning of the mother’s experience of music-caring. If successful in her formulation, the themes would somehow touch the core of the notion the researcher was trying to comprehend. In this research, themes were developed from labels (sub-categories) when highlighting some relation between them.

McLeod (2000, as cited in Rolvsjord, 2007, p. 31) describes three areas of knowledge generation within qualitative research in counselling and psychotherapy:

- 1 Knowledge of the other
- 2 Knowledge of phenomena and
- 3 Reflexive knowledge.

Focusing on the mothers' voices through the documentation of their experiences was instrumental in producing knowledge in all these three areas: knowledge of mothers having children with special needs, knowledge about a special way of working with them, and a reflexive knowledge when the researcher intentionally paid attention to her own development as a person and professional throughout the research period. Qualitative research and thematic analysis is an emergent process. The researcher learns how to do the research while doing it, and to adapt to what is happening from moment to moment (Bruscia, 2005b, p. 186). The feeling is like travelling alone in the unknown. One has to be adventures and flexible, trust one's own strength and insight, be rational and careful, and have the endurance to complete the journey despite the odds. All the researcher could hope for was that when she reached her goal her questions would be answered with depth and understanding.

To summarize:

- The researcher read personal information provided by each mother.
- The researcher read written answers to questions given to them in the preparatory phase.
- The researcher listened to minidisk recordings of ten music-caring sessions.
- The researcher wrote memos and summarized main issues (discussions/ occurrences) from each session.
- The researcher read the mothers' diaries.
- The researcher studied their song texts/poems which were translated into English by an excellent translator, Bernard John Scudder.
- The researcher listened to all the music making in the sessions and compiled some excerpts on a CD that she gave to the mothers in the group interview.
- The researcher transcribed the group interview.
- The researcher transcribed the individual interviews.
- The researcher focused on each mother.
- She read through the transcribed interviews (detailed line-by-line approach) several times to really hear her and feel each mother.
- The researcher wrote notes (analytic memos) on margins. ('Free thought', anything that popped up, initial impressions, etc.).
- The researcher found and labelled meaning units in the margins next to each unit. She divided the text in some way that made sense. What is this section about? She used one word or as few as possible. The labels could become tentative titles for categories. Sometimes the same meaning unit

received more than one label. Meaning units could also overlap (see Appendix Ó).

- The researcher selected verbatim narratives to link the raw data to the labels/categories (third reading) (see Appendix P).
- The researcher studied the previous steps and revised them if needed.
- The researcher listed all the labels (codes) or sub categories together that referred to the same family of experience (or core category). A long list of sub categories (statements) was created when working with the data across participants. For example:
 - Belonging to the group created positive feelings.
 - Belonging to the group gave strength.
 - The group gave perspective.
 - The group allowed comparison.
 - Belonging to the group brought forth sympathy.
 - Belonging to the group brought forth empathy.
 - Belonging to the group created feeling of common experience.
 - Belonging to the group created a feeling of togetherness.
 - Belonging to the group created a sense of continuity.
 - In the group you were able to give and to receive.
 - The group created a feeling of intimacy.
 - The group shared knowledge.
 - The group shared emotions.
 - The group shared experience.
 - This was a special type of group.
 - Being a participant created a feeling of gratefulness.
 - The group supported you.
 - The group created a feeling of belonging.
 - The group understood you.
- Each category/label that appeared (even those appearing once) was listed.
- A category that did not fit into a family of experience (core category) stood separately.
- A category that occurred once only could be very important for that mother and thus for the research.
- The mothers related their experiences in the music therapy group introduced as music-caring to the following core categories (family of experiences):
 - The group
 - Musicking
 - Songwriting
 - The CD

- The therapist
- Me and my time
- Process-change
- The diary

Now the researcher felt she was grounded in her data and capable of developing themes.

Themes developed by highlighting some relation within and between labels (codes) or sub-categories. Categorization and thematic analysis reduced the complexity of the empirical material and imposed order.

CHAPTER 17

EMPIRICAL EXPLORATIONS

Hermeneutic research is not the type of inquiry that offers proof of the existence of any phenomenon, unless, of course, we want to say that we exist because we understand. It is an open-ended and circular process that can be marked by diversity and creativity as well as increasing levels of understanding. It also reflects the profound complexity of our human condition and encourages examining these dilemmas through a variety of interpretations. (Kenny, Jahn-Langenberger, & Loewy, 2005, p. 347)

What follows is a presentation of the empirical explorations which focused on the lived experience of a group of mothers having children with special needs, participating in a music therapy programme introduced as music-caring within the framework of early intervention. From a hermeneutic phenomenological perspective the process of empirical explorations has been an interactive and an abductive one travelling back and forth on a spiralling path with and within the mothers' own voices, the researcher's interpretative phenomenological analysis, literature reviews and the process of writing as a construction of meaning. Travelling with the mothers through the elaboration of themes was a process of reduction where certain aspects were highlighted while others may have been rendered peripheral. It could also be argued that experiences exemplifying certain categories and themes may be overlapping and describe similar processes (Rolvjord, 2007, p. 118).

As the primary aim of this research was to develop an understanding of the mothers' experience of the music-caring offered to them it was vital for the researcher to remain true to them by allowing them to speak for themselves and not lose their voices in the process of reducing the complexity of the empirical material through meaning condensation via analysis. Only in that way could the researcher attempt telling about their stories without "harming the secret or the magic," as Esja words it:

I felt that what we did somehow was a secret. It is personal, between me and them, my time. Sharing it might harm the secret or the magic.

But describing it to others I would say:

We sing together.

We tone.

We play instruments.

We give tones.

We give sounds to feelings.

Then we talk.

We bring up the things that are bothering us.

We talk about it and sing about it perhaps.

And we listen to music.

And it is a journey in maturing/developing and this helps you to do it better.

Music-caring helps you to travel better.

To travel through, to mature and to reach some success of being - and of being the mother of a disabled child.

This has made me stronger (Esja, SP II 002).

Just as the music therapy programme was a collaborative process braiding together music and relationships within a certain framework, so was the following elaboration on core categories and themes. It was weaving together different threads into a tapestry, the goal of which was to answer the research questions proposed:

- 1 What is the experience of mothers of special-needs children participating in a music therapy group introduced as music-caring?
- 2 How does the mothers' experience define music-caring?

The mothers' experiences were about belonging to the group, they were about musicking and songwriting, about themselves and relationships, processes and changes, the therapist and even diaries and CDs. What follows is an explanation of core categories and themes. A separate section will be devoted to each core category which has been formulated into a question. Each question will then be answered by elaborating on the thematic statements.

What did belonging to the group contribute to the mothers' experiences?

- The group created a feeling of belonging.
- The group built trust and diminished defences.

- The group honoured individuality and the freedom of expression.
- The group gave perspective.
- The group created empathetic understanding and support.
- The group created possibilities, built awareness and strength.
- The group created feelings of joy, anticipation and gratefulness.

What did musicking alone and with the others contribute to the mothers' experiences?

- Music created a relaxing, welcoming and a caring atmosphere.
- Music brought joy and beauty.
- Musicking brought closeness (togetherness) and supported empathetic listening.
- Musicking empowered awareness of emotions.
- Musicking facilitated and deepened emotional expression.
- Musicking brought change and created possibilities.

What did songwriting contribute to the mothers' experiences?

- Songwriting gave structure and shape.
- Songwriting was a creative challenge.
- Songwriting was an enjoyable experience.
- Songwriting honoured individuality and strengthened identity.
- Songwriting gave perspective.

What did the CD contribute to the mothers' experiences?

What did the therapist contribute to the mothers' experiences?

What did music-caring contribute to the mothers' experiences of me and my time?

What was the process - change experienced during the music-caring period?

What did the diary contribute to the mothers' experiences?

17.1 Validation

As previously noted the novice researcher designed the study to the best of her ability to provide answers to the research questions. In her role as a participant observer, she was the mothers' music therapist, the interviewer, the transcriber, the analyst/interpreter, and the narrator. The topic of her investigation, i.e. music-caring, was also based on her personal and professional experiences.

“These features, personal involvement and engagement, are part of the essence of qualitative research, which is intended to involve participants as fully and humanly as possible,” say Wheeler and Kenny (2005, p. 65). They warn against being judgmental but emphasize the importance of being empathic and fully present when observing or interviewing. These attributes “help in conducting research in an intentional, thoughtful, manner that builds upon the researcher’s relationship with the participants, while still allowing him or her to maintain the distance necessary to conduct the research in a trustworthy manner” (2005, p. 65).

In Parts I and II of this thesis, the researcher contextualized her research from a personal, professional and a disciplinary perspective, but she also needed to consider the trustworthiness and the validity of her work. Having interviewed the mothers, and analyzed and interpreted their answers, the researcher needed to ask herself whether she been using a method that investigated what it was intended to investigate. Was this a true reflection of the mothers’ experiences?

Validation as a quality of craftsmanship involves continually checking, questioning, and theoretically interpreting research findings, writes Kvale (1996, p. 241). Furthermore, validity concerns all stages of an interview investigation (thematizing, designing, interviewing, transcribing, analysing, validating and reporting) and is not only a matter of the methods used but also the person and the moral integrity of the researcher. “The complexities of validating qualitative research need not be due to an inherent weakness in qualitative methods, but may on the contrary rest on their extraordinary power to picture and to question the complexity of the social reality investigated” (Kvale, 19996, p. 244).

According to Miles and Huberman (1994, as cited in Kvale, 1996, p. 242) and Aigen (2005, p. 359), there are no dependable decision-making rules for establishing the validity of qualitative research. However, there are several tactics for testing and confirming qualitative findings, four of which are: persistent observation²¹, prolonged engagement²², triangulation and getting

²¹ Persistent observation provides depth to a researcher’s perceptions and analyses. “It makes it possible for a researcher to discern those elements arising in a study that are of greater importance by providing criteria, explicit or implicit, for focusing a researcher’s attention on elements of greater saliency” (Aigen, 2005, p. 359).

²² Prolonged engagement provides breath to a researcher’s perceptions and analyses. “Prolonged engagement means that the researcher stays engaged with the research study and milieu long enough to establish trust with participants, learn the milieu of study well enough to grasp the context of the culture in which the meaning of events and experiences is found, and filter out intentional and unintentional distortions and examples of selective perceptions reported by research participants” (Aigen, 2005, p. 359).

feedback from informants. Besides using the aforementioned tactics, this researcher also presented quotes and narratives to support her categorization and thematizing. As mentioned before, sharing the data (the mothers' answers to interview questions number two and seven) with her fellow PhD students and having them label meaning units was also instrumental in validating the researcher's own process. Arguing for the use of quotes from the interviews, it was of importance to the researcher to let the mothers' voices be heard. Thus the researcher used transcribed and translated quotes from the interviews to support her empirical analysis. When using meaning condensation, i.e. presenting something from the mothers but in the researcher's own words, the comment is acknowledged with reference to the transcripts but not marked as a quotation.

As discussed earlier (section 3.3) an anchor for this research was found within hermeneutic phenomenology. Being connected, both practices are process oriented and seek understanding by circling back and forth, revisiting the subjects of the study and re-analysing and re-interpreting data until essences (phenomenology) have been discovered or meaning assigned (hermeneutics) (Kenny, Jahn-Langenber, & Loewy, 2005). Acknowledging the mothers' experiences in this shared process by sounding their voices in the way it is done is fundamental to the understanding gained. Hermeneutic phenomenology involves a "phenomenological sensitivity to lived experience" and a "hermeneutic ability to make interpretive sense of the phenomena of the life world," writes van Manen (1997, p. 2). In the last phase of this research the mothers were sent an e-mail (on 16 September 2010) asking them to read an attached document presenting the researcher's analysis of core categories and related thematic statements (Appendix T). They were encouraged to express their reaction to this in writing (via e-mail) or verbally during an informal meeting planned by one of the mothers for 24 September 2010. It was hoped that in this meeting, discussions would evolve around the researcher's 'hermeneutic ability' to interpret their lived experience or 'the phenomena of the live world'.

As it turned out, only two of the mothers read the compilation of the research findings sent to them by the time of the meeting. Thus the therapist/researcher decided not to initiate discussion about her research findings. Instead, another e-mail was sent to them on 30 September. The therapist/researcher thanked the mothers for a wonderful evening together and again reminded them of her need to have the research findings validated. The researcher then received e-mails from them dated 4, 5, 6, October, two e-mails on 12 October, and two e-mails on 13 October. The mothers' verification will be reflected upon in the discussion part of this thesis.

17.2 The group

What did the group contribute to the mothers' experiences?

- The group created a feeling of belonging.
- The group built trust and diminished defences.
- The group honoured individuality and the freedom of expression.
- The group gave perspective.
- The group created empathetic understanding and support.
- The group created possibilities for building awareness and strength.
- The group created a feeling of joy, anticipation and gratefulness.

According to the mothers' answers to question number six from the questionnaire "S", six mothers received support from a spouse and close relatives to a greater or lesser degree. Five of the mothers felt that they had never been invited to participate in a support group before. Two of them mentioned open parent groups that they had known about and attended and one mother talked about "a very good course" which was introduced to her at *The State Diagnostic and Counselling Centre*. In this course she learned about the different disabilities and parents in small groups discussed among themselves issues related to having a disabled child; they then shared these ideas with the entire group. At the time this research was undertaken, five of the mothers were not participating in group work of any kind. Two of the mothers attended informal open meetings at their respective associations (*The Downs Syndrome association* and *The Autism Society*). The mothers' answers to question number four from the questionnaire was interpreted in such a way that only one of them was receiving assistance for herself from a psychiatrist at the time this research was implemented.

Despite anxious anticipation and worries expressed in diaries during the waiting period prior to the first music-caring session, the mothers' motivation for wanting to participate was strong enough to sustain their interest. Klamra wrote in her diary:

I was very excited when I read about music-caring, an excellent opportunity which could not be missed. Now I can perhaps begin working on some emotional tangles, open up a little bit, try to get rid of my super sensitivity, become stronger and work on some old troubles at the same time. ... I have to admit that when it drew nearer I began to worry, oh won't I be crying there all the time and not be able to utter a single word. Why did I sign up, this will

run into other things, the choir, F.'s swimming lessons, driving H. to her ballet lessons - and I run away from everything.

Right away in the first session I was myself. I felt relaxed, even though all the participants are surely a little bit insecure. A little bit surreal to sit there as a group and to play together on unfamiliar instruments in this serious atmosphere and not feel silly. On the contrary it was cosy. I immediately got a good feeling for the group and the leader.

One of the 'good feelings' that emerged in the group was that of belonging to people who had had similar experiences.

17.2.1 The group created a feeling of belonging

The mothers talked about common feelings that they had experienced, which reduced the feeling of aloneness and was perhaps instrumental in connecting them so quickly. They talked about how good it was to take part, how good the group felt, how everyone was focused on being open and how feelings merged. They also talked about how comfortable it was to be around people that understood you. They enjoyed getting to know each other, to receive and to give back and to be part of this first group when everything felt fresh and exciting as Klambra worded it (SP I 01). Other comments from the mothers included:

It is quite special to have a disabled child. Each child is unique, no two children are alike but surely we the mothers have the same feelings. In a group like this, people are dealing with the same feelings. It is extremely good to get an outlet for that. To realize that you are not alone in the fight like you were having leprosy. ...This is what one needed in the beginning. To be with other women like this who had experienced the same. One was so alone somehow (Esja, SP I 003).

One was a little worried to begin with - did not know quite. But I felt this was a very good group and good to take part. The worries disappeared right away after the first or in the first session. In the end one worried that this was finishing. ...One increasingly became part of the group. Knew better what was about to happen. The feelings-both mine and theirs-merged (Einræn, SP I 004).

Everyone was focused on being open. Perhaps a little strange to become so close, and you feel the need to continue that. But one cannot hold on to something good forever. It is also a good feeling to be able to let go without being sorrowful. Because one knows one can always speak to them if need be

(Góa, SP I 001). ... I think it must have been sheer luck how good the group was (Góa, SP I 009).

It was comfortable to be around people who are experiencing something similar and who understand you; people that have common connection. That is very comfortable (Hanna, SP I 001). ...To get to know others who understand you due to common knowledge and experience was particularly helpful. You cannot get this support from friends. And this is a lasting support and relationship. Thinking about them gives me strength when dealing with various issues. ... Yes of course I feel a little bit richer. I am meeting them again while in therapy with H. They are such good women, good individuals and so good to talk to them and to get information and advice from them (Hanna, SP I 002).

Remarkable how quickly we connected. That makes me feel good. I feel richer after having participated in this. It was enjoyable to get to know them. It was something special to be part of this first group, everything so fresh and exciting (Klambra, SP I 001).

The most important thing was to meet them and to be with them. You know, this human togetherness, which is the most important thing (Kristjana, SP II 002). To be allowed to attend and to talk, express emotions and to listen to others and the togetherness (Kristjana, SP II 004).

I thought it was terrific fun to get to know people with common experience. You know, to be able to receive from them and to give back. I thought it was a wonderful time; everything was just wonderful (Skonza, SPI 001).

The mothers' strong feelings of connection and belonging can be directly related to Stern's motherhood constellation and needs connected to the supporting matrix theme and the identity re-organization theme (1985). As discussed in Part II, the supporting matrix theme revolves around how the caretakers create and permit the necessary support systems to fulfil their obligations. With the birth of a child with special needs the available support system is limited. Relatives and friends do not know how to behave. Despite the best intentions the parents may feel abandoned and failing in keeping up a supporting matrix. In a state of shock they cannot make necessary use of the first information or initial support they receive. They may find themselves wanting as parents or judged inadequate and even destructive. Their earlier parental experience doesn't suffice. Their pain, self-accusations, or other feelings may

compromise their parental capabilities. They may become co-dependent, and fused with the baby in their parental role. They do not have any role models with whom to identify, and support from friends and family may be limited. As Esja expressed: “This is what one had needed in the beginning. To be with other women like this that had experienced the same. One was so alone somehow” (Esja, SP I 003).

For years to come, the struggle for their child’s rights will remain a source of anger and sorrow to each mother. Thus to get to know others who understand you due to common knowledge and experience is particularly helpful. Perhaps one could compare it to being reborn into a family where you feel supported, guided, valued, appreciated and instructed.

The identity re-organization theme relates to the caretakers’ ability to transform their self-identity to permit and facilitate their parental functions. The model needed for identification is only partially there, due to the special needs of this unexpected constellation. Identifying with the caretakers’ own parents doesn’t provide the right model to feel secure in the new and difficult role (Stern, 1995, p. 180).

I missed information and guidance for us the parents. How were we supposed to treat the child and where could we find help? Would we sustain the pressure which awaited us? Why had this happened to us? Was there a cure to be found? (Hannan, 1975, p. 15) ...When we came home from the hospital friends and relatives visited us one by one. They showed us sympathy and listened patiently but they could not say anything which really helped; they could not give us any advice. Sympathy in itself is worthless. It is very comfortable to know of people’s sympathy, but this time it was of little value to me trying to cope with and handle this difficulty and to accept what had happened (ibid., p. 19).

Hannan’s words describe how the birth of a baby with a disability is an event that can mark one out and separate from the group. The need for belonging is innate and to be alone in the sense of not belonging is terrifying. Described as trauma it can cause a feeling of being disconnected not only from society, but also from the flow of one’s life. “With no useful history to feed a vision of the future, we are filled with fear,” wrote Gill (1997, p. 18). Not sharing traumatic events (like that of losing the ideal child) is a type of inhibition requiring physiological work that may become detrimental to one’s psychological and physical health.

The music-caring group provided much-needed social networking for the mothers. Based on commonality of experience where feelings merged they developed intersubjectivity and a sense of belonging that encouraged disclosure and enabled empowerment through the act of helping others. As Skonza worded it: “You know, to be able to receive from them and to give back” (Skonza, SP I 001). They no longer “had leprosy” and felt understood and respected. Feelings such as luck, joy and excitement were openly expressed. Finally, the mothers had met others who spoke the same language; this may have changed their subjective evaluation of being helped (Niccols & Mohamed, 2000; Shonkkoff et al 1992, as cited in Hooste & Maes, 2003, p. 302). They were not alone anymore and felt comfortable around others who could understand them – people who knew what they were talking about. So they were capable of opening up, expressing their true feelings, and of receiving and giving support.

Furthermore, belonging to the group was enjoyable, comfortable and enriching.

Góga was surprised by how enjoyable it was to experience the first meeting. She wrote in her diary:

The first session on a Saturday with Valgerður. I cried a little at the beginning of the meeting but managed to contain myself. But how enjoyable it was to experience this first meeting. It was as I had expected, but somehow it was also a surprise. Is that possible? Yes, I expected it would surprise me ... haha. What follows will most surely be joyful and educational. Perhaps one learns something new about oneself.

The first session(s) is the moment of social and psychological birth for the group, writes Benson (2001). It is the beginning of familiarization, association, and commitment by individuals to the group life. According to him, “cohesion is a primary factor in keeping a group together and a major determinant of the quality of the climate and the effectiveness of the group. Cohesion develops through the acknowledgement of common elements so it is important to look for emotional themes and patterns in the early stages of the group” (p. 94).

Terms like relaxed, cosy, warmth, enjoyable, liked the participants, companionship, interesting task, support, empathize with, and unity, which were all taken from the quotes above, are indications of cohesion and a positive psychological birth of the music-caring group. Einræn, for example, worried that this support she was experiencing would come to an end: “My worries were

connected to not seeing/meeting them again and that one would not continue to get support like this. Seeing them weekly like this gave me support” (Einræn, SP 1 002).

The mothers saw themselves not just as passive beneficiaries of group cohesion, but also as generators of that cohesion, creating durable relationships. They had belonged to groups, have had a group history, and now all of a sudden in their new constellation they do not belong anymore. Thus the sheer successful negotiation of a new and fulfilling group experience may in itself have been therapeutic. Belonging in the group raises self-esteem and meets members’ dependency needs in a way that also fosters responsibility and autonomy, as each member contributes to the group’s welfare and internalizes the atmosphere of a cohesive group. As Yalom words it: “Relationship is at the heart of a good therapy. Therapy groups generate a positive, self reinforcing loop: trust-self-disclosure-empathy-acceptance-trust” (2005, p. 56). Driven by relationships the group built trust and diminished defences.

17.2.2 The group built trust and diminished defences

Despite information provided in the individual meetings with each mother in the preparation phase and the information written in the brochure and in the folder given to them, a dimension of ambiguity-clarity existed in the first sessions. This dimension refers to the mothers’ perception of the helping relationship being somewhat vague yet also structured. According to Brammer (1979, p. 47), initial ambiguity allows the mothers to project needs, concerns and feelings into the relationship without constraint. Here are some examples from the interviews:

The importance of having a closed group. It is very good, like in music-caring, always to be seeing the same women. In AA you only meet a lot of people, and you do not know them and you forget them at once. ... But it becomes much more personal when you always meet the same women and you get to know them a little. ... Yes, the connection is stronger (Esja, SP I 003).

Liberating to be in a group where I did not know anyone. It is a type of freedom. I felt I could say just about anything. They were open. It is terribly good to have a group like that where you can say almost anything you like. I felt I developed self-security within the group. I was not scared or shy (Góa, SP I 001).

You do not know the people and you do not know what is about to happen. So you wonder and are not really at ease. Then in the end it turns into being a comfortable experience with a group and good friends. I think I would have

dared to sing alone. The expression became somehow more and deeper, because you were not checking what the others were doing. Also you did not wonder about what was expected from you. There was a complete feeling of safety (Hanna, SP I 004).

A little insecure to begin with. Did not know how this would be and worried about it. But as I said, that disappeared after the first or in the first session. And in the end one worried that this was coming to the end. ...I thought it was easier than I thought it would be to express myself. One worried in the beginning that perhaps one would have to speak. But that also was just easier than I thought it would be (Einræn, SPI 002).

What the mothers are referring to in the above quotes may be related to both the content or the 'what' of the group experience and the process or the 'how' of the group experience. The way the group discussed and acted together was reflected in the quality of the group experience, reflected in what the mothers felt. They were neither scared nor shy but open and self-secure and thought it was easier than they had expected it would be to express themselves. The group was conducive to self-disclosure, of being able to say and hear their stories out loud so that they could make sense of what had happened and what was going on in the present (Gill, 1997, p. 24).

Driven by the need to belong, to relate and to communicate, spontaneous interaction emerged immediately in the group. The mothers knew they did not have to speak unless they felt like it. Hanna said (SP I 004) that "you did not wonder about what was expected from you. There was a complete feeling of safety." They felt accepted by each other; they were open and felt it refreshing to have a group like that where they could say almost anything they liked. It can be assumed that obstacles blocking the process of growth were at a minimum and the atmosphere in the therapy group ideal for effective sharing and acceptance by others. These factors, namely trust and cohesiveness, are of paramount importance for effective self-disclosure.

For trust to develop, the mothers needed to have confidence in each other as well as in the therapist. It is believed that the researcher's self-disclosure, stating clear motives for the music-caring group, generated trust. The motives were attractive to the mothers and became apparent as the sessions progressed. In an atmosphere of trust, the mothers perceived themselves as being warmly received and valued, which encouraged their willingness to reveal their own feelings honestly. The mothers experienced the relationship as a shared effort towards growth.

“All sorrows can be borne if you put them into a story or tell a story about them,” wrote Gill (1997, p. 24). The mothers in the music-caring sessions were telling their stories, and they were telling them when they felt like it and how they felt like it. They had spoken about being silenced when someone told them not to worry and the difficulties they often had in being honest about their true feelings, even to their closest relatives. In a context where ‘silence and endurance’ was the motto, this freedom of expression was a welcome relief.

17.2.3 The group honoured individuality and the freedom of expression

Having gone through the stage of inclusion expressing their desire to connect to and associate with others, having built relationships of trust and cohesiveness with the other mothers and having expressed a feeling of belonging, the mothers talked about how the group honoured individuality and the freedom of expression. Excerpts from their interviews detail this:

I thought it was very good to have this freedom; one could say anything or discuss anything. There was no specific topic for discussion. One could bring up anything. It is very good to emphasize that. You also emphasized that one could choose any instrument there was and you always had a good collection. One did not have to speak if one did not feel like it. Yes, this freedom to be oneself, to attend or not to attend. But if you are doing it for yourself then of course you will attend regularly. It was good to come (Góa, SP II 005).

It was helpful talking together and talking about what had happened during the week – releasing a little steam. ... Sometimes one was silent and then you just benefited from listening to the others (Skonza, SP II 002). If structured, it would have been quite a different atmosphere. This was a little free. One could tell and bring forward what you were feeling. If everything had been organized and everyone had known beforehand then it would not have been possible. And also because we were all so different then it would have been much more difficult (Skonza, SP II 006).

To be able to discuss my situation. To get insight into their situations/thoughts. Somehow get permission to talk about anything. Useful to tell others about yourself. To be able to elaborate on things. Their experience opened up something I could talk about (Klambra, SP I 001).

Appelgate and Bonovitz stress that the therapist “must temper his or her interventions sensitively so as to ‘hold’ the beginning relationship while affording the client as much control as possible over the parameters of closeness and distance. The ideal is to remain supportive while not becoming too confining” (1995/2004, p. 96).

The freedom the mothers had within the security of a given structure encouraged their involvement. They had freedom to be themselves and to ‘play’ in a personal way. They could remain silent or they could speak and bring forward what they were feeling in the moment with minimum risk, like children beginning to wake up to the world around them through playing in it. Or as Winnicott words it: “Play belongs to health: playing facilitates growth and therefore health; playing leads into group relationships; playing can be a form of communication...”(Winnicott, 1971/2005, p. 56). In a cohesive group like the music-caring group seems to have been, self-disclosure drew out more disclosure, generating a constructive loop of trust, self-disclosure, feedback and interpersonal learning.

Klambra commented that “it was useful to tell others about oneself and to be able to elaborate on things. Their experience opened up something I could talk about” (SP I 001). The mothers’ mutual need to reveal subjective experiences developed as well as their desire to know and to be known. One could also say, as Richards and Davies word it (2002, p. 38), that the mothers’ desire to connect with life and the process of living in a personal and a playful way developed. According to Winnicott (1971/2005), an insufficiently adaptive environment in time of crisis can result in an impaired sense of play and corresponding self-deficit. An important step towards healing and self-acceptance is the gradual permission one gives to others to know one as one really is, to be able to talk about one’s self freely and honestly, knowing that it is acceptable and in the process gain insight and new learning. Speculating about the possibilities this freedom gave in creating herself anew, Góa wrote in her diary on 14 October 2006:

One thing is also good about these Saturday sessions. Few ladies meet without knowing each other beforehand and we start by learning the names of each other and about our families and perhaps about our work, but everything else is unknown in the beginning. I am thus a blank slate in the eyes of the others in the same way they are blank slate for me. This gives us freedom to say more than we would otherwise say to relatives or friends but one sometimes feels they have had enough of you. People who have known you all your life listen differently, and you talk differently to them; the interaction

has its particular course. It can perhaps be said that they have some prejudice against you! Góá is like this, and has always been, I know her. But I have perhaps become completely different from how I used to be. These speculations work of course both ways – perhaps I am expecting beforehand certain reactions from people that I ‘know so well’. We Saturday women can decide for ourselves whether or not we will continue to cultivate our friendship but something tells me that this group will meet again after this course is over. The feeling regarding this freedom is so strong within me. I know no one in this course, no one knows me except through what I tell them about me, and they about themselves. Perhaps we will approach the truth in ourselves in this way. I can choose whether or not I repeat what I have told to others or whether I use new words, a new way of narration and in that way even discover a new truth.

17.2.4 The group gave perspective

Asked about what it was in her experience that felt particularly helpful, Góá answered:

To listen to other women. To listen to their perspectives and to hear how they listened to others. And they listened to me. ... If one can put oneself into others’ shoes then there comes an understanding that others can put themselves into your shoes. One sees that one is important but also that one needs not to take things too seriously. The negative sides are not as noteworthy as one feels sometimes. ... If you think about the group you see a red thread – something everyone is dealing with. So there is a certain relief and also a freedom to stop thinking about oneself as a martyr that always has it worse than others (Góá, SP I 001) ...I feel that [my son’s] situation is better than I felt before. When one has heard all these stories, there are many with difficult disabilities and somehow lifetime sentence. I have stopped pitying him as much as I did. He has not such bad cards on hand. He has cognitive abilities. One has focused too much on him. His siblings do not get enough attention (Góá, SP II 002).

For Góá the perspective she got gave her freedom and relief from her own worries. She began to see her own life and her son’s life in a different light and to shift her focus from martyrdom towards other things, other people and new possibilities.

Because they were different, their children were dealing with different disabling conditions. The children were different ages and the mothers were dealing with different issues regarding their children’s special needs. The

mothers had somewhat different backgrounds and different living conditions and they were experiencing and going through somewhat different emotions. Yet at one time or another they had all been dealing with the same traumas. As Kristjana words it:

Because we are all different, I got a new insight into common experience. To listen to how others have experienced it. Interesting to get to know people. More interesting when people have something in common (Kristjana, SP I 001).

The researcher's initial concerns about the mothers' differences, turned out to be an asset for their shared experience. Some mothers had progressed more than others and could share how they had felt and what they had done when experiencing the same feelings or when finding solutions to the same or similar problems.

I did not feel it should be any different, that the disabilities should be similar or something. It is like with everything else, we are different. And it gives you a broader perspective into what others are dealing with (Hanna, SP I 001). ... It is so difficult when no one understands you. It is so difficult to understand something that you have not experienced. You learn about your emotions when you hear others talk about them. Yes, I have felt like this. It is like a school (Hanna, SP II 005).

Even Einræn, who was dealing with enormous difficulties found some support in hearing about how others were doing: "I felt it was just good to see such varied circumstances" (Einræn, SP I 006). For her, being able to reflect on her situation and the warm presence and the caring support she got from the other mothers was helpful.

A little difficult with Einræn because her difficulties are so enormous and it is difficult to put oneself into her shoes. Most of us have overcome the sorrow. One cannot imagine what she is going through. One could feel how heavy this was for her. Some cannot talk about things like this. But it helps to hear others speak about it (Esja, SP I 001).

Even if one cannot talk about such difficulties oneself it helps to hear others speak about it, as Esja said. Concerning what she felt particularly helpful, Klambra said:

To be able to discuss my situation and to get insight into their situations/thoughts. Somehow get permission to talk about anything. Useful

to tell others about yourself. To be able to elaborate on things. Their experience opened up something I could talk about. ...Comparing with the group you downgrade your own problems if they seem little compared to someone else's. Then you restrain or contain yourself. ...When Esja started talking about the paranoia I became so awakened and started thinking about this feeling. Is this paranoia or not being sensitive or is it both? To let others put you off balance, to always find the blame with oneself. ...It has been so giving just to think about others and to think about human nature. To think about how they deal with all theirs (Klambra, SP III 005).

Having small children was making Hanna tired. Her child's disability was making her tired. The demands made her tired. A lack of understanding from others and trying to find the best for her child also made her tired. Then she thought about the other mothers, and she realized she needed to make the most of herself.

The struggle is beginning now. I am grateful for not feeling as bad as I think they did. Now I am on guard. And I have to make the most of me. Try my best. Make everything work so that my child gets what he needs (Hanna, SP I 002).

As reflected so clearly above, the 'facilitating environment' or, to use Winnicott's term, the 'holding environment' in the group elicited self-disclosure, which provided the mothers with helpful perspectives and insights into the lives of the others but also, and more importantly, into their own lives. In a safe, facilitating and supportive environment and a helping relationship the mothers were able to voice their feelings and to situate themselves on the emotion continuum.

17.2.5 The group developed empathetic understanding and support

In any therapy in which relationship serves as the crucible for change, empathy is imperative, as it is the connection which sparks the relationship. Without empathy there is no meaningful relationship and no access to experiences and data by which the self becomes known. Only empathy can offer a convincingly safe invitation to a meeting attended by patient and therapist in which the subjective world of the patient creatively unfolds. As such, empathy is a prerequisite for all other therapeutic interventions (Donner, 1991, pp. 53-54 as cited in Tudor & Worrall, 2006, p. 118).

"Empathy is imperative as it is the connection which sparks the relationship," wrote Donner (ibid.). The word empathy derives from the German word *Einfühlung*, meaning 'feeling into'. It is an ability to identify with and

understand somebody else's feelings or difficulties. A therapist's empathy is a central method in understanding the client and enabling him or her to feel understood. The therapist tries to see the world as the client perceives it from his or her own frame of reference. The client uses the therapist's empathy for his or her own self-understanding and to gain confidence in his or her ability to solve his or her own problems. Empathy is manifested through the therapist's ability to perceive what is going on in the client's feelings and to communicate this perception clearly to the client. Einræn said in her interview:

You felt somehow they supported what you were saying. And they said they had been thinking about me (Einræn, SP I 004). ...I felt it was a growing process, always some crescendo in each session - becoming stronger and stronger somehow. I cannot describe this well enough. The empathy became stronger (Einræn, SP I 006).

Einræn's words perfectly describe the growing empathetic support the mothers felt in this helping relationship. The mothers were the researcher's co-therapists. Their genuineness, their unconditional positive regard and the empathy they were capable of are qualities that have been emphasized as among the most important aspects of a positive therapeutic relationship (Brammer, 1979; Rolvsjord, 2007; Rogers, 1961; 1980; Yalom, 2001/2008). Being the therapist's task to function as a facilitator creating conditions favourable for self-expansion, the mothers explored their feelings and experiences in relation to each other. "These women know the wounds you carry having had a child with a disability," said Esja (SP I 003). With their genuineness as real human beings, with real problems, real thoughts, and real feelings, as opposed to an all-knowing and controlling therapist, their manner in this trusting relationship was free of pretence.

One feels empathetic towards them all but perhaps find stronger connection to some than others. ...And this feeling to grow with a group is very special. So carefully going step by step ... And to be able to look the others in the eye and somehow everything is changed. Everything is changed from the first session. Yes, because this is so heart-rending sessions. One somehow falls into them - the others. And one thinks about them somehow which is both good and exciting. Yes, I would describe it as a very special experience because this is so unexpected/unforeseen (Klambra, SPII 004). ...It is a learning experience: One thinks about how it is best to support another being, by sharing own experience or by just listening (Klambra, SPII 005).

In her diary, Klambra wrote about common understanding, encouragement and empathy in the group:

I wrote words on the whiteboard. It was interesting. One woman wrote paranoia and explained why. I felt I understood her very well and I could truly sympathize with this feeling. It evoked some thoughts. This was an exciting task. I realized how much help can be experienced when someone else words the things that one knows so well and it encourages one to participate in the discussions. Or at least it draws out empathy. (From Klambra's diary. Researcher's translation.)

The mothers accepted each other for what they were and connected to and cared for one another, although they "felt a stronger connection to some than others" (Klambra, SPII 004). They had all been there, in the same or a similar situation, so their understanding of each other was an accurate and an empathetic one. Empathy was not a skill that needed to be taught to them. They had the ability to enter each other's worlds and understand the essence of it, their thoughts and feelings, without judging them. They accepted each other for who they were and where they were in their lives. They could play with the idea of being another while remaining fully aware that they were not (Applegate & Bonovitz, 1995/2004, p. 56).

Concerning the peculiar satisfaction in really hearing someone, Rogers wrote: "It is like listening to the music of the spheres, because beyond the immediate message of the person, no matter what that might be, there is the universal" (1980, p. 8).

The ability to 'hear deeply' is a skill that an experienced helper acquires through years of experience. This researcher, on the other hand, continuously worried about whether she was mature enough and experienced enough to communicate the many facilitative traits or characteristics of an effective therapist, i.e. empathy, caring, genuineness (self-disclosure), positive regard and respect, concreteness and specificity (Brammer 1979; Rogers 1961; 1980).

In comparison to the empathetic understanding the mothers expressed, the therapist's attempts at empathetic understanding were perhaps merely reflective listening in an effort to understand the mothers' frame of reference. The researcher accepted them all and was somehow grateful for them all, but all she could do in this relationship was to be herself in the most authentic way possible. In her empathetic efforts, the therapist/researcher tried to be warm and caring, and to show concern and interest. Although the mothers expressed how lucky

they felt to participate in this first group and expressed their gratitude and admiration of the therapist's conduct she often felt like an outsider. Feeling at times that the mothers did not need a therapist and that she did not really belong to this group, the therapist/researcher contained her feelings, thoughts, and problems and sought outside help from a clinical supervisor.

According to Brammer "caring is a term closely related to warmth but it is regarded as more enduring and intense emotionally; it means showing deep and genuine concern about the welfare of the helpee [the client]" (1979, p. 38). In the early stages of the therapeutic process, the supportive value of warmth and caring are helpful in building a trusting relationship. It is also helpful when the client is going through a crisis or a difficult period in his or her treatment. Supported by research, an awareness of the facilitative or debilitating effect of warmth and caring concern in the therapeutic relationship is important and has long been known (Hadley & Strupp, 1976, as cited in Brammer 1979, pp. 38-39). Rogers words it in the following way:

If I can help bring about a climate marked by genuineness, prizing, and understanding, then exciting things happen. Persons and groups in such a climate move away from rigidity and toward flexibility, away from static living toward process living, away from dependence toward autonomy, away from defensiveness toward self-acceptance, away from being predictable toward an unpredictable creativity (1980, p. 43).

17.2.6 The group created possibilities for building awareness and strength

The mothers were at the centre of the music-caring group. The group provided them with a supportive context, supportive relationships through which they could activate their awareness and strength towards self-healing (Bohart & Tallman, 1999, as cited in Rolvsjord, 2007, p. 94).

"I just came because I had decided to," said Góa (SP I 002). She had the choice to participate or not to participate and she had the choice of sharing or not sharing, depending on how she felt in the moment. She was allowed to find it within herself – find her own agenda and her own ways of sharing, while at the same time working towards the group goal.

For me the most difficult thing was the feeling of not having completed something – not having shared something. I did not have the courage to go all the way. And when I got home I felt that I should have and I regretted it. Maybe I

thought that it was not suitable for this group or something. One does not necessarily have to bring all the shit to the same place. It is like a rollercoaster. You open up certain things and sometimes completely and then not further, etc. This was my choice the group did not stop me (Góa, SP I 002).

Honouring the mothers' individual needs and wants, their self-determination whilst working towards the group goal contributed to a positive group experience and the group process itself. Within the therapeutic approach the mothers could work on their own goals in a manner that suited them. Góa's quote above is indicative of the need to approach and involve herself and also her tendency to avoid it because of the possible frustrations and even pain it might cause. She wrote in one of her poems: "We tend the wounded yet avoid something, want to stay alive." A quote from her diary expressed the same: "I want to gain as much as possible from these sessions, thus it is important to be sincere. I have sometimes not been able to discuss the things I would like because I fear starting to cry."

Esja said that "there were certain things one did not want to discuss with everybody. Like I was saying in the last session. One would have wanted to discuss some things privately" (SP I 001).

Based on foreknowledge about the emotional needs of mothers having children with special needs and her research agenda, the therapist/researcher imposed goals on the mothers to a certain extent. Nevertheless, the therapeutic approach was figuratively speaking a co-operative process providing a 'free playground' within a 'secure frame', thus there was nothing that took the mothers away from one another in an attempt to establish their positions and identities. They were at home with each other, learned from each other, and became stronger with each other.

It strengthens you meeting other women who are dealing with the same [issues] as you (Esja, SP I 001) ...When the session was over and one went home and thought about it one realized what it had given you. ...Yes, I feel better and more capable of dealing with difficulties. Because inside it has been sorted out what you want - what emotions are inside. Yes, I feel better. If you feel better then you are stronger. Also so very strengthening to hear that you have left behind so many things the others were dealing with. You realize that you have moved on and that does you good (Esja, SP II 004).

One tries of course to be positive and to care for oneself. I know that one has not been putting oneself first. One has always been somewhere in the last row. Hopefully one becomes more capable of taking care of oneself and the ones around you, and feels better in general (Einræn, SP I 006).

I have learned that from this group or these sessions that it is all up to you. It is important to focus on the positive things rather than the negative ones. This course has taught me to be more aware of what I need to do to feel better so that others around me feel better (Góa SP I 010).

Good feeling that this was one's own making. We created it and that felt good. The challenge lies in doing something you have not done before. You have to step out, there is an initiative. This is like magic. There is magic in doing it for the first time, not knowing what comes next and all of that. And to find it grow. Although one has progressed in the discussion then it could be fun to continue it in fact (Klambra, SP III 004).

The music-caring was the mothers' own doing. They put their own energy into it and invested in the group. They were successful in completing the goal and based on this success they wished to continue the group, as Klambra pointed out.

17.2.7 The group created joy and feelings of anticipation and gratefulness

Schutz defined joy as a feeling that comes from the fulfilment of one's potential and, along with that, other feelings such as excitement and anticipation (1967, as cited in Izard, 1977, p. 272). Thus, if one is incapable of fulfilling one's potential then one is less likely to experience joy. Schutz also discussed obstacles of a different nature to the realization of joy, such as superficial and hypercritical relationships; beliefs related to, for example, child rearing, making it difficult for the individual to know himself and to like and trust himself; the high values placed by our society on material success and achievement; methods used by social institutions which muffle creativity and lead to over-control; and poor physical health. According to the literature:

Joy increases the individual's capacity to savour and appreciate the world. This means that the joyful person is more likely to see beauty and goodness in nature and in fellow human beings. While experiencing joy, people are more inclined to savor an object than to dissect it or analyze it. They appreciate the object as it is rather than wanting to change it. They feel

closeness with the object rather than wanting to objectify it and put it at a distance. The object is seen as enhancing the self of the perceiver. Joy makes you feel that you have a distinctive bond between yourself and the world. Joy is more than a positive attitude toward self and the world. It is a special kind of link or bond. This has been described as a keen sense of belonging, or of oneness with the object of joy and with the world. Joy is often accompanied by feelings of strength and vigour, ... and the feelings of confidence and competence. [A joyous person experiences herself as] more than or different from [her] usual self. Joy [is also said to accompany a feeling] of harmony and unity with the object of joy. [However,] there are great individual differences in the way joy interacts with perception, memory, thought and imagery, and consequently there may be great individual differences in the way people describe their joy experience and the phenomena that are typically associated with it (Izard, 1977, pp. 270-271).

An optimistic or positive emotional or affective tone is often cited as an important factor in successful groups. Studies by Hackman, (1991), and Williams and Sternberg (1988, as cited in Brewer & Hewstone, 2004, p. 102) show that a positive emotional character or “internal group harmony” can be the most important component in determining the quality of group outcomes. Along with being active (which contains the dimensions of engagement, energy, self-realization and freedom), good interpersonal relations (which are realized through friendship and intimate relationship) and self-confidence (which has to do with self-esteem and self-acceptance), Næss lists “basic sense of happiness”, as an important constituent of a high quality of life. According to her, basic sense of happiness is maintained through “emotional experiences, safety and joy” (as cited in Ruud, 1998, p. 55).

Frederickson’s work, known as ‘the broaden and build theory of positive emotion’, provides an explanation for the role positive emotion could and should play in our lives. Frederickson’s thesis is that positive emotion both signals and has the capacity to encourage well-being and flourishing. Frederickson argues that while negative emotions narrow people’s perspectives and keep them focused on the specific problem at hand (e.g. flight or fight), positive emotions broaden people’s likely thoughts and actions as well as their behaviour. In other words, when we are experiencing positive emotions we have more ‘behavioral flexibility’ and this allows us to build ‘intellectual and psychological resources’. When feeling positive we are more likely to be inquisitive, to learn, to explore and to be creative than if we are

negative. If we experience a negative emotion, such as fear, we are more likely to withdraw and avoid.

Frederickson's theory states that when we are experiencing positive emotions we are able to build personal resources that have long-term benefit to us and hence help us cope better with adversity. It is also in a positive frame of mind that we are more likely to build relationships with others. The term 'positive emotions' includes the "positive meanings and optimistic attitudes that trigger positive emotions as well as the open minds, tender hearts, relaxed limbs, and soft faces they usher in. It even includes the long-term impact that positive emotions have on your character, relationship, communities, and environment" (Fredrickson, 2009, p. 6).

So for various reasons, positive emotions such as humour and joy help to establish a strong therapeutic relationship. In the interviews, the mothers talked about anticipation and positive excitement, which, among other things, accompanied discovering new things, gratefulness for having been part of this group and for having been able to grow with each other step by step towards increased self-understanding.

In music-caring it is positive that you are always meeting the same women. That becomes personal. You get to know them and it becomes more enjoyable (Esja, SP I 003). I was very excited. One was a little shy to begin with but then this was such an adventure, yes, just amusing to take part in it. As you can see I only skipped one session. I thought this was just marvellous. I must say that. And though you did not know what this was in the beginning then just the same one walked with expectations and anticipation in heart when one was beginning. I looked forward to having time for myself and a time with you (Esja, SP I 004).

I was excited. Things were a little unclear in the beginning. That was both positive and negative. Positive because one did not know what was ahead and there was a certain excitement – positive excitement. One could discover things. I was pleased with the women in the group. I felt they were ready to share. Yes, I was excited right away. And I pictured something good without knowing what. I also decided that I was going to take part in it [be active]. I looked back and I was very happy with the time and I experienced in the last session the feeling of being grateful, but also a little empty because there was nothing that would replace it. In many ways I wanted to continue. Yes, I was very grateful for having been a part of it (Góa, SP I 004).

And then I started thinking in that connection how great it is having been so lucky to fall into this. To be able to participate in this and to sit there with some people in this big world. And someone takes this step and is able to talk about it so personally. And this feeling to grow with a group is very special. So carefully going step by step. And to be able to look the others in the eye and somehow everything is changed. Everything is changed from the first session. Yes, because these are such heart-rending sessions (Klambra, SP II 004).

A good experience for me. It is always amusing to be in a group, to be with people (Kristjana, SP I 001).

Bradburn showed that people who became socially involved and had more new or varied experiences reported more positive affect (1969, as cited in Izard, 1977, p. 276). With reduced stress or negative emotion states, and from recognition of the familiar “to be with other women like this who had experienced the same” as Esja worded it (SP I 001), as well as from resourceful endeavour, joy emerges. Joy creates a kind of openness and receptivity associated with intuition and creativity, and through the communication of emotions the bonding between the women became even stronger. The music-caring was about the growth-enhancing climate in this particular group. As Einræn said: “It would be different to participate in a new group so I would prefer meeting the same women” (SP I 008). Kemper (1990, as cited in Hess & Kirouac, 2000, p. 369) supports this when suggesting that “members of different social groups differ in their evaluation of emotion-eliciting events and their consequences, and that these differences may lead to differences in emotional reactions.” Music-caring was about the growth promoting climate in this particular group. It would be different with other mothers.

17.3 Musicking

As referred to in chapter 11 of this thesis, research and clinical experience in the area of infant development, music and music therapy has given striking evidence of the importance of sound and its enormous impact on emotional development and the structuring of the sense of self and others (Dissanayake, 2000; Sloboda, 2000; Stern, 1985; Trevarthen, 1993). From birth, and even before it, musicking is of central importance to our humanness and it is vital to realize the function it serves and can serve in our lives so we can use it for our own development and well-being as well as that of others. The interplay which occurs between the mother’s voice and a foetus’s ear followed by an interplay between the mother’s

and the infant's voices is essential to human contact. It creates a feeling of presence and absence, "the sense of recognizing and being recognized, and the sense of communication, validation and agency. It represents and expresses the whole range of human emotion in the context of a relationship" (Frank-Schwebel, 2002, p. 195).

Musicking was one of the core categories that evolved from the thematic analysis. Not only in interplay between a mother and a child, but also in the context of adults, is musicking together instrumental in creating and expressing various feelings. These feelings were explored through the following thematic statements concerning what musicking alone and with others contributed to the mothers' music-caring experience:

- Musicking created a relaxing, welcoming and caring atmosphere.
- Musicking brought joy and beauty.
- Musicking brought closeness and supported empathetic listening.
- Musicking empowered awareness of emotions.
- Musicking facilitated and deepened emotional expression.
- Musicking brought change and created possibilities.

Small's definition of the term 'musicking', as used in this research, is:

Musicking covers all participation in a musical performance, whether it is active or passive, sympathetic or antipathetic, constructive or destructive, interesting or boring. It is only by understanding what people do as they take part in a musical act that we can hope to understand the nature of music and the function it fulfils in human life (1998, p. 8).

The mothers' musicking in the music-caring group was both active and receptive and it occurred individually as a solo playing in the presence of the others, but also in combinations, both vocal and instrumental, ranging from a duet to an octet.

The mothers' written answers to question one from the questionnaire 'S', given to them in the preparatory phase of the research, revealed that for five of them music was a motivating factor for their participation (Appendix R). It was the enjoyment of music, singing with others, working with emotions through music, and strengthening oneself through music therapeutic work that sparked the mothers' interest in participating in the music-caring group.

Concerning aesthetic material having social valence in and through their circumstances of use, DeNora wrote (2000, p. 4): “Musical and social matters are understood to be reflexively linked and coproduced.” It is thus important to bear in mind that musicking in the music-caring group took place in a relationship(s) and in a cultural context. Like Klambra said in her diary: “Music-caring is wonderful. It draws out many feelings. To sound with the group is very entertaining. One somehow tries to contain oneself like in any group work and tries not to be different.”

It could thus be argued that in order to find answers to the research questions it is impossible to separate the mothers’ experience of musicking (both individually and with others) from its social context. That is, from it being experienced socially within the music-caring group. However, the research method itself follows this movement back and forth from studying parts to studying the whole; from reflecting upon prior knowledge of music and its use towards gaining new insights and understanding; from moving back and forth on the mothers’ life continuum in the process of sharing narratives through their musicking or creative play. It is hoped that “this circling from part to whole and back again results in progressive understanding that, in principle, is unending, although hopefully it reaches a kind of stability, at least within the horizon of the particular hermeneut” (Kenny, Langenberg & Loewy, 2005, p. 342).

17.3.1 Musicking created a relaxing, welcoming and caring atmosphere

“[In playing] ...and perhaps only in playing, the child or adult is free to be creative,” wrote Winnicott (1971/2005, p. 71). According to him, playing is therapeutic in itself and music as one form of playing embedded in a context of social interaction can become an agent of therapy or healing; however, it can also be “a little surreal” as Klambra wrote in her diary when describing her experience in the first session:

Immediately in the first session I find myself at ease. Relaxed despite all the participants most surely feel a little insecure. A little surreal to sit there with the group and play together on foreign instruments in such a serious atmosphere and not become filled with a feeling of foolishness but instead to feel comfortable.

In a preface to her book *Music in Everyday Life*, DeNora suggests that “it is probably impossible to speak of music’s powers abstracted from their contexts of use,

though, within certain settings and in relation to particular types of actors, music's effects on action may be anticipated to varying degrees" (2000, p. x).

Traced to Theodor Adorno and ethnographic studies in the 1970s²³, one of the most promising trends in the new sociology, according to DeNora, is the discovery of how music can be used by and on behalf of actors as a resource to construct self-identity and to create and maintain a variety of emotions. In-depth interview studies reveal that listeners are not merely passively affected by music, but rather are actively constructing their own ability to be moved by it. Moreover, the studies reveal how people use music to regulate, enhance and change qualities and levels of emotion. They show considerable awareness about the music they need to hear in different situations and at different times to influence aspects of themselves and their self-conceptions (DeNora, 2000; DeNora, as cited in Juslin & Sloboda, 2001/2002, pp. 161-180).

The music used in this research was of different genres and the musicking was both receptive and expressive as mentioned before. It had its beginning in the initial interview with each mother, where music playing in the background from the disk *Madredeus Antologia* set the tone. The term 'receptive musicking' refers to receptive²⁴ as used in music therapy. It encompasses techniques where the client is a recipient of a music experience instead of actively making music. The music used in what could be called the initial 'musical contact' was Fado music from Portugal. The music was chosen by the researcher and it is believed that the mothers had no associations with this particular CD (*Madredeus Antologia*). Neither the therapist/researcher nor the mothers understood the lyrics, which were sung by a female voice in Portuguese. The therapist/researcher had some idea about the mothers' favourite musical genres, having had them express themselves about their musical interests in the initial interview. She had received answers such as: "I am musical. I like to dance. I sing relatively well and enjoy it. I like music that is tranquil, comfortable, old and beautiful" but felt she could not base her choice on information such as this.

²³ Theodor W. Adorno, a German philosopher. "Adorno's work represents the most significant development in the twentieth century of the idea that music is a 'force' in social life, a building material of consciousness and social structure" (DeNora, 2000, p. 2).

²⁴ "In receptive experience, the client listens to music and responds to the experience silently, verbally or in another modality. The music used may be live or recorded improvisations, performances, or compositions by the client or therapist, or commercial recordings of music literature in various styles (e.g., classical, jazz, country, spiritual, new age). The listening experience may be focused on physical, emotional, intellectual, aesthetic, or spiritual aspects of the music, and the client's responses are designed according to the therapeutic purpose of the experience" (Bruscia, 1998, p. 120).

The musical selection was based on the therapist/researcher's initial emotional reaction to this particular type of music and in particular to this CD. So the music was somewhat foreign to the therapist/researcher as were the mothers and the whole encounter. To the therapist/researcher, the music sounded somewhat soothing yet at the same time sorrowful and intense. One could say that to the therapist/researcher it sounded both caring and empathetic with a promise to calm her perceived insecurity. The music was the therapist/researcher's ally; it helped her to create a workspace conducive to her objectives. The therapist/researcher also believed that in some way the music reflected what she anticipated to be the emotional frame of the mothers. As DeNora describes it above (2000), the therapist/researcher was using it on behalf of the mothers as a resource to create and maintain a caring atmosphere. The same background music was played at the beginning of the first music-caring sessions while waiting for all the mothers to arrive. Whether or not some of them realized that the same music was being played is not known, but it may have been instrumental in creating the welcoming and the caring atmosphere they talk about.

The importance of setting the tone by having the 'correct' background music playing while waiting for all the mothers to arrive is acknowledged in the following quotes used to emphasize the first category explaining what musicking individually and with the others contributed to their experience.

It was always good to come to the sessions. The background music was good and created a welcoming atmosphere. If there had been rock music in the background it would have been different (Esja, SP I 006).

The music relaxes you and encourages more participation (Góa, SP II 006).

I think this always felt cosy. ...The group felt comfortable, it had a comfortable presence (Kristjana, SP1 004).

Asked about how she experienced musicking in the group, Einræn answered: "The music always makes things better" (SP1 002). Comparing a support group where there is no music to one where there is music, she tearfully commented:

I felt somehow it became how should I say it – it became closer to you when the music was used. It makes a big difference to have the music. Somehow it feels more caring when there is music compared to when it is not (Einræn, SP1 008).

Although no music is guaranteed to invoke 'preferred' or appropriate action frames, it has the power to compose situations, says DeNora. Music may influence

how people feel in terms of energy and emotion about themselves, about others, and about situations. To be in control of this soundtrack of social action is to provide a framework for the organization of social activity, a framework for how people consciously or subconsciously perceive potential avenues of conduct (2000, pp. 9-17). The researcher's intention to create a soothing and caring atmosphere in order to relieve or diminish possible tension seems to have worked. Applying the 'iso-principle' – selecting music that the therapist believed resonated with or reflected the mothers' feelings, moods or attitudes – seem thus to have been instrumental in contributing to the perceived 'comfortableness of the group'. The musical material on the disk *Madredeus Antologia* and some others used throughout the research for the same purpose (creating a relaxing and welcoming atmosphere) seems to have been active in the process of calming anticipated or perceived worries and anxieties as reflected above.

17.3.2 Musicking brought joy and beauty

Describing what distinguishes music therapy interventions from other forms of therapy, Bruscia talks about a combination of three elements: sound, beauty and creativity. Attending therapy for various reasons, peoples' problems "have rendered them unable to find the beauty and meaning of their lives – they can no longer live their lives to the fullest," he wrote (1998a, p. 42). Bruscia emphasizes that it is the therapist's task to ensure that the context for the sound experience in music therapy is an aesthetic one. It should be motivated by the search for beauty, and the meaning that beauty brings to life through music.

When reflecting on what being part of the group contributed to the mothers' experiences, the feeling of joy was one of the primary memories. According to the mothers, the musicking also brought joy and beauty to their experience:

It was terribly fun to play and I enjoyed it. I was trying to make some beautiful sounds, or trying to make something different – something gloomy trying to fit. It was great fun when we were all playing together. There was a feeling of happiness to be allowed to play and to make some sounds, to make a feeling. I thought it was terrific fun (Hanna, SP I 004).

Esja (SP I 006) and Góa also spoke of how good it was that the instruments sounded beautiful.

Discovering new and interesting sounds/instruments, some drums and the sansula it sounded so beautiful. ...There is a positive energy that is released when singing and laughing. Besides, it is enjoyable to sing (Góá, SP I 005).

Kristjana speculated that she might have got a different outlet if she had known something about music. Despite feeling a little insecure in her experimentation with the instruments, she enjoyed the experience (SP I 001).

Having the freedom to choose and to explore instruments, to make beautiful sounds and all kinds of sounds and to sing was enjoyable. It released positive energy and created a feeling of happiness and fun. There were no instructions, no right or wrong, but unconditional creative freedom through which the mothers experienced beauty and meaning of life.

As discussed in the theoretical part of this thesis (10.3) the term ‘quality of life’ refers to a subjective state of well-being, purpose and happiness rather than an objective set of criteria in the form of material conditions (Ruud, 1998). According to Næss, components that constitute a good quality of life include:

Activity, which contains the dimensions of engagement, energy, self-realization, and freedom; 2. good interpersonal relations, which are realized through friendship and intimate relations; 3. self-confidence, which has to do with self-esteem and self-acceptance; and 4. a basic sense of happiness, which is maintained through emotional experiences, safety and joy (as cited in Ruud, 1998, p. 55).

When feeling positive we are more likely to be inquisitive, to learn, to explore and be creative than if we are negative. If we experience a negative emotion, such as fear, we are more likely to withdraw and avoid says Frederickson (2009). Frederickson’s theory states that when we are experiencing positive emotions we are able to build personal resources that have long-term benefit to us and hence help us cope better with adversity. It is also in a positive frame of mind that we are more likely to build relationships with others. Experiencing joy and beauty are thus “not positive side-effects of music therapy,” as Rolvsjord words it, but central and valuable therapeutically (2007, p. 310).

For these various reasons, positive emotions, such as humour and joy, help to establish a strong therapeutic relationship. The mothers talked about anticipation, positive excitement, which among other things accompanied discovering new things, gratefulness for having been part of this group and for

having been able to grow with the other mothers step by step towards greater self-understanding.

According to Harris, (2000/2004, p. 281) our ability to know and report on the emotions that we feel is limited. Thus he emphasizes that scientific studies on our emotional lives should not be restricted to aspects of emotions that are accessible to awareness but also include emotional processes that may escape our awareness, yet reveal themselves via facial expressions or various psycho physiological indices. Harris emphasizes that our awareness of emotions, however partial, can change and improve developing insight into our own emotional lives, as well as those of other people. He argued: “At first we may rely on an immediate attunement to the way they express their emotions. However, our full understanding may depend on less immediate and more reflective mediation on their history and their subjective appraisal of events” (ibid.).

In an introduction to the “first scientific anthology ever devoted specifically to musical emotions,” Juslin and Sloboda (2001/2002, p. 5) wrote that the study of emotion and the difficult topic of emotion in music had been neglected due mainly to the difficulty of observing emotion under laboratory conditions and to the fact that the field of emotion in music had been dominated by cognitive science, leading to an emphasis on cognitive aspects of musical behavior, whether perceiving them or expressing them.

Authors in the field of music and emotion have expressed their doubts that current theories of emotion are sufficient when studying emotion in music. Currently the field is served by a multiplicity of approaches making it difficult to present a coherent story resulting in the stance that instead of dealing with this difficult topic inadequately it is better not to deal with it at all. Most of the available academic studies are limited to a particular way of listening related to abstract and aesthetic properties rather than emotions or everyday feelings about music. The central aim of music psychology has been to understand the mechanisms that intervene between music reaching a person’s ears and an emotion being perceived, or experienced, by that person as a result of hearing that music.

Other important aims have involved understanding of the roles of emotions in composing and performing music. Juslin and Sloboda suggest that failure to see the many ways that music may represent and induce emotions has contributed to the controversies that have characterized the field of music and

emotion. “No single theory is likely to be able to account for all emotional responses to music,” they argue (2001/2002, p. 9).

Observing the mothers in this research bravely explore the various instruments, experimenting with them and sounding them creatively and systematically evoked in the researcher an image. This was an image of children exploring and connecting to new play things, projecting their feelings onto them and through sounds both instrumental and vocal, expressing emotions such as joy, wonder and excitement. When encouraging the mothers to explore and experiment through creative play, it seemed to the therapist/researcher like they were attuning to suppressed emotions, engaging in conversation about emotions and relating empathetically to how the others were feeling. It could be compared to a conversation between a mother and a child, where they help each other to organize their world – emotionally, cognitively and socially. It could also be described by the concept of ‘interactional synchrony’, which “can be seen as a dance between persons, in which each adapts and shifts eye gaze, head movements, body movements, and vocal sounds in order to personally ‘fit’ and ‘exchange’ with the communicating partner” (Feldstein & Welkowitz, 1978, as cited in Bunt & Pavlicevic, 2001, p. 194).

Yes, it was exactly what happened. You put thoughts and feelings in a creative form and music and you felt empathy. You got to know others and to feel kindness for them and to empathize with what they were experiencing. And you want to show them that you understand this and feel this and that you are not alone. Because [being alone] is such a terrible feeling. I admire so many of them (Hanna, SP I 008).

Like Hanna describes it, in her ‘subjective appraisal of events’ the closeness and the empathetic listening that musicking supported in the group evoked a range of feelings and reactions to their self-consciousness and thus could be communicated about.

Whether the mothers participating in the research have, due to their life’s experience, become naturally more empathetic, more able to assess how other mothers feel and more willing to engage in conversations about it given favourable circumstances, will not be speculated about in this context, although that may very well be the case. According to research, emotionally charged episodes in one’s life are frequently the subjects of sharing and recall both with children and adults. Thus adults who have gone through an emotionally charged

experience are prone to sharing that experience repeatedly with other people and throughout a longer period of time (Harris 200/2004, p. 284).

Research has shown that ‘feelings come first’, and that reason and reasoning as well as cognition depends on and is built on emotion. Damasio has argued that the rational part of the brain does not work on its own; it functions only at the same time as the basic regulatory and emotional parts of the brain. “Nature appears to have built the apparatus of rationality not just on top of the apparatus of biological regulation, but also *from* it and *with* it” (Damasio, 1994, p. 128 as cited in Gerhardt, 2004, p. 6).

17.3.3 Musicking brought closeness and supported empathetic listening

As discussed in section 9.1 of this thesis, empathy is a facilitative trait that enables the therapist to understand the client and enables the client to feel he is understood. It is the capacity to identify with or understand what another person is experiencing. According to Bruscia (1998a, p. 61), empathy is the basis for all helping interventions and music, with its adaptability and its multiplicity, is an ideal medium for empathy. Concerning empathy, Einræn commented:

One increasingly became part of the group. Knew better what was about to happen. The feelings, both mine and theirs, emerged. When we got to know each other better the feeling of empathy grew. You felt somehow they supported what you were saying. And they said they had been thinking about me (Einræn, SP I 004). ... Sounding all of us together, sounding our emotions together, something increased. We were together and there was some fusion/merging that was different from when we were alone talking about feelings (Einræn, SPI 005).

Einræn experienced some fusion in the music that was different from when they were ‘alone talking about feelings’.

Góa talked about having experienced a certain connection to each other while musicking. “We were all doing the same” she said (SP I 007).

By singing it together one participated in it, became part of it and the tones gave life to the text, gave it more weight. ... We are all doing the same thing – there is a certain connection, which brings forth the empathy. ... The music connected us. We were all doing the same. Perhaps we had different instruments but there was a connection to each other. Yes, the important

thing is the connection and also when we succeeded and there came beautiful harmonies from us then it felt good to listen to it (Góa, SP I 007).

Hanna also expressed herself about this closeness:

I start alone and then I feel everyone is playing with me and trying to express my emotion, to help both me and you [the therapist] also. This quietness and this listening and myself also trying, this I consider music-caring. They hear how I have started and how I have set the tone that is music-caring for me (Hanna, SP I 008).

For Hanna and Skonza music-caring was about closeness and the connection experienced through musicking together. “Everyone is playing with me trying to express my emotion,” Hanna said. What was very helpful for Skonza was:

When we were playing the instruments and singing together. Yes, perhaps mostly when we were sounding us together and singing the songs together and also to hear all the poems that they made. I thought that was very helpful (Skonza, SP II, 002).

The mothers looked each other in the eye and somehow everything had changed from the first session. There was a fusion, certain connection that brought forth the empathy. Musicking together made possible an inter-subjective communication where they contained each other’s experiences and shared an empathetic understanding of their reality.

Just like the infant’s ability to express itself musically grows, so did the mothers’. They learned to use sounds, which, according to Esja, expressed the feeling as it was much better than words alone could do. “The sounds described the feeling, it was dark and that told it so well. The sound told how the heaviness in the chest is when you get it.” (Esja, SP I 003) According to Esja’s experience, musicking seems to have brought them closer to their emotions and aided an accurate examination and description of them.

17.3.4 Musicking empowered an awareness of emotions

“Being alone in the world I did not know anyone like this. The first year was a time of waiting, waiting for life to become normal. Strange how much alone one felt at first,” said Kristjana (SP I 005). Perhaps feeling alone (like Kristjana did), withdrawn into themselves for protective reasons trying to maintain ‘psychic equilibrium’, withdrawn from surroundings where they had become lost in a life

that lacks adequate emotional support, the mothers' spontaneous playing and singing reconnected them to deep layers of feelings, and encouraged an expression of an emotion which empathetically touched the others. Their musicking became a psychodynamic process, mediating between their inner and outer reality. Or, as Esja worded it:

It would be difficult just to talk, you know. The music moves you on. I think that if you were just to talk then that would not move you on and not give you as much as the music and one would take longer to go through this. Yes, the music moves you forward in a bigger journey somehow. It takes you to more places; you see music brings up feelings. I think music does unbelievably much. It moves you so much. ...One feels somehow that there are so many colours in it and a channel (Esja, SP II 008).

“Emotions are first and foremost our guides to action: they are about going towards things or going away from them,” wrote Gerhardt in her book *Why Love Matters* (2004, p. 33). As a tool for memory retrieval, music can be used as a device for the reflexive process of remembering or constructing who one is, argued DeNora (2000, p. 63).

Like Esja describes it, music is both a movement between an inner and an outer reality and a forward movement through a ‘big journey’. Thus it is not only a device of artifactual memory but also a device for the generation of future identity and action structures, according to DeNora (2000, p. 63). The group musicking acted like an ideal family, encouraging an accurate awareness and report of emotions. Like Esja said: “The sound expressed the emotion perfectly. It has been put into shape and distanced itself from you” (Esja, SP I 003).

To sound the paranoia and to say goodbye to it was good. The sounds described the feeling, it was dark and that told it so well. The sound told how the heaviness in the chest is when you get it. And just by hearing it, perhaps similar to when you write the feelings on a paper, it has been shaped into this form. Then the emotion has left you a little, gone away from you. The sound expressed the emotion perfectly. It has been put into shape and distanced itself from you (Esja SP I 003).

Music helps us “to experience emotional nuances, to experience and express various degrees of intensity and to maintain precise concepts about feelings,” said Ruud (1998, p. 58). Similarly, Einræn talked about how singing the poems made them become more alive for her. The text became clearer and reached one

better somehow, she said (SP I 002). Expressing herself about Einræn's song, Góa said:

We had sung it few times or listened to it and then somehow I realized the crescendo in the song. It was the word pain or torment that was on the highest note that was intense. It was like the melody highlighted the text. One realizes better what was being sung about (Góa, SP I 007).

Identifying the emotional state with a musical structure is like playing music as a virtual means of expressing or constructing a particular emotion, says DeNora. In that way "music is both an instigator and a container of feeling – anger, sorrow and so forth" (2000, p. 58).

Hanna experienced how musicking opened up the possibility of expressing emotions that otherwise would not be discussed. Music, "being so pure and close to one's heart," expressed the feeling, made it deeper somehow, brought it out somehow. Talking is different, she believed: "You have to think before you talk" Hanna said (SP I 005).

When you speak the emotion, people just have to imagine something based on what you are saying. That is different, much different. When talking, one tries to avoid saying this and that. There are certain standards what one can speak about and one cannot - how one can behave and how one speaks (Hanna, SP I 005).

"The act of musicking brings into existence among those present a set of relationships, and it is in those relationships that the meaning of the act of musicking lies," said Small (1999, p. 13). Concerning the relationships established between the participants within the performance space, the mothers empathetically knew what each other was expressing, whether through words or sounds. They did not have to pretend any more. They could put feelings into words, examine them and express them in sounds exactly like they were experiencing them. Klambra said:

It makes me think about what place this emotion in me has. How is it in me? How do I experience it? Is it something that I have some control over or is it terribly deep and endless somehow? Is it breaking me? When writing, you are thinking so much about the words, if you are going to rhyme it or word it somehow. That is totally different. It is a new aspect to sound it. It makes you think. What is this anyway? What is this emotion? Does it gnaw on you

because that is the way you are trying to express it so very deep and dark or quickly and constantly bugging somehow or what (Klambra, SP I 006)?

“One senses [one’s emotion] better when you sound it,” said Skonza (SP II 003). By sensing it better when sounding it, one would think that it somehow becomes better understood. “It became a bigger statement,” as Kristjana put it (SP I 011). Musicking added colour to it. “At first I had thought, wait a minute, I had not thought of it like that,” Kristjana said. “Then I started to look at it and yes, I considered it is actually like this because before I had not thought of it as something important or noteworthy” (Kristjana, SP I 011).

Shaping the emotions into a musical form or ‘structuring them’ made them containable, and seems to have created a deeper awareness of them, more closeness to them and more exact communication about them. In sounds the mothers’ feelings could be expressed exactly like they were experiencing them.

17.3.5 Musicking facilitated and deepened emotional expression

In the following quotes, the mothers describe how active and passive musicking facilitated and deepened the expression of emotion. The mothers came to realize the power of music and how they could use it for various purposes. They felt, for example, that by shaping difficult feelings such as worries into the music, they could get rid of them. Musicking also transformed them so they completely forgot themselves in the music.

Comparing groups where music is used to support groups where there is no music, Klambra and Skonza felt that musicking and creativity added more depth to the therapeutic work as well as making it more personal and intimate. Skonza said:

If I were to choose between groups I would choose one where there is music. It is difficult to compare in words a group with no music and a group with music but somehow there is a much more depth in a music group. ...Now you listen to music more in order to get some relaxation and to make you feel better. You realize better that you can use music for various purposes (SP III 002).

Musicking had a cleansing and loosening effect for both Skonza and Góa. If they had been deeply into something boring or difficult, musicking provided an outlet and gave room for feelings of comfortableness and well-being (Góa, SP I 001; Skonza, SP II 007). Transformed through her musicking, Skonza was relieved of her worries when they had been shaped in the music:

If you had some worries or if you were feeling bad then you could somehow loosen it or get rid of it and somehow shape it in the music. I felt that was very good (Skonza, SP II 003)... When I was playing I completely forgot myself while doing it. The sounds came to you and one somehow went on a different level, or I do not know. I completely just forgot myself and one was perhaps a little more. First, when one was beginning, one was a little careful then when it progressed then one became introverted, listened to the music and played fully, and it was very comfortable. One forgot time and place and forgot oneself in the music (Skonza, SP II 004). ...I had been very worried and there they just floated away from me. I felt this enormous relief somehow. It felt very good but maybe that is not the right word. The worries had been so overwhelming and when they went I was capable of getting rid of them and they floated away and you sat behind somehow. I need a word to describe it, so comfortable and so good you know are not strong enough terms to describe how I felt. It was so, oh, irritating when you do not find the right word. And afterwards it was such a terribly good feeling of well-being and relief of great proportions (Skonza, SP II 007).

Skonza felt irritated because she lacked the right words to describe her experience, to describe how, by coming to her, the sounds somehow transported her to a different level. Feeling comfortable and feeling good were not strong enough terms to describe how she felt. Skonza felt like musicking was capable of both containing and transporting her worries away from her. Hanna experienced the same when “sounding an emotion through the music” and getting rid of it somehow, as she worded it:

To sound an emotion through the music also gave an unexpected emotional outlet and a liberating feeling. I also experienced emotional outlet through the expression of another mother who was expressing something else (Hanna, SP I 002). ...I could talk about what was bothering me, my main issue at that time, and then play it and in that way get rid of it somehow. That felt terribly good to me. Somehow I got rid of it out of my system (Hanna, SP I 005).

Klambra talked about a more personal and a deeper expression in the music.

I felt it particularly when we had the words and it was possible to dive into them. It was somehow such a deep expression in the music when one had begun to express some word or some emotion (Klambra, SP I 005). ...It is much more personal with the music and much deeper. ...Just by sitting here and listening to a beautiful song or when singing a beautiful song together.

You find how it stirs up the emotions. Music just has this quality and the creation also (making music). There is no creativity in the other group. That is completely different. It is much more personal and intimate with the music (Klambra, SP III 005).

Why does this depth and this liberating feeling that comes with the music exist? Besides being in an empathically attuned companionship, what is it that defines and explains this experience? Schneck and Berger are of the opinion that without requiring higher forms of cognitive awareness, “music makes immediate sense, reaching directly into the emotional brain to convey or echo moods, sensations, and feelings. In fact, words are inadequate even to describe the musical experience. It can only be experienced” (2006, p. 30). Whether the mothers’ experiences are based on the emotions and feelings aroused by the structural properties of the music (the absolute/ expressionistic explanation of the meaning of music) or whether the mothers’ experiences are explained from a referential view point, (that is, that the meaning of music is derived from the extra musical and contextual association of the sounds), is difficult to assert. Most likely it is a combination of various factors that are brought together in the here and now of their experience. The mothers refer to beautiful sounds and beautiful songs (absolute musical meaning in the sense that it is intrinsic to the sounds themselves), “just by sitting here and listening to a beautiful song or when singing a beautiful song together. You find how it stirs up the emotions. Music just has this quality and the creation also [making music]” (Klambra, SP III 005). Not knowing exactly what it was in her own experience that was particularly helpful, Skonza said:

It was just, I do not know. Like the time when we were playing the instruments and singing. I felt that was very helpful and also you know when we were talking together. Talking about what had happened during the week and to be allowed to let off a little. Yes, and perhaps mostly when we were sounding us together and singing the songs together and also to hear all the poems that they made. I thought that was also very helpful (Skonza, SP II 002; SP II 004). ...Because it came so close to you and it is so difficult to put it into words for others who did not experience it. Something private just for oneself and people would never understand exactly what you were trying to tell (Skonza, SP II 007).

“People would never understand exactly what you were trying to tell,” said Skonza. Skonza’s feelings are somewhat similar to Esja’s who wrote in her

diary: “I felt that what we did somehow was a secret. It is personal, between me and them, my time. Talking about it might harm the secret or the magic.”

Skonza mentions that music she has heard in the radio has often described exactly the way she is feeling; but talking together, sounding together, singing the songs together, hearing all the poems they had made, that “does very much for you.” She is describing how engaging creatively with other minds and how empathetically attuned positive relationships have ordered, facilitated and deepened her emotional expression.

“It is a creative appreciation more than anything else that makes the individual feel that life is worth living,” wrote Winnicott (1971/2005, p. 87). “Contrasted with this is a relationship to external reality which is one of compliance, the world and its details being recognized but only as something to be fitted in with or demanding adaptation.” The new constellation the mothers experience with the birth of a special-needs child involves unreliability and demands compliance. A deprived person is unable to play because the play area is no longer there. In defence, the true self is compliantly in hiding, causing an unhealthy state lacking enrichment through living experience. The music-caring group provided a new play area, encouraging creative and healthy way of living. It encouraged the mothers to take part in life and to become aware of their creative impulses

... something that of course is necessary if an artist is to produce a work of art. But also as something that is present when anyone – baby, child, adolescent, adult, old man or woman – looks in a healthy way at anything or does anything deliberately, such as ... prolonging the act of crying to enjoy a musical sound (Winnicott,1971/2005, p. 87).

The mothers may have gone through this process before in early childhood, where they related emotionally and used music and musical sounds emotionally to be soothed in times of distress or when they used music in a creative way to express their own emotions and to project themselves and their own understanding. As adults they are given this opportunity again through music-caring. Through musicking individually and together they are encouraged to use their creative impulses to reconnect to their emotions, to form them and shape so the world may witness. It is unlikely that anyone will either be able to explain the creative impulse or ever want to explain it, argued Winnicott, but the link can usefully be made between creative living and living itself “...and the reasons can be studied why it is that creative living can be lost and why the individual’s feeling that life is real or meaningful can disappear” (Winnicott,1971/2005, p. 93).

17.3.6 Musicking brought change and created possibilities

From the mothers' discussions, it is evident that their creative play through the act of musicking in an empathetic and supportive relationship brought change and created possibilities. It taught them new ways of dealing with emotions, of mobilizing them and sustaining the good ones. Bad emotions could somehow be loosened and shaped so that it became easier to get rid of them. Lacking words to describe the way she felt when the overwhelming worries floated away from her and how good she felt afterwards when a "terribly good" feeling of well-being and relief took over to great proportions, Skonza would perhaps agree on having been created anew. Something was finished. Participating in the music-caring group was a turning point. Constantly thinking about the home, the children and "doing nothing for myself," as Hanna emphasized, would not work anymore. She demanded a creative living for herself:

I think it was exactly what each one of us needed. I am dramatic and there I wrote about exactly what was going on in my life there and then and I could not get out of it. And for me when I had done it and then I had read it out loud and sounded it, that for me finished it (Hanna, SP I 005). ... I felt like it was a turning point around this group. It did not work anymore, just always thinking about the home, the children and doing nothing for myself (Hanna, SP II 001).

Kristjana, feeling "strange" about being finished the therapy, felt that musicking had taught her new ways to deal with emotions and to mobilize them, to sustain them somehow through music (SP II 002):

Like for instance now I am happy and then I want to listen to this or to sing this song. ...I believe that so much can be done with music or poems whether sounds come along with it or not. I believe this is quite terribly big and unploughed field, music-caring that is. I believe that one can take very many roads and this method to make us make music and to put feelings into poems, that is very clever for women like us who are dealing with emotions. We are not dealing with illness necessarily; we are dealing with emotions and the illnesses of others. So it is clever. I have the feeling that music-caring can be much more without realizing it. I have the hunch that this is something terribly big and enormous and that we have been just a little bit in it (Kristjana, SP II 002).

Klambra felt she had taken a step forward (SP I 004). For her, the feeling of growing with the group was very special.

So carefully going step by step and to sing [the farewell song] “the session is over” which I enjoyed so much; to be able to look the others in the eye and somehow everything is changed from the first session (Klambra, SP II 004).

Góa mentioned that she had become more accepting of being where she was, but that she was also ready to focus on something new, to see something new in front of her. “You ask personal questions that get one to start thinking and then one sees some possibilities that one wants to explore.”

I have discovered poetry, and I took with me renewed energy from the sessions (Góa, SP I 001). ...Yes, I feel that I am somehow more secure in myself. I am happier and have decided not to be bothered with certain things. And it has been confirmed in these meetings that there are so many things one can get rid of – something negative and that one should try to focus on the good things. I think the biggest thing is that one needs to be positive (Góa, SP I 010).

The music-caring sessions helped Esja to realize what she wanted and what she wanted to work with. Musicking took her on a bigger journey. It moved her forward and she realized that she was only capable of changing herself and not others (SP II 005).

This music-caring has truly helped me in that after these sessions one had provisions for the week to come and one was often thinking about this. Perhaps one was driving and then one was thinking about what had happened in the sessions. Thinking about what one wanted and what one wanted to work with, so that was very good (Esja, SP II 005). ...It would be difficult just to talk. You know the music moves you on. I think that if you were just to talk then that would not move you on and not give you as much as the music. And one would take longer to go through this. Yes the music moves you forward on a bigger journey somehow. It takes you to more places. You see the music generates feelings (Esja, SP II 008).

17.4 Songwriting

Using literature review and a long acquaintance with mothers of young children with special needs, the researcher identified group needs and set the goal,

choosing songwriting as the central music therapeutic approach. The researcher's rationale for using songwriting has been discussed earlier, as well as the progression of it in some detail through the ten sessions (see Part III: The preparation phase and Part IV: The implementation phase).

According to Benson, any therapeutic approach should: provide context for members to engage in and interact, provide structured experience, influence both directly or indirectly the group and its individuals, aim at achieving particular results or desired objective, be able to modify or control undesirable behaviour, and facilitate the development and the growth of a group. Furthermore, the therapist should always be able to say why she is using a certain activity or engaging the group in a particular project, although the programme chosen should never be an end in itself (Benson, 2001, p. 31). The focus was thus not on the songwriting activity as such but on the mothers' experiences of participating in it as a part of the music-caring programme. The songwriting approach used in this research could be described as an improvised yet structured exercise directed towards a particular outcome.

The core of the researcher's clinical work has been carried out in private practice in which she works with individuals of different ages and with different therapeutic needs, including individuals with mental retardation, learning disabilities, multiple disabilities, psychiatric disorders, social, emotional and behavioural problems, sensory impairments, communication disorders, physical and orthopaedic disabilities, neurological impairments, and other disabling conditions. Their functional abilities, experiences, needs, and strengths vary greatly. This has demanded a comprehensive approach to music therapy, an approach that is eclectic in nature and rooted in many different treatment theories and methodologies. On occasion, she has used various songwriting activities with children and adolescents, but never before with non-clinical adults. It was thus not her competence or prior experience with songwriting that guided her towards choosing it, but guarantees in the literature stating its effectiveness. The possibility it held as a structured activity whereby one could aim at achieving a particular result and also be able to modify or control undesirable behaviour also felt reassuring.

As has been previously stated, songwriting as a way of musicking and the central music therapeutic approach is defined in this research as "the process of creating, notating and/or recording lyrics and music by the client or clients and therapist within a therapeutic relationship to address psychosocial, emotional, cognitive and communication needs of the client" (Baker & Wigram, 2005, p. 16).

The mothers were told that singing and songwriting is a valued tool in the music therapists' toolkit and that research has shown that creative work is an effective approach in therapeutic work with different client groups (Baker & Wigram, 2005). The importance of singing as a cultural phenomenon and the place singing holds in our culture was also mentioned. The researcher talked about how singing together in a group could develop group cohesiveness, encourage social interaction, provide group support and be the source of joy, that singing facilitates expression, reduces isolation and loneliness, and in singing one has an opportunity to experience joy and happiness even during difficult times. To create one's own song would only be a small step away from singing the songs of others. One's composition could be performed again and again. One could share it with others and keep it. The therapeutic meaning and importance of the song would thus not only be connected to the song itself as a specific means of expression, but also to connections which evolve in the process of its making and during its use within therapy and beyond. The mothers were told that for many who had tried songwriting it had proved to be a joyful experience and a confirmation of an important period in their life.

The following is an excerpt from the group interview where Klambra describes her experience of songwriting in the music-caring group. It is an account of what she felt at the beginning of this activity when "so much opened up for" her.

Klambra: So delightful, just much more so than. I felt that it was unbelievable giving when we, from the time we went to the whiteboard and everyone wrote some words. I felt that so much opened up for me. And to take these words home, and to be looking at them, and to be thinking about them and trying to work with them and from them and begin to compose something. I thought that was just wonderful and to review each one of you and all sorts of comments and lot of different things. It deepened it a great deal for me I felt.

V: So for you the beginning was at the whiteboard.

Klambra: Yes, truly that is how I felt, yes. And then I felt it was fantastic to bring all these words and to read, and everyone reads her own, and I felt this you see, the music gave the words five times more their own life.

Klambra: I felt that when I sat at home with the guitar and played my own words it gave me enormously.

V: Is that something you have done before?

Klambra: Yes, I have done it a little.

Klambra: I felt also, I felt it was not very easy to come here and to play it.

V: No.

Klambra: I thought it was fun after I had done it.

Esja.: I thought it was great.

Klambra: I was pleased with myself.

Hanna: You can be that.

Klambra: I felt I had maybe not opened up as much in the sessions as many others. I felt maybe that this [her song/lyrics] was something mine instead. That gave me a good feeling.

(Group interview, SP II 004.)

Giving, delightful, fantastic, wonderful, deepening, thought provoking are terms Klambra uses to describe her experience. Having felt rather silent in the sessions and not having opened up as much as the others did she describes her songwriting as “unbelievable” giving leaving her with a good feeling about herself. And “the music gave the words five times more their own life” (SP II 004).

Once in a while throughout the semi-structured interview with each mother they referred to their songwriting experience, like Einræn does below, but two of the questions (#8 and #9) addressed it in particular: What are your thoughts about the themes which developed for the songwriting? What are your thoughts about the songwriting experience as such? Asked whether there was anything that stood out for her when thinking about the musicking the group did together, Einræn answered:

I feel it was when we sang the lyrics that had been made. Yes, I think that was the most influential maybe. Somehow it became more alive. Like the text became much clearer somehow or reached you better somehow (SP I 002)...

As I said before I believe writing the song was the biggest challenge for me and I think it did you good to accept this challenge (Einræn, SP I 004).

Like Klambra, who felt that the music gave the words five times more their own life and that it was not very easy to play her song for the group, Einræn talked about how the music gave the text more life as it became “much clearer or reached one better somehow.” She also talked about the songwriting activity as “the biggest

challenge” of her participation. All the mothers accepted this challenge and wrote one or more lyrics (from one to five) which they shared with the group. Five mothers wrote one lyric, one mother wrote five lyrics which she shared with the group, and one mother wrote two lyrics which she shared and others, which she only wrote in her diary, where she commented on them. Out of the twelve lyrics which were introduced to the group, four were only recited. Two were ‘painted with sounds’, the six other lyrics were both ‘painted with sounds’ and given melody. Two mothers created their own melody the researcher wrote the other four melodies. Appendix Q contains the mothers’ songs.

Participants	Number of lyrics shared/recited	Lyrics painted with sounds	Number of lyrics painted and sung	Two mothers created their own melodies	Melodies provided by the therapist
Hanna	1	1	1		x
Einræn	1	1	1	x	
Skonza	1	1	1		x
Kristjana	1	1	1		x
Esja	1	1	1		x
Góa	2	2	0		
Klambra	5	1	1	x	

As the tabular presentation of the above information shows, all the mothers participated in the songwriting to a greater or a lesser extent, both receiving from it and giving through it.

Thematic analysis of the mothers’ songwriting experience revealed that:

- The songwriting process gave structure and shape.
- Songwriting was a creative challenge.
- Songwriting was an enjoyable experience.
- Songwriting gave perspective.
- Songwriting honoured individuality and strengthened self-identity.

17.4.1 Songwriting gave structure and shape

Yalom (2005, p. 469) uses the term 'structured exercise' to describe an activity where a specific set of directions is followed. Structured exercise can be the central focus of a group or incorporated as a small component of a broader group intervention. This is regarded as 'an efficiency oriented accelerating device'. If successful, it can circumvent ritualized introductory social behaviour and speed up each individual member's work through techniques designed to help members connect quickly with suppressed emotions, or other unidentified parts of themselves. Particularly in brief group therapy format, they may be invaluable tools for both plunging the group more quickly into its task and maintaining its focus on it. Like Benson quoted above (2001, p. 31), Yalom stresses that if structured exercises are used it is important to keep their purpose in mind.

The following citations talk about the structured exercise experienced while progressing through the songwriting activity. Góa said:

Everything had been so free-floating until we sounded the lyrics. One could play with some image behind it. One tried to sound the emotion that was in the lyric (Góa, SP I 005)... The structure has floated onwards and when one thought that there was not going to be any structure then you always brought something. The first two sessions we were sounding very much and one thought this would be like that the whole time. Then you brought the whiteboard and it was not quite as easy and more into it [focused] and some meditation (Góa, SP I 008).

You gave us the freedom. We had the structure. But for me it was finished. I had read it and sounded it and then I had overcome it. And then maybe the following day something wonderful would happen (Hanna, SP I 005).

Songwriting is a way of creating music in a structured and articulate way and the process itself has within it an important order of time and a clear purpose, says Derrington (2005, p. 81). In the above quotes, Góa and Hanna talked about the flow, freedom and structure which was woven together from one session to another, allowing it to sway in rhythm with the needs and wishes of the mothers until the goal was reached and the music-making came to an end.

Working towards the goal, each session was structured in a known way with a songwriting activity as an exercise or a forward step in the progression of the songwriting. It was believed that the technique for lyric creation would be allowed to develop in the group based on individual and collective needs and

ability. It was anticipated that the songwriting would advance in stages, moving from themes, to words, to sentences, to phrases, to verses. Similarly the technique of music creation in the songwriting process was believed to develop in the group based on needs and abilities. That is exactly what happened. The organization of the longitudinal progression (see Part III: The preparation phase, section 14.2) provided a framework to follow. It was assumed that the needs of the mothers, the group process itself and other unforeseen elements would be the actual controlling factors influencing how the songwriting process would evolve from one session to another.

In the above quotes, Góa and Hanna are seemingly referring to this when they talk about the “important order” or structure that was inherent in the songwriting process itself as organized by the therapist. That is, how experimenting with instruments and sounds, free and structured discussions, sharing thoughts by writing words on the whiteboard, “painting feeling words” with sounds, etc. gradually developed – “floated onwards”, as Góa words it – and how the therapist “brought them something” to move them forward towards the goal. This something could be questions for thought or purely a verbal reminder of the common task. The mothers were not told how many songs they should write, what each song should be about, or how they should structure their compositions. Only very briefly were they informed about possible song structures, such as to write a chorus and verse/s, bridges or refrains, use collage technique, etc. Each mother found her own emotion(s), named it, described it through sounds, and gave meaning to it by making sure that the sounds told the feeling as it was.

“The melody did very much for the lyrics. They became more than just words. The melody gave them more feeling, more life” said (Skonza, SPII 004). Exciting as it was, it seems to have been vital for the group members to have both structure and freedom of choice while progressing through this creative challenge.

17.4.2 Songwriting was a creative challenge

“The act of creation offers a way forward into the future,” wrote Aldridge (1996, p. 233). Discussing different types of processes involved in music therapy (i.e. developmental, educational, interpersonal, artistic, creative, scientific), Bruscia talks about the creative process as a way of identifying, exploring, testing and selecting alternatives.

“For the client, this means solving problems and meeting one’s own needs through new, creative ways” (1998a, p. 35). Creativity is a process of discovery, of doing something new and enjoyable, free from old conflicts and open to new

challenges. For the music therapist working creatively this could mean searching for new methods of working and evaluation, and seeing fresh alternatives for the client (ibid.). Bruscia argues that the client's very participation in music therapy requires the creative process. Both therapy and the creative process involve the same or similar factors he says, namely: detailed examining of something, identifying problems and challenges, exploring alternatives and options, playing with available resources, trying out ways of problem solving, selecting pleasing options and finally organizing decisions into an outcome that is beautiful and significant. "The way sounds become beautiful and meaningful is through the creative process," he argues (1998a, p. 42).

Smyth (2002, p. 76) discusses creativity as central to the process of healing from trauma and as a way of overcoming helplessness. Creating something new is an act of defiance in the face of destruction. Ziolk (1991) encourages grieving parents to express their feelings through talking, crying, exercising, or engaging in creative work. She also recommends that reassurance and support be received from other grieving people. Dixon talks about the act of making music (particularly improvised music), as a process of creative interaction, and as a particularly intimate form of engagement between people (2000, p. 128).

The improvised songwriting method used in this research did not engage the mothers in writing one song together focusing on a central theme(s). Instead, they had the creative and challenging freedom to focus on their own issue(s). The improvised songwriting was, however, a parallel process and an interpersonal one through which each mother developed her own song(s), sharing thoughts, feelings and emotions prevailing at that particular point in time. The songwriting method was an intimate form of engagement between them as they shared in its making in various ways and through various media.

According to Csikszentmihalyi it is never easy to break new ground or to venture into the unknown. The pursuit of creativity is rarely easy:

It is impossible to accomplish something that is truly new and worthwhile without struggling with it. The less well defined the problem, the more ambitious it is, and the harder it is for the creative person to get a handle on it. ... When the challenges are just right, the creative process begins to hum, and all other concerns are temporarily shelved in the deep involvement with the activity (Csikszentmihalyi, 1996, pp. 117-118).

Being a somewhat new and challenging way of working for the therapist/researcher, it appears that songwriting to some extent was also challenging for the mothers. For Skonza the challenge involved both brushing up on an old ability and also knowing what to write about. She said:

It was challenging for me when I was making the lyric. I have not made a lyric for many, many years. It was challenging to do that again. It was a challenge in the beginning. One did not know what to write about (Skonza, SP II 002).

Klambra was fearful but did not know why. But she faced the challenge and felt good when it was done.

When I played my song, I felt it was difficult. To sing it was somehow, and I wondered why it was difficult for me. Why? But I felt it and I felt it was good to have done it and I felt it was a victory for me to have done it, a victory to challenge one's own fears and to win, to stand by oneself (Klambra, SP I 005).

It can be speculated that having each mother write her own song to "challenge one's own fear" was more difficult for them than having them write one or more songs together. On the other hand, a group approach, although perhaps less challenging, could have been at the cost of forfeiting each mother's voice.

As discussed in the theoretical part of the thesis, the concepts of positive reappraisal, confronting coping, escape avoiding and distancing have been used to explain how people react in painful situations. Positive reappraisal involves personal growth, which can be accomplished through being creative and finding new and important concerns in life. Confrontive coping involves fighting for the child's rights, taking changes, and finding ways to express feelings such as anger. Positive reappraisal and confrontive coping can lead to increased well-being. Escape avoidance, on the other hand (such as hoping for miracles, using food or drugs, avoiding others), is a negative coping mechanism that may lead to increased depression and spousal difficulties. Distancing oneself from difficult life events by behaving like nothing has happened or by trying to forget has also been associated with increased depression. (Lazarus & Folkman, 1991; Dunn et al., 2001).

The theory of inhibition developed by Pennebaker (1985, as cited in Barry & Singer, 2001) relates confiding traumatic events to negative health outcomes. Not sharing traumatic events (like that of losing the ideal child) is a type of

inhibition requiring physiological work which may become detrimental to one's psychological and physical health. Complex interventions are not always needed for restoring. Activities as simple as brief journal writing capable of providing temporal organization, increased understanding and sequencing thoughts and feelings have been associated with reduced psychological distress, decreased intrusive thoughts, decreased physical stress, and decreased long-term stress-related illness (Barry & Singer, 2001).

In the music-caring sessions the improvised yet structured form of songwriting was an act of positive reappraisal through which the mothers could share anything they felt like in a trusting and empathetic relationship. Challenging their fear and rediscovering their creativity through this songwriting process may have been instrumental in overcoming helplessness, arriving at new understandings and insights, and building a sense of self that was more secure and coherent.

What distinguishes creative individuals from the rest of us is their remarkable ability to adapt to almost any situation and to make do with whatever is at hand to reach their goals says Csikszentmihalyi (1996, p. 51). Solving musical problems can be conceived as similar to the process of resolving life problems says Bruscia and the skills learned through finding musical resolutions may well apply to life situations too (1998a, p. 43).

17.4.3 Songwriting was an enjoyable experience

In retrospect, the creative act of songwriting was not only giving, delightful, fantastic, wonderful, deepening and thought provoking, like Klambra said above. It was also an enjoyable experience.

It did take me by surprise how much it did for you and how enjoyable it was. Like Ö's lyric: *Now we are stuck...* One smiled in the berry picking. It is enjoyable to hear things like this. My lyric, this is what I wanted for myself and this is my contribution (Esja, SP I 010).

Perhaps worrying about her ability to engage in the creative act of songwriting, Esja was taken by surprise when she began to realize how much the activity did for her and how enjoyable it was.

Comparing an act of creativity to being in a flow, Csikszentmihalyi says that we do not usually feel happy while in it because when in flow we only feel what is relevant to the activity.

It is only after we get out of flow, at the end of a session or in moments of distraction within it, that we might indulge in feeling happy. And then there is the rush of well-being, of satisfaction that comes when the poem is completed or the theorem is proved. In the long run, the more flow we experience in daily life, the more likely we are to feel happy overall. But this also depends on what activity provides flow (1991, p. 123).

To varying degrees the mothers are inhibited from a flow experience in daily life. Occupied with worries concerning their children, uncertain about what the future might hold and inhibited in their new and often extreme parenting role they have no choice but to cope and learn to live with it. The needs of the child come first and foremost and the mothers (caretakers) may feel different from before with an identity that is undermined. Thus sharing knowledge, sharing experience and feelings, voicing fears and concerns is an important coping strategy (Dempsey, 2008, p. 33; Whiteman & Roan-Yager, 2007). Doing it creatively through systematic interaction with empathetic persons can produce flow experience and enjoyment of a caring and curing nature.

A song coming from elsewhere it is maybe different [from sounding the emotion] but it is enjoyable. Or I think so although you are not perhaps getting as much outlet in it. I would not have wanted to miss it. I felt happy with the song it fitted and I enjoyed singing it when we were singing it together. For me it served an amusement purpose because the emotion was not an issue for me anymore. I had got rid of it. And there was nothing else I felt needed to be expressed in that way (Hanna, SP I 006).

Referring to the melody created by the therapist for her lyric Hanna enjoyed singing her song together with the other mothers. Singing it served an amusement purpose. She found joy in a job well done.

Creativity can generate enjoyment, says Csikszentmihalyi. It involves the production of novelty and the process of discovery. "The process of discovery involved in creating something new appears to be one of the most enjoyable activities any human can be involved in" (1996, p. 113).

Based on research, Csikszentmihalyi describes nine main elements which were mentioned over and over again to describe how it feels when an experience is enjoyable (regardless of the activity that produced it). These are: 1. There are clear goals every step of the way. 2. There is immediate feedback to one's actions. 3. There is a balance between challenges and skills. 4. Action and

awareness are merged. 5. Distractions are excluded from consciousness. 6. There is no worry of failure. 7. Self-consciousness disappears. 8. The sense of time becomes distorted. 9. The activity becomes autotelic (1996, p. 111).

From the viewpoint of the mothers participating in this research there were relatively clear goals every step of the way. In a flow one always knows what needs to be done, contradictory to what happens at home where the demands and their purpose may often be unsure. Sharing their songwriting in the group the mothers always got immediate feedback on how well they were doing. Although songwriting felt challenging to some it did not exceed the skill they had for participating in it and receiving enjoyment from it. Busily cleaning the house or making dinner, the mothers' thoughts may evolve around worries about the children, important decisions to make, or information that needs to be clarified. In a flow, in the midst of creating something, our concentrated awareness is actively focusing on the task at hand. Sharing in the here and now, enjoying "singing it when we were singing it together," as Hanna worded it, excludes worries and other possible distractions from the mothers' consciousnesses, distractions which in everyday life may cause and be caused by various anxieties.

Even though challenges had to be faced in the songwriting process there were no actual fears of failure expressed. The reason for this is that when in flow we know what needs to be done and we rest certain in our ability to carry out the task. In the new and often very strenuous role as a caretaker of a special needs child, parents are burdened with the challenge of trying their best to care for their children, and anxious to make a favourable impression on family and professionals alike. The caretakers' identity changes due to this and they may experience self-doubt and loss of confidence in who they are. Paradoxical as it sounds, forgetting themselves or stepping out of what confines them may actually expand the self. It may give the mothers a chance to revise their sense of themselves, forging a new identity. In a flow, time becomes irrelevant or the sense of it becomes distorted. A songwriting hour may feel like a passing moment or lasting for half a day. Like Góa wrote in her diary: "The session this morning was so interesting that time basically flew on. ...I wish I could have stayed longer, I felt it was boring having to stand up and to say goodbye."

In an existence where so much revolves around time, forgetting time and its boundaries may contribute to the perception of joy when in a creative flow. Skonza described how she forgot time and place and herself in the music in the following way:

I think it is difficult to choose. I thought it was terribly good when we were doing the lyrics. When we were singing them and sounding them. I also felt it was very good when we were sounding us together. I do not know. It is a little difficult to choose between what was best and what was the most difficult. When I was playing I completely forgot myself while doing it. The sounds came to you and one somehow went on a different plane. I completely just forgot myself and when it progressed one became introvert, listened to the music and played fully. And it was very comfortable. One forgot time and place and forgot oneself in the music (Skonza, SPII 004).

The last factor Csikszentmihalyi mentions (1996, p.113) when describing whether an experience or an activity is enjoyable is when it becomes autotelic or an end in itself. An activity producing most of the above conditions is such an undertaking. Challenging as it was, the mothers participated in the songwriting activity and learned to do it in the way that best suited their own needs. While doing it, they resided in an enjoyable creative flow conducive to a happy life.

17.4.4 Songwriting gave perspective

Feelings change from one moment to another and one's capability to sort them out, accept them or adjust to them is a challenging task which can depend on many factors, including beliefs and attitudes about disability and illness, available support, spiritual beliefs, and expectations about parenting (Ragnarsson, 1997; Whiteman & Roan-Yager, 2007, p. 52). It is a common behaviour to want to get rid of painful feelings as quickly as possible, "filing them away for a less busy day that never seems to come," as Whiteman and Roan-Yager word it (2007, p. 49). Much of our energy is thus spent on ignoring or trying to get rid of these feelings without examining them and exploring what our feelings may be telling us. Acknowledging one's feelings, shaping them and sharing through the songwriting process gave perspective that was instrumental for awareness and understanding.

I think of my feelings about my daughter like a skein of yarn with many colours, all twisted together. I feel them *all* at the same time – sadness, anger, joy, acceptance. I don't have to choose one feeling (as cited in Whiteman & Roan-Yager, 2007, p. 48).

These are the words of a mother of young adult woman with severe developmental disabilities commenting on linear and discrete emotion stages of adjustment often used to describe how people may adjust to adversity such as

learning that your child has special needs. Limited as they may be, linear models provide a framework allowing one to put feelings in a context and to realize possible movement and progress. The quote above supports the decision of not choosing one or more central themes for the mothers to work on in their songwriting, but instead allowing the mothers to write about feelings or issues that for them were the most prevalent. Like Skonza said:

Writing the lyric helped me get through the stress I was dealing with at this time. It helped me realize what was most important. And to work through this stress helped you to get a grip on the feeling. Everything became clearer. The stress that had been building up sailed away (Skonza, SPII 006).

Giving the mothers this freedom of choice provided them with an educative perspective instrumental in helping them to realize possible movement and progress, as the following quotes exemplify:

One could find in all the poems something that one had experienced or a feeling one had felt (Skonza, SPII 005).

Superwoman [one of Klambra's poem] and Einræn. I understood the feeling although I cannot imagine how terrible it must be. This teaches you so much about life. To get to know people and to hear their feelings and in the process you learn to know yourself better and your own feelings (Hanna, SP I 006).

In her songs, Klambra expressed both feelings and wishes with these terms: anxieties, sorrow, worries, fatigue, standing up to challenges, enjoying life, exploring colours, learning new ways, finding peace, and letting positive thinking in. Kristjana sang about invisible strain, endless waiting and torment, and the importance of being able to name feelings and having someone who listens without criticising. Hanna sang about her tiredness. Góa's poems voiced her intentions to manage insecurity fear and anxiety. Einræn sang about the sorrow and torture she experiences watching her child's pain. Skonza's song expressed her fatigue, worries, fear, guilt and the stressful life that burdened her. She also addressed the fleeting precious moments with her child. Esja sang about living in the present, about all the good things she hoped for and her life's philosophy:

I have been there where everything is so difficult and miserable. I am not going to stay there anymore. The only thing I can do is to work with myself and that is what I wanted to tell in this poem. When I went to these sessions I

wanted to fix my shortcomings. I am in my situation, in my life and if it is miserable the only thing that can change that is me; because, most of these situations are uncontrollable. I cannot change my daughter's disability or fix my mothers' problem. ...And I felt it was very good to hear this from Kristjana, – endless torment and difficulty and things like that. But I am so happy. I felt it so clearly when I heard her poem. It had left me and I am not going to stay there anymore. Like they teach in Al-Anon, the only person you can change is yourself. Like [Icelandic troubadour] KK says: "Stop talking about others, think about you." And in this poem I wanted to do this. You see, I have all sorts of shortcomings. I am what I live, see and tell. One is what one thinks, it is just like that. And by seeking inner strength, then one can better deal with this. Truly misery can be a choice. I have been in misery and I do not want to be there anymore. To hear Kristjana felt so good and also what Hanna said, that she was sometimes so tired. I have been there. Everything they shared, everything they brought to this tray it was helpful to hear it. Both the things you had yourself experienced and also those things that you had not yet but will later (Esja, SP I 009).

Discussing premises influencing therapeutic approaches in helping individuals dealing with nonfinite loss and grief, Bruce and Schultz (2001, p. 70) stressed that the grieving process would involve cyclical themes of yearning and searching, protest/demand, defiance, despair/resignation, and integration as well as anger, bitterness, and sadness. Esja "had been there" and it was helpful to hear about all the different themes "the things you had yourself experienced and also those things that you had not yet but would later," as she worded it. She was not going to stay "there" anymore. Having lived through the initial shock, and the multifarious feelings accompanied with disorganization, Esja had reached the phase of resolution where, according to Blacher (1984, as cited in Flagg-Williams, 1991, p. 240), the task is acceptance or adjustment.

17.4.5 Songwriting honoured individuality and strengthened self-identity

In the literature, 'identity' is defined in different ways, without general agreement about how to do it. The different definitions do however distinguish between the personal and the more social identity. Personal identity refers to an individual's unique qualities, ideals, attributes and personal history and is sometimes differentiated further between the private and the more public self. The private self is the self that only you know, your own desires, aspirations, and

beliefs about yourself that you may or may not wish to communicate with others (Crozier, 1997).

“There were certain things one did not want to discuss with everybody,” said Esja. “Like I was saying in the last session. One would have wanted to discuss some things privately” (Esja, SP I 001). In her poem *Likn (Care)*, Góa wrote: “We tend the wounded yet avoid something want to stay alive.”

The public self refers to the person you present to others, the ‘you’ that others know. In some sense, identity then refers to an individual’s particular combination of personal characteristics, such as name, age, gender, profession, or traits that distinguish people (Crozier,1997).

Social identity is a distinction sometimes used to refer to the social categories to which people belong, aspire to or share important values with. Social identity is an important determinant of relationships within and between groups. From this perspective, “identity refers to a person’s consciousness about ‘being the same’, the experience of continuity, and about being unique from others” (Crozier,1997, p. 71; Ruud, 1998, p. 35). Erikson wrote: “The conscious feeling of having a personal identity is based on two simultaneous observations: the perception of the self sameness and continuity of one’s existence in time and space and the perception of the fact that others recognize one’s sameness and continuity” (Erikson, 1968, as cited in Ruud, 1998, p. 38). The shaping of our identity is from this perspective a developmental process, something never completed. Seen from a humanistic perspective self as used in this research refers to “what I feel and think about myself” or my own person, “the very me” (Ruud, 1998, p. 35). It includes both the evaluative aspect of the self as self-esteem and the more cognitive processing of the self-concept (ibid.).

What happens when the sameness is felt no more and the continuity of one’s existence is interrupted with unexpected challenges associated with different themes where earlier parental experience doesn’t suffice? It can be speculated that to a lesser or greater extent both one’s personal and one’s social identity changes. With the birth of a baby with special needs the feeling of self-sameness and continuity is distorted. The caretakers may lose themselves while fighting for the child. Putting their own needs last takes its toll and as the years pass parents may even become unclear about what they want, where they are heading and how they can get there. Various feelings and stress factors related to parental functioning may set in: lack of competence, feelings of inadequacy, social isolation from peers, relative and other emotional support systems, deterioration

in parental health as a result of parenting, feelings of being controlled and dominated by the child's needs, depression due to dissatisfaction with self and life circumstances, lack of physical or psychic strength to fulfil responsibilities, inability to be assertive or authoritative enough, and more. The new parenting role restricts and frustrates when attempting to maintain identity.

As discussed earlier, the demanding job of taking care of children with special needs may for various reasons change the caretakers' identity when, among other things, they experience self-doubt and loss of confidence in who they are. An opportunity to step out of what confines them may give them a chance to revise their sense of themselves, thus encouraging development of a stronger self-identity. It can be stated that within the music-caring group, the mothers had various opportunities to present both their personal and their social identities in different ways. Skonza said:

I think it works better that way to do it yourself. Then it is your own words and emotions that you put on paper, rather than when the whole group is working together. That would have been different. Then perhaps someone could have become silent and withdrawn just following others and not being able to express what she felt like. That is the danger when done as a group experience (Skonza, SPII, 002).

Skonza felt the songwriting method used in this research supported her personal identity by allowing her to honestly present her public self. Writing song(s) together as a group may have silenced some who could not have expressed how they felt like Einræn said:

I believe one is better able to bring forth one's own issues if you do it alone rather than doing it as a group (Einræn, SP I 004).

Góa agreed and thought that their [the mothers'] way of doing it was the only right one:

I think that our way of doing it is the only right one. If mixing together I believe it would have been thin somehow. Coming from different individuals one holds back and flattens oneself out to a common level instead of each one being allowed to express herself and to have different types. ...There are many different ways but I think it is necessary that each one of us does this for herself. One possibility would be to do it together when you have done the other thing. The poems are personal. Also one listens to the poems of

others and they are all different so one gets more out of it. You know instead of one poem that all have made together. Also the form of the poem is special for each one (Góa, SP I 006).

Góa realized that if all the mothers had shared in the making of one or more song lyric “it would have been thin somehow.” In one way or another, it would have constrained their creativity and individuality to a “common level” instead of allowing each one to express herself. Doing it their way gave them a conscious feeling of having a personal identity, and the possibility to share personal meaning from which they all could learn. Then later perhaps they could “do it together when [they] have done the other thing.” Interestingly, she also stated that the “form of the poem is special for each one.”

Hanna agreed with Góa, noting:

A theme is about what you are dealing with so it is the truth. A central theme would not have been from the heart. I think it was exactly what each one of us needed. I am dramatic and I wrote about exactly what was going on in my life there and then and which I had not been able to get out of. And for me when I had done it, and I read it out loud and sounded it. That for me finished it. Then I enjoyed hearing it. The others brought something else. Some are perhaps stuck in something they feel bad about and can't get rid of and then it is so genius to write it and try to express it that way and get rid of it and then I felt it was good because I became a participant in it. That is healing yes, because we are so different. I mean, we worry about different things and then the characters are so varied. Some are very pessimistic or have worries or maybe the issues people are dealing with have to do with the disability (Hanna, SP I 005).

“The others brought something else,” said Hanna. “And then it is so genius to write it and try to express it that way and get rid of it. Then I felt it was good because I became a participant in it.”

Kristjana also felt that she had participated in the other women's poems:

It is clever to get many poems. Each poem reflected the personality. I could find myself in their shoes but I also felt it was theirs. The poems are theirs but you are part of it because one has talked about it and has participated in it. Or you know when they were created. So they do not own it alone you know, but nonetheless it is theirs. The tiredness was there and I believe we are all tired. They were different but I think one could find everything in them. Was there any happiness? It was the only thing that did not appear on

the whiteboard. You know sometimes there are fun and positive feelings connected to it. Perhaps we would have needed more time. First we dig into the difficult things, the emotional things, and then we would have wanted to talk about the positive sides (Kristjana, SP I 009).

According to Day (2005, p. 86), it is essential for a group to “have as much choice in the creation of their songs as possible” to ensure that all feelings and thoughts are represented and acknowledged within the songwriting process. Being a participant in the process seems to be a necessary condition for the development of an identity. Josselson wrote:

Although identity is in part distinct, differentiated self-hood, it is also an integration of relational contexts that profoundly shape, bound, and limit but also create opportunities for the emergent identity (Josselson, 1994, p. 89 as cited in Ruud, 1998, p. 39).

In various ways throughout our lives music helps to construct our sense of identity, both personal and social, and as such it is an “active ingredient in the care of the self,” says DeNora. “Music is a resource – it provides affordances – for world building” (2000, p. 44).

Being with each other, reflexively rediscovering their uniqueness, and sharing it without shame or fear of being different, “becoming more fully themselves in relation” to perceived sameness and continuity, created opportunities for the mothers to rediscover and develop their self-identity (Josselson, 1994, as cited in Ruud 1998, p. 39).

Eriksson (1968, as cited in Ruud 1998, p. 41) also emphasized how one’s identity not only concerned the “core” in the individual but also had to be sought in one’s communality with others. Becoming more fully themselves in a relationship which provided a feeling of sameness and continuity, the songwriting activity honoured the mothers’ individuality and strengthened their self-identity.

Just as the songwriting activity was instrumental in strengthening their self-identity, it may also have been instrumental in it becoming more flexible and coherent. A flexible identity composes and adjusts a personal narrative in accordance with how life is perceived and lived. The concept of self entails awareness of feelings, agency, belonging and meaning, and creates a strong identity.

You have become stronger when you realize who you are and what you need and what you want. So the journey has done me good. It has made me stronger (Esja, SP II 002).

17.5 Procedures for creating the music

In part III of this thesis (section 14.4) the vertical session structure centred on songwriting as the primary therapeutic approach was described. The songwriting was planned as follows: a songwriting activity would be a step in the progression of the songwriting process. The technique for lyric creation would be allowed to develop in the group based on individual and collective needs and abilities. It was anticipated however that the songwriting would advance in stages, moving from themes, to words, to sentences, to phrases, to verses. The technique used for lyric creation in this improvised yet structured exercise resembled different techniques identified by Wigram (2005, pp. 258-260), in particular therapeutic lyric creation, guiding free brainstorming, selecting words from a list of words, client writes a poem, and structural reframing.

Similarly to the technique of lyric creation the plan for the music creation in the songwriting process was that it would be allowed to develop in the group based on individual and collective needs and abilities. The horizontal structure of the songwriting process (described in Part III, section 14.5) in sessions eight to ten was planned as follows:

- A. Music is created and rehearsed. It could be a word painting technique where music is created that represents or describes the general mood, an emotion or an image of a word or a phrase.
- B. The music is graphically notated by the mothers and the researcher.
- C. The 'song creation' is performed and recorded.

As listed above, twelve lyrics (poems) were recited in the group. Of those twelve, eight were 'painted with sound'. Six lyrics were both painted and sung. Two mothers wrote their own melodies. The therapist composed four melodies. The songs were rehearsed (performed) and recorded in the last two sessions. In the group interview (session eleven) the mothers listened to the CD the therapist had made with recordings of their songs and some examples of their various music making in the ten music-caring sessions (all the sessions were recorded on a minidisk).

As anticipated, the lyric creation developed based on the mothers' individual needs, i.e. not as a group project centred on one or more collective themes. Sound/word painting technique was also used for all the mothers (eight poems) to portray the general mood, an emotion or an image of a word or a phrase (Davies, 2005, p. 51; Wigram, 2005, p. 260). When sound/word painting their poems, the mothers chose an instrument(s) and a player(s) who they felt would "tell the emotion as it was" (Esja, SP I 003).

In the following quote, Esja described her experience of sound/word painting. Asked to identify what it was in the music-caring experience she felt was particularly helpful, she replied:

I would of course say it was sounding the paranoia. When you disbelief in yourself then this paranoia is so terribly bad. One feels you have not done [something] correctly enough or spoken correctly enough. Then I felt very good saying goodbye to it with sounds. Also this to sound the optimism and that I felt was very good. The emotion was expressed, or it was yes you know the dark sounds told how it is. You know it was interpreted, it was not just told with my words; it was told how it is. The piano and your sounds expressed that it is dark like this, and that described it so well. Yes, just the sounds tell you know how the heaviness is on your chest when you get it. And just by hearing it and, it is perhaps similar to when you write the feelings on a paper it has been shaped into this form. The emotion has left you a little – has gone away from you a little. And the form, you know, the sound was just very good and described it perfectly (Esja, SP I 003).

Góa was the only woman whose poems were not sung. An attempt was made to graphically notate the sound painting of her poems. It was a trial that worked more as a register, listing what instruments were used rather than showing how Góa wanted the group to play them to express her poems. The therapist/researcher worried about not having been able to write music for Góa's poems. Thus Góa was asked in the individual interview about her thoughts regarding that. Góa replied:

In the beginning I felt that it was lacking a melody and I did not want to press you to make a melody, do you understand. I was thinking about humming something myself into a cassette. I thought it was just exciting to go and come up with something, to just go home and do something like that, more amusing. But then nothing came of it. It would perhaps have become a terrible mess-up. Then just nice I felt, in the end just very acceptable. I do not

hold any ill-feeling towards you for having left me out, but then it was maybe, yes I do not know maybe it was not quite [acceptable not having got a melody or perhaps not suitable for a song]. Because there were irregular and lengthy lines and I enjoyed sounding it. I would not have wanted to miss that either in fact because then I started maybe to try to do it with care, to express it with sounds – to tell something (Góa, SP I 007).

Asked to compare the two methods, i.e. to sound paint the poem and to turn it into a song by giving it a melody, Góa said:

You see I think it is because we had been sounding so much in the sessions just jamming really. The other thing, to make a song, it was like a variation. We could say it was different, like certain finality. The other thing was more like we had always been doing. But you see both have their importance. But the song is more educated. ...Yes not necessarily better you see but **not worse** [said with an accentuated voice] (Góa, SP I 007).

On 18 November 2006, Góa wrote in her diary about the same issue:

The session this morning was amusing. There was lot of singing and talking and Valgerður had made songs to many of our poems. It turned out to be very good, and it was joyful to sing these poems because somehow they gained another life by doing that. I would like a little bit to try to compose music for my poems, but I do not know if I can do it. I felt this morning that the poems needed formal songs so it would be possible to sing them, because I saw how much it did for the other poems.

It seems that Góa had ambivalent feelings regarding not having had her poems turned into songs. She felt that both methods were important, but that a song did a lot for the poem. It was more educated and represented a closure - a finished task, as she worded it.

Other than sound painting the poems, the procedure for creating the melodies had not been carefully thought through. As it turned out, both lack of time and lack of experience influenced how it was done for Esja's, Hanna's, Skonza's and Kristjana's songs. They had read their poems in the group. The poems had been sounded with instruments by players they chose themselves. After having been presented in this way the therapist/researcher took the poems home and between sessions she composed music herself that she felt matched the lyrics. In the following session the therapist presented her melodies by

singing them for the mothers with a piano accompaniment. Then the mothers were encouraged to join in the singing. Afterwards, the mothers were encouraged to voice their opinions regarding the melody, whether they felt it fitted their poems or if they wanted it to sound differently. The mothers could neither choose between two or more melodies they felt best fitted their poems, nor could they discuss a preferred musical genre, accompaniment styles, instrumentation, harmonic progression, dynamics, or tempo. Although encouraged to voice their opinions about the song, it can hardly be said that the mothers had an opportunity to contribute to the piece of music as to ensure a greater ownership of the completed song.

Hanna expressed herself regarding this experience in the following way:

It was enjoyable. I felt it was enjoyable to get a song. In fact, I also enjoyed sounding the emotion. Sounding it is more your own, you put everything you can into it. A song coming from elsewhere is maybe different but it is enjoyable. Or I think so, although you are not perhaps getting as much outlet. It is very amusing to sing your own song. It is very amusing. To sound it was perhaps more mine somehow – to get rid of it. But I would not have wanted to miss getting a song. I was right away happy with the song. I felt it suited the poem and it was enjoyable to sing when we were singing it together (Hanna, SP I 006).

Like Hanna said, sounding the emotion was more her own. A song coming from elsewhere was different because one did not get as much outlet when singing it. Nevertheless, she felt that the melody fit and that it was enjoyable to sing it together with the others.

A melody to Kristjana's song was introduced in session #9 when she was absent due to work. It was presented to her in session #10 with the addition of some drums suggested by one of the mothers. Kristjana felt that being able to sing and play the poem did a lot for it. Somehow it sustained it and fastened it in a certain mode. "If you have a gentle sound then you have a gentle poem" she said. "If you have a strong sound, then you have an aggressive poem. Then it has been decided that the poem is like that, because sounds give a certain feeling. There is happiness and sorrow in sounds etc. So it has pros and cons and I think that it does not always fit." (Kristjana, SP I 011). Although Kristjana felt it was an enjoyable experience to get a melody for her poem, her experience was somewhat different from Hanna's.

About my song, I felt it was a little and I thought, yes is it like that? Is it so much anger? I had not myself realized that. I did not write it down with so much anger necessarily. I did not write it down with any particular music in mind. But I felt it did fit. I think I would also have felt it fitted if it had been [a] mellower [melody] (Kristjana, SP I 011).

At first, the melody that had been composed for her poem surprised her, but when she heard it again she felt it was okay. In fact, she felt that whatever would have been done it would always have surprised her at first. Kristjana felt it was a strange experience to hear music to something she had written, but she felt it had not turned out badly. The music gave the poem something new as it became a bigger statement. The music added colour to it. At first she thought it did not sound like it should, because she did not think of her poem as “something important”. Then she started to listen to it closer and upon reflection she thought it was actually like that. To “fasten it” and make it more permanent that way, was an important part of the “treatment” Kristjana felt. Not something just said, finished and then gone and forgotten. “Yes,” she said, “I believe we could not have skipped that” (SP I 011).

To the therapist’s/researcher’s ears, Kristjana’s poem was important. There was pain, anger and frustration in it, which needed to be acknowledged and sounded with no fewer colours than the sorrow and pain in Einræn’s song. They were “sisters in arms”. Perhaps restraining herself emotionally, because in comparison with some of the other mothers and in comparison with what was happening around her and at work Kristjana felt she “did not have such bad cards at hand.” However, Kristjana wrote in her diary when caught in a conflict between work and her duties at home: “I wanted so badly to scream out of the window ‘I cannot carry on any more!’”

Rolvjord (2005) describes three basic techniques she uses in her songwriting method for creating melodies: Therapist creates melody between sessions. Therapist creates melodies within the therapy session. Therapist and client improvise melodies together. Rolvjord stresses that when the therapist creates melodies between sessions, suggestions from the client need to be taken into consideration and that the song should be presented as an idea that could be further developed or rejected. Considered from a positive point of view, melodies created by the therapist in this way could be experienced as a confirmation of the collaboration and the therapist’s commitment in the therapeutic process:

When the therapist creates the song out of the poem, she also shares some of her responses (interpretations, associations and emotions), as expressed in the music with the client. Such an emotional relational experience might be very useful for the client in order to achieve contact and insight into his/her emotions (Rolvsjord, 2005, p. 102).

Memos the therapist/researcher wrote after session #9, on 11 November, voice her thoughts about writing the melodies and finishing the songwriting task:

I felt unusually anxious before this session. At home I had worked on writing melodies for the poems that they had already presented. It took me a long time because I worried about them not being good enough and lacking decent arrangements. I made a melody to Hanna's poem because she had not wanted to paint it. She felt the melody fitted nicely. Perhaps I did not give her any choice. Would they have asked for another melody or criticised the one I gave them? Esja felt that the melody I wrote for her poem worked. The lightness in it was to her liking because she said she was so tired of always being pessimistic. We also sang Kristjana's song although she was not present. We have to repeat it in the next session and sing Skonza's song if she brings a poem. I felt I used the session relatively well to practice the songs. Klambra brought two new poems. They were brilliant. I feel she has discovered a new talent and an interest that she will continue developing when we finish music-caring.

Skonza sent her poem in an e-mail between sessions #9 and #10 so the therapist/researcher managed to compose a melody which was introduced in session ten. Skonza felt that the songs did very much for the poems. Somehow they became elevated with more feelings than word alone could convey. Skonza thought that the song she got fitted the poem very well and that Góa's suggestion to include bells and tinkles was a good idea, as it made the song livelier (Skonza, SP II 004).

The two mothers who composed their own melodies were those who had the most experience with music. One is a piano teacher and the other has sung in a choir for some years and also knows how to play the guitar. Expressing herself about the songwriting, Einræn said:

Because they were discussing the fact that I had a music education sometimes I felt that was bad. You were somehow expected to do well. In connection with composing the song I felt myself I had to do it. I just had to do it and for me that was perhaps the biggest challenge. I worried about it in the beginning

and felt that I would not be able to do it and I felt it was not good enough. But then after I talked to you and you looked at it with me I felt better. And when you had sung it with me then it was different from when I had been trying to write it (Einræn, SP I 001).

Talking about Einræn's song, Góa felt that the melody drew her attention to the emotion, the sorrow and the pain, which was sung on the highest tone. Maybe her attention had not been focused on the lyric well enough, Góa said, but when they sung it together then she focused differently and she realized how the melody emphasized the content. The poem gained a new life. "Because we did not make the poems together then we were united when the poems were sounded or sung" (Góa, SP I 007).

When singing their songs the mothers at times suggested using some instruments along with the piano or the guitar accompaniment. This can be heard in Skonza's song for example. Góa suggested to Skonza that the group play along on bells and finger cymbals and Skonza accepted her suggestion. Góa's last words in her diary (Day 93, Monday 11 December 2006) were: "I hope that the bells in Skonza's song do not overshadow the poem. If so I will die of shame."

Klambra also composed a melody for one of her poems. After session #7, she wrote in her diary:

I sang my poem today with a guitar accompaniment. It was not very easy. I heard how my voice echoed my insecurity. Afterwards I felt it had been a victory for me. An 'original' song was of course just chanting with easy chords on the guitar something borrowed from many other songs. But it was okay: I am sure no one expected anything great. While singing I was thinking why on earth I was so stressed. Wasn't I situated in a soft cotton nest with lot of wonderful women whom I trusted? It is strange this insecurity which engulfs one. I hope this will be regarded as a worthy trial on my behalf because I have perhaps not been as free spoken as many of the others. At least I feel I have done my share. A good feeling. ...

Klambra's final words in her diary were:

Magnificent and wizardry when we wrote words on the whiteboard. A brilliant finale when Valgerður set music to the poems. They became many times stronger. The experience of creation flew over waters, giving and enjoyable. I personally also gained very much by composing my own song and playing it. Lastly I say: Thank you for a marvellous time together.

Baker and Wigram (2005) stress that the therapeutic effect of writing a song “is brought about through the client’s creation, performance and/or recording of his or her own song. The role of the therapist is to facilitate the process and to ensure the client’s ownership of it by being true to his or her own personal needs, feelings and thoughts (Day, Baker & Darlington, 2009, p. 134). Klambra’s words eased the therapist’s/researcher’s worries about having neither enough time to work with each mother on her melody, nor having done a very good job composing the melodies for Hanna, Skonza, Esja and Kristjana.

17.6 The CD

The music-caring was impending closure. The final task was to rehearse (sing and play together few times) and to record the songs. This was accomplished in session #10. Between sessions #10 and #11 the therapist/researcher listened to minidisk recordings of all the musicking done in the ten sessions. She compiled samples of it on a CD, which also included the six songs which were sung, three poems which were painted with sounds and three other poems which were only recited. The content of the accompanying CD is listed in Appendix S. In session #11 the CD was played for the mothers and a copy was given to them as a memento of their time together.

In their first music-caring session together, the mothers had been told that their recorded song creation could be kept, performed repeatedly and shared with others. The songwriting experience would thus, figuratively speaking, carry on beyond the music-caring group. From that point of view, the importance of the songwriting would not only be connected with relations which would evolve in the process of its making or the song itself but also its use within and beyond the music-caring group.

The recording or the use of the CD was not addressed in particular in the interviews. The mothers were only asked if they had listened to the CD between session #11 (the group interview) and session #12 (the individual interview). Nevertheless, to varying degrees the mothers referred to the CD and how they felt when listening to it. When talking about how she felt when the music-caring was coming to an end, Skonza said:

It had become cosy and joyful. The only thing I feared a little was to lose contact with them. I did not expect it would have enormous effect on me but just some effect maybe. I listen to the CD a lot at work. I have been thinking so much about them and about you. I did not think it would affect me so

much in the end, that I would miss you as much as I in fact do. It is terribly good to listen to the CD. You know, one goes back and feels good. Yes it is very comfortable. One somehow gains peace in one's heart, you know. Yes one somehow feels better. Maybe I cannot explain it well enough. It was somehow always when the sessions were over, one felt peace and some relief and one felt a lot better and you know it comes back when you listen to the CD (Skonza, SP II 003).

Einræn who also had listened to the CD, felt: "When listening to the CD one senses a feeling of gratitude for having been allowed to take part. This somehow comes back to you when you listen to the CD" (Einræn, SP I 003).

Esja had not listened to the CD between session #11 and #12 (the group interview and the individual interview). Asked about it, she answered that at home there was no peace and that she needed to have it in the car to be able to listen to it. But listening to it in session #11 surprised her.

I was very surprised what it was one heard. It sounded differently from when you were making the music and I felt it had a soothing effect. I was thinking about the good effect it had because one went into a trance somehow, especially with the sansula (Esja, SP I 001).

Góa hadn't either listened to the CD again. Hearing it in the group for the first time she felt was both special and surprising because she had not realized how it would be put together. "There was so much material on it. I do not understand why I haven't listened to it" (Góa, SP I 004).

Asked whether she had listened to the CD between the interview sessions Hanna replied in the affirmative. The therapist/researcher complimented her for that and later in the individual interview she was asked about how it had been for her to do that.

I felt it was so cosy. It was in the background. It was like I had somewhat finished the emotions but this was nonetheless enjoyable. It is because it is connected to good memories (Hanna, SP II 004).

Asked if there had been any particular memories that were awakened, Hanna replied:

Maybe mostly enjoyable to review the songs because you forget them, in fact. You know, I have forgotten them again in fact. You are always hearing

some music. You had started to learn the song quite well but then if you do not hear it then you lose it. ... I am quite certain I will have it in the background (Hanna, SP II 004).

Klambra had not listened to the CD again. She felt that some time needed to pass before she would do that and she did not feel she could do that quite yet. However, she acknowledged it needed to be done before too long: “One has to be fresh when doing it” (Klambra, SP II 007).

Kristjana who also had not listened to the CD again, felt that although some things sounded a little strange, the CD sounded better than she had expected. “Yes, but I felt it was unbelievable what came out of this and that there were songs that came out of it” (Klambra, SP I 008).

The CD, a tangible product, was proof of a completed task, a memento capable of preserving the emotional tone of the music-caring group. As such, the mothers could use it to validate their emotional journeys (Baker, Kennelly & Tamplin, 2005, p. 127).

17.7 The therapist

Besides a unique theoretical foundation, every music therapist is endowed with an individuality in which the psyche and the soul of the work is contained, wrote Kenny (1989, p. 8). While contextualizing this research from the personal and the professional stance of the therapist/researcher, thoughts were shared concerning the belief that in music therapy, as in other helping relationships, it is this individuality, the uniqueness of those involved, and the uniqueness of the whole that sets the foundation. After years of clinical work, it had become clear to the therapist/researcher that a caring attitude, her need to help, her intuition, communication skills, attitudes, affection and respect for the client was as significant for the positive outcome of therapy as the underlying theories or methods. Furthermore, it had become evident that the client’s perception of the therapist’s attitude towards him or her as a whole being was equally as important, if not more so, than her theoretical framework or the therapeutic methods.

Also, as stated in the introduction of this thesis, the therapist/researcher believed that in order to be true to her research intent she needed to be available for the mothers, recognize their uniqueness by listening and responding to them as valued members of the group and, through individualized concern for them, aim to elicit positive feelings such as trust, comfort and security. Furthermore, using the applied method, she needed to ensure that the mothers were given

ample opportunity to express their personal needs, feelings and thoughts. All she could hope for was to provide the mothers with a rich and positive experience that would address their needs in some way, and by doing that, learn from them in various ways.

Mitchell-DiCenso (1996, as cited in Conner & Nelson, 1999) recognized a caring personality of a helper as an important domain in parent satisfaction. Parents themselves report that caring, sympathetic, emotional, physical and spiritual support an opportunity to talk and to be heard, an opportunity to show feelings, an effort to make parents feel better and to feel accepted, and being given enough time, are all favourable approaches to care influencing perceived satisfaction (Able-Boone, Dokecki, & Smith, 1989; Baas, 1991; Blackington, & McLauchlan, 1995; Jacano, Hicks, Antonioni, et al., 1990; Kenner, 1990, as cited in Conner, & Nelson, 1999). According to Riemen (as cited in Halldórsdóttir, 1996, p. 11), three themes identify a caring therapist-client interaction. They are:

- 1 An 'existential presence', or being available for the client.
- 2 A recognition of the client's uniqueness by listening and responding to the client as a valued individual and a human being of value.
- 3 An individualized concern for the client that results in him or her feeling comfortable, secure, at peace and relaxed.

Perhaps the clients' perception of a caring, sympathetic, accepting and supportive therapist, a therapist who the client feels makes a real effort to make him or her feel better, are the elements which effective therapeutic relationships have in common. It is the general helper characteristics and facilitative traits, and in music therapy they colour the way music is used and influence its effectiveness in the therapeutic relationship.

As discussed in chapter 13 of this thesis, there was neither a manual to follow on how to perform music-caring in this context nor information available on what type of musicking would best support a music-caring experience. Thus, the therapist/researcher prepared as well as possible before implementing the music-caring sessions. Each session was pre-planned and written in an outline form as a manual that could be followed step by step. As it turned out, the plan did not hold and the therapist/researcher had to rely on her intuition and creativity, often acting on the spur of the moment. In the research interviews, the mothers talked about leadership style and the therapist's qualities that they felt were conducive to a successful group. Asked about her thoughts regarding ways

of leading a group, Einræn said she realized that the degree and ways of leading a group was a matter of opinion, but that for her it was important to be allowed to be herself, to decide for herself whether or not she would express herself (SP I 007). Referring to this therapist/researcher's character or stance, "something which all conductors needed to have" (SP II 004), Klambra said:

The director is unique, giving and understanding and unbelievable sensitive. [The name] Valgerður must mean well made or the one who does well. You are not a psychologist but so sensitive and ready for it (Klambra SP II 003).

It matters who conducts a group like this. I think it is very important. One needs to be pushed a little bit, because there are some activities and it is expected that you participate. But one has complete freedom to set the limits oneself. One cannot be totally passive; but this calmness and tranquillity that you have is a very good quality. This deliberate or reflective calmness has such a good effect on the group. You open up for everything. Although you have everything very well shaped and thought through in your mind or on paper, then you also know how to act on what is going on. That I think is a good quality, not having to finish the programme just because you had thought it through in a special way. ...This ingrained sensitivity that a conductor needs to have and that perhaps few have. To be able to inspire the participants, I think that is something invisible also (Klambra SP II 004).

Based on Klambra's words, the therapist/researcher's leadership style and her method of working in the music-caring group seems to have been conducive for both the individual and the group needs. The calm and tranquil presence, being able to inspire the participants and intuitively act on what was going on instead of keeping to a program opened up for everything as Klambra said. In her diary (Sunday 12 November, 2006), Góa wrote:

It is also good to have a director who leads the process forward. We tell and listen in peace, but it is good not to get stuck too long with the same issue, to have some structure in the sessions. It is a free structure, which Valgerður has managed to shape very successfully and to intervene in the right moments.

Benson wrote:

If group work is to be a powerful and humane medium, it requires: That the worker intervene at least as stylistically as the artist who bases his work on intuitive, affective, and aesthetic judgments. That the worker function out of

a deep conviction and vision of the wholeness, creativity, and possibility inherent in the group which matches the faith of the believer who knows what is and what can be (2001, p. 156).

To judge how stylistically or aesthetically this therapist/researcher intervened is impossible. But according to Góia and Klambra the therapist's intuitive and affective judgments were good enough to work with the possibilities inherent in the music-caring group.

According to Benson (2001, p. 38), different groups demand different leadership styles. A group of ADHD children might need more directive approach with structure and containment, whereas a bereavement group would possibly benefit more from non-directive leadership. As each group moves through developmental phases it may also require a variety of behaviours and responses from the leader. Thus the style of leadership should be flexible and adapted to the needs and functioning of each member as well as the group as a whole. Benson described four leadership styles: directive, permissive, facilitating and flexible. The directive leader is responsible for arranging, guiding, identifying tasks, and maintaining the flow of ideas and emotions. The permissive leader is non-directive and believes that if the purpose is clear and acceptable, the group members can accomplish their goals. The group is thus allowed to determine its own behaviour, incentives and strategy. The facilitating leader regards himself as a member of the group but with knowledge, role, and function that is different from other members. The facilitating leader tries to be supportive, encouraging and involved, but places major responsibilities for group process and task accomplishment on the group members themselves. The flexible leader adapts "to his assessment of group functioning, needs of members, and the task and will take up any of the other three leadership styles if it appears appropriate to do so" (Benson, 2001, p. 40).

Klambra admired how well prepared the therapist/researcher always was. "The sessions were not just played by ear – or maybe a little because we had leeway to speak freely if someone had the need" (SP II 002), she said. But she always felt a thread or a continuity that gave her the feeling of safety and being taken care of. Klambra felt that the mothers did not have to finish the programme/sessions in a certain way just because the therapist/researcher had thought it through in a special way (SP II 002). In her undertaking, this therapist/researcher sees herself as being a flexible leader adapting her position to the needs of the mothers, the group functioning and the group task. At times

the therapist/researcher even felt that the mothers with everything they had in common – their collective experience, cohesion, and genuine concern, empathetic support and participation in each other’s musicking and verbal expressions – were informally co-leading the group, even to such an extent that the therapist/researcher occasionally felt left out. There was no need to look for common elements and emotional themes; the mothers openly reached out for each other in the first music-caring session.

Dileo (2000, p. 27) wrote:

At the heart of music therapy is the person of the therapist. The qualities, virtues, and character of this individual are indeed central to the music therapy process, and contribute to the ultimate success or failure of therapy.

Giving, understanding, sensitive, calm and tranquil are words that Klambra used to describe the therapist/researcher’s qualities that she felt had positive influence on her. She also talked about the right amount of forward direction given (“being pushed a little bit”), despite what she described as a “complete freedom to set the limits oneself”. Einræn (cited above) also seems to have appreciated this when talking about being allowed to be herself and to decide for herself, whether or not she would participate (SP I 007). Góa as well appreciated a free structure that was successfully shaped to intervene in the right moments.

Dileo describes the ‘virtuous’ music therapist as one who acts not out of fear of professional or legal sanctions, but according to ideal principles for the benefit of the clients and their own intrinsic merit. The ideal and virtuous therapist could be described with a long list of desirable qualities, Dileo wrote. Of several prevalent models of virtues relevant to therapists, she listed three: 1) the trust-facilitating model, 2) the autonomy-facilitating model, and 3) the human welfare model (Cohen 1994 as cited in Dileo, 2000, p. 27). In the trust-facilitating model, trust is a central virtue in the therapeutic relationship and process because of the client’s vulnerability. The therapist must possess honesty, sincerity, competence, diligence, loyalty, fairness and discretion to merit the trust of the client. The autonomy-facilitating model focuses on virtues that are helpful for enhancing independence and self-actualization in the client. The virtues needed in this model include congruence, unconditional positive regard and empathy. Virtues emphasized in the human welfare model are: respect for human worth and dignity, moral autonomy, and caring (Rogers, 1977 & Cohen, 1994 as cited in Dileo, 2000, p. 28). From the perspective of the therapist/researcher, different virtues were playing together

consciously and unconsciously among the participants at any given time in the music-caring sessions. In the therapeutic relationship, where the mothers were the focus there was honesty, sincerity, diligence, discretion, congruence, unconditional positive regard, empathy, respect for human worth, moral autonomy and caring.

‘Relationship therapy’ is a term Rogers used when he began to emphasize the significance of the therapeutic relationship more than specific therapeutic techniques. This term was developed in his book *Client-Centred Therapy* from 1951 and elaborated upon in the book *On Becoming a Person* (Rogers, 1961). These developments included a view of the therapeutic relationship as experienced by the client, a therapy characterised by the personal involvement of the therapist, and a greater emphasis on relational issues. According to Rogers’s “Person-centred approach”²⁵, human beings have an innate and unforced tendency to actualize their potential if provided with a favourable environment. By co-creating the most conducive environments possible with the clients, person-centred therapists work to support this tendency. In person-centred therapy, the relationship between therapist and client is central to potential healing (Rogers, 1961, Rogers, 1980, Tudor & Worall, 2006). Benson used the phrase ‘creative group work’ to denote “the means by which a worker creates the psychological space necessary for the range of possibilities inherent in his vision of the group to emerge, and intervenes in a way which affirms members and facilitates the achievement of the group purpose” (2001, p. 172). According to Benson, examples of what might be termed creative group work include:

Being able to work intuitively and imaginatively when familiar or traditional approaches do not seem appropriate in a situation. ...Being able to work with process to help individuals or the group when stuck flat or tense. Working effectively with feelings. ...Helping members articulate and work at their own operating principles rather than imposing a structure or vision upon them (ibid.).

Hanna said of the therapist that, “one does not have to pretend around you. I think you are a complete genius” (SP II 005). Hanna’s words speak of conditions sympathetic to self-revelations and expressions of feelings. Her words are perhaps indicative of a therapeutic relationship characterized by a positive help-

²⁵ “The central hypothesis of this approach [is that] individuals have within themselves vast resources for self-understanding and for altering their self-concepts, basic attitudes, and self-directed behaviour; these resources can be tapped if a definable climate of facilitative psychological attitudes can be provided” (Rogers, 1980, p.115).

giver attribution toward the mothers, an atmosphere that limits threats to their autonomy and self-esteem, and a co-operative manner.

Aigen listed seven elements of the researcher's biography that might influence a research study (introduced previously in section 1.2 of this thesis). Three of these elements are: 4) Biases, shortcomings or personal difficulties that may distort the findings and render them incomplete. 5) The nature of the relationship between the researcher and the research participants. 7) How the research process changed the researcher.²⁶ The therapist/researcher was aware of her enormous responsibility as she advanced on her research journey. Working towards a set destination, the therapist/researcher's dilemma was her many parallel journeys. These include: her administrative duties at work, which incorporated fighting for equal educational rights for children with special needs; her day-to-day, full-time commitment at work striving towards becoming a more competent music therapy practitioner and a special music teacher; the commitment to her academic/research journey; the therapist/researcher's personal journey, which the everyday difficulties of life itself challenged on various levels. Biases, shortcomings and personal difficulties may thus very well have bent the findings and rendered them too personal and incomplete.

Being in a dual role as a therapist and a researcher was often challenging. It required interventions based on intuitive and affective judgments where the needs of the mothers were prioritized above the needs of the researcher. The therapist/researcher realized that compromises made in the therapy would be confronted when in her role as a researcher. So like Klambra said above, although the therapist/researcher had everything very well shaped and thought through in her mind or on paper, she also knew that she had to act intuitively and sensitively to what was happening in the group and with each mother.

Concerning the music therapist's responsibility for competence, Dileo wrote:

Personal and professional competence is a day-to-day commitment of the music therapist. As such it is both a process and journey to which all efforts must be directed, rather than a destination to which anyone ever fully arrives. This

²⁶ The other elements of the researcher's biography Aigen listed are: 1) Motivation for conducting the study. 2) Experiences and beliefs which have shaped the area of inquiry which influence data collection and analysis. 3) Information such as the researcher's gender, ethnicity, socioeconomic status, position of employment, etc. allowing consideration of political and social issues which may have influenced the study. 6) Intuitions and expectations about research findings prior to its beginning (1995, p. 294). These were discussed in section 1.2.

continual striving for greater competence is the essence of music therapy practice (Dileo, 2000, p. 57).

Having been fortunate enough to take on this research endeavour, the therapist/researcher realized that this was a growth and a learning experience, a continual journey towards greater personal and professional competence, as Dileo words it. Approaching the stage where she had to deliver her work, the therapist/researcher realized Dileo's words, feeling that on this continual and spiralling journey, the final destination would never fully arrive. As her analytic memos verify, music-caring was in many ways a challenging journey, personally, interpersonally, professionally, artistically and creatively. It brought her closer to her individuality and taught her to question assumptions. The process reinforced courage for action and created possibilities and realization of lifelong learning. Sharing personal vignettes from analytic memos written after sessions one, three, five, six, seven, eight, nine and ten, casts some light on the therapist/researcher's realization and challenges while conducting the music-caring group (Appendix V).

A long time has passed since the music-caring sessions were run. However, reading the memos brings back memories, thoughts and feelings, some of which the therapist/researcher did not write down. The academic relevance of including examples of the memos in the Appendix, as well as in the text below, is questionable and possibly holds relevance only for this therapist/researcher as she reflects on her own process:

Session #1

...I felt happy about how it went, but when I listened to the recording I spoke hesitantly. My voice was in the background, and it was like I let the mothers take over, which perhaps was okay. I did not know quite how to participate in their discussions, but I wanted to sound supportive, strengthening, and wise in order to deepen what they were talking about.

Session #3

I felt that my role was mostly that of a timekeeper. They empathize so nicely with one another that I feel more like a foreigner in the group. Sometimes I feel left out and lonely because I do not have the same experience as they. I wondered about what they thought about me. Do they feel they are receiving enough from me, what are their expectations? Am I capable of giving them

something, to console them or empower them? Am I doing that by just creating this opportunity for them to meet – the campfire feeling lives on? ...

Session #6

I worried about how this session would turn out. I feel like I have reached a point where product has gained power over process. ...I worry about that there is not enough music and too much talking and then I worry about that I talk too little ...

Session #7

My silence constantly confronts me. They talk so much and I cannot share my experience with them because I do not have it. Their experience is special and I realize it better and better. They even cannot completely empathize with each other. Does my role change from one session to another or am I just a timekeeper? Do they feel I am pushing them like for example at the end of this session when they still needed to talk when I wanted to lead them through relaxation?

Reviewing her memos taught the therapist/researcher at least one important lesson that she wants to share. What the therapist/researcher experienced as being her weakness or inadequacy was experienced by at least one mother as an important quality, namely the “calmness and tranquillity” Klambra mentioned. The therapist/researcher brought her old therapist’s self to a new clinical situation. To use Kenny’s words: she brought her individuality in which the psyche and the soul of her work was contained (1989, p. 8). Working in this research with verbal and high functioning adults, the therapist/researcher worried that both her musical and her therapeutic skills, which had been developed with different clientele, were not adequate for the mothers. She felt she needed to act more on the verbal level, to be more exploratory and interpretive instead of just listening, supporting and accepting empathetically. Backer and Camp’s words were sympathetic:

When we act too much on the verbal, concrete level we lose touch with the basics and we lose ourselves in mental and intellectual reasoning, forgetting the emotions. An excess of words can extinguish emotional experiences. Words can slow down the affective experiences or even make them impossible (1999, p. 16).

Concerning music therapists' listening approach, Backer and Camp wrote that a therapist should listen to a client like a mother gives meaning to a situation which feels chaotic to a child: "With reverie the mother puts the particular experiences of the child into a kind of order" (1999, p. 21). The therapist/researcher is aware that the way words are used in music therapy varies, depending, for example, on the functional abilities of the clients, their needs and the goal of therapy, as well as on the theoretical orientation of the therapist. However, trying to come to terms with her own performance anxiety in the music-caring group, the above quote calmed the therapist/researcher. It argues for modest use of words to ensure affective experiences. The therapist/researcher attentively listening and intuitively acting on what was going on (providing free structure, as Góa put it) provided the mothers with a suitable balance between musicking and verbal language, a balance which was conducive for lending the mothers' emotions a new tone. Klambra wrote in her poem:

To Valgerður

I shall not soon forget my benefactor,
with feeling and warmth she gives precious advice
and lends the emotions a new tone,
beating the rhythm with drum and xylophone.
Between us she weaves a tight bond,
my thankfulness is almost beyond words.

Klambra

17.8 Me and my time

In the introduction of this thesis it was discussed that parents with special needs children face a risk of neglecting their own needs when faced with all kinds of strenuous demands and stressful situations in an achievement oriented care for their children. Their often-demanding role as the prime carers of the children affects both the caretakers as individuals and their relationships with others. As Gill (1997, p. 11) worded it, the parents' identities are forever changed, "the whole shape of ourselves and our lives is being pulled into a new form" (as cited in Sorel, 2004, p. 23).

Parents themselves also emphasize that parents of children with special needs should not only be offered personal help but that such help should be mandatory. The fact is, however, that within early intervention services, parents themselves and the potential psychological distress they experience are more

often than not a forgotten factor in the overall support and treatment schemes offered to them. In order to move forward and to find the best ways to support and empower mothers of children with special needs, one needs to make their voices heard, argued Kingston (2007, p. 23).

Music-caring was directed at mothers' needs. What brought them together was what they had in common, i.e. their children with special needs. Time and again in the music-caring sessions, their focus had to be redirected from their children to issues related to themselves, to questions such as: Why am I here? What are my hopes or my fears with regard to the group? What is my aim for being in the group? What is the aim of the group? Skonza said: "One could have forgotten oneself just talking" (SP III 002).

The analysis of the transcribed interviews revealed that music-caring was instrumental in creating awareness to a greater or a lesser extent of the importance of taking care of oneself. Later in this section, the mothers speak for themselves on themes concerning their self-importance, how they take care of themselves, and the idea that how each mother cares for herself and feels about herself is as important for her own well-being as it is for the well-being of her whole family. The following narratives relate to the theme of 'Me and my time' and are the researcher's compilations and reconstructions from the transcribed material of anecdotes told by the mothers. As such, they could be regarded both as a narrative approach to the interview analysis/interpretation and also as a form of validation whereby "the researcher tries to keep his or her interpretations within the interviewee's context of understanding as seen by the researcher" (Kvale, 1996, p. 217).

17.8.1 Kristjana's account

I was going to write in the diary directly after the first session but I did not find the time to do it. This first session was very good. It was enjoyable to meet new people who are dealing with the same [issues] but are yet so different. It was enjoyable to do something that you have never done before. I have never played an instrument before hardly touched an instrument even, and I was thus a little scared before this began. But then it was just comfortable. Best of all was that this was MY time (an excerpt from Kristjana's diary, dated 29 September 2006).

Music-caring was the only thing I had seen which was available for mothers. Things are always directed towards the child. All of a sudden it was about me. This is something I had wanted for myself before. But I would perhaps not have accepted it then because I was so confused somehow when my son was

newborn. I was alone in the world and did not know anyone like this. The first year was a time of waiting, waiting for life to become normal. Strange how alone one felt at first. Perhaps one is first ready just now. However something was needed during the first two years. Music-caring was a new treatment, something I had never heard about before, for stay-at-home mothers, nobodies. Mothers staying at home are nobodies and are never offered anything (SP I 001).

I was doing this for myself. One does not do anything for oneself directly unless it is organized like this. So it is about my emotions and me. Someone is interested in that. I feel that is in itself an experience. You have told me that my emotions and I make a difference. This does not always evolve around the disabled child. That is of course an unbelievably good feeling (SP II 002).

We all matter. Every sound is important. That makes you think: I do matter; I am important. What I do and say matters and it matters how I do it. It matters how I raise my child, how I talk to them. It matters how I do things. You know it is noticed and it colours everything around. You know if I play badly, if I scream at my children it does not sound good. If I try to do it well then it is better (SP II 005). One feels one is making something, that one makes a difference. I am doing something and I am making something permanent, leaving something behind. Here one is both receiving and giving both for oneself and for others. To be able to give is a healing process. At the same time one is receiving something for oneself and then one is giving something to others. That is terribly good. I only remember myself playing; I do not remember exactly what I was saying. I got a different perspective on myself when others chose some instruments for me. Aha, I thought, is this how they see me. It was good to be able to leave home, to stop thinking about the daily things and to come here and think differently. It was good to come and to leave all the responsibilities at home. It is out of your hands (SP II 007).

17.8.2 Esja's account

What was most challenging for me was to map the mind, to map everything that was happening within me, to be able to sort it out a little. After a few sessions one found how one began to be better able to realize what was happening within oneself. One starts to realize cause and effect, how one behaves and things like that. That is what I hoped to get to begin with, to become better aware of how I am feeling, what it is that is happening inside of me. Because often there is something that is happening and one feels bad, and one does not realize for a few days what caused it. For me, the biggest challenge was to sort out my

emotions. I felt very good to find somehow after these sessions where I stood, with whom, with what feelings and to realize what I wished for. This is what one had needed in the beginning, to be with other women like this who understand the same [challenges]. One was so alone somehow. Now I looked forward to having time for myself and with the group (SP I 004). Part of music-caring is learning about yourself. That includes tackling this impatience and trying to contain my temper towards my daughters when they are acting out. All sorts of self-improvement must be beneficial. It does not matter what it is, just that there are these two hours in the week that are just for you. You slow down and listen to others and they listen to you. Listening to others who are in similar position somehow does you good, instead of having this all tangled up and then the tangles become more tangles. One does not realize what is happening and what situations create these feelings. It has changed the way I feel and think about myself. I believe I think more beautifully about myself now, not that I am impossible and not good enough. One must think nicely about oneself. When you do that then you automatically start thinking that now you should do something good for yourself. To maybe organize something once a week, because one feels how much good these sessions have done; to have a good and a beautiful time with oneself and of course to be with these women. I feel there is a change, because it is somehow different when one reads self-help books. It somehow becomes real when you participate in a group. Here one is active and that is different (SP II 004).

I am just Esja who wants to become a little better or to feel a little better with my dark side, and my shortcomings. Impatience was one of my biggest shortcomings and now I feel I have become more patient. Also I have stopped being depressed, which is just terrific. I worked systematically towards it. I worried about I would again become depressed with this birth [her third daughter was born 11 November 2006]. But I knew right away that that would not happen. I want to be happy. That is the purpose and now I have started thinking about learning Spanish next fall. One should let one's dreams come true. Then I really would like to check out if I could sing. I would very much like to sing in a choir. I am not going to get old in front of the TV. It feels very good to have finished sorting things out and to realize that only I am capable of changing myself. Music-caring has truly helped me doing that and after these sessions one had provisions for the week to come and one was often thinking about this.

On was often thinking about [the sessions]. Perhaps one was driving and then one was thinking about what had taken place in the session. Thinking about what one wanted to work with within oneself. So that was very good. Of course I had wanted to

be in this when I had my daughter V. And when there were all these difficulties. Perhaps then this would have affected me differently. Then I would not have participated in order to strengthen myself but just to get over it, to go through the trauma. At that point, even though I would not have wanted to go to psychologist or something like that, then I think music-caring would have done me very good because it is like an unknown journey. I could not think myself going to a psychologist and telling him that I feel bad. Rather, in music-caring the emotions would have found outlet in the music, instead of sitting with a psychologist and talking about oneself. One would have needed to stay with the feeling and to sound it. I think that would have been very good, some sorrowful tones, to put it forth and to acknowledge it. Because when you were in the sorrow you never said if anyone visited you. Oh, I feel so bad. You know, one does not acknowledge it like that. Perhaps one told a friend what was happening and such but you never told it in clear words. You don't speak the truth in order to stay alive. In order to stay strong, you somehow lose your own feelings, your self-identity. You don't speak the truth (SP II 005).

17.8.3 Einræn's account

One is always trying to think more about oneself or better [about oneself] or how should I word it. This music-caring hopefully helps me to do that. One tries of course to be positive and to care for oneself. I know I have not been putting myself first. I have always been somewhere in the last row. Through music-caring I will hopefully become more capable of taking care of yes somehow myself and the ones around me. That would make me feel better in general (SP I 006).

But I do not know if I have progressed at all in a positive direction. I do not quite know. If he [her son] is happy, smiles or laughs, then I can find purpose in this. Otherwise it is difficult when he gets these fits and is difficult to handle. Then I become depressed and feel everything is hopeless (SP I 007).

17.8.4 Góa's account

In the beginning one is happy with everything. Having gone through this and stirred up so many things one has become terribly unhappy somehow. I took with me renewed energy from the sessions, and I thought about the others between sessions and it was enjoyable to get something new into your life, something which was about this group. If one can put oneself into others' shoes then one learns to understand that others can put themselves into your shoes. One sees that one is important, but also that one needs not to take things too seriously. The negative sides are not as noteworthy as one feels sometimes (SP I 001).

If music-caring is to be for women to help them emotionally – caring for them, then I feel it is very good exactly to evoke thoughts, to ask intrusive questions in the beginning. To shake things up a little so that one starts thinking about something else than what is planned for dinner. That opens up [the possibility of] whether one wants to be open, receptive and giving or something else. Either you open up or close down. I think it must have been sheer luck how good the group was (SP I 009).

I feel that I am somehow more secure in myself, more self-secure. I am happier. I have decided not to be bothered with certain things. These meetings confirmed that there are so many negative things one can get rid of and that one should try to focus on the good things. I think the biggest thing is that one needs to be positive. The closeness to others and the discussions encourage one to start thinking about something deeper than just one's daily life. It has an evolving effect. Besides, demand increased to get something for oneself. This has elicited the awareness of the importance of being positive, to think more positively and to think about the future, which is something one does not do when you stay at home. I have learned that from this group or these sessions. It is all up to you. It depends on oneself [to be positive and think positively]. It is important to focus on the positive things rather than the negative ones. This course has taught me to be more aware of what I need to do to feel better so that others around me feel better (SP I 010).

Although I reasonably accept myself as I am, I realize that certain things need to be fixed. I regard that as an exciting task. Yes, I am accepting life as it is and I am a little bit more self-confident than before. I accept that I am not perfect, and that one does not need to be perfect; one can be happy with being stupid and frail. If you accept yourself then you do not care what others think of you and then you become more self-secure. I am happy with the fact that this is a process and that one is developing and having fun. I would like to work with something that nourishes me. I want to be around people. I would like to take up translations, but that is work you do alone. Nevertheless, I am going to contact the broadcasting station to see if they have any work available.

I have been just on my way to doing something. I'll be damned if I don't achieve that this year. Also I will try to take care of my health to be able to play with the children and carry my son. One wants good things for the family. But I have realized that if you can make yourself feel good it influences how well your family feels. So apparently you can be a little selfish. I also need to start working. I could not continue studying becoming a librarian because I could not

give a lecture but I plan to attend a workshop on creative writing and I want to take a computer course (SP II 003 – 004).

17.8.5 Hanna's account

This experience was different from most things I have done before, the things I know how to do or I am used to doing. Maybe this is because here I was alone and I was attending to myself a little. In general I am inhibited and that is not good. If you only do something for others it does not end well (SP I 004).

I felt like this group was a turning point. Constantly thinking about the home and the children and doing nothing for myself didn't work anymore. It is important that everyone gets his opportunity (SP II 001).

The need to take care of parents of children with special needs is great. It is so difficult when no one understand you. It is so difficult to understand something that you have not experienced. You learn about your own emotions when you hear others talk about them. This is how I have felt. It is like going to school (SP II 005).

17.8.6 Klambra's account

If you are working with yourself and you have stepped forward then it must show. To work towards this goal, towards inner peace and to find reconciliation, then one can do just anything. Then the joy and the feeling of safety comes too – so many things that come along with it, and not just only to know oneself. This is a step towards change and this is a good feeling. To work with oneself must change the whole thing (SP II 008). There is always some conflict evolving around if you are doing enough or not enough. It is important to use the time when he is so young, but then you have to sacrifice something else. I have often thought about the choir. But I feel I need to do it. Singing in the choir makes me stronger (SP II 008).

17.8.7 Skonza's account

I am very sensitive and breakable somehow. But I try to be positive and have always done so. Sometimes and some days it is difficult trying to play Pollyanna games. Maybe I am a little more aware of what I want do for myself. I want to go back to school. I want to have more children. I want to get married. I guess in the end one becomes stronger after all of this. I hope so at least. I know it takes time to work through this, but it is worth it when it is over (SP III 001).

17.8.8 Concluding remarks

The scope of the mothers' narratives centring on me and my time and the importance of taking care of themselves vary in length, depth and focus. Perhaps indicative of different awareness and emphases in life, these differences may also reflect varying levels of adjustment, varying degrees of support from significant others, the seriousness of the child's disability, and more.

As introduced in the theoretical section of this thesis it is the person's sense of being cared for which is therapeutic. It is also the caring attitude with all its elements that in many helping relationships may be the single most important factor. Kristjana supports this when stating that just the thought that someone showed an interest in 'me and my emotions' was an unbelievably good experience (SP II 002). She had noticed that music-caring was the only thing which was available for mothers at that time. It was healing to be able to give at the same time they were receiving from others who knew the same challenges. Music-caring was a welcome opportunity to learn about one's feelings and needs. It did not really matter what it was, just that there were "these two hours in the week that were just for yourself," as Esja worded it (SP I 004). Esja was perhaps referring to what successful therapies have in common, namely a caring concern and a warm presence. Elements conducive to building trust, which enables the one cared for to accept the help given and to feel cared for (Benner & Wrubel, 1989, p. 6).

To learn to sort things out, to think positively about oneself, to take better care of oneself and those around one, was conducive to a feeling of well-being in general. Góa and Klambra said that if you could make yourself feel good it would influence how well one's family felt. To work with oneself would change the whole thing (Góa, SP II 004; Klambra, SP II 008). Góa's and Klambra's experiences support the reciprocal nature of the clinical system in parent-infant psychotherapy previously described by Stern (1995, p. 15) (introduced in Part II of this thesis. The clinical system asserts, that if a support system were to be directed towards the mother it would have its greatest effects on the mother's representations, affecting how she regarded herself as a mother and a person. Consequently it would affect what she would do behaviourally with the child. If music therapy interventions, for example, were to successfully change the mothers' feelings it would, according to Stern's model, have direct or indirect effects on all the other elements in their relationships. It would change how the mothers subjectively experienced themselves as mothers and as persons and thus

change the interactions with their families. Like Góa said: “If I can make myself feel good, it influences how well my family feels” (SP II 004).

17.9 Process and change

Whether groups are time-limited or open ended “group dynamic forces operate in all groups to influence their development,” wrote Yalom (2005, p. 309). Various group development theories have been articulated, describing between three and five stages. Schutz (as cited in Benson, 2001, p. 79) suggested a three-stage scheme: 1. inclusion, 2. control, and 3. affection. Tuckman described five stages: 1. forming, 2. storming, 3. norming, 4. performing, and 5. adjourning. Garland, Jones, and Kolodny also described five stages: 1. pre-affiliation, 2. power and control, 3. intimacy, 4. differentiation, and 5. separation (ibid.). Yalom advises against taking group developmental sequences too literally and stresses that no linear course exists.:

At times the development appears linear; at other times it is cyclical with a reiterative nature. It is also apparent that the boundaries between phases are not clearly demarcated and that a group does not permanently graduate from one phase. ...Thus it is more accurate to speak of developmental tasks rather than developmental phases or a predictable developmental sequence” (Yalom, 2005, p. 320).

Knowledge of group developmental stages can be advantageous as it enables the therapist to maintain objectivity and to recognize if the group is progressing or not. However, for the novice group therapist it can be dangerous to take group developmental ideas too seriously by using them as a template for clinical practice via a certain treatment manual. Standardized therapy lessens the possibility of caring engagement. A manual can possibly sacrifice reality and authenticity in the therapeutic relationship, which according to Yalom is the heart of psychotherapy (Yalom, 2005, p. 323).

The novice therapist/researcher in this study did not consciously follow a ‘group developmental manual’. She had however designed ten music-caring sessions and the research design itself mainly to help her focus on each important step in her research endeavour (see Part III: The preparation phase).

“Going from the unknown to the known”; “an inner and outer journey”; “moving on”; “moving from the fear of sharing to wanting to give more” are all expressions which evolved when the researcher was coding meaning units during the phase of interpretative phenomenological analysis. These expressions

are suggestive of processes occurring throughout and at different levels within the therapeutic and the clinical research context of music-caring. Braided together, processes both within the therapy and the research and on an individual and a collective level were evolving until the very end of this study. In order to cast some light on the complicated non-linear weaving of internal and external processes experienced by the participants, they will, for the sake of simplicity, be viewed linearly from the perspective of each mother.

The following questions asked in the individual interviews addressed the issue of process and change somewhat specifically:

- What was it like being in the group at the beginning?
- What was it like being in the group at the end?
- How-would you describe the music-caring process itself?
- What has coming to the group been like for you?
- Have you noticed any changes in your life since being part of the music-caring group?
- Have you noticed any changes in the way you think or feel about yourself?
- Have you noticed any changes in the way you think or feel about your child?
- How would you describe yourself today?
- How would you describe your child today?

The last two questions were also asked in the questionnaire completed in writing by each mother prior to the first group session. The theme of process and change could also be analysed in the mothers' answers to other interview questions not directly addressing it.

Starting with the therapy itself, Bruscia (1998a) emphasizes that what qualifies as a process does not automatically qualify as therapy. However, "What defines therapy is the process of intervention, not the outcome, whether it be positive or negative" (p. 38). "The 'process' of music therapy always involves *repeated* engagements in assessment, treatment, and evaluation," he continues (p. 34).

Having signed the informed consent form the mothers engaged themselves to participate throughout the ten music therapy sessions and the two assessment (interview) sessions. Based on her theoretical and clinical foundation (Part I and Part II of this thesis) the therapist/researcher intervened in the lives of the research participants by inviting them to participate in a music therapy group. The therapist/researcher also committed herself to complete the task she set out to do, which meant a prolonged engagement beyond the ten music-caring sessions and the two planned interview sessions in order to study that which was being done (the music-caring intervention).

Distinguishing further between different types of therapeutic processes depending on how the music therapy is applied, the type of clientele, the nature of the problem being addressed, and the therapist's theoretical orientation Bruscia describes six different types of processes: developmental, educational, interpersonal, artistic, creative and scientific. These processes are not mutually exclusive as they overlap even within the same session. Thus one experience may be approached as scientific and another one as creative or interpersonal, or both (1998a, p. 36). Neither focusing on appropriate developmental milestones nor curricular subject matters, the therapeutic processes occurring within the music-caring group could be described as interpersonal, artistic, creative and scientific.

17.9.1 An interpersonal process

A process is interpersonal when the sequence is based on stages in developing relationships with people. For both the mothers and the therapist/researcher this involved: "establishing rapport, making contact, exploring limits, gaining trust, defining roles, helping, separating, and so forth," (Bruscia, 1998a, p. 35). Einræn talked about how she felt a little insecure in the beginning and that she worried about having to do things she did not feel comfortable doing. Little by little things became clearer she said, and she felt a progression in each session, like everything became stronger and stronger somehow. Her anxiety disappeared and she stopped worrying. She became part of the group, her knowledge about what was about to happen increased and feelings emerged. When the music-caring approached closure she worried about having to say goodbye to the mothers and she also worried about not being able to continue receiving support like what she had been getting from the group (SP I 002-004).

Realizing that the group condition had changed when approaching the end, Kristjana talked about how they knew each other better, how they spoke together more openly or differently and how good she felt afterwards. She sensed that as time passed she felt better and better and became more accepting. She got an outlet through speaking, playing and the diary and mentioned that she should have used the diary before as a proof of process and change (SP I 008).

On a personal level, talking about an inner and an outer journey, the greatest challenge for Esja was to map her mind, to be able to sort all the things that were happening within her – cause and effect, how she reacts and behaves, and what it is within her that makes her feel bad. She felt that after these sessions she could sort her emotions a little to find where she stood and with whom, "with what emotion, what it was she wanted and such things" (SP I 004).

In the beginning, everything was unfamiliar and strange, unknown and unmapped, also these feelings you had. In the end, everything is known and the emotions have been sorted somewhat - I have realized my hopes and desires. Going through this has made one more aware of the music and oneself. So this is what I feel has been accomplished in this journey. (SP I 004).

This was such a joyful journey. One visited many places. ...[It was] both a journey around myself and also with different characters. And also [there was] the music. Maybe some places surprised you but this journey was enjoyable (Esja, SP I 010).

Klambra described her experience in a similar manner. She talked about having “read the group and the situation” to begin with and then little by little relaxed into it and introducing more sides of her personality. Describing the process as “slow”, there was never anything that she felt she was not prepared for (SP I 002).

If you are working with yourself and you have stepped forward then it must show. And this goal that one needs to find an inner peace and to find reconciliation. Then you can do just anything. Then the joy and the feeling of safety comes also – so many things that come along with it and not just only to know oneself. This is a step towards change and this is a good feeling. To work with oneself must change the whole thing (Klambra, SP II 008).

Based on the above the process of intervention in the music-caring group seems to have been therapeutic, as well as resulting in a positive outcome. From being together for the first time where the mothers introduced themselves, where they were provided with additional information about the group, where self-disclosure, trust and intimacy began to evolve, all the mothers seem to have stepped forward. Being co-travellers in an enjoyable journey they seem to have become more aware of their own feelings, needs, and hopes.

17.9.2 An artistic and a creative process

Based on the fact that music therapy is a synthesis of art and science, music and therapy, the process of music therapy can also be described as artistic or creative, Bruscia argues (1998a). Music therapy as an artistic process is concerned with a progression involved in musicking. For the mothers in this study, this involved learning how to play unfamiliar instruments, improvising, writing songs, expressing thoughts and feelings through music. “There was

something that built up. At first one was a little hesitant and then one got to know the instruments better, to organize oneself better and to choose something special” (Góá, SP I 008).

In Klambra’s experience everything was challenging: “To participate in a group with strangers, to be active and to give input, to talk about feelings, and to express yourself musically for a group of people was challenging” (SP I 001).

Describing her experience of musicking, Kristjana felt it was both strange and surreal to begin with. Little by little she became more secure “but never completely in the music.” She accepted not knowing what she was supposed to do with the instruments and how to make music. Gradually she eased into it when trying more and more instruments. Kristjana described her experience like being thrown into the swimming pool and not knowing how to swim. When she felt she was able to do something with the instruments, then it became fun. Sometimes the group focused on her and at other times she tried to stay in rhythm with the other members. “But mostly I was trying not to do something which sounded very bad” (SP I 008).

For the therapist/researcher, the artistic process concerned bringing music-caring to the mothers, engaging them through musicking and musically interacting with them. “[The artistic process] is the art of hearing the client’s music and understanding it in the context of his/her life. It is also the art of being a therapist and of making the therapeutic experience an aesthetic one” (1998a, p. 35).

Music therapy as a creative process involves stages in “identifying, exploring, testing, and selecting alternatives” (Bruscia, 1998a, p. 35). For the mothers, this meant solving problems and meeting needs through new and creative ways. Creatively exploring ‘new lives’ free from old conflicts and open to new challenges. For the therapist/researcher, music therapy as a creative process involved finding creative ways of working with the mothers, seeing fresh alternatives in problem solving, searching for new methods of working, “and being open to creative changes in oneself as a therapist” (Bruscia, 1998a, p. 35).

Sharing her thoughts about the song-writing process, Klambra said: “It is like a process where everything has its place until one decides: ‘This is the way I want it to be. I am going to share this and to sound it.’ It is a completely new experience” (SP I 006). Open to new challenges, the process involved in musicking and the songwriting touched on Klambra’s old habit of not wanting anyone to listen to her or to watch her, and on her quest for constant improvement. Small steps towards becoming more receptive of herself, being able to accept all kinds of feelings, define them, sort them out, and to work

through them were taken. She felt happy about her own participation and her own performance.

It is much easier to talk to you now than before music-caring started. That is a good change, which tells me that I have stepped forward in the right direction. I don't think I have finished everything, addressed all the different feelings, and I did not expect that would happen by coming here (Klambra, SP II 007).

Esja was of the opinion that participating in the music-caring group had changed the way she thought about herself and how she felt. She became more capable of dealing with difficulties because she had sorted out the emotions inside. Feeling better, she felt stronger and knew what she wanted. Thinking more beautifully about herself, she had stopped thinking that she was not good enough. Esja believed that if one thought nicely about oneself then one automatically started thinking about doing something good for oneself and in an organized manner. Because, as she worded it:

One has felt in these sessions how much good they have done, how good it has been to have a beautiful time with oneself and of course to be with these women. Yes I feel there is a change. Music-caring is different from reading self-help books. It becomes real when you actively participate in a group (SP II 004).

Einræn was unsure about whether she noticed any changes in her life since being part of the music-caring group. She was, however, more aware of the need to take better care of herself for her own benefit and for those around her (SP I 006). Góa, on the other hand, was of the opinion that she was feeling happier and more self-secure. She had become to realize that there were so many negative things she could get rid of and that she should try to focus on the good things in life. "I think the biggest thing is that one needs to be positive," she said. Becoming close to the other mothers and having deep discussions with them had made Góa start thinking about her future and what it was she needed in order to feel better (SP I 010).

Like Einræn, Hanna was not sure if she had noticed any changes in her life since being part of the music-caring group, but she felt a little bit more aware of the effect of music and she also felt a little bit richer having got to know them all. "I truly remember now that music has a healing influence and maybe I use it a little bit more now," she said. Hanna liked the other women a lot and thought of them as good individuals who had been wonderful to talk to, and get

information and advice from. Getting acquainted with them had made her much richer, she said (SP II 001).

Skonza felt that she had learned to appreciate the time she had with her daughter and that she had become a little more aware of what she wanted to do for herself. She wanted to go back to school, to have more children and to get married. “I guess one become stronger after all of this in the end. I hope so at least. I know it takes time to work through this but it is worth it when it is over” she said (SP III 001). Skonza felt that after the sessions she listened to music more in order to feel better and to relax (SP III 002).

Kristjana felt that she did not know if she had noticed any changes in her life since being part of the music-caring group. She realized, however, that “everyone matters”:

Every sound is important and that makes you think I do matter, I am important. What I do and say matters and it matters how I do things. It is noticed and it colours everything around. If I play badly, if I scream at my children it does not sound good. If I try to do it well then it is better (SP II 005).

17.9.3 A scientific process

The mothers were aware that they were participating in a research project involving sequential steps. Klambra, for example, felt it was something special to be part of this first group and that it was also their responsibility to make music-caring a success (SP I 001). Góa was thankful and pleased for having been “led towards this” and described it as a “strange interplay” that had done her tremendously good (SP II 006). Concerning how good she felt about the group, and how fortunate it was for the group to get along so well, Góa said:

It is perhaps because we are beginning something, because this is research, and there is a certain theoretical background. I do not know if that is more stressful because you [the therapist/researcher] are asking these questions. You will perhaps not ask questions like this [the interview questions] when you continue with this work. You would not be asking these questions afterwards [when the music-caring group is finished], so this is like something additional. One has to be thinking retrospectively and to be searching one’s brain about how all of this was. It is so easy to forget (SP I 010).

Góa’s words support what Brusia wrote about therapy as a scientific process. According to him, therapy as a scientific process involves gaining more reliability in

observing oneself, making more valid interpretations, and more objectivity about one's life and that which influences it (1998a).

Being in a dual role as a therapist and a researcher, the scientific process involved continuously evaluating the effects of music-caring for both clinical and research purposes. Bruscia says that "clinical practice is aimed at helping clients achieve health" whereas "research is aimed at increasing or modifying the knowledge base in music therapy" (ibid., p. 241). To integrate these two purposes or make them consistent with one another is challenging. Both are concerned with gathering information. The former is concerned with how the data can help the client or the therapeutic process whereas the latter is concerned with how the data will add to our knowledge base. Focusing on the needs of the mothers, the therapist was also progressing as a researcher, focusing on being true to her methodological and theoretical orientation.

17.9.4 The music-caring process

Asked to describe the music-caring process itself, Einræn felt it was somewhat difficult but that she could describe it as a growing process with a crescendo in every session where the empathy became stronger and stronger (SP I 006). Reflecting on her experience to consider if there was anything in particular she would consider music-caring, Einræn answered: "It was both sounding the feelings and singing our poems, and yes sounding all of us. I think that was the highlight" (SP I 005).

Describing music-caring as "tones that touch you and make you feel better" (SP I 011), Esja talked about the music-caring process as a journey that had made her stronger. This journey was not easy to talk about to others as it somehow was a secret, something personal between "me and [the other women]. Talking about it might harm the secret or the magic" (SP II 002). Describing a situation in which music-caring occurred for her Esja said:

You can go to the session feeling rather down and you start doing the music and then somehow the feeling floats with you. I remember one instance in particular. You can somehow play the feeling away from you. Then you feel much better afterwards. The feeling somehow merges in with the tone. You feel like you have got an outlet afterwards. I am not saying that you become very happy afterwards you just felt much better. I would say that is music-caring (SP II 002).

Having compared her experience of music-caring to going to the opera, Esja said:

First there comes the silence and then the music starts and you get goose bumps all over your body, it is so magnificent. It is so strange the thing that brings this on. It must be caring or something that engulfs you and brings forth such strong emotions that one cries. It is a strange and a sensational experience (SP I 011).

Describing the music-caring process to others Esja would say:

“We sing together. We tone. We play instruments. We give tones. We give sounds to feelings. Then we talk. We bring up the things that are bothering us, talk about it and sing about it perhaps. We listen to music, and it is a journey within and around oneself. This is a journey in maturing and this helps one do it better. Music-caring helps you travel better, to travel through, to mature, and to reach some success of being, and of being the mother of a disabled child. This has made me stronger. I feared having the third child and having take care of this whole thing [mother of three children, and one with special needs] but I feel I am stronger and I know I can do this. You have become stronger when you realize who you are and what you need and what you want. So the journey has done me good” (SP II 002).

For Góa music-caring was about musicking, to find an outlet by playing, singing and listening; listening not only to talking, but also to sounds that were calming and comfortable. She was referring to comfortable sounds that supported relaxation and sounds that helped to set free or express various emotions. People arrived in the sessions in different emotional states and could choose to hit the drum or play a little triangle depending on what the specific feeling was that they wanted to get rid of, she said. “We are all doing the same thing and there is a certain connection which brings forth the empathy” (SP I 008). Góa described the music-caring process in the following way:

There was a feeling of uncertainty to begin with, not knowing how the sessions would be and not knowing the others. Despite an introduction in the brochure I did not quite know what was ahead but I think that is good. With uncertainty comes some daring. When looking back I do not know what it is that one could change. You built this up fine having us begin with getting to know the instruments and each other. You gave us ample time to talk but also time with the instruments and told us also what we were going to do. Then the emotions are brought in a little early so one could build on them. There was never any moment when I thought ‘why does she do this now’ or ‘isn’t there a time for doing this’. I believe that this process was fine – getting to know each other and then getting

deeper into it with discussions and the songwriting, etc. If it is to be for women, to take care of women and help them emotionally then I feel it is very good to evoke thoughts, to ask intrusive questions in the beginning. To shake things up a little so that one starts thinking about something else than what is planned for dinner. That opens up the idea of whether one wants to be open and receptive or giving or something. Either you open up or close down (SP I 009).

To get an outlet for feelings and thoughts through music was what Hanna considered music-caring. She felt safe, got peace and leeway to get rid of something, and to express herself through music. Trust had been built and one dared, could and was allowed.

It was your turn, you could choose; find out what it was you wanted to get rid of and express that. You started alone and then everyone came along, trying to express my emotion, helping me and you also, this quietness and this listening. They heard how I had started and how I had set the tone that was music-caring for me. To be able to ask for a special song that we could sing together that was also music-caring (SP I 008).

Describing the music-caring process itself, Hanna said:

To begin with you are insecure and you walk slowly and then you become stronger and walk with security. You know what is about to happen and what you can get out of this and then in the end you are reconciled because you got what you wanted out of it. I did not know what to expect but I did get what I needed. I put thoughts and feelings into a creative form and music and I felt empathy. I got to know the others and to feel kindness for them and to empathize with what they were experiencing. You want to show them that you understand what they are experiencing and feel the way they are feeling and that you are not alone, because that is such a terrible feeling (SP I 008).

For Klambra everything was music-caring - the whole process. It was good to come and talk to the group and to listen. It was good to try something new; it would not be music-caring if there were no music. It was very good to loosen emotions by listening to music and to sound the words, for example. But that alone would never accomplish what it did unless everything else was there also – somehow “the whole thing” she said (SP II 002). Describing the process for others, Klambra wanted to organize music-caring in the following way:

One observes from a safe spot. Then one approaches gradually, takes part and withdraws again. One does not want to take up too much space. One feels oneself part of the whole, during the journey and also afterwards. One feels caring, empathy, understanding, new learning. One wonders why one didn't do a little bit more: this was my chance. During [the music-caring] everything was just good and fine. There was a feeling of admiration. One could work with all kinds of feelings, not just the ones that are about having a child with a disability, which is not something you do with your friends. There is a good feeling that prevails after this journey. One feels that one could have been bolder but one does not change one's character in an instant. We supported each other and tried to understand each other. This was a learning experience and one thinks about how it is best to support another human, by sharing a personal experience or by just listening. The journey was not difficult. Everyone managed to make her mark in my mind. I feel I have many different things in my bag after this, things of a different kind. I have good feelings but also a feeling of pity and sympathy. Seen from different perspectives it was just marvellous to have participated in this. Music helps you truly see all the beauty of nature with different eyes (SP II 005).

Thinking of music-caring as something terribly big and enormous, something which she had been "just a little bit into", music-caring for Kristjana was about being taken care of through the music and much more. It was like a verbal therapy, listening, giving and taking "and all that". Like a tool, it was the music that accomplished this therapy, and she felt, like Esja, that she did not know how to explain it. Kristjana had the feeling that this could have been developed much further, longer and more, because she felt that little by little one sensed what this was. One became more skilled at playing the emotions into the music, to use music to experience or awaken emotion and then to get rid of them. Having realized the potential of music-caring it felt like being at the beginning of something and it felt strange being done (SP II 002).

Describing a situation in which music-caring occurred for her, Kristjana said it was somehow just "the whole thing". But besides being enjoyable, she felt that it was a "very good feeling" when everybody was making something together. "To get this time for oneself and be allowed to attend, to talk, to express emotions and to listen to others, and the togetherness" (SP II 004). Describing the music-caring process itself, Kristjana said that "music-caring was a good therapy, and if the aim was to make people feel better then it was successful. But this cannot just be over with, that from now on I will always feel good." She continued:

The goal of making us feel better was reached but there is no cure. It was very good to be able to get away from the daily things, meet others and to

discuss how one felt and to do something new like this, to use music to make one feel better. That happened. Emotions remain however, and all sorts of feelings and all sorts of things will emerge. Because of that, it would be so nice to be able to receive from it again or to attend some kind of treatment like this (SP II 004).

Concerning how she experienced herself both receiving and giving both for herself and for the others, Kristjana said that being able to give was “a healing process”.

At the same time one is receiving something for oneself then one is giving something to others. That feels very good. One is making something, making a difference and making something permanent, leaving something behind. “I only remember myself playing; I do not remember exactly what I was saying” (Kristjana, SP II 007).

Skonza also felt it was a difficult task to describe to others the music-caring process itself. “One is a little worried in the beginning. Then one gets to know the therapist/ researcher, the girls, and all this emotional heaviness that one is experiencing. It is difficult, if not impossible, to describe that to others somehow. Because it came so personal it is difficult to put it into words for others who were not there to experience it. This is something private, just for oneself, and people would never understand exactly what you were trying to tell” (SP II 007).

Being able to sound herself, the way she felt and her feelings, the words on the whiteboard, the songwriting process and the poem, but perhaps most of all what they were doing together as a group, was what defined music-caring for Skonza (SP II 007). Describing a situation in which a music-caring occurred for her, Skonza talked about the session when the song “Vetrarsól” had been sung and afterwards the mothers sounded themselves alone.

Singing this song and sounding myself had an enormous effect on me. I had been very worried and there [my worries] just floated away from me and I felt this enormous relief somehow. The worries had been so overwhelming and they just floated away and I sat behind lacking the correct words to describe the way I felt. It was so comfortable and so good, such a terribly good feeling of well-being and relief to great proportions (SP II 007).

“One of the most common metaphors for musical experience in post-nineteenth-century Western culture is the metaphor of ‘transport’ in the sense of being carried

from one (emotional) place to another (and indeed, at times, being ‘carried away’), wrote DeNora, (2000, p. 7).

As can be seen from the above quotes and narratives the metaphor of ‘transport’ in the sense of movement from one place to another can be used to describe the mothers’ experience. Hesitant in the beginning while going from the unknown to the known, in the end, the mothers walked stronger and more secure. Some hopes and desires had been sorted out and future signposts mapped. Moving on, they realized the importance of taking good care of their physical and emotional health, the importance of nourishing themselves, of being happy and of being around people who understood them. Whether by learning Spanish or by singing in a choir they realized that if they could make themselves feel good it would influence how well their families felt.

17.10 The diary

As presented in section 16.2, diaries, along with instructions for their usage, were given to the mothers when they visited the research site in the preparatory phase. The mothers were told that they could begin to use the diary in the time period between the first individual preparation meeting and the first music-caring session. At the end of each session, the therapist/researcher verbally encouraged the mothers to use the diary to privately reflect, both subjectively and objectively, on their experiences. At the beginning of each session, the mothers were asked if there was something in their diaries they wanted to share with the group. Five of the seven mothers used their diaries during the research period. After session #11 the researcher collected the diaries. She returned them to the mothers in their individual interviews in session #12.

The five mothers who used the diaries all found their own special way to do it. They wrote about personal matters that they did not share with the group. They also wrote about the music-caring sessions to a greater or lesser extent, from writing some thoughts about almost every session to only mentioning that the CD had been listened to a lot. One diary in particular had been meticulously used. Besides notes on that mother’s music-caring experience and her daily life, thoughts and feelings, the diary included photos and reflections on the questions for thought given to the mothers in the sessions. The first dates of the diary entries were as follows: 3 July 2006, 10 September 2006, 22 September 2006 (the day before the first music-caring session). In two of the diaries the first entries were not dated.

While discussing what she felt particularly helpful in her music-caring experience, Klambra spoke of how the diary somehow shortened the distance between her emotions and being able to talk about them in the group:

You have the freedom to express yourself but you restrain yourself a little or it takes some time to start, to decide that you are going to talk about this and that. The diary is very helpful in that respect. Then perhaps one starts to write something and that shortens the time it takes for one to start talking about it (SPI 001).

Klambra was of the opinion that diaries are practical tools to “express oneself from difficult emotions.” She would not have wanted to share with the group “just anything” she had written in it and worried that the therapist/researcher would ask the mothers to do just that (SPI 006). As mentioned above, the mothers were asked in every session if there was something they had written in their diaries that they wanted to share. None of them ever did that and they never felt any pressure from the therapist/researcher to do so.

As introduced in section 8.2 of this thesis, Pennebaker (1985, as cited in Barry & Singer, 2001) relates confining traumatic events to negative health outcomes. His theory of inhibition states that not sharing traumatic events requires physiological work that may become detrimental to one’s psychological and physical health. As Klambra mentions in her excerpt above, writing in a diary can, figuratively speaking, be thought of as sharing events.

According to Barry & Singer (2001), complex interventions are not always needed for restoring health. A tactic as simple as brief journal writing can be capable of providing temporal organization, increased understanding and sequencing thoughts and feelings, and has been associated with reduced psychological distress, decreased intrusive thoughts, decreased physical stress, and decreased long-term stress-related illness. Talking about her experience with the diary, Kristjana realized how writing in a diary could provide temporal organization, bearing witness to process and change:

I should have used the diary before as proof of a process and a change. I did not have any time when he (her son) was in intensive care (SP I 005).

Putting it on paper is like fastening it. The things you just say are gone. Like the diary, it fastens it a little and keeps it. Then you can always go back and

examine it you know. This is the way I felt and do I still feel like that? It is a certain form of healing to be able to say how you are feeling, but it is much better to be able to write it down and to look at it later (SP I 011).

Concerning different techniques of creative group work, Benson (2001, p. 223) advised people to write notes about exercises they participated in or incidents in the group, as an aid to discussion. He also advocated the use of journal writing as a way of helping members to communicate emotions that were too painful or compacted to be released verbally. Sharing thoughts about her use of the diary, Góa said:

The diary was very good. You had freedom to use it or not although [Valgerður] had stressed that we should write something in it about our experiences. In the diary, I wrote down the feeling I got that I did not want to know more about them [the mothers]. I feared that if I got to know them better they would change. Perhaps I had made them into goddesses. I wanted to have them like they were. In the diary, you could write about things you could not share in the sessions (SP II 006).

Using her diary as a container for thoughts and feelings that she felt she could not share with the group, Góa wrote in her diary on 7 October 2006: “Is the healing power of writing in the diary such?” Góa was referring to the fact that in the session of the same day she was capable of writing on the whiteboard the word “death”, a word which she was unable to share with the group the week before, because she feared the consequences. Between sessions, Góa used the diary to express her thoughts and feelings related to this challenge.

According to Yalom, clients “profit enormously simply from the experience of being fully seen and fully understood” (2001/2008, p. 18). For the therapist/researcher, having access to the diaries assisted her in more accurately glimpsing the mothers’ worlds, thus supporting some characteristics of an effective client-centred therapy as presented by Rogers, namely: accurate empathy, positive regard and genuineness (Brammer, 1979, p. 36; Rogers, 1980, p. 307).

On Saturday, 18 November 2006, Góa wrote in her diary four new poems that she did not share with the group. Góa’s complete diary was informative in many ways for the therapist/researcher. It was a validation from Góa of the importance of the music-caring group for her. It was a reminder of the challenging task of being sensitive to and receptive of the individual in the group. Furthermore, the therapist/researcher got to know a terrific woman much better than she would ever have been capable of based

solely on Góa's participation in the group. If the group had continued formally after the completion of the research, the information in the diary could have proved helpful from a therapeutic perspective.

17. 11 Concluding remarks

Part V of this thesis was devoted to data collection, interpretive phenomenological analysis and empirical explorations. Having transcribed, coded, and categorized the data, the therapist/researcher's interpretive account of the significance of the mothers' participation was delivered through various theoretical perspectives. A separate section of the chapter was devoted to the eight core categories: the group, musicking, songwriting, the CD, the therapist, me and my time, process – change, and the diary. Each category was formulated into a question that was then answered by elaborating on thematic statements that developed in the analysis.

Going through this process was like journeying in the unknown. New sensations, sights and sounds continuously revealed themselves. Yet the therapist/researcher always endeavoured to be clear about what she was doing and why she was doing it. She acknowledges her active role in identifying and reporting core categories and themes while providing an interpretive account of what it meant for the mothers to participate in the music-caring group. As only the participants themselves are experts on their own experiences, the therapist/researcher tried to remain true to the mothers' voices through verbatim examples used for illustration and support. The amount of verbatim data that was used in the analysis might be considered overly extensive but highlights the perceived importance of learning from the insiders' perspectives.

The research tool, interpretive phenomenological analysis through coding and categorizing was perhaps too flexible for a novice researcher. Evolving into eight core categories with 18 associated themes, some of which overlapped across categories, did not simplify the writing of the analysis. It challenged the therapist/researcher's creativity and knowledge base, while inductively and deductively dialoguing between the empirical data and theory.

Ruud suggested that one could use improvisation as a metaphor for understanding an individual. Improvisation can also be used as a metaphor for one's life and work. The novice researcher strongly relates to this idea and used it to conclude Part V of this thesis:

In improvisation, we often start from scratch, from some preliminary ideas we want to follow. Although we may have some broader ideas of where we want to go, we can never be sure of either the route to follow or the final goal. The whole process involves other people. The music we make is influenced by others in a circular manner, as are the plans for life we make. In the process, we may find a new tempo, transpose, take risks, and meet crises involving a possible breakdown in the improvisation – much in the same way as in life. ... Through the process of improvisation, we may come up with a product in a certain style, creating our own piece of musical identity, much in the same sense that personal identity is improvised and narrated (Ruud, 1998, pp. 28-29).

PART VI CONCLUSION

Part VI addresses the research questions which provided the focus for this study (presented in Part I) by synthesizing the relevant theoretical framework presented in Part II, the empirical explorations presented in Part V and other related research and theoretical perspectives which have informed this study after the completion of data collection and its analysis.

Part VI also discusses the research from the perspective of knowledge gained, possible limitations, implications for education and clinical practice and recommendations for implementation and further research in this area.

CHAPTER 18

MUSIC-CARING WITHIN THE FRAMEWORK OF EARLY INTERVENTION

When seven women meet then everything is important somehow. Also what they are saying [is important too], although one does not take it in or sympathize with it. Because when one respects each other, what the others have had to sound but I not, then one just listens to it respectfully. So no, there is nothing I would have wanted to leave out. It felt very good to play the drum and to release the anger. You know, just the whole thing, and even though I had not been angry then it was just good the same. I would not have wanted to have all sessions like that. I believe a mixture of things is best. We are also so mixed inside. You know, we are not just angry or in possession of strong emotions that we would like to get rid of. There are so many things, so many threads. This somehow creates one whole, everything we did. I miss them, I miss the music, just everything. Just to come here and there is such good music in the background and one meets you and that is enjoyable, everyone is smiling and you know everything just feels good (Esja SP I 008).

Describing her experience of music-caring, Esja felt that she did not exactly know what it was that created it. Having earlier compared it to a “hard to describe secret” she could not favour one thing over another. Esja experienced many threads, creating a whole working towards making her feel better and of becoming better aware of her emotions and of who she was.

Many threads were spun together from the beginning to the end of this study, creating a web of understanding which was about the lived experiences of Esja, Kristjana, Góa, Hanna, Einræn, Klambra and Skonza participating in a music therapy group introduced to them as music-caring. Following a hermeneutic phenomenological method, the therapist/researcher was also realizing her own lived experience. She had no given procedural system to follow: she had to be reflective, insightful, sensitive to language and constantly open to new lived experiences while realizing what that experience was. Despite feeling that she could still continue on a spiralling path, analyzing in an interpretive phenomenological way to understand the secret and despite thinking that she could speculate some more and bring in new theories to inform and develop the study further, the researcher’s challenge was to conclude this journey by

addressing the research questions which provided the initial focus for her research.

As stated in Part I of this thesis, the therapist/researcher was interested in undertaking research that would serve her as a music therapist, serve music therapy as a profession, and primarily benefit the chosen clientele. The therapist/researcher wanted to provide mothers of young children with special needs with a music-caring experience and from their perspective, their lived experience, develop an understanding of it. She wanted to find out whether the music-caring experience would affect the lives of the mothers in some way. Bearing in mind Stern's graphic model presented in section 6.2, she also wanted to find out if their experiences would possibly affect the way they related to their children. She wanted to learn from the mothers about the music-caring processes at work, and through disseminating the findings inform others working within the framework of EI (early intervention) of the possibilities of music-caring for therapy. Furthermore, the therapist/researcher wanted to use this learning experience to develop her own clinical practice within the field of EI. Designed towards this end, the study sought to find answers to the following research questions:

1. What is the experience of mothers of special needs children participating in a music therapy group introduced as music-caring?
2. How does the mothers' experience define music-caring?

In the preface to his book *Researching Lived Experience*, van Manen wrote:

To be sure there is no guarantee that our subjectively felt experiences are identical to those of other people. For example, if I experience pain or anxiety, then it seems as if this inner experience is so special and so undeniably mine that no other person could possibly understand and describe exactly what I have undergone. . . . Even for myself I can never fully give an account of what I experience in a particular moment or place. What belongs to my inner life seems quite beyond words. The most carefully crafted poem falls short. No one can quite feel what I feel. No one can quite see what and how I see, no matter how hard he or she may try. This means that in any particular situation we may not understand things as does the person next to us. And yet, within certain cultural limits and contexts we use the same words and the same language to describe our experiences. What, then does language describe? (1997, p. xii).

As Esja described it above, music-caring was the whole experience and for her to favour one aspect of music-caring over another was difficult. Being an experience hard to describe Esja was perhaps thinking and feeling like van Manen above when he wrote, “this inner experience is so special and so undeniably mine that no other person could possibly understand and describe exactly what I have undergone” (1997, p. xii). Van Manen provided four explanations about if and how language can describe our experiences:

1. Language is essentially social and it is only through the collectivity of language that we can access the experience of others as well as our own: “The unique and private qualities of inner experience will ultimately be beyond our linguistic reach” (1997, p. xiii).
2. Language creates and describes an intersubjective life world:

Thus we recognize differentiated possibilities of meaning that adhere to the socio-cultural context to which a given language belongs. Moreover our life worlds are made up of different experiential regions that border each other, partially overlap, and are nested within each other. ... Through phenomenological language we explore these experiential possibilities and we navigate life worlds and their hermeneutic horizons (ibid.).

3. “Language lets us know what is experienceable” (ibid.). Words are found which discover our inner experiences and vice versa. That is to say:

Through experiences we discover the words to which they seem to belong. ... certain words or certain expressions may hold personal meanings for an individual that no one else can ever fully grasp. In these senses hermeneutic phenomenology employs a heuristic of discovery: we discover possibilities of being and becoming (ibid., p. xiv).

4. The mode of discourse employed within hermeneutic phenomenology directs one towards intellectual or conceptual knowledge of things, as well as experiencing them in “corporeal, relational, enactive and situational modalities” (ibid.).

Thus, hermeneutic phenomenological method tries to “explicate” meanings that in some sense are implicit in our actions. We know things through our bodies, through our relations with others, and through interaction with the things of our world (ibid.).

Troughout this research, the therapist/researcher has to the best of her ability, tried to explicitly acknowledge her theoretical positions and values. Through the collectivity of language the mothers shared their life worlds, which were made up of different overlapping experiential regions. The therapist/researcher, as a participant observer, used interpretive phenomenological analysis as a research tool, and explored their experiences through hermeneutic phenomenological language presented in writing.

18.1 What was the experience of mothers of special needs children participating in a music therapy group introduced as music-caring?

However paradoxically it may sound to describe unique experiences, that was the task at hand and language the medium for doing so. Based on clinical and theoretical pre-undestanding, music-caring systematically explored in a new context developed an understanding of its core for these particular research participants. Through the collectivity of language, the mothers shared their 'life worlds', which were made up of different overlapping experiential regions. The therapist/researcher systematically explored their experiences, both the parts and the whole, and came to the conclusion that the whole of the music-caring experience for these mothers was about:

The group. Belonging to a joyful group honoured individuality and the freedom of expression, a group where an atmosphere of trust was conducive for diminishing defences, creating empathetic understanding and support. Encouraging the sharing of ideas, thoughts, and feelings, the group built awareness and strength, gave possibilities and perspectives. Belonging to the first music-caring group also created a feeling of anticipation and gratefulness.

Musicking. Musicking brought joy and beauty, change and possibilities, as well as encouraging a relaxing, welcoming and caring atmosphere. Musicking together brought closeness, supported empathetic listening, and an empowered awareness of emotions by facilitating and deepening emotional expression.

Songwriting. The challenging yet enjoyable experience of songwriting gave structure, shape and perspective, honoured individuality and strengthened self-identity.

The CD. The CD was a momento capable of preserving the emotional tone of the music-caring group and validating the mothers' emotional journeys.

The therapist, whose character of intuitive sensitivity and deliberate, reflective calmness was conducive to the mothers' feelings of safety and being taken care of.

Me and my time. Realizing the importance of having quality time for oneself, a quality time through which one could strengthen one's self-identity and well-being for the benefit of the whole family.

A process and change. A process and a personal change towards greater awareness about needs, thoughts and feelings.

The diary. A diary that served both as a container and a mediator: A container for various thoughts and feelings that arose in and between sessions and that the mothers chose not to share with the group, either because they were thought to be too difficult or because they were thought of as trivial.

Discussing what makes phenomenon a phenomenon, van Manen wrote:

For purpose of clarity we need to make the distinction again between incidental themes and essential themes. Not all meanings that we may encounter in reflection on a certain phenomenon or lived experience are unique to that phenomenon or experience. And even the themes that would appear to be essential meanings are often historically and culturally determined or shaped. ...In the process of apprehending essential themes or essential relationships one asks the question: Is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon? Does the phenomenon without this theme lose its fundamental meaning? (1997, p. 106-107).

It could be argued that all eight core categories listed above were essential for the mothers' lived experience of music-caring. However, their order of importance for each mother and the group as a whole may have been arranged from the most significant to the ones regarded as incidental. Also, for some mothers belonging to the group may have weighed more in the overall music-caring experience than the musicking itself at one time or another and vice versa. The importance of the category 'me and my time' could have been realized in a group where there was no music and in any effective therapeutic group, 'process and a change' may be experienced. Furthermore, the positive benefits of the diary as expressed in this group are not regarded unique to this experience. Thus without the incidental categories of me and my time, process and change, and the diary, the mothers' experiences would perhaps not have lost their fundamental meaning (despite Esja's words above).

18.1.1. Validation

As discussed in section 17.1, getting feedback from informants is one possible tactic for testing and confirming qualitative findings. On 16 September 2010 (see Appendix T) the mothers were sent an e-mail asking them to read an attached document introducing them to the researcher's analysis of core categories and related thematic statements. They were encouraged to express their reaction to this in writing (via e-mail) or verbally during an informal meeting planned by one of the mothers for 24 September 2010. It was hoped that in this meeting discussions would evolve around the researcher's 'hermeneutic ability' to interpret their lived experience or the phenomena of their 'life world'. At the time of the meeting, only two of the mothers had read the compilation of the research findings. It was thus decided not to initiate any discussion about it. Instead, another e-mail was sent to the mothers on 30 September 2010 (see Appendix T). In this letter, the mothers were thanked for a wonderful evening together and reminded of the important task of validating the research findings. They were again asked to read the researcher's compilation of categories, themes and supporting quotes, sent to them as an attachment and to comment on the impression(s) they got when reading it. If they had any questions they were encouraged to contact the researcher. The researcher received e-mails from the mothers dated approximately three years and nine months after the completion of the final interview.

The instruction given to the mothers for validating the research findings was deliberately kept simple and non-directive. They were given the opportunity to examine the research and comment on the collectivity of language used for exploring the "unique and private qualities of their inner experiences" and how language was used to create and describe the intersubjectivity of their music-caring experience.

Written permission was obtained from the mothers to present their answers/validation verbatim (Appendix U) below. The mothers' validation was translated from Icelandic to English by Dr. Lilja Ósk Úlfarsdóttir.

Skonza

Sorry, I completely forgot about this. Hopefully I am not too late. I read the document yesterday while cooking the rice porridge, nice to have something to read while you stir.

I am not completely sure what you are asking for, but as I was reading this, all these emotions bubbled up that I was dealing with during that time and how far I have come with all this by now. I got tearful a few times while reading and when I read

the answers from the others, then I understood completely what they were talking about and they worded it so well and I agreed with them. I think you have analysed this very well and your sensing of it is right on, the sorting and all that.

If you want something more or more details then get in touch.

brgds. Skonza

Klambra

I had many reactions from reading the text.

Caring.

A considerable time has passed since the days of music therapy in Hátún. I think about that time with warmth and respect. We have kept in touch and the group holds a very special place in my heart. We have enjoyed many a happy moment together on various occasions, home invitations, theatre, cinema, dining out, coffee shops, hikes and trips to a summerhouse that one of us owns. We are all friends on Facebook. Are continually getting to know each other better and joy and caring dominate the group.

Curiosity and introspection.

I felt curiosity and excitement when reviewing the quality time and reflections of the group. Excited to figure out who had what pseudonym. Wondered about my own reflections; I remember that I tried to just be myself and not to ‘dramatize’ or make something up, but to let the emotions flow although they often reflected insecurity. Caution against motor-mouthing was perhaps needlessly strong at times in my responses (but I am in fact usually not very verbal). The manner of speech I used was not very high quality at times (a lot of “one does”, “one thinks”...). Different also to see this in English.

Three remarks about matters of interpretation:

In the section ‘Songwriting was a creative challenge’ I am describing ‘the performance’ itself, that is to say to perform for the group, which was a big step and challenging but the creative part itself was first and foremost exciting.

In Klambra’s account when I ask myself whether I am doing enough, (“There is always some conflict ...doing enough or not enough ...”), I am referring to the tension whether I am really doing everything I can in **training my child**, while he is young and receptive.

In the diary I thought the following was odd: “You do not have to be present when someone reads the diary. Someone can read it and I do not know how you react to it”. Could perhaps rather be: You may not be present when someone reads (your) diary. Someone can read it and I do not know how he reacts to it??? Or what? Can’t actually remember how I worded this in Icelandic.

Contemplation about development.

During the reading, delicate feelings came back to me and [it is] tempting to try to compare how I feel now with how I felt then. What has been gained?

How desirable it would be to be less inhibited, more open and less afraid, both then and also now! All in all, evidently much water has passed under the bridge and I consider myself involved in continued work with myself. Am on a long journey towards increased development, well-being and confidence.

How good it was to play.

The instruments were wonderful, that will not be forgotten. Particularly strings and xylophones. Now I will collect fun small instruments. Have recently acquired a small tabletop harp, Jewish harp and ukulele. The spark is of course the music therapy way back then and I want to extend the chord in this way.

Respect and gratitude.

I remember how generous and supportive it was to participate in the project and how much warmth characterized the togetherness in the group. It was a privilege to get to know the others' reality and to be trusted with their emotions and experiences.

Nobody has delved as deeply as the thesis-carpenter and my thoughts often go to her work around this project, which calls for incredible accuracy and is executed with unique sensitivity and warmth. It is very fortunate to have come into contact with such talented, giving and solid music therapist with whom my child now also gets to blossom.

It is a great living treasure to have had a part in such special supervision and personal work and to be able to look back and see what a beautiful journey this was and experience how the growth and friendship that I am still harvesting gives me plenty.

Heartily thanks.

Góa

Can I send this to you like this? ...

I opened my mail late in the evening and could not resist just checking the content. I was drawn into the narratives and could not stop reading. Soon I figured out what pseudonym was referring to me (had forgotten about it) and read with acute attention what I had said and written. Then later I read the complete text more carefully, regardless of who was speaking. I was checking whether I recognized what was related from what I said, and most of it I remembered, although not everything, but it was all correct and came back to me. The analysis that was put forth is complete and good.

The feeling I felt while, and particularly after, reading was surprising. I felt sadness, but did not realize completely what was causing it, but it was leaning towards the idea that the

difficult and mournful feelings that I had dug up and fought with while the music group was running would be the explanation. That I was experiencing again the feelings that had been bursting within me in 2006. When I think more carefully about it I rather think that was mourning these intense music therapy sessions. They are in the past. Although we women in the group meet regularly, the music part is missing. The music started all sorts of things and the structure that the sessions had is of course not there when we meet today. It is certainly something I miss. That I feel intensely when I read my own narrative of the experience of this time.

But I don't only experience sadness when I look at this. I am also very grateful for having participated in this project, and to have got so much out of it at the time. It was an influence that lasted a long time and is still there, although I have not done everything I anticipated at the time and intended to do. And yet again, it is a nudge to have to think a bit, look at the past, think about the future. Can I still draw something good from this experience? At least I know that I would repeat the game in an instance if it were offered.

Wit best regards, Góa.

Hanna

My dearest Valgerður!

Now I have read through and enjoyed:)... Really nice to recall this... I felt a little bit like crying even sometimes during the reading:)... This was a really good time – lovely... and our friendship is witness to that!:) Hurray for kazoo-ladies!

I can truly say that I feel everything is correct and rings true in what you have written. Completely. Fantastic summary you have made, correct and true to you, the material and us.

Funny also that I can also see through with me that I was still in a bit of denial – well not seriously ...maybe rather repressed... trying to be strong... trying to survive... not to be afraid – be positive – strong and merry. But that is in a way characteristic of me although I can of course also be sad (like today – really sad somehow today:(

Yes, thank you my dearest Valgerður – you are a lump of gold.

Hugs and good luck with finishing,

Xxx

your Hanna

Kristjana

I have read this twice now and there are very special and mixed feelings that arise. There is much emotional turmoil. Special feeling that comes after the reading. A bit uncomfortable, but still not really.

I agree with the way you group and subgroup our experiences. Now I am going to look back:

The group is clearly very important and how we managed to connect internally [is also important]. The dynamic in the group when it met was of course unique. It is not always a given that you open up like this with your feelings about your baby and yourself and are able to tell how you feel, even without embellishing, softening or simplifying the facts because the group was comprised of women who were in similar positions and had similar feelings and we could empathize with each other.

It was also amazing to get the opportunity to put certain emotions into music, to let them sound. Whether it was feelings that one wanted to play away or hold on to. It was a method that I had never tried. To make music together reinforced our ties as a group. Although everyone was doing it for themselves we were also doing for each other and empathizing. That is what I felt. Then I am referring to the music making and song and lyrics construction.

This was my time. I did this for me and it felt good to do this for me. This was clearly MY time and it was important.

It was rummaging in emotions and it was often difficult but when time has passed then you see that it was good.

A lot remains in the mind and it is also incredibly fun to have left lasting and earthly memories (the CD). You can recall, look back and see that you have progressed.

I have not looked at the diary, I don't want to, at least not yet. I can't remember what I wrote, but it was the sentiment of that day and that time. It is good to be able to write to break away from emotions and thoughts. It is a relief. I think I did break away from certain emotions and difficulties through writing.

The therapist is so very important. The person and how she approaches the group and treats it and the stuff that comes from it. The outcome would no doubt have been different with another therapist. Our therapist is a unique person who has especially good presence, inspires confidence and warmth. Our therapist is as important as the group but that is because she (the therapist) is who she is. It is like some sort of aura surrounds her, good beautiful aura.

I am grateful for having been able to participate. I am richer for having got to know these fantastic mothers and you, Vala.

Good luck with your thesis dearest Vala, I hope I did understand you correctly and that I am replying in the manner that I was expected to.

Kristjana :-)

Einræn

Dearest Valgerður, sorry how late I am replying! I have to admit that I was dreading a bit to read this through as I was feeling really bad in the beginning when we all met. At first uncomfortable feelings arose during the reading but that soon passed. It was fun to

recollect many things like making lyrics, music and then to see that this changed things as we got closer and got to know each other better. Yes some unbelievable impressions formed that are difficult to describe without experiencing them personally. I thought of all this in retrospect an incredible ‘tool’ if you can call the music caring that which can have much positive effect and then of course to acquire the whole group as friends. I don’t know what else to say but all positive and good.

Love, Einræn.

Esja

How do you do Valgerður

I have read through from you and can’t but admire you.

I do so agree with what emerges and especially what I said (of course...)

I don’t know what I wrote more about this but the group, the tone, the songs and everything merged to make me feel better and overcome various mental ailments (e.g. the paranoia) and led me to understand what music has done for me since I was a little girl. That was perhaps the big magic, I just think that the music has kept me alive and particularly the Mozart picture as I had discussed with you.

This is fantastic and can hopefully be realized so that others may enjoy.

Best regards, Esja.

“If researchers want to claim that their constructed interpretations of the realities experienced by their participants are credible, it is important for these participants to have the opportunity to comment upon them,” wrote Aigen (2005, p.359). That is what the mothers have done above by validating one stage of the therapist/researcher’s study, namely her interpretive analysis (Kvale, 1996, p. 237). The mothers “agree with what emerges,” supporting the concluding discussion of this thesis.

The therapist/researcher has allowed herself to group together under one subheading the core categories: *the group*, *the musicking*, *the songwriting* and *the CD*, discussing them jointly. The category, *the therapist*, will stand separately and include some speculation about the concept of care. The ‘incidental’ categories of *me and my time*, *process and change*, and *the diary* will be discussed together. Chapter 18 concludes by providing an answer to the second research question namely, how the mothers’ experience defines music-caring in this research context.

18.1.2 The essential categories: The group, musicking, songwriting, and the CD

The group	Musicking	Songwriting	The CD
<p>The group created a feeling of belonging.</p> <p>The group built trust and diminished defences.</p> <p>The group honoured individuality and the freedom of expression.</p> <p>The group gave perspective.</p> <p>The group created empathetic understanding and support.</p> <p>The group created possibilities for building awareness and strength.</p> <p>The group created a feeling of joy, anticipation and gratefulness.</p>	<p>Musicking created a relaxing, welcoming and a caring atmosphere.</p> <p>Musicking brought joy and beauty.</p> <p>Musicking brought closeness and supported empathetic listening.</p> <p>Musicking empowered awareness of emotions.</p> <p>Musicking facilitated and deepened emotional expression.</p> <p>Musicking brought change and created possibilities.</p>	<p>The songwriting process gave structure and shape.</p> <p>Songwriting was a creative challenge.</p> <p>Songwriting was an enjoyable experience.</p> <p>Songwriting gave perspective.</p> <p>Songwriting honoured individuality and strengthened self-identity</p>	<p>The CD was a memorabilia of a completed task.</p> <p>The CD preserved and brought back the emotional tone of the music-caring group.</p> <p>Listening to the CD created a soothing feeling, a feeling of gratitude, and brought joyful memories.</p>

In the empirical explorations (Part V of this thesis), the different themes in the core category *the group* were discussed from the perspective of Stern's motherhood constellation and needs connected to the supporting matrix theme and the identity reorganization theme (1985), group dynamics and processes, the concept of empathy, positive psychology, play, and the helping relationship/facilitating environment.

The core category of *musicking* was discussed from the perspectives of developmentally informed theories, musicking as defined by Christopher Small, the concepts of affordance and appropriation as presented by Tia DeNora, theories on quality of life, positive psychology, reflection on music and emotion, the helping relationship and empathy, and play and creativity as explained by Winnicott.

Songwriting was discussed from Yalom's notion of a structured exercise, Csikszentmihalyi's theory on flow, and some speculations on the personal and the social self and the formation of self-identity (the social psychology of music).

The group

The mothers' participation in the research was voluntarily and sparked by their interest to work with emotions and music. When their children grew older and the life-changing nature of their children's disabilities settled, the mothers'

feelings and needs may have changed. Progressing through stages of loss, they may have realized some unhappiness, recognized unfulfilled needs and the fact that change was necessary. When introduced to the possibility of participating in the music-caring group, they were ready to take some risk if it could possibly help them to work with emotions.

As revealed through the thematic analysis, the music-caring experience for these mothers was about this particular group, which was joyful, and honoured individuality and the freedom of expression. An atmosphere of trust was conducive for diminishing defences, creating empathetic understanding and support. Encouraging the sharing of ideas, thoughts, and feelings, the group built awareness and strength, gave possibilities and perspectives. Belonging to the first music-caring group also created a feeling of anticipation and gratefulness.

Discussing what defines caring (see section 9.1), the therapist/researcher stated that in a therapeutic relationship it is the person's sense of being cared for which is perhaps the single most important therapeutic factor. This factor (a caring therapist-client interaction) is identified by a therapist who is available for the client and recognizes the client's uniqueness by listening and responding to him/her as such. This caring, individualized concern for the client results in him/her feeling comfortable, secure, at peace and relaxed (Benner & Wrubel, 1989; Halldórsdóttir, 1996).

A caring relationship occurs in a context and this context is central. The music-caring experience would have been different with other mothers in it. Klambra felt, just like the therapist/researcher, that it was remarkable how quickly the group connected (Klambra, SP I 001). Perhaps the main reason for that was that the mothers got an outlet for feelings in a group of people who were dealing with the same issues: "To realize that you are not alone in the fight as if you were a leper" (Esja, SP I 003). So they were focused on being open. Feelings emerged and merged, and they were capable of receiving from each other and giving back (Einræn, SP I 004; Góa, SP I 001; Skonza, SP I 001). Feeling herself making a difference, making something permanent and leaving something behind was very good, said Kristjana (SP II 007). To be able to give and to feel valued was in itself a healing process.

The music-caring group provided a much-needed social networking opportunity for the mothers, supporting research findings that advocate group-based interventions over individual interventions (Dunst, Trivette & Deal, 1994, as cited in Niccols & Mohamed, 2000; Cunningham, 1995, as cited in Niccols & Mohamed, 2000). Based

on commonality of experience where ‘feelings merged’, they developed intersubjectivity and a sense of belonging which encouraged disclosure and enabled empowerment through the act of helping others.

The mothers’ experiences confirmed research studying effective support groups and parent-to-parent groups. In these groups, participants are matched with a parent who has been trained as a helper. The common bond between the helper (the trained parent helper) and the helpee facilitate intimate emotional sharing, instrumental in acknowledging feelings, giving social support, enhancing coping, and strengthening families. The most important factor in a parent-to-parent programme and support groups is the emotional support realized by having someone who shares experiences listens and understands. Researchers also hypothesize that psychological closeness and mutual caring among personal networks could have competency-enhancing effects affecting parental attitudes, perceptions of children, family functioning, the quality of parenting style and parental well-being (Dempsey, 2008; Dunst et al, 1997, as cited in Hooste & Maes, 2003; Hodapp, 1995, as cited in Hooste Maes, 2003; Guralnick, 1998, 1999, as cited in Hooste & Maes, 2003; Kingston, 2007; Santelli, Turnbull, Marquis & Lerner, 1997; Singer, Mardquis, Powers, Blanchard, Divenere, Santelli, et al, 1999; Whiteman & Roan-Yager, 2007).

In the music-caring group there were seven mothers who listened, and shared experiences, and empathetic understanding. The abundance of psychological closeness (the ‘common bond’ mentioned above) and mutual concern and caring built awareness and strength, gave possibilities and perspectives, and created anticipation and gratefulness. In her validation, Klambra wrote:

I remember how generous and supportive it was to participate in the project and how much warmth characterized the togetherness in the group. It was a privilege to get to know the others’ reality and to be trusted with their emotions and experiences.

For the therapist/researcher, this group felt perfect, so for her it would have become a different experience with different mothers. She felt like she could not have chosen more ideal participants, even if she had chosen the participants herself. Perfectly complementing each other, the mothers’ characters and way of being seemed in harmony and facilitated effective interaction. It could possibly be argued that based on a ‘common bond’, any music-caring group with five to ten mothers of special needs children in it, and planned in a similar way, would

function similarly well. Nevertheless, a different group would have created a different atmosphere, different interaction and could perhaps have become more challenging in various ways, particularly from a therapeutic perspective. Einræn realized this. When asked whether she would participate in a new group if given the opportunity, she said: “Yes, very much so. It would be different to participate in a new group. I would prefer meeting the same women” (SP I 008). Emphasizing the uniqueness of each therapy group and of each therapeutic process, Yalom wrote:

Every therapy group, with its unique cast of characters and complex interaction, undergoes a singular development. ...Given the richness of human interaction, compounded by the grouping of several individuals with maladaptive styles, it is obvious that the course of a group over many months or years will be complex and, to a great degree, unpredictable (Yalom, 2005, p. 309).

Research confirms that not all parent groups show evidence of benefits for all participants (Krauss, Upshur, Shonkoff & Hauser-Cram, 1993). There are negative cases to be found where mothers feel compelled to listen to the complaints of others or are obligated to share their feelings before they are ready to do so (Affleck et al, 1989, as cited in Krauss et al, 1993). Esja and Kristjana talked about how difficult it was to take in all the stories and to realize how the world could be unjust. Having overcome their sorrow, it was difficult to put oneself into the shoes of others who were experiencing enormous difficulties (Esja, SP I 001; Kristjana, SP I 003-004). Esja also mentioned that there were some things she did not want to discuss with the group (Esja, SP I 001). Concerning when and what kind of help was needed, Kristjana said that something was needed the first two years with a disabled child. Having wanted something for herself at that time, Kristjana said that because she was so confused when her son was first born, perhaps she would not have accepted that help (Kristjana, SP I 001). Esja was of the same opinion that she would have wanted something for herself earlier, when enduring all the difficulties she had with her daughter. However, Esja thought that music-caring at that time would have worked differently for her. Then she would not have participated in order to strengthen herself but in order to “go through the trauma,” as she put it. Not having wanted to go to a psychologist at that time to talk about how bad she felt, Esja believed that music-caring would have done her good by recognizing and acknowledging her own feelings in and through music and sound.

Instead of sitting with a psychologist and talking about oneself, emotions would have found an outlet in the music and such. One would have needed to stay with the feeling and to sound it. I think that would have been very good, some sorrowful tones; to acknowledge the feeling and recognize it. Because when you were in it you never said if someone visited: oh, I feel so bad. You know, one does not put it forth like that. Perhaps one told a friend what was happening and such but you never told it in bare words (Esja, SP II 005).

Both Esja and Kristjana suggest the possibility of a different form of music-caring perhaps less expressive and more receptive, focusing on recognizing, acknowledging and affirming feelings.

Self-psychology, devised by Heinz Kohut,²⁷ is based on the idea that something within us (a self), which one experiences as a structure, keeps things together in our life. The birth of a baby with a disability has been described as a trauma that can cause a feeling of being disconnected not only from society, but also from the flow of one's life, which all of a sudden may feel like falling apart. The 'inner structure' becomes disintegrated, and psychic disturbances may arise. According to self-psychology, individuals are driven by an inner force which struggles to create interpersonal experiences that can awaken, maintain and develop the individual's sense of having a coherent self. Self-realization is a basic human motivation and people are driven by a wish to feel whole, vital, valuable and understood by significant others.

With the birth of a baby with special needs, one may knowingly or unknowingly forfeit personal motivations and wishes. By changing the way one feels or thinks about oneself, defence mechanisms may take over and feelings of being disconnected not only from society, but also from the flow of one's own life, emerge. Perhaps there is no one in a person's family or social network who can share similar experiences or provide the right model to follow (the supporting matrix theme and the identity reorganization theme, discussed in section 6.1 (Stern, 1995)). In a state of shock, one feels abandoned and wanting as a parent, and all sorts of feelings may compromise parental capabilities as well as one's self-identity.

²⁷ The psychoanalyst Heinz Kohut (1913-1981) first conceptualized a psychology of the self. "Self psychology was the first major psychoanalytic movement in the United States to recognize the critical role of empathy in explaining human development and psychoanalytic change. ...Kohut's work has developed into the study of self- object experiences, experiences (usually with other people) that nourish the self and which define the experience of the self and self-esteem." <http://www.selfpsychology.com/whatis.htm>

People are driven by the wish to feel whole, vital, valuable and understood by significant others. According to self-psychology, our relation to others, our ways of tuning in with others in a mutual 'being-with' should be emphasized in a self-psychological approach. "Kohut termed any dimension of an object that had the function of supporting ourselves 'self objects'. Such self objects had to do with the subjective aspects of anything that could maintain, support, restore, or confirm the self" (Ruud, 2003b, p. 116; 2010, p. 175). According to Kohut's theory, a self object could denote other people which through certain actions and ways of being support the individual's experience or sensation of having a self²⁸. In this way, other persons perform self object functions by giving individuals a sense of vitality, coherence, safety and capability. Based on commonality of experience where feelings merged the mothers performed self object functions for each other throughout the music-caring offered to them, developing inter-subjectivity and a sense of belonging. They did not consider themselves to be passive beneficiaries of group cohesion, but as generators of that cohesion, creating durable relationships. They had belonged to groups, had had a group history, and now all of a sudden in their new constellation they did not belong anymore. Thus the sheer successful negotiation of a new and fulfilling group experience where they experienced the sensation of having a self, may in itself have been therapeutic. The mothers' new and developing selves may have contributed to the feeling of being "whole and continuous in time and space", (Ruud, 2010, p. 175) which encouraged disclosure and the felt sense of vitality, coherence, safety and competence. Belonging to the group raised self-esteem and met members' dependency needs, but in a way that also fostered responsibility and autonomy, as each member contributed to the whole group's welfare. This supports Rolvsjord's finding from 2007, which emphasized the importance of nurturing the client's strengths and competences through collaboration rather than intervention in a resource-oriented approach to music therapy (p. 233).

²⁸Kohut deliberately did not define the self and explained his reason for not doing so in the following way: "My investigation contains hundreds of pages dealing with the psychology of the self - yet it never assigns an inflexible meaning to the term self. But I admit this fact without contrition or shame. The self is, like all reality, not knowable in its essence. We can describe the various cohesive forms in which the self appears, can demonstrate the several constituents that make up the self ...and explain their genesis and functions. We can do all that, but we still will not know the essence of the self as differentiated from its manifestations." <http://www.psychologyoftheself.com/kohut/>

The mothers' genuineness, their unconditional positive regard and the empathy they were capable of are all qualities that have been emphasized as among the most important aspects of a positive therapeutic relationship (Brammer, 1979; Rogers, 1961; 1980; Rolvsjord, 2007; Yalom, 2001/2008). The mothers talked about anticipation, positive excitement and gratefulness for having been part of the group. Becoming socially involved in a resourceful group, where empathetic and growth promoting climate prevailed created joy, encouraged openness and strengthened the bonds between the mothers. According to Kristjana:

The group is clearly very important and how we managed to connect internally [was also important]. The dynamic in the group when it met was of course unique. It is not given that you open up like this with your feelings about your baby and yourself and are able to tell how you feel, even without embellishing, softening or simplifying the facts because the group was comprised of women who were in similar positions and had similar feelings and we could empathize with each other (from Kristjana's validation above).

Thus the music-caring group can be viewed as a confronting coping or positive reappraisal device (described in section 7.2) leading to personal growth and increased well-being (Dunn et al., 2001; Lazarus & Folkman, 1991).

Another important aspect of the quality of group outcome is the positive emotional character or 'internal group harmony'. As introduced in section 17.2 Frederickson's 'broaden and build theory of positive emotion' emphasized the importance of positive emotions in our lives as they have the capacity to encourage well-being and flourishing. Frederickson argues that while negative emotions narrow people's perspectives and keep them focused on the specific problem at hand (e.g. flight or fight), positive emotions broaden people's likely thoughts and actions as well as their behaviour. In other words, when we are experiencing positive emotions we have more behavioural flexibility and this allows us to build intellectual and psychological resources. When feeling positive we are more likely to be inquisitive, to learn, to explore and to be creative than if we are negative (Fredrickson, 2009).

Musicking

It was not only the group itself that was joyful and honoured individuality and the freedom of expression. Musicking in the music-caring group brought joy and beauty, change and possibilities, as well as fostering a relaxing, welcoming and caring atmosphere. By facilitating and deepening emotional expression

musicking together created closeness and an empowered awareness of emotions, and supported empathetic listening.

As previously stated, it was through the commonality of experience that the mothers served self object functions for each other as inter-subjectivity and a sense of belonging developed. According to Ruud, it is not only people, but also cultural concepts such as music, which can serve important self object functions (Ruud, 2010, p. 175). Thus in the music-caring group, the mothers had access to an additional self object, namely that of musicking.

Through musicking, a chord was created which Klambra wanted to extend, and Góa wrote in her validation that although the women in the group met regularly, she felt the musical dimension was missing: “The music started all sorts of things and the structure that the sessions had is of course not there when we meet today.” Esja’s participation led her to understand what music had done for her since she was a little girl: “That was perhaps the big magic, I just think that the music has kept me alive and particularly the Mozart picture as I had discussed with you.”

Besides being instrumental in establishing a strong therapeutic relationship, the joy and beauty the mothers felt while musicking may have provided regulation of the sometimes intense emotions experienced and expressed by the mothers. But in the context of the music-caring group, the mothers clearly felt capable of expressing any type of emotion, which the music started or created as Klambra and Góa put it.

The music’s powers to instigate emotion are constituted by the actors themselves, wrote DeNora: “the music’s power derives from the ways one interacts with it” (2001, p. 169). Appropriating the psychologist James J. Gibson’s notion of affordances, the sociologist Jürgen Streeck (1996, as cited in DeNora, 2000, p. 39) argues that material objects possess properties that can be lent to some uses more easily than others. Thus one should focus on ‘how to do things with things’ or the interactions between people and things. So whether one adheres to Gibson’s conception of affordance, which talked about how objects afford things independently of how users appropriate them (comparable to the use of music as therapy) or one thinks of the concept more reflexively, whereby “an object’s affordances are constituted and reconstituted in and through projected courses of action within settings” (Anderson & Sharrock, 1993, pp.148-149, as cited in DeNora, 2000, p. 40) (perhaps more in line with the use of music or musicking in therapy), musicking can encourage a variety of

world-making activities. “[Musicking] is a workspace for semiotic activity, a resource for doing, being and naming the aspects of social reality, including the realities of subjectivity and self” (DeNora, 2000, p. 40). The mothers were capable of using musicking to regulate, enhance and change the qualities and levels of their emotions. They became aware of how music had affected them emotionally. For the first time, they became consciously aware of how music could be used to express emotions, both for oneself and for others (in collaboration and through shared responsibilities):

It was also amazing to get the opportunity to put certain emotions into music, to let them sound. Whether it was feelings that one wanted to play away or hold on to. It was a method that I had never tried. To make music together reinforced our ties as a group. Although everyone was doing it for themselves we were also doing it for each other and empathizing. That is what I felt. Then I am referring to the music making and song and lyrics construction (from Kristjana’s validation).

The mothers also became interested in using musicking in the future to afford mood regulation. When writing about how good it had been to play, Klambra said:

The instruments were wonderful, that will not be forgotten. Particularly strings and xylophones. Now I will collect fun small instruments. Have recently acquired a small tabletop harp, Jewish harp and ukulele. The spark is of course the music therapy way back then and I want to extend the chord in this way (from Klambra’s validation).

The mothers’ musicking together “which took them to so many places” (Esja, SP II 008) afforded the possibility to create and maintain a variety of emotions as they were actively constructing their own ability to be moved by it. Musicking afforded self object function as it enabled the mothers to ‘know and musically report’ on their own emotions as well as those of others, much more effectively than was possible through words alone. Like for example Klambra said when comparing groups with and without musicking:

It is much more personal with the music and much deeper. Just by sitting here and listening to a beautiful song or when singing together a beautiful song. You find how it stirs up the emotions. Music just has this quality and the creation also [musicking]. There is no creativity in the other group. That

is completely different. It is much more personal and intimate with the music (Klambra, SP III 005).

To give the mothers an experience of being empathetically understood was a process towards the reparation of the self and an important function of music-caring.

Pavlicevic wrote about improvisation and its opportunity to re-create ways of being. It enables the therapist and client to experience:

...how it feels to be in the world within an environment that has potential for playing, for fun, for abandonment and for personal growth, in whatever dimension that growth needs to take place. Part of this personal growth may involve ...intentionality in vocal sounds; ...it may be an opportunity to express difficult or taboo feelings; it may be about freeing oneself from inhibiting constraints imposed by families or society – and so on (1997, p. 134).

Alanne (2010) found that music psychotherapy with three refugee survivors of torture increased the consciousness of patients regarding their traumatic experience. The three subjects responded positively to their music therapy treatment and demonstrated some improvement despite varying degrees of satisfaction. Music was perceived as related to positive imagery and pleasurable experiences, and as an aid in calming and relaxation.

Smyth emphasized the importance of creativity in the process of healing after victimization. Associating victimhood with helplessness, silence and dependence, she stressed that the victim must become an active participant in the healing process. Gaining insight and understanding by processing events creatively is one way of doing that, Smyth argued (2002, p. 57). Through musicking in the music-caring group the mothers both receptively and expressively explored their thoughts and emotions creatively.

Emotional creativity has been defined as “the ability to experience and express novel and effective blends of emotions” (Averill & Thomas-Knowles, 1991, as cited in Ivcevic, Brackett & Mayer, 2007, p. 204). It is highly correlated with openness to experience and involves the ability to generate new emotional reaction. According to these authors, three criteria may be used to evaluate a creative response (people’s emotional creativity): 1) Novelty when compared to a person’s past behaviour or to typical behaviour in society as a whole. Learning and development may involve an acquisition of novel behaviour and thus some degree of creativity. 2) Effectiveness when considered of a potential benefit to

the individual or the group. Effectiveness involves achieving an aim inherent to the emotion or its appropriateness and beneficial consequences when shared. Emotions, that do not have aims beyond themselves, such as joy or grief, fear or fearlessness, can be expressed well or inadequately, suitably or unsuitably. 3) Authenticity as an expression of the self. A creative expression or a response is authentic when it is alive with new possibilities and when it reflects personal experiences, values and beliefs. “Conversely, an inauthentic response is a copy or caricature; cut off from the source of its vitality, the self, it leaves little room for further development” (ibid.; Averill, 1999, p. 333). The following quotes from Hanna (previously cited in sections 17.3.4 and 17.3.5) may be an example of emotional creativity with measures of novelty, effectiveness and authenticity:

To sound an emotion through the music also gave an unexpected emotional outlet and a liberating feeling. I also experienced emotional outlet through the expression of another mother that was expressing something else (Hanna, SP I 002).

When you speak the emotion people just have to imagine something based on what you are saying. That is different, much different. When talking, one tries to avoid saying this and that. There are certain standards what one can speak about and one cannot - how one can behave and how one speaks. ...I could talk about what was bothering me, my main issue at that time, and then play it and in that way get rid of it somehow. That felt terribly good to me. Somehow I got rid of it out of my system (Hanna, SP I 005).

Csikszentmihalyi defines creativity as “any act, idea, or product that changes an existing domain, or that transforms an existing domain into a new one” (1996, p. 28). He defines a creative person as “someone whose thoughts or actions changes a domain, or establishes a new domain” (ibid.). It may be argued that the music-caring group was an act of emotional creativity as it seems to have brought some effective change to the mothers’ lives as they jointly created it. Musicking being a method she had never tried before (novelty) “every one was doing for themselves” as well as “for each other and empathizing” (authenticity) Kristjana wrote in her validation. According to the above definition, the mothers were acting as creative individuals as their thoughts and actions influenced change both within the music-caring group and beyond it.

Winnicott wrote:

It is a creative appreciation more than anything else that makes the individual feel that life is worth living. Contrasted with this is a relationship to external reality which is one of compliance, the world and its details being recognized but only as something to be fitted in with or demanding adaptation (1971/2005, p. 87).

Defining primary creativity as an innate drive towards health, Winnicott places the roots of creativity at the very beginning of life and at the heart of the mother-infant relationship (Abram, 1996, p. 105). In this relationship musicking takes place. Even before birth, the child is capable of identifying, comparing, remembering and making contextual identifications of sounds. Perhaps our capacity for auditory perception of acoustical nuances was an evolutionary process concerning aspects of sound that are basically musical in nature. DeNora (2000, p. 37) wrote that we cannot talk about a foetus's sense of what the music signifies because there are no social relations, no assigned meaning in a foetus. One may however, speculate that for the unborn baby music could be an active ingredient in the organization of the self, the shifting of mood, energy level, conduct style, mode of attention and engagement with the world.

Through its acoustic communication repertoire, a newborn baby learns how to elicit desired emotional responses from its caretakers. This is instrumental in creating a foundation for an emotional relationship with the mother. Taylor wrote (1997, p. 23):

It [the enhanced system] also establishes the motivation to acquire language by attending to the mother's rhythmic and other musical sounds, listening, analyzing and storing those sounds, and generating similar sounds that lead to positive emotional feedback resulting from limbic reward dispensed by front limbic sections of the cortex. It is this same biological relationship between the brain's response to music/speech elements and its own capacity for reward and motivation that the music therapist activates and utilizes in the treatment process (ibid., p. 24).

Winnicott writes about how the child is capable of remembering, unconsciously, the mother's protection and good object-presenting at the early moments of life. "This experience is internalized and thus creates an internal resource from which to live creatively" (Abram, 1996, p. 111). Primary creativity is not confined to the state of infancy but persists as long as the person is alive. It is thus possible to discuss creativity from the perspective of "how we fit in with the world and its details, and the degree with which we can be both

part of, and separate from, the world and its objects” (Pavlicevic, 1997, p. 147). According to Pavlicevic, the expression of the creative impulse is related to our capacity to perceive the world objectively and subjectively:

These two interplay with one another constantly, throughout our lives. The capacity to hold both means that we need to be strong enough and confident enough to distinguish the boundary between ourselves and the ‘outer’ world (i.e. what is ‘me’ and what is ‘not me’) and to acknowledge the constantly shifting balance between our inner world and the outer world. We relate to the world of objects ‘out there’, but also through internalising the world, knowing it form the ‘inside’, in other words we need to be able to create it within, for ourselves (Pavlicevic, 1997, p. 148).

Providing the mothers with an opportunity to reconnect with their innate creative resource and potential involved possibilities, which changed their domains. Perhaps the deep empathy they felt in the group, the ease with which they explored their emotions musically, all the different places the musicking took them to supports the therapist/researcher’s feeling that in the music-caring group they were able to reconnect unconsciously to a mother’s protection and good object-presenting from early moments of life. Musicking in the group may have enabled reconnection to the mothers’ creativity, to their playfulness, their relational existence, and the caring empathy of their infancy. For the mothers who had, in the new motherhood constellation and their non-finite loss, compromised their self-identity and forfeited their self-actualization potential, creatively exploring in a safe place strengthened their ability to perceive the world both objectively and subjectively anew. In their own culture (having experienced the same) they musically and jointly created a genuine empathetic relationship (mutuality), encouraging personal development, a stronger and more vital self, creative emergence and a new understanding of their world.

Richards wrote:

From the distance we have travelled, one can see the core of everyday creativity across domains, as a dynamic, conscious, open, and healthy way of encountering life, a complex process (or set of processes), and perhaps also a set of states of mind (embedded within our “structures of consciousness”), which hold for us all a means of coping, thriving, growing, seeing more complexly, finding deeper meaning, and working more harmoniously together in a rapidly changing world. We may also, perhaps, meet opportunities for new understandings and transformation that will amaze us (2007, p. 313).

Describing important concerns in creative functioning and development for both individuals and groups, Richards identified 12 characteristic and potential benefits of living more creatively. When people are creative they are: 1. Dynamic and process-oriented. 2. Conscious and attentive to present experience, self and environment. 3. Healthy, focusing on lifestyle, which stimulates sound physical and psychological functioning, active participation in life and creative coping with adversity. 4. Non-defensive and alert working towards limiting forces that may restrict inner awareness. 5. Open and welcoming new experiences. 6. Integrating multiple sensory modalities and states of consciousness. 7. Observing actively, open to demands and goal oriented. 8. Caring and aware of interconnection and unity. 9. Collaborative and co-creating with others. 10. Androgynous (beyond stereotypes and societal limits). 11. Developing together as persons and species. 12. Bravely accepting and welcoming risks when exploring the unknown (Richards, 2007, p. 290).

To what extent the 12 characteristics and benefits identified by Richards were operating in and beyond the music-caring group or for each mother is hard to tell. However, the benefits seem more or less congruent with the lived experience of the mothers in this research as revealed through the interpretive phenomenological analysis. Although not systematically assessed, the benefit of the novelty, connection, richness of experience, comfort with self and others, personal development, awareness and caring, enhanced well-being, effectiveness and authenticity in the emotional creativity was surely present in the music-caring group. This supports Bruscia's notion (previously referred to in section 17.4.2) that the client's very participation in music therapy requires the creative process when examining something in detail, identifying problems and playing with resources, exploring alternatives and solutions, and organizing decisions/choices into beautiful and significant outcomes (1998a, p. 35).

Validating her experience in the music-caring group, Góa wrote:

It was an influence that lasted a long time and is still there, although I have not done everything I anticipated at the time and intended to do. And yet again it is a nudge to have to think a bit, look at the past, and think about the future. Can I still draw something good from this experience? At least I know that I would repeat the game in an instance if it were offered.

Songwriting

In this research, songwriting was used as a structured exercise or the central therapeutic approach around which the sessions evolved. Yalom (2005, p. 469) described a structured exercise as an efficiency-oriented accelerating device speeding up group members' work through techniques designed to help people connect quickly with suppressed emotions or other unidentified parts of themselves. The challenging, yet enjoyable experience of songwriting was such a device for the mothers. This device gave them structure, shape and perspective, honoured their individuality and strengthened their self-identity.

It is the researcher's belief that songwriting facilitated the development and the growth of the group and was instrumental in achieving the desired objective. The songwriting activity provided the mothers with a structured experience that influenced them both as individuals and as a group directly and indirectly. Directly, as it allowed them to work with their own feelings and issues, and indirectly, as it gave them an important perspective and the feeling of having empathetically supported each other. This support was accomplished as the mothers shared experiences, thoughts and emotions throughout the songwriting process (receptively and expressively, verbally and through musicking). The songwriting encouraged an intimate form of engagement between them as in various ways and through different media, they shared in its making. Empathetically supported, gradual expressions of words and music, developed into each mother's central theme(s). Ruud wrote:

When music penetrates such uninvestigated areas of body and language and the resulting experiences are translated to or represented by verbal language, possibilities for reaching new verbal or bodily based experiences arise. Such experiences often have to be conceptualized, however, and thus our language not only delimits or conquers our experiences but also makes them explicit. Our inner landscape, the energy-like stream of movement and tension, is given conceptual correlates; in therapy, these are often in the form of defining an image or emotion (1998:24).

Combining both verbal and nonverbal means was important for the mothers in the music-caring group. The structure in the songwriting process moved them forward and writing words (the ones the mothers wrote on the whiteboard) helped them to focus. The words moved them "into it" (Góá, SP I 008) or helped to make their experiences explicit. Conversely, musicking without words (the instrumental improvisation used as a warm up or as preparation activities in the songwriting

process) also provided a welcome relief when the mothers had been intently focused on something. The themes of the stories the mothers told in their songwriting were varied. They talked about despair, emotional pain and deep sorrow but also love, enjoyment and hope. Other subject areas and themes were also brought up and shared while the core theme for each mother was being developed (see Appendix L). Kristjana wrote in her validation:

It was also amazing to get the opportunity to put certain emotions into music, to let them sound. Whether it was feelings that one wanted to play away or hold on to. It was a method that I had never tried. To make music together reinforced our ties as a group. Although everyone was doing it for themselves, we were also doing it for each other and empathizing. That is what I felt. Then I am referring to the music making and song and lyrics construction.

A web-based survey intended to explore trends in the clinical practice of songwriting found that the most frequently addressed goals were:

- 1 Experiencing mastery, develop self-confidence, enhance self-esteem.
- 2 Choice and decision making.
- 3 Develop a sense of self.
- 4 Externalising thoughts, fantasies, and emotions.
- 5 Telling the client's story.
- 6 Gaining insight or clarifying thoughts and feelings.

(Baker, Wigram, Scott & McFerran, 2008, p. 115).

A literature review undertaken prior to this survey revealed relatively similar goal areas, i.e.: Externalising, clarifying or exploring thoughts, fantasies and emotions (in two thirds of the reviewed literature); experiencing mastery, developing and enhancing self-confidence/self-esteem (identified in half of the literature). Other important goal areas mentioned were: gaining insight, validating experiences/coping, reducing anxiety, anger and tension, offering choice and developing a sense of self (Baker, et al., 2008, p.109). The survey found a high usage of songwriting within psychiatric groups addressing the above mentioned goal areas. The literature review and the survey, as well as the findings of this research, support the use of songwriting as a positive reappraisal and a confrontive coping device (earlier discussed in section 17.4.2) (Lazarus & Folkman, 1991; Dunn et al., 2001).

The theory of inhibition, discussed in section 17.4.2 (Pennebaker, 1985, as cited in Barry & Singer, 2001) relates confiding traumatic events to negative health outcomes. Valued as a therapeutic tool for trauma victims, songwriting offers a socially acceptable and creative form to channel difficult emotional experiences (Davies, 2005, p. 46), a container for emotions (song as a product) (Rolvsjord, 2005, p. 98), and a medium for telling the client's story combining both verbal and nonverbal means. "Placing the client's story within the context of a song may be experienced as less threatening and a more appropriate medium to share their story with significant others" (Day, 2005, as cited in Baker, et al., 2008, p. 118).

Supporting the importance of group work with this clientele, Baker et al. (2009) found that songwriting in small group therapy was indicated as relevant in the area of psychiatry. In the music-caring group, musicking together reinforced the group's ties as they were not only participating for themselves but also "doing it for each other and empathizing" (Kristjana's validation).

The songwriting process itself (both within each session and throughout the music-caring sessions) was a structured exercise creating an important framework. Yalom wrote:

What is important in the use of structured exercises are the degree, accent, and purpose associated with them. If structured interventions are suggested to help mould an autonomously functioning group, or to steer the group into the here and now, or to explicate process, they may be of value. In a brief group therapy format, they may be invaluable tools for focusing the group on its task and plunging the group more quickly into its task (Yalom, 2005, p. 474).

In her validation, Góa discussed how she missed the intense music therapy sessions: "The music started all sorts of things and the structure that the sessions had is of course not there when we meet today. It is sure to say that it is something I miss." As mentioned before, the songwriting process was for the therapist/researcher an effective device to steer the group into the here-and now. For the mothers, the songwriting goal seems to have been both realistic and clear and thus conducive for gaining full group effort in the process. According to Yalom:

You facilitate collaboration ...by clarifying for the members how the procedure of the therapy group will help them attain those goals. In time-limited specialized groups, the goals must be focused, achievable, and tailored to the capacity and potential of the group members. It is important that the group be a success

experience: clients enter therapy often feeling defeated and demoralized; the last thing they need is another failure (2005, p. 478).

The songwriting process in the music-caring sessions was outlined in stages (see section 13.2.3) focusing on a warm-up/preparation in sessions one to three, lyric development/sharing in sessions four to seven, and music creation, rehearsing and recording in sessions eight to ten. Initially presented as a framework, this plan contributed to a successful songwriting experience in the group and to the achievement of goals. According to Baker, et al., several authors construct the songwriting process in stages, as was done in this research. The stages may include “brainstorming, lyric creation, grouping ideas into a song structure, music creation, and rehearsing, performing, and recording” (2009, p. 37). The music creation itself may also involve stages “such as selecting a genre, choosing tonality, creating melody and harmony, accompaniment style, and instrumentation” (ibid.).

In the music-caring group the mothers were responsible for writing their own lyrics before the music was composed. This is in accordance with the aforementioned survey, which found that in psychiatry lyrics were generally created first and that except for two cases, clients had most or all responsibility for creating them. Factors influencing this could be available time as well as the physical, communicative and cognitive abilities of the clients. As mentioned in section 17.4.1, the mothers were briefly informed about possible song structures such as how to write a chorus and verse/es, bridges or refrains, and collage technique, although each mother found her own structure (see Appendix Q).

The survey revealed that in almost half of all cases, the therapist was fully responsible for creating the music. This was most apparent within psychiatry. In all but two cases in the music-caring group, the therapist/researcher created the music. When a poem/lyric was introduced to the group, music that the therapist/researcher had composed at home was brought to the following session. The respective lyricist was encouraged to react to it, i.e., approve of it, reject it or recommend some changes. The other mothers were also encouraged to give input. With the exception of one mother, everyone responded positive to the music created for them.

Various factors may have prevented the music creation process from occurring collaboratively and in stages, as would have been ideal. These factors include too many poems being written and difficulty with keeping them on task, thus limiting available time in the last three music-caring sessions for the music to be created. For this particular group, more sessions would have been needed

in order to provide building music in stages. Shortening the preparation phase (sessions 1-3) could possibly have given more time for the music making in the last sessions.

Approximately half of the papers surveyed by Baker, et al., reported songs emerging from improvised music (2009). The instrumental improvisation (for example, the word painting) directed by the mothers in the first sessions was a preparation for songwriting as it set the emotion's dynamic, which later developed into a lyric and became a song. Supporting this thought are Hanna's words (previously cited in section 17.5) when saying:

It was enjoyable. I felt it was enjoyable to get a song. In fact I also enjoyed sounding the emotion. Sounding it is more your own, you put everything you can into it. A song coming from elsewhere is maybe different but it is enjoyable. Or I think so although you are not perhaps getting as much outlet. It is very amusing to sing your own song. It is very amusing. To sound it was perhaps more mine somehow – to get rid of it. But I would not have wanted to miss getting a song. I was immediately happy with the song. I felt it suited the poem and it was enjoyable to sing when we were singing it together (Hanna, SP I 006).

Comparing an act of creativity to being in a flow Csikszentmihalyi wrote that “when the challenges are just right, the creative process begins to hum, and all other concerns are temporarily shelved in the deep involvement with the activity” (1996, p. 118). He also argued that it was after one gets out of flow or in moments of distraction within it that one might experience feeling happy (ibid., p. 123). In their interviews, the mothers described their songwriting process as “giving”, “delightful”, “fantastic”, “wonderful”, “deepening”, “thought provoking” and “enjoyable” (Esja, SP I 010; Hanna, SP I 006; Skonza, SP II 004). The songwriting also proposed some challenges for the mothers, such as knowing what to write about, and presenting it to the others (Skonza, SP II 002; Klambra, SP I 005). In her validation, Klambra wrote that performing her song for the group was challenging but that the creative part itself was exciting. Einræn wrote that “it was fun to recollect many things like making the lyrics, music and then to see that this changed things as we got closer and got to know each other better”. Hanna wrote:

Now I have read through and enjoyed :)... really nice to recall this... I felt a little bit like crying even sometimes during the reading :)... this was a really good time –

lovely... and our friendship is witness to that! :) Hurray for kazoo-ladies! (From Hanna's validation).

As discussed in section 17.4.3, the caretakers of disabled children are to varying degrees inhibited from a flow experience in daily life due to their often extreme parenting role. Providing the mothers with an opportunity to experience flow through the creative act of songwriting generated enjoyment. These sessions with songwriting as a 'structured exercise' and the central therapeutic approach provided the mothers with enjoyable creative flow experience contributing to both increased well-being and a stronger self-identity. According to Csikszentmihalyi, "the more flow we experience in daily life, the more likely we are to feel happy overall" (1991, p. 123). Describing potential benefits of living more creatively, Richards wrote that, "we might even come to see self and life in a whole new way" (2007, p. 291). Authentically reflecting on their personal experiences through the songwriting process the mothers used this opportunity to step out of what confined them in their daily life and to revise their sense of themselves; they reflected on their identity or their self-in-context, as Ruud defined it (2010, p. 40).

18.1.3 The therapist

Kristjana's and Klambra's validations above confirm that the core category 'the therapist' was important for the mothers' lived experience of music-caring. Kristjana wrote:

The therapist is so very important. The person and how she approaches the group and treats it and the stuff that comes from it. The outcome would no doubt have been different with another therapist. Our therapist is a unique person who has an especially good presence, inspires confidence and warmth. Our therapist is as important as the group but that is because she (the therapist) is who she is. It is like some sort of aura surrounds her, a good beautiful aura.

I am grateful for having been able to participate. I am richer for having got to know these fantastic mothers and you, Vala.

Being a nurse and now in the role of one receiving help, Kristjana may perhaps have realized more than the other mothers the importance of the therapist's presence and her role for the outcome of therapy. Also supporting the significance of the therapist for group outcome Klambra wrote in her validation:

Nobody has delved as deeply as the thesis-carpenter and my thoughts often go to her work around this project, which calls for incredible accuracy and is executed with unique sensitivity and warmth. It is very fortunate to have come into contact with such talented, giving and solid music therapist with whom my child now also gets to blossom.

It is a great living treasure to have had a part in such special supervision and personal work and to presently be able to look back and see what a beautiful journey this was and experience how the growth and friendship that I am still harvesting give me plenty.

Based on the fact that the group continues to meet and that the children of five of the mothers now attend the therapist/researcher's special music school, these quotes may very well be biased. Kristjana's and Klambra's words above are also in accordance with how they expressed themselves in their interviews prior to the continuation of the group and their children's enrolment at the music school (Tónstofan). The group continued to meet after the interviews had been conducted, but while the interviews were still being transcribed and analyzed. The children began in Tónstofan after the interviews had been transcribed, coded and analyzed. To keep the children on Tónstofan's waiting list for five years would have been unethical. Weighing her dilemma the therapist's ethical conduct defeated that of the researcher's.

Kristjana and Klambra support this therapist/researcher's own conviction that motivation for action based on deep caring is fundamental in any therapeutic relationship. It is what sustains a therapeutic relationship and it influences the therapist's presence and how she approaches her clientele. As previously cited in section 6.2, Horden (2000/2001) and Stern (1995) advocate that various parent-infant therapies work equally well and that it may be difficult to find differences in outcome between different therapies. What the different therapies share seems thus to account for more of the beneficial effects than the differences do. According to Stern all the different therapies have common features that are non-specific to any one of the therapeutic approaches (1995, pp. 2-4). In section 1.2 of this thesis, the therapist/researcher talked about her goal of discovering the essential elements upon which effective therapeutic relationships must reside. She believed: that these elements were essential for effective therapeutic relationships, whether the techniques were derived from psychoanalysis or behaviourism; that these elements were what effective helping interventions might have in common, including both general helper characteristics and facilitative traits; and that although diffuse, they could be grouped under the

concept of caring or care. As was written in section 9.1, it is the caring attitude with all its elements, which in many helping relationships may be the single most important factor.

These speculations were based on years of clinical practice with diverse clientele. As part of the preparation for this thesis, the therapist/researcher learned about the Common Factors approach to therapy, which focuses on discovering what common factors across different therapies are responsible for the benefits of therapy, independent of theoretical orientation. Common factors offer a common ground for all the different therapies and theoretical orientations, but they neither provide fixed techniques nor generalizations about clients. In a study relating process and outcome variables, Orlinsky and Howard (1987, as cited in Castonguay, 2000, p. 264) found numerous common factors and combined them within five dimensions: therapeutic contract, interventions, bond, states of self-relatedness, and realization. Reviewing the work of 50 authors, Grenvage and Norcross (1990, as cited in Castonguay, 2000, p. 264) identified around 90 common factors which they grouped into five categories: client characteristics, therapist characteristics, change processes, treatment structure, and relationship elements. Castonguay stresses that it would be naïve to think that one could effectively work with a variety of clinical problems while restricting oneself to interventions that are common to all orientations. In other words, not only do the common factors always take a specific form within a particular approach, but they are also frequently used in combination with therapeutic methods that are unique to a particular approach. As argued by Garfield (1992, as cited in Castonguay, 2000, p. 265), the proper use of common factors and variables unique to particular orientations will probably be the most effective approach for clients. So it is through the specific model of therapy chosen for the specific clientele that the common factors work.

Perhaps the individual competence of a skilled therapist, which according to the Common Factors approach could be placed in two of Grenvage and Norcross categories above (the therapist characteristics and relationship elements), is an important element when defining the concept of care and of caring. Dileo's argument supports this notion when she believes that it is just as ethically imperative to be competent in how one 'is' with clients as being competent in what one 'does' with clients (2000, p. 44). She stresses that self-awareness is one of the key characteristics of effective therapists:

No matter what the music therapist's theoretical orientation, the use of the self in the therapeutic relationship is as significant as the use of music: these are the only two tools the music therapist has at his or her disposal (Dileo, 2000, p. 47).

So the music therapist with her flexible and adaptable leadership style, musicking as a tool, and a caring concern for the mothers was focused on acting in their best interest.

Caring is a foundational virtue for a music therapist, wrote Dileo (2000, p. 28). Furthermore, it is a central vehicle for music therapists' effectiveness and the heart of the therapeutic process (Doherty, 1995, as cited in Dileo, 2000, p. 28). Dileo lists caring, empathy, courage, and prudence as essential virtues for true helping and the attainment of ethical thinking in music therapy. A truly caring therapist has an openness to receive from the client and a willingness to go beyond the self to help the client. As stated in the introduction of this thesis, one of the motives for this undertaking was the therapist/researcher's need for personal and professional growth and work satisfaction. Grounded in her old personal and professional self and her notion of music-caring, the therapist/researcher took a risk and went beyond herself into a new clinical situation. Dileo wrote: "Having courage requires that the therapist make clinical decisions geared toward addressing the client's problems rather than the therapist's own anxieties" (2000, p. 32). The therapist/researcher's motivation was strong enough to allow the virtue of courage to confront her anxieties, which were partly based on words of warning from expert music therapists in the preparation stage of this research (see section 1.2). As previously shared in part 17.10, the anxieties were many and of different kinds during this undertaking. In retrospect, they can be looked upon as favourable for the virtue of prudence, as they kept the therapist/researcher alert and questioning her every move. According to Dileo, the virtue of prudence involves knowing how to use virtues in the right way for the client. It is the one virtue that balances all the others:

Prudence assures that caring does not lead to excessive client dependence, that courage does not lead to vigilantism, and that empathy does not lead to the loss of boundaries (Dileo, 2000, p. 33). ...Prudence involves both good judgment and wisdom. Because of the human tendency to over-generalize new knowledge, therapists may be at greatest risk for poor judgment when new information is obtained (Doherty, 1995 as cited in Dileo, 2000, p. 33).

As previously mentioned, the qualities or virtues which positively influence clients could be a long list and vary from one situation to another. Klambra felt that the therapist/researcher's qualities that had positive influence on her were generosity, sensitivity understanding, calmness and tranquillity (quoted in section 17.10). Mayeroff who defines caring as "helping the other to grow,"

stresses characteristic virtues of a caring therapist such as patience, honesty, courage, humility, hope and knowing (1971, as cited in Dileo, 2000, p. 28).

Like the various combinations of the word 'care' attest (e.g. Medicare, day-care, legal care, health care, after school care) it has many uses and meanings. For example, people care for their environment, for justice and for peace. The word 'caring' is also used when talking about professional activity carried out by health workers, social workers and others (van Hooft, 1995, p. 29). Van Manen believes that the word 'caring' is overused by professionals at a time when one no longer knows what it means to care. According to him, the term 'care' possesses dual meaning in its most common usage. On one hand, its meaning evolves around worries, trouble, anxiety, and lament, while on the other hand it evolves around charitableness, love, attentiveness, and benefice.

According to this argument the therapist/researcher worries about the mothers' well-being and mitigates them of 'care' by attending to their emotional needs. Like an adult who cares for a child, the task "is to tactfully 'care for' the child in such a way that the adult does not take the place of the child but rather that he or she prepares such place wherein and whereby the child is empowered to be and to become" (van Manen, 1997, p. 59). From this perspective, caring and music-caring can be understood as a fundamental motivational disposition (van Hooft, 1995, p. 30). A motivational disposition that is based on the therapist/ researcher's insight into the emotional state of health often accompanying a non-finite loss as experienced by the caretakers of her former and present clientele. In this motivational disposition, different virtues were needed and caring was one of them.

Understanding what it means to exist as human beings requires that we engage in ontology believed van Hooft. He argues that something we deem important and are committed to is grounded in what one cares about. "It is our caring which grounds the feeling that we 'must' do something," he wrote (1995, p. 4). Van Hooft also wrote that "we understand ourselves when we understand what we do, feel, and say as an expression of the kind of being that we enjoy: namely, being as caring" (1995, p. 8). Van Hooft defines deep caring as a motivational attitude that defines the self as it relates to others and to the world around it. It comprises two aspects: caring as self-project and caring as caring-about-others. This motivational comportment of deep caring will express itself in all aspects of our lives, in our ethics as well as our morality. "Deep caring is a mode of our being from which commitment springs" van Hooft wrote (1995, p. 29).

According to Noddings, an important aspect of the motivational component of caring is its reciprocity (as cited in Dileo, 2000, p. 28; van Hooft, 1995, p. 34). The therapist/researcher communicates her commitment and concern by offering music-caring to the mothers. The mothers whom she cares for positively respond to her offer by acknowledging it and positively reacting to it, thus sustaining the relationship. Dokecki used the word 'interdependence' to describe a helping relationship, which helps the therapist to grow through her act of helping others. According to him, this occurs particularly when caring helps clients to go beyond themselves, to care for others and to become caring and responsible for themselves (Dokecki, 1996, as cited in Dileo, 2000, p. 28). The mothers in this research developed a caring concern and a respect for each other in addition to developing an awareness of the importance of taking care of their personal needs and wants. They realized that being responsible for themselves was important when working towards increased well-being. Referring to Mayeroff, who said that "the other for whom I care is a completion of my own personal identity," van Hooft wrote:

In Mayeroff's view, caring for another involves some concern for the status of one's own being as well. This point is reinforced when we notice that if one describes caring for the other as involving a characteristic set of virtues in the way that Meyeroff does, then one's own ethical status is implicated in one's caring and becomes a matter of concern to the one who cares. It seems that caring for the other is an orientation which is not directed exclusively outwardly but involves a turning inwards towards oneself as well (van Hooft, 1995, pp. 33- 34).

Caring for others also helps the therapist to grow both personally and professionally. Offering a model of caring which is dyadic, Noddings (as cited in van Hooft, 1995, p. 34) stresses the same point and emphasizes the inner attitudinal and motivational aspects of caring. On the part of the one caring, there is an engrossment in the other, as Kristjana's and Klambra's validations above so clearly affirm.

The engrossment is motivated not only by a concern for the one cared for, but also by a concern for the agent's own ethical self. The person cared for contributes to the dyad by acknowledging the caring and by showing the one caring the growth or benefit to which the caring gives rise (van Hooft, 1995, p. 34).

Discussing the concept of mutual empowerment Rolvsjord (2004; 2007) talked about how the music therapy processes of her clients also affected her very much:

These are collaborations and therapeutic processes in which I feel that I have used myself in a diversity of ways, in which I have been challenged personally and professionally, but in which I have also felt that each session has been important not only for the clients, but for me as well (2007, p. 208).

Working with her clients provided her with an opportunity to develop her voice, her confidence in singing, her ability to sing duets, to sing for other professionals, to sing through a microphone, to learn new songs, to make recordings, and write songs. “Together with these clients I have had an opportunity to ‘find’ again the joy of doing this,” Rolvsjord wrote (2007, p. 209). She also realized how the informants in her research facilitated for her greater professional acknowledgement and respect in her position at the hospital where she worked, “in the university and in the wider world of music therapy academia” (ibid.). This therapist/researcher became empowered through what she did in relation to her informants. A successful music-caring group nurtured, developed and confirmed her personal and professional capabilities, whether or not her work would be recognized by EI professionals in the future.

The reciprocity involved in the music-caring group was twofold. The mothers acknowledged the benefits of music-caring for their well-being and thus supported the therapist/researcher’s notion of music-caring for this clientele. The mothers’ investment in it also necessitated that it be successfully completed so that other mothers might enjoy and hopefully benefit from it. Esja wrote in her validation: “This is fantastic and can hopefully be realized so that others may enjoy”. “The best test for commitment is action,” wrote van Hooft (1995, p. 27). This challenges the therapist/researcher’s commitment to continue acting through music-caring in pursuit of mothers having children with special needs.

18.1.4 The incidental categories: Me and My Time, Process and Change, the Diary

The thematic analysis of the transcribed interviews revealed that music-caring was instrumental in creating awareness of the importance of having quality time for oneself, a quality time through which one could take care of oneself, and strengthen one’s self-identity and well-being for the benefit of the whole family. The music-caring experience was also about process and personal change towards greater awareness about needs, thoughts and feelings. The use of the diary served an important function for the mothers as a container and a mediator for various thoughts and feelings that arose during and between sessions and the mothers chose not to share with the group, either because they were considered too difficult, or because they were considered trivial.

Writing can be cathartic, liberating, and confidence-building and can affirm the viability of one's truth, wrote Chavis (2011, pp. 153-154). Chavis believes that growth and healing occur not only within the creative process itself but also during the reflection and discussion that focuses on the written piece. Based on years of facilitating poetry therapy sessions, Chavis believes that individuals are usually excited to share with others what they have written. The five mothers who used their diary wrote about personal matters and the music-caring experience to a varying degree as was discussed in section 17.10. Although encouraged to share with the group the mothers, contrary to Chavis's belief, were reluctant to do so directly. The freedom to share or not to share their writing, was important in this context and conducive for the diary's function as both a receptacle and a releaser of emotions. The mothers' experienced their diary writing as being cathartic and liberating, and like Klambra said it somehow shortened the distance between her emotions and being able to talk about them in the group (SP I 001). Supporting Benson's recommendation (as previously cited) that people should write notes about their experiences as an aid to discussing about them (2001, p. 223). So indirectly, on their own terms and at their own pace, they were sharing their experiences and emotions with the group.

Another important healing component of the diary writing was what Kristjana experienced as a temporal organization bearing witness to process and change. Speculating about data source triangulation, Aasgaard wrote that if his project had included diaries from his informants (hospitalized children and their caretakers) then "the answers as to process and meaning of the song creations would have been more complete" (2002, p. 224). Chavis wrote:

Writing is a form of empowerment, when we have the courage to identify the demons, externalize them onto the page, and view them from a different perspective. ...When we write, our natural creativity finds new ways to view ourselves and the world. We renew ourselves, and in some sense, we are born again (Reiter, 2009 as cited in Chavis, 2011 p. 158).

Music-caring using songwriting as a central therapeutic approach is also empowering and seems to have much in common with creative writing and poetry therapy. Developing songwriting further as a therapeutic approach for this clientele one could thus learn from experts in the fields of poetry therapy and creative writing.

In section 18.1, the idea was put forth that the three categories above could be considered incidental or a derivation of a successful therapeutic experience.

In other words, they could have been recognized in any successful group work and were thus not specific to the music-caring experience per se. However, if the categories ‘me and my time’ and ‘process and change’ had not been identified in the analysis, the music-caring experience would have been less advantageous for the mothers.

The mothers’ validation in section 18.1.1 verifies the meaning of the above categories. As Kristjana wrote, it was clearly her time and to be doing something for herself was both good and important. She realized that however difficult the emotional work was that took place it was good in retrospect. Also, with the help of the diary Kristjana could “break away from certain emotions and difficulties ...the sentiment of that day and that time.” Klambra wrote:

During the reading, delicate feelings came back to me and [it is] tempting to try to compare how I feel now with how I felt then. What has been gained?

How desirable it would be to be less inhibited, more open and less afraid, both then and also now. All in all evidently much water has passed under the bridge and I consider myself involved in continued work with myself. Am on a long journey towards increased development, well-being and confidence.

What was it in the mothers’ experience that contributed to their experience of ‘me and my time’, ‘process and change’? Based on the narrated accounts of the mothers’ lived experience presented in section 17.7, just the fact that someone offers something to “home mothers” and “nobodies” “is in itself an experience which tells you that I and my emotions are important” (Kristjana, SP I 001; SP II 002). It did not really matter what it was, “just that there were these two hours in the week that were just for yourself” (Esja, SP I 004). As previously cited and emphasized numerous times, the feeling of making a difference, making something permanent and leaving something behind, to be able to give and to feel valued (the reciprocity discussed in sections 9.1 and 18.1.3) was also experienced as “very good” (Kristjana, SP II 007) – a healing process in itself.

The mothers used these hours for their own needs in diverse ways, as should be apparent by now. Their discussions evolved around various themes: their child’s diagnoses, their relationship with professionals and service providers, stress and coping, grief, joy, hope, how their children had had an impact on their lives both personally and professionally, and how their child had affected the whole family, including siblings and extended family. They also discussed

prejudices related to disability. All the above themes were important for the mothers' 'me' experience, but in order to have them turn inward and reflect from the stance of how they really felt to what they were experiencing, their focus often had to be redirected to the task at hand. As previously cited, Skonza said: "One could have forgotten oneself just talking" (SP III 002).

As detailed in section 17.8, the mothers talked about the music-caring offer, the group itself, how well they understood each other, the reciprocity, and how they realized the importance of taking care of themselves for the benefit of the whole family. In the therapist/researcher's narrated account of the mothers' experience reflecting on the core category 'me and my time' the mothers did not refer specifically to the way musicking in the group contributed to their 'me' experience. Throughout the empirical explorations of the core categories 'musicking' (in section 17.3) and 'songwriting' (in section 17.4), the mothers talked about how songwriting gave perspective, honoured individuality and strengthened self-identity and how musicking empowered awareness of emotions, facilitated and deepened emotional expression, brought change and created possibilities. The only direct reference to music in the narrated account (section 17.7) was when Klambra mentioned that she felt she needed to continue singing in the choir because it nurtured her self and made her stronger. This presented a dilemma for Klambra, however, as it resulted in diminishing the time she could devote directly for the benefit of her son (SP II 008). So although she may have realized the importance of taking better care of herself for the benefit of her whole family (the reciprocal nature of Stern's dynamically and interdependent system presented in graphic form in section 6. 2), she was still struggling somewhat with her own conscience when shifting the focus towards her own personal needs.

Dixon wrote:

Music created through a process of interaction between people can take on a life of its own, and in turn transform those who create it. The transformation is temporary, but the experience of having been transformed, and the discovery of new possibilities, are more permanent (Dixon 2002:128)

How did musicking in the music-caring group influence the mothers' experience of having been transformed? How did it aid in their discovery of new possibilities? How did musicking contribute to self-object functioning and their 'me' experience? Referring to herself, Kristjana felt that every sound was important. Similarly it could be argued that the different models of understanding and all the different relational

ways of musicking in the group contributed towards their experience of ‘me and my time’: the background music/music listening, singing songs, bringing preferred music, the improvisation, and the songwriting. Like Pavlicevic wrote:

Through this inter-subjective music experience where the client’s music is being responded to as expressively and communicatively meaningful, the client has a sense that the therapist knows how he/she feels and the therapist gets a clear sense of how the client experiences himself (1997, p. 117).

United not only in and through the music, but also because the mothers could from an internal frame of reference empathetically identify with or experience each others’ worlds, their sense of being understood was enhanced.

Supportive musical experiences that carry messages of comfort and nurturing highlight identity and support the ‘me’ experience in both individual and group treatment, wrote Summer (2009, p. 8). The background music played at the beginning of each session was deliberately chosen in order to create an atmosphere of support and safety, and the songs which were sung together often in the beginning of the sessions reflected common themes. This was instrumental in creating a bond among the mothers as it carried with it a message of comfort, and nurturing without threatening the ‘me’ experience. Hanna and Klambra asked for specific songs to be sung and Klambra and Esja brought CDs to be played for the group. According to Summer, “pieces with fixed meanings for the client provide a supportive reflection of the self in sound, the ‘me’ experience.” Furthermore, “utilizing a musical genre or a specific piece of preferred music (rather than therapist’s prescriptive choice) also allows for a supportive ‘me’ experience for the client.” The client’s music stirs memories, feelings, and thoughts that validate the client’s present and past state of being (2009, p. 7).

Successfully supporting the client’s experience of himself through the aesthetic domain of improvised music could be “likened to the re-enactment of the successful and natural development of Winnicott’s mother-child dyadic relationship,” wrote Summer (2009, p. 6). Spontaneously improvising with the therapist, the client is able to be simultaneously composer, performer, and listener, expressing and communicating his inner ‘me’ experiences to the therapist. In a supportive therapeutic framework the therapist reinforces the client’s identity. In the music-caring group, both the therapist and the mothers were capable of matching each other’s tempo, rhythms, tonality, and dynamics. This provided a “musical background or accompaniment that reverberates the

client's feeling while also offering a musical structure for containing their release" (Bruscia, 1987, p. 552). Likening this sympathetic and structured musicking to a "holding" device, it "allows the client to project his inner experiences of himself outward into sound" ...and "feel a strong sense of support for his identity, his 'me' experience" (Summer, 2009, p. 6). Esja's account in section 17.8 supports this. "In order to stay strong you somehow lose your own feelings, your self-identity. You don't speak the truth" (SP II 005). She would have wanted to stay with the feeling and to sound it, to acknowledge the sorrow through sound in order to stay alive.

In the paper "Communication between Infant and Mother" Winnicott defines two types of non-communication:

- 1 A simple not-communication.
- 2 A not-communicating that is active or reactive.

"The simple not-communicating refers to the quiet moments of unintegration and being between mother and infant" (as cited in Abram, 1996, p. 83). It is like a state of relaxation or resting which can change into communication and then reappear naturally. An active not-communicating position is based on choice and belongs to a healthy state. A reactive not-communicating position springs from an environment that inhibits adequate growth, contributing to pathological condition (ibid.).

Providing the mothers with a structured, safe and supportive environment and encouraging them to use their emotional creativity to explore and experiment with 'me' and 'not-me' experiences afforded possibilities to reconnect to themselves. Through musicking they could break away from reactive not-communicating stance, which may have evolved when forfeiting their own voices in order to stay alive. Providing the mothers with new and challenging 'not-me' experiences was conducive for mastering their anxiety and encouraging psychological growth. Like the child who encounters an unfamiliar experience, a new toy for example, this 'not-me' experience may at first produce anxiety. However, with support from the parent this anxiety can be a call to action. The child can be encouraged to play with this toy and to incorporate it into his repertoire of comfortable 'me' experiences, and thus expand his abilities, behaviours, and feelings, his sense of being in the world (Summer, 2009, p. 8). In the musical space which was created in each session, the mothers could empathetically support each other. They had all 'been there' and could thus

easily translate the quality of the feeling into their musicking. Contrary to mere imitation of musical elements (rhythm, tempo, pitch, dynamics, etc.) they could tune into each other's feelings and musically reflect on their subjective inner states. Distinguishing between imitation and affect attunement, Stern wrote:

...True imitation does not permit the partners to refer to the internal state. It maintains the focus of attention upon the forms of the external behaviours. Attunement behaviours, on the other hand, recast the event and shift the focus of attention to what is behind the behaviour, to the quality of feeling that is being shared. ...Imitation renders form; attunement renders feeling (Stern, 1985, p. 142).

In relation to Stern's graphic model of a reciprocal and interdependent support system presented in section 6.2, the therapist/researcher expressed the thought, that if music therapy interventions were successful in changing the primary caretakers' feelings (representations) then they would, according to Stern, have direct or indirect effects on all the other elements in the relationship. It would change how the mother subjectively experienced herself as a mother and thus might change her interaction with her infant. This would be due to the nature of the support system, which makes it difficult to restrict therapeutic intervention to one port of entry alone. This system constantly crosses boundaries between the interpersonal and the intrapersonal, the individual and the shared (Stern, 1995, pp. 16-17).

The mothers expressed various thoughts on whether they had noticed any changes in the way they thought or felt about their children since participating in the music-caring group. Thinking about her son was difficult, since it made her depressed, Einræn said. "If he smiles and is happy then I can find a purpose in this. But when he gets these fits and is difficult to handle then one becomes depressed and feels everything is hopeless" (SP I 007). Einræn said she did not know if she had advanced any on the "positive track." She had, however, become more aware of the emotions she had repressed, the ones "hidden in the dark" as she worded it (ibid.).

Esja did not experience any changes in the way she thought or felt about her daughter. She had already learned to accept her daughter as she was and had stopped wishing that she would be different. Esja felt that she had become more tolerant towards her daughter's acting out behaviour as she was unable to upset her immediately, as used to happen before (SP II 005).

Góa said that after hearing how the other children were doing, she had stopped pitying her son as much as she had done before. She felt she had become more positive in her attitude towards him and was now capable of lessening her demands on him. After all, her son had cognitive abilities and was thus not necessarily in the worst situation (SP II 002).

Hanna had not noticed any changes in the way she thought or felt about her son since participating in the group. “When you have a disabled child, life is always so complicated,” she said. “The child needs to know that you love him but you also have to be strong and not pity him. I know that he is unique and everyone knows who he is. He will learn a lot because of his disability and get many things in return” (SP II 002).

Skonza felt that participating in the music-caring group had made her learn to appreciate the time she had with her daughter (SP III 001).

Kristjana said that her feeling of being “pissed off” on her sons’ behalf would not change. Sometimes thinking about “having been greedy” by wanting another child [her son] she would never become mad at him. “He is just like that” (SP II 005).

Working with oneself is a step forward which changes the whole situation said Klambra:

Perhaps the feeling of complete reconciliation never comes because one continuously needs to be trying to improve. It is that kind of a disability. One does not know how he will develop and what he will learn. I do not think of it in order to change him but in order for him to develop and mature like everybody else. So that he will be more capable of expressing himself, understanding things and taking care of himself. I am always in a conflict if I am doing enough or not enough. It is never enough. It is important to use the time when he is so young and to sacrifice then something else (SP II 008).

Concerning how much time she should take for her own interests, Klambra said: “I have often thought about the choir. I feel I need to participate in it. It makes me stronger. Finding inner peace and reconciliation creates safety and joy, which is empowering. You feel you can do anything” (SP II 008).

The mothers’ answers to whether they had noticed any changes in the way they thought or felt about their children since participating in the music-caring group somewhat reflected the severity of each child’s disability and how far each had progressed on the loss continuum. Realizing that caring for a disabled child would

always remain complicated the mothers' answers to the question varied: from experiencing no change, having stopped pitying the child, appreciating more time with it, becoming more tolerant towards difficult behaviour, having realized that the child's condition controlled the mother's own feelings, and realizing that quality time for oneself was needed if one were to carry out the demanding task of continuously trying to improve the child's condition.

As discussed in Part II, the quality of the human relationship and the care experienced by the children is important for their health, psychosocial development and learning. Thus it is important to acknowledge the close relationship between the child's well-being and that of the mother and to enable the mothers to recognize their own aspirations and needs for self-fulfilment.

The mothers' sense of being cared for (as discussed in section 9.1), their access to an intimate form of engagement in an environment rich with a caring attitude and possibilities (both structured and improvised) conducive for emotional creativity, empathy, and attunement encouraged and supported not only their experience of 'me and my time' but also their experience of 'process and change'. The mothers' experiences could perhaps be related to that of Trolldalen's informants. Trolldalen found that mutual recognition, meaning 'I am me and you are you, and we understand each other and share a relationship', is fundamental to processes of change. She also found that mutual 'recognition' in a musical dialogue could promote positive development (previously cited in 8.1) (Trolldalen, 1997, p. 109; Trolldalen, 2000, p. 74).

As discussed in section 17.9, the mothers realized processes and changes on different levels. For example, Klamra considered herself involved in continued work with herself: "Am on a long journey towards increased development, well-being and confidence." She continued:

It is a great living treasure to have had a part in such special supervision and personal work and to be able to look back and see what a beautiful journey this was and experience how the growth and friendship that I am still harvesting give me plenty (From Klambra's validation).

Góa also experienced a long lasting influence from the music-caring group and was grateful for having "got so much out of it at the time":

It was an influence that lasted a long time and is still there, although I have not done everything I anticipated at the time and intended to do. And yet again it is a nudge to have to think a bit, look at the past, and think about the

future. Can I still draw something good from this experience? At least I know that I would repeat the game in an instance if it were offered.

Despite Bruscia's view that "what defines therapy is the process of intervention, not the outcome, whether it be positive or negative" (1998a, p. 38), the therapist/researcher admits her interest in learning about the perceived changes experienced by the mothers as an outgrowth of their participation. For example, what was the growth Klambra is still harvesting and the long lasting influence Góa spoke about in her validation which she is perhaps still drawing from? As discussed in section 17.9, some interview questions specifically addressed the issues of process and change. The mothers were asked to describe how they felt in the group at the beginning and at the end. They were asked to describe the music-caring process itself and if they had noticed any changes in their life, or in the way they felt about themselves since participating in the group. They were also asked to describe themselves again. Their initial self-description was shared in section 11.3. How the mothers described themselves in the individual interviews after the completion of the ten music-caring sessions is shared in Appendix W.

Since the mothers were co-travellers through the interpersonal, the artistic/creative and the scientific process, various positive steps were taken towards increased self-awareness and change. But, like Klambra said and previously shared, "I don't think I have finished everything, addressed all the different feelings, and I did not expect that would happen by coming here" (SP II 007). The mothers talked about the way they felt about themselves and how they dealt with difficulties had changed because their emotions inside had been sorted out. They talked about feeling stronger, happier and more self-secure, and realizing the need to take better care of themselves. They acknowledged that they knew more what they wanted for themselves in order to feel better, and that they had become to realize the importance of their own well-being for those around them. The mothers expressed gratitude for having gained enriching friendship and knowledge about how to use music for their own benefit.

18.2 How do the mothers' experiences define music-caring?

As presented in section 3.1, the aim of this research was to study the lived experience of a group of mothers of special-needs children participating in a music therapy group introduced as music-caring. Furthermore, this study was intended to examine how the mothers' experiences define music-caring? How do

the mothers' experiences as explored in part V and summarized above define music-caring? In Part I of this thesis the concept of music-caring was introduced. It was stated that being of a humanistic origin, music-caring was perhaps not a new concept to practicing music therapists, but because it was somewhat intertwined in tacit knowledge, its importance was perhaps not realized and its meaning not elaborated. The concept of music-caring as preliminarily defined in this research was based on years of clinical practice with diverse clientele where eclecticism had prevailed as the only rational way of working. Despite the use of different treatment theories – or perhaps because of it – the notion of music-caring evolved as something of central importance in the music therapeutic relationship. Despite years of practice, the therapist/researcher had neither become a specialist in working with certain clientele nor in applying certain treatment theories. But something in her way of working seemed conducive to a positive outcome, whether it was in the music, in her caring stance or both.

The therapist defined the notion of music-caring as an empathetic and emotionally supportive relationship that an act of musicking brings into existence. She then introduced this form of music-caring to an unfamiliar clientele. This required an enormous amount of courage as she had not previously worked with such high functioning, non-clinical adults. The therapist/researcher questioned her professional ability, including her musical proficiency, and since she was conducting a research study, she also worried about possibly revealing her shortcomings to fellow music therapists. However, strongly sympathizing with this clientele and believing that they might benefit from an empathetic and supportive relationship created through the act of musicking the research was implemented despite all fears.

The two research questions were explored throughout the empirical part of this thesis and the answer to the first research question has been summarized above. What follows is a summary of how the mothers experienced the music-caring process and how, based on their experiences, they would define music-caring.

18.2.1 Music-caring

In the music-caring process, everything has its place. One opens up to a new experience and new creative challenges and there is a development in every session. Little by little, one relaxes into it, introduces more of oneself and strengthens. One dares to share and to sound and feelings emerge. One speaks more openly, and gets to know others better as the empathy grows. One discusses things that are bothersome, talks about them, writes about them, and sings about them. One gives tones, and sounds to feelings, and

listens to music. Throughout this process, one puts things into shape and becomes better aware of who one is, what it is that one needs and wants. One clarifies hopes and desires, cause and effect, behaviours and reactions, and what it is within that makes one feel bad. This is a journey within and around oneself, a journey through which one matures and learns to sort one's emotions. It changes the way one feels and thinks about oneself. It touches on old habits of wanting not to be seen or heard and always wanting to do better. In small steps, one moves towards becoming more accepting of oneself, towards being able to acknowledge all kinds of feelings, to define them, and to work through them. When one thinks positively about oneself, then one automatically starts thinking about doing something good for oneself. Reconciled, one makes room for joy. A small step forward changes the whole thing. One learns to travel better, to take better care of oneself, how to better support another being, and to reach some success of being. This includes being the mother of a disabled child. On this journey, creativity, empathy, caring, new understanding, increased awareness of the power of music, and new and lasting friendships makes one feel stronger and richer. The secret journey does one good. (Einræn, SP I 002-004, SP I 006, SP I 006; Esja, SP I 004, SP II 004; Góa, SP I 008, SP I 010; Hanna, SP I 008, SP II 001; Klambra, SP I 002, SP I 006, SP II 007, SP II 008; Kristjana, SP I 008, SP II 005; Skonza, SP III 001, SP III 002).

For the mothers, music-caring was the whole of what was offered to them in the music-caring group, and that includes the process they underwent. The mothers felt it was good to come, good to talk to the group and to listen, and good to try something new. Not surprisingly, the mothers emphasized that it would not have been music-caring if there had not been any music. They felt it was very helpful to loosen emotions by listening to music and to sound the words, “but that alone would never accomplish what it did unless everything else was there” (Klambra, SP II 02). “It was somehow just the whole thing, and how it was brought together,” said Kristjana (SP II 004). When describing music-caring to others, the mothers might say:

Musicking.

Sounding feelings.

The words on the whiteboard.

The songwriting process.

The poems.

Singing the poems.

Sounding all of them together.

Being together as a group.
Tones that touch you and make you feel better.
Playing feelings away from oneself.
Making feelings merge with tones.
An engulfing sensation, which brings forth strong emotions.
A strange and sensational experience.
Finding an emotional outlet by playing, singing and listening to words and sounds that were calming and comfortable.
Comfortable sounds that supported relaxation.
Togetherness that brought forth empathy.
An access to various instruments through which one could play away certain feelings.
To get an outlet for feelings and thoughts through music.
To be able to ask for a special song that could be sung together.
To be heard.
To listen to others.
To be allowed.
To feel safe.
To have peace and leeway to get rid of something unwanted.
To be enabled.

(Einræn, SP I 005; Esja, SP I 011, SP II 002; Góa, SP I 008; Hanna, SP I 008; Skonza, SP II 007)

Asked to describe in more detail a music-caring situation, the mothers might express themselves like Skonza did when she referred to a particular session in which music-caring had occurred for her (previously cited in section 17.9.4). Skonza talked about the session when the song “Vetrarsól” had been sung and afterwards they sounded themselves alone.

Singing this song and sounding myself had enormous effect on me. I had been very worried and there they [the worries] just floated away from me and I felt this enormous relief somehow. The worries had been so overwhelming and they just floated away and I sat behind lacking the correct words to describe the way I felt. It was so comfortable and so good, such a terrible good feeling of well-being and relief to great proportions (SP II 007).

As has been cited earlier, Kristjana thought of music-caring as something “terribly big and enormous”, something which she had been “just a little bit into.” Like the other mothers, she felt it was the music that accomplished this, but did not know exactly how to explain it. Kristjana had the feeling that music-

caring could have been developed much further, because slowly she realized what it was. “One became more skilled at playing the emotions into the music, to use music to experience or awaken emotions and to get rid of them. Having realized the potential it felt like being at the beginning of something and it felt strange being done” (SP II 002, SP II 004).

The therapist/researcher’s preliminary definition of music-caring was inspired by numerous factors, including her past experience as a music therapist where caring encounters have mattered, assimilation of theories developed in helping professions such as nursing, Stern’s interaction theory (1995), his model of psychopathology, and Small’s definition of musicking (1998). The therapist/researcher hoped that the empathetic and emotionally supportive relationships created through musicking together would positively influence difficult feelings brought on by the mothers’ experiences of having a child with special needs, and thus it could possibly have direct or indirect effects on various aspects in their lives and relationships. As the interpretive analysis of the mothers’ lived experiences revealed, the therapist/researcher’s hopes (shared in section 10.4) were supported. Musicking in a caring context was indeed a resource capable of addressing the mothers’ various needs.

Based on the above, the therapist/researcher’s preliminary definition of music-caring holds in this context. Music-caring for these research participants turned out to be a particular kind of participatory helping experience contributing to empowering consequences. The music therapist, with her flexible leadership style and caring concern, along with musicking as a tool with its variability, adaptability and multi-various power, was capable of acting in the mothers’ best interests. The quality of the therapist-client relationship and variables unique to musicking and the process of songwriting proved to be a highly effective combination in this clinical research situation. This supports Castonguay’s belief (2000) that the proper use of common factors and variables unique to particular orientations will probably be the most effective approach for clients.

Music-caring with a group of mothers having children with special needs must be implemented with sensitivity, taking into account the variability of each group and its individual members. For the mothers in this research, musicking was adjusted to their needs at any given moment. Music-caring provided an avenue for them to connect to their core, to their primary creativity or innate drive towards health. It gave shape to their feelings and reshaped their identity.

18.3 The group closure and continued life

Benson talks about the importance of being visible with one's expectations for the group members and about the importance of having them join in or invest in its completion.

This seems to make ending less threatening and more in the nature of a normal passage or development. ...The important point is that you should create an end for the group which celebrates, synthesizes and symbolizes for members what the group was all about (2001, pp. 148-149).

In session eight the mothers were reminded of the approaching group closure and the function their songs could serve once the music-caring finished. Feelings associated with parting and the tasks ahead (to practice the songs and finalize them for the CD) were also discussed in session nine. At the beginning of session ten (the last music-caring session) the therapist/researcher mentioned the contrasting feelings the mothers might experience associated with the closure of the music-caring sessions. At the end of session ten, the mothers were also provided with some closure in the form of a brief overview (Appendix N). It was intended as both a review and preparation for the group interview (session 11). In the group interview, the mothers got a second chance to say goodbye to each other. It was an end for the group, which synthesized for the mothers what the group was all about. They were encouraged to conceptualize what the music-caring group had meant to them and evaluate their involvement and progress. The mothers could determine the value of the group for each one of them and assess whether the group's goals had been achieved. The mothers could also determine what aspects of the group could be modified. According to Benson, reflecting on personal experiences helps group members to view their participation in an objective light and lessen feelings of grief or sadness by showing how personally beneficial involvement in the group was (2001, p.153).

In the individual interview (session 12), all the mothers mentioned that they wanted to continue meeting. It is difficult to assert whether this wish was an indication of a successful music-caring group, an untimely completion of it, a separation anxiety, a combination of all of these, or something else. Einræn said:

My worries were connected to not seeing them again, that this companionship and the support I got would not continue. Seeing them weekly like this gave me support (SP I 002). One would have wanted to have

more sessions but there must be some structure or time limit. But personally I wanted to have it longer, even though it would not be more than just once a month, like a follow-up (SP I 004).

In her diary, Góa wrote: “We Saturday women can decide for ourselves whether or not we will continue to cultivate our friendship, but something tells me that this group will meet again after this course is over.” In her interview, Góa also expressed the same wish:

It is something that many of us would like. I do not know if it would be under the same conditions, but the connection already made would hold. Yes, I find the need within me. I do not want to break the ties. It is a good feeling that we are going to meet again (SP I 009).

Góa was referring to the meeting scheduled by the therapist/researcher for 27 January 2007. That day, the mothers met at Tónstofan to do the collage self-portraits presented in section 11.3 and to share pictures of their children. Hanna also spoke of a continued friendship that would not disappear. “I can ask them. They know various things,” she said (SP I 002). Klambra talking about the magic in trying music-caring for the first time, not knowing what would come next and to find it grow, mentioned that it could be fun to continue (SP III 004). Feelings remain and different things will emerge, said Kristjana. “Thus it would be so nice to be able to receive from it again, or continue to attend some kind of a treatment like this” (SP II 004). Describing what it was like being in the group at the end, Skonza said, “the only thing I feared a little was to lose the contact with them” (SP II 003).

After the formal completion of the music-caring sessions (the group interview on 11 December 2006 and the last individual interview on 4 January, 2007) and the supplementary session on 27 January 2007, the mothers continued to meet informally four to five times a year (Appendix J). Góa organized these meetings by sending out an e-mail to find a time and place to suit everybody. Between three to seven mothers attended each of these meetings, just like the music-caring sessions. The researcher likes to think of these meetings as a validation of a successful music-caring group, in which the mothers had formed a lasting and supportive relationship that they wanted to cultivate.

Despite some ethical considerations associated with the therapist/ researcher’s multiple roles in this context, she decided to attend these meetings. The researcher worded her reservations about it at the first meeting but no formal discussion took

place among the mothers whether or not this was something they wanted. The decision was thus completely the researcher's. It is hard to tell if, and then how, this decision influenced the researcher's data analysis. Her personal and perhaps biased opinion is that it did not. It is hoped that the perhaps excessive quoting of the mothers throughout the text supports what is believed to be an objective, realistic and honest interpretation. The therapist/researcher's presence in the continual meetings may, however, have had some influence on the mothers' tone used in their validation presented above.

Continuing the group informally after the completion of the music-caring group was not foreseen and could thus be regarded as an alteration of the planned research structure. In future music-caring groups, the possibility of continuing the group informally could be introduced at the outset. In light of experience the purpose of a continued group life, the group's preference of including or excluding the therapist and his or her role in a continuing group should be discussed at the onset.

Important as the continued meetings seem to be for the mothers, they also hold a great value for the researcher. She has been able to observe how the personal work the mothers started in the music-caring group continues and becomes realized in various ways. She has noticed how their developing friendship encourages openness and honours their personal characteristics. From the stance of the researcher, the meetings have been instrumental in sustaining her through the completion of the study. The mothers were always curious about its progression and interested in knowing when it would be finished so new music-caring groups could be formed for other mothers to experience. Concerning the continued life of the group Klambra wrote:

Considerable time has gone by since the days of music therapy in Hátún. I think about that time with warmth and respect. We have kept in touch and the group holds a very special place in my heart. We have enjoyed many a happy moment together on various occasions, home invitations, theatre, cinema, dining out, coffee shop, hikes and trips to a summerhouse that one of us has. We are all friends on Facebook. We are continually getting to know each other better and joy and caring dominate the group (from Klambra's validation).

CHAPTER 19

ASSESSING THE RESEARCH

LIMITATIONS AND RECOMMENDATIONS

19.1 Limitations of this research

In section 1.3 of this study, it was declared that the therapist/researcher had neither worked with this target group before nor devised or conducted research at this academic level. The greatest limitation of this research was therefore perhaps learning by doing. This undertaking was devised with the best of ability but informed decisions evolved slowly. Intimidated by big words, big theories and multi-various possibilities, the therapist/researcher felt somewhat insecure, lacking authority in supporting her journey. However, having contextualized her study she embarked on this journey and remained as authentic and reflective as possible from start to finish. Strongly motivated by her research proposal, she brought into her awareness everything possible with regard to her study, acted and took full responsibility for what she did and did not do in relation to it, as Bruscia taught (1996, p. 82). Exploring the limitations of this study from the stance of a novice researcher sounds somehow contradictory and will by definition be incomplete. Facing the challenge of debating her work with experts in the field of music therapy research, she hopes to learn about limitations and possibilities in order to gain confidence on further research routes. As previously pointed out, the researcher designed, conducted and documented her research with a rigorous integrity of the novice ‘reinventing the wheel’.

19.1.1 The mothers’ perspectives

The main research focus was on the meaningfulness and relevance it held for the informants. Thus it was important for the researcher to know if the mothers had any recommendations concerning future work in this area, recommendations which could also address the limitations of this study. What follows are practical suggestions from the mothers that address both limitations and strengths of the clinical part of this work.

Einræn did not have any recommendations regarding how to conduct music-caring differently. For her everything was “just fine” (SP I 008). The only thing Esja wanted more of was deep relaxation on a mattress: “that would surely be very good” (SP II 007). From the perspective of the therapist/researcher, Esja’s

exhaustion and anxiety caused by her pregnancy may have coloured her wish. Esja also commented on the time structure, which she felt was good. She thought that if the group had more or unlimited time, then they would perhaps have progressed more slowly. Esja also commented on the summaries/overview they were given and said they had encouraged her to continue and not to stay on the same issues session after session. Being able to take the summaries home and to reflect on the different issues worked well for her (SP II 007).

There was nothing in particular Góa wanted to pin point that could have been left out but she wanted to sing more. However, she was unsure if more singing would have benefited the whole group. She would have also liked to practice the songs more, although she did not know if they would have turned out differently. Practicing the songs would possibly have taken time away from something else, she said.

Góa felt some rushing at the end, which she thought might have been due to rehearsing the songs for the recording. Góa stressed that musicking and the freedom to sound always remain. She suggested that the group be encouraged to express themselves about each session and asked regularly if they felt something was missing. Góa felt the structure of the sessions was in many ways very good and thought there was no need to change that. She felt that it would be good to emphasize the freedom the mothers had for sharing and discussing, i.e. that there was never any specific topic for discussion, that they could bring up anything they wanted to, and that they did not have to speak if they did not feel like it. Like Esja, Góa felt that it would have been nice to practice more relaxation, although it was “not a big issue” for her. She had gotten what she needed from the sessions.

Concerning something that could be done differently, Góa mentioned continuity. She believed that many of the mothers would like to continue seeing each other, although it might be under different conditions. Góa did not want to break the ties that had been formed between them. Concerning advice for future participants, Góa emphasized the importance of being sincere, open, and willing to give and receive from others, and said it was vital not to be shy with the instruments, to listen carefully, to attend regularly and to take the time to use the handouts to reflect between the sessions. Góa also remarked that perhaps it would have been good if the mothers had been encouraged to write more poems. Admitting that her view was coloured by her own interest, she said that it was difficult to generalize and that she was not sure if the others would have benefitted from it (SP I 008; SP I 009; SP II 005).

When Klambra was asked if there was something she felt was missing from her experience, she said that she wished that their singing had not been so “laid back”. She believed that it would have been very “entertaining” if the group had been “more daring” while singing. Klambra also wondered whether it might have been better to have some kind of a programme so that she could have prepared herself better for the sessions and thus performed better, although she also acknowledged that it was exciting not knowing what would come next. Klambra felt that allowing the mothers the freedom to be themselves and just to encourage them to open up and to give and receive worked much better than insisting on a certain type of involvement. Klambra thought that allowing the music-caring to progress freely worked “fine” (SP II 003).

Klambra’s recommendations for a new music-caring group were that people should be encouraged to “give more” while singing and not to be scared to approach the instruments and to bring in power. But she noted that it would have been difficult to have one person always making some noise because that person had been given permission. Klambra thought that the relaxation they did needed to be longer as it “did not quite work” the way it was done. Klambra thought that it was a good that music-caring was the mothers’ own creation. She also felt that the challenge was doing something she had not done before, to step out and show initiative. Klambra felt she had progressed in the discussion, but that it would have been fun to continue the group (SP III 004).

Kristjana commented on the singing and said that she would not have wanted to sing more but that one could have been “encouraged more in the singing”. To have a balance between the spoken word and the music was important, as was always having the various categories on the whiteboard. Kristjana also felt that although all the “heavy things” needed an outlet, the mothers could have focused more on positive aspects.

Was there any happiness? It was the only thing that did not appear on the whiteboard. You know, sometimes there are fun and positive feelings connected to it [having a disabled child]. Perhaps we would have needed more time. First we dig into the difficult things the emotional things and then we would have wanted to talk about the positive sides (Kristjana, SP I 009).

Kristjana believed it was important to attend the sessions with an open mind and to allow ideas to evolve and flow freely, but that someone needed to direct the sessions because each one could take so many directions. Also, if one had certain expectations one might become disappointed. She felt that the time was short and that they should

not have talked more because they always started talking about the children. The combination of talking and playing was “good” but she added that her own focus was perhaps too much on how she sounded instead of what emotion she was sounding. Kristjana was open to continued meetings in one form or another, and to attend some kind of therapy because “emotions remain and all sorts of feelings and things will continue to emerge” (SP II 002, SP II 004, SP II 006, SP II 007).

Hanna was certain that a new music-caring group would be as useful and as joyful as theirs was, but realized that it would depend on the participants. She believed that people having disabled children were special because of their experiences, which changed their way of thinking and so many other components of their lives. Hanna was sure that the therapist/researcher could look forward to joyfulness prevailing in all the future groups. Hanna emphasized that it was important in the beginning of music-caring to get to know each other through words. Feeling comfortable with each other would make it easier for them to express themselves through music; they would feel safer and more capable of accurately mirroring themselves and the others through musicking. Hanna felt that the balance in the session was “normal and fine”, as they increasingly got to know each other (SP II 004).

Skonza commented on the balance between the spoken word and the music and said that for her it was “good” as there was never too much of either. She thought that the way the therapist/researcher had conducted it worked well, otherwise they could have “forgotten themselves just talking”. Skonza said that music-caring was something she would encourage other mothers to participate in (SP III 002).

In summary, the mothers in general spoke positively about their experiences. What they would have wanted to see more of or to do differently was the relaxation and the singing: they also wanted to see some form of continuation of the sessions. One could say that their comments also draw attention to what worked for them. They were introduced to the possibility of relaxation with music, realized its possibilities and wanted more. With regard to the singing, the therapist/researcher’s dilemma was twofold. She did not want to dominate them and thus felt unconfident in her own singing. This stance may have contributed to the mothers’ inhibition while wanting to project more energy into their singing. If the therapist had assertively projected more it would undoubtedly have encouraged the mothers to do the same.

Kristjana’s comment that the mothers should perhaps have focused more on positive sides is important. It suggests a value in exploring opposite emotions, as well as joy through creative playfulness made possible while musicking

together. Knowing about their wish to continue seeing each other should have generated conscious decisions regarding how it could be organized to optimize its usefulness for them. Instead, Góa has taken the initiative of bringing them together for informal meetings that the therapist/researcher also attends.

19.1.2 The therapist/researcher's perspective

In the article “Toward an Agenda for Evaluation of Qualitative Research”, Stige, Malterud and Midtgarden propose an evaluation agenda to be used in qualitative research. The authors' purpose with designing this agenda was “to propose a practical approach to evaluation that acknowledges the pluralism of current qualitative research and encourages reflexive dialogue in the evaluation process” (2009, p. 1504). Intended as a flexible guide, the acronym EPICURE stands for the agenda's individual items: engagement, processing, interpretation, critique, usefulness, relevance and ethics. In what follows, the research study will be reflected through the agenda's lens in order to cast some light on its limitations and possibly its strengths as well. Some of the issues discussed below were already realized in earlier stages of this undertaking and have previously been discussed. For example, matters related to ethics were discussed in section 3.5.

Engagement

Engagement “refers to the researcher's continuous interaction with and relationship to the phenomenon or situation studied” (Stige, Malterud & Midtgarden, 2009, p. 1508). The notion of music-caring from which this research developed was based on years of clinical practice. In order to avoid the researcher's preconceptions being confused with findings, a convincing level of reflection was required. Also, as previously mentioned in section 3.4, studying one's own clinical practice as a participant observer brings forth important ethical and methodological concerns. Thus the therapist/researcher, through her contextualization in the preparation phase, disclosed any personal and professional factors that could possibly have a bearing on her research. Throughout the different parts of her study, she also openly acknowledged and reflexively incorporated her subjectivity into the study. Nevertheless, the therapist/researcher's own shortcomings, perspectives and biases colour and shape all aspects of the study, including the findings (Aigen 1996, p.15; Bruscia, 2005a, p. 131).

The shared subjectivity experienced by the mothers and the therapist/researcher has both pros and cons. Having been a participant observer

and the subjects' therapist may possibly have enhanced the research, but it may also have caused a problem of inauthenticity (Bruscia, 1996, p. 83; Smeijsters, 1996, p. 186). The therapist/researcher carried with her the caveat that it might be impossible to pursue both roles with equal devotion and knew that her intent should never be at the expense of the mothers in their roles as research participants. To prevent against bias, the therapist/researcher could possibly have hired a research assistant to transcribe and code the interviews. But doing it herself was a welcomed opportunity to distance herself from the role of a therapist towards becoming more of a researcher. From a hermeneutic point of view, it was perhaps also the only 'right' thing to do. To hire someone for the task was at the time also thought not feasible due to financial limitations.

To establish the validity of her research, the therapist/researcher engaged in persistent observation, prolonged engagement, triangulation and member checking through feedback from the informants (as previously discussed in sections 17.1 and 18.1.1). As mentioned before (18.1.1), having the mothers' children on the Tonstofan's (a special music school) waiting list and the fact that the participants continued seeing each other after the sessions concluded may have been unethical from a research point of view, as it may have contributed to a more partial validation of the music-caring experience.

Another limitation of this research is the therapist/researcher's role as an interviewer. Kvale stresses that the outcome of an interview depends on the knowledge, sensitivity and empathy of the interviewer (1996, p. 105). Perhaps the sensitivity and the empathy was sufficient, but the 'how to do knowledge' was scarce, inhibiting the interview from being shaped in the process as advocated (Ely, 1991/1998; Kvale, 1996). As stated before, the felt dilemma was that the interview guide (intended to provide focus on themes relevant to the research questions) may have been too limiting. Instead of having her own pre-understanding, biases and shortcomings reverberate in the interviews, she could have had a research assistant carry out either an in-depth group interview or the individual interviews. But like Ely wrote, learning about questioning never ends for qualitative researchers (Ely, 1991/1992, p. 63). So perhaps being the instrument herself was a necessary and an important part of learning how to conduct research.

Processing

Processing "refers to the process of producing, ordering, analyzing, and preserving empirical material" as well as the process of writing. This item "requires reflexivity in relation to the context-sensitive development of focus

and perspective, procedures for data production, analysis and presentation” (Stige, Malterud & Midtgarden, 2009, p. 1509). The focus for this research was clear. It was the lived experience of a group of mothers having young children with special needs. The therapist/researcher wanted to develop an understanding of music-caring from the mothers’ perspective and to discover whether the music-caring experience had an effect on the lives of the mothers and the way the mothers related to their children. She wanted to learn from the informants about the music-caring processes at work, and through disseminating the findings inform others working within the framework of EI of the effects of music-caring. Furthermore, she wanted to use this learning experience to develop her own clinical practice within the field of EI.

Related to the processing is the groundedness of a research study. It is a term used to denote how well the researcher:

orients research processes, data, and findings around the participants and phenomena in their original, living contexts. In a well grounded study, the researcher’s constructions of research phenomena are consonant with the way these phenomena were originally expressed and experienced. Groundedness does relate directly to a qualitative study’s trustworthiness, however, as the more clearly the researcher’s constructions are linked to the original data, the more solid the foundations of those constructions tend to be (Abrams, 2005, p. 249).

The way data are collected supports groundedness. Prolonged engagement and persistent observation (for example and intense involvement with the research participants as a participant observer) “helps ensure that the resulting constructions are grounded in the sense of being as well-informed and holistic as possible” (ibid.). Through the above means the therapist/researcher did her best to ensure the groundedness of the study.

The chosen research method, hermeneutic phenomenology, requires reflexivity on the part of the researcher circling back and forth, revisiting the subject of the study and re-analyzing and re-interpreting data until meanings have been discovered. In the interpretive analysis, different perspectives have been presented, broadening possibilities of understanding rather than representing a singular ‘truth’ (Kenny, Jahn-Langenber, & Loewy, 2005; Rolvsjord, 2007, p. 257; van Manen, 1997). This is in line with an eclectic way of working and understanding, although the breath and variety may have been at the cost of a ‘thick description’, or a “focused reflection upon a specific method

or level of interpretation” (Alvesson & Sköldbberg, 2000, p. 248). According to Abrams, presenting the empirical material or communicating the study’s groundedness is accomplished through thick description. How well the therapist/researcher managed thick description is hard to tell; she can only hope that the notion of music-caring has been conveyed “with sufficient depth and detail to illustrate all of its unique, individual qualities while simultaneously proposing possible meanings of the phenomenon based upon the situational and cultural context in which it unfolds” (Geertz, 1993 and Lincoln & Guba, 1985 as cited in Abrams, 2005, p. 250).

According to Robson (2005) both hermeneutics and phenomenology are difficult methods to follow when conducting research studies, hermeneutics mainly “because of the tension between being closely embedded in the context and process of explanation and the research need to be honest and balanced” (p. 198), and phenomenology because of its “highly specialized vocabulary” and the need for “solid grounding in some challenging philosophy” (ibid., p. 196). The therapist/researcher’s inability to know how well her research was carried out along the line of hermeneutic phenomenology is seen as one of its limitations. It can only be hoped that it has not seriously violated the methods ‘grounding philosophies’.

The focus for this study, as well as the researcher’s position and perspective, were clearly stated at the onset. How well the empirical material was processed, analysed and presented is another story. The interpretive analysis and the generation of core categories and related themes were supported by liberal use of quotes and narratives. In this way, the mothers’ voices were not lost in the analysis. The novice’s position can perhaps be likened to both Kvale’s traveller approach, whereby the “analyst co-creates with the subjects the meanings he or she reports, and through interpretation constructs elaborate stories” (1996, p. 207), and to the ad hoc use of different approaches and techniques for generating meaning, namely meaning categorization, meaning condensation, meaning interpretation or meaning structuring through narratives.

The liberal use of quotes could also be an indication of some tension between phenomenology (closeness to the empirical material and an exploration of a lived experience examined entirely from being in that experience) and hermeneutics (construction and interpretation), which the novice did not know how to resolve. Following strict methodological procedures, for example the phenomenological seven-step process applied as microanalysis to interview data developed by McFerran and Grocke (2007), would perhaps have reduced the therapist/researcher’s insecurity in her analysis and thus increased the level of authenticity.

The therapist/researcher was aware of the possibility of using computer software such as ATLAS/ti or NUD*IST (Robson, 2005, p. 462) as an aid in her analysis but decided against it mainly on the basis of the time and effort believed necessary to gain proficiency in their use. Instead she used Excel to help organize the data.

Interpretation

Interpretation “involves the act of creating meaning by identifying patterns and developing contexts for the understanding of experiences and descriptions” (Stige, Malterud & Midtgarden, 2009, p. 1509). From the perspective of this therapist/researcher, interpretation is related to processing. According to Stige et al., issues to discuss in relation to this item are “the possibility of multiple interpretations and why and how certain interpretations could be more adequate for the purpose of the study than others.” Another issue that warrants discussion is how the researcher’s theoretically informed interpretations relate to the participant’s own interpretations.

Theoretical explorations in the preparatory phase of this research were based on preconceptions and intuition. The following words and phrases steered initial investigation through the use of various computer search engines: care, caretakers, music, early intervention, support groups, loss, and mothers of special needs children. Music therapy journals and books were also searched. This search led the therapist/researcher towards theories on loss and grief, theories on stress and coping, theories on quality of life, Stern’s motherhood constellation, maternal representations, developmentally informed theory, theories of care defined by health care practitioners, working models for parent-support groups, Small’s definition of musicking, theories on music and emotion, and theories on quality of life.

As the study progressed through the stage of analysis and interpretation of the empirical material, new literature and new theories informed the therapist/researcher. It was thus the empirical material itself that challenged and informed the theoretical explorations. In addition to the aforementioned theories, core categories and themes were discussed from the following perspectives: group dynamics and processes, the concept of empathy, positive psychology, play and the helping relationship, the concepts of affordance and appropriation as presented by DeNora (2000), emotional creativity, Yalom’s notion of a structured exercise (2005), Csikszentmihalyi’s theory on flow (1996), some speculations on the personal and the social self, empowerment, and the common factors approach. Why these and not other theories were used, could be

considered as limitations of the researcher's competence in seeing and understanding clearly. It may also be the result of the clinical context in which this research was conducted – a considerable distance from academia. Some of the theories/concepts which were used may have warranted deeper discussion than others, and different concepts, theories, and ways of working could possibly have fit the empirical material better. New literature and research continues to be published that could have informed and directed this study along different paths.

When discussing the development of standards for qualitative research, Bruscia wrote:

The main difficulty is that there are myriad philosophies that come together under the umbrella of nonpositivistic or qualitative research, each with significantly different positions on what it is possible to know, the ways in which it can be known, and the kinds of evidence that are needed to know that one knows it (1998d, p. 176).

Regarded as an asset instead of a problem, the endless possibilities inherent in qualitative research renders it a personal and a creative construct which challenges the researchers' truthfulness to her research participants, as well as her values and integrity.

Critique

Critique "refers to the appraisal of merits and limits of research." ... "Critique is the overlapping item of the two dimensions EPIC and CURE", and involves both self-critique and social critique (Stige, Malterud & Midtgarden, 2009, p. 1510). When the researcher is the instrument in use it is particularly pertinent to engage in self-critique. Self-critique should assess the researcher's reflexivity in relation to matters such as engagement, processing, and interpretation as well as an assessment of the relationships between these items. In sections 3.4 and 3.5 some ethical issues regarding the role of the researcher as a participant observer and the use of unfamiliar techniques, and methods were discussed. As Dileo advised, the therapist/researcher tried to be aware of her own beliefs, values, biases, self-perception and needs (2000, p. 44). She realized that self-awareness is not only a key characteristic of effective therapists but also an important attribute of an effective researcher. The researcher admits that she had high hopes that the music-caring group would be successful, but she also realized that regardless, the research would possibly inform about different methods, different ways of working, and different research possibilities.

From a social-critique perspective, this research idea developed from a perceived neglect that was thought detrimental to both caretakers and their special needs children. This research project was therefore implemented for this clientele. The positive outcome of the mothers' participation in this study are known, supporting the idea that implementing new music-caring groups for mothers of special-needs children might advance the current function of EI services as practiced in Iceland and elsewhere.

Usefulness

Critique is related to usefulness, which refers to the value of a study "in relation to practical contexts" (Stige, Malterud & Midtgarden, 2009, p. 1510). This research has developed an enhanced understanding of music-caring and created knowledge that warrants it being implemented and explored further. The positive outcome indicates potential for other participants in new music-caring groups. The findings also encourage the promotion of music-caring within the framework of EI as a possible means of addressing the psychological distress of caretakers. Advocated and implemented in that context, music-caring could contribute to important developments within EI. Once disseminated, the findings of this study might encourage other music therapists to explore the use of music-caring with caretakers of special-needs children or engage in research within this area. It is hoped that adequate descriptions provided throughout this study, or the research's comprehensibility²⁹, will be instrumental towards that end. The possibilities are limitless.

Relevance

By relevance, the authors of EPICURE are referring to how a particular study contributes to the development of its discipline(s) and how it correlates to academic discourse in a (inter)disciplinary context (Stige, Malterud & Midtgarden, 2009, p. 1511). Some questions to be considered when reflecting on this issue could be: Did this study advance the original perspectives which informed this study or did it contribute to new knowledge? What is the relevance of this study for the discipline of music therapy? Does the study fit with relevant literature? Bruscia wrote:

²⁹ Comprehensibility is "the extent to which the research report is accessible and understandable both to those directly involved in the research and to others interested in learning about the research and its findings (Glaser & Strauss, 1967, as cited in Abrams, 2005, p. 251).

The ultimate goal of research is to move us beyond our past and present experiences of a phenomenon to new constructions of what the phenomenon can be when we experience it differently. Thus, what a creative research study creates is some form of enlightenment. An enlightening study is one that helps the researcher, participants, and/or audience to develop an expanded consciousness, new insights and understandings, more varied and informed perspectives, enlarged constructions, more vivid values, more deeply felt experiences, clearer connections, greater creativity, more significant meanings, and greater appreciation. These are all forms of enlightenment (Bruscia, 1998d, p. 193).

This study was meaningful and beneficial in many ways for both the mothers and the therapist/researcher and thus it was both relevant and enlightening. It developed an expanded consciousness and a new insight and understanding of the notion of music-caring, and it empowered the mothers as well as the therapist/researcher. Furthermore, the study contributed to new practical knowledge regarding how music-caring can be implemented. Assessing to what degree the study is extrinsically relevant, i.e. to the discipline of music therapy and other health care professionals, would be mere speculations about what the future holds. It is hoped that the therapist/researcher has managed to present her findings in such a way that it holds relevance for a varied audience (students and professionals alike) within the health sector.

This study holds relevance for the discipline of music therapy as it honours music as a unique medium, supports the adaptability and effectiveness of musicking and encourages further exploration of it for this population in both clinical and research contexts. This study also suggests that through or in musicking, the common factors of effective therapies may somehow have become enlarged, encouraging further exploration of the beneficial workings of musicking for this particular clientele.

A new music-caring group conducted as research in the same manner as this one, but with other informants would render new findings and so would a stepwise replication.³⁰ As previously cited (section 14.1):

One of the principles of qualitative research is that each situation is unique, and there is no possibility of generalization from one setting to another.

³⁰ A procedure used for the purpose of triangulation “in which another researcher applies the same research method with different samples so that emerging themes might be compared and contrasted between groups” (Guba, 1981, as cited in Abrams, 2005, p. 249).

When the results of qualitative research are applied to other areas, it is because of an understanding of the case that was presented, and thus an ability to apply it to a similar setting (Wheeler & Kenny, 2005, p. 67).

As the progression of the music-caring sessions have been described somewhat thoroughly in this thesis, others interested in working with this population might be able to use this approach (songwriting in music-caring) as a referential template to some extent.

Ethics

The last item on EPICURE is ethics. “Ethics refers to how values and moral principles are integrated in the actions and reflections of research” (Stige, Malterud & Midtgarden, 2009, p. 1511). Issues related to ethical conduct have previously been discussed in section 3.5 and will not be elaborated on further.

19.2 Implications

Studying music-caring for the first time as to validate a need and to show possibilities, the researcher realizes an overtone of a neverending story. That story will hopefully inform and stimulate new learning when exploring music-caring in new clinical contexts. As previously stated, the therapist/researcher hoped that the music-caring group would be successful, but regardless, it would inform about different methods, different ways of working, and different research possibilities.

Abrams wrote:

The value of a given qualitative research study depends upon the rigor and integrity with which it is designed, conducted, and documented, as well as the richness, meaningfulness, relevance, and sophistication of the new knowledge it produces (2005, p. 246).

This study had a situated meaningfulness and relevance for this therapist/researcher as it was based on her clinical work. In this context, the study produced new knowledge. As it turned out, the music-caring group was successful from the perspective of the informants as well as the therapist/researcher, encouraging implementation of music-caring for this clientele within the framework of EI. The mothers wholeheartedly and proudly participated in the first group hoping that in the future music-caring would benefit other mothers. For this therapist/researcher, this study has been a multifarious learning experience and part of it was learning to work

in a group situation with new clientele. The therapist/researcher realizes that if conducted in the same or similar manner, a new music-caring group may or may not prove beneficial in a comparable manner to new participants. But increased awareness about the possibilities of music-caring could lead to meaningful and constructive implementation of it within various settings. As the core of this therapist/researcher's work has been carried out in one-to-one situations, music-caring group work would considerably expand the use of music therapy in Iceland. Disseminating the findings of this research and implementing it clinically would thus contribute to an advancement of the music therapy profession.

The research results validate the use of songwriting as a clinical method for this population. As an efficiency-oriented accelerating device, the songwriting process carries with it an important order of time and a clear focus that is ideal for a small group and a short-term therapy. The songwriting process, whether improvised or structured, carries with it techniques that facilitate emotional creativity. Due to its adaptability to various individual and group needs, it helps people connect quickly with suppressed emotions or other unidentified parts of themselves, identify problems and needs, and creatively explore alternatives and solutions and shape them into significant and even beautiful outcomes. The songwriting method and its techniques need to be adjusted anew according to the specifics (needs, functional ability, and both individual and group progression) of each group. Some groups might need a different structure, more guidance, or different warm-up exercises, for example. So long as needs have been recognized and goals and objectives clearly defined, a therapist has an extremely effective method at his/her disposal when coupled with intuition, empathy and a caring stance.

Music therapy education and training throughout the world varies considerably and is constantly evolving. Exciting literature continues to be published based on clinical practice and research in diverse music therapy fields. Realizing this variability limits the discussion of the educational implication this research holds to the biased view of this therapist/researcher. The particular focus of this research casts some light on the importance of developing one's own theory of helpfulness, learning about and realizing the primacy of caring in clinical practice, learning about ethics as it relates to music therapy practice and research, learning skills in human relations that promote an understanding of the self and others, learning about emotional creativity as a potential mechanism of change, and familiarizing oneself with the empirical literature about the process and outcome of different orientations, different research methods and therapeutic

methods and techniques. When working with people, continuous education and lifelong learning should be self-evident.

19.3 Further research

19.3.1 Further theoretical explorations

Throughout chapter 17 and in sections 18.1 and 18.2, above the findings of this study have been related to theoretical perspectives and previous research as presented in Part II. Insights into new perspectives and knowledge gained through this research process have also been presented when considered relevant and informative for this study.

Seeing Double.

A father said to his double-seeing son, "Son, you see two instead of one." "How can that be?" the boy replied. "If I were, there would seem to be four moons up there in place of two." (Shah, 1988, p. 189)

Like the citation above points out, every one of us seeks to find answers to the perplexities of their world in their own intelligent and rational way. There are many realities, and the genuineness of the research participants has informed this researcher about important areas to explore in relation to music-caring for mothers within the framework of early intervention. Some of these areas informed the present study in a minuscule way while empirically exploring the mothers' experiences. Others were not presented but hold the possibility to inform if music-caring is developed further, whether in a clinical or a research context.

Research and theory with a potential to contribute to greater understanding of music-caring for this clientele, would be interesting to explore in the following areas: humanistic or existential psychology, philosophy of ethics (caring), philosophy of emotions, salutogenic theories, positive psychology, empowerment philosophy, feminist theory, ethnography, common factors approach, person-centered therapy, systems theory, theories on creativity, theories on emotions and emotional creativity, culture-centered music therapy, resource-oriented music therapy, music psychotherapy, the biology of music, and music psychology.

Clearly, the therapist/researcher's level of understanding about philosophies, theories and methods has changed since the beginning of this undertaking. Re-reading and re-studying literature and re-doing the research would provide different insights and a different level of knowledge. There is a feeling of regret

when in retrospect one feels that a deeper or different understanding could have informed one's study. This is something the therapist/researcher has had to come to terms with when finalizing her study.

19.3.2 Further empirical explorations

Qualitative research methods that consider the clients' voices within the context of their experiences is important for the advancement of services. The interpretive phenomenological method chosen for this research was such a method and warrants further use in this context. The use of action research or evaluation research could also work well in this context, in order to discover if the clients' needs are met in a music-caring program, to assess the outcomes of a music-caring program, improve a music-caring program, find out how a music-caring program is operating, assess the efficiency of a music-caring program, and understand why a music-caring program works or doesn't work. "Collaboration between researchers and those who are the focus of the research, and their participation in the process, are typically seen as central to action research" (Robson, 2005, p. 217).

The mothers in this research could be invited to participate again in a music-caring group, that incorporates more relaxation, vocalizing as a warm-up technique, more vigorous singing, more joy, the creation of individual poem(s)/lyrics as well as one made in collaboration based on a central theme, more time for the creation of the music. Through their participation in an action research they could promote change(s) based on their previous experiences.

The use of mixed methods design would also work in this context using pre- and post- tests to evaluate outcome measures in a music-caring group. A quality of life scale or a stress index could be used for that purpose. Research focusing on measures of emotional creativity and its correlation to positive therapeutic outcome in a music-caring group could turn out to be an interesting study. Through a form of microanalysis, the musical parameters of musicking (for example, the musical elements and the sound qualities in musical interaction) in a music-caring group could be studied. Microanalysis focuses on "minimal changes in relationships or interactions between people or minimal changes in the music and in dynamic forces" (Wosch & Wigram, 2007, p. 14). The connection or relationship between musical parameters and the perception/notion of care and joy could also be studied. A study which focuses on how music-caring group work empowers participants' in their everyday lives or influences their use of music is also a possibility.

Another research idea, based on the mothers' suggestions, would be to study music-caring for mothers of younger infants (birth to one year old), based on a more receptive form of musicking. Music-caring could also be studied with a group of mothers who were also receiving individual music therapy. Yet another idea would be to use music-caring for a group of mothers who were also attending a music-caring group with their children. Researching music-caring for a group of fathers is an important undertaking as well, making possible a comparison between men and women based on gender issues. Furthermore, music-caring for grandparents and siblings of children with special needs holds potential which warrants research.

The above ideas, mentioned as possibilities for further empirical explorations, are mere speculations that would require thorough investigation before being evaluated as pragmatic possibilities. It is easy to get carried away with the rich material and broad perspectives this research provided access to. Although cited before, it is relevant that Kristjana's words conclude this section:

I have the feeling that music caring can be much more without realizing it. I have the hunch that this is something terribly big and enormous and that we have been just a little bit in it. ...I had the feeling that this could have been developed much further, longer and more. Both because one did not know what his was and little by little one realizes it (Kristjana, SP 002).

19.4 Final summary

Caretakers of disabled children continue to express themselves about their experience, their non-finite loss, in journals and in newspapers. Gudrun Hreinsdottir, a medical doctor, talked in a newspaper interview about her disabled son:

Each and everyone want to win in a good lottery. In fact this was not such a bad lottery, although it was difficult to begin with and difficult to reconcile oneself to the fact. A certain sorrow which never disappears follows, because he is not healthy and will not be capable of doing the same things as his contemporaries, no matter in which life span he is (Fréttatíminn 19 – 21 November, 2010).

In books, fathers and mothers also continue to share their experiences of extreme parenting, and the issues and concerns are still the same. They say that their greatest source of support comes from other families experiencing the same

and that the support they get must be emotional. They talk about how their identity can become undermined when their child is diagnosed. Parents also say that if the well-being and concerns of the parents are overlooked then professionals are failing the child. The caretakers need help to cope. In order to find a better way to support caretakers it is important to listen to what they have to say about themselves as subjects and their experiences. Despite variations in children's disabilities, the caretakers' feelings of stress and depression is similar. (Dempsey, 2008; Harrison, Henderson & Leonard, 2007; Kingston, 2007). Stress factors vary, but as reported by Kingston, the child itself may not be the main cause of grief and sadness, but rather the lack of appropriate support from society. Lack of support contributes to marginalization and isolation of families having disabled children (Kingston, 2007, p. 162).

The degree of coping can thus depend on environmental support, whether it be formal or informal. In a narrative study interviewing 18 mothers of disabled children, Kingston found that mothers rarely acknowledged their own needs and aspirations because as long as they focused on their children they would be considered good mothers. Kingston speculated that perhaps they were afraid of being considered "bad" and "selfish". In her study, a second level of self-silencing became evident in a form of self-censoring when the mothers wanted the interviewer to omit negative expressions towards their children (*ibid.*, p. 174). The mothers in Hodapp's study (1995, as cited in Hooste & Maes, 2003, p. 302), the mothers in Kingston's study, as well as the mothers in this study, all appreciated talking to other mothers who were familiar with the experience of mothering a child with special needs. In line with Thoit's theory of social support (introduced in section 7.3) a special kind of intersubjectivity develops in these groups based on the commonality of experiences. The person being helped senses that her feelings are understood, respected and empathized with. The above study, as well as the finding of this research, supports the importance of a group intervention over individual interventions for mothers of special-needs children.

Since the undertaking of this research, no changes have been made within EI services in Iceland to accommodate the psychosocial needs of caretakers of special-needs children. No new support groups have been developed, no new courses taught, and no advancements in the delivering of crisis counselling within the hospital system for this clientele have been made. As before, counselling is based on the caretakers' own initiative who may request and pay for services from a social worker or a psychologist.

Three years and nine months after the completion of the music-caring sessions, the summary that was given to the mothers for validation purposes brought up bubbling emotions, emotional turmoil, delicate feelings and uncomfortable feelings. Sadness was felt, tears flowed and the need to cry was pressing. Trying to understand the cause of her reactions, Góa did not know if it was the difficult and mournful feelings that she had dug up and fought with while the music group was running or if she was mourning the end of the intense music therapy sessions. It can be claimed that expanding and enriching the mothers' emotional creativity through songwriting, regardless of the intensity of the sessions, was an enabling experience as it empowered awareness of the mothers' emotions.

“Empowerment is always relational as it is always negotiated in relationships between individuals, or between individuals and communities,” wrote Rolvsjord (2007, p. 207). Furthermore “in order to be empowered in the relationship, people need to contribute to as well as to benefit from relationships” (Sprague & Hayes, 2000, p. 683, as cited in Rolvsjord, 2007, p. 208). To be able to give and to feel valued in the music-caring group was in itself a healing process, like Kristjana said, when talking about how “terribly good” it was to feel herself “making a difference, making something permanent and leaving something behind” (SP II 007). According to Dunst, Trivette and Deal, helping relationships and empowerment practices need to consider the following: 1. That persons are already competent or have the capacity to become competent (referred to as a proactive stance in a helping relationship). 2. If people are unable to display competence it is not due to deficits within the person but because the social systems do not create opportunities for competencies to be displayed generating enabling experiences. 3. A person is empowered if he/she attributes behaviour change to his or her own actions (1988, p. 4). These three assertions provide a basis for viewing empowerment from a broader-based social systems perspective that suggests the importance of the help giver's behaviour or the manner in which needs are met are conducive for enabling and empowering families.

In accordance with beneficial principles advocated by EI specialists, namely emphasizing strengths, control, access, and collaboration, musicking through the use of songwriting in the music-caring group seems to have been instrumental in enabling and empowering these mothers. They opened up and welcomed new and challenging experiences, which made them more aware of themselves and their environment. They worked towards limiting forces that had restricted their

awareness and participation in life and they creatively, collaboratively and caringly set new goals for the development and well-being of themselves and those around them.

In section 1.3, it was stated that the therapist/researcher's personal needs, shortcomings, losses and aspirations would affect the research. Thus, to the best of her ability, she focused on being consciously aware of the different personal needs and feelings influencing the research throughout. The therapist/researcher acknowledged her subjectivity and incorporated it into her study. Realizing the multiple, simultaneous, reciprocal relationships in the music-caring group, she continuously evaluated her own beliefs, values, biases, self-perception and needs, in order to avoid destructive types of countertransference issues. The therapist/researcher realizes that knowing about the mothers' continued friendships has sustained her in the last stages of this undertaking. This sort of role reversal is an indication of mutual empowerment, and the reciprocal nature of a helping relationship. A successful music-caring group nurtured, developed and confirmed this therapist/researcher's personal and professional capabilities, encouraging further work in this area.

From a personal perspective, this research was compared to a pilgrimage whose purpose was to discover the essential elements upon which effective therapeutic relationships must reside. These elements, being both the general helper characteristics and facilitative traits, were thought essential and common to all effective therapeutic relationships. These elements were believed to colour the way music is used and to influence its effectiveness in the therapeutic relationship. Furthermore, without them, the best methods and the most elaborate techniques would become ineffective and there could be no music-caring. The mothers' experiences in the music-caring group supported the therapist/researcher's preliminary notion of music-caring as an empathetic and supportive relationship that an act of musicking brings into existence. The music-caring group was a particular kind of participatory helping experience contributing to empowering consequences.

19.5 Epilogue

The Arrow and the Song

I shot an arrow into the air,
it fell to earth, I knew not where;
for, so swiftly it flew, the sight
could not follow it in its flight.

I breathed a song into the air,
it fell to earth, I knew not where;
for who has sight so keen and strong,
that it can follow the flight of song?

Long, long afterward, in an oak
I found the arrow, still unbroken;
and the song, from beginning to end,
I found again in the heart of a friend.

Henry Wadsworth Longfellow (1807-1882)³¹

This research has been a very personal process, with different variables guiding me forward and backwards on a spiralling path studying the flight of my arrow. I have stood humble in front of all the knowledge there is and realized the context of my own work and being. I feel privileged to have been able to conduct this research, and proud to have completed it with enough courage to continue working through music-caring.

An admiration and gratitude towards the mothers prevails for their genuine interest in this work, which empowered and sustained me throughout. The arrow is still unbroken, and the song I breathed into the air six years ago can be found reverberating in their hearts from beginning to end. Thank you.

In memory of those who have breathed a song into my heart.

³¹ http://www.poemhunter.com/i/ebooks/pdf/henry_wadsworth_longfellow_2004_9.pdf

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ENGLISH SUMMARY

Music-caring within the framework of early intervention

The lived experience of a group of mothers of young children with special needs, participating in a music therapy group

Introduction

In the narrowest sense, the term ‘early intervention’ (EI) refers to what is done early in the life of a child to influence its developmental course. EI applies to children from birth to the age of six and their families. The various definitions of EI collectively emphasize the importance of influencing the developmental course of at-risk and disabled children with systematic interventions as early as possible. Interventions include various educational, developmental and therapeutic activities as well as support networks of a public and personal nature (Innocenti 2001; Sigurdsson 2001; Shonkoff & Phillips 2001).

Despite developments in the field of EI, and an increase in the variety of available services, the needs of caretakers of children with disabilities have not received enough attention. The caretakers and the potential psychological distress they experience having a disabled child are more often than not the forgotten component in the existing support and treatment schemes. An acquaintance with my clients’ caretakers for over 20 years of clinical practice has revealed glimpses of feelings, needs, and struggles associated with having a child with a disability. Caretakers need to come to terms with the fact that their child differs from other children and to integrate both that child and his or her disability into their lives. For many this is a difficult task, and in the process, dysfunctional patterns of parenting may develop. The parents themselves draw attention to all the striving and their wishes, as well as the importance of meeting other parents who have similar experiences. They talk about their powerlessness, their non-finite loss, and a grief that never perishes. They say that as parents, they speak the same language, that they understand and receive the most important information from one another.

Research has shown that families with special-needs children have higher stress levels than other families and the mothers’ stress levels tend to be higher than the fathers’. Also, mothers and fathers are affected differently by parenting a child with a disability and use different defences against stress. Research indicates that mothers derive more benefit from their social support networks

than do fathers (Whittick, 1988, as cited in Webster, 1992, p. 3). Providing mothers with an opportunity to work through issues of loss and grief in a safe and creative environment with other mothers may significantly alter their ability to cope with life. This focused the author's attention on the idea that mothers of disabled children could benefit from music-caring. Music-caring was preliminarily defined as an empathetic and emotionally supportive relationship that an act of musicking would bring into existence.

The clinical method and focus

A hermeneutic phenomenological research was designed which focused on the lived experience of a group of mothers of young children with special needs participating in a music therapy group introduced as music-caring. Seven mothers participated in the research. The inclusion criteria for the mothers were that they were neither acquainted with one another nor the researcher and that they had children with special needs born between 2001 and 2006 (0-5 years old). Their children did not participate in the research.

The purpose of the research was to develop an understanding of the participants' lived experiences through the mothers' voices, their descriptions and interpretations; to develop an understanding of music-caring from the mothers' perspectives and to discover whether the music-caring experience would affect their lives and the way the mothers related to their children in some way. The researcher wanted to learn from these mothers about the music-caring processes at work, and through disseminating the findings inform others working within the framework of EI of the effects of music-caring. Furthermore, the researcher wanted to use this learning experience to develop her own clinical practice within the field of EI. Designed towards this end, this study sought to find answers to the following research questions:

1. What is the experience of mothers of special-needs children participating in a music therapy group introduced as music-caring?
2. How do the mothers' experiences define music-caring?

The central music-caring phase encompassed ten 90-minute to two-hour consecutive weekly sessions. Songwriting was used as a process and a central method of musicking in the group. In this context, songwriting was defined as "the process of creating, notating and/or recording lyrics and music by the client or

clients and therapist within a therapeutic relationship to address psychosocial, emotional, cognitive and communication needs of the client” (Baker & Wigram, 2005, p. 16). Songwriting has been described as “one of the most powerful methods in music therapy” (Ruud, as cited in Baker & Wigram, 2005, p. 9). According to Baker and Wigram, songs assist in developing group cohesiveness, encourage social interaction, provide group support, provide opportunities for one to experience joy, and facilitate the development of therapeutic relationships (ibid., p. 11).

A vertical session structure centred on songwriting as the primary therapeutic approach was planned around the following activities: A welcome activity which provided an opening to what was ahead. It acknowledged each mother and the group as a whole. A warm-up activity was designed to break the ice and to encourage the mothers’ ‘musical selves’ to appear. The warm-up activity was also used as a preparation for the songwriting activity used later in the same session or in the following sessions. A songwriting activity was another step in the progression of the songwriting process. The technique for lyric creation was allowed to develop in the group based on individual and collective needs and ability. The songwriting process advanced in stages, moving from themes, to words, to sentences, to phrases, to verses. Similarly, the technique of music creation in the songwriting process was allowed to develop in the group based on individual and collective needs and ability. A break for refreshments and an informal chat was provided after the songwriting activity when nearing the end of each session. The break offered an opportunity to share information and develop friendships. It also provided a needed distance from the sometimes intense emotional material brought up in the songwriting activities. A concluding activity was used to bring closure to the sessions. A horizontal structure of the songwriting process was as follows: Sessions one to three warm-up and preparation. Sessions four to seven lyric development and sharing. Sessions eight to ten music creation and rehearsals for recording the songs.

The research methodology

An anchor for this research was found within the interpretive phenomenological framework. Being closely connected, both phenomenology and hermeneutics require a deep reflexivity on the part of the researcher. Both practices are process oriented and seek understanding circling back and forth, revisiting the subject of the study and re-analysing and re-interpreting data until essences (phenomenology) have been discovered or meaning assigned (hermeneutics) (Kenny, Jahn-Langenber, & Loewy, 2005). The mothers in this research were the ones to describe their experience, and their self-interpretation was

fundamental to any understanding gained. “These human experiences happen relationally, in a shared reality, a shared subjectivity” (Kenny, 1996, p. 64) experienced by both the mothers and the researcher. Prior to being studied, this experience already has a meaning for the participants and as such has already been interpreted. Furthermore, expression or presentation through writing is in itself an interpretation, or as van Manen (1997) puts it: “The aim of phenomenology is to transform lived experience into a textual expression of its essence – in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience” (p. 36).

The empirical material and theoretical frameworks

The empirical material consisted of one semi-structured group interview, one individual semi-structured interview with each mother, and artefacts. The therapist/researcher was a participant observer. Being “fellow travellers” and of service to one another, as Yalom words it (2001/2008), both therapy and research is dynamic and ever-evolving with a continuous sequence of experiencing and then examining the process. As a participant observer, the therapist/researcher gained a lot of important information from the inside of the group. This information was necessary for analytical reflections about therapeutic processes and other aspects of the group’s functioning, as well as information about their understanding and experience of music-caring.

For validation purposes, the informants were asked to read a summary of the interpretive analysis. The instruction given to the mothers for validating the research findings was deliberately kept simple and non-directive. The mothers were given an opportunity to look at and comment on the collectivity of language used for exploring the “unique and private qualities of their inner experiences” (van Manen, 1997, p. xiii) and how language was used to create and describe the intersubjectivity of their music-caring experiences.

Throughout the different stages of this research, various theories, practices and research encouraged, supported and informed this study. In the empirical explorations, the different themes in the core categories were discussed from the following perspectives: Stern’s motherhood constellation (1995) group dynamics and processes, the concept of empathy, positive psychology, play, the helping relationship, developmentally-informed theories, musicking as defined by Small (1998), the concepts of affordance and appropriation as presented by DeNora (2000), theories on quality of life, reflection on music and emotion, emotional

creativity, Yalom's notion of a structured exercise (2005), Csikszentmihalyi's theory on flow (1996), some speculations on the personal and the social self and the formation of self-identity, empowerment, and a common factors approach. Theories on loss and grief, stress and coping, and care as defined by health care practitioners and working models for parent-support groups, also lent their support to this study.

Research findings

Since the primary aim of this research was to develop an understanding of the mothers' experiences of the music-caring offered to them, it was vital for the researcher to maintain their integrity by allowing them to speak for themselves and not losing their voices in the process of reducing the complexity of the empirical material through meaning condensation via thematic analysis. Only in that way could the researcher attempt to explain the experiences without "harming the secret or the magic," as one of the mothers put it (Esja, SP II 002).

Based on clinical and theoretical understanding, music-caring explored in a new context developed an understanding of its core for these particular research participants. Through interpretive phenomenological analysis, the therapist/researcher systematically explored their experiences and concluded that the music-caring experience for these mothers was about:

The group. Belonging to a joyful group honoured individuality and the freedom of expression. It was a group where an atmosphere of trust was conducive for diminishing defences, creating empathetic understanding and support. Encouraging the sharing of ideas, thoughts, and feelings, the group built awareness and strength, gave possibilities and perspectives. Belonging to the first music-caring group also created a feeling of anticipation and gratefulness.

Musicking. Musicking brought joy and beauty, change and possibilities, as well as the relaxing, welcoming and caring atmosphere. Musicking together brought closeness, supported empathetic listening, and an empowered awareness of emotions by facilitating and deepening emotional expression.

Songwriting. The challenging yet enjoyable experience of songwriting gave structure, shape and perspective, honoured individuality and strengthened self-identity.

The CD. The CD was a memento of the course capable of preserving the emotional tone of the music-caring group and validating the mothers' emotional journeys.

The therapist, whose character of intuitive sensitivity and deliberate, reflective calmness was conducive to the mothers' feelings of safety and being taken care of.

Me and my time. Realizing the importance of having quality time for oneself a quality time through which one could strengthen one's self-identity and well-being for the benefit of the whole family.

A process and change. The music-caring experience was a process and a personal change towards greater awareness about needs, thoughts and feelings.

The diary, which served both as a container and a mediator. It was a container for various thoughts and feelings that arose in and between sessions and which the mothers chose not to share with the group, either because they were thought to be too difficult or because they were thought of as trivial.

What follows is a summary of how the mothers experienced the music-caring process and how, based on their experience, they would define music-caring:

In the music-caring process everything has its place. One opens up to a new experience and new creative challenges and there is a development in every session. Little by little one relaxes into it and introduces more of oneself, strengthening everything. One dares to share and to sound, and feelings emerge. One speaks more openly, and gets to know each other better as the empathy grows. One brings up things that are bothersome, talks about them, writes about them, and sings about them. One gives tones, gives sounds to feelings, and listens to music. Through this process one puts things into shape and becomes better aware of who one is, and what it is that one needs and wants. One clarifies hopes and desires, cause and effect, behaviours and reactions, and what it is within that makes one feel bad. This is a journey within and around oneself, a journey through which one matures and learns to categorize one's emotions. It changes the way one feels and thinks about oneself. It touches on old habits of wanting not to be seen or heard and always wanting to do better. In small steps, one moves forward towards becoming more accepting of oneself, towards being able to acknowledge all kinds of feelings, define them, and to work through them. When one thinks positively about oneself then one automatically starts thinking about doing something good for oneself. Reconciled, one makes room for joy. A small step forward changes the whole thing. One learns to travel better, to take better care of oneself, how to support another being, and to reach some success of being. That includes being a mother of a disabled child. In this journey creativity, empathy, caring, new understanding, increased awareness

of the power of music, and new and lasting friendships makes one feel stronger and richer. The secret journey does one good. (Einræn, SP I 002-004, SP I 006, SP I 006; Esja, SP I 004, SP II 004; Góa, SP I 008, SP I 010; Hanna, SP I 008, SP II 001; Klambra, SP I 002, SP I 006, SP II 007, SP II 008; Kristjana, SP I 008, SP II 005; Skonza, SP III 001, SP III 002).

For the mothers, music-caring was the whole of what was offered to them in the music-caring group, and that includes the process they underwent. They felt it was good to gather together, to talk to the group and to listen, and to try something new. Not surprisingly, the mothers emphasized that it would not have been music-caring if there had not been any music. They felt it was very helpful to loosen emotions by listening to music and to sound the words while acknowledging that “that alone would never accomplish what it did unless everything else was there” (Klambra, SP II 02).

Kristjana thought of music-caring as something “terribly big and enormous”, something which she had been just a little bit into. Like the other mothers, she felt it was the music that accomplished this but did not know exactly how to explain it. Kristjana had the feeling that music-caring could have been developed much further because slowly she realized what it was: “One became more skilled at playing the emotions into the music, to use music to experience or awaken emotions and to get rid of them. Having realized the potential, it felt like being at the beginning of something and it felt strange being done” (SP II 002, SP II 004).

The therapist/researcher’s preliminary definition of music-caring was inspired by her past experience as a music therapist, assimilation of theories developed in helping professions such as nursing, Stern’s interaction theory and his model of psychopathology (1995), and Small’s definition of musicking (1998). The therapist/researcher hoped that empathetic and emotionally supportive relationships created through musicking together would positively influence difficult feelings brought on by the mothers’ experience of having a child with special needs, and thus the music-caring could possibly have direct or indirect effects on various aspects in their lives and relationships. As the interpretive analysis of the mothers lived experiences revealed, the therapist/researcher’s hopes were supported. Musicking in a caring context was a resource capable of addressing the mothers’ various needs.

Based on the above the therapist/researcher’s preliminary definition of music-caring holds in this context. Music-caring for these research participants

turned out to be a particular kind of participatory helping experience and contributed to empowerment-type consequences. The music therapist, with her flexible leadership style and caring concern, as well as musicking as a tool with its variability, adaptability and multivarious power, was capable of acting in the mothers' best interests. The quality of the therapist-client relationship (the common factors) and variables unique to musicking and the process of songwriting proved to be a highly effective approach in this clinical research situation. This supports Castonguay's belief (2000), as well as that of this therapist/researcher that the proper use of common factors and variables unique to particular orientations will probably be the most effective approach for clients.

Music-caring with a group of mothers of children with special needs must be implemented with sensitivity and take into account the variability of each group and its individual members. For the mothers in this research, musicking was adjusted to their needs at any given moment. Music-caring provided an avenue for them to connect to their core, to their primary creativity or innate drive towards health. It gave shape to their feelings and reshaped their identities.

Some implications for education, clinical practice and further research

Education

The focus of this research casts some light on the importance of developing one's own theory of helpfulness, learning about and realizing the primacy of caring in clinical practice, learning about ethics as it relates to music therapy practice and research, learning skills in human relations that promote understanding of self and others, learning about emotional creativity as a potential mechanism of change, and familiarizing oneself with the empirical literature about the process and outcome of different orientations, different research methods and therapeutic methods and techniques. When working with people, continuous education and lifelong learning should be self-evident.

Clinical practice

As it turned out, the music-caring group was successful from the perspective of the informants as well as the therapist/researcher, encouraging the implementation of music-caring for this clientele within the framework of EI. The mothers wholeheartedly and proudly participated in the first group, hoping that in the future music-caring would benefit other mothers. The therapist/researcher is encouraged by this and believes that if conducted in the same or a similar manner, a new music-caring group might prove beneficial in a

comparable manner to new participants. Increased awareness about the possibilities of music-caring could also lead to its meaningful and constructive implementation within various settings.

The research results validate the use of songwriting as a clinical method for this population. As an efficiency-oriented accelerating device, the songwriting process carries with it an important order of time and a clear purpose that is ideal for a small group and a short-term therapy. The songwriting process, whether improvised or structured, carries with it techniques which facilitate emotional creativity. Adaptable to various individual and group needs, it helps people connect quickly with suppressed emotions or other unidentified parts of themselves, identify problems and needs, and creatively explore alternatives and solutions and shape them into significant and even beautiful outcomes. The songwriting method and its techniques need to be adjusted according to the specifics (needs, functional ability, and both individual and group progression) of each group. Some groups might need different structure, more guidance, or different warm-up exercises, for example. So long as needs have been recognized and goals and objectives clearly defined, a therapist has an extremely effective method at his/her disposal when coupled with intuition, empathy and a caring stance.

Further research

Qualitative research methods that consider the clients' voices within the context of their experiences is important for the advancement of services. The interpretive phenomenological method chosen for this research was such a method and warrants further use in this context. The use of action research or evaluation research could also work well in this context to find out, for example, if the clients' needs are met in a music-caring program, to improve a music-caring program, to find out how a music-caring program is operating, and to understand why a music-caring program works or doesn't work. The mothers in this research might be invited to participate again in a music-caring group, which incorporates more relaxation, vocalizing as a warm-up technique, more vigorous singing, more joy, the creation of individual poem(s)/lyrics as well as one made in collaboration based on a central theme, and more time for the creation of the music. Through their participation in an action research they could promote change(s) based on their previous experiences.

The use of mixed methods design would also work in this context using pre- and post- tests to evaluate outcome measures in a music-caring group. A quality

of life scale, for example, or a stress index might be used for that purpose. A research study focusing on measures of emotional creativity and their correlation to positive therapeutic outcomes in a music-caring group could make an interesting study. Through a form of microanalysis, the musical parameters of musicking (for example, the sound qualities in musical interaction) in a music-caring group could be studied. Microanalysis focuses on “minimal changes in relationships or interactions between people or minimal changes in the music and in dynamic forces” (Wosch & Wigram, 2007, p. 14). The connection or relationship between musical parameters and the perception/notion of, for example, care and joy could also be studied. A study that focuses on how a music-caring group work empowers participants in their everyday lives or influences their use of music is also a possibility.

Another research idea that is based on the mothers’ suggestions would be to study music-caring for mothers with younger children (0 to one year old), based on a more receptive form of musicking. Music-caring could also be studied with a group of mothers who were also receiving individual music therapy. Still another idea would be to use music-caring for a group of mothers who were also attending a music-caring group with their children. Researching music-caring for a group of fathers is an important undertaking as well, and would make possible a comparison between men and women based on gender issues. Furthermore, music-caring for grandparents and siblings of children with special needs holds potential which warrants research.

The above ideas, mentioned as possibilities for further empirical explorations, are mere speculations, which require thorough investigation before being evaluated as pragmatic possibilities. It is easy to get carried away with the rich material and broad perspectives to which research provided access.

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DANSK RESUMÉ

Musikalsk pleje inden for rammerne af tidlig indgriben

De levede erfaringer I en gruppe mødre til små børn med særlige behov,
under deltagelse I en musikterapigruppe

Indledning

I snævreste forstand refererer udtrykket ”tidlig indgriben” (TI) til, hvad der gøres tidligt i et barns liv for at påvirke dets udviklingsmæssige forløb. TI gælder for børn fra fødslen til 6-års alderen og deres familier. De forskellige definitioner af TI understreger kollektivt betydningen af at påvirke udviklingsforløbet for børn i risikogruppen og handicappede børn gennem systematiske indgreb så tidligt som muligt. Indgrebene omfatter forskellige indlæringsmæssige, udviklingsmæssige og terapeutiske aktiviteter såvel som brug af støttenetværker af offentlig og personlig art. (Innocenti 2000, Sigurdsson 2001, Shonkoff & Phillips 2001).

Trods udvikling på TI området og et øget udvalg af tilgængelige muligheder har der ikke været nok fokus på behovene hos de personer, der tager vare på børn med handicaps. Disse mennesker og den potentielle psykologiske belastning, de oplever ved at have et handicappet barn, er som oftest den glemte komponent i eksisterende støtte- og behandlingsplaner. Bekendtskabet med mine klienters støttepersoner igennem 20 års klinisk praksis har afsløret glimt af følelser, behov og kampe i forbindelse med det at have et handicappet barn. Støttepersonerne bliver nødt til at komme overens med den kendsgerning, at deres barn adskiller sig fra andre børn, og at de skal integrere både barnet og dets handicap i deres liv. For mange er dette en vanskelig opgave, og undervejs kan der udvikles u hensigtsmæssige mønstre i forældrefunktionen. Forældrene selv henleder opmærksomheden på alle bestræbelserne og deres ønsker samt til vigtigheden af at møde andre forældre, som har lignende erfaringer. De taler om deres magtesløshed, deres endeløse tab og en sorg, der aldrig får ende. De siger, at som forældre taler de samme sprog, at de forstår og modtager de væsentligste oplysninger fra hinanden.

Forskning har vist, at familier med børn med særlige behov har højere belastningsniveauer end andre familier, og mødrenes belastningsniveau er ofte højere end fædrenes. Mødre og fædre påvirkes også forskelligt af at være forældre til et barn med et handicap og bruger forskellige forsvarsmekanismer

mod belastningen. Forskning viser, at mødre har større udbytte af deres sociale støttenetværker end fædre (Whittick, 1988, som citeret i Webster, 1992, s. 3). Ved at give mødrene mulighed for at arbejde sig igennem problemerne med tab og sorg i et trygt og kreativt miljø med andre mødre kan i væsentlig grad ændre deres evne til at håndtere deres liv. Dette henledte forfatterens opmærksomhed på den ide, at mødre til handicappede børn kunne have gavn af musikalsk pleje (music-caring). Musikalsk pleje blev foreløbigt defineret som en empatisk og emotionelt støttende relation, som kunne skabes gennem musikalske seancer.

Den kliniske metode og fokus

En hermeneutisk, fænomenologisk forskning blev designet til at fokusere på levede erfaringer hos en gruppe mødre til små børn med særlige behov, der deltog i en musikterapi gruppe, der blev lanceret som musikalsk pleje. Syv mødre deltog i forskningen. Mødrenes deltagelseskriterier var, at de hverken var bekendt med hinanden eller med forskeren, og at de havde børn med særlige behov født mellem 2001 og 2006 (0-5 år gamle). Deres børn deltog ikke i forskningen.

Formålet med forskningen var at udvikle en forståelse for deltagernes levede erfaringer gennem mødrenes stemmer, deres beskrivelser og fortolkninger; at udvikle en forståelse af musikalsk pleje set fra mødrenes perspektiv og at konstatere, om erfaringen med musikalsk pleje ville influere på disse mødres liv og måske på deres relationer til deres børn. Forskeren ville gerne høre fra disse mødre om processerne i forbindelse med musikalsk pleje i praksis og ville, ved at sprede resultaterne, informere andre, der arbejdede inden for TI, om virkningerne af musikalsk pleje. Derudover ville forskeren gerne bruge dette læringsmateriale til at udvikle sin egen kliniske praksis på TI området. Undersøgelsen, der var designet til dette formål, søgte svar på følgende forsknings spørgsmål:

1. Hvilke erfaringer har mødrene til børn med særlige behov gjort ved deres deltagelse i en musikterapi gruppe lanceret som musikalsk pleje?
2. Hvordan definerer mødrenes erfaringer musikalsk pleje?

Den centrale fase i den musikalske pleje omfattede ti 90-minutters - to timers sammenhængende, ugentlige seancer. Sangskrivning blev brugt som en proces og en central musikudøvelsesmetode i gruppen. I denne sammenhæng blev sangskrivning defineret som "klientens/klienternes og terapeutens proces med skabelse, nodeskrift og/eller optagelse af tekster og musik inden for rammerne af

en terapeutisk relation - med henblik på at imødekomme klienternes psykosociale, emotionelle, kognitive og kommunikationsmæssige behov” (Baker & Wigram, 2005, s. 16). Sangskrivning er blevet beskrevet som ”en af de mest virkningsfulde metoder i musikterapi” (Ruud, som citeret i Baker & Wigram, 2005, s.9). Ifølge Baker og Wigram bidrager sange til at udvikle gruppesamhørighed, til at befordre social interaktion, til at muliggøre personernes oplevelse af glæde og til at lette udviklingen af terapeutiske relationer (sammesteds, s. 11).

En vertikal sessionsstruktur centreret omkring sangskrivning som den væsentligste terapeutiske metode blev planlagt omkring følgende aktiviteter: en velkomstaktivitet, der orienterede sig mod det, der derefter skulle ske. Den anerkendte mødrene og gruppen som en helhed. En opvarmningsaktivitet designet til at bryde isen og opmuntre mødrene til at åbenbare deres ’musikalske selv’. Opvarmningsaktiviteten blev også brugt som en forberedelse til sangskrivningsaktiviteten, der skulle finde sted senere i samme eller i efterfølgende sessioner. En sangskrivningsaktivitet var et skridt videre i sangskrivningsprocessen. Der blev givet mulighed for, at tekstskabelses-teknikken udviklede sig i gruppen i overensstemmelse med individuelle og kollektive behov og evner. Sangskrivningsprocessen skred frem i stadier, idet den bevægede sig fra temaer, til ord, til sætninger, til fraser, til vers. På lignende måde blev det gjort muligt, at musikskabelsesteknikken i sangskrivningsprocessen kunne udvikle sig i gruppen på basis af individuelle og kollektive behov og evner. Der blev indført en pause til forfriskninger og en uformel snak efter sangskrivningsaktiviteten, når man nærmede sig afslutningen på hver session. Pausen gav mulighed for at dele information og udvikle venskaber. Den skabte også en nødvendig distance til det til tider intense emotionelle materiale frembragt under sangskrivningsaktiviteterne. En afslutningsaktivitet sluttede sessionerne.

En horisontal struktur på sangskrivningsprocessen var som følger: Session et til tre – opvarmning og forberedelse. Session fire til syv – tekstudvikling og information-sdeling. Session otte til ti – musikskabelse og prøver til optagelse af sangene.

Forskningsmetodikken

Man fandt frem til en forankring af denne forskning inden for tolkningsmæssige fænomenologiske rammer. Som tæt forbundne kræver både fænomenologi og hermeneutik en dyb refleksivitet fra forskerens side. Begge praksiser er procesorienterede og søger forståelse ved at cirkulere frem og tilbage, gentænke emnet for undersøgelsen og genanalysere og genfortolke data, indtil essenserne (fænomenologien) er fundet eller meningen bragt på plads (hermeneutik) (Kenny, Jahn-Langenber, & Loewy, 2005). Det var mødrene i dette

forskningsprojekt, der skulle beskrive deres erfaringer, og deres selvfortolkning var grundlaget for at kunne komme frem til at forstå noget som helst. ”Disse menneskelige erfaringer gøres i relationen, i en fælles virkelighed, en fælles subjektivitet” (Kenny, 1996, s. 64) oplevet både af mødrene og forskeren. Før den blev studeret, har denne erfaring allerede en mening for deltagerne og er som sådan allerede blevet fortolket. Derudover er ytring eller præsentation i skriftlig form i sig selv en fortolkning eller, som van Manen (1997) udtrykker det: hensigten med fænomenologi er at omforme levet erfaring til et tekstmæssigt udtryk for essensen i den – på en sådan måde, at virkningen af teksten på samme tid er en refleksiv gen-gennemlevning og en reflekterende tilegnelse af noget meningsfuldt: et koncept, hvor en læser bliver kraftigt bestyrket i sin egen levede erfaring” (s. 36).

Det empiriske materiale og de teoretiske rammer

Det empiriske materiale bestod af ét halvstruktureret gruppeinterview, ét individuelt halvstruktureret interview med hver af mødrene, og artefakter. Terapeuten/forskeren var deltager og observatør. Som ”rejsende sammen” og hinandens støtte er både terapi og forskning, som Yalom udtrykker det (2001/2008), dynamiske og under stadig udfoldelse i en vedvarende kæde af erfaringer og undersøgelser af processen. Som deltager/observatør høstede terapeuten/forskeren en masse vigtig information inde fra gruppen. Denne information var nødvendig for analytiske refleksioner over terapeutiske processer og andre aspekter af gruppens funktion samt som information om deres forståelse af og erfaring med musikalsk pleje.

Med henblik på valideringen eller gyldigheden blev informanterne bedt om at læse en sammenfatning af den tolkningsmæssige analyse. De instruktioner, der blev givet til mødrene vedrørende valideringen af forskningsresultaterne, var med vilje holdt i enkle og ikke-bydende vendinger. Mødrene fik lejlighed til at se på og kommentere hele det sprog, der blev brugt i udforskningen af ”deres indre erfaringers unikke og private kvaliteter” (van Manen, 1997, p. xiii), og hvordan sproget blev brugt til at skabe og beskrive inter-subjektiviteten i deres erfaringer med musikalsk pleje.

Igennem de forskellige stadier af dette forskningsprojekt fremmede, støttede og underbyggede forskellige teorier, praksiser og forskning denne undersøgelse. I de empiriske udforskninger diskuterede man de forskellige temaer i nøglekategorierne ud fra følgende perspektiver: Sterns moderskabskonstellation (1995), gruppedynamik og processer, empatikonceptet, positiv psykologi, leg,

den hjælpende relation, udviklingsmæssigt understøttede teorier, musikudøvelse (musicning) som defineret af Small (1998), koncepterne om de fremkomne muligheder (affordance) og tilegnelse (appropriation) som præsenteret af DeNora (2000), teorier om livskvalitet, refleksion om musik og følelse, følelsesmæssig kreativitet, Yaloms begreb om en struktureret øvelse (2005), Csikszentmihalyis teori om flow (1996), nogle ideer om det personlige og sociale selv og dannelsen af egenidentitet, selvstændiggørelse og en fællesfaktor metode. Teorier om tab og sorg, belastninger og at magte dem, omsorg defineret af sundhedsarbejdere og arbejdsmodeller for forældre støttegrupper var også til støtte i denne undersøgelse.

Forskningsresultater

Efter som hovedformålet med denne undersøgelse var at udvikle en forståelse af mødrenes erfaringer med den musikalske pleje, der blev tilbudt dem, var det af yderste vigtighed for forskeren at fastholde deres integritet ved at give dem lejlighed til at tale for sig selv og ikke miste deres stemmer i processen med at reducere kompleksiteten i det empiriske materiale gennem meningssammenlægning via tematisk analyse. Kun på den måde kunne forskeren forsøge at forklare erfaringerne uden ”at skade det hemmelige eller det magiske”, som en af mødrene udtrykte det (Esja, SP II 002).

På basis af klinisk og teoretisk forståelse udviklede musikalsk pleje udforsket i en ny sammenhæng en forståelse af sin kerne for disse særlige forskningsdeltagere. Gennem tolkningsmæssig, fænomenologisk analyse udforskede terapeuten/forskeren systematisk deres erfaringer og konkluderede, at oplevelsen af musikalsk pleje for disse mødre handlede om:

Gruppen. At høre til i en glad gruppe imødekom individualitet og frihed til at ytre sig. Det var en gruppe, hvor en atmosfære af tillid førte frem til reduktion af forsvarspositioner og dermed oprettelse af empatisk forståelse og støtte. Ved at opmuntre til, at man delte erfaringer, tanker og følelser, opbyggede gruppen bevidstgørelse og styrke, åbnede muligheder og perspektiver. Det skabte også en følelse af forventning og taknemmelighed at tilhøre den første gruppe med musikalsk pleje.

Musikudøvelse. Musikudøvelse bragte glæde og skønhed, forandring og muligheder og også den afslappede, imødekommende og omsorgsfulde atmosfære. Musikudøvelse i fællesskab bragte nærhed, fremmede empatisk lytning og selvstændig bevidsthed om følelser ved at lette og uddybe emotionelle udtryk.

Sangskrivning. Den udfordrende og alligevel gode erfaring med at skrive sange gav struktur, form og perspektiv, imødekom individualitet og styrkede mødrenes egen identitet.

CD'en. CD'en var et memento om det forløb, der kunne bevare gruppens emotionelle tone og validere mødrenes emotionelle rejse.

Terapeuten. Terapeutens intuitive sensitivitet og velovervejede, reflektive ro førte til mødrenes følelse af trykthed og omsorg.

Jeg og min tid. Erkendelse af det vigtige i at have kvalitetstid til sig selv, en kvalitetstid, hvor man kunne styrke sin egen identitet og sit velbefindende til gavn for hele familien.

En proces og forandring. Erfaringen med musikalsk pleje var en proces og en personlig erfaring hen imod større bevidsthed om behov, tanker og følelser.

Dagbogen, der tjente både som opbevaringssted og mediator. Den var opbevaringssted for forskellige tanker og følelser, der opstod under og mellem sessionerne, og som mødrene valgte ikke at dele med gruppen, enten fordi de anså for for svære, eller fordi de anså som trivielle.

Det efterfølgende er en sammenfatning af, hvordan mødrene oplevede processen med musikalsk pleje, og hvordan de på basis af denne oplevelse ville definere musikalsk pleje:

I processen med musikalsk pleje har alt sin plads. Man åbner op for en ny oplevelse og nye kreative udfordringer, og der finder udvikling sted i hver session. Lidt efter lidt slapper man af i situationen og giver mere af sig selv, hvilket styrker det hele. Man vover at dele sine tanker og at lade høre fra sig. Man taler mere åbent og kommer til at kende hinanden bedre, efterhånden som empatien øges. Man bringer ting på bane, som er besværlige, taler om dem, skriver om dem og synger om dem. Man giver toner fra sig, sætter ord på sine følelser og lytter til musik. Gennem denne proces giver man tingene form og bliver mere bevidst om, hvem man er, og hvad det er, man har brug for og ønsker. Man klargør sine håb og ønsker, årsag og virkning, adfærd og reaktioner, og hvad det er indeni en, som får en til at føle sig dårligt tilpas. Dette er en rejse inden i og omkring en selv, en rejse, gennem hvilken man modnes og lærer at kategorisere sine følelser. Den ændrer den måde, man føler og tænker på omkring sig selv. Den rækker ved gamle vaner med ikke at ville ses eller høres og altid at ville gøre alting bedre. Med små skridt bevæger man sig fremad mod en større accept af sig selv, mod at kunne erkende alle slags følelser, at definere dem og arbejde sig igennem dem. Når

man tænker positivt om sig selv, så begynder man automatisk at tænke på at gøre noget godt for sig selv. Efter afklaringen giver man plads til glæde. Et lille skridt fremad ændrer det hele. Man lærer at rejse på en bedre måde, at tage bedre vare på sig selv, hvordan man støtter et andet levende væsen og at nå frem til en slags succes ved at være, inklusive det at være mor til et handicappet barn. På denne rejse får kreativitet, empati, omsorg, ny forståelse, øget bevidsthed om musikens kraft og nye og vedvarende venskaber en til at føle sig stærkere og rigere. Den hemmelige rejse gør en godt. (Einræn, SP I 002-004, SP I 006. Esja, SP I 004, SP II 004. Góa, SP I 008, SP I 010. Hanna, SP I 008, SP II 001. Klambra, SP I 002, SP I 006, SP II 007, SP II 008. Kristjana, SP I 008, SP II 005. Skonza, SP III 001, SP III 002).

For mødrene var musikalsk pleje det hele, de blev tilbudt i denne gruppe, og det inkluderer den proces, de var igennem. De følte, det var godt at samles, at tale med gruppen og at lytte og prøve noget nyt. Ikke overraskende understregede mødrene, at det ikke ville have været musikalsk pleje, hvis der ikke havde været noget musik. De følte, det hjalp meget at løsne op for følelserne ved at lytte til musik og at slippe ordene ud, idet de erkendte, at ”det alene ville aldrig udrette det, det gjorde, med mindre alt det andet var der (Klambra, SP II 02).

Kristjana tænkte på musikalsk pleje som noget ”frygtelig stort og enormt”, noget som hun havde været bare en lille smule inde i. Ligesom de andre mødre følte hun, det var musikken, der udrettede dette, men vidste ikke nøjagtigt, hvordan hun skulle forklare det. Kristjana havde følelsen af, at musikalsk pleje kunne have været udviklet langt videre, for langsomt blev hun klar over, hvad det var: ”Man blev dygtigere til at lege følelserne ind i musikken, at bruge musikken til at opleve eller vække følelser og komme af med dem. Efter at være blevet klar over potentialet følte det som at være i begyndelsen af noget, og det følte mærkeligt at være færdig” (SP II 002, SP II 004).

Terapeuten/forskerens foreløbige definition af musikalsk pleje var inspireret af hendes tidligere erfaring som musikterapeut, af assimilering af teorier udviklet i støtteerhverv som fx sygepleje, Sterns interaktionsteori og hans psykopatalogimodel (1995) og Smalls definition af musikudøvelse (musicking (1998)). Terapeuten/forskeren håbede, at empatiske og følelsesmæssigt støttende relationer skabt ved at udøve musik sammen ville influere positivt på svære følelser opstået gennem mødrener erfaringer med at have et barn med særlige behov; og derved kunne musikalsk pleje muligvis have direkte eller indirekte virkninger på forskellige aspekter af deres liv og relationer. Som den

tolkningsmæssige analyse af mødrenes levede erfaringer afslørede, blev terapeuten/forskerens håb understøttet. Musikudøvelse i et omsorgsfuldt miljø var en ressource med kapacitet til at adressere mødrenes forskellige behov.

På grundlag af det foregående, holder terapeuten/forskerens foreløbige definition af musikalsk pleje stik i denne sammenhæng. Musikalsk pleje for disse forskningsdeltagere viste sig at blive en særlig slags gavnlig deltageroplevelse og havde visse selvstændighedsfremmende konsekvenser. Musikterapeuten var med sin fleksible ledelsesstil og omsorgsfulde opmærksomhed i stand til i forbindelse med musikudøvelse som redskab med dens variationsmuligheder, tilpasningspotentiale og mangeartede kraft at handle i mødrenes bedste interesse. Terapeut-klientforholdets egenskaber (de fælles faktorer) og variabler, der er unikke i forhold til musikudøvelsen, samt sangskrivningsprocessen viste sig som en højst effektiv tilgang i denne kliniske forskningssituation. Dette understøtter Castonguays (2000) samt denne terapeut/forskers overbevisning om, at den rigtige brug af fælles faktorer og variabler, der er unikke i forhold til indsatsmulighederne, efter al sandsynlighed vil være den mest effektive metode for klienterne.

Musikalsk pleje med en gruppe af mødre med børn med særlige behov må iværksættes med sensitivitet og må tage hensyn til hver gruppes og dens enkelte medlemmers variationspotentiale. For mødrene i dette forskningsprojekt blev musikudøvelsen justeret til deres til enhver tid aktuelle behov. Musikalsk pleje udgjorde en vej for dem, ad hvilken de kunne få kontakt med deres inderste kerne, med deres primære kreativitet eller medfødte drive mod sundhed. Den gav deres følelser form og omformede deres identitet.

Nogle konsekvenser i forhold til uddannelse, klinisk praksis og yderligere forskning

Uddannelse

Fokus i denne forskning illustrerer til en vis grad vigtigheden af at udvikle sin egen teori vedrørende gavnligheden, af at lære om og realisere den høje prioritet, som omsorg har i klinisk praksis, at lære om etikken, som relaterer sig til musikterapiens praksis og forskning, at tilegne sig færdigheder i menneskelige relationer, der fremmer forståelse af selv og andre, at lære om følelsesmæssig kreativitet som en potentiel forandringsmekanisme og at gøre sig fortrolig med den empiriske litteratur om proces og resultater for forskellige indsatsmuligheder, forskellige forskningsmetoder og terapeutiske metoder og

teknikker. Når man arbejder med mennesker, turde vedvarende uddannelse og livslang læring selvsagt være indlysende.

Klinisk praksis

Som det skulle vise sig, var gruppen med musikalsk pleje en succes set fra informanternes såvel som terapeuten/forskerens perspektiv, idet den opmuntrede til introduktion af musikalsk pleje for dette klientel inden for TI. Mødrene deltog stolte og med liv og sjæl i den første gruppe og håbede, at musikalsk pleje ville komme andre mødre til gode i fremtiden. Terapeuten/forskeren føler sig opmuntret af dette og tror, at hvis en ny gruppe med musikalsk pleje bliver kørt på samme eller en lignende måde, vil den vise sig gavnlig på en sammenlignelig måde for nye deltagere. Øget bevidsthed om musikalsk plejes muligheder kunne også føre til en meningsfuld og konstruktiv anvendelse i forskellige andre sammenhænge.

Forskningsresultaterne validerer sangskrivning som klinisk metode for denne klientgruppe. Som et effektivitetsorienteret accelereringsinstrument medbringer sangskrivningsprocessen en vigtig tidsmæssig struktur og et klart formål, som er ideel for en lille gruppe og et kortvarigt terapiforløb. Sangskrivningsprocessen, hvad enten den er improviseret eller struktureret, bringer teknikker med sig, som fremmer følelsesmæssig kreativitet. Justerbar, som den er, i forhold til forskellige individuelle og gruppemæssige behov hjælper den mennesker til hurtigt at komme i kontakt med undertrykte følelser eller andre uopdagede dele af sig selv, finde frem til problemer og behov og på en kreativ måde udforske alternativer og løsninger og forme dem til betydningsfulde og endog smukke resultater. Sangskrivningsmetoden og dens teknikker skal justeres i forhold til det specifikke for hver gruppe (behov, funktionsevne og både individuel og grupperelateret progression). Nogle grupper kan have brug for en anderledes struktur, mere vejledning eller andre opvarmningsøvelser, for eksempel. Så længe behovene er blevet erkendt og mål og hensigter klart defineret, har terapeuten en yderst effektiv metode til sin disposition koblet med intuition, empati og en opmærksom indstilling.

Yderligere forskning

Kvalitative forskningsmetoder, som agter på klienternes stemmer inden for konteksten af deres oplevelser, er væsentlige af hensyn til optimering af de tilbudte ydelser. Den tolkningsmæssige, fænomenologiske metode, der blev valgt til dette forskningsprojekt, var en sådan metode og taler for yderligere brug i denne sammenhæng.

Handlingsforskning eller evalueringsforskning kunne også virke godt i denne sammenhæng fx for at finde ud af, om klienternes behov opfyldes i et program med musikalsk pleje, for at finde ud af hvordan et sådant program fungerer, for at forbedre programmet og for at forstå, hvorfor et sådant program ikke virker. Man kunne opfordre mødrene i dette forskningsprojekt til igen at tage del i en gruppe med musikalsk pleje, som omfatter mere afslapning, sang som opvarmningsteknik, mere livlig sang, mere glæde, skabelse af individuel(le) digtning/tekster, og ét af dem lavet i samarbejde omkring et centralt tema samt mere tid til skabelse af musik. Gennem deres deltagelse i et handlingsforskningsprojekt kunne de befordre forandring(er) med udgangspunkt i deres tidligere erfaringer.

Et forløb med blandede metoder ville også fungere i denne sammenhæng, idet man bruger før/efter tests til at evaluere målingsresultater i en gruppe med musikalsk pleje. En skala for livskvalitet, fx, eller et belastningsindeks kunne bruges til det formål. En forskningsundersøgelse med fokus på målinger af følelsesmæssig kreativitet og deres korrelation til positive terapeutiske resultater i en gruppe med musikalsk pleje kunne være en interessant undersøgelse. Gennem en form for mikroanalyse kunne man studere de musikrelaterede parametre ved musikudøvelse (fx lydkvaliteterne i musikalsk interaktion) i en gruppe med musikalsk pleje. Mikroanalyse fokuserer på ”minimale ændringer i relationer eller interaktioner mellem mennesker eller minimale ændringer i musikken og i de dynamiske kræfter” (Wosch & Wigram, 2007, s. 14). Forbindelsen eller relationen mellem musikrelaterede parametre og opfattelsen af/begrebet om fx omsorg og glæde kunne også undersøges. En undersøgelse med fokus på, hvordan arbejdet i en gruppe med musikalsk pleje selvstændiggør deltagerne i deres dagligliv eller øver indflydelse på deres brug af musik, er også en mulighed.

Et andet forskningsemne foreslået af mødrene kunne være at undersøge musikalsk pleje for mødre med mindre børn (0 – et år gamle) på grundlag af en mere receptiv form for musikudøvelse. Musikalsk pleje kunne også undersøges med en gruppe mødre, som også modtog individuel musikterapi. Og nok en ide ville være at bruge musikalsk pleje i en gruppe mødre, som også deltog i en gruppe med musikalsk pleje med deres børn. Forskning i musikalsk pleje for en gruppe fædre er ligeledes et vigtigt tiltag og ville muliggøre en sammenligning mellem mænd og kvinder i henseende til kønsproblematikken. Yderligere har musikalsk pleje for bedsteforældre og søskende til børn med særlige behov et potentiale, som ville være værd at forske i.

Ovenstående ideer nævnt som muligheder for yderligere empirisk udforskning er rene spekulationer, som kræver grundig undersøgelse, før de kan vurderes som pragmatiske muligheder. Det er nemt at blive revet med af det righoldige materiale og de vide perspektiver, som forskningen gav adgang til.

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APPENDICES

Included in the appendices are:³²

Appendix A: The ethical approval from the National Bioethics Committee.

Appendix B: A registration with the Data Protection Authority.

Appendix C: The brochure used to introduce the research.

Appendix D: Informed consent form the participants signed prior to the beginning of this research.

Appendix E: A consent form signed by the mothers allowing the CD to accompany the dissertation.

Appendix F: A letter of support from Sjónarhóll (counselling centre for parents of children with special needs in Iceland).

Appendix G: The questionnaires, labelled 'A' and 'S', and instructions for the diary.

Appendix H: A list of the Icelandic songs included in the folder that was given to each mother in the initial individual interview when the therapist/researcher introduced the research.

Appendix I: An overview of the mothers' attendance in the music-caring sessions as well as the dates of their individual introductory meeting and the dates of their individual interviews (session #12).

Appendix J: Dates and places of the mothers' meetings after the completion of the music-caring sessions.

Appendix K: An example in Icelandic of the outline form used for the music-caring sessions.

Appendix L: An example from the handout given to the mothers with a compilation of categories/themes which were discussed in sessions #1 to #5.

Appendix M: An example of the poems composed by the therapist/researcher and distributed to the mothers as a prompt for their own writing.

³² Due to the Icelandic context of this research some of the documents are only presented in Icelandic.

Appendix N: A postlude in Icelandic used in the last music-caring session.

Appendix O: An Excel document showing an example of how all the music-caring sessions were summarized and analytic memos written.

Appendix Ó: An example of how the transcribed interviews were analyzed in the first three readings.

Appendix P: An example of how the research questions, quotes and the categories were put together in an Excel document.

Appendix Q: The mothers' songs.

Appendix R: The mothers' answers to questions from the questionnaire 'S'.

Appendix S: Contents of the accompanying CD.

Appendix T: The document sent to the mothers for validation of the researcher's analysis of core categories and related thematic statements.

Appendix U: An e-mail sent to the mothers asking for a written consent (e-mails) allowing verbatim use of their verification.

Appendix V: Vignettes from analytic memos written after sessions one, three, five, six, seven, eight, nine and ten.

Appendix W: The mothers' self-description shared in the individual interviews after the completion of the ten music-caring sessions.

Appendix A

The ethical approval from the National Bioethics Committee.

AFRIT

Greiningar- og ráðgjafarstjóð ríkisins
Tryggvi Sigurðsson, sálfræðingur
Digraunesveg 5
200 Kópavogi



VÍSINDASIÐANEFND

Vegmíla 1, 108 Reykjavík,

Sími: 551 7100, Beðsim: 551 1444

netfang: vísindasiðanefnd@vsn.is

Reykjavík 7. mars 2006

Tilvísun: VSN:2006023008/03-7 Námsverkefni - nemararannsóknir atvinnur/BH2-

Vardar: 06-020-S1 The lived experience of a group of mothers having infants with special-needs, participating in a music therapy program defined as music-caring within the framework of early intervention. "Tónræn-Umönnun".

Vísindasiðanefnd þakkar svarbréf þitt, dags. 03.02.2006 vegna áhursendra athugasemda við ofangreinda rannsóknaráætlun sbr. bréf nefndarinnar dags. 21.02.2006. Í bréfinu koma fram svör og skýringar til samræmis við athugasemdir Vísindasiðanefndar.

Ejallað var um svarbréf þitt og önnur innsend gögn á fundi Vísindasiðanefndar 07.03.2006 og voru þau tahn fullnægjandi.

Rannsóknaráætlunin er endanlega samþykkt af Vísindasiðanefnd. Nefndin áættrar nauðsyn þess að þúinn verði til lykili milli dulnefna og persónugreinanlegra upplýsinga á öðru blaði

Vísindasiðanefnd bendir rannsakendum vinsamlegast á að birta VSN tilvísunarnúmer rannsóknarinnar þar sem vitnað er í leyfi nefndarinnar í birtum greinum um rannsóknina. Jafnframt fer Vísindasiðanefnd fram á að fá send afrit af birtum greinum um rannsóknina. Rannsakendur eru minntir á að tilkenna rannsóknarlok til nefndarinnar.

Með kveðju,
Elh. Vísindasiðanefndar,

Ólafur Ár Atladóttir, framkvæmdastjóri

Appendix B

Registration at The Data Protection Authority.

Tilkynning um vinnslu persónuupplýsinga	Númer S2847
Er um að ræða nýja tilkynningu eða breytingu á eldri tilkynningu?	Ný tilkynning
Eldra tilkynninganúmer sé um breytta tilkynningu að ræða:	
Nafn	Tryggvi Sigurðsson
Nafn forsvarsmanns (s.s. forstjóra) ef ábyrgðaraðili er fyrirtæki/stofnun:	
Nafn þess sem fyllir tilkynninguna út:	Valgerður Jónsdóttir
Heimilisfang:	Laugateigi 35
Póstnúmer:	105
Staður:	Reykjavík
Símanúmer tengiliðs:	862 2040 5885088
Titill verkefnis(ss. nafn á skrá eða heiti rannsóknar)	The lived experience of a group of mothers having infants with special needs, participating in a music therapy program defined as music-caring within the framework of early intervention

Appendix C

The brochure used to introduce the research.

Fraeilegur grunnur

Rannsóknin heitir á ensku „The lived experience of a group of mothers having infants with special-needs participating in a music therapy program defined as music-caring within the framework of early intervention.“

Rannsóknin byggir m.a. á klínískum aðferðum fröðgreinarnar músíkþerapiu, hugmyndum um lífsgeði, hugmyndum heilbrigðisétta um umhyggju, hugmyndum Daniel Stern um líðan nýbakaðra mæðra og um jökvað áhrif sem inngríp af ólíkum toga geta haft á líðan fjölskyldumeðlima, hugmyndafræði stuðningsþópa, rannsóknir á áhrifum tónlistar á tilfinningar og líðan fólks.

Vísindalegur ávinningur/gildi

Í snemmtækri íhlutun er lögð áhersla á að greiningu sé fylgt eftir með úrræðum sem í ljósi núverandi þekkingar séu líkleg til að draga úr áhrifum fötlunar á líf barns og fjölskyldu þess. Lögð er áhersla á að bæta horfur barnsins, efla lífsgeði þess og sjálfsæði. En fá úrræði eru til sem hafa það að markmiði að huga beint að foreldrunum sjálfum. Valgerður og ábyrgðarmaður rannsóknarinnar telja að ef vel tekst til geti Tónræn umönnun komið til móts við þarfir sem forráðamein barna með sérþarfir fjá sig um í ræðu og riti og því sé rannsókn af þessum toga tímabær. En það er nauðsynlegt að þátttakendur sjálfir fái að fjá sig um reynslu sína og taka þátt í að þróa Tónræna umönnun svo hún þjóni sem best tilgangi sínum. Ef vel tekst til verður um ávinning að ræða fyrir þátttakendur. Einnig ber að líta á reynslu þeirra sem veggvisi til framtíðar fyrir rannsakanda og aðrar mæður sem taka þátt í Tónrænni umönnun.

Ábyrgðarmaður rannsóknarinnar er dr. Tryggvi Sigurðsson, sálfræðingur og sérfræðingur í fötlun barna.

Stjórn Sjónarhóls – ráðgjafarmíðstöðvar ses er kunnugt um rannsóknina. Stjórnin telur víðfangsefni hennar áhugavert og verðugt. Enn fremur telur stjórnin að þátttaka í rannsókninni geti reynst mæðrum barna með sérþarfir gagnleg til úrvinnslu á erfðri reynslu.

Rannsóknin hefur verið samþykkt af Vísindasáðanefnd og tilkynnt til Persónuverndar.


Ef þú hefur spurningar um rétt þinn sem þátttakandi í vísindarannsókn eða vill hætta þátttöku í rannsókninni getur þú snúið þér til Vísindasáðanefndar, Veggmála 3, 108 Reykjavík. S: 5517100 Fax: 5511444

Rannsóknin er námsverkefni til doktorsprófs í músíkþerapiu við háskólann í Álaborg. Rannsakandi er Valgerður Jónsdóttir, B.M., M.A., RMT

Tónstíola Valgerðar
Hátúni 12
105 Reykjavík
S: 561 2288
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588 5088
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Kynningarblað vegna þátttöku í rannsókninni Tónræn umönnun

Mynd á forsíðu
Asmundur Sveinsson **MODIR JÖRD**
Ljósmyndari Inger Helene Bøasson
© Listasafn Reykjavíkur



Inntak rannsóknar og markmið

Rannsakandinn Valgerður Jónsdóttir, byggir rannsóknina m.a. á 20 ára starfsreynslu sem músikþerapisti og tónlistarsérkenntari í Tónstofu Valgerðar. Hún hefur starfað með einstaklingum á öllum aldri sem glímt háfa við ólíkar fátlanir og sjúkdóma. Þeir háfa átt það sameiginlegt að háfa nýtt sér áhrifamatt tónlistar og þau tengsi sem myndast í tónlistar-reynslunni til að efla ferni og beta líðan. Valgerður hefur einnig kynnst forráðgjöfnum skólustjórnara sinna og þá einnig meðrunum og fengið innsyn í líf þeirra. Tilfinningar, líðan og þarfir sem þær tjá fá samhljórn hjá foreldrum sem í reðu og riti háfa sagt frá þeirri reynslu að eignast og eiga börn með sérþarfir. Hugmyndirfræði rannsakanda og kynni af meðrunum varð kveikjan að þeirri rannsókn sem nú er í undirbúningi. Valgerður telur að ávinningur sé af þátttöku í Tónrænni umönnun þar sem samvera og tónrenn fjáning miðar m.a. að því að laða fram, styrja og styrkja samhygð, efla meðvitund um tilfinningar og líðan og veita tilfinningum útrás.

Um er að reða eiginlega rannsókn þar sem fylgt verður reynslu 4-6 mæðra af þátttöku í höptinum sem nefndir eru Tónrenn umönnun. Mæðurnar eiga það sameiginlegt að eiga börn með sérþarfir á aldri 0-3 ára. Í rannsókninni eru börn með sérþarfir skilgreind sem börn er greint háfa með væg eða alvarleg þroskafrávik (s.s. líningagalla, efnaskiptagalla, hreyfihömlun, senþroska) og börn í áhættuþöpi vegna t.d. sjúkdóma, slysa, félagslegrar stöðu, áfalla á meðgöngu eða á burðarmálskeiði. Börnin taka ekki þátt í rannsókninni. Valgerður verður virkur þátttakandi í höpunum. Rannsóknin stendur yfir í þrjú mánuði. Þátttaka er meðrunum að kostnaðarlausu.

Frankvæmd

Rannsóknin fer fram í húsnæði Tónstofu Valgerðar sem er tónlistarskóli fyrir nemendur með sérþarfir að Háttumi 12, 105 Reykjavík. Rannsókninni er skipt í þrjú tímabil:

1. Inngangur/Undirbúningur hefst vorið 2006 með kynningu á rannsókninni. Móðir sem áhuga hefur á þátttöku hefur símasamband við Valgerði og fær munulegar upplýsingar um inntak rannsóknarinnar, markmið og framkvæmd. Háfr hún hug á þátttöku verður henni boðið að skóla vettvang rannsóknarinnar og fær þá afhent rannsóknargögn sem samansanda af:
 - skriflegum upplýsingum um inntak, markmið og framkvæmd rannsóknarinnar.
 - eyðublaði sem veitir alþemrar upplýsingar um þátttakanda. Eyðublaðið þarf að fylla út og skila á þessum fyrsta fundi.
 - eyðublaði sem veitir upplýst samþykki og skila þarf til rannsakanda áður en rannsókn hefst.
 - spurningablaði sem svara þarf skriflega og skila áður en rannsóknin hefst.
 - dagbók.
 - söngtextum.
2. Tónrenn umönnun felst í tíu höptinum. Höpurinn hittist einu sinni í viku og vinnur saman í um eina til tveir klukkustundir í seun. Tímarnir hefjast eigi síðar en haustið 2006. Framkvæmdin felur í sér hvorttveggja, lóðréttu framvindu (hver tími) og láréttu framvindu (rannsóknarinnablið) sem byggir m.a. á tónrænni fjáningu tilfinninga. Lóðrétt framvinda (hver tími):
 - Heilsuunst á tónrennan máta.
 - Hítum upp og „musisurum“ saman.
 - Tónrenn fjáning þar sem hugsanir/hugmyndir er kvikna hjá þátttakendum verða að stéfi/yrkisefni sem þróast að vild í tónrennum spuna.
 - Hlé og næring.
 - Kveðjumst á tónrennan hátt.

Viðfangsefni Tónrennar umönnunar miða að því að efla samhygð, gera mæðurnar meðvitandi um eigin tilfinningar og líðan, að örva tjáningu þeirra og að þróa stefnu/yrkisefni í heilisteypta mynd sem seija má í iónrennt form og flytja. Á hverjum tíma munu þarfir mæðranna, höpferlið sjálf og aðrir óvæntir þættir háfa áhrif á lóðréttu jafnt sem láréttu framvindu þeirra. Tónrænu umönnunar sem á sér stað. En eins og áður segir er markmið rannsóknarinnar að fá mæðurnar til að taka þátt í Tónrænni umönnun, tjá sig um reynslu sína og meta hvort og þá hvernig hún kemur til móts við þarfir þeirra og líðan.

3. Úrvinnsla/niðurlag felst í höptima sem skipulagður verður tveimur vikum eftir lók Tónrennar umönnunar og einstaklingstíma sem skipulagður verður innan mánaðar frá síðasta höptima. Í þessum tímum fara fram opin og hálf-opin viðtöl. Tímarnir verða teknir upp og umritaðir án persónuökenna.

Trúnaður við þátttakendur

Trúnaður verður varðveittur á þann hátt að persónuökenni verða engin, hvorki í afritum og úrvinnslu gagna né í miðlun niðurstaðna ur rannsókninni. Auk þess starfar rannsakandi í samræmi við starfs- og síðareglur fagfélaga sinna sem eru: Félag músikþerapista á Íslandi, The American Music Therapy Association og The European Music Therapy Confederation. Þar sem kveðið er á um trúnað við skólustjórnara. Mæðurnar í rannsókninni má skilgreina sem skólustjórnara Valgerðar á meðan á rannsókninni stendur. Mæðurnar verða upplýstar um mikilvægi þess að taka hátt í rannsókninni allri en þó sé fjálfst að enda þátttöku hvenær sem er á tímabilinu. Þær verða jafnframt hvattar til að háfa samband við rannsakanda hvenær sem þörf krefur.

Appendix D

Informed consent from the participants signed prior to the beginning of this research.

UPPLÝST SAMÞYKKI

Yfirlýsing um samþykki vegna þátttöku í náms-rannsókninni „The lived experience of a group of mothers having infants with special needs, participating in a music therapy program defined as music-caring within the framework of early intervention“ sem fengið hefur íslenska vinnuheimið

Tónræn umönnun.

Undirskrift mín er staðfesting á þátttöku í rannsókn sem fengið hefur íslenska vinnuheimið Tónræn umönnun.

Undirskriftin byggir á ítarlegum munnlegum og rituðum upplýsingum um: Tilgang og framkvæmd rannsóknarinnar, öflun, varðveislu og eyðingu gagna, hvernig kynningu á niðurstöðum rannsóknarinnar verður háttað, og upplýsingum um hugsanlegan ávinning/áhættu.

Undirrituð hefur jafnframt verið upplýst um mikilvægi þess fyrir alla hlutaðeigendur að taka þátt í öllum þremur tímabilum rannsóknarinnar en að undirrituð geti eigi að síður hvenær sem er hætt þátttöku eftir að rannsóknin er hafin.

Staður: _____

Dagsetning: _____

Þátttakandi: _____

Rannsakandi staðfestir með undirskrift sinni að rannsóknin hafi hlotið samþykki Vísindasiðanefndar og að eðli hennar og tilgangur hafi verið kynntur þátttakanda í samræmi við lög og reglur þar um.

Staður: _____

Dagsetning: _____

Rannsakandi: _____



Tónstofa Valgerðar

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Appendix E

A consent form signed by the mothers allowing the CD to accompany the dissertation.

Samþykki vegna notkunar á geisladiski

Með undirskrift minni veiti ég rannsakandanum Valgerði Jónsdóttur heimild til að láta geisladisk með hljóðritunum úr tímum í Tónrænni umönnun fylgja doktorsritgerðinni: *Music-caring within the framework of early intervention. The lived experience of a group of mothers having young children with special needs, participating in a music therapy group.*

Á geisladiskinum er eftirfarandi efni:

1. *Vetrarsól* sungin #9
2. Hóphljómur í tíma #1/2
3. Góa les ljóðið *Tilraun* #10/1
4. Ljód Góu hljómað #8/2
5. Góa les ljóðið *Líkn* #10/1
6. Ljód Góu *Líkn* hljómað #9/2
7. Einræn les ljóðið sitt *Ytra og innra haust* #10/1
8. Ljód Einrænnar *Ytra og innra haust* sungið #10/1
9. Kristjana les ljóðið sitt *Óvissa* #10/1
10. Ljód Kristjönu *Óvissa* sungið #10/1
11. Samhygðin hljómuð tími #5/2
12. Skonza les ljóðið sitt *Preyta* #10/1
13. Ljód Skonzu *Preyta* sungið #10/2
14. Hanna les ljóðið sitt *Ég elska börnin mín svo heitt* #6/2
15. Ljód Hönnu *Ég elska börnin mín svo heitt* sungið #10/2
16. Trommusláttur #7/2
17. Esja les ljóðið sitt *Lausnir* #10/2
18. Ljód Esju *Lausnir* sungið #10/2
19. Sansala hljómur úr tíma #4/2
20. Ljód Klömbrau *Rigning og ró* sungið #9/1
21. Klambra les ljóðið *Ó* #9/1
22. Klambra hljómar langspilið #6/2
23. Klambra les *Frábærar konur* #9/1
24. Klambra les *Til Valgerðar* 9/1
25. Hóphljómur úr tíma #10/2
26. Klambra les *Superwoman* og hópurinn hljómar #9/1
27. Andstæðar tilfinningar hljómaðar af hópnun kvíði/áhyggjuleysi #8/2
28. *Óskasundin* sungin #7/1

Staður: _____

Dagsetning: _____

Þátttakandi: _____



Tónstofa Valgerðar

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Appendix F

A letter of support from Sjónarhóll (counselling centre for parents of children with special needs in Iceland).

Reykjavík, February 23, 2006

**A statement about the doctoral thesis of music therapist Valgerður Jónsdóttir
“The lived experience of a group of mothers, having infants with special-needs,
participating in a music therapy program defined as music-caring within the
framework of early intervention.”**

To whom it may concern.

The directorate of Sjónarhóll, a counselling center for parents of children with special needs, is aware of the doctoral thesis that music therapist Valgerður Jónsdóttir is conducting.

The directorate of Sjónarhóll considers the undertaking of the thesis interesting and worthy and furthermore expects that participation in the research may prove helpful for mothers of children with special needs in the process of reflecting on their feelings in relation to their experience with their children.

Sincerely, on behalf of the directorate of Sjónarhóll,

Andrés Ragnarsson, chairman

Valgerður Jónsdóttir
Iðnstofa Valgerðar
Hátúni 12
105 Reykjavík



Reykjavík, 23. 2. 2006

Efni: Bréf Valgerðar Jónsdóttur, músikþerapista, til stjórnar Sjónarhóls – ráðgjafarmiðstöðvar ses. dags. 5. janúar 2006.

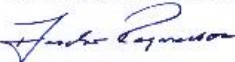
Kæra Valgerður,

Stjórn Sjónarhóls – ráðgjafarmiðstöðvar ses. ræddi ofangreint bréf frá þér á fundi 11. janúar 2006. Í bréfinu óskar þú eftir stuðningi frá stjórn Sjónarhóls við doktorsrannsókn þína um stuðningshópa fyrir mæður barna með sérþarfir þar sem tónlist er beitt til að tjá reynslu og tilfinningar. Stuðningurinn sem þú ferð fram á er í þremur liðum og var hver þeirra afgreiddur fyrir sig á eftirfarandi hátt:

- 1) Ósk um leyfi til að kynna rannsóknina á heimasíðu Sjónarhóls var **samþykkt**.
- 2) Ósk um stuðningsyfirlýsingu eða meðmælum frá Sjónarhóli var **samþykkt sbr. meðfylgjandi bréf**.
- 3) Ósk um leyfi til að nota lógó Sjónarhóls í bæklingi sem gerður verður til að kynna rannsóknina fyrir væntanlegum þátttakendum var **hafnað**.

Virðingarfyllt,

Eh. stjórnar Sjónarhóls – ráðgjafarmiðstöðvar ses.


Andrés Ragnarsson, formaður

Appendix G

The questionnaires labelled 'A' and 'S', and instructions on how to use the diary.

Þátttakandi: 200608M7

Fæðingardagur: _____

Lögheimili: _____

H-sími: _____ Gsm-sími: _____ Netfang: _____

Menntun: _____

Starf: _____

Hjúskaparstaða: _____

Greining barns: _____

Nafn: _____

Börn: _____

Nánasta fjölskylda/vinir (ekki nöfn): _____

Líkamleg heilsa: _____

Andleg heilsa: _____

Tónlistarnám: _____

Hljóðfæri á heimili: _____

Tónlistaráhugi (hljóðfæri, tegund tónlistar, hljómsveit o.s.frv.): _____

Notar þú tónlist? (Ef Já, þá hvernig og hvenær?) _____

Athugasemdir eða eitthvað sem þú vilt tjá: _____

Vinsamlegast veldu dulnefni til notkunar í rannsókninni: _____

S

Vinsamlegast svaraðu eftirfarandi spurningum skriflega. Númeruð svörin þarf að afhenda á meðfylgjandi blöð þegar Tónræn umönnun (rannsóknin) hefst. Þér er frjálst að sleppa þeim spurningum sem þú vilt ekki svara.

1. Hvað kveikti áhuga þinn á þátttöku í Tónrænni umönnun (rannsókninni)?
2. Hefur þér áður verið boðin þátttaka í stuðningshóp af einhverju tagi?
3. Hefur þú áður tekið þátt í eða ertu núna þátttakandi í stuðningshóp af einhverju tagi?
Ef þú svarar þessari spurningu játandi þá vinsamlegast lýstu hópnum.
4. Hvers konar stuðning/aðstoð færðu frá sérfræðingum í heilbrigðisþjónustunni?
5. Tengist sá stuðningur/aðstoð barninu þínu á einhvern hátt?
6. Hvers konar stuðning (tilfinningalegan, aðstoð við dagleg störf, aðstoð við umönnun barnsins o.s.frv.) færðu frá fjölskyldu þinni (maka, börnum, ættingjum)?
7. Lýstu sjálfri þér eins vel og þú getur og á þann hátt sem þú kýst. (Í orðum, ljóði, sögu, mynd, o.s.frv.)
8. Lýstu barninu þínu eins vel og þú getur á þann hátt sem þú kýst. (Í orðum, ljóði, sögu, mynd, o.s.frv.)
9. Hverjar eru vonir þínar og framtíðardraumar?

Dagbókin

- Þú ert hvött til að nota dagbókina.
- Dagsetja þarf hverja notkun.
- Notaðu dagbókina frjálstlega til að tjá hvað sem er.
- Það getur verið orð, setning, ljóð, teikning, myndir, o.s.frv.
- Það getur verið eitthvað um þig sjálfa, þátttöku þína í rannsókninni, fjölskylduna, barnið þitt, draumana þína, tilfinningarnar, náttúruna, atburð, árangur, væntingar, vonir o.s.frv.
- Það er allt í lagi ef þú vilt ekki nota dagbókina.
- Dagbókin verður afhent rannsakanda í lok þriðja tímabils rannsóknarinnar.
- Rannsakandinn gæti óskað eftir því að nota eitthvað sem þú hefur sett í dagbókina við úrvinnslu gagna og skráningu niðurstaðna en einungis með samþykki þínu og án persónuauðkenna.
- Dagbókin verður þín að lokinni rannsókn.

Appendix H

A list of the Icelandic songs included in the folder that was given to each mother in the initial individual interview when the therapist/researcher introduced the research.

Barnagæla

Aðalsteinn Ásberg Sigurðsson

Dagur er risinn

Heimir Pálsson

Ef þig langar að syngja

Heimir Pálsson/Karl-Fredik Jehrlander.

Ég ann þér

Jóhann Helgason

Ég leita

Jóhann Helgason

Fræ í frosti sefur

Sigurbjörn Einarsson

Hljóðnar nú haustblær

Sigríður I. Þorgeirsdóttir

Með mér

Jóhann Helgason

Nú hverfur sól í haf

Sigurbjörn Einarsson

Nú vil ég enn í nafni þínu

Kvöldbænina orti Hallgrímur Pétursson

Óskastund

Anna Pálína og Aðalsteinn Ásberg

Vetrarsól

Ólafur Haukur Símonarson

Vögguljóð – rituð á jólakort

Benedikt Gröndal

Þú styrkir mig

Hjálmar Jónsson

Appendix I

An overview of the mothers' attendance in the music-caring sessions as well as the dates of their individual introductory meeting and the dates of their individual interview (session #12).

Dates of the individual	#1	#2	#3	#4	#5	#6	#7	#8	#9	#10	#11	#12
introductory	23.9.	20.9.	7.10.	14.10.	21.10.	28.10.	4.11.	11.11.	18.11.	25.11.	11.12.	
meeting	2006	2006	2006	2006	2006	2006	2006	2006	2006	2006	2006	
Esja 12 June	X	X	X	X	X	X	X		XX	XX	XX	29.12.2006
Klambra 20 June	X	X	X	X	X	X	X	X	X		X	2.1.2007
Skonza 22 June	X		X			X		X	X	X		30.12.2006
Kristjana 9 July	X	X	X		X	X	X			X	X	29.12.2006
Hanna 17 July	X		X		X	X	X	X	X		X	3.1.2007
Góa 10 September	X	X	X	X		X	X	X	X	X	X	2.1.2007
Einræn 20 September	X	X			X	X	X	X		X	X	4.1.2007

Appendix J

Dates and places of the mothers' meetings after the completion of the music-caring sessions.

2007

- 2 May, Vox restaurant
- 6 September, Hanna's home
- 4 October, Góa's home
- 19 December, Cafe Paris

2008

- 21 February, Tónstofan (the mothers' choice).
- 16 June, B5 restaurant.
- 2 October, Geysir restaurant
- 3 December, Tónstofan (with the children)

2009

- 28 May, Caruso restaurant
- 20 August, mountain hike
- 2 September, Súpubarinn restaurant
- 26 November, A. Hansen restaurant
- 16 December, a theatre performance

2010

- 26 February, Krúska restaurant
- 27 May, Austurvöllur restaurant
- 24 September, Góa's summerhouse
- 15 December, Cafe Paris

2011

- 5 April, Caruso restaurant
- 24 May, Góa's home

Appendix K

An example in Icelandic of the outline form used for the music-caring sessions.

Tími # 5 21. 10. 2006

Ljúf tónlist leikin í bakgrunni á meðan mæðurnar er að koma sér fyrir.

Secret Garden.

Inngangur – heilsumst á tónrænan hátt.

- *Í síðasta tíma sungum við lag sem ég valdi vegna þess að mér fannst það einhvernvegin endurspegla allt sem þið rædduð um í þriðja tímanum. Þetta lag heitir Barnagæla og við skulum syngja það saman aftur.*

Til umhugsunar.

Kveikti þessi söngtexti einhverjar tilfinningar eða hugsanir?

Er eitthvað sem þið viljið deila með okkur sem gæti tengst efni söngtextans?

Hvernig var það fyrir ykkur að nota dagbókina þessa viku?

Er eitthvað í henni sem þið gætuð deilt með okkur?

Ég afhendi þeim ljósritin.

Í þeim tímum sem við höfum átt saman hafið þið rætt ýmislegt, m.a.:

- Hvað það gæti verið erfitt að hafa stjórn á tilfinningum við erfiðar aðstæður.
- Hvað það gæti verið þreytandi og erfitt að vera mamma og að leika aðalhlutverk í lífi barnanna.
- Að það væri til tvöskonur þreyta, líkamleg og andleg, og að þegar maður væri þreyttur væri svo stutt í grátinn.
- Að það að vera mamma væri stundum eins og að vera stofnun sem hefði það hlutverk að leysa öll vandamál heimilismédlima.
- Að það vanti inn í umræðuna um móðurhlutverkið að það geti verið virkilega erfitt að vera mamma.
- Hvað það væri mikilvægt, gagnlegt og gott að hitta þá sem hafa svipaða reynslu að baki.
- Hvað það væri mikilvægt að tjá tilfinningar sínar og líðan, að fá að nefna tilfinninguna og að hafa einhvern sem bara hlustar gagnrýnislaust.
- Að það væri kannski mögulegt að ákveða bara að vera jákvæður og stjórna þannig tilfinningunum.
- Að það væri stundum nauðsynlegt að láta skynsemina taka völdin og takast á við sorgina meðvitað eins og hvert annað verkefni.
- Þið rædduð um áhyggjur af því að standa ekki undir væntingum í hlutverki sem maður hefði ekki lært, þ.e. að vera móðir barns með sérþarfir.
- Maður ætti bara að vera duglegur en upplifði hjálparleysi og vanmáttakennd

- Hvernig mæta ætti áföllum væri ekki kennt og viðhorfið að þegja, þola og þrauka væri oft ríkjandi.
- Að maður hugsaði öðruvísi þegar maður ætti barn með sérþarfir.
- Lífið fengi miklu fleiri liti, en að það þyrfti að raða öllu upp á nýtt.
- Að völdin væru tekin af manni og aðrir stjórnuðu utanfrá og að fjölskyldan væri undir smásjá.
- Að það væri ósýnilegt álag á mæður sem fælist m.a. í endalausri bið og þeirri kvöl að horfa upp á sársauka barnsins.
- Að foreldrar þurfi að fá meiri tíma hjá sérfræðingum.
- Að það geti verið erfitt að kyngja eða sætta sig við athugasemdir frá fólki.
- Að reynslan við að eignast barn með sérþarfir sé dýrkeypt og sársaukafull.
- Að það sé svo dýrmætt að njóta dagsins í dag og að dvelja í núinu því að framtíðin sé alltaf óráðin hverjar sem aðstæður manns séu.
- Að það væri óþægilegt þegar maður yrði var við það að sérfræðingar væru að ráða ráðum sínum án þess að maður væri viðstaddur. Það væri svona eins og verið væri að grípa fram fyrir hendurnar á manni.
- Að óvissan væri svo erfið og það að fá ekki skýr svör við spurningum varðandi þroskaskerðingu barnsins síns.
- Að það væri gott að geta skrifað sig frá erfiðleikum sem koma upp.
- Að það að eiga barn með sérþarfir gerði mann sennilega viðkvæmari en ella.
- Að armæðan gæti verið lúmsk og læðst að manni.
- Að maður væri svo flinkur að rífa sig niður og því væri svo gott að fá jákvæðar athugasemdir og hvatningu.
- Að það þýddi ekki að hafa áhyggjur af því sem maður gæti ekki breytt og því væri svo gott að geta tamið sér jafnaðargeð.
- Og þið nefnduð einnig sorgarferlið og komust að raun um að þið væruð kannski staddir á mismunandi stöðum í þessu ferli.

Afneitun – doði, vera tekin úr sambandi.

Reiði – getur beinst að hverju sem er Guði, örlögunum, lækninum, sjálfum okkur, barninu.

Samningar – ef ég fórna mér algjörlega fæ ég frið í sálina, ef ég verð nægilega bænheitur, ef ég legg mig alla fram.

Geðlægð – staðreyndin blasir við, samningar duga ekki fötlunin komin til að vera, hleypum sorginni að, gefast upp í auðmýkt og hleypa sársaukanum að. Fara í gegnum hann eina leiðin út.

Sættir – við sleikjum sárin, erum ekki endilega sáttnar en lærum að lifa við það sem gerst hefur. Tilveran byggir á nýjum reynsluheimi. Njótum aukinnar lífsreynslu sem gefur meiri dýpt og þroska. Æðruleysið er fyrirheitna landið Og að geta hvílst eftir mikil átök. Viðurkenna vanmáttinn.

Muna eftir spólunum!

Upphitun

Þetta er tími #5 eins og þið vitið og við erum því hálfnaðar fyrir utan viðtalstímanna #11 og #12.

Því skulum við staldra aðeins við og velta upp nokkrum spurningum. En áður en við gerum það skulum við beina athyglinni inn á við.

- *Við lokum augunum og drögum djúpt inn andann nokkrum sinnum. Við spyrjum okkur sjálfar er eitthvað sem kallar á athygli mína núna? Tilfinning, hugsun, ímynd, litur, hljóð eða eitthvað annað. Og við spyrjum:*
 - ✓ *Hver er ég?*
 - ✓ *Hverjar eru þarfir mínar?*
 - ✓ *Hvernig líður mér núna?*
 - ✓ *Hvaða tilfinningar hef ég núna? (Þreytu, sársauka, depurð, reiði, einmanaleika, missi, örvæntingu, vanmáttarkennd!!)*
 - ✓ *Hvað eigum við sameiginlegt?*
 - ✓ *Hvaða tilfinningar eru sameiginlegar?*
 - ✓ *Hvaða þarfir eru sameiginlegar?*
 - ✓ *Hvernig getum við tjáð einstaklingsbundnar og sameiginlegar tilfinningar, þarfir og reynslu?*
 - ✓ *Hvert er markmið okkar í hópnum?*
 - ✓ *Hvert er markmið hópsins?*
- *Við dveljum með því sem kemur upp í hugann eða því sem við finnum í líkamanum. Við veitum því athygli líkt og við sætum hjá því og fylgdumst með því.*
- *Þegar tónlistinni líkur skrifum við niður á blað það sem kom upp í hugann, það sem við sáum eða það sem við veittum athygli. Við getum líka gefið því sem við veittum athygli nafn.*
- *Ég spila Arvo Part Alina*
- *Ræða um að nú sé komið að sönglagagerðinni eða því að setja í form það sem við höfum rætt um, það sem okkur hefur legið á hjarta hingað til og allt það sem við eigum eftir að tjá okkur um.*

Sönglagagerðin.

Í síðustu tímum höfum við valið orð af töflunni og hljómað þau. Við höfum rætt um og fengið að heyra aðsóknarkenndina, og að muna að lifa í núinu. Í síðasta tíma ræddum við um og fengum að heyra þreytuna og ósk um jákvæðni. Við skulum halda áfram þangað til þið hafið allar valið orð af töflunni.

- *Verkefnið felst sem sagt í því að velja orð og síðan hljóðsfæri eitt eða fleiri og hljóðsfæraleikara til að leika eða hljóma orðið.*

Til umhugsunar:

Hvernig var það fyrir ykkur að mála hugsanir/orð með tónum? (Hvernig fannst ykkur að mála orð með tónum?) Fundið þið einhver tengsl á milli orðanna, þeirra tilfinninga sem þau tjáðu og þess hvernig þau síðan hljómuðu eða voru tjáð tónrænt.

Tónræn sjálfsmynd.

Mæðurnar verða beðnar um að velja hljóðfæri og hljóma það á þann hátt sem þeim finnst best lýsa því hvernig þeim líður núna eða hefur liðið þessa viku.

Þær geta líka hljómað það hvernig þeim hefur liðið í hópnum eða á ákveðnu tímabili í lífi þeirra.

A. Við hljómunum þetta allar saman.

B. Ein og ein hljómar sig.

Til íhugunar:

Hvað var það við hljóðfærið sem þú valdir sem þú fannst tengingu við.

Getur þú útskýrt hvers vegna þú valdir þetta hljóðfæri eða hljóð og hvað þú varst að tjá?

Hvernig var það fyrir ykkur að gera þetta sem hópur eða sem einstaklingar.

Hressing

- *Nota Secret Garden í bakgrunni.*

Kveðjustund – niðurlag.

- *Í síðasta tíma völdu þær sem voru mættar sér kazoo. Þetta er blásturshljóðfæri sem hljómar þegar við syngjum í það eða tölum við það. Láta allar prófa.*
- *Svo getum við sungið aftur Barnagæluna en í kazoo*
- *Þá er samverustundinni að ljúka í dag.*

Íhugun.

Hafið þið þörf fyrir að tjá ykkur um hvernig það var að vera þátttakandi í dag.

Í síðasta tíma tókum við með okkur heim, jafnaðargeð, jákvæðni og orku.

Hvað hafið þið þörf fyrir að taka með ykkur núna?

- *Minna þær á dagbækurnar.*
- *Syngjum kveðjusönginn minn.*

Appendix L

An example from the handout given to the mothers with a compilation of categories/themes which were discussed in sessions #1 to #5.

<p>Eiginleiki</p>	<ul style="list-style-type: none"> ▪ Að geta hlustað á aðra. ▪ Kunna tjáningu. ▪ Að gera sig skiljanlegan. ▪ Að geta treyst. ▪ Samhygð (empathy). ▪ Að geta sett sig í spor annarra. ▪ Að muna að lifa í núinu. 	<p>Mikilvægt að tjá tilfinningar sínar og líðan, að fá að nefna tilfinninguna og að hafa einhvern sem bara hlustar gagnrýnislaust.</p> <p>Mikilvægt, gagnlegt og gott að hitta þá sem hafa svipaða reynslu að baki.</p> <p>Dýrmætt að njóta dagsins í dag og að dvelja í núinu því að framtíðin er alltaf óráðin hverjar sem aðstæður manns eru.</p> <p>Það er óþægilegt þegar maður verður var við það að sérfræðingar séu að ráða ráðum sínum án þess að maður sé viðstaddur. Það er svona eins og verið sé að grípa fram fyrir hendurnar á manni.</p> <p>Þó að samhygðin sé nauðsynleg getur enginn alveg sett sig í spor annarra.</p> <p>Maður skilur aldrei alveg annan og það sem hann er að ganga í gegnum.</p> <p>Því er svo mikilvægt að kunna að hlusta.</p> <p>Svo vont að vera í sorginni og óvissunni.</p> <p>Maður verður bara að fara í gegn – það er til góðs að vinna.</p> <p>Samkenndin og útrásin sem felst í að hlusta á aðra tjá tilfinningar og hugsanir sem maður upplifir sjálfur.</p>
<p>Einstaklingur</p>	<ul style="list-style-type: none"> ▪ Ég ▪ Gandhi ▪ Vinnuveitandi ▪ Guð ▪ Vera ▪ Barnið ▪ Fagfólk 	<p>Að eiga fatlað barn gerir mann sennilega viðkvæmari en ella.</p> <p>Það er til tvenns konar þreyta, líkamleg og andleg.</p> <p>Þegar maður er þreyttur er stutt í grátinn.</p> <p>Armmæðan getur verið lúmsk og læðst að manni.</p> <p>Maður getur verið svo flinkur að rífa sig niður og því er svo gott að fá jákvæðar athugasemdir og hvatningu.</p>

Appendix M

An example of the poems composed by the therapist/researcher and distributed to the mothers as a prompt for their own writing.

Hver dagur er einstakur,
rétt eins og þú.
Njótum hans saman.
Verum hér og nú.
Orð geta sært þig.
Spyrð, hver elskar þig nú?

Þú sérð mína fötlun en ég er rétt eins og þú.
Ég er barnið þitt núna og ljæ lífinu lit.
Þú ert barnið mitt núna og ljærð lífinu lit.

En ég er ekki bara mamma,
þetta'er tími fyrir mig.
Styðjum hver aðra,
lofum sorginni'að flæða,
já sjálfsagt að gráta
þegar viðkvæmnin knýr.

Hvert smáskref stórt,
og dýrkeypt reynslan.
Tilfinningin er eðlileg.
Finum samhljóm.
Í gegnum augað
er eina leiðin, leiðin út.

Appendix N

A postlude in Icelandic used in the last music-caring session.

Í upphafi fyrsta tíma talaði ég m.a. um að það væri von mín að Tónræn umönnun og viðfangsefni tímanna myndu efla samhygð, gera ykkur meðvitaðri um eigin tilfinningar og líðan og örva tjáningu þeirra á skapandi hátt. Ég talaði líka um það að Tónræn umönnun hefði ekki verið framkvæmd áður með þessu sniði svo að reynsla hvarrar og einnar aflaði mikilvægrar þekkingar og myndi verða vegvísir til framtíðar fyrir mig, aðra músíkþerapista og aðrar mæður sem ættu eftir að taka þátt í Tónrænni umönnun.

Ég nefndi það líka að það væri mikilvægt að hver móðir fengi notið sín og að rödd hennar fengi að hljóma á þann hátt sem hún kysi sjálf hverju sinni. Í tímunum fengjum við tækifæri til að tjá okkur um það sem okkur lægi á hjarta. Við ferðuðumst saman um stund, veittum hver annarri innsýn í líf okkar, tilfinningar og hugsanir, gæfum af okkur og þægjum frá hver annarri í formi tóna, hljóða, nærveru og hins talaða orðs.

Allt tekur enda. Tímanum líkur senn og við gerum okkur grein fyrir að bráðum er komið að leiðarlokum Tónrænnar umönnunar. Þá takið þið með ykkur allt það góða sem þið gáfuð hver annarri með nærveru ykkar og einlægru tjáningu. Einlægnin, traustið, samkenndin, stuðningurinn, hluttekningin og vináttan mun hljóma á disknum og fylgja ykkur áfram.

Í næsta tíma munum við í sameiningu skoða þetta ferðalag. Þið tjáið ykkur um það sem ykkur þótti markvert á leiðinni og eins um það sem ykkur þótti miður fara. Að leiðarlokum skoðum við væntingar ykkar, vonir og ótta varðandi þátttöku í hópnum. Við skoðum hvernig ykkur leið í hópnum og hvernig það var fyrir ykkur að taka þátt í viðfangsefnunum. Við ræðum um hvort þið söknuðuð einhvers, hvað ykkur þótti erfitt, hvað ykkur líkaði og hvers þið nutuð. Við veltum fyrir okkur gildi viðfangsefnanna, hlutverki tónlistarinnar og ágæti sönglagagerðarinnar. Og við skoðum hverju mætti breyta og hvað mætti bæta.

Veltið fyrir ykkur í hverju Tónræn umönnun felst og þeim augnablikum sem ykkur þótti Tónræn umönnun rísa hæst. Þið getið einnig velt fyrir ykkur eftirfarandi spurningum. Hvernig líður mér núna? Hvað gaf þessi þátttaka mér? Mun þessi reynsla fylgja mér áfram? Mun hún á einhvern hátt hafa áhrif á líðan mína og daglegt líf (lífsgæði)? Hverjir eru hinir sameiginlegu þræðir/reynsla/tilfinningar sem við höfum verið að flétta saman? Tókst okkur að láta allt þetta hljóma í ljóðunum okkar (sönglagagerðinni) eða eigum við enn eftir að tjá það?

Appendix O

An Excel document showing an example of how all the music-caring session were summarized and analytic memos written.

Session # 6 28.10.2006

Mættar: Esja, Klambra, Kristjana, Einræn, Hanna, Skonza, Góa

Analytic memos

I worried about how this session would turn out. I feel like I have reached a point where product has gained power over process. I wondered for a long time how the songwriting process could be moved forward. I was also worried about Einræn and did not know what to expect from her attendance. She expressed such concerns and I felt that the group was not taking care of her as it should. I even wondered if I should call her to see how she was doing. Would I be compromising the research somehow by doing that? I forget that I am a researcher and feel that I am not a good enough music therapist. I found being in this dual role difficult. This was the second time that all the mothers were in attendance and somehow the group felt heavy and slow. Four of them had done their homework and read it aloud. Skonza spoke more than she had done before and she gave Einræn some advice. Einræn got a good opportunity to express herself and I believe she felt empathy. Góa cried when we were listening to the music Klambra brought. Perhaps I am struggling with some countertransference issues. The mothers talk about the feeling of never doing well enough. This is a problem I can relate to - never doing well enough. Not being a good mother. ... I am not a good enough therapist and now I am not doing good enough research and not taking good

Time Issues

Secret Garden í bakgrunni.
Einræn kemur fyrst. Ég býð hana velkomna. Maður er svo vanafastur, sest alltaf í sama stólinn. Mér fannst þetta svo erfitt. Hann vaknaði upp aðra nóttina í röð hágrátandi. Við vorum að reyna að gera eitthvað fyrir hann þá beithan mig héra og klóraði. Ég ræð ekkert við hann. Hann er of sterkur. Ég athugaði hvor hann væri þyrstur. Svo furðulegt, svo virkur um leið og hann vaknar. Grætur og æpir, en getur ekki tjáð sig með orðum og maður verður svo hræddur. Veit ekki hvort honum líður illa. Hann meiðir sjálfan sig og líður örugglegga illa í þessum sárum.

Klambra skiptir um sæti. "Tekur svolítið á." Það er þægilegast að sitja á sama staðnum. Klambra kom með Pál Óskar. Svo yndislegur diskur. Hún hlustaði á diskinn til að fá andann yfir sig, svo fékk hún það á heilann. Esja kemur. Þú ert enn á ferðinni? Ég er svo ólétt. Hvað segið þið þæjur?
Einræn var að segja okkur frá erfiðri viku. Það var hringt í mig ... Hann er allur í sárum, og komin sýking í þau. Þau vildu ekki taka hann. ... Svo líður manni svo illa. Horfir á þetta en getur ekert gert. Sýndu okkur sárin. Almáttugur... Alveg hræðilegt.
Klambra: Svona sjálfsmeiðingar eru mjög algengar hjá einhverfum. Áreitir eru svo brengluð að þau ráða ekki við þau. Þetta kom þegar minn sonur varð eldri.
Esja: Eins og alkahólistar. Hún talar um

enough care of them.
I need to feel the power of the music in
the group. I worry about that there is not

bókina hans Njarðar P. Þegar hann var að
taka á móti syni sínum. Auðvitað þykir manni
alveg gríðarlega vænt um börnin sín, en

Appendix Ó

An example of how the transcribed interviews were analyzed in the first three readings.

Offers of this kind are rare

opnaði mig. Já í fyrsta lagi er þetta eitthvað sem ég er að gera fyrir mig. Bara fyrir mig það er náttúrulega maður gerir ekkert fyrir sjálfan sig beinlínis. Nei nema eitthvað svona ef það er eitthvað svona skipulagt (aha, já). Þannig að þetta er svolítið svona bara já. Þetta snýst um mig og mínar tilfinningar. Einhver hefur áhuga á því. Mér finnst það vera nú svolitil upplifun (já).

V.: Getur þú myndað þér að þú að þú takir það með þér. Ef við hugsum um eitthvað sem þú takir með þér héðan. Fyrir utan sem sagt minninguna á diskinum og tilfinningarnar sem þar eru skráðar og lífa áfram og þú getur sótt í. Hvað fleira.

The group kind of

U.: Já það er náttúrulega líka bara svona tilfinning eins og þú, þú ert búin að segja mér það að ég skipti máli og mínar tilfinningar (já). Þetta snýst ekki alltaf bara um barnið satlaða barnið (já). Það er náttúrulega bara ótrúlega góð tilfinning.

V.: Þannig að það er þín upplifun þú tekur það partur af því sem þú tekur með þér. Að þú skiptir máli, þínar tilfinningar.

U.: Já ég held það.

V.: Næstu spurningar eru kannski svolítið eins og að mjólka (já)

004

Quest. (13)

V.: Getuðu list því í smástríðum einhverjum tíma eða einhverjum aðstæðum sem þú lentir í í tímunum þar sem þú upplifðir Tónræna umönnun svona sterkast fyrir þig einhvert sterkt augnablik þar sem þú fannst svona aha eða

Is the love playing as a concept of a household?

U.: Ég held að það hafi verið. Þetta er samt einhvern veginn bara allt (já) hvernig það kemur saman (já). En það er náttúrulega voða gott, það var rosalega góð tilfinning þegar allir spiluðu saman.

V.: Tilfinning af hvaða tagi?

U.: Þegar ég náði að hætta að hugsa um það að ég kunnist ekki að spila og mætti ekki spila ljótt (já) þú veist illa að þá bara var voru allir að gera eitthvað svona saman að búa til eitthvað saman og mér fannst það já gaman. En líka það er í rauninni bara allt. Að bara fá þennan tíma. Fá að mæta (já) og að og að hérna þú veist tala eða þú veist tja tilfinningar hlusta á hina og samveran. Það er eiginlega bara það sem að mér fannst skipta mestu máli.

V.: Svona það samanlagt.

MO 27
SELF-IDENTITY
IT IS ABOUT ME

I am doing this for myself.
• One does not do anything for oneself directly unless it is like this organized.
• So it is about me and my emotions.
• Someone is interested in that. I feel that it is itself an experience.
• You have told me that I make a difference. I find my emotion.
• This does not always evolve around the handic child.
• That is for me a unbelievable good feeling

MO 26
MUSIC CARING MOMENT

• It is somewhat just the whole thing. How it is brought together. But it is of course very good to possibly good feeling when everybody played together.
• Everyone was making something together.
• And to just get the time.
• It allowed it all.

MO 28
TOGETHERNESS

Tónræn umönnun. Einstaklings viðtal 29. 12. 2006. Viðmælandi [REDACTED]

36

Einraen	Góa	H anna	Klambra
Difficult time of year	Belonging to the group	My role in the research	The diary
The child	Trust and freedom	Tired	Belonging to the group
Introduction	Liberating feeling	Belonging to a group that understands you	Helpful experience
Information on music-caring	Trust	Comparison	Challenges
Belonging to the group	The music was enjoyable	Perspective	Process change
Positive experience	To belong to the group	The lack of official support	Comparison
The group	Joy	Understanding	Participants
Anxious	To let go	Sharing common knowledge	Making music
Helpful experience	A resource	Emotional outlet	Peak musical experience
Demands	Helpful experience	Liberation	Developing themes
Challenge	New perspective	Demands	Songwriting
Songwriting	To be listened to	Challenge	Expressing feelings through songwriting
Process change	The effect of the music	Process change	Appealing characteristics
Separation anxiety	Music was a release	Making music	Your old self
The group	Self-identity	Togetherness	Sharing and expressing emotions
Support	Feeling of acceptance	Enjoyment	Sharing knowledge and experiences
Musicking	Accepting oneself	Focus on me	The structure of music-caring
The highlight	New possibilities	Quality of life	What is music-caring
Songwriting process	Quality of life	To take care of oneself	What I missed
Developing themes	new perspectives	Emotional expression	What I liked
Optimism	Empathy	Music vs. words	Giving and receiving help
CD	Common experience	Developing themes	A music-caring moment
Gratefulness	Challenges	Sounding through words vs. sounds	Good leadership characteristics
Need for opposite emotions	Process change	Structure and time frame	Gains
Words vs. music	Gratefulness	Trust	Reconciliation
The structure.	The CD	My time	Attitude
Empathy	Making music	To be heard	Uncertainty
Music-caring	Musicking	Supporting	Acceptance
Togetherness	Songwriting	Gain	Hope
Sounding emotions	Balance	Power of music	Conflict
Singing our song	Words vs. music	Enriched	Taking care of yourself
Insecurity	Highlight	Using music	Wishes
Mixed group	Structure	Quality of life	Self-portrait
Quality of life	Beautiful sound	Taking care of oneself	Susceptible
Self-identity	Sounding the poems	Self-identity	Touchy
Awareness of feelings	A release	Finding balance	The child
Hopes	Themes for songwriting	Conflicting feelings	Future dreams
Leadership styles	Methods of songwriting	The child	Suggestion
Recommendations	Structure of music-caring	Protecting the child's rights	
Caring	Recommendations	Self-portrait	
Sorrow	Music-caring	Future dreams	
Using music	Together	The CD	
Continuing the group	Continuity	Truth in music	
Making self-portrait	Changes		
The diary	The child		
	Hopes and dreams		
	Freedom of expression		
	The diary		

<p>Kristjana</p> <p>Introduction</p> <p>To be part of the group</p> <p>An interesting offer</p> <p>Self-identity</p> <p>Musical knowledge</p> <p>Helpful experience</p> <p>Sympathy</p> <p>To give and to receive</p> <p>Challenges</p> <p>Empathy</p> <p>Comparison</p> <p>Perspective</p> <p>Different support group</p> <p>Process and change</p> <p>The diary</p> <p>The initial shock</p> <p>To make music</p> <p>Musicking</p> <p>The CD</p> <p>Song themes</p> <p>Expressing emotions</p> <p>Empathetic listening</p> <p>Missing feeling</p> <p>Songwriting</p> <p>The lyric</p> <p>The structure</p> <p>Finding balance</p> <p>Togetherness</p> <p>Music-caring</p> <p>It is about me</p> <p>Continuing</p> <p>Hopes and dreams</p> <p>The child</p> <p>Recommendations</p>	<p>Skonza</p> <p>Introduction</p> <p>Belonging to the group</p> <p>Empathy</p> <p>To give and take</p> <p>Wonderful time</p> <p>Process and change</p> <p>Awareness of own feelings</p> <p>Depth of expression</p> <p>Expressing feelings</p> <p>Daily life issues</p> <p>Information about music-caring</p> <p>The diary</p> <p>What was helpful</p> <p>Playing instruments</p> <p>Singing</p> <p>Talking together</p> <p>To hear their poems</p> <p>The participants</p> <p>Challenges</p> <p>Songwriting process</p> <p>Group size</p> <p>The CD</p> <p>Musicking together</p> <p>Cleansing</p> <p>Well-being</p> <p>Giving shape</p> <p>Words vs. music</p> <p>Highlight</p> <p>To forget oneself</p> <p>Singing the poems</p> <p>Developing themes</p> <p>The structure or lack of structure</p> <p>Introducing music-caring</p> <p>What defines music-caring</p> <p>Taking care of needs</p> <p>Self-identity</p> <p>Self-awareness</p> <p>Time</p> <p>My child</p> <p>Recommendations</p> <p>The director researcher</p> <p>Relationship</p>	<p>Esja</p> <p>The CD</p> <p>Belonging to the group</p> <p>Positive feelings</p> <p>Comparison</p> <p>Gives perspective</p> <p>Empathy</p> <p>Prior experience</p> <p>Always meeting the same</p> <p>Feeling of stability</p> <p>Intimacy</p> <p>Trust</p> <p>Helpful experience</p> <p>Words vs. music</p> <p>Sounding emotions</p> <p>Giving shape</p> <p>Become aware of emotions</p> <p>Self-identity</p> <p>Common experience</p> <p>Empathy</p> <p>Process change</p> <p>Excitement</p> <p>Being shy</p> <p>Expectations</p> <p>Nurturing</p> <p>Peace</p> <p>Awareness</p> <p>Process and change</p> <p>From the unknown to the known</p> <p>Hopes and desires</p> <p>New acquaintance</p> <p>Sharing</p> <p>Empathy</p> <p>Self-identity</p> <p>Sharing</p> <p>Comparing</p> <p>Making music</p> <p>Enjoyable</p> <p>Beautiful sounds</p> <p>Creating welcoming atmosphere</p> <p>Singing</p> <p>Voice quality</p> <p>Song texts</p> <p>The whole</p> <p>Braiding together</p> <p>Music vs. words</p> <p>Singing</p> <p>The importance of the whole</p> <p>The whole thing</p> <p>Everything important</p> <p>Self-identity</p> <p>Themes for songwriting</p> <p>Her gift to them</p>
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		<p>Her message Empathy Perspective Process vs. change Her way of surviving Comparison Helping each other by caring To be listened to and heard. The structure of MC The songwriting process Enjoyable Empathy Music-caring Music and emotions Music caring Musicking The process in music-caring Becoming stronger Inner and outer journey Comparison Learning about oneself by listening Self-identity To become a better person Self-identity Moving on Well-being Self-image Positive change Personal growth Recommendation The power of music to bring Change Future hopes and dreams Emotional outlet</p>
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Appendix Q

The mothers' songs.

EINRÆN 7 EINRÆN

úti í fyrir rignir það haust og bláinn fall á þrjúna það

haust er einnig innræð með sögja er alkröð andi

tárin fall á og ég kveðst yfir þú að hafa á

Sjáfar aukna barns minnis enfa engu um þó breytt

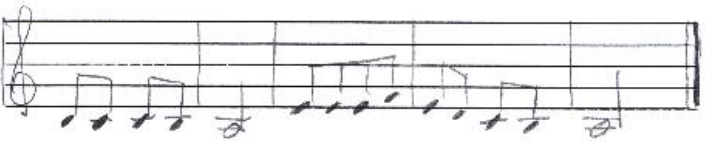
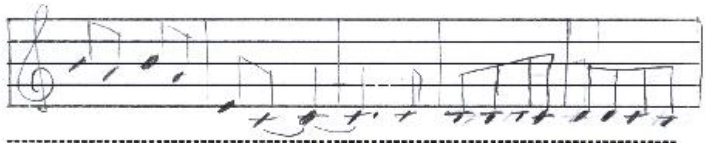
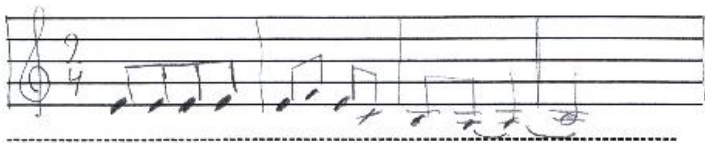
Esja VALGERÐUR JÓNSSDÓTTIR

The musical score is written on six staves. The first staff begins with a treble clef, a key signature of one flat (B-flat), and a 2/4 time signature. The notes are: G4 (quarter), A4 (quarter), Bb4 (quarter), C5 (quarter), Bb4 (quarter), A4 (quarter), G4 (quarter), F4 (quarter), E4 (quarter), D4 (quarter), C4 (half). The second staff continues with: C4 (half), Bb4 (quarter), A4 (quarter), G4 (quarter), F4 (quarter), E4 (quarter), D4 (quarter), C4 (half). The third staff continues with: C4 (half), Bb4 (quarter), A4 (quarter), G4 (quarter), F4 (quarter), E4 (quarter), D4 (quarter), C4 (half). The fourth staff continues with: C4 (half), Bb4 (quarter), A4 (quarter), G4 (quarter), F4 (quarter), E4 (quarter), D4 (quarter), C4 (half). The fifth staff continues with: C4 (half), Bb4 (quarter), A4 (quarter), G4 (quarter), F4 (quarter), E4 (quarter), D4 (quarter), C4 (half). The sixth staff continues with: C4 (half), Bb4 (quarter), A4 (quarter), G4 (quarter), F4 (quarter), E4 (quarter), D4 (quarter), C4 (half).

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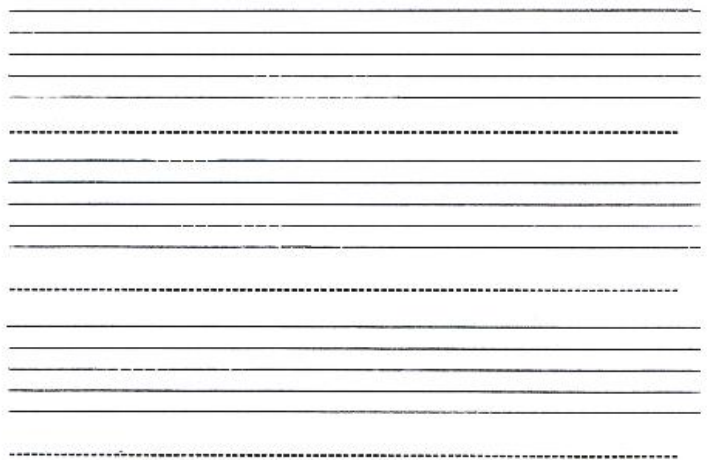
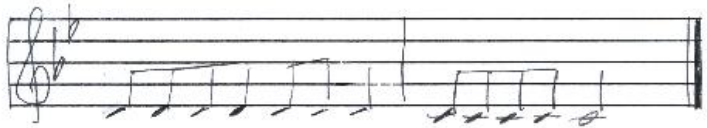
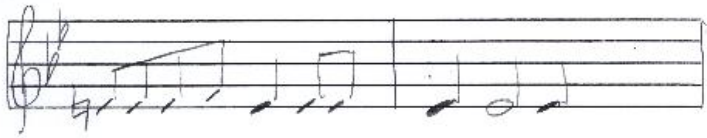
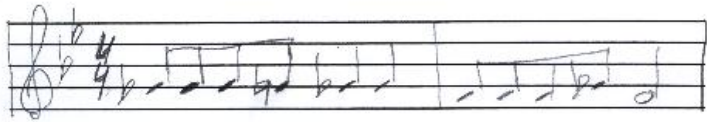
HANNA VAIGRÓUR JÓNSD.

KIAMBRA KIAMBRA



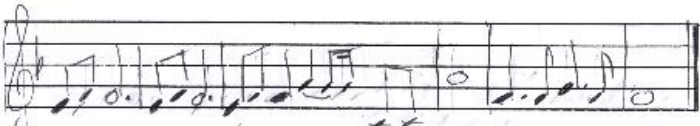
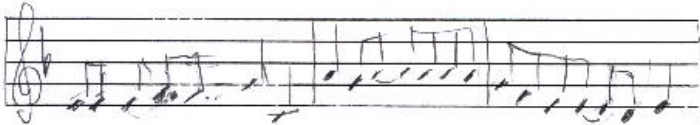
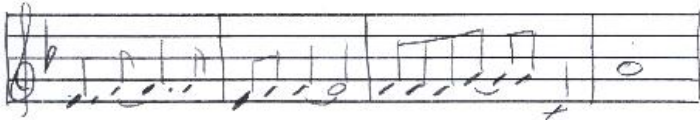
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KRISTJANA VINGRÁUR JÓNSDÓTTIR



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Skansa VAIGERÐVEGJING



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Appendix R

The mothers' answers to questions from the questionnaire 'S'

1. What sparked your interest in participating in this programme?
 - “My son’s physiotherapist told me about this research. I was very excited because I have always enjoyed music. I was certain that I would find this both helpful and enjoyable.” (Hanna)
 - “The goal [using musicking to work through emotions] which was the focus of the research.” (Skonza)
 - “Because music is used in the research.” (Einræn)
 - “I have felt that the ability to become enthusiastic about something has decreased with age. However, music is different in this respect. I feel I have to work with myself emotionally, not least with emotions that are connected to my son’s disability, and it is exciting to do that through music. Besides, I am in a choir and I study music theory and I think this complements the research. I also think this is quite a challenging project and I believe it will do me good. It is interesting to see if I will manage to open up.” (Klambra)
 - “I heard about Tónstofa Valgerðar [the special music school] in connection with my daughter’s disability. I noticed, both with myself and with other parents of children with disabilities, that one needs help to work through one’s emotions and help to handle the daily life that goes with taking care of the disabled child. It is important for parents not to forget themselves in all the daily routine. In this [research] I saw a possibility to take part in music therapeutic work. I also wanted to strengthen myself because I am pregnant and nobody knows if this baby will be disabled or not.” (Esja)
 - “An exciting research project. The researcher is well spoken of. Everything she does is so positive and excellent. Enjoyable to be able to participate in a project such as this. If I can do something to help mothers of children with special needs then I am a game. The need is great I believe the subject matter is exciting. One always wants to feel better.” (Kristjana)
 - “The wrong information! I thought that the course was about being together with mothers of children with special needs and the children themselves. That the mothers and children would meet once a week and sing together. I was interested in such a sing-along, but this turned out to be a misunderstanding. I have since changed my mind and I am grateful for this misunderstanding because I believe that I would not have registered for this if I had known in the beginning what this was about. I have become accustomed to the thought and have begun to look forward to it although I have a little knot in my stomach.” (Góa)

Two of the mothers said that the use of music sparked their interest in participating. Four of them mentioned both music and working with emotions (also helping mothers feel better) as a reason for their interest in participating. One mother became interested based on a misunderstanding that this would be merely a sing-along with mothers and children. She said that she would not have registered if she had known the true objective of the study.

2. Have you previously been invited to participate in a support group of some kind?

- “No never.” (Hanna)
- “No, I have not been invited to participate in another support group.” (Skonza)
- “No.” (Einræn)
- “I saw an advertisement on the Internet about monthly open meetings at Umsjónarfélag einhverfra [Autism association] and they have often been pointed out to me.” (Klambra)
- “I have not been invited to participate but there are courses at Greiningarstöð ríkisins and I have myself attended Al Anon meetings.” (Esja)
- “No.” (Kristjana)
- “No, not really. My son’s first physiotherapist made me realize that it could be good to discuss issues with other mothers of children with special needs and she introduced me to two mothers who also brought their children to her. Sometimes we spoke together a little bit after the therapy, but that cannot be called a support group and was rather casual. I also went with my husband to a course at the State Diagnostic and Advisory Centre when our son was about one and a half years old. There we heard lectures about the disabilities or diseases that our children had. There was also some group work and we were given the task to find out, for example, what experiences we had in common and to talk about how we experienced having become the parents of a disabled child – to exchange real life stories. That was a very good course that M., a social worker at the centre, had encouraged us to attend. Neither my husband nor I regretted that. We gained a lot of support from this course and benefitted from it for a long time. I hope I am not forgetting any invitation to attend a support group but I cannot remember anything except the above. I have also been invited to participate in a support group offered by Tilvera, which is an association for people who are infertile. I did not accept that; I do not believe that this association even exists anymore. This was eight or nine years ago.” (Góa)

Five of the mothers felt that they had never been invited to participate in a support group. Two of the mothers mentioned open parent groups that they knew about and attended and one mother talked about “a very good course” which was introduced to her at *the State Diagnostic and Advisory Centre*. In this course, she learned about the different disabilities and in small groups, parents discussed issues related to having a disabled child, and then shared these thoughts with the bigger group.

3. Have you or are you currently participating in a support group of some kind? If, yes then please describe the group.

- “No.” (Hanna)
- “No, I am not participating in another group.” (Skonza)
- “No.” (Einræn)
- “I have attended these meetings [Autism Association] and found them useful.” (Klambra)
- “No.” (Esja)

- “No. Parents of children with Down’s syndrome meet regularly. These meetings are not a formal support group, but are supportive in a way, albeit indirectly.” (Kristjana)
- “No.” (Góa)

At the time this research was conducted, five of the mothers were not participating in a support group of any kind. Two of them attended informal open meetings at their respective associations (Down’s Syndrome Association and the Autism Association).

4. What kind of professional support/assistance are you receiving from health care professionals?

- “My son goes to a physiotherapist three times a week. My mother was instrumental in booking a few sessions with a psychologist when I was still pregnant. This was at the Landspítali University Hospital and I only paid a minimum amount for the sessions. But my mother had to pursue it. Nobody offered it to us.” (Hanna)
- “Very little support, close to none.” (Skonza)
- “A psychologist and a psychiatrist.” (Einræn)
- “None.” (Klambra)
- “I have my own family doctor who knows me and my family. Then I have a contact person at the State Diagnostic and Advisory Centre who is a social worker. There is trust between us.” (Esja)
- “I do not receive direct support from this party [specialists] but I know it exists. I know I can seek assistance from doctors and nurses in the health care system and at the hospital but to do so I have to look for it myself. That is more difficult.” (Kristjana)
- “That support is all directed towards finding solutions and services for my son. I have not asked for support for myself and I have not been offered any.” (Góa)

The mothers’ answers to question number four can be interpreted in such a way that only one of them was receiving assistance for herself (psychologist/psychiatrist) at the time the question was asked.

5. Is that assistance related to your child in any way?

- No answer. (Hanna)
- “All the support that we get is directed towards the child.” (Skonza)
- “Yes.” (Einræn)
- “No.” (Klambra)
- “Yes, the social worker is an employee at the State Diagnostic and Advisory Centre, but the family doctor is for the whole family.” (Esja)
- “As my son is today, then it is just the regular childcare from the health care system. There is a little support for [myself] there!” (Kristjana)
- “Yes, in every way. I have not had to seek health care for anyone other than my children (and [for my husband and I] to be able to conceive them).” (Góa)

According to answers to question number five, all the help the mothers got was directly related to their children and not themselves. Understandably, even the help Einræn received personally she related to the difficulties her son has caused due to his severe disabilities.

6. What kind of support (emotional, assistance with daily tasks, assistance with taking care of the child, etc.) are you receiving from your family (spouse, other children, relatives)?
- “I have wonderful parents and parents-in-law and I can always ask all of them for assistance. But my children really just want to be with their breastfeeding mother. My son likes his grandparents. I am not going to start working right away so I take care of my children myself and have always done so. I rarely let others take care of them, except the first weekend each month. At that time, my parents take them on Saturday at noon and return them on Sunday. That is wonderful. They have done that since I had my first child. My husband works long hours and he helps out, but I direct the home and take care of everything and everybody. It is like that. It is my responsibility. I do not yet need special help for my son. I take him myself to the physiotherapist. My husband and I usually go together to the orthopaedist but I also go alone. I could ask my mother to go with me but I feel that is unnecessary. I could also ask my father and my brother but I think that is unnecessary. I do not like to ask people for favors, although it is easier to ask members of one’s family.” (Hanna)
 - “I receive support from my spouse to take care of the child. I also get emotional support from him. Also, right after giving birth I received much support from my parents-in-law.” (Skonza)
 - “Very little, almost none.” (Einræn)
 - “My immediate family helps, - my spouse and my daughter help with my two sons (four years old and three years old (autistic)). Since I am unemployed I take care of the daily tasks at home. I also train my younger son at home and interact with other specialists. Seeking information and education about autism and everything with regard to my son’s disability has mostly been my responsibility. My parents are willing to help out with the boys. Emotional support is available in the form of discussions and listening.” (Klambra)
 - “My friends, grandmother and sister-in-law lend me their ears. It is also supportive to meet other parents of children with special needs. My spouse gives me much emotional support. I receive almost no support with daily tasks. My child attends a day care and goes to a support family once a month. This support person is our aunt and her family. Our child’s paternal grandmother occasionally takes her overnight. Then we as a family try to help each other out: a mother, a father and a big sister.” (Esja)
 - “I take myself almost total care of the child. My spouse works ten to 14 hours a day. I take care of all daily tasks, the household and other things regarding my children. For example, the school, homework, leisure activities. I receive much help from my eight- year-old daughter and she is also the best support and friend of her little brother (who is the child with the disability). My parents and in-laws are relatively willing to help out. Sometimes they babysit, but it is not pleasant to always having to ask. ...They are young, have their own jobs and are very busy themselves. But anyhow, they are there.” (Kristjana)
 - “Support from my family is good. I am unemployed and because of that I take care of the regular tasks such as taking the children to school and to day care, and I take our son to his therapy. The housekeeping tasks are also mostly mine. My husband works long hours and all the children are so young that they cannot help yet. The oldest child is seven and she sometimes watches her siblings when I go across the

street to the store to buy milk. She does that very responsibly. I have four sisters who sometimes offer their assistance, for example to babysit the children or to bake a cake for a birthday and they themselves or their daughters babysit in the evening if needed. My elderly father-in-law who lives in the same house as us, is always prepared to assist if it is something he can manage, and the children themselves seek his company to chat or for some treats.” (Góa)

According to the above, all mothers except one received support from her spouse and close relatives to a greater or lesser extent.

Appendix S

The Contents of the accompanying CD

1. The song *Vetrarsól* sung in session #9
2. The group sound improvisation from session #1
3. Góa reads her poem *Tilraun* in session #10
4. Góa's poem, sounded in session #8
5. Góa reads her poem *Líkn* in session #10
6. Góa's poem *Líkn*, sounded in session #9
7. Einræn reads her poem *Ytra og innra haust* in session #10
8. Einræn's song *Ytra og innra haust* sung in session #10
9. Kristjana reads her poem *Óvissa* in session #10
10. Kristjana's song *Óvissa* sung in session #10
11. Empathy sounded in session #5
12. Skonza reads her poem *Preyta* in session #10
13. Skonza's song *Preyta*, sung in session #10
14. Hanna reads her poem *Ég elska börnin mín svo heitt* in session #6
15. Hanna's song *Ég elska börnin mín svo heitt* sung in session #10
16. Drumming in session #7
17. Esja reads her poem *Lausnir* in session #10
18. Esja's song *Lausnir*, sung in session #10
19. Sansula improvisation from session #4
20. Klambra's song *Rigning og ró*, sung in session #9
21. Klambra reads her poem *Ó* in session #9
22. Klambra improvises on the dulcimer in session #6
23. Klambra reads her poem *Frábærar konur* in session #9
24. Klambra reads her poem *Til Valgerðar* in session #9
25. Group sound improvisation from session #10
26. Klambra reads her poem *Superwoman* and the group sounds her poem in session #9
27. Contrary emotions (anxiety and light-heartedness) sounded in the group in session #8
28. The song *Óskasundin*, sung in session #7

Appendix T

The document sent to the mothers for validation of the researcher's analysis of core categories and related thematic statements.

The interpretive phenomenological analysis revealed that your experience in the music therapy group introduced as music-caring was related to the following core-categories:

- The group
- Musicking
- Songwriting
- The CD
- Me and my time
- Process-change
- The therapist
- The diary
-

The group

What did the group contribute to the mothers' experience?

- The group created a feeling of belonging.

It is quite special to have a disabled child. Each child is unique, no two children are alike but surely we the mothers have the same feelings. In a group like this, people are dealing with the same feelings. It is extremely good to get an outlet for that. To realize that you are not alone in the fight like you were having leprosy. ... This is what one needed in the beginning. To be with other women like this that had experienced the same. One was so alone somehow (Esja, SP I 003).

One was a little worried to begin with - did not know quite. But I felt this was a very good group and good to take part. The worries disappeared right away after the first or in the first session. In the end one worried about that this was finishing. ... One increasingly became part of the group. New better what was about to happen. The feelings—both mine and theirs—merged (Einræn, SP I 004).

Everyone was focused on being open. Perhaps a little strange to become so close, and you feel the need to continue that. But one cannot hold on to something good forever. It is also a good feeling to be able to let go without being sorrowful. Because one knows one can always speak to them if need be (Góa, SP I 001). ... I think it must have been sheer luck how good the group was (Góa, SP I 009).

It was comfortable to be around people who are experiencing something similar and who understand you; people that have common connection. That is very comfortable (Hanna, SP I 001). ... To get to know others that understand you due to common knowledge and experience was particularly helpful. You cannot get this support from friends. And this is a lasting support and relationship. Thinking about them gives me strength when dealing with various issues. ... Yes of course I feel a little bit richer. I am meeting them again

while in therapy with H. They are such good women, good individuals and so good to talk to them and to get information and advice from them (Hanna, SP I 002).

Remarkable how quickly we connected. That makes me feel good. I feel richer after having participated in this. It was enjoyable to get to know them. It was something special to be part of this first group, everything so fresh and exciting (Klambra, SP I 001).

The most important thing was to meet them and to be with them. You know, this human togetherness, which is the most important thing (Kristjana, SP II 002). To be allowed to attend and to talk, express emotions and to listen to others and the togetherness (Kristjana, SP II 004).

I thought it was terrific fun to get to know people with common experience. You know to be able to receive from them and to give back. I thought it was a wonderful time; everything was just wonderful (Skonza, SPI 001).

- The group built trust and diminished defenses.

The importance of having a closed group. ... It is very good like in music-caring, always to be seeing the same women. In AA you only meet a lot of people, and you do not know them and you forget them at once. ... But it becomes much more personal when you always meet the same women and you get to know them a little. Yes the connection is stronger (Esja, SP I 003).

Liberating to be in a group where I did not know anyone. It is a type of freedom. I felt I could say just about anything. They were open. It is terribly good to have a group like that where you can say almost anything you like. I felt I developed self-security within the group. I was not scared or shy (Góa, SP I 001).

You do not know the persons and you do not know what is about to happen. So you wonder and are not really at ease. Then in the end it turns into being a comfortable experience with a group and good friends. I think I would have dared to sing alone. The expression became somehow more and deeper, because you were not checking what the others were doing. Also you did not wonder about what was expected from you. There was a complete feeling of safety (Hanna, SP I 004).

A little insecure to begin with. Did not know how this would be and worried about it. But as I said, that disappeared after the first or in the first session. And in the end one worried about that this was coming to the end. ... I thought it was easier than I thought it would be to express myself. One worried in the beginning that perhaps one would have to speak. But that also was just easier than I thought it would be (Einræn, SPI 002).

- The group honoured individuality and the freedom of expression.
- The group gave perspective.
- The group created empathetic understanding and support.
- The group created possibilities for building awareness and strength.
- The group created a feeling of joy, anticipation and gratefulness.

Musicking

What did musicking alone and with the others contribute to the mothers' experience?

- Music created a relaxing, welcoming and a caring atmosphere.

It was always good to come to the sessions. The background music was good and created a welcoming atmosphere. If there had been rock music in the background it would have been different (Esja, SP I 006).

The music relaxes you and encourages more participation (Góa, SP II 006).

I think this always felt cosy. ...The group felt comfortable, it had a comfortable presence (Kristjana, SP I 004).

I felt somehow it became how should I say it – it became closer to you when the music was used. It makes a big difference to have the music. Somehow it feels more caring when there is music compared to when it is not (Einræn, SP I 008).

- Musicking brought joy and beauty.

It was terribly fun to play and I enjoyed it. I was trying to make some beautiful sounds, or trying to make something different – something gloomy trying to fit. It was great fun when we were all playing together. There was a feeling of happiness to be allowed to play and to make some sounds, to make a feeling. I thought it was terrific fun (Hanna, SP I 004).

Discovering new and interesting sounds/instruments, some drums and the sansula it sounded so beautiful. ...There is a positive energy that is released when singing and laughing. Besides, it is enjoyable to sing (Góa, SP I 005).

- Musicking brought closeness and supported empathetic listening.

One increasingly became part of the group. Knew better what was about to happen. The feelings, both mine and theirs, emerged. When we got to know each other better the feeling of empathy grew. You felt somehow they supported what you were saying. And they said they had been thinking about me (Einræn, SP I 004). ... Sounding all of us together, sounding our emotions together, something increased. We were together and there was some fusion/merging that was different from when we were alone talking about feelings (Einræn, SP I 005).

When we were playing the instruments and singing together. Yes, perhaps mostly when we were sounding us together and singing the songs together and also to hear all the poems that they made. I thought that was very helpful (Skonza, SP II, 002).

- Musicking empowered an awareness of emotions.

It makes me think about what place this emotion in me has. How is it in me? How do I experience it? Is it something that I have some control over or is it terribly deep and endless somehow? Is it breaking me? When writing, you are thinking so much about the words, if you are going to rhyme it or word it somehow. That is totally different. It is a new aspect to sound it. It makes you think. What is this anyway? What is this emotion?

Does it gnaw on you because that is the way you are trying to express it so very deep and dark or quickly and constantly bugging somehow or what (Klambra, SP I 006)?

To sound the paranoia and to say goodbye to it was good. The sounds described the feeling, it was dark and that told it so well. The sound told how the heaviness in the chest is when you get it. And just by hearing it, perhaps similar to when you write the feelings on a paper, it has been shaped into this form. Then the emotion has left you a little, gone away from you. The sound expressed the emotion perfectly. It has been put into shape and distanced itself from you (Esja SP I 003).

- Musicking facilitated and deepened emotional expression.
- Musicking brought change and created possibilities.

Songwriting

What did songwriting contribute to the mothers' experience?

- Songwriting gave structure and shape.

Everything had been so free-floating until we sounded the lyrics. One could play with some image behind it. One tried to sound the emotion that was in the lyric (Góa, SP I 005)... The structure has floated onwards and when one thought that there was not going to be any structure then you always brought something. The first two sessions we were sounding very much and one thought this would be like that the whole time. Then you brought the whiteboard and it was not quite as easy and more into it [focused] and some meditation (Góa, SP I 008).

You gave us the freedom. We had the structure. But for me it was finished. I had read it and sounded it and then I had overcome it. And then maybe the following day something wonderful would happen (Hanna, SP I 005).

- Songwriting was a creative challenge.

It was challenging for me when I was making the lyric. I have not made a lyric for many, many years. It was challenging to do that again. It was a challenge in the beginning. One did not know what to write about (Skonza, SP II 002).

When I played my song, I felt it was difficult. To sing it was somehow, and I wondered why it was difficult for me. Why? But I felt it and I felt it was good to have done it and I felt it was a victory for me to have done it; a victory to challenge one's own fear and to win, to stand by oneself (Klambra, SP I 005).

- Songwriting was an enjoyable experience.

It did take me by surprise how much it did for you and how enjoyable it was. Like Ö's lyric: Now we are stuck... One smiled in the berry picking. It is enjoyable to hear things like this. My lyric, this is what I wanted for myself and this is my contribution (Esja, SP I 010).

- Songwriting gave perspective

One could find in all the poems something that one had experienced or a feeling one had felt (Skonza, SP II 005).

Superwoman [one of Klambra's poem] and Einræn. I understood the feeling although I cannot imagine how terrible it must be. This teaches you so much about life. To get to know people and to hear their feelings and in the process you learn to know yourself better and your own feelings (Hanna, SP I 006).

- Songwriting honoured individuality and strengthened self-identity.

It is clever to get many poems. Each poem reflected the personality. I could find myself in their shoes but I also felt it was theirs. The poems are theirs but you are part of it because one has talked about it and has participated in it. Or you know when they were created. So they do not own it alone you know, but nonetheless it is theirs. The tiredness was there and I believe we are all tired. They were different but I think one could find everything in them. Was there any happiness? It was the only thing that did not appear on the whiteboard. You know sometimes there are fun and positive feelings connected to it. Perhaps we would have needed more time. First we dig into the difficult things, the emotional things and then we would have wanted to talk about the positive sides (Kristjana, SP I 009).

I believe one is better able to bring forth one's own issues if you do it alone rather than doing it as a group (Einræn, SP I 004).

The CD

It had become cosy and joyful. The only thing I feared a little was to lose contact with them. I did not expect it would have enormous effect on me but just some effect maybe. I listen to the CD a lot at work. I have been thinking so much about them and about you. I did not think it would affect me so much in the end, that I would miss you as much as I in fact do. It is terribly good to listen to the CD. You know, one goes back and feels good. Yes it is very comfortable. One somehow gains peace in one's heart, one somehow feels better. Maybe I cannot explain it well enough. It was somehow always when the sessions were over, one felt peace and some relief and one felt a lot better and it comes back when you listen to the CD (Skonza, SP II 003).

I was very surprised what it was one heard. It sounded differently from when you were making the music and I felt it had a soothing effect. I was thinking about the good effect it had because one went into a trans somehow, especially with the sansula (Esja, SP I 001).

The CD, a tangible product, was a proof of a completed task; a memorabilia capable of preserving the emotional tone of the music-caring group. As such it could be used by the mothers to validate their emotional journey.

Me and my time

What did music-caring contribute to the mothers' experience of me and my time?

In the introduction of this thesis it was discussed that parents with special needs children face a risk of neglecting their own needs when faced with all kinds of strenuous demands and stressful situations in an achievement oriented care for their children. Their often-demanding role as the prime carers of the children affects both the caretakers as individuals and their relationships with others. As Gill (1997, p. 11) worded it, the

parents' identities are forever changed, "the whole shape of ourselves and our lives is being pulled into a new form" (as cited in Sorel, 2004, p. 23).

Parents themselves also emphasize that parents of children with special needs should not only be offered personal help but that such help should be mandatory. The fact is, however, that within early intervention services, parents themselves and the potential psychological distress they experience are more often than not a forgotten factor in the overall support and treatment schemes offered to them. In order to move forward and to find the best ways to support and empower mothers of children with special needs, one needs to make their voices heard, argued Kingston (2007, p. 23).

Music-caring was directed at mothers' needs. What brought them together was what they had in common, i.e. their children with special needs. Time and again in the music-caring sessions, their focus had to be redirected from their children to issues related to themselves, to questions such as: Why am I here? What are my hopes or my fears with regard to the group? What is my aim for being in the group? What is the aim of the group? Skonza said: "One could have forgotten oneself just talking" (SP III 002).

The analysis of the transcribed interviews revealed that music-caring was instrumental in creating awareness to a greater or a lesser extent of the importance of taking care of oneself. Later in this section, the mothers speak for themselves on themes concerning their self-importance, how they take care of themselves, and the idea that how each mother cares for herself and feels about herself is as important for her own well-being as it is for the well-being of her whole family. The following narratives relate to the theme of 'Me and my time' and are the researcher's compilations and reconstructions from the transcribed material of anecdotes told by the mothers. As such, they could be regarded both as a narrative approach to the interview analysis/interpretation and also as a form of validation whereby "the researcher tries to keep his or her interpretations within the interviewee's context of understanding as seen by the researcher" (Kvale, 1996, p. 217).

Kristjana's account

I was going to write in the diary directly after the first session but I did not find the time to do it. This first session was very good. It was enjoyable to meet new people who are dealing with the same [issues] but are yet so different. It was enjoyable to do something that you have never done before. I have never played an instrument before hardly touched an instrument even, and I was thus a little scared before this began. But then it was just comfortable. Best of all was that this was MY time (an excerpt from Kristjana's diary, dated 29 September 2006).

Music-caring was the only thing I had seen which was available for mothers. Things are always directed towards the child. All of a sudden it was about me. This is something I had wanted for myself before. But I would perhaps not have accepted it then because I was so confused somehow when my son was newborn. I was alone in the world and did not know anyone like this. The first year was a time of waiting, waiting for life to become normal. Strange how alone one felt at first. Perhaps one is first ready just now. However something was needed during the first two years. Music-caring was a new treatment, something I had never heard about before, for stay-at-home mothers, nobodies. Mothers staying at home are nobodies and are never offered anything (SP I 001).

I was doing this for myself. One does not do anything for oneself directly unless it is organized like this. So it is about my emotions and me. Someone is interested in that. I

feel that is in itself an experience. You have told me that my emotions and I make a difference. This does not always evolve around the disabled child. That is of course an unbelievably good feeling (SP II 002).

We all matter. Every sound is important. That makes you think: I do matter; I am important. What I do and say matters and it matters how I do it. It matters how I raise my child, how I talk to them. It matters how I do things. You know it is noticed and it colours everything around. You know if I play badly, if I scream at my children it does not sound good. If I try to do it well then it is better (SP II 005). One feels one is making something, that one makes a difference. I am doing something and I am making something permanent, leaving something behind. Here one is both receiving and giving both for oneself and for others. To be able to give is a healing process. At the same time one is receiving something for oneself and then one is giving something to others. That is terribly good. I only remember myself playing; I do not remember exactly what I was saying. I got a different perspective on myself when others chose some instruments for me. Aha, I thought, is this how they see me. It was good to be able to leave home, to stop thinking about the daily things and to come here and think differently. It was good to come and to leave all the responsibilities at home. It is out of your hands (SP II 007).

Esja's account

What was most challenging for me was to map the mind, to map everything that was happening within me, to be able to sort it out a little. After a few sessions one found how one began to be better able to realize what was happening within oneself. One starts to realize cause and effect, how one behaves and things like that. That is what I hoped to get to begin with, to become better aware of how I am feeling, what it is that is happening inside of me. Because often there is something that is happening and one feels bad, and one does not realize for a few days what caused it. For me, the biggest challenge was to sort out my emotions. I felt very good to find somehow after these sessions where I stood, with whom, with what feelings and to realize what I wished for. This is what one had needed in the beginning, to be with other women like this who understand the same [challenges]. One was so alone somehow. Now I looked forward to having time for myself and with the group (SP I 004).

Part of music-caring is learning about yourself. That includes tackling this impatience and trying to contain my temper towards my daughters when they are acting out. All sorts of self-improvement must be beneficial. It does not matter what it is, just that there are these two hours in the week that are just for you. You slow down and listen to others and they listen to you. Listening to others who are in similar position somehow does you good, instead of having this all tangled up and then the tangles become more tangles. One does not realize what is happening and what situations create these feelings. It has changed the way I feel and think about myself. I believe I think more beautifully about myself now, not that I am impossible and not good enough. One must think nicely about oneself. When you do that then you automatically start thinking that now you should do something good for yourself. To maybe organize something once a week, because one feels how much good these sessions have done; to have a good and a beautiful time with oneself and of course to be with these women. I feel there is a change, because it is somehow different when one reads self-help books. It somehow becomes real when you participate in a group. Here one is active and that is different (SP II 004).

I am just Esja who wants to become a little better or to feel a little better with my dark side, and my shortcomings. Impatience was one of my biggest shortcomings and now I feel I have become more patient. Also I have stopped being depressed, which is just terrific. I worked systematically towards it. I worried about I would again become depressed with this birth [her third daughter was born 11 November 2006]. But I knew right away that that would not happen. I want to be happy. That is the purpose and now I have started thinking about learning Spanish next fall. One should let one's dreams come true. Then I really would like to check out if I could sing. I would very much like to sing in a choir. I am not going to get old in front of the TV. It feels very good to have finished sorting things out and to realize that only I am capable of changing myself. Music-caring has truly helped me doing that and after these sessions one had provisions for the week to come and one was often thinking about this.

On was often thinking about [the sessions]. Perhaps one was driving and then one was thinking about what had taken place in the session. Thinking about what one wanted to work with within oneself. So that was very good. Of course I had wanted to be in this when I had my daughter V. And when there were all these difficulties. Perhaps then this would have affected me differently. Then I would not have participated in order to strengthen myself but just to get over it, to go through the trauma. At that point, even though I would not have wanted to go to psychologist or something like that, then I think music-caring would have done me very good because it is like an unknown journey. I could not think myself going to a psychologist and telling him that I feel bad. Rather, in music-caring the emotions would have found outlet in the music, instead of sitting with a psychologist and talking about oneself. One would have needed to stay with the feeling and to sound it. I think that would have been very good, some sorrowful tones, to put it forth and to acknowledge it. Because when you were in the sorrow you never said if anyone visited you. Oh, I feel so bad. You know, one does not acknowledge it like that. Perhaps one told a friend what was happening and such but you never told it in clear words. You don't speak the truth in order to stay alive. In order to stay strong, you somehow lose your own feelings, your self-identity. You don't speak the truth (SP II 005).

Einraen's account

One is always trying to think more about oneself or better [about oneself] or how should I word it. This music-caring hopefully helps me to do that. One tries of course to be positive and to care for oneself. I know I have not been putting myself first. I have always been somewhere in the last row. Through music-caring I will hopefully become more capable of taking care of yes somehow myself and the ones around me. That would make me feel better in general (SP I 006).

But I do not know if I have progressed at all in a positive direction. I do not quite know. If he [her son] is happy, smiles or laughs, then I can find purpose in this. Otherwise it is difficult when he gets these fits and is difficult to handle. Then I become depressed and feel everything is hopeless (SP I 007).

Góa's account

In the beginning one is happy with everything. Having gone through this and stirred up so many things one has become terribly unhappy somehow. I took with me renewed energy from the sessions, and I thought about the others between sessions and it was enjoyable to get something new into your life, something which was about this group. If one can put oneself into others' shoes then one learns to understand that others can put

themselves into your shoes. One sees that one is important, but also that one needs not to take things too seriously. The negative sides are not as noteworthy as one feels sometimes (SP I 001).

If music-caring is to be for women to help them emotionally – caring for them, then I feel it is very good exactly to evoke thoughts, to ask intrusive questions in the beginning. To shake things up a little so that one starts thinking about something else than what is planned for dinner. That opens up [the possibility of] whether one wants to be open, receptive and giving or something else. Either you open up or close down. I think it must have been sheer luck how good the group was (SP I 009).

I feel that I am somehow more secure in myself, more self-secure. I am happier. I have decided not to be bothered with certain things. These meetings confirmed that there are so many negative things one can get rid of and that one should try to focus on the good things. I think the biggest thing is that one needs to be positive. The closeness to others and the discussions encourage one to start thinking about something deeper than just one's daily life. It has an evolving effect. Besides, demand increased to get something for oneself. This has elicited the awareness of the importance of being positive, to think more positively and to think about the future, which is something one does not do when you stay at home. I have learned that from this group or these sessions. It is all up to you. It depends on oneself [to be positive and think positively]. It is important to focus on the positive things rather than the negative ones. This course has taught me to be more aware of what I need to do to feel better so that others around me feel better (SP I 010).

Although I reasonably accept myself as I am, I realize that certain things need to be fixed. I regard that as an exciting task. Yes, I am accepting life as it is and I am a little bit more self-confident than before. I accept that I am not perfect, and that one does not need to be perfect; one can be happy with being stupid and frail. If you accept yourself then you do not care what others think of you and then you become more self-secure. I am happy with the fact that this is a process and that one is developing and having fun. I would like to work with something that nourishes me. I want to be around people. I would like to take up translations, but that is work you do alone. Nevertheless, I am going to contact the broadcasting station to see if they have any work available.

I have been just on my way to doing something. I'll be damned if I don't achieve that this year. Also I will try to take care of my health to be able to play with the children and carry my son. One wants good things for the family. But I have realized that if you can make yourself feel good it influences how well your family feels. So apparently you can be a little selfish. I also need to start working. I could not continue studying becoming a librarian because I could not give a lecture but I plan to attend a workshop on creative writing and I want to take a computer course (SP II 003 – 004).

Hanna's account

This experience was different from most things I have done before, the things I know how to do or I am used to doing. Maybe this is because here I was alone and I was attending to myself a little. In general I am inhibited and that is not good. If you only do something for others it does not end well (SP I 004).

I felt like this group was a turning point. Constantly thinking about the home and the children and doing nothing for myself didn't work anymore. It is important that everyone gets his opportunity (SP II 001).

The need to take care of parents of children with special needs is great. It is so difficult when no one understand you. It is so difficult to understand something that you have not experienced. You learn about your own emotions when you hear others talk about them. This is how I have felt. It is like going to school (SP II 005).

Klambra's account

If you are working with yourself and you have stepped forward then it must show. To work towards this goal, towards inner peace and to find reconciliation, then one can do just anything. Then the joy and the feeling of safety comes too – so many things that come along with it, and not just only to know oneself. This is a step towards change and this is a good feeling. To work with oneself must change the whole thing (SP II 008). There is always some conflict evolving around if you are doing enough or not enough. It is important to use the time when he is so young, but then you have to sacrifice something else. I have often thought about the choir. But I feel I need to do it. Singing in the choir makes me stronger (SP II 008).

Skonza's account

I am very sensitive and breakable somehow. But I try to be positive and have always done so. Sometimes and some days it is difficult trying to play Pollyanna games. Maybe I am a little more aware of what I want do for myself. I want to go back to school. I want to have more children. I want to get married. I guess in the end one becomes stronger after all of this. I hope so at least. I know it takes time to work through this, but it is worth it when it is over (SP III 001).

Process-change

What was the process/change experienced during the music-caring period?

Asked to describe the music-caring process itself, Einræn felt it was somewhat difficult but that she could describe it as a growing process with a crescendo in every session where the empathy became stronger and stronger (SP I 006). Reflecting on her experience to consider if there was anything in particular she would consider music-caring, Einræn answered: "It was both sounding the feelings and singing our poems, and yes sounding all of us. I think that was the highlight" (SP I 005).

Describing music-caring as "tones that touch you and make you feel better" (SP I 011), Esja talked about the music-caring process as a journey that had made her stronger. This journey was not easy to talk about to others as it somehow was a secret, something personal between "me and [the other women]. Talking about it might harm the secret or the magic" (SP II 002). Describing a situation in which music-caring occurred for her Esja said:

You can go to the session feeling rather down and you start doing the music and then somehow the feeling floats with you. I remember one instance in particular. You can somehow play the feeling away from you. Then you feel much better afterwards. The feeling somehow merges in with the tone. You feel like you have got an outlet afterwards. I am not saying that you become very happy afterwards you just felt much better. I would say that is music-caring (SP II 002).

Having compared her experience of music-caring to going to the opera, Esja said:

First there comes the silence and then the music starts and you get goose bumps all over your body, it is so magnificent. It is so strange the thing that brings this on. It must be caring or something that engulfs you and brings forth such strong emotions that one cries. It is a strange and a sensational experience (SP I 011).

Describing the music-caring process to others Esja would say:

We sing together. We tone. We play instruments. We give tones. We give sounds to feelings. Then we talk. We bring up the things that are bothering us, talk about it and sing about it perhaps. We listen to music, and it is a journey within and around oneself. This is a journey in maturing and this helps one do it better. Music-caring helps you travel better, to travel through, to mature, and to reach some success of being, and of being the mother of a handicapped child. This has made me stronger. I feared having the third child and having take care of this whole thing [mother of three children, and one with special needs] but I feel I am stronger and I know I can do this. You have become stronger when you realize who you are and what you need and what you want. So the journey has done me good (SP II 002).

For Góa music-caring was about musicking, to find an outlet by playing, singing and listening; listening not only to talking, but also to sounds that were calming and comfortable. She was referring to comfortable sounds that supported relaxation and sounds that helped to set free or express various emotions. People arrived in the sessions in different emotional states and could choose to hit the drum or play a little triangle depending on what the specific feeling was that they wanted to get rid of, she said. “We are all doing the same thing and there is a certain connection which brings forth the empathy” (SP I 008). Góa described the music-caring process in the following way:

There was a feeling of uncertainty to begin with, not knowing how the sessions would be and not knowing the others. Despite an introduction in the brochure I did not quite know what was ahead but I think that is good. With uncertainty comes some daring. When looking back I do not know what it is that one could change. You built this up fine having us begin with getting to know the instruments and each other. You gave us ample time to talk but also time with the instruments and told us also what we were going to do. Then the emotions are brought in a little early so one could build on them. There was never any moment when I thought ‘why does she do this now’ or ‘isn’t there a time for doing this’. I believe that this process was fine – getting to know each other and then getting deeper into it with discussions and the songwriting, etc. If it is to be for women, to take care of women and help them emotionally then I feel it is very good to evoke thoughts, to ask intrusive questions in the beginning. To shake things up a little so that one starts thinking about something else than what is planned for dinner. That opens up the idea of whether one wants to be open and receptive or giving or something. Either you open up or close down (SP I 009).

To get an outlet for feelings and thoughts through music was what Hanna considered music-caring. She felt safe, got peace and leeway to get rid of something, and to express herself through music. Trust had been built and one dared, could and was allowed.

It was your turn, you could choose; find out what it was you wanted to get rid of and express that. You started alone and then everyone came along, trying to express my emotion, helping me and you also, this quietness and this listening. They heard how I had started and how I had set the tone that was music-caring for me. To be able to ask for a special song that we could sing together that was also music-caring (SP I 008).

Describing the music-caring process itself, Hanna said:

To begin with you are insecure and you walk slowly and then you become stronger and walk with security. You know what is about to happen and what you can get out of this and then in the end you are reconciled because you got what you wanted out of it. I did not know what to expect but I did get what I needed. I put thoughts and feelings into a creative form and music and I felt empathy. I got to know the others and to feel kindness for them and to empathize with what they were experiencing. You want to show them that you understand what they are experiencing and feel the way they are feeling and that you are not alone, because that is such a terrible feeling (SP I 008).

For Klambra everything was music-caring - the whole process. It was good to come and talk to the group and to listen. It was good to try something new; it would not be music-caring if there were no music. It was very good to loosen emotions by listening to music and to sound the words, for example. But that alone would never accomplish what it did unless everything else was there also – somehow “the whole thing” she said (SP II 002). Describing the process for others, Klambra wanted to organize music-caring in the following way:

One observes from a safe spot. Then one approaches gradually, takes part and withdraws again. One does not want to take up too much space. One feels oneself part of the whole, during the journey and also afterwards. One feels caring, empathy, understanding, new learning. One wonders why one didn't do a little bit more: this was my chance. During [the music-caring] everything was just good and fine. There was a feeling of admiration. One could work with all kinds of feelings, not just the ones that are about having a child with a disability, which is not something you do with your friends. There is a good feeling that prevails after this journey. One feels that one could have been bolder but one does not change one's character in an instant. We supported each other and tried to understand each other. This was a learning experience and one thinks about how it is best to support another human, by sharing a personal experience or by just listening. The journey was not difficult. Everyone managed to make her mark in my mind. I feel I have many different things in my bag after this, things of a different kind. I have good feelings but also a feeling of pity and sympathy. Seen from different perspectives it was just marvellous to have participated in this. Music helps you truly see all the beauty of nature with different eyes (SP II 005).

Thinking of music-caring as something terribly big and enormous, something which she had been “just a little bit into”, music-caring for Kristjana was about being taken care of through the music and much more. It was like a verbal therapy, listening, giving and taking “and all that”. Like a tool, it was the music that accomplished this therapy, and she felt, like Esja, that she did not know how to explain it. Kristjana had the feeling that this could have been developed much further, longer and more, because she felt that little

by little one sensed what this was. One became more skilled at playing the emotions into the music, to use music to experience or awaken emotion and then to get rid of them. Having realized the potential of music-caring it felt like being at the beginning of something and it felt strange being done (SP II 002).

Describing a situation in which music-caring occurred for her, Kristjana said it was somehow just “the whole thing”. But besides being enjoyable, she felt that it was a “very good feeling” when everybody was making something together. “To get this time for oneself and be allowed to attend, to talk, to express emotions and to listen to others, and the togetherness” (SP II 004). Describing the music-caring process itself, Kristjana said that “music-caring was a good therapy, and if the aim was to make people feel better then it was successful. But this cannot just be over with, that from now on I will always feel good.” She continued:

The goal of making us feel better was reached but there is no cure. It was very good to be able to get away from the daily things, meet others and to discuss how one felt and to do something new like this, to use music to make one feel better. That happened. Emotions remain however, and all sorts of feelings and all sorts of things will emerge. Because of that, it would be so nice to be able to receive from it again or to attend some kind of treatment like this (SP II 004).

Concerning how she experienced herself both receiving and giving both for herself and for the others, Kristjana said that being able to give was “a healing process”.

At the same time one is receiving something for oneself then one is giving something to others. That feels very good. One is making something, making a difference and making something permanent, leaving something behind. “I only remember myself playing; I do not remember exactly what I was saying” (Kristjana, SP II 007).

Skonza also felt it was a difficult task to describe to others the music-caring process itself. “One is a little worried in the beginning. Then one gets to know the therapist/researcher, the girls, and all this emotional heaviness that one is experiencing. It is difficult, if not impossible, to describe that to others somehow. Because it came so personal it is difficult to put it into words for others who were not there to experience it. This is something private, just for oneself, and people would never understand exactly what you were trying to tell” (SP II 007).

Being able to sound herself, the way she felt and her feelings, the words on the whiteboard, the songwriting process and the poem, but perhaps most of all what they were doing together as a group, was what defined music-caring for Skonza (SP II 007). Describing a situation in which a music-caring occurred for her, Skonza talked about the session when the song “Vetrarsól” had been sung and afterwards the mothers sounded themselves alone.

Singing this song and sounding myself had an enormous effect on me. I had been very worried and there [my worries] just floated away from me and I felt this enormous relief somehow. The worries had been so overwhelming and they just floated away and I sat behind lacking the correct words to describe the way I felt. It was so comfortable and so good, such a terribly good feeling of well-being and relief to great proportions (SP II 007).

“One of the most common metaphors for musical experience in post-nineteenth-century Western culture is the metaphor of ‘transport’ in the sense of being carried from one (emotional) place to another (and indeed, at times, being ‘carried away’), wrote DeNora, (2000, p. 7).

As can be seen from the above quotes and narratives the metaphor of ‘transport’ in the sense of movement from one place to another can be used to describe the mothers’ experience. Hesitant in the beginning while going from the unknown to the known, in the end, the mothers walked stronger and more secure. Some hopes and desires had been sorted out and future signposts mapped. Moving on, they realized the importance of taking good care of their physical and emotional health, the importance of nourishing themselves, of being happy and of being around people who understood them. Whether by learning Spanish or by singing in a choir they realized that if they could make themselves feel good it would influence how well their families felt. “So you can be a little selfish it does return” (Góa, SP II 004).

The therapist

It matters who conducts a group like this (Klambra SP II 004). Certain characteristics are important: Calmness (deliberate reflective calmness), intuitive sensitivity, to be giving and understanding. The leader needs to provide the right balance between structure and freedom. She needs to be well prepared, to be able to direct the group forward, and to be able to inspire the participants.

The diary

It was good to have this freedom to use the diary or not. You can write in it things that are more personal and that you do not want to share in the sessions. You do not have to be present when someone reads the diary. Someone can read it and I do not know how you react to it. Writing things on paper is like fastening it. The things you just speak about are gone. You can always go back to your diary and examine it. You know, this is the way I felt. Do I still feel like that or have I made some progress? I should have used a diary before as a proof of progress and change. Perhaps the mothers’ worries about that the researcher was going to read from it aloud prevented them from writing in it.

Thank you very much!

Appendix U

An e-mail sent to the mothers asking for a written consent (e-mails) allowing verbatim use of their verification.

Kæru kasúkonur.

Ég skrifa þennan póst til að láta ykkur vita um framgang Tónrænnar umönnunar og til að fá frá ykkur formleg leyfi.

Mér mistókst að skila inn ritgerðinni fyrir 21. janúar eins og til stóð. Ég mun því ekki verja í maí 2011. Ef ég ætla að verja í haust er næsti skilafrestur 1. júní. Það ætti að vera viðráðanlegt fyrir mig.

Þegar ég hafði síðast samband við handleiðendurna mína var mér bent á það að ég þyrfti sennilega skrifleg leyfi frá ykkur til að hafa staðfestingu ykkar á úrvinnslunni minni með í ritgerðinni (því sem ég sendi ykkur í tölvupósti 30. september 2010). Tölvupósturinn sem ég sendi ykkur 30. september hljómaði svona:

Ég þakka ykkur kærlega fyrir yndislega samveru í bústaðnum hjá Önnu Kr. Eins og þar á góma þar stuttlega (og í tölvupósti til ykkar áður) þá þarf ég á einhvern hátt að staðfesta túlkun mína á viðtölunum við ykkur. Ég veit að þið hafið mikið meira en nóg að gera, eruð alveg uppfyrir haust og viljið sennilega vera lausar við þetta viðfangsefni. Samantektin sem ég sendi til ykkar er einnig löng en það var svo að þið gætuð tengst þessu betur því að langt er um liðið.

Nú bið ég ykkur um að svara þessu erindi mínu sem fyrst ef þið hafið nokkur tæk á því, vegna þess að það tengist því sem ég á eftir að fjalla um í ritgerðinni. Ég er ekki að biðja ykkur um að skrifa ritgerð heldur bara athugasemdir um þau hughrif sem þið verið fyrir þegar þið lesið þetta og hvort ykkur finnist upplifunin hafa verið á einhvern þann hátt sem ég lýsi. (Þ.e. flokkarnir (core categories): The group, musicking, the songwriting, the CD, the therapist, me and my time, process-change, the diar. Og undirflokkarnir (themes).

Skjalið fylgir sem viðhengi. Ef þið hafið einhverjar spurningar hafið þá endilega samband við mig!

Kær kveðja, Valgerður

Þið urðuð við þessari beiðni minni samviskusamlega og er ég afar þakklát fyrir það.

En vegna þessarar ábendingar frá handleiðurunum mínum spyr ég ykkur nú formlega og vænti svars í tölvupósti:

Má rannsakandinn nota orðrétt í ritgerðinni athugasemdir ykkar við úrvinnsluna eins og þið senduð hana til undirritaðrar í tölvupósti?

Kær kveðja, Valgerður

Appendix V

Vignettes from analytic memos written after sessions one, three, five, six, seven, eight, nine and ten.

Session #1

Everyone was present. Surprisingly, my anxiety disappeared and I felt calm. I almost felt good in the group. The group took off somehow, like it did not need me. I speculated about my role. I had provided them with physical needs like light, heat, nourishment, instruments, chairs and candles. They had also been nourished intellectually, as much as I felt necessary, by my telling them what sparked this research interest, what music therapy is, how the sessions would be structured, why I had chosen songwriting as a central therapeutic approach, and that we needed to honour the individuality of each mother, her personality, feelings and state of being.

I felt happy about how it went but when I listened to the recording I spoke hesitantly. My voice was in the background, and it was like I let the mothers take over, which perhaps was okay. I did not know quite how to participate in their discussions, but I wanted to sound supporting, strengthening, and wise in order to deepen what they were talking about. It appeared that when they left the session they felt happier and more at ease than when they arrived. Their worry about not being able to play instruments seemed to be gone.

I think I can be pleased with this start. The preparation has taken a long time. These sessions are built on a deep need for so many things including to break from professional isolation, to get an opportunity to undertake new things, and to have the chance to do that with supervision and with such deliberation is priceless. What seemed in the far distance almost insurmountable seems to be transpiring. My hope is that the music-caring group will meet the needs of the mothers and that their experiences will bear witness to the importance of this idea.

Session #3

I was calm before this session but somehow I felt a sorrow lurking. I felt lonely in the group, but I could not tell them how I was feeling or what I was dealing with, although I could perhaps have alluded to my own feelings when the discussion evolved around who was living a normal, happy family life and who was not. There need not be more happiness where there is no disability, the mothers said. In this session I felt that my role was mostly that of time keeper. They empathize so nicely with one another that I feel more like a foreigner in the group. Sometimes I feel left and lonely because I do not have the same experience as they. I wondered about what they thought about me. Do they feel they are receiving enough from me? What are their expectations? Am I capable of giving them something, consoling them or empowering them? Am I doing that just by creating this opportunity for them to meet?

When the music-caring session was over the mothers continued to talk in the hall. They talked about their experiences which they had to pay dearly for. Do we want to be without it, they said? If so, then it means that we want to be without our disabled children. That is a thought we cannot allow ourselves. What is the disabled child's point of view?

Wondering about my own performance in the group, wanting some guidance, when I arrived home I drew an angel chart based on one created by Dr. Doreen Virtue. This pleased me as I allowed it to comfort me and ensure me that I was doing alright.

Session #5

I had great difficulty preparing this music-caring session. I worried about how I could introduce the songwriting process in order to reach the set goal. I decided to experiment with it myself. I brought together discussions from previous sessions, sorted them thematically and printed it out. On Tuesday, I wrote some poems/verses myself. The writing went well I thought and it calmed me. According to the plan, I am on the right track and I asked the mothers to experiment themselves at home and to write at least one poem/verse. Whether we will compose music to their poems together remains to be seen, but we could also paint them with sounds, like we have been doing with words. I need their opinions on what they feel would be suitable.

Einræn attended the session and it was obvious that she is going through a very difficult time. ... It was hard for her to select a word from the whiteboard and instruments to sound it but after some consideration she chose the keep the word empathy and the same instruments as had previously been used to sound it. She expressed her dislike of how she sounded on the kalimba. I shared the feelings and thoughts I experienced when listening to recordings of my own expressions. ... Afterwards, I did not feel so good having done that. ... I did not stick to my written programme but I think that it went just as well. We sang, listened, played, talked, and had fun with kazoos. ... They talked about my hair. I felt it was rather uncomfortable. I don't like when attention is drawn to the way I look. I am insecure about how I look, what to wear and how to arrange my hair. So somehow I thought this was inappropriate. But at the same time it tells me a lot about how open and sincere the group is. Somehow I was not surprised that Skonza did not come today. I will call her.

Session #6

I worried about how this session would turn out. I felt like I had reached a point where product had gained power over process. I wondered for a long time how the songwriting process could be moved forward. I was also worried about Einræn and did not know what to expect from her attendance. She expressed such concerns and I felt that the group was not taking care of her as it should. I even wondered if I should call her to see how she was doing. Would I be compromising the research somehow by doing that? I forget that I am a researcher and feel that I am not a good enough music therapist. I found being in this dual role difficult.

This was the second time that all the mothers were in attendance and somehow the group felt heavy and slow. Four of them had done their homework and read it aloud. Skonza spoke more than she had done before and she gave Einræn some advice. Einræn got a good opportunity to express herself and I believe she felt empathy. Góa cried when we were listening to the music Klambra brought.

Perhaps I am struggling with some countertransference issues. The mothers talk about the feeling of never doing well enough. This is a problem I can relate to –never doing well enough. Not being a good enough mother. ...I am not a good enough therapist and now I am not doing good enough research and not taking good enough care of them.

I need to feel the power of the music in the group. I worry about that there is not enough music and too much talking and then I worry about that I talk too little. ... The session took two hours and fifteen minutes. I want there to be joy, laughter and cleansing, despite all these difficulties, but I do not have the courage to loosen up myself. The warm-up could be powerful and energetic but somehow everything takes so much time. Nevertheless, everything is moving in the right direction.

Some mothers shared four poems with the rest of the group and Klambra mentioned that she had also composed some music using the three guitar chords she knew. ... Now I am going to try to be positive. Maybe Einræn got the support she needed. Four poems were written and they continue to work on their songwriting at home. Then I need to find a way so that we can dwell longer with the songwriting. Hanna questioned whether Einræn was receiving enough support and mentioned a psychiatrist she had spoken to herself. Somehow I felt that Hanna's words were a declaration that the music-caring sessions were perhaps not giving anything to her.

The week has been difficult. The difficulties of my clients are overwhelming and I feel there are so many struggles, the system is not working, and those working in the field accomplish so little. I feel so many are breaking down and that the only way is "to silently endure", as Hanna put it.

Session #7

I have been sick in bed for a week. My mother has taken care of my children and me, and in so many different ways showed me loving care. ... I focused on regaining strength so that I could conduct session #8. I postponed my clinical supervision and my supervisor called me and asked if I was trying to be a superwoman. I explained to her that I felt the group was at a sensitive spot and that one of the mothers was going to have her baby and thus it was important to run the session.

I have been worrying about whether the songs would be written at all, but one by one they are. Each one of them is special. I have encouraged the mothers to do their homework – to write their lyrics at home. ... When reviewing my session plan, everything seems to be going according to plan, although not consciously aware of it while conducting the sessions. According to the plan, sessions eight to ten should be devoted to setting the poems to music.

Each poem is special, and reflects its author. I have received poems from everyone except Skonza. It appears that the mothers feel insecure about their lyrics/poems, perhaps Esja in particular. She also worried about giving birth to her baby. She is scheduled to have a Caesarean section on 14 November. She did not choose an instrument for me to participate in sounding her poem. It somehow troubled me. Why did she not choose an instrument for me to play? Then I wonder how my silence affects them – what they think about it. They talk so much among themselves and I cannot share my experience, which is different from theirs, since I do not have a child with special needs. Their world is special and that is continually becoming clearer to me. They cannot even at times put themselves in each other's shoes.

Often it appears that Hanna is leading and perhaps somewhat dominant in the group. She is so spontaneous and giving and I think her way of acting is very good, especially for Einræn. But then I feel somehow that she is somehow usurping my role as leader of the group. What is my role? Is it different from one session to another? Am I only a timekeeper? Do they feel I am rushing them, for example at the end of this session when

I introduced a relaxation activity but a long time passed until I felt I could start the music? Will I always be the same silent Vala lacking authority?

Hanna arrived 15 minutes late. I went straight from the introductory song to their songs and did not give them any time for a warm-up. Sometimes I feel like the group is losing its drive. That is how I felt after the last session, but when I listened to it a lot of things seem to be happening, at least if their discussions are a measure of a normal group process. Different issues are brought up -difficulties from childhood, difficulties with their other children, difficulties in their marriages, losses and grieving. They also talked a lot about professionals and how unsympathetic and unprofessional they can be. The mothers said the pros are inconsiderate and do not follow up on how people are doing.

When I think about the research protocol, I realize I have not managed to bring them towards one central theme. Perhaps I can focus on it in our next session. What do we have in common? What bothers us the most? What do we want to express? Can we do that in a common narrative, in a joint song? In our next session we are supposed to rehearse notations of their song painting and also create music.

Session #8

The planning for this session went fine. I have managed to get rid of almost all my previous anxiety but I sense that the end is near. The feeling that nothing can then be changed is a little bit overwhelming. I must look upon this as one big learning process.

Session #9

I felt unusually anxious prior to this session. I had worked on writing music to their lyrics and it took a long time because I worried about that it was not good enough. I made music to Hanna's song because she had not wanted to sound it herself. She liked it - but then, she had no choice. Would they have asked for different music or criticized the music I wrote for them? Esja felt that her song suited her poem. It had the right amount of cheerfulness because she was so tired of being negative. We also sang Kristjana's song, although she was not there to comment on it. We have to do it again in the next session, as well as Skonza's song if she sends her poem to me.

I felt I used the session adequately to practice the songs. Klambra brought two new poems that were brilliant. I think she has found a new talent that she will continue to develop after we finish our sessions.

We need to look at how they want to arrange the content on the CD. Then it would perhaps be nice to have one song that we have sung in the sessions at the beginning and then end on "Vikivaki" or "Vetrarnótt".

It is always difficult to set a time limit for the sessions. This session took two hours and twenty minutes. In the end they sat silently and to me it felt like they were reluctant to leave. I did not address that because I had previously talked about feelings they might possibly experience, feelings associated with completing a support group like this.

Session #10

Today is 6 December. When I was going to write my notes after the last session I actually punched a hole on the cord of the electric transformer for my computer. It took two days to get a new one. I used what was left of the battery to print out transcripts of all the sessions to review before the last session, because of the music that I was going to put on the CD.

Somehow I did not feel good enough after this last session. Hanna was not present and I did not know why. Klambra was on a trip with her husband and Einræn had to leave early because her students were playing in a concert at the music school. I also felt that the agenda itself lacked the time for the mothers to finish recording their songs and the conclusion itself shifted the focus away from the mothers. The attention was moved away from them towards the project/task itself. I felt bad about that. I also worried a lot about how the recording would turn out. I felt I played badly and too fast, that I sang the loudest and that their voices would not be heard in the recording. I would have needed at least two additional sessions to teach them the songs, to arrange them better and to work more on the CD recordings so that one could be proud of it.

Esja brought her baby girl but somehow there was a feeling of sadness around the visit. The child is adorable, so delicate and beautiful. I was allowed to record her daughter too.

The week was devoted to selecting musical excerpts and to arrange a time with Þórdís at the studio to make the CD. I would never have managed it myself in the time available. Þórdís has some connections to the group. She has a child with special needs and she was thinking about participating but did not have the time. I sat with her in the studio. I had edited the excerpts so she did not hear any of the conversations.

Today it is 7 December and I still have not listened to the CD. It was finished Thursday 30 November, and copied for the group on Monday 4 December. I have tried a lot to find time for the group interview when they can all meet. That is important. Christmas is a busy time and all sorts of activities are taking place: Christmas concerts, Christmas dances, Christmas handicrafts, husbands abroad, mothers-in-law not in town, so for various reasons it has been impossible to find a time within the frame I had set myself (within two weeks of the last music-caring session). Luckily they can all attend on 11 December. Hurray!

I have been worrying about Einræn. Her boy will be admitted to the Children's Psychiatric Hospital today. She is therefore not doing so well but she holds herself well. Hopefully nothing will happen that might hinder her participation. I have been in e-mail correspondence with all of them and that has kept the connection with them, but Einræn has not responded to my messages. So I decided to call her yesterday. It was good that I did because she told me that her computer connection was bad these days and always closing down so it is not clear if she saw the e-mails.

I have started to miss the group and I hope our session 11 December will go well. Our task is to look at this journey as a group. We will listen to the CD. I will offer them hot chocolate and cookies, and I think I will move the tables together, and put candles and tablecloths on them. We will not sit in a circle around the "fire" as usual but along this table with a "long fire". It remains to be seen whether I will manage to direct the discussion in such a way as to discover the core of the matter and obtain answers to the burning questions.

Appendix W

The mothers' self-description shared in the individual interviews after the completion of the ten music-caring sessions.

Einraen

How would you describe yourself today?

I am afraid that that would not be positive. What can one say about oneself? I do not know if I should say that I am closed or that I do not find it easy to get to know strangers. That is the first thing that comes to mind. I do not know. It depends most on myself. I felt good when they [the mothers] listened and agreed to what I was saying, or just when they listened. I have often wanted to open up more. But that does not happen in a situation unless the relationship with others is close. It does not just happen out there in everyday life (SP I 007). [Do you have more words to describe yourself?] Perhaps I could use the word conscientious. It is directed towards everything regarding work and everything else one has to do. One feels one has to stick to everything one has said (SP I 007).

Esja,

How would you describe yourself today?

I am just Esja, who wants to become a little better or to feel a little better despite my dark sides and my shortcomings. I feel I have become more patient and that was one of my biggest shortcomings. Also, I have stopped being depressed, which is just terrific, and I worked systematically towards it. I worried that I would become depressed again after this birth [11 November 2006]. But I knew right away that that would not happen. I want to be happy, that is the purpose, and now I have started thinking about learning Spanish next fall. One should let one's dreams come true. Then I really want to see if I can sing. I want to sing in a choir. I feel good going to church and there are various other things that I feel are good to do. I am not going to get old in front of the TV (SP II 005).

Góa

How would you describe yourself today?

I am reasonably tolerant of myself, but there are things that need to be fixed. I regard that as an exciting task. I am accepting life as it is and I am a little bit more self-confident than I was before. I accept that I am not perfect, and that one does not need to be perfect – to be happy with being stupid and frail. If you accept yourself then you do not care what others think of you, and then you become more self-confident. I am happy

with the fact that this is a process and that one is developing and having fun. But I am fearful of changes (SP II 003).

Hanna

How would you describe yourself today?

I am happy and optimistic, dramatic, a perfectionist. I want to do everything very well. I make everything complicated. I am bossy and want to control. I am a good person. I do not want to see anyone feeling bad. I think I have the complete emotional scale. I am not scared. I am daring. I am a good mother. I am happy. I love my husband, my children and my family. I look forward to the future and do not worry about my son. I know it will be difficult, but I think it will work out (SP II 003).

Klambra

How would you describe yourself today?

I am rather a private person. I worry too much. Maybe I am not lively enough, and do not have enough energy – but I'm not closed. I am ready for something. I am ready to open up more and become free from prejudices. One believes that one is not intolerant or narrow-minded but then one encounters something. I am ready to work with myself and I am always taking some small steps. New and generous friendships move one forward in life. ...I know where I want to go, but I do not know how to get there. Maybe I am taking too small steps forward. If I would look for help I could maybe take bigger steps yes, most surely (SP III 001).

I need more drive. One must endure one's whole life. I have progressed to an extent, but I often consider myself to be old and still struggling with [various issues] ... We found out that it is not enough to be silent and to endure. One must know how to go through the eye of the needle. Perhaps it is like pretending to work on something but then one is not actually; like, working with being touchy. It is a very big question. ... Yes, I feel actually that not enough is happening, like working with being touchy. It is simpler to keep one's emotions in check. ... (SP III 002).

Kristjana

How would you describe yourself today?

It is more difficult to describe myself. I do not know. I am told that it is not easy to get to know me. I can believe that. But I think once you have got to know me, then I am not like that. I think I am rather pleasant to be around. But I can become very angry if I feel something is unfair. I have a strong sense of justice. I feel things should be correct and fair. I feel I am responsible and I take responsibility for how things go. If my son is not

quick enough to learn how to speak, then I feel I have not been thorough enough with his assignments. If he is not walking up the stairs yet, then it is because I have not been exercising him enough. ... I am rather social. I like being around people. But I also like to be alone, to have time alone at home when everyone has gone to school and to work. Sometimes I do not want to go to sleep because I want to enjoy this time alone to its fullest. I do not know how I could describe myself differently (SP II 006).

Skonza

How would you describe yourself today?

I am very sensitive and breakable somehow. But I try, and have always tried, to be positive. Sometimes and some days it is difficult to be positive, and then I play “Pollyanna” games. Maybe I am a little more aware of what I want to do for myself. I want to go back to school, to have more children, and to get married. I guess one becomes stronger after all of this in the end. I hope so at least. I know it takes time to work through, but it is worth it when it is over. (SP III 001)