

Home-based Art Therapy in Families with Seriously Ill Children: A Heuristic Inquiry

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A Research Paper

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of

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## Abstract

Title: The Home-based Art Therapy in Families with Seriously Ill Children: A Heuristic Inquiry

By: Karin Derouaux

This heuristic study is an exploration of an art therapy student's practicum experience working with ill children and their siblings in their homes. Pragmatic issues include isolation, therapist safety and challenges of travelling, scheduling, and providing art materials. Therapeutic issues are difficulties collecting information from busy parents, acclimating to the overwhelming physical and emotional space, and tolerating chaos in the therapy environment. The emotional effect of seeing medical paraphernalia in the home, as well as issues surrounding privacy, instruction, and discipline are also explored, as are the therapeutic frame, accepting food and gifts, and the role of language in the therapy. Balancing family focus with client focus, interacting with parents, countertransference reactions to the home environment, client secrecy, and termination issues were also relevant. Finally, the author describes in detail her emotional and philosophical reaction to the death of a client, and explores the meaning of home.

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## Home-based Art Therapy in Families with Seriously Ill Children:

### A Heuristic Inquiry

This heuristic study is an in-depth exploration of my experience conducting art therapy with children in the private contexts of their homes. I explore the pragmatic and therapeutic issues that arose, as well as emotional and existential preoccupations that were inherent in the experience. The research is based on my practicum, in which I established an art therapy program for a community organization that provides respite services to families in which a child has a terminal, degenerative illness. The program was offered to all family members, either individually or in groups; however, my clients were all children, aged four to fourteen years. In some cases I worked with the child who is ill, while in other cases I worked with a sibling or siblings of the ill child. I conducted the art therapy in the homes of the clients and kept in contact with the agency through bi-weekly supervision meetings, as well as through as-needed emails and telephone conversations.

There is very little literature on home-based art therapy and none that focuses on this population. Therefore, this paper represents a new foray in the field. Herein, I identify themes for further exploration in research and give art therapists who are considering home-based programs a foretaste of one therapist's experience. I hope that this qualitative account, written from the first-person perspective, will be an important step in disseminating information in the field.

#### *Assumptions, Limitations, and Delimitations*

The purpose of this study is to explore, from the therapist's perspective, the experience of art therapy in the homes of children with serious, chronic illnesses. In



doing so, I assume that art therapy is a worthwhile and helpful endeavour, that there is a need for home-based therapy with this population, and that I am able to engage in a prolonged, profound examination of my own feelings and experiences. The goal is to allow the reader a window into my experience. Framing this window is an understanding that the information shared herein should be of interest to other mental health professionals who may be considering engaging in home-based therapy.

### *Methodology*

This qualitative study follows the model for heuristic research proposed by Clark Moustakas (1990). Heuristic research is founded on the assumption that there is meaning inherent in human experience; that this meaning can be discovered; that the tacit dimension is both real and accessible through focusing and indwelling; that knowing the subjective experience of a person has value; and that there are similarities in the human experience. Heuristic research is an “organized and systemic form for investigating human experience in which attention is focused *inward* on feeling responses of the researcher to the outward situation rather than exclusively to relations between the pieces of that outside situation” (Sela-Smith, 2002, p. 59).

Sandy Sela-Smith’s (2002) articulate description of this methodology touches on a number of elements that are at the heart of heuristic inquiry. This is a research methodology which breaks with the convention of the researcher as a neutral third-party observer of the phenomenon being studied. In a heuristic study, the researcher is the agent through whom the experience flows. The goal of the research is to examine subjective experience in order to come to a deeper understanding of a phenomenon, to find its essential meaning (Moustakas, 1990). Knowledge is produced through self-

awareness and self-understanding and, instead of distancing herself, the researcher is transformed by the act of carrying out the research (1990).

This research focuses on my reactions to the experience of acting as an art therapist in the home context. The reactions of the clients and their families are not directly considered, nor are therapeutic outcomes. In all cases, the child's illness is of a chronic and life-threatening nature, but it is not necessarily the case that the immediate prognosis for each individual child is dire. Some of the children are considered to be at the palliative care stage, but for others, the illness is long-term, and the outcome is unknown.

### *The Research Questions*

#### *Primary research question.*

As this is a heuristic inquiry, my primary research question was open-ended and exploratory. It was: What is my experience of being an art therapist in the home of a seriously ill child?

#### *Subsidiary questions.*

I examined my question from pragmatic, therapeutically-oriented and existential perspectives. In what ways did I have to adapt to working in the home? What therapeutic issues emerged in relation to being in the home? To working with ill children? To working with their siblings? From the perspective of how I acted as a therapist, how did the in-home art therapy differ from conventional art therapy? What emotional issues arose?

### *Operational Definitions*

The Committee on Children with Disabilities and Committee on Psychological Aspects of Child and Family Health (1993) define chronic illness as:

Illnesses or impairments that are expected to last for an extended period of time and require medical attention and care that is above and beyond what would normally be expected for a child or adolescent of the same age, extensive hospitalization, or in-home health services. (p. 876)

The norm is that a chronic illness is one that has endured, or is expected to endure, more than three months (The Committee on Children with Disabilities and Committee on Psychological Aspects of Child and Family Health, 1993).

Life-threatening illnesses have the potential to end in death (Sourkes, 1995), and are, more often than not, chronic. Sourkes observes that because of “medical advances, many diseases of childhood that were once of short duration and uniformly fatal have become chronic in nature and do not necessarily result in death... Whether or not the threat of death transforms into actuality, profound uncertainty prevails” (p. xi).

All therapy was done in the home of the client. *Home* will be defined as the current, physical residence of the client. However, it is important to be aware that the concept *home* is not only physical space, but that it is “constituted, experienced, and relational” (Ward, 2003, p. 83). Place cannot be understood outside of the filtered social and cultural experience of the person experiencing the place. Place embodies, not just physical ecology, but also cultural and social realms and is thus constantly in flux (2003). The word *family* will refer to all people who live in the client’s home. People who are identified as family members but who do not live in the home are considered extended

family members. A *sibling* refers to a brother or sister of the ill child. Siblings can share one or both parents, or may be siblings through parental marriage.

The terms transference and countertransference will be defined in the broad sense used by Judith Schaeffer (1998). In her study “Transference and countertransference interpretations: Harmful or helpful in short-term dynamic therapy?” she defines transference as:

Both the past-dependent reaction of patients to therapists and the unconscious organizing activity in which patients engage during therapy. Signs of its presence are associations, affect, desires, images, fantasies, sensations, and cognitive schema that recreate or reenact the past in order to organize and give meaning to denied or repressed experience. (p. 1-2)

Both clients and therapists experience their special relationship with each other in the context of present and past experiences in other relationships. By exploring transference, the client and therapist can get a better understanding of how those relationships have affected the client’s way of interacting in his social world.

Countertransference is defined as “the emotional, physical, and cognitive reaction of the therapists in the therapeutic milieu and the organizing activity in which they engage in response to past relationships and the patients’ present behaviours” (Schaeffer, 1998, p. 2).

For the purposes of simplifying and amalgamating related terms that appear in the literature, the terms internalizing and externalizing will be used to group and qualitatively describe various adjustment difficulties that can be experienced by ill children or their siblings. Externalizing behaviours encompass socially disruptive difficulties such as

aggression, delinquency and cruelty. By contrast, internalizing adjustment difficulties are more inwardly focused and include depression, low self-esteem, and anxiety.

### *Chapter Overview*

The remainder of this paper begins with a summary of current literature and includes chapters on home-based therapy, therapy with children, children who are seriously ill, therapists working with ill children, siblings of seriously ill children, and my therapeutic approach. Next, the methodology chapter addresses the basic tenets of heuristic research, methods of data collection and analysis, including the six phases of heuristic research as outlined by Moustakas (1990), and the generalizability, reliability and validity of the results of heuristic research. The results chapter is divided into three broad sections: pragmatic issues, therapeutic issues, and existential concerns. Pragmatic issues include isolation, safety, traveling, scheduling, and art materials. The therapeutic issues section deals with the initial parental interview, the environment of the therapy, chaos, medical paraphernalia, intrusion and privacy, discipline, the therapeutic frame, negotiating boundaries and professional distance, favours, food and gifts, language and verbal communication, client focus versus family focus, interacting with parents, secrecy, and termination. The existential concerns section includes chapters on the dying client, personal mortality, and finding meaning in home. Finally, the conclusion addresses avenues for future research and includes a synthesis of the results.

## Summary of current literature

### *Home-based Therapy*

Although home-based intervention is generally considered an innovative mode of reaching clients whose needs are underserved by more conventional methods of mental health service delivery, it has a long history. In the United States at the turn of the 20<sup>th</sup> century, social workers, calling themselves *friendly visitors*, initiated a home-based assistance program for people in need that focused on the family unit and on the relationships between family members (Cortes, 2004). This systemic orientation is the theoretical foundation for modern-day home-based therapy programs.

The individual is understood in the context of the many social systems that act upon him. By reaching out to the client where he lives, the therapist is better able to observe and gain an understanding of the client's social world. The multisystems model can be conceptualized as a series of concentric circles. At its heart is the individual. Surrounding the individual and closest to him is his immediate family, including the individual relationships, called subsystems, he has with each family member, and that each family member has with the others. Surrounding the family household is extended family, friends, and neighbours. Next are the church and community and, finally, social service agencies and other outside systems (Boyd & Bry, 2000).

The bulk of the literature on home-based mental health programs is based on early intervention programs and short-term social service programs focusing on crisis intervention in the social work field. The little art therapy literature available focuses on the home-bound elderly. Unfortunately, I have not found any literature on engaging in therapy in the homes of children with serious illnesses. It seems that either my program is

unique, or that similar programs have not yet been reported in the literature. So, lacking specific research that targets the same population, I have attempted to provide as broad an overview as possible. Information has been gleaned from fields as diverse as social work, psychiatry, art therapy, occupational therapy and nursing.

In general, home-based therapy programs can benefit clients in a number of ways. Even when working with an individual, the therapist can directly observe family relationship dynamics and the ecological context of the client (Boyd & Bry, 2000; Liddle & Hogue, 2000; Reiter, 2000). The therapist's willingness to make house calls may be interpreted as a reflection of genuine interest in the client and his problems (Boyd & Bry, 2000; Reiter, 2000; Wood, Barton, & Schroeder, 1988 in Christensen, 1995). Clients may feel more comfortable, less defensive (Christensen, 1995), and more in control of the therapeutic process (Balgopal, Patcher, & Henderson, 1988). Home-visiting can make therapy accessible to those who have difficulty traveling to therapy (Christensen, 1995; Liddle and Hogue, 2000), to families with children whose needs cannot be met easily in an office, and to families that are too large to be accommodated in a small office space (Christensen, 1995). Scheduling difficulties may also be alleviated, since home-based therapy is both flexible and convenient. This improves the rates of recruitment and on-going participation (Liddle and Hogue, 2000).

Safety is a concern. Home-based counsellors have expressed apprehension for the safety of their clients and themselves. The therapist, fearing for her personal safety, may be hesitant to address volatile issues (Christensen, 1995; Lawson, 2005). Boyd and Bry (2000) provide safety guidelines for home-visiting professionals. Prior to the first visit, therapists are urged to familiarize themselves with the area, particularly the route to and

from the client's home. Carrying a cellular telephone is recommended, as is scheduling visits during daylight hours. Visits should be confirmed with the client, or parent, on the day of the appointment, and a colleague, friend, or family member of the therapist should be apprised of her schedule. The therapist should be attired in a manner that blends into her surroundings, generally comprised of casual clothing and comfortable shoes. Items that appear valuable, including jewellery, should not be carried or worn, nor should the therapist drive a new or expensive car. The therapist should be accompanied by a co-worker on the first visit. Upon arrival, the therapist (if driving), should park in a populated, illuminated area. Once in the home, the therapist must remember that her own safety takes precedence. If a family member becomes violent, the therapist should leave immediately, calling the police on her cellular phone only after vacating the residence. At the end of the session, the therapist may ask a family member to accompany her to her car, particularly if it is night time.

The increased familiarity inherent in home-visiting can make it difficult for the therapist to maintain a professional distance and negotiate boundaries (Christensen, 1995; Lawson, 2005). Gold and Cherry (1997) define the frame as "the relatively constant structure in which therapy takes place, generally understood to be characterized by a regularly scheduled time, place, and fee, and by therapist anonymity, neutrality, and abstinence" (p. 147).

Conventionally, psychodynamic therapists are encouraged to maintain a relatively rigid and inflexible frame, and to understand any deviation as an impediment to the therapist's ability to understand the client and communicate that understanding (Gold and Cherry, 1997). In recent discourse, however, therapists have recognized that greater



flexibility can benefit the client. Gold and Cherry say that the frame serves the client only if it enables the therapist “to listen, to understand, and to respond to the client in a productive, meaningful manner” (p. 149) and when the client does not feel “controlled, patronized, and misunderstood” (p. 150). While the therapeutic frame is a vital component in establishing the distinctness of the therapeutic relationship, in providing a safe environment for the exploration of transference and countertransference, and in assisting the therapist in setting aside self-interest, rigid conformity to prescribed rules creates a counter-therapeutic environment (1997). There is, however, a trade-off: Flexible therapists are more likely to commit technical errors than therapists who require strict adherence to rules (1997). Traditional therapists see the errors resulting from spontaneity as a tax on the therapeutic alliance. Others argue that therapist errors can be therapeutic themselves if acknowledged and explored with the client (1997).

In the unconventional context of home-based therapy, it is unrealistic to expect the therapist to adhere to a rigid therapeutic frame. The home-based therapist does not have adequate control over the environment to eliminate interruptions. Instead, she must determine what aspects of the frame can be maintained, when control can be preserved and when it must be relinquished. She must consider the ramifications of her flexibility. Through interviews with counsellors, Symons and Wheeler (2005) studied the aspects of frame-breaking that create uncertainty and emotional discomfort. They examined how, or if, that distress was resolved. They found that anxiety is provoked in a number of ways. Frame breaks are experienced by counsellors in discrete stages: First, a *trigger event* threatens the therapeutic frame. Second, the counsellor realizes she is in a position where she must make a choice. Third, she makes a decision and fourth, acts by either

maintaining or altering the frame. Last, there is an outcome. A break in the frame can become an anxiety-provoking dilemma for the counsellor at any of these stages. Symons and Wheeler concluded that there are different kinds of dilemmas related to a broken frame. These are associated with the stage at which the counsellor feels unable to understand or respond to the situation. For example, her anxiety may not be brought on by the trigger event itself. She may even be confident that there is only one proper way to act. Her distress may, instead, arise from an inability to address or resolve the consequence of the broken frame.

Because the therapist can be overwhelmed by the sheer amount of information available, and the number of problems that are observable, therapist demoralization can be a problem (Lawson, 2005). Home-based therapists must contend with distractions (Christensen, 2005). Uncomfortable living conditions and interruptions are of particular concern. Christensen says that, while observations of the home context and the family dynamics of clients are interesting, therapists have difficulty incorporating the information into their treatment goals and intervention strategies. Instead, therapists see the activities in the home as obstacles to be overcome or ignored (2005).

The relationship dynamic between the professional and the client is different in home-based therapy than in conventional therapy. When a client sees a therapist in an office setting, the therapist is clearly the authority figure; in the home, the therapist is less authoritarian. It is the therapist, and not the client, who must adapt to the context in which the therapy takes place (Kunstaetter, 1987).

Value conflicts can arise when therapists are faced with customs and beliefs that differ from their own. While these can arise in conventional therapy as well, they may be

emphasized in home-based therapy given the increasingly intimate knowledge of the client's lifestyle (Bryant and Lyons, 1991). Hiscox and Calisch (1998) describe culture as an intricate tapestry, saying that:

Culture includes such features as attitudes, forms of emotional expression, patterns of relating to others and ways of thought. It is a patterned, organized and integrated collection of characteristics and traits like a weaving or tapestry.

Members of a particular culture share common threads with the group as a whole while also retaining some individuality. (p. 9)

It behoves the culturally aware therapist to be sensitive to the client's complex relationship with culture: to consider both how the client is a differentiated individual in the cultural tapestry, and how the client's identity is embedded within it (Hiscox and Calisch, 1998).

In home-based therapy, the therapist may find it difficult to focus on the client. In fact, there is some debate over whether the individual client or the entire family constitutes the home visitor's client (Bryant and Lyons, 1991). There may be issues surrounding honesty and confidentiality, given the presence of other family members and the intimate knowledge the therapist has of the client's private life (1991).

To help therapists navigate the unconventional and ethically ambiguous context of home-based therapy, Boyd and Bry (2000) posit the following guiding principles for conducting home-based interventions. (a) "Remember your 'home training'" (p. 38): Therapists should consider how they would feel having a professional stranger come into their own home. In doing so, the therapist will understand the importance of putting the family at ease by displaying a pleasant and warm demeanour. (b) "You are on the clients'

‘home turf’” (p. 38): Rigid boundary setting during the initial session is ill-advised. Instead, the therapist should take behavioural cues from the parents. (c) “When in doubt, join” (p. 38): While therapists are often trained not to accept “gifts” from clients, it is particularly important in the initial sessions that the therapist demonstrates good manners by joining with the family in eating, drinking, or playing together. Gifts of food may also be culturally relevant, particularly in Latino families. (d) “Never underestimate the power of praise” (p. 38): The therapist may actively seek out things to praise as long as she is sincere and genuine. (e) “The effective use of self is the most powerful technique” (p. 38): While this is the case for all types of therapy, it is particularly relevant in home-based therapy. Understanding herself in the context of her own family can heighten the therapist’s sensitivity to conflicts between her own experiences and her work with families. (f) “Empowerment is the goal, not helping” (p. 38): The therapist’s role is to guide the clients to develop tools which allow them to interact more effectively and to find their own solutions.

Art therapy introduces the element of art materials to the home setting. McElroy, Warren, and Jones (2006) describe how the therapist in their home-based program brought a variety of art materials in a plastic storage box. However, packing the box required organization, and for the safety of the therapist, care had to be taken to ensure that the box was not too heavy. In addition, the home-based art therapist must take over a significant amount of space in the client’s home, using it as her professional area. McElroy et al. say that this did not pose a problem for the clients in their project, as long as all furniture was returned to its original position at the end of the session.

A concept of particular importance for home-based art therapists is the portable studio. Kalmanowitz and Lloyd (1999) worked without studio space in the former Yugoslavia, bringing art therapy to refugee camps. They say that the portable studio is based on “the premise that the internal structure we carried with us as art therapists could allow for work to physically take place inside and outside: in the bedroom, in the dining room, in the town dump” (p. 24). The therapeutic space takes place, not in the physical setting, but in the person of the therapist.

### *Therapy with Children*

Arlene Litwack (1985) says that in order to conduct effective therapy, therapists who work with children must strike a balance between creating a positive alliance with parents and understanding the child in his world. The child therapist must empathize with both the child and his parents. This, she says, can be difficult to do, particularly when these aims are in conflict with one another. Litwack says that there are six factors that foster over-empathy with the child. The therapist must be aware of these as pitfalls to establishing an alliance with parents. (a) Child therapists may over-identify with the child because he elicits regression transference of a hurt, unloved child within her. (b) The therapist may have fantasies of herself as an idealized nurturing parent who can rescue the child from bad parents. (c) The child may be an extension of the therapist's narcissistic self, so that her actions gratify her own needs rather than respond to the child's needs. (d) The therapist may identify with the child's anger or rebellion against his parents. (e) The therapist may have an unconscious need to compete with the child, to be more successful or more loved. (f) The therapist may feel judged by the parents,

eliciting a narcissistic reaction in which she feels demeaned. An overly strong alliance with the child may bolster her self-esteem.

*Children who are Seriously Ill*

The Committee on Children with Disabilities and Committee on Psychosocial Aspects of Child and Family Health of the Council on Child and Adolescent Health (1993) say that, in the United States, approximately 10% of children are diagnosed with a chronic condition. For 2% of children, the impairment is severe enough that it affects their daily lives. Canadian statistics are comparable, with Statistics Canada optimistically reporting that “a full 89% of the population younger than 12 was reported to be in excellent or very good health in 1996/97” (National Population Health Survey Overview 1996/97, p. 3). The prevalence of psychological symptoms among children and adolescents with chronic health conditions is twice that of children and adolescents from the general population (Committee on Children with Disabilities and Committee on Psychosocial Aspects of Child and Family Health, 1993; Gupta, Mitchell, Guiffre and Crawford, 2001). Health care providers identify psychosocial concerns in 20.2% of healthy children and 36.8% of chronically ill children (Billfield, Wildman & Karazsia, 2006). Although many adapt well, having a chronic illness puts children at additional risk for psychological disturbance.

Children with chronic illness experience a variety of psychosocial difficulties including internalizing, externalizing, anxiety and self-esteem problems (Lavigne & Faier-Routman, 1992; Thompson & Gustafson, 1996). That some quantitative studies found no significant correlation between chronic illness and psychosocial problems (Garstein, Short, Vannatta & Noll, 1999; Hamlett, 1992; Nelmas, 1989 reported in Lash,

2005; Wallander & Varni, 1989) may be because chronic illness encompasses a wide variety of physical impairments and, thus, a wide variety of childhood experiences. Chronic illnesses in childhood differ greatly in etiology, symptomology, course, prognosis, and treatment (Lash, 2005). It is therefore logical to expect some differences in consequent risks.

While the empirical research seeks to correlate illness with diagnostic symptomology, clinicians focus on emotional experience and regard distress in terms of normal unwellness. Normal unwellness refers to psychological suffering that emerges naturally and normally from unpleasant and stressful life experiences (Winnicott, 1958 reported in Copeland, 1983). Childhood illness can be conceptualized in terms of psychic trauma – a term coined by Lenore Terr (1990). “Psychic trauma occurs when a sudden, unexpected, overwhelmingly intense emotional blow or series of blows assaults the person from the outside. Traumatic events are external, but they quickly become incorporated into the mind. A person probably will not become fully traumatized unless he or she feels utterly helpless during the event or events” (Terr, 1990 p. 8). Clinical treatment focuses on providing emotional support and helping children come to terms and cope with the situation (Copeland, 1983).

Art therapy takes place within the conceptual framework of normal unwellness. Traumatic distress is reflected in play and art (Copeland, 1983), and the therapist’s role is to foster the expression of feelings and psychological state (Sourkes, 1995). The therapist is a non-judgmental, encouraging, and supportive other in the play space (Rogers, 1983). Fred Rogers observes that the sick child has little control over body, treatments, environment, or the freedom to move within that environment. Art-making gives the

opportunity to be in control. Art and play therapy can also help children come to a developmentally appropriate, cognitive understanding of their illness and treatment.

#### *Therapists Working with Ill Children*

Rogers (1983) says that professionals who work with ill children experience a threat to their own identities when a child's life is threatened. As a result, therapists are both drawn to and repelled by seriously ill children (Khushalani, 1983; Vaux, 1983). The children are facing their mortality, confronting us with the transience of our own lives. Because therapists make the effort to understand and empathize with the sick client, "they are subject to the same emotions and fear experienced by their patients, and they deal with those emotions and fear with much the same defences. They become angry; they deny the truth; they avoid the problem" (Khushalani, 1983, p. 288).

Khushalani (1983) identifies the conditions that must be present for therapists to avoid burnout: personal attributes (emotional stability, coping skills, sensitivity, empathy), work environment factors (a team approach that includes sharing problems, emotional discomfort and humor with colleagues), and life-style characteristics (maintaining a professional identity separate from the work with sick children, having a recreational activity – a hobby, vacation spot, or sport).

#### *Siblings of Seriously Ill Children*

Siblings of children with impairment are at heightened risk for problems in psychological adaptation. Phoebe Dauz Williams (1997) performed a meta-analysis of 47 studies that examined the risk of maladjustment on siblings of children with chronic illness. Sixty percent of the studies reported that they are at greater risk in three categories of maladjustment: externalizing, internalizing, and lower social competence. In



a large, impressively rigorous Canadian study, Cadman, Boyle, and Offord (1988) found that children who had a sibling with a chronic illness were twice as likely to experience an emotional disorder and had a 1.6 times greater chance of having poor peer relationships than a control group. So, siblings of ill children are as likely to experience psychosocial adjustment problems as the ill children themselves.

Stress pervades all of the relationships in families who have a child with special needs (Baxter, Cummings, and Yiolitis, 2000). Familial stress is associated with higher reports of maladjustment in all children in a family (Cuskelly, Chant and Hayes, 1998). Furthermore, parents who are under stress interpret normal child behaviour as problematic (1998). Because mothers naturally devote more time to the needier child, their perceptions of the unimpaired child may be skewed by feelings of guilt and of being torn between adequately mothering the ill child and spending time with the unimpaired child. Also, because of the additional time spent with the ill child, mothers are fatigued and stressed when they interact with the unimpaired child (Quittner and Opiari, 1994).

Therapy with siblings of children with serious illnesses has generally consisted of highly directive group work. Barrera, Chung, Greenberg & Fleming's (2002) cognitive-behavioural program is a good example. In each of eight sessions, the therapist focuses on a particular theme: medical information, family context, feelings, sibling relationships, the school context, hope, coping and problem-solving skills, and graduation from the program. I object to this treatment approach. The literature suggests that children with siblings lack individualized attention, but highly directive therapy conceptualizes brothers and sisters only in relation to their sibling's illness. I argue that siblings can be better served by engaging in non-directive art therapy. The therapist can help the child come to

an understanding of their own value, separate from their ill sibling, and yet allow the child to address the above themes in a naturalistic way.

### *Therapeutic Approach*

When working with both ill children and their siblings, my therapeutic approach has been influenced by the wisdom of several art therapy theoreticians who have worked with children: Nathalie Rogers, Diane Waller, and Edith Kramer.

Nathalie Rogers, daughter of Carl Rogers, founder of humanistic psychotherapy, incorporates the creative arts in applying her father's person-centred approach to therapy. She calls her approach *person-centred expressive art therapy* (Sommers-Flanagan, 2007). The therapeutic attitude inherent in person-centred expressive art therapy has influenced my way of being as a therapist. Like Carl Rogers, Nathalie Rogers emphasizes the importance of the relationship between the therapist and the client. The client must feel valued by the therapist in order to heal (2007). Further, the therapist must trust in the client's ability to know their trauma, and, instinctively, to know what will heal his or her emotional wounds. Thus, the approach is non-directive (2007). Adding to the basic tenets of her father's theory, Nathalie Rogers has incorporated an understanding of the healing power of the creative process. For her, the art serves as a mode of expression for the client, and as an alternative language between the client and the therapist. The expressive arts are the language of healing, allowing the client to peel away their defences and access their emotions (2007).

The writings of Diane Waller and Edith Kramer have both been instrumental in formulating an understanding of the power of art-making for children. In her article "Art

therapy for children: How it leads to change,” Waller (2006) lists five fundamental principles inherent in effective art therapy:

1. Visual image making is an important aspect of the human learning process;
2. Art made in the presence of an art therapist may enable a child to get in touch with feelings that cannot be easily expressed in words;
3. The art can act as a ‘container’ for powerful emotions;
4. It may be a means of communication between the child and therapist;
5. It can serve to illuminate the transference. (p. 272)

She adds, also, that art-making can foster confidence, particularly in children who have difficulty playing, and that, in group contexts, it can create opportunities for social interaction and thus help improve social skills and problem behaviours (Waller, 2006).

For Edith Kramer (1998), art is not used in therapy, but art is therapy. Art is not conceived of as a tool for use by a therapist; rather, it is the creative act within the context of the therapy that cultivates psychic strength and organization. Art therapy is fundamentally different from and complementary to more traditional, verbal therapies. Kramer says that children have a special relationship to the visual arts. It is the art therapist’s job to:

- Set the stage by providing art materials, time, and space; by being receptive to the unforeseen and respectful of the child’s imagery and sense of form; by being understanding of the single-minded intensity, of the extravagance of creative fervor, and protective of the need for extra time and privacy during periods of heightened productivity, even if this interferes with the smooth functioning of scheduled activities. (p. 14)

Kramer's (1998) arts-based approach to art therapy proved particularly appropriate in the context of home-based therapy. While in more conventional therapy, sensitive verbal exchanges between the client and therapist are made easier by the assurance of privacy, in home-based therapy, the presence of other family members can make spoken communication awkward. Understanding and trusting in the therapeutic power of art-making alleviated the pressure to promote stilted conversation, and allowed me to focusing on setting the stage for meaningful creative exploration to take place.

## Methodology

### *Heuristic Research: Basic Tenets*

I am the central participant in my research. The personal, subjective nature of the inquiry dictates that the researcher is the core of heuristic research (Sela-Smith, 2002). This work integrates my experience of conducting home-based therapy in four different homes. The clients with whom I work are not considered to be research participants. Rather, they are a part of the stimulus to which I am reacting.

Moustakas (1990) describes the heuristic process as a “way of knowing” (p. 10) that is infinitely subjective. Everything that is inside the researcher, that which she can access and bring to consciousness is data in the study. Raw data may be perceptions, senses, intuitions, or knowledge. Whatever the investigator experiences and acknowledges becomes a part of the investigation. Data collection is the act of cultivating conscious self-awareness, and of recording the process of self-search, self-awareness and self-discovery. The researcher’s “primary task is to recognize whatever exists in [her] consciousness as a fundamental awareness, to receive and accept it, and to dwell on its nature and possible meanings” (p. 11).

In my research project, there is a harmonious balance between my therapeutic approach and the methodological framework for examining my own experience. The theoretical frame of the analysis is Rogerian, systemic, and existential. Carl Rogers’ humanistic psychology informs Moustakas’ (2002) research process and is present in every phase of the inquiry. Moustakas writes that Carl Rogers “has summarized the essential qualities of discovery in terms of openness to one’s own experiences, trust in one’s self-awareness and understanding, an internal locus of evaluation, and a willingness

to enter into a process rooted in the self” (p. 17). Since a systemic frame is also used in the therapy, it makes sense to likewise examine my reactions from the perspective of my own relationships and the ecological context of my life. The third theoretical element is existentialism. As Fred Rogers (1983) described, the existential struggles of the seriously ill child echo within the therapist.

#### *Data Collection and Analysis*

In heuristic research, data collection is the act of cultivating conscious self-awareness, and of recording the process of self-search, self-awareness and self-discovery. The researcher’s “primary task is to recognize whatever exists in [her] consciousness as a fundamental awareness, to receive and accept it, and to dwell on its nature and possible meanings” (Moustakas, 1990, p. 11). The goal of cultivating that awareness is to reach an understanding of the critical human experience that underlies the research topic. Heuristic research searches for the universal by examining the personal.

Moustakas (1990) outlines six steps for engaging in heuristic self-inquiry: (a) initial engagement, (b) immersion into the topic and question, (c) incubation, (d) illumination, (e) explication, and (f) culmination. In the initial engagement phase, the researcher’s task is to identify a phenomenon about which she passionately wants to search for meaning, to formulate a question, to engage in self-dialogue, and to elucidate the context of the inquiry. Next, the researcher immerses herself in her question, becomes intimate with it, and cultivates openness to all possible avenues of meaning. In the incubation phase, the researcher distances herself from the question. Moustakas says that this allows the researcher to integrate the experience at the level of tacit knowledge. The next phase, illumination, emerges naturally from the incubation phase. It cannot be

forced. In illumination, knowledge is reordered. Eureka! A transformation of understanding occurs. The explication phase examines this awakening. The researcher looks for layers of meaning in the experience. The final task is creative synthesis. The researcher is challenged to integrate her knowledge, to create a whole. Creative synthesis can take many forms, including a narrative, an artwork, a poem, a story.

*The initial engagement.*

My initial engagement with my research question emerged naturally during the months preceding my engagement at the practicum agency. I felt the need to be better prepared for the daunting task ahead of me. A cursory search for literature on home-based art therapy in paediatric palliative care yielded no results. Literature on home-based counselling and therapy was plentiful, as was literature on paediatric palliative care, but the focus of the research was, invariably, on the ways in which the therapy suits or is inappropriate to the needs of clients (Later, I was able to locate some excellent literature on the experience of therapists working in paediatric palliative care, including Khushalani (1983), Rogers (1983), and Vaux (1983). These appear in the literature review section of this paper). I was left with a somewhat apprehensive uncertainty... *but what will it be like for me, as a therapist?* I worried that witnessing the dying of a child would be traumatizing. I was concerned that I would feel overwhelmed, unsafe, or inept working in the non-traditional context of the home. A desire to answer this question for future therapists embarking on similar endeavours spurred my desire to pursue this undertaking.

*The immersion phase.*

The immersion phase of the research project was the most enduring, lasting the entire eight months of my practicum term. During this period, my primary mode of recording my experiences was a reflexive journal. Journal entries were diary texts that examined internal processes relevant to my research question, self-dialogues (written interviews with myself, which took the shape of a Rogerian therapeutic encounter with oneself, as outlined in Moustakas, 1990), drawings and photographs of artwork produced in relation to my question, and any other material that I deemed relevant to my inquiry. Case notes, reflections made in academic papers, creative responses to situations (drawings and paintings), and conversations with colleagues, professors and supervisors are other data sources. This list is intentionally broad since, in Moustakas' conception, all avenues to meaning are appropriate in heuristic inquiry.

Journal entries took two forms: diaries and self-dialogues. The diaries are train-of-thought records that generally described problematic or remarkable situations that occurred in the therapy, and my reactions to them. They are also a record of my personal state of being in the moment, of what I was thinking about, or of what moved me on an emotional level. The self-dialogues are formal interviews with myself. In them, I employed Moustakas' (1990) method of asking myself questions, as a therapist might prompt a client in humanistic therapy. The goal was to come to a deeper understanding of an emotional phenomenon. Generally, I employed self-dialogue as a means to understand my countertransference to clients or their families. As is human nature, I inadvertently biased the journal entries towards negative experience. My frustrations, anxieties and sadness were more likely to appear on its pages than my successes, comforts and joys because I had a more pressing need to process them.



My art productions were made either in a private sketchbook, in my journal itself, or as larger, individual artworks intended for studio presentation. In the sketchbook and journal, artwork tended to be very personal, with little regard given to the aesthetic quality of the piece. It can be categorized into three types: spontaneous manifestations of current emotional states, visual reflections on therapy encounters, and playful escapism and experimentation with materials. The public works, intended for presentation to an audience of artists, educators, or art therapists, were more structured, less spontaneous, and were generally meant to convey a message. The messages varied; sometimes my intention was to send a politicized message, other times to describe my state of being and psychological preoccupations.

*The incubation phase.*

The incubation phase, in which I distanced myself from the research project, took place in the month following termination with the clients in the art therapy program. During this period, I set aside my research question, focusing on presenting an unrelated aspect of my practicum experience (one which focused on client outcomes) at a local conference. While I had been joyfully anticipating the incubation phase after the intensity of eight months of data collection in the immersion phase, I found it surprisingly difficult to completely abandon, albeit temporarily, the project. Instead, unsolicited ideas would present themselves, and I felt compelled to jot these down in a notebook.

*The illumination phase.*

While Moustakas (1990) implied that illumination would present itself in a moment of enlightenment, my own experience can be better characterized as a series of small illuminations. Reflecting on particular occurrences, reviewing my journals, and

talking to colleagues about different aspects of the experience all contributed to moments of clarification in which I came to a better understanding of my role and reactions. The complex experience of the academic year cannot be boiled down into one overarching and all-encompassing theme. Instead, a series of related themes have emerged and it is possible to witness the development and transformation of my preoccupations over time.

*The explication phase.*

This phase was characterized by a great need to organize and arrange the literature I had amassed, and the data I had collected. The moments of illumination, jotted down in various ways for future reference were compiled and checked for validity against my written accounts of the experience of the art therapy program. I consider that the phase culminated in the compilation of an extremely detailed outline for this paper.

*The culmination phase.*

While compiling the detailed outline that characterized the explication phase felt like an exercise in organizational competence, the writing process felt like a re-enactment of the experience. While writing each section, I felt like I was reliving the academic year with emotional intensity. It was both exhausting and rewarding. The resulting document reflects, I hope, the expressive nuances of the entire experience.

*Generalization of Results, Reliability and Validity*

Heuristic methodology cannot be used to draw conclusions about causation, nor can outcomes be predicted (Moustakas, 1990). The methodology differs from more mainstream qualitative methodologies in that it is extremely subjective. Where most qualitative methodologies acknowledge the subjectivity of the researcher, heuristic methodology embraces it. Subjectivity is the *raison d'être* of the heuristic researcher.

Therefore, conclusions are drawn from the subjective experience of the researcher and do not attempt to be universal. However, the hope is that the research will “disclose the nature, meaning, and essence of the phenomenon being investigated” (Moustakas, 1990, p. 44).

Reliability is a moot issue in heuristic research. There is no expectation that a completely subjective experience will be replicable. At the same time, heuristic research is founded on the assumption that there is some universality or, at least, generalizability, in human experience. Otherwise, there would be little reason to conduct the research. This is paradoxical. On one hand, the researcher does not attempt to find something universal. On the other, universality is implied in the act of searching for essence, for meaning.

In addressing validity, Moustakas (1990) cautions that, because of the intensely qualitative nature of heuristic inquiry, quantitative assessment of validity would be meaningless. Validating heuristic research involves assessing whether the meaning ascribed to the phenomenon is accurate and complete. Moustakas states that, because the research is deeply subjective, the only person who can evaluate the validity of the study is the researcher. The central concern is: “Does the ultimate depiction of the experience derived from one’s own rigorous, exhaustive self-searching and from the explications of others present comprehensively, vividly, and accurately the meanings and essences of the experience?” (p. 32). Throughout the process, the researcher is expected to make appraisals of the significance of the data (1990). Moustakas avers that there are no rules for verifying conclusions: truth is completely subjective; the researcher must judge the relevance of findings.

I am uncomfortable with this extremist rejection of more conventional validity assessments. While it is true that the researcher's goal is to explicate an intensely subjective experience, if the essence of that experience is not transferable to others, or if others cannot relate to the meaning ascribed to the phenomenon by the researcher, then her idiosyncratic understanding of the phenomenon has little value as research (although it may have value as a literary document). Peter Martin (2005) takes a moderate approach to conceptualizing the validity of his own heuristic research. While he is attracted to the safety of retreating to subjectivity in (what he describes as) a hostile academic world, he feels the need for scientific rigour in order to aid communication of his findings. He struggles to "find a way to be subjective yet subject to discipline" (p. 211). He states that truth lies in agreement, in inter-subjectivity. In this research, inter-subjectivity is reflected in pre-existing literature on my topic and in discussions held, prior to the writing process, with colleagues and supervisors. Most importantly, however, inter-subjectivity is evaluated by each new reader of the text. I invite the reader to consult their own subjective experiences and internal states, evaluating whether my descriptions resonate within them.

## Results

What follows is an account of my experiences over the course of the in-home art therapy program for children with terminal, degenerative illnesses or their siblings. A preliminary note on the use of gender pronouns throughout this section is necessary: Throughout the text, the therapist is referred to as feminine. This is not a manifestation of gender-bias, but reflects that, in this first-person account, the therapist in question is a woman. The appropriate masculine and feminine pronouns are used to describe particular clients or their family members. However, to increase comprehensibility in non-specific references, masculine pronouns are attributed to clients or family members, so that *she* and *her* refers to the therapist and *he* and *his* refers to the client.

The results chapter is divided into three broad categories that reflect qualitative differences in the kinds of issues that emerged over the course of the year. These are: pragmatic issues, therapeutic issues, and existential concerns. The order in which these are presented reflects the order in which they became primary concerns for me over the course of the therapy. In the initial weeks, solving pragmatic problems like packing and transporting art materials and feeling safe were my most pressing concerns. As these began to be resolved, I was able to turn my attention to what was happening in the therapy and how it differed from more conventional therapies. Finally, as my attachment for my clients and their families grew, and as I was confronted with the realities of working with seriously ill children, my primary concerns evolved into a more personal, emotional existential struggle. Throughout the text, I will illustrate my findings by sharing the content of my journals and some of the artwork I produced during the year.

### *Pragmatic Issues*

*Isolation.*

Soon after I began my work, it became clear to me that feeling isolated from colleagues and the referring agency would be an unavoidable by-product of this in-home therapy program. It was difficult not having colleagues in the immediate vicinity who could listen to me when I needed to vent my emotions or did not know how to proceed. I had no daily contact with the agency or its staff. Regular supervision became absolutely vital both at the agency and at school, as did finding time to talk to colleagues in a more casual way. Discussing my experiences (while respecting client confidentiality) helped to allay feelings of isolation. Dialogues with colleagues also gave me a way to check my assumptions and opinions, and to judge with greater objectivity whether my reactions to my clients and the context of the therapy were accurate. Nonetheless, the fact that my colleagues (with one exception) and supervisors had never met my clients or worked in an in-home context sometimes made communication and dialogue difficult.

In my reflexive journal, I wrote of feeling at a loss to help a client: "I don't know how to interact with this child at all - to have any kind of meaningful communication with him. I question whether I know any way to help him." My fear and frustration shouts from the pages of my journal, but, in group supervision, I felt misunderstood. I was unable to accurately describe the child, and felt that my colleagues' natural propensity to slot children into developmental and diagnostic categories was counter-productive in this case. Because the child defied easy categorization, verbal communication was extraordinarily difficult.

In the end, the situation became resolved through a long, open dialogue with my faculty supervisor in which I expressed my perception of being misunderstood, research

and reading on my part which helped me to develop a more sensitive vocabulary, extensive journaling, and subsequent visits to the client which made it easier for me to pinpoint the difficulties. This extra work was fruitful in the end; I was able to change my way of working in order to take into account my better understanding of the client's needs.

*Safety.*

The issue of isolation also relates to that of safety. However, in my experience, feeling unsafe inside the homes of my clients was not a factor. Perhaps because of the population with which I was working (as far as I know none of my clients or their family members had a history of aggression), I never feared aggression or violence. Because the families were under inordinate stress, I occasionally witnessed strained tempers and verbal arguments between family members; however, these never reached a threshold in which I felt my own safety, or the physical safety of my clients or their families, to be threatened. Nonetheless, because I was entering a private, isolated space, I took steps to ensure my safety. I carried a cellular phone, and only made home visits after referral by an agency coordinator who had previously met the families both at the agency and in their homes. That coordinator accompanied me on my first visits, introducing me to the families and helping to make all involved more at ease.

Although at no time did a client or family member even raise his voice to me, I adopted a more submissive pose than I would have in an institutional setting. This was due less to an expectation of aggression on the part of the clients than to a heightened awareness of being an invited visitor in the home. While my professional responsibility dictated that I impose upon the family and take over the space in ways a social visitor

never would, I was alert to the need to minimize this intrusion. In fact, rather than fearing for my own safety, I worried that my presence would be suffered by family members as an intrusion. I feared being an inadvertent aggressor in already frazzled, sensitive families.

Travelling to and from therapy sessions was of greater concern. Because I do not drive, I travelled to unfamiliar areas of a large city using public transportation. Basic safety precautions involved finding well-lit populated routes to and from sessions. It was not possible to avoid travelling after dark. My own desire to avoid night-time journeys was superseded by the needs of families to schedule therapy appointments after school and working hours.

*Travelling.*

Travelling to and from therapy sessions was enormously tiring and time-consuming. In a March journal entry, the harsh Canadian winter weather was disheartening:

Outside is cold and grey, and being outside, going from place to place is physically painful. Commutes that were no big deal in September are awful right now. I wait for the bus until I can't feel my fingers and toes. Walking down the street, lugging my cases through unplowed snow banks, the wind whips my face, stinging almost unbearably. And as cold as my extremities are, I'm often sweating underneath my parka, overheated because I'm working so hard to get where I'm going. I sit through my sessions, damp and uncomfortable, knowing the trip home - darker and colder - will be even worse.



Sometimes, the added convenience for the clients and their families of having art therapy in the home felt like it was taken at my expense. There were days when I was



*Figure 1: Frazzled*

pulled in many directions, journeying to the four corners of the earth (or of the city) in any given day.

On one such day, my sketchbook reflected my weariness and irritation. The quick sketch “Frazzled” (figure 1) shows the toll of traveling to clients. On those days, it was necessary to remind myself that, for families homebound by the needs of an ill child, access to therapy is prohibited unless a therapist exerts herself to visit the client. To come to a realistic

solution to the problem of travel, one that balanced both the needs of the clients and my own limitations, I resolved to limit the number of in-home visits per day to one (although this number probably could have been increased if I were driving).

In addition to the physical trials of travelling to and from sessions, reliance on public transportation dictated that I relinquish some control over the time frame of the sessions. One January day, I wrote:

[The subway] broke down [on the way to see a client] and I sat in an underground station for fifteen minutes - making me late for my session. At first, I was feeling really guilty about it until I realized there was nothing I could do about it, or could have done to avoid it... Yes, I could have left early for my session. I could leave early for every session. But frankly, that is unrealistic for a couple of reasons. First, because I don't have the extra time to build into my schedule for each and

every client I see... Second because if I was to leave early, on most occasions, I would arrive early. I can't show up at the homes fifteen minutes early - my sessions would be prolonged and that would be rude. I can't, either, wait outside of the homes, because it's -15° [Celsius] some days! There isn't usually somewhere indoors I can go to pass time without discomfort to myself--lugging my bags, having to pay for something, etc... It's better to take the risk that I will be late some days.

In the end, instead of placing unrealistic expectations upon myself to succeed in arriving at all sessions on time despite uncontrollable external circumstances, I addressed the issue in my sessions with my clients. We came to the agreement that, if I was late arriving at a session, it would be prolonged by that amount of time. That way, the client would be confident that they would benefit from the full duration of the sessions regardless of what time it began. I also assured the clients that, if I would be more than fifteen minutes late, I would use my cellular phone to call and inform them. This arrangement alleviated my guilt and afforded the clients with the safety of predictability.

### *Scheduling.*

The requirement of travelling to sessions necessarily limited the total number of clients I could see. Travelling time and fatigue had to be factored into my schedule. However, because I was seeing the clients in their home environments, eliminating their travelling and seeking them out where they are most comfortable, sessions could be longer than in conventional therapy. The length of sessions also had to take into account the time spent setting up materials and cleaning and packing up at the end - activities usually outside the bounds of conventional therapy. Furthermore, cancellations were rare,

since little effort was required on the part of clients to attend the therapy sessions. In fact, on one occasion, I arrived to discover that a client had been too ill to attend school. However, because art therapy did not require her to leave home, her parents did not cancel her session with me.

*Art materials.*

Art materials were limited to what I could safely carry. For each session, I attempted to provide a variety of materials and media for drawing, painting, and working in three dimensions. Because I could not carry all the materials to every session, I had to anticipate what materials would be therapeutically useful for each child. Because each child was different, my bags had to be repacked before each session. Time had to be factored into my schedule for this vital preparation. In the latter weeks of the therapy, the clients began requesting that I bring particular materials. Some clients would make me lists of materials to bring the following week. In doing this, they took an active role in their therapeutic process.

Invariably, there were weeks in which I had to live with the guilt of being a poor provider. Sometimes, I would forget an item on a child's list. Other times, I would not have anticipated a material that was wanted or needed. In my most glaring lapse, I compiled developmentally inappropriate materials for my first session with a young child whose condition was not adequately communicated to me. After the session, I wrote

The problem is that I didn't have appropriate materials with me and was, frankly, concerned about the child's safety given the materials I had provided. Quickly, I hid the scissors and glue and tried to distract him from the sharp pencil crayons,

gearing him towards the stamping markers which, though he could not manipulate, were unlikely to cause him harm.

Poor communication about a child's condition can happen in conventional therapy as well as in the context of this agency. However, in conventional art therapy, the therapist would have easy access to a wide variety of materials appropriate for different developmental levels. I was constricted by my preconceived notions about the child, and unable to be as flexible as I would have liked. As a result, an accurate assessment of the child's art-making abilities could not be made in the initial session.

During the first months of the therapy, I transported all artwork created by the clients to and from each and every session in an attempt to give my clients easy access to their previous productions. Soon, however, this became unwieldy. Instead, I began photographing the artwork each week. The photos were pasted in a file for each child, along with a description of the art-making process. This file was brought each week instead of the works of art. Periodic art reviews were scheduled in which I would bring all of the artwork.

### *Therapeutic Issues*

#### *The initial parental interview.*

Each family was recommended for art therapy by the agency, was contacted by an agency coordinator, and engaged in the program voluntarily. Initial sessions began with an introduction from the coordinator, who accompanied me to this session and stayed for only fifteen minutes. Prior to the first sessions, I had anticipated that an attainable goal for the initial contact would be to ensure that parents had a solid understanding of what art therapy is, and to glean information from them on the background of the children and

on why they had chosen to have art therapy visits. My in-home experience dispelled my expectations of calm, easily communicative families awaiting my arrival. I wrote:

It felt chaotic! My first home visit and the family wasn't even there when I arrived. Nobody home! Then, the dad arrived with the child I'm seeing in tow - and [the child] didn't even know that I was coming, or why I was there. In fact, the dad didn't even seem clear on it... the mom wasn't there (she had a meeting at the [children's hospital])... when she came, she had no time to talk to me... The whole time I was there, I felt like everybody was being pulled in different directions.

Each family presented different and unexpected reasons that made a formal, or even informal, interview difficult. In one family, the high anxiety and self-consciousness of the parents made it difficult to converse. In another, the immigrant parents' language difficulties precluded communication. In all cases, the parents were busy and preoccupied with the ill child's needs and the business of running a household. My status as a visitor in the home made it inadvisable for me to impose my own agenda.

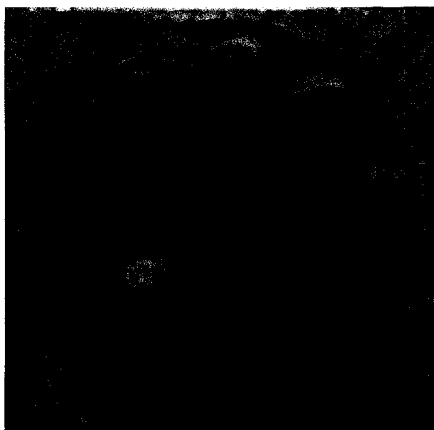
*The environment of the therapy.*

One of the most striking aspects of working in the home is the irresistible quality of the emotional tone of the household. The physical environment is overwhelming and, twinned with it, is an emotional environment that is inescapable. Entering the home, I absorbed this atmosphere. In anxious homes, I felt anxious. In angry or sad homes, I struggled with anger and sadness. In joyous homes, I, too, felt happy. Shifts in the emotional tone of a household were immediately palpable.

The physical and emotional milieu was enveloping, inundating all of my senses. One of the most emotionally gripping and unexpectedly powerful senses employed was the sense of smell. Each home has its scent, reflecting the lifestyle, culture and habits of the family that inhabits it. After only a couple of visits, I found that I had formed a strong emotional association between that scent and the family linked to it. Returning home, I noticed that the scent of a household would cling to my clothes and hair. Even though the aromas were not unpleasant, its disconcerting presence prompted me to change my clothes immediately upon entering my own home. Doing so, I felt I had left my work life behind.

*Chaos.*

When visiting stressed, overburdened families in their homes, it is a given that the therapist will sometimes encounter chaos and mess. I chose to ignore these. Commenting on them would have been seen as judgemental and would have shamed the parents and



*Figure 2: Regeneration*

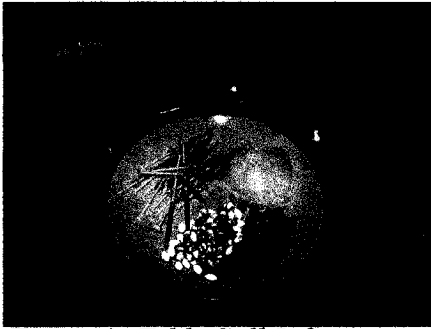
the children. Luckily, I have a high tolerance for physical disorder and was not bothered by any disarray I encountered. Psychological turmoil, however, was more anxiety-provoking. My response after a particularly chaotic session was to retreat into the relative peace of my own home. My

“Regeneration” (figure 2) painting is, in part, a visual reaction to my longing for peace and protection. After creating it, I wrote in my journal that:

The painting depicts a woman curled into a foetal position inside a circle. The artwork is meant to be placed on the floor so the woman appears to be inside of a hole. I guess the mandala symbolizes the womb-like quality of my home. The woman, while in a vulnerable position, is not meant to be weak. In fact, I intentionally made her muscular, her features are not delicate. Instead, I see her as a spent warrior, retreating to the womb of mother earth to regenerate. In front of her, at her abdomen, is a glowing circle of light. This light is her energy, her power. It also calls to mind a pregnant woman's stomach. This is depicted in this way for a couple of reasons. This woman... is a nurturer and a warrior. From her womanly instinct to care for the vulnerable comes the strength to fight, to advocate for them and to take on their pain. Of course, it's the fight that makes her so vulnerable, that hurts her. She chooses to be a victim so others can overcome their victimization. She hurts. Her armour crumbles away and she, too, would break down if she could not retreat to regenerate. She is the centre of her home. Her moon-like glowing crown of hair pays homage to how she is the queen of her domain. At home, she is selfish.

*Medical paraphernalia.*

An unexpectedly difficult element in adjusting to working in the homes of ill children was becoming accustomed to seeing medical equipment in a private space. Perhaps because I had steeled myself to temper my reaction to the ill children themselves, it became misplaced on the portentous paraphernalia that surrounded them. I reacted to it with shock and upset. After an educational training session at the agency which explained the functions of various equipment encountered in the home, I wrote that "I got really sad



*Figure 3: Table Still Life*

listening to all of the things that can go wrong with children's bodies - all the tubes, the holes that we put into their little bodies."

My creative response to this was the creation of the "Table Still Life" (figure 3) which reflected the experience of seeing the trappings of dying incongruously displayed in family homes – hospital beds in children's bedrooms, oxygenators in hallways, tubing everywhere. Sometimes, medical equipment was absurdly attached to the children themselves – gavage tubes in the stomachs, tracheotomies in their throats – nourishing them, keeping them alive. In the families, mortality could not be hidden – humanity's secret was out. At the same time, these children and their families, like me, are struggling to stave off the inevitable. I use cold medications, cough syrup, pills and injections to erase the symptoms of the ultimate human weakness. I use vitamin pills for comfort, to give myself the illusion that I can stave off death.

In the table still life, I wanted to send a message about our discomfort with the fragility of life, and our rejection of those who remind us of our own mortality. In my own experience, I had to fight the feelings of repulsion that mingle with the instinct to care for sick people. This tablescape is set for one--nobody wants to eat with the sick person, who is represented by a fragile chair (not pictured).

*Intrusion and privacy.*

While in the homes, I was constantly aware of the need to negotiate with the families in order to balance privacy and intrusion. From my perspective, the therapy required that I maximize privacy and minimize intrusion into the therapeutic space. The



family members, too, had a right to privacy in their own homes, and my presence represented an unavoidable intrusion. My own need for privacy exacerbated the sense that I was intruding as it required family members not directly involved in the therapy to change their at-home routines. Yet, I had to let go of the expectation that this would be a completely private therapy. Although this is a basic tenet of conventional therapy, it was an unrealistic expectation in this context. An insistence on complete privacy would have placed expectations on the family members that they would not be able to achieve. Instead, I tried to set up the therapy in a way that allowed for interruptions without compromising the therapeutic relationship. I established a broader level of openness with the parent than I would otherwise, allowing and even occasionally encouraging the client to share his therapy experiences with his parents. Sometimes, the parents were invited to participate in the art-making or in verbal interactions. A good time to do this was during pre-holiday sessions (assuring, of course, that the holiday in question was culturally relevant to the family). A social activity (e.g. cookie-decorating) would be planned, allowing the child to invite his parents to participate (either in the decorating itself, or in eating the cookies). In some families, where parents were particularly curious or anxious about what was happening in the therapy room, I would negotiate scheduled interruptions into the session. For example, parents would be invited to join in the art therapy during the last ten minutes of each session.

In the end, I came to terms with the fact that some degree of intrusion was unavoidable. My professional responsibility required that I negotiate how the therapy would proceed, how and in what location the materials would be set up, and how the

family members should act in my presence. Otherwise, I felt unprofessional and out of control, and the clients felt emotionally unsafe.

Feeling intruded upon in the home was not the exclusive domain of my clients and their families. Because my own home was my base of operations, where I wrote my case notes and stored the art materials and client artwork, I sometimes felt overwhelmed



*Figure 4: Tree*

by a lack of distinct boundaries between my home and work lives. A fear of inundation was clearly on my mind when I drew “Tree” (figure 4) and wrote:

I drew an enormous, very wide tree. I was drawing without really consciously thinking about what I was doing or why... as I drew, the branches of the tree, from left to right, they became more complex, gnarled, fighting each other for space on the page. At some point during the process of the drawing, I came to the realization that I am resentful of the lack of boundaries between my home life and my practicum life. The lives of my clients are invading the space of my private life. Art materials--ones that I do not use myself--have infiltrated my personal art studio. My bags are cluttering my hallway. I have to devote home time to work tasks. I have no agency to work at. Home is work. And so, the part of me that resents the lack of boundaries in my life right now is avoiding work.

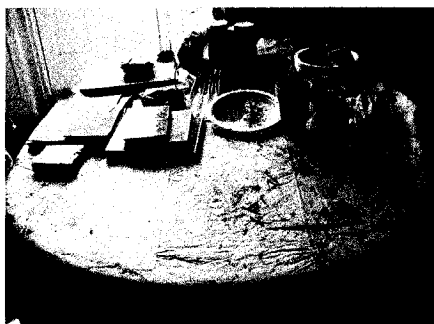
#### *Discipline.*

Establishing a disciplinary framework for the sessions was important. Not doing so would have abdicated my professional responsibility and the clients would have felt

insecure. Nonetheless, I was aware that it would be inappropriate to discipline a child in the presence of a parent. So, when enjoying privacy with a child, I expected that they obey the rules established for the therapy and corrected them accordingly. When the parent was in the room, however, their practices took precedence and the role of disciplining the child fell under their auspices. This was sometimes a difficult principle to follow. For example, on one occasion, I reacted with unexpressed, internal outrage to the strict manner of an authoritarian father. Afterward, I wrote:

Why am I so angry? Because it reflected a basic disrespect of who this child is, a devaluing of him... This dynamic would not be as evident to me if I was not working in the home. At the same time, I would not feel so hopeless about my ability to have any positive influence on this child's life course.

*The therapeutic frame, negotiating boundaries and professional distance.*



*Figure 5: Therapeutic Space*

Minimizing interruptions and maintaining discipline were important factors in the creation of clear and communicable physical and temporal boundaries for the art therapy sessions. A padded vinyl table protector (figure 5) provided a literal and symbolic foundation for all in-home therapy encounters. The mat was placed on the kitchen or dining table and the art materials were arranged on it. At the outset of the therapy, I explained to my clients that, each week, I would bring an art studio to the home and that the mat was the floor of that studio. While all materials were confined to the mat, the children were free to be messy on it. The unfurling and refolding of the mat and the ritual of arranging and cleaning up the art materials became an important means of

bounding the play. One non-verbal child used the mat as a way to communicate his needs to me.

At [this client's] house, I lay [the mat] on the floor of the playroom and I put all of the things I brought with me onto it. At the end of the session, the mat gets folded up and put into my bag. This marks that I am leaving. Normally, while I am doing this, [the client] plays... This time, the moment I put the mat in my bag, he marched [out of the room]. Clearly, he understood that the session was over!

Later in the course of the therapy, the child began to actively manipulate the mat, folding it to communicate that he needed a break from the interactive play, and unfurling it when he was ready to play again.

There are several key components to the therapeutic space created by the mat. Because I brought it with me, it became symbolically associated with me, and the therapeutic relationship. In effect, I was the art therapy studio, a therapeutic safe space. The set-up and take-down rituals defined the temporal boundaries of each session. The rules inside the art space were different than those in the home, making it a special place. For example, in the art space, the child was allowed to make a mess, to regress, and to create works that were violent or "ugly." It's important to note that, while messes within the confines of the mat were common, I rarely had to caution a child to avoid making messes outside that area.

The rules created for the mat had to take into account the tolerance of the parents for mess or violent imagery. When an issue arose, open communication was imperative. I would explain the rules of the therapy, making clear the importance of allowing the child to be messy or depict uncomfortable imagery. Generally, this was enough to allay any

parental concerns. However, when the rules of the therapy caused the parents to feel anxious, they had to be adapted to accommodate their needs.

Because of my own experiences, I was unduly concerned about the reaction of parents to the creation of mess in their homes. Even though I was careful to leave the space as I had found it, I was sometimes preoccupied during sessions about containing the mess made by clients in the art-making process. My countertransference reaction is abundantly clear in this journal entry:

I find that I am very concerned in my sessions with containing the mess that the children make--and this is *during* the session, not at the end. I am much more concerned, I think, than I would be if I were not in someone else's home. I have a high personal tolerance for mess... but my experience of parents, my own in particular, is that any mess is unacceptable. I find myself apologizing even when I have successfully eradicated all traces of mess. My parents cannot tolerate any mess, not even for a few minutes, so I find myself following the children around, frantically cleaning up after them. I think that, deep down, I am afraid that the parents are going to yell at me, to put me in the role of the messy, unruly child.

*Favours, food and gifts.*

While Boyd and Bry (2000) advise home-based therapists to join with families in eating and drinking, as a general rule, I did not accept food from the adult family members in home-based therapy. In most families, I would be offered food or drink during the first session. Ordinarily, declining the offer politely was acceptable to the parents, and allowed me to establish myself as something other than a social guest in the home. My respectful refusal communicated to adult members of the families that my

presence should not create an additional tax on their resources. The creative tasks involved in the art therapy process gave me an acceptable excuse for declining nourishment; a table laden with messy art materials is not conducive to eating or drinking. There was one notable exception to this: In one particular household, it was very important that I accept what was offered. In this South American family, offers were invariably food or drinks that were associated with their culture. Furthermore, the act of sharing food with guests is important in the family's culture. Rejecting what was offered was a rejection of that culture, and hence the family, and caused the mother and oldest sibling to experience undue anxiety. To accept that offering was to symbolically accept that part of the family's identity. Once I came to this realization, I began graciously agreeing to consume something at each session. Sometimes, this could be as little as a glass of water. Other times, it may be a beverage or dessert.

Children occasionally offered me food or small gifts (often the art production created during the session). When they did so I usually accepted the gift, then addressed the generous impulse in the therapy. Offering me food or a small gift was often a socially appropriate way for the child to display affection and to proprietarily demonstrate to their household that I was their guest in the home.

*Language and verbal communication.*

Language was a factor that affected me in ways that are unique to my situation. As an English person who speaks French capably but not entirely fluently, living in a large, mainly French city, I was often required to carry out my duties in my second language. As a result, in almost every context, I was perceived by the family as a cultural outsider and had to be sensitive to this added way in which I may be perceived as an

intruder. Switching languages was natural way for me, as a therapist, to psychologically frame the sessions for myself. However, it also altered my behaviour as a therapist.

Constant simultaneous translation was sometimes exhausting, and finding the appropriate nuanced term (or *mot juste*) for every situation was difficult. Often, I felt tongue tied and frustrated with my reduced ability to express myself.

At the same time, the arresting nature of the art-making process, compounded with the presence of other family members and my reduced verbal capacity, created a tendency for the clients to be less verbal and more focused on the art-making than they might have been in other contexts.

In a unique cross-cultural situation, the linguistic context in one household made for an unusual situation and actually heightened my sense of comfort in the household environment. I describe the situation in the following journal entry:

[An] unanticipated reason why I feel quite comfortable in this home is related to language. French is the second language in this home, and while it is the common language among us--they don't speak English and I don't speak their language--there is camaraderie in our shared difficulty communicating. Unlike me, this family must experience the communication barriers every time they leave the house. Perhaps my bringing my own language difficulties into their home and, perhaps, bringing the art as a means of overcoming that barrier, gives us a shared experience, and allows us to operate on an even footing. Perhaps I am just projecting my own feelings onto them, but I thought that I perceived a lessening of tension, particularly with the mother, when they realized that French was my second language too.

As the course of therapy proceeded, I discovered that these clients were far more verbally uninhibited than the other children I was visiting. I believe that linguistic context of the therapy was fulfilling an important role: providing a veil of privacy for both the therapeutic interactions and the family's interactions with each other.

*Client focus versus family focus.*

Throughout the course of the year, I was frequently presented with situations that called for me to balance the needs of the individual client with consideration for other family members. To some degree, my systemic theoretical orientation, coupled with the agency's family mandate, required that I consider the effect of my actions on the welfare of all members of the family. However, putting this ideal into practice was sometimes difficult because of conflicts between the needs of the client and the needs of other family members. When this happened, I had to operate in an anxiety-provoking grey area.

This struggle evidenced itself in my discomfort when a client's preschool-aged sibling repeatedly interrupted our sessions and asked to be allowed to share in the art-making. The therapeutic needs of my client clearly dictated that he would benefit from individual attention. However, excluding a small child from a clearly enjoyable activity was difficult, guilt-inducing and conflicted with a whole-family focus. Eventually, I realized that the home context required coordination between the mother and me. I had to be flexible, allowing for less privacy and more intrusion than would be accommodated in conventional therapy. In turn, the client's mother had to be enlisted to minimize interruptions by explaining to her other child that the art therapy was a "special time" for her brother that required him to be left alone with me. In the end, this had an unexpected benefit for my client: In creating a space for his therapy, his mother had reinforced to him



that he was valued, and that his needs were important. The young sibling, too, benefited from the arrangement, enjoying exclusive time with her mother during my sessions with her brother.

*Interacting with parents.*

Home-based therapy, which necessitates a flexible therapeutic frame, means that the therapist develops a more involved relationship with the child client's parents than she would in conventional therapy. Parents are naturally curious about what is happening in the art therapy and concerned that the experience be a positive one for their child. The parents, whose participation in the program was voluntary, were sometimes overly solicitous, trying to persuade their child to develop a positive relationship with me, and encouraging their children in the art-making. It was important to remember that the parents were motivated only by their desire to support the child. In general, I was thankful to be working in caring families. Reacting to a first visit in one family, I wrote:

Even the siblings seemed to have a taken-for-granted niceness with one another. This felt like a loving whirlwind. My first impression is that the family really wants to support each other, but that the demands of daily life are very much in the way.

Nonetheless, sometimes misguided efforts to encourage and accommodate the therapy would be counter-therapeutic or make me uncomfortable. I felt pressured to perform, and to help the child perform, to the expectations of concerned parents. This feeling surfaced in the following journal entry:

I worry that his parents have the expectation that I'm a miracle worker... I feel watched. I don't know how to do my job under their watchful, very, very anxious

eyes. I spend more time trying to reassure the parents... than working with [the client].

To some degree, this feeling of being scrutinized subsided as the therapeutic relationship developed with the child, as the parents' anxieties about my professionalism and trustworthiness were quelled, and as the family became more comfortable with my presence in their home. Furthermore, I became more at ease with the reality of the reduced privacy in home-based therapy. After several months of weekly contact, I wrote:

Lately, I've been reflecting that I seem to have achieved a reasonable level of professional comfort when working in the homes of my clients--and they (and their families) seem to have become somewhat more at ease with my being there. In [the client above's] family, his mom and dad rarely interrupt my sessions.

*Countertransference reactions.*

As in all therapy, therapist countertransference was both a bountiful source of information about the state of the client and his family, and a somewhat taxing wellspring for personal growth. In home-based therapy, I quickly discovered that countertransference reactions could be towards the client, the family as a whole or any of its individual members, and even towards the physical environment of the home. One home in particular sparked a strongly ambivalent countertransference reaction in me because of its similarity to my childhood home. I wrote, "on one hand, it's strangely comforting to be in this unsettlingly familiar environment. On the other hand, I struggle with having over-exaggerated countertransference reactions, both negative and positive."

*Secrecy.*

An assumption I made before working in the homes of clients was that their lives would be open books. This is not the case. I was amazed by the power of the impulse that clients and their families had to hide those aspects of their lives that they felt ashamed of. Secrecy was sometimes thinly veiled, particularly when the keeper of the secret was a child. In fact, even though they were aware of why I was sent to visit, siblings of ill children would commonly avoid making any reference to the ill child or his condition. This was disconcerting:

The [client has] never mentioned [her ill sibling] and I have never seen her. Only [the mother] makes reference to [the ill child] and then only in pragmatic ways (e.g. I won't be here next week because [the ill child] will be at the hospital). It's weird, like she doesn't really exist [(for me)] and the longer I go without seeing/hearing/meeting her, the more she becomes a theoretical abstraction to me and not a living, breathing person.

When presented with issue avoidance and secrecy, I faced the dilemma of whether it would be more appropriate to address the matter with the client or to allow the client to control the magnitude and timing of her own disclosures. Generally, I applied the principle that, since in conventional therapy, the therapist must await client revelation to become aware that an issue exists, clients in home-based therapy have the right to be given similar command over their own disclosures. Those aspects of a client's life that he attempts to conceal from the therapist are likely to be the most sensitive. Therefore, addressing these issues prematurely may be overly intrusive and traumatizing to the client. At the same time, I tested whether the client was avoiding the subject deliberately. In the example related above, I made sure to occasionally mention the name of the ill

child, demonstrating to the client that I was aware of her existence and condition. After months of establishing a positive therapeutic relationship and building up trust with the client, she spontaneously invited me to meet her sibling.

### *Termination.*

The nature of my academic program dictated that the therapy be compulsorily terminated at a predetermined date. This forced termination, already difficult in conventional therapy, had some additional complications in the home context.

Termination was with not only the client, but their entire family. While the client was saying goodbye to the therapist and the weekly art-making activities, the family was parting with the reassurance of having a weekly respite period from the demands of caring for the child seen in therapy. Parents were also ending their relationship with the therapist. While throughout the year I was careful to make myself, as a professional, distinct from social visitors in the home, the fact that I was a weekly visitor in the home



*Figure 6: The Hug*

created some ambiguity in the termination process. In all cases, during the last session parents invited me to *drop in* on the family in the future. In all cases, I had to carefully explain that this would not be possible as an unethical dual relationship would be created if I were to interact with the child as a social visitor.

I explored the emotional ramifications of saying goodbye after one particularly difficult ending

session with a client in “The Hug” (figure 6). The sketch, made immediately upon returning home, depicts the feelings of closeness and connection with the client, with

whom I shared a strong bond in the therapeutic relationship. That the mother looked on during the shared moment (not depicted in the image, but reflected upon afterward) seemed apt. By inviting me into their home, and fostering an environment in which the relationship could be cultivated, she had been in attendance to all aspects of the therapy.

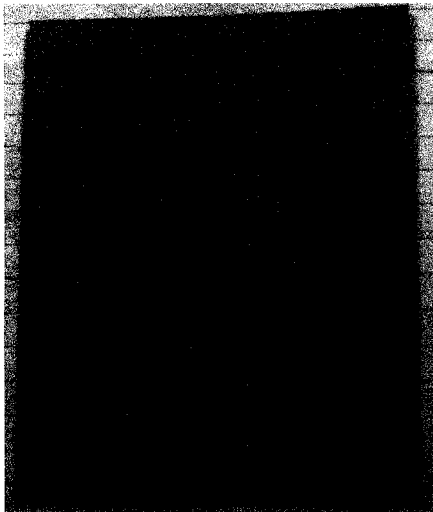
### *Existential Concerns*

#### *The dying client.*

To have a client die during the course of the therapy was my greatest fear going into my practicum. After several months, my fear was realized. A reflection on my experiences would be grossly incomplete without touching on this experience. The experience, far from being traumatizing, sparked serious self-reflection and exploration which has allowed me to come to a deeper understanding of who I am and why I have chosen this field of work.

To understand what it was like to live through this child's death, I have to begin, not with hearing the news that she had passed away, but with our first meeting. I had been informed upon referral to this child that she was living through the final stage of her disease, and that care was now palliative. I was aware, then, going into the first session, that this child would likely die before the termination deadline imposed by my academic program. What I did not expect was that she would pass away within weeks of my meeting her.

Meeting the client, I was struck by her frailty and her normalcy. This was a normal child, bright and sweet, happy to have a visitor and behaving in an age-appropriate way. She was also the thinnest, most delicate person I had ever seen. To psychologically protect myself, in the journal I wrote after our first meeting, I



*Figure 7: Self-Portrait*

unconsciously focused on the accoutrements of the client's illness rather than on the client herself. I

wrote:

The first thing I noticed going into her house was the adaptive devices--the bars in the bathroom, the seat in the shower, her hospital bed in her bedroom. It's the first home I've been in where the paraphernalia of dying are so evident--and with a client who is so

obviously frail... I think this is the first time I've seen a hospital bed outside of the hospital. I think it's the conjunction of home and hospital that I find very off-putting. It normalizes something that a large part of me really does not want to be normal. If death can happen to [this child], it can happen to anyone, including me and my loved ones.

I was unable to suppress my reaction to the physical condition of my client in my art creations. Two artworks, consciously created as self-portraiture during this time, could



*Figure 8: Little Bird*

as easily be interpreted as subconscious portraits of the child. The first (figure 7) depicts a sad, delicate woman-child, engaged in a submissive and soulful pose, as if waiting an inevitable and hopefully enlightening event. I created "Little Bird" (figure 8)

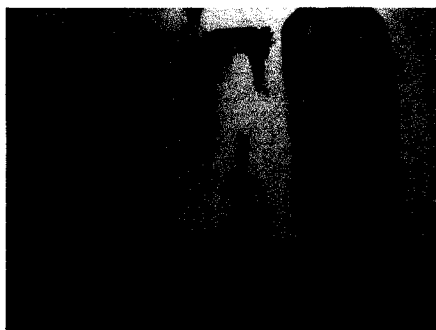
during an art therapy workshop. The instructions were to select an animal figurine (to represent oneself) from a wide variety of animals, and to create a three dimensional home for it that is safe, comfortable and secure. Uncharacteristically, I chose a delicate and

girlish bird to represent myself, creating a nest for it that sheltered and cradled it. I felt a strong desire to protect and comfort my little bird. That the client and I are twinned in these portraits highlights how much her illness provoked my own human fear of mortality.

During the following weeks, I struggled with my own feelings of inadequacy in the face of the inevitability of the child's demise. These feelings dredged up long-buried childhood traumas. I wrote:

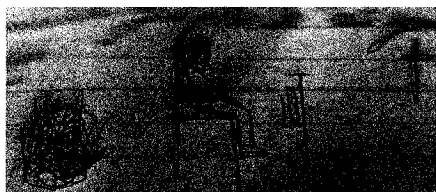
I know what I am feeling--it's that horrible gnawing guilt in the pit of my stomach, the same guilt I used to feel when I was a kid and I went to Sunday school or church and I realized that, no matter how well-intentioned I was, no matter how hard I tried, I could never be good enough. Tonight, I am that little girl who is not good enough.

After writing that entry, I created the artwork "You can't be good enough, you



*Figure 9: You can't be good...*

crucify me every day" (figure 9). The artwork contains the words of the title hidden in stained glass panels flanking the Roman Catholic altar depicted in the image. A sketch of myself as a small, church-going child (figure 10) also made its way into onto the pages of my journal. Behind her lurks the welling pit of guilt making its way into her stomach where it would hibernate until awoken by my sense of inadequacy in the face of my client's illness.



*Figure 10: At Church*

After several weeks, I learned that the client had been admitted to the hospital and would probably not recover. I was stunned, unprepared for the potential proximity of her death. My first reaction was a strong desire to avoid facing the reality of the situation.

That day, I wrote:

I don't even know what to write about this. I'm feeling sad, of course, but my feelings are so complex that I feel strongly that I don't want to share them in this journal. I don't want to get something out of this for my research.

As the reality of the situation set in, I forced myself to acknowledge my feelings. Later that same day, in my journal, I cycled through shock, denial, feeling unsure of the appropriateness of my reactions, guilt, and anger:

Okay, I'm sucking it up... I am not, at all, prepared to have her at the end of her life already. Maybe she is not, maybe I am jumping to the worst conclusion... I feel like I just started to feel attached to her but at the same time... I am also in emotional limbo. How much is it appropriate to care...? I also have a feeling of nagging guilt because I cancelled my session with [her] last week [because I was sick]... What was the point of shielding her from illness when she is so sick anyway?

Later that day, fear, self-directed anger and self-doubt were my preoccupations: The last day, I've been thinking "why am I doing this?" I could be doing something else. I don't have to put myself in the position to know this stranger, to be attached to a child who is going to die. It may not be right away, but [I'm not being] fatalistic. It's realistic. And not in a broad, existential way, either. This



child is going to die soon. I've put myself into a position where I am caring in a hopeless situation.

Why would I do this? I asked that question [in group supervision] today, and somebody said "it's because you're nice." Frankly, I could be nice and not doing this... So why am I drawn to work so closely with death...? I think it has to do with a really deep-seated fear of suffering before dying. Maybe I am getting close to the suffering as a way to normalize it. I am bothered by the fact that, although we all die, we never see people dying. We shun them because we fear them. I don't want to be shunned.

This self-exploration sparked a deeply personal realization about why I have chosen to work in this field:

I identify with these sick children because they are the ultimate social pariahs-- and as a child, I was [ostracized by my peers]... Maybe by spending time with children who everyone is afraid to spend time with, I am repairing the wounds of my childhood trauma.

Two weeks later, the client passed away. Her death coincided with some worrying personal news about the health of an extended family member. I quickly learned that it is not possible to compartmentalize my working life from my personal life. Traumatic events in my personal and professional lives became emotionally convoluted. The news of my family member's illness came closely on the heels of learning about my client's death and:

I was levelled. All day Tuesday, I felt undefined emotional pain. Tears welled up over and over, yet I could not let them go, lose control... I was already exhausted when I got the news. I simply did not have the emotional resources to deal with it.

Over the next few days, I learned the importance of self-care. I reordered my priorities, delaying those academic responsibilities that could be set aside and spending relaxed time with my family. My impulse was to retreat into my private life but this was balanced with a sense of responsibility towards the families I was seeing in my professional life:

At the end of my life I will not regret it if it took me longer to get through school, or if I got B's instead of A's. It will be important if I can look back and say, I helped people in their families to make them better, more peaceful. I deserve that gift, too. The most important thing in my life is my relationship with [my husband]. That is the building block of the family we will have.

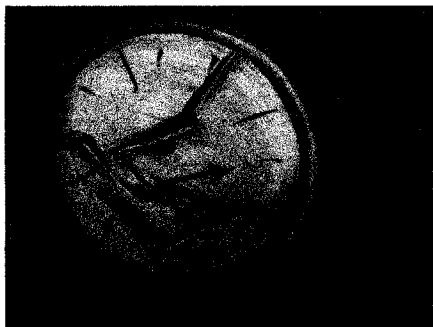
I was also concerned about the ambiguity of my professional role now that my client had passed away:

I wish that [the client] and I had had more time together, to know each other better and build a more solid relationship... Then maybe my role would not seem so ambiguous... Since so much of what happened between us was undefined in her life, it's not surprising that it is ambiguous after her death as well. What is my role now?

Days later, frustrated anger was a pervasive emotion:

I hoped for a miracle - a movie-magic transformation to a long and happy life for [my client]. It was not to be. One of the hardest things to acknowledge here is the

bleak reality of the world... There is nobody to be angry with, no one to hate, to fight against... This is so unfair. It's disgusting. [My client] was so normal - she was just a regular kid.



*Figure 11: Broken Clock*

Time was a theme that emerged over and over in my thoughts. A drawing of a broken clock (figure 11) symbolizes the fragility of life. It also reflected my feeling of that time that I was always hurrying, too pressed for time to enjoy my life. I felt like there was not enough time to know my clients, to know

myself, to know my family. My life was defined by the rigours of time. I felt like I was running a losing race.

I can never get enough time. Time is the source of my stress, of my fears, of my sadness. I don't have enough time. What if I don't have time to do it all? What if time runs out? Time will run out.

Attending the funeral, combined with intense individual supervision and personal counselling, provided some closure to my immediate grief. Seeing my client's parents surrounded by extended family and friends also allayed concerns I had for their welfare. Observing the large number of children who attended the funeral also brought to the surface a latent memory of the death of a schoolmate when I was a child. I was strangely comforted by the reminiscence. I wrote:

I hardly knew that boy. Really, he was just a name and a face at the time.

Probably, if he had lived, I wouldn't even remember him at all--since he died, he

has been indelibly marked in my memory... For some children, [my client] will be [the child who marks them]. She'll never be forgotten by them.

Attending the funeral helped me reconnect with my own spirituality. That the mass was conducted in the religion of my upbringing spurred reflection on how my spiritual beliefs have evolved since childhood. I recognized my own resilience, the "spirit, soul--that thing inside of me that brings strength and joy." Immediately after the funeral I was exhausted, but felt surprisingly liberated. The ritual of closure furnished me with a well-defined, appropriate role to fulfill, which gave me an outlet for my ambiguous feelings of grief. The funeral provided an outlet to grieve for all of the sick children I was seeing.

*Personal mortality.*

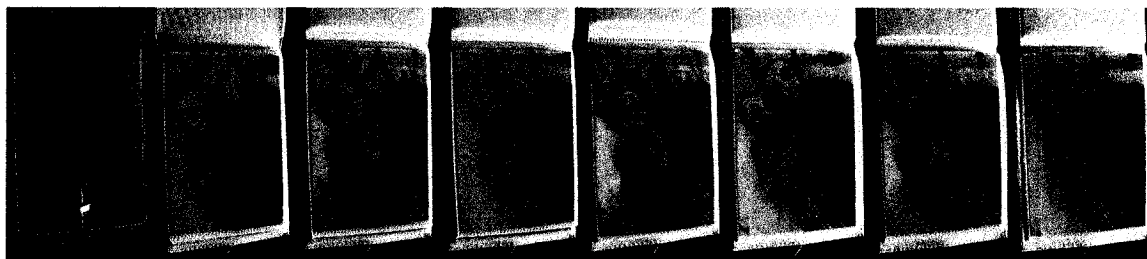
I achieved some closure for my grief through attending my client's funeral, supervision, self-exploration, and personal counselling. However, my existential concerns and new awareness of my life's priorities persisted. Of course I continue to feel sadness and anger about her death, but the immediacy of those emotions was tempered by finding appropriate outlets for them. While I was, on one hand, adjusting to a new, tenuous conception of life, and dealing with it head on, I was also struggling with a (not life-threatening) chronic illness that is exacerbated by stress. I learned to understand my symptoms as a manifestation of anxiety and to react to it as an alarm, cautioning me to evaluate my priorities on a daily basis, balancing my responsibilities and the demands of others with my own need to care for myself.

As time went on, I came to the realization that the work I was doing to understand my reaction to my client's death was changing my relationship with death altogether. I



*Figure 12: The Quilt*

began to focus on the entire life cycle, from birth until death. In “The Quilt” (figure 12), I unconsciously explored my own birth and death. My original intention was to depict my great-grandmother’s hands swaddling me as a newborn. In the art-making process, however, I realized I was unwittingly giving the piece more depth of meaning. First, I drew a portrait of myself as a newborn. Next, I sketched in the position of the hands, using my own hands as models. Once this was done, I set about aging those hands. I realized in the process that this too was self-portraiture. The process was strangely comforting, and I became entranced by the beauty of the gnarls and whorls on the old skin. Gauging the reaction of the audience when the finished drawing was presented, however, I had to come to terms with the fact that this beauty was not the most emotionally arresting element in the work. While the viewers interpreted the work as an ominous foreshadowing of death, I see it as an expression of the natural human curiosity to demand: what came before birth, and what will come after death?



*Figure 13: The Appleheads*

A second artwork, entitled “The Appleheads” (figure 13) is a more light-hearted effort to explore the life cycle. It represents, perhaps, a desire to move away from fear of mortality, towards a focus on what is important during life. The work consists of a series of eighteen photographs, presented in a small leather photograph album. The photographs

depict two handmade dolls. Their bodies are made of stuffed flannel, their heads are carved apples. The photographic series shows the slow decay of the apples. The dolls, a man and a woman, symbolize an ideal aging process, one which I hope to enjoy with my husband. Although they are decomposing, they become both uglier and more aesthetically pleasing over time. They rot at approximately the same rate, leaning into one another in an intimate and supportive pose. The work represents my hopes for a long and fulfilling life.

*Finding meaning in home.*

A newfound respect for my own need for personal regeneration ignited an exploration of the meaning and function of home. Home was a recurrent theme in my artwork. "The Quilt," (figure 12), helps to illustrate the depth of meaning imbued in the objects that surround me in my home. An article by Shawn McNiff (1995), who posits that physical objects can be imbued with special, spiritual significance, was the impetus for the investigation. He says that *ensouled things* are sacred carriers of memories. Testing his ideas, I began to journal about the objects that surround me in my own living room. After filling pages with memories associated with the people who loved, owned, used, or gave me the objects in my surroundings, I realized that my home is imbued with the presence of my social ecology. "The Quilt" depicts one such object: a quilt that was made for me by my great grandmother when I was born. The drawing depicts the many levels of meaning I associate with that loving, intergenerational act. Whether I call this sacred, meaningful, or simply comforting, it is clear that home is more than a geographical place where I rest my head. My psychological history and the physical environment that I have created are inextricably tied together.

What are the ramifications for this in the home-based therapy situation? If my home is so richly imbued with spirit, are my clients' homes similarly emotionally complex? This is an area I never explored in therapy. In a self-dialogue, I questioned why I was reticent to do so. The most obvious reason was fear of intrusion and difficulty raising the topic.

I already feel like an intruder into the lives of my clients and their families. To some extent, I think I unconsciously try to avoid prying unnecessarily into the lives of my clients. To call attention to the physical surroundings of the family uninvited feels like an unnecessary intrusion and seems disrespectful... And it's a subject that I don't quite know how to broach. We're really not trained for this.

What do I say?

Another factor was the therapeutic frame. While its creation was absolutely necessary for the establishment of an emotionally safe space in which the therapy could occur, its physical boundaries made forays outside of it difficult.

Clients are generally enthusiastic about the art-making and I don't know how to shift the focus away from this towards the surroundings in the home... Thus far, I have been working really hard to separate, in a physical and psychological way, the therapy from the home environment... I've never turned my effort on its head to examine the negative ramifications of that frame. It has never occurred to me that I could selectively reach outside of it to broaden the scope of the therapy.

The exclusionary therapeutic frame functioned to provide me, as well as the client, with a psychological safety. While the physical environment that I created in the family homes limited the amount of information coming in from the surrounding

environment, it kept me from feeling overwhelmed. “My fear is that, by becoming more flexible and paying more attention to the environment in which the therapy is taking place, I will be bombarded with more information than I can handle as a therapist.”

In my journal, I also explored the significance of home as an idealized, psychological construction:

Home goes beyond being a place. It is an internal state... I know I idealize this cottage of mine when I am not in it... The home in my imagination is perfect and wonderful. All of my time there (in my nostalgic reminiscence) is spent curled up in front of a roaring fire with a mystery novel and playing scrabble with [my husband]. This musing has relevance for my cross-cultural [client who] longs for her birth country. Her memories of home are, most probably, no more accurate than mine of [my cottage].

I concluded that the images I include and exclude from my idealized idea of home are particularly illustrative of my character and identity. For some people, their ideal picture of cottage life might include swimming, sunbathing, or frequent visits from friends. Others may even fondly remember small wildlife such as mice, bats, squirrels or frogs. That these don't constitute my immediately accessible vision of my home says something important about my values and identity. The way I reminisce about the cottage also illustrates how I see myself. My vision of home reflects my vision of self.



## Conclusion

### *Avenues for Future Research*

This research paper represents an initial foray into the field of enquiry. My goal was to furnish the reader with a detailed first-person description of the experience of being a home-based art therapist working with seriously ill children and their families. I refrained from making judgements on the efficacy of such a program, focusing instead on the flexibility and sensitivity required to carry it out. It remains to be seen, in future research projects, whether navigating the minefield of challenges inherent in establishing and maintaining such a program is warranted. Studies that explore the generalizability of certain aspects of my experience, as well as those that address the client outcomes of the in-home art therapy program, and those that engage in cost-benefit analyses, are the logical next steps in the inquiry.

### *Synthesis*

To synthesize the experience of the past year is difficult. Writing this work has been both a means of reliving the experience and of laying to rest its more difficult aspects. Reviewing what I have written, I realize that the negative characteristics of my experiences during the past year speak perhaps more loudly than the positive experiences. This is partly due to ethical constrictions. When I undertook to do heuristic research, I made the decision to, as much as possible, omit any particulars about my clients from the text. The clients and their families, however, were my great motivating force. Braving yet another snowstorm, I knew that I would see smiling, welcoming faces when I arrived at my destination. Dealing with feeling like an intruder, and having the therapeutic space intruded upon, were challenging experiences; connecting with children, laughing and

playing with them, was pure joy. Although negotiating with the families of my clients and accommodating their needs was sometimes taxing, learning to do so has made me a better, more flexible and more sensitive therapist. It has given me a broader perspective that can only be beneficial to future clients. The death of a client was, perhaps, the most difficult aspect of my experience. Going into my practicum, I feared that I would be scarred by the death of a child. Surprisingly, the tragic event was not traumatizing. Instead, it provoked a deeply significant personal exploration that has allowed me to explore and heal childhood wounds, and to evaluate what is important in my life. Continuing this journey of self-discovery, I hope to become a more peaceful, gentler, and human being.

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