

**Singing, background music and music-events in the communication between persons
with dementia and their caregivers**

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Stockholm 2003

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“Nu är det viss jag som sjunger för honom,
sjunger honom tillbaka i vårt levande förflutna.
E ser på mig och ler - om åt min iver
eller mina falska toner vet jag inte.
Men plötsligt börjar han sjunga själv:

En herde spelar på sin flöjt om kvällen
Och flöjten vänjer sig och låter bra.
Och regnet faller ner på vissa ställen
Och marken vänjes vid vad den ska ha...

Vi ser varann i ögonen och gråter visst båda.
Det var så länge sen.”

Ur Ulla Isaksson (1994): Boken om E.

”Later, we listen to carols and Christmas music. And I have the illusion, which fortunate Alzheimer’s partners must feel at such times, that life is just the same, has never changed. I cannot imagine Iris any different.“

Ur John Bayley (1999): Elegy for Iris.

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Abstract

The overall aim of this thesis is to illuminate the impact of singing and music on persons with dementia and their caregivers, and to describe a concept based on caregiver singing. The aim of **Study I** was to illuminate the importance of music events and the reactions and social interactions of patients with dementia or suspected dementia and their caregivers before, during and after such events, including the remainder of the day. The ethnographic method was used. Patients displayed the ability to sing, play instruments, perform bodily movements and make jokes during the music events. While singing familiar songs, some patients recalled distant memories, which they seemed to find pleasurable. During and after the music events, the personnel experienced a bonding with the patients, who seemed easier to care for. In **Study II**, the aim was to examine the employment of active music-making by caregivers during the course of their actual caregiving activities, focusing on verbal communication. The phenomenological-hermeneutic method was used. In the absence of music, patients communicated with cognitive and behavioral symptoms associated with dementia. During caregiving activities, the caregivers devoted their verbal communication to narrating and explaining the activities to the patients. However, the patients and the caregivers had difficulties understanding one another. When background music was playing, caregivers reduced their verbal instructions and narrating, while the patients communicated with an enhanced understanding of the situation, both verbally and behaviorally. When caregivers sang to the patients, a paradoxical influence was observed. Despite an evident reduction in the amount of verbal narration and description by the caregivers, the patients tacitly understood what was going on. In **Study III**, the aim was to illuminate the movement and sensory awareness characteristics of persons with dementia and their caregivers during usual morning care sessions, morning care sessions with background music playing, and morning care sessions in which caregivers sang to and/or with patients. Qualitative content analysis was used. It revealed that during the usual morning care session, patients exhibited slumped posture, sluggish and asymmetric motion, listlessness, minimal awareness of both their egocentric and physical environment, and a poor ability to perform activities necessary for personal care to completion. Both background music playing and caregiver singing had a strong influence on body and sensory awareness. Particularly during caregiver singing, patients displayed straight posture, strong and symmetric movements, and greatly increased sensory awareness of themselves and their environment. In **Study IV**, the aim was to illuminate vocally expressed emotions and moods between caregivers and persons with severe dementia when caring for patients during usual morning care sessions, morning care sessions with background music playing, and morning care sessions in which caregivers sang to or with the patients. Qualitative content analysis was conducted. Emotions/moods and vitality were interwoven. It sounded as if the patients regained vitality when listening to music and caregiver singing. In one group, positive emotions were dominant from the start and were enhanced when listening to background music and singing. Between one caregiver and patient, negative emotions and moods were dominant from the start and intensified during music listening and caregiver singing. **Study V** is a description of an active way of singing by caregivers, and patients are invited to sing along, but they can also respond in a receptive way and just listen to the singing. Conclusions: Listening to background music and particularly caregiver singing had a positive influence on the patients and caregivers.

Keywords: background music, caregiver, caregiving, concept, dementia, emotion, mood, movements, music events, patient, singing, sensory awareness, verbal communication

Original Studies

This thesis is based on the following five studies, which will be referred to in the text by their Roman numerals:

- I Götell, E., Brown, S., Ekman, S-L., (2000) Caregiver assisted music events in psychogeriatric care. *Journal of Psychiatric and Mental Health Nursing* 7 (2) 119- 125.
- II Götell, E., Brown, S., Ekman, S-L., (2002) Caregiver singing and background music in dementia care. *Western Journal of Nursing Research* 24(2) 195-216.
- III Götell, E., Brown, S., Ekman, S-L. The influence of caregiver singing and background music on posture, movements and sensory awareness in dementia care. *International Psychogeriatrics* 2003 (in press).
- IV Götell, E., Brown, S., Ekman, S-L. The influence of caregiver singing and background music on vocally expressed emotions and moods in dementia care. (manuscript).
- V Brown, S., Götell, E., Ekman, S-L. (2001) "Music-therapeutic Caregiving": the necessity of active music-making in clinical care. *Arts in Psychotherapy* 28 125-135.

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Abbreviations

AD	Alzheimer's disease
BPSD	Behavioral and Psychological Symptoms of Dementia
DNAT	Dementia of non-Alzheimer Type
MMSE	Minimal Mental Status Examination
RN	Registered Nurse
SCU	Special Care Unit
VaD	Vascular Dementia

FOREWORD

A glance at my pre-understanding

In 1984, I worked as a registered nurse (RN) on a long-term care ward with mostly elderly patients. Many of the patients were, as we said, “senile”. Perhaps most of them would have been diagnosed with a dementia disease if that had been possible then. The head nurse was in favor of any kind of intervention that might stimulate the patients. For example, she had introduced memory stimulation for the patients led by a “study circle” leader, and social dancing for the patients and the personnel. A band played dance music for one hour every other week, and the combined living/dining room of the ward was transformed into a dance floor. It was wonderful to dance with the old patients, and to see them dance along with the staff, which consisted of mostly young women and men. I have always enjoyed singing, and I have a large repertoire of popular sing-along songs and folk songs. I asked the head nurse if she thought it would be a good idea for me to sing along with the patients. She agreed, and one morning after the patients had had their breakfast, I sat down on a chair in the living/dining room and started singing. I noticed that it had a dramatic influence on the patients. Some of them came running into the room immediately and wanted to sing along. This seemed amazing, since many of them usually had difficulties finding their way on the ward. Apparently, my singing helped them to find the room I was in. For many more mornings after that, the rest of the personnel and I organized sing-alongs in the living/dining room for the patients. I also remember some patients who were shy and afraid to leave their rooms. When they heard the singing, they asked their caregivers to help them get dressed quickly so they could go to the living/dining room and sing. After the singing, those patients stayed for lunch in the same room—something they usually declined to do because they were scared.

In 1984, I didn’t have a clue that many years later I would be given the opportunity to do research on music and singing in everyday dementia care. I am a registered nurse with some experience in dealing with the difficult issues of communicating with persons with dementia, however, I have few skills and no formal education in music and singing.

INTRODUCTION

Dementia diseases and treatment

In Europe the prevalence of dementia is around 0.8 percent in the group age 65-69 years, and 28 percent at the age of 90 and older (Lobo *et al* 2000). Further, in Europe, the number of people with dementia in 2000 was 5,649,304. Of these persons, 131,643 lived in Sweden, and in 2010 the approximate number of persons having dementia in Sweden will be about 200,000 (Alzheimer Europe, 2000). It is estimated that more than 70 conditions cause dementia in the elderly. The most common is Alzheimer's disease (AD), which strikes about 50 percent of all persons with dementia. Vascular dementia (VaD) affects about 15-20 percent of the patients. Persons with combined AD and VaD account for about 20 percent. The prevalence of persons with Lewy body dementia is estimated to be as high as 20 percent (Bains, Birks & Dening, 2003). All dementia diseases are progressive: in the beginning they have a mild impact on the affected person, but they progress moderately as time goes by, with the final stage being severe dementia where the person needs to be cared for day and night—in many cases in a nursing home (Wimo, Ljunggren & Winblad, 1997).

Persons with dementia display general symptoms: memory impairment, aphasia (language impairment), apraxia (impaired ability to carry out motor activities despite intact motor function), agnosia (failure to recognize or identify objects despite intact sensory function), and disturbances in executive functioning (planning, organizing, sequencing, abstracting) (DSM-IV, 2002). Other frequently occurring dementia symptoms have been defined as BPSD - behavioral and psychological symptoms of dementia (Finkel, 1996). These symptoms are normally identified by observations of patient behavior, and are comprised of aggression, screaming, restlessness, agitation, wandering, culturally inappropriate behaviors, sexual disinhibition, hoarding, cursing, and shadowing. In families caring for loved ones with dementia and BPSD, such symptoms burden the daily lives of the family members (*ibid*).

Finding strategies or activities that may prevent the risk of developing dementia is a major public health concern. Verghese *et al.* (2003), suggest that leisure activities such as reading, playing board games, playing musical instruments and dancing are associated with a lower risk of developing dementia. Currently, there are no cures for dementia diseases. However, AD patients with mild to moderate symptoms can be treated with cholinesterase inhibitors that can be effective on cognitive and behavioral symptoms, and patients tolerate these drugs

satisfactorily (Gauthier *et al.*, 2002). Fifty percent of all persons with dementia are diagnosed with AD, but the remaining dementia sufferers are presently left without pharmacological treatments for their symptoms. To relieve the symptoms of BPSD in these patients, and to ease the burden on caregivers, medical treatment with antipsychotics, anticonvulsants, and antidepressants are clearly indicated (IPA-online, 2003a).

Despite the fact that pharmacotherapy is indicated, it is suggested that other kinds of therapies, so-called non-pharmacological treatments, be used to help persons with dementia to live their daily lives, in order to achieve as good a sense of well-being as possible (Herrman, 2001; Bartels *et al.*, 2002; Gräsel, Wiltfang & Kornhuber, 2003; IPA-online, 2003b). Such therapies can include communication between patients and caregivers through environmental interventions, exercise, sensory stimulation such as massage, therapeutic touch, aromatherapy, enhanced social interactions, pet therapy, and listening to music (Forbes, 1998; Opie, Rosewarne & O'Connor, 1999; Finnema *et al.*, 2000). Looking exclusively at music, Aldridge (2001c) argues that music therapy provided by a music therapist, and the use of music by family and professional caregivers are potentially important non-pharmacological approaches.

Communication in caregiving

The word *communication* comes from the Latin word *communicare*, which means, “to make common” (Your Dictionary, 2003). According to Watzlawick, Beavin Bavelas and Jackson (1967), human beings are always communicating; every communication situation has both a content and a relation aspect, and is interwoven in the individual’s language, gestures, and emotions. In nursing, the relationship between the nurse and the patient is crucial (Rooke, 1995; Kirkevold, 2000). Paterson and Zderad (1988) emphasized the relationship between the caregiver and patient in being and doing. In developing contemporary nursing theories, there is an ongoing discourse that nursing interventions should consist not only of providing care (*doing*), but should also consider *being* with the patient, since this can have a positive influence on the caregiving situation. Furthermore, it is suggested that interventions that include the caregiver being with the patient should be included in nursing research.

Verbal and nonverbal communication in dementia care

In communication between human beings, verbal language is considered crucial. Although persons with dementia have language impairments, their language can be understood, and

caregivers use communication strategies that they think will improve communication with the person suffering from dementia (Hart & Wells, 1997; Acton *et al.*, 1999; Small & Gutman, 2002). Normann (2002) suggests a conversation strategy and finds that a supportive attitude promotes lucidity in dementia patients. This communication style includes supporting patients in various ways, such as supporting the patients' language by repeating and reformulating the patient's remarks, reinforcing them by using positive remarks, sharing the patient's point of view, and avoiding making demands (*ibid*). Another communication strategy seems to be needed when encouraging the patient to take action. To increase patient communication and participation, caregivers should use the necessary prompting and should praise appropriate behavior (Altus, Engelman & Mathews, 2002). But it is also essential to note that despite the fact that caregivers use reaffirming statements and speak more when giving verbal instructions during caregiving situations, such actions might not lead to patients changing their way of communicating (Burgio *et al.*, 2001). There are immigrants in many countries that suffer from dementia diseases. These persons often forget the language of their "new" countries, and revert to their native language. Ekman *et al.* (1993), and Runci, Doyle & Redman (1999), suggest that to help these patients communicate, bilingual caregivers that speak the patient's native language should be engaged in their care, since they understand when the patients are speaking their native tongue, and can be helped to communicate as clearly as possible and to use their latent competence. Even though verbal communication is reported to be crucial, non-verbal communication (gestures and emotions) is also involved in communication. It was found that persons with dementia can communicate non-verbally in interpretable ways, and that they themselves seem to be able to understand the non-verbal communication of other people (Hubbard *et al.*, 2002).

Aggression between persons with dementia and caregivers

Persons with dementia communicate verbally and non-verbally depending on how their disease is interwoven with cognitive decline, aphasia, agnosia, apraxia, and BPSD. One of the ways they may communicate is with violent aggression. Such reactions usually occur in response to intrusions into the patient's personal space by the caregiver. This violence has an enormous affect on the caregiver (Chou, Kaas & Fern Richie, 1996; Brodaty & Low, 2003). According to Åström *et al.* (2002), staff members exposed to violence most dominantly experienced the following feelings: powerlessness, sadness, anger, and insufficiency, as well as exhaustion, stress, burden, and burnout. Additionally, they experienced difficulties in interpreting the patient's wishes, and when the caregivers strained to make appropriate

decisions, it often resulted in ethical conflicts (*ibid*). A caregiver's violence against a family member with dementia was also likely to occur, and enhanced risk situations that could lead to the use of violence in caregiving arose when caregivers were older, had deteriorated health or problems of their own, and felt angry about the burden of caring for the person afflicted with dementia (Grafström, Nordberg & Winblad, 1993; Saveman & Sandvide, 2001).

Caregiver commitment

Research in dementia nursing care has stressed that formal caregivers might have difficulties being committed to persons with dementia. According to Ekman & Norberg (1988) and Ekman *et al.* (1991), caregivers had difficulties understanding the patients' wishes, and they spent less time with them than with patients who were lucid. Edberg, Sandgren & Hallberg (1995), and Hallberg *et al.* (1995), emphasize that nurses become impatient and stressed by a patient's communication problems resulting in a strong task orientation and a decrease in their verbal interaction. Such a communication style seems to increase or decrease a patient's vocal activity. When the caregivers did not keep pace with the patient, cooperation was mainly task-oriented, resulting in acts of resistance, the use of force, loss of attention or turning to others, or the patient wanting to escape. However, when the caregivers kept pace with the patients and employed mutual cooperation, they reacted to each other as persons as well as to the tasks (*ibid*). Even though an abundance of studies confirm that caregivers who manage to have a good relationship with their patients seem to promote good caregiving (Häggström, Jansson & Norberg, 1998; Rundqvist & Severinsson, 1999; Zingmark, Sandman & Norberg, 2002), it is crucial to understand that some problems cannot be solved by caregivers when interacting with patients (Graneheim, Norberg & Jansson, 2001).

Since obstacles involving communication, interaction, and commitment to persons with dementia may arise, dementia care managers should be obligated to educate caregivers in how to keep up their communication skills with their patients. An abundance of studies (Kihlgren *et al.*, 1996; Holst, Edberg & Hallberg, 1999; Rogers *et al.*, 1999; Edberg & Hallberg, 2001; Hansebo & Kihlgren, 2002; Mi Lim, 2003) report that if staff are provided with knowledge of, supervision in, and the opportunity to implement a positive climate and environment, their patients will present a rich pattern of cognitive and emotional reactions and enhanced abilities despite their dementia.

Music and singing

Music can be regarded as a form of communication (Fagius, 2001). When asking people if they are musical, some will deny it. If asked if they enjoy listening to music, most people will agree, if they can choose what music they want to listen to and have some control over the context. According to Ruud (1997), being musical can be defined as “to have cognitive ability where music can create memories, associations and narratives¹”. Such musicality seems to exist in human beings during their whole life span. An infant’s contact with music seems to evoke excitement. Trehub (2000) found that despite the fact that mothers and other caregivers have no way of knowing about an infant’s music perception skills, it is interesting that they provide musical experiences for them that are both accessible and enjoyable. Infants prefer the most universal song form - the lullaby - and the typical performer is a woman singing in an infant-directed style.

Music therapy in dementia care

In an evaluation of research using randomized controlled trials on music therapy and persons with dementia, it was found that no studies were suitable for inclusion according to the criteria of the review (Koger & Brotons, 2000). So, if exclusive acceptance of randomized controlled trials is the research method, then, at present, music therapy cannot be recommended as a non-pharmacological intervention for patients with dementia. Aldridge (2001a-b) argued, however, that music therapy and the use of music show very positive results. They just lack rigorous research methods to capture their benefits. In nursing, use of music is accepted as a useful therapeutic intervention. The research being conducted within this field preferably applies quantitative methodologies. In music therapy research, and use of music research as a whole, other insights on the influence of music may emerge when using qualitative methods (ibid). Additionally, Orb *et al.* (2001) argued that to facilitate best practice in psychogeriatric care, the incorporation of qualitative methodologies could be a step forward in integrating scientific evidence with psychosocial and cultural aspects of human behavior.

When quantitative methodologies were used to capture the effects of music on persons with dementia, certain characteristics in the findings were found. Persons with dementia seemed to have an interesting responsiveness to music, and despite memory loss and aphasia, they

¹In Norwegian: Å være musikalisk betyr å råde over et kognitivt system hvor musikken kan frambringe minner, skapa assosiasjoner og historier (p. 58).

continued to sing old songs, dance to old tunes, and enjoy listening to certain background music (Swartz *et al.*, 1989; Aldridge, 1993, 1995, 2000; Brotons, Koger & Pickett-Cooper, 1997; Snyder & Chlan, 1999). Music therapy influenced them in such a way that they displayed enhanced memory, attention span, social interaction, eye contact, verbal communication, mood, and presented reduced depressive symptoms. It also stimulated mental function and facilitated recall (Riegler, 1980; Pollac & Namazi, 1992; Lord & Garner, 1993; Smith-Marchese, 1994; Ashida, 2000; Gregory, 2002). Brotons & Koger (2000) observed improved performance of both speech content and fluency dimensions in the spontaneous speech of patients with dementia. Brotons & Pickett-Cooper (1996) found that regardless of the musical background of the patients, they were all less agitated during music therapy. Staff members also gave unsolicited reports that after music therapy, the patients acted with reduced agitation, became calmer, were more cooperative and responsive, and even “nicer”. Such changed behavior lasted for the remainder of the day that they participated in music therapy.

Use of background music in dementia care

According to Glynn, 1992; Gerdner & Swanson, 1993; and Gerdner, 2000, individualized background music preferred by patients with dementia will reduce their agitated behaviors. Formal caregivers have even reported that individualized background music seems to be an underestimated intervention, as it can make the patients less agitated (Ragneskog & Kihlgren, 1997). According to Tabak, Ehrenfeld & Alpert (1997), family caregivers are advised to speak calmly and play familiar background music during caregiving sessions in order to *distract* (emphasis added) their loved one with dementia. Ragneskog *et al.* (1996a-b), and Denney (1997) observed that during mealtime situations, patients were influenced by background music; soothing and quiet music in particular influenced them to become less restless and irritable, and they showed less fear-panic and depressed mood. Additionally, the authors suggest that there may be a favorable influence on the caregivers during the dinner serving situation (*ibid*). During bathing sessions with background music playing, Clark, Lipe & Bilbrey (1998) suggested that patients with AD showed reduced aggression and hitting behaviors, and caregivers frequently reported an improved effect and a general increase in cooperation with the bathing task.

Also, when listening to background music, the facial expressions of persons with dementia were studied. The patients reacted differently to music than to touch and object presentation (Norberg, Melin & Asplund, 1986). Jansson *et al.* (1993), suggest that most patients smiled, looked amused, happy, attentive, and interested, and Ragneskog *et al.* (2001), suggests that two patients became calmer. Jansson *et al.* (1993), and Ragneskog *et al.* (2001), noticed that there were a few persons who were not influenced by the music in a positive way.

Music therapy singing sessions in dementia care

According to Olderog, Millard & Smith (1989), singing is one of the most popular activities for patients with dementia. Almost all patients sang along during a music therapy session with group singing. Even those who rarely spoke would sing. Staff often reported that the patients seemed calmer and expressed an enhanced awareness of the present after the singing sessions (*ibid*). Prickett & Moore (1991) found that patients recalled the words to songs dramatically better than they recalled spoken words or spoken information. When a man with AD who usually communicated with unprovoked aggression sang, he ceased being hostile (Kaser Vaughn, 1993).

Caregiver singing in dementia care

Singing may arouse patients with severe dementia, and singing could therefore be a crucial method of providing a sense of well-being in these patients (Clair, 1996 b, 2000). Clair (2002) wrote that when a family caregiver sang and danced with their severely demented loved one, the two of them had a mutual engagement, which increased over a series of sessions and had a positive influence on the significant others when they visited the patients to just be with them.

Similar anecdotes are reported in clinical experiences of caregivers singing for patients in dementia care. It was even suggested as a method that may help to solve complicated caregiving situations. In 1984, Bolger & Judson reported on a nurse who sang familiar songs while helping a woman with dementia to breathe. During the activity, the demented woman vociferously sang along and cooperated in following the nurse's breathing instructions. Sander (2002) suggested that when helping people with dementia to stand, singing for the patient might alleviate the situation. During bathing, Rader (2002) reported that when a nurse sang with the patient, she was able to wash the patient's entire body. According to the

patient's family, their loved one with dementia had refused to get in a shower or tub for ten years prior to coming to the care facility.

Movement and dance in dementia care

The human body has bilateral symmetry. That is, the body is divided into two equal halves, usually right and left halves that mirror each other. Moving in bilateral symmetry - in the middle line of the body - is the most suitable way for persons to move (Colombia Encyclopedia, 2001). According to Rosberg (2000), when people experienced their body's middle line, they felt more oriented in space, and this middle line was like a mental refinement backbone. When moving, good body balance promoted security and stability, and helped the person to feel emotionally connected to life. When people lost their ability to function in their body's middle line, they became lost in the space (ibid).

Persons suspected of having dementia often display apraxia: the impaired ability to carry out motor activities despite the fact that they have intact motor functions (DSM-IV, 2002). However, current research by Pettersson, Engardt & Wahlund (2002) reports that persons in the early stages of AD have deficiencies in motor performance, and that other functional performances than gait seem to be impaired, since their activities were diminished and their postural control was afflicted.

Dancing is most often done to music. Many people enjoy dancing and relish participation in exercises to music. Healthy elderly people moving to music reported a sense of heightened connection between body and space; they experienced enhanced posture awareness and an ameliorated sense of balance (Teel *et al.*, 1999). It was even suggested that dancing might lower the risk of developing dementia (Verghese *et al.*, 2003). When elderly persons with dementia moved to rhythmic music in group exercise activities, they displayed an overall enhanced involvement (Mark Mathews, Clair & Kosloski, 2001). In dementia care during social dancing, Palo-Bengtsson & Ekman (1997, 2002) reported that dancing to a band playing music that was familiar to the patients was a good stimulus for making social contacts. All patients knew how to execute movements in dancing. Earlier-trained social patterns, old social habits, and general rules seemed to be awakened to life in the patients. Their body awareness, body posture, and physical capacity seemed to increase when they moved and stretched their bodies. It was crucial that the caregivers showed support, creativity,

and spontaneity when dancing with the patients (ibid). In dance therapy, Nyström (2002) reported that persons with dementia seemed to participate to a great extent when concurrently dancing and singing. Groene *et al.* (1998), found that during sing-along sessions and exercise sessions, most patients responded quite well to both, although most of them responded better to exercise than to sing-alongs.

Sacks (1970) wrote an interesting story about a man who mistook his wife for a hat. He was concerned about how the man managed his daily life activities, such as dressing and eating. The man's wife said that her husband could accomplish such activities if he sang at the same time. He sang all the time: eating songs, dressing songs, bathing songs. When he was disrupted and lost the thread and stopped singing, he was unable to recognize his clothes or even his own body.

Emotions and moods

According to Planalp (1999), social life is sometimes described as a fabric, and the emotions are its colors. In research, facially expressed emotions have been in focus. However, vocally expressed emotions are probably equally as important. In research about vocally expressed emotions, people can recognize emotions in each other's voices, and it is known that the voice carries information about whether emotions are positive or negative (ibid). Currently among researchers focusing on emotions, there is an ongoing discourse on how to methodologically capture and define emotions (Planalp, 1999; Greasley, Sherrad & Waterman, 2000; Jasper, 2002; Wosch, 2002; Scherer, 2003). Planalp (1999) describes emotions and moods in process theories and emotions as:

- Emotion - the affective aspect of consciousness having an object and lasting for a limited time.
- Mood - similar spirit/state of mind as emotion but of extended duration and indistinct object.

It has been argued that the personality and general intelligence of people aged 70-100 are crucial to having the ability to experience positive and negative emotions and moods (Isaacowitz & Smith, 2003).

Emotions and moods in dementia care

Although they are affected by BPSD, persons with dementia seem to have an intact emotional system. According to Magai *et al.* (1996), they expressed an intact and functional emotional system. Even during stages of severe dementia, one third of the patients expressed sadness when their relatives left the ward. Additionally, Lavenu *et al.* (1999), reported that persons with dementia were able to understand emotional facial expressions. Powell Lawton, Van Haysma & Klapper (1996) conducted direct observations of facial expressions, body movements, and other cues in order to design an affect rating scale for assessing the emotions of persons with dementia. The positive affects they expressed were pleasure, interest and contentment. The negative affects were sadness, worry/anxiety, and anger (*ibid*). Negative emotions of persons with dementia seem to be difficult for caregivers to experience. Family caregivers living with relatives who have dementia and who display a loss of motivation, apathy and depression, find it increasingly problematic to live with their loved one when she/he reacts with depression (Thomas *et al.*, 2001).

Music and emotions

Music has been suggested as the meeting place of emotions and cognition, and has a mood altering influence on people (Sloboda, 1999). However, when reviewing music and emotions, Vink (2001) suggests that in contemporary research, far-reaching conclusions cannot be made about this relationship. There were too many methodological and theoretical problems to be able to clearly describe this relationship. Vink concludes that studies being conducted have used emotion checklists with fixed categories. There seems to be a clear distinction between the emotions experienced during listening to music and playing music, which is generally ignored in research. The preferred music was classical music without vocals, and most studies focused on the emotions expressed in the music, not the emotions experienced by the listener. The research also lacked information about music's influence on people in day-to-day situations (*ibid*).

Rationale for the study

There are many persons suffering from dementia who currently only have limited options regarding medical treatment to relieve the symptoms of their cognitive impairment and BPSD. In communicating with persons with dementia, many family caregivers as well as professional caregivers conceded that they found it difficult to understand persons with dementia (Ekman *et al.*, 1991; Tabak *et al.*, 1997; Åström *et al.*, 2002). When caregivers find it demanding to communicate with a person with dementia, perhaps it is also challenging for the caregiver to develop a good, caring relationship with them. In nursing, Paterson and Zderad (1988) argued that the relationship between the caregiver and the patient is crucial. Other kinds of treatments than pharmacotherapy were recommended to soothe, or perhaps even to deter difficult behavior by persons with dementia. The use of background music as a nursing intervention has been suggested (Glynn, 1992; Snyder & Chlan, 1999; Aldridge, 2000; Gerdner, 2000). Such interventions were conducted during mealtime (Ragneskog *et al.*, 1996b; Denney, 1997) and bath time (Clark *et al.*, 1998). The outcome of these interventions reported positive influences for persons with dementia since their BPSD decreased. No study was found that investigated whether background music influenced the caregivers. Playing background music is considered a passive way of providing music. There are few studies of caregivers actively participating in music making, such as playing an instrument while singing with patients (*cf.* Clair, 2002).

In this thesis, the focus is on the caregivers and patients in order to reveal if background music, playing a musical instrument, or singing has an influence on them during day-to-day care. The thesis will give a perspective on the influence that music events, background music and singing have on patient and caregiver language, movements and emotions. The results may reveal whether such interventions have any value in the everyday care of dementia patients.

THE AIM OF THE THESIS

The overall aim of this thesis is to illuminate the impact of singing and music on persons with dementia and their caregivers, and to describe a concept based on caregiver singing.

The specific aims of the studies

Study I: To illuminate the importance of music events and the reactions and social interactions of patients with dementia or suspected dementia and their caregivers before, during and after such events, including the remainder of the day.

- **Study II:** To examine the employment of active music making by caregivers during the course of their actual caregiving activities.
- **Study III:** To illuminate the movement and sensory-awareness characteristics of persons with dementia and their caregivers during usual morning care sessions, morning care sessions with background music playing, and morning care sessions in which caregivers sang to and/or with patients.
- **Study IV:** To illuminate vocally expressed emotions and moods between caregivers and persons with severe dementia when caring for the patients during usual morning care sessions, morning care sessions with background music playing, and morning care sessions in which caregivers sang to or with the patients.
- **Study V:** To introduce a new term *music therapeutic caregiving* to describe an active form of music making by caregivers to and /or with patients during course of actual caregiving activities.

METHODS

Qualitative methods

In all research, the aim is to convey new knowledge and develop theories. In qualitative studies, a theory can account for (i.e. thoroughly describe, understand and interpret) a single phenomenon and the researchers often endeavor to develop a conceptualization of the phenomena being studied (Polit & Hungler, 1999; Fridlund & Hilding, 2000; Porter, 2000; Dahlberg, Drew & Nyström, 2001; Karlberg, Hallberg & Sarvimäki, 2002). In many qualitative studies, it is suggested that the focus should be on the everyday experiences of the participants (ibid).

The research settings and design

Table 1. Overview of the different studies, persons, data collection and methodological approaches.

Paper	Persons	Data collection	Methodological approaches
I	Forty eight patients, thirty five caregivers	Participant observations, interviews, document reading,	Ethnographic method
II	Nine patients, five caregivers	Video recording	Phenomenological hermeneutics
III	Nine patients, five caregivers	Video recording	Qualitative content analysis
IV	Nine patients, five caregivers	Video recording	Qualitative content analysis
V	Nine patients, five caregivers	Video recording	Concept description

The data collection was done at two geriatric clinics in an urban area of Sweden. When conducting research in naturalistic settings, it can be difficult to get access to the research site. It is suggested that persons in positions of authority and power introduce the researcher (Mullhall, 2003). In **Study I**, the chief physician introduced the author to the personnel, and the head nurse gave permission for the author to stay on the ward during the time needed to do the data collection. This was done on a ward used for investigations of persons with dementia or suspected dementia. The staff was educated in dementia care. They had organized the ward into a special care unit (SCU) for 28 patients, and the environment was furnished in the style of the 1940s and 1950s. To encourage the patients to use their abilities, the staff invited the patients to participate in daily activities such as setting and clearing the table. The patients were dressed in their own clothes. The staff was dressed in uniforms. The music events being investigated had been an ongoing cultural activity for eight years preceding the study, and were inspired by the music event method suggested by Bunne (1986). Four to eight patients were invited to participate, together with the same number of personnel. The group sat on chairs, with the personnel and patients sitting interspersed. This was done two mornings per week in a dining/living room on the ward. A sociotherapist and an occupational therapy assistant led the music events. The leaders played guitars and all participants played instruments and sang, did exercises, and danced. The registered nurses in charge and the rest

of the staff decided which of the patients and personnel would participate each morning just before the music event was to take place.

In **Studies II-V**, the author was introduced by a registered nurse teacher who had been working at and was conducting research at the clinic. She introduced the author to the head nurse of the ward, and she invited the author to stay on the ward to conduct the necessary data collection. The data collection was done in an SCU with 24 patients having severe dementia. The staff had long experience in geriatric care, and they had furnished the SCU to resemble as homelike an atmosphere as possible. This was done in order to help the patients recognize the environment. To give them a sense of individuality, the patients were dressed in their own clothes, and their rooms were furnished with their own furniture. The personnel wore uniforms. The staff routinely baked bread and cookies in the ward's kitchen. During such activities, they encouraged patients to participate. During and after the baking, the scent of freshly baked bread could be smelled on the entire ward. The SCU had a large dining/living room, where many of the patients spent a good deal of their daily lives. In a central area, there was a large aquarium with brightly colored fish. Additionally, during the daytime hours, two dogs belonging to one of the staff members visited the SCU regularly. The dogs spent their days with the patients and staff in the dining/living room. Patients and personnel walked the dogs together. The data collection for the morning care sessions was done in the facilities connected to the patient bedrooms.

When conducting research on patient wards, Leininger (1985) emphasized the importance of the researcher maintaining her role as researcher during the entire study. When the researcher is an RN, it is easy to slip back into the role of nurse and start performing nursing activities. When doing so, the objective perspective can be lost. The role will then be nurse, not researcher (ibid). When the author prepared for the data collection for **Study I**, it was decided that she should look different from the staff in their uniforms, so she wore her own clothes during the data collection. In that way, the patients probably would not mistake her for a staff member. To identify herself, the author wore a nameplate, which had her first name and surname written in large letters. It also included the title *Assistant Researcher*. In this way, the patients as well as the staff could read her name and understand her reason for being on the ward. During data collection for **Studies II-V**, the author continued to wear her own clothes and the nameplate for the same reasons as in **Study I**.

Data collection in Study I

Ethnographic methods

In **Study I**, the main data collection was done by means of participatory note-taking observations during 35 music events. Each observation occasion lasted about 4-6 hours. A day of observation usually started about one hour before the music events took place, during patient breakfast time. The observations continued during the music events. After the music events, the observations went on for about another two hours. Data collection was also performed using taped interviews lasting between 40 and 60 minutes with the chief physician of the clinic, the head nurse of the ward, and the leader in charge of the music events. The interviews took place in their offices. About 50 pages of unpublished and published documents from the SCU were read. The documents consisted of descriptions of the organization and caregiving philosophy of the SCU. The author also participated in two days of in-service education in the music event method. In total, the data collection took about nine months.

Data collection in Studies II-V

For the first month of **Studies II-V**, the author stayed on the ward in order to get to know the patients and personnel. Also during that time, the head nurse was asked to suggest ten patients and five caregivers who had an extensive history of interaction. She suggested the patients, and helped the author to acquire the necessary written consent from the next of kin or guardian to allow the patient's participation. The author asked the suggested caregivers to participate.

Choice of music

After formal consent was given, the author needed to find out what kind of music to use. In the literature, it is suggested that persons with dementia should listen to music of their own choosing (Glynn, 1992; Gerdner & Swanson, 1993; Clair, 1996a, 2000; Gerdner, 2000). Patients with severe dementia have a diminished ability to speak and answer questions, so interviewing them was not an option. Instead, the author interviewed a relative, or a caregiver if the patient had no relatives. The interviews were conducted in the relative's home, or on the ward when the relative visited their family member with dementia. One patient had no relatives, so the caregiver was interviewed. After that, several CDs with the suggested music were bought, and the author played the music for the patients in the dining/living room. While

listening to the music, they were able to communicate both verbally and with facial expressions as to which music they preferred. They seemed to favor popular songs that they had listened to in their youth, such as music sung by a male singer accompanied by an orchestra. Later, the music was played in the background during one of the caregiving sessions. The author also told the caregivers to sing during one of the morning care sessions. It was suggested that they sing songs they knew, preferably sing-along songs or children's songs. These types of songs and folksongs were sung during the caregiving sessions.

Video recordings

Video recordings have two principal advantages: richness and permanence (Bottorff, 1994; Adomat, 1999; Elder, 1999; Latvala, Voukila-Oikkonen & Janhonen, 2000; Spiers, Costantino & Faucett, 2000). The data's richness is greater than other kinds of data recordings. The recorded data remains the same and it allows the researcher to analyze the data in different ways. Through filming, it is possible to capture in detail interactions in caregiving situations and catch verbal as well as non-verbal communication (ibid). It should therefore be used when conducting research with persons with dementia, as cognitive decline and aphasia hamper their use of verbal language (Ekman *et al.*, 1993; Kihlgren *et al.*, 1996; Hansebo & Kihlgren, 2002; Palo-Bengtsson & Ekman, 2002). Videos can help the researcher to explore and examine the non-verbal communication of persons with dementia. In dementia care research, video recordings of morning care sessions have previously been made to document the interaction between patients with severe dementia and their caregivers (Ekman *et al.*, 1993; Kihlgren *et al.*, 1996; Hansebo & Kihlgren, 2002)

For this thesis, all morning care sessions were videotaped except for one. For technical reasons, one morning care session was documented by means of note-taking alone. A typical morning care session was as follows:

1. Patients sat on the toilet, and their nightclothes were removed.
2. Their faces and upper bodies were washed, and deodorant, skin lotion, and perfume (for the women) or aftershave (for the men) was applied. When patients were naked, only their upper bodies were filmed. When dressed, their entire bodies were filmed.
3. Clothes, socks, and shoes were put on.
4. The patients stood up, were led to the sink (one patient used a wheelchair), and were directed towards the mirror.

5. While at the sink, their teeth were brushed, their hair was combed, and their hands were washed.
6. While facing the mirror, patients were encouraged to look at their image.

The interventions

The first session took place during the *usual morning care session*. This was done to have a start and control situation. The first intervention was *background music playing* while the usual activities took place. The second intervention was *caregiver singing for or together with the patient* while the usual morning routines were carried out. The schedule of the three sessions varied due to the patients' state of health and ability to participate as well as the caregivers work schedules. The second session (i.e., background music) occurred, on average, 3 days after the first (1-27 day range). The third session (i.e., caregiver singing) occurred, on average, 9 days after the second (1-21 day range). Thus, the average observation period for a patient was 13 days, but varied between 3 and 49 days.

After the videotaped morning care sessions, the caregivers were interviewed with an audio tape recorder about how they experienced the sessions. Later the same day in a staff room, the caregiver and the author watched the video, and once again the caregiver was interviewed to be able to change or add something to her experience. The caregiver was also interviewed in order to obtain personal data and their professional caregiving experience. Only in **Study II**, the interviews were part in the results. The data collection period lasted about five months.

Participants

Study I

In **Study I**, an opportunistic sampling strategy was used. The available participants guided who would participate; such sampling is typically used when ethnographic methods are utilized (Patton, 2002). Forty-eight persons with dementia or suspected dementia, between the ages of 43 and 90, participated in the study. Thirty-five were women and thirteen were men. Among the personnel, 33 women and 2 men participated. Their ages were not known. So, a total of 83 persons participated. The staff job titles consisted of licensed practical or mental health nurse, nurse's aid, RN, physiotherapist, occupational therapist, teacher, and students of these professions. See Table 2.

Table 2. Participants in the music events of Study I.

	Women	Men	Total	
Personnel	33	2	35	
Patients	35	13	48	
Total	68	15	83	

Studies II-V

In **Studies II-V**, a purposeful sampling was used. In such sampling, participants give rich and in-depth information that illuminates the research questions of interests (Patton, 2002). Ten patients with severe dementia between the ages of 80 and 90 were chosen. One of them dropped out, as she did not want to be filmed. So, nine patients participated throughout the entire data collection process; seven of the patients were women and two were men. They were all native Swedish speakers. The patients scored between 0 and 4 points on the Mini Mental Status Examination (MMSE), a cognitive test invented by Folstein, Folstein & McHugh (1975). They had been living on the ward from 1 year and 4 months to 5 years and 9 months. According to their medical records, one of them was diagnosed with AD, and the other eight had been diagnosed with dementia of non-Alzheimer's type (DNAT). Regarding their musical background, they all enjoyed listening to music and dancing. At least five of the women had sung for their children when they were small. One had played the guitar and sung in public, and one had sung in a choir. Their names are assumed. All patients participated once in each morning care session and interacted with the same caregiver for all three sessions. See Table 3.

Table 3. Patients in Studies II-V.

Patients	Age	Diagnosis	MMSE	Living in SCU
Leif	84	DNAT	4	1 y. 4 m.
Nora	90	AD	0	5 y. 9 m.
Olga	85	DNAT	0	3 y. 3 m.
Peggy	80	DNAT	0	3 y. 3 m.
Rune	81	DNAT	0	3 y. 1 m.
Svea	81	DNAT	0	3 y. 5 m.
Tora	89	DNAT	0	3 y. 2 m.
Ulla	84	DNAT	0	4 y. 4 m.
Vera	85	DNAT	0	2 y. 7 m.

The caregivers were five women educated as licensed practical or mental health nurses. Their ages were between 20 and 39. They had been working in geriatric care for between 2 and 19 years. They all spoke Swedish fluently. One had Spanish as her mother tongue. None

of the caregivers had listened to music or sung during morning care sessions prior to the study. Regarding their musical background, they all enjoyed listening to music and dancing. As for singing, one of the caregivers had sung in a choir, the rest of them sang at birthday celebrations or hummed to themselves. The names of caregivers are assumed. Four of the caregivers participated twice in each session, that is, they cared for the same two patients in the three morning care sessions. One caregiver participated with one patient, as the second patient she was supposed to care for did not want to be filmed. See Table 4.

Table 4. Caregivers in Studies II-V.

Caregiver	Age	Experience with Elder care (years)
Anna	31	10
Birgit	20	2
Cecilia	33	12
Doris	25	8
Elsa	39	18

Data analysis

Ethnography

The ethnographic method was used in **Study I**. Nursing research defines ethnography as a “systematic process of observing, detailing, describing, documenting and analyzing the lifeways of particular patterns of a culture (or subculture) in order to grasp the lifeways or patterns of the people in their familiar environment” (Leininger, 1985, p. 35). The methods can vary depending on the study’s research aims. There are guidelines to get ideas from, but the researcher has to design each specific study (Sidenvall & Fjellström, 2000).

After the author had been on the ward for about six weeks and the pattern of caregiving routines as well as patient and caregiver characteristics in their interactions and communication emerged, particularly during the music events, it was decided that the ethnographic method should be used for **Study I**. During the music events, recurrent patterns were noticed that became major themes of the different parts of the music events. All of the data collected was interwoven in the study.

Phenomenological hermeneutics

In Study II the phenomenological-hermeneutic method was used. This method has been developed at the Department of Nursing Science at Umeå University, Sweden and The Department of Nursing Science at the University of Tromsø, Norway (Lindseth *et al.*, 1994). The method is continuously being developed and has been used in other nursing research projects (Nilsson, Sarvimäki & Ekman, 2000; Ebbeskog & Ekman, 2001; Hansebo & Kihlgren, 2002). Norberg (2003), who is one of the researchers developing the method, states that they got their inspiration from the philosopher (Ricoeur, 1976). They suggest using this method when trying to reveal the meaning of a text. The method consists of three steps. The first step is *the naïve reading*, which involves reading the text several times in order to look for things that concern her/him. In this step, a naïve interpretation of the whole is made that is clear and focused and can be used as a guideline in the second step: *the structural analysis*. This analysis validates the first interpretation, preferably using a thematic analysis. When analyzing the text, it is divided into meaning units that are then condensed. In the third step, *interpretation of the whole*, the naïve reading, the structural analyses, and the formulated themes are summed up and reflected upon.

In Study II, the verbal communication from the three morning care sessions was transcribed from the videos. The text was read several times and a *naïve first interpretation* was done. In the structural analysis, the verbal communication was divided into meaning units. In this case, the meaning units consisted of particular caregiving routines (e.g., when washing the face, what did they say and do). The meaning of the verbal communication was condensed, and sub-themes were formulated. The sub-themes were summarized and themes were formulated. In the third step, *interpretation of the whole*, the themes were deepened and more widely understood. During the entire analysis, the videos as well as the transcribed text were used.

Content analysis

In Studies III-IV, qualitative content analysis was conducted: a methodology for describing the content of data as objectively and systematically as possible (Morgan, 1993; Berg, 2001). The method has a manifest component, which is comparable to the surface structure in the message, and a latent (qualitative) component that is the deep structural meaning conveyed in the data. When conducting qualitative content analysis, researchers should offer detailed excerpts from relevant statements that serve to document the researcher's interpretation (Berg, 2001). This method has been used in geriatric nursing research by Hansebo & Kihlgren

(2000), Hertzberg (2002), and Randers & Mattiasson (2000). A tripartite structure was used, i.e., movement between whole–part–whole, when analyzing the data and formulating the sub-themes and themes. Additionally, a constant comparative analysis was conducted (Hewitt-Taylor, 2001). When conducting the analysis, the videos as well as the transcribed texts were used. In **Study III** patient and caregiver movements, actions and senses were analyzed, and in **Study IV**, the emotions and moods expressed by patients and caregivers during the morning care sessions were analyzed.

Development of a concept

In **Study V** a new concept was described. Concepts are the foundation for theory development in all science, and concept analysis must be based on rich and comprehensive data. According to Morse *et al.* (1997), when conducting a concept analysis based on qualitative methods, the descriptions must be comprehensive and detailed. The research must be logical, rigorous, and creative with a clearly developed and systematic presentation of the results. Additionally, the results should make a contribution to current knowledge and the findings should make intuitive sense, in that they are recognizable, yet appear innovative. New concepts should provide new insights into phenomena and lead to new areas of research by permitting the identification of empirical questions and facilitating inquiry (*ibid.*).

In the process of naming the concept described in this thesis as *music therapeutic caregiving*, a semantic analysis was conducted:

- *Music*: Vocal or instrumental sounds possessing a degree of melody, harmony and rhythm. Origin from the Greek *mousike* or *muse*, and in Greek mythology any of the nine daughters of Mnemosyne and Zeus (Your Dictionary, 2003). The muses were goddesses of singing, music, poetry, and learning (Nationalencyklopedin, 2003).
- *Therapeutic*: Having or exhibiting healing powers. Origin from the Greek *therapeuein* - to serve, administer and treat (Your Dictionary, 2003).
- *Caregiving*: From the Old English *cearu*. A caregiver is described as an individual, such as a physician, nurse, or social worker, who assists in the identification, prevention, or treatment of an illness or disability (Your Dictionary, 2003).

When describing and analyzing the concept *music therapeutic caregiving*, the findings of **Studies II-IV** were focused on. However, to describe and understand the phenomenon in depth, an interdisciplinary literature review was conducted.

Ethical considerations

Persons with dementia have the ability to take part in decision-making regarding participation in interventions and research projects (Dewing, 2002; McCormack, 2002; Moore & Hollett, 2003). In **Study I**, the author informed the patients that a study was being conducted to investigate the music events on the ward. The caregivers participated of their own free will, but also participated in the music events as a requirement of their job duties. In **Studies II-V**, the patients had diminished linguistic abilities and a diminished ability to sign forms if they wished to participate. Therefore, the patient's next of kin or guardian was asked for permission (Sverne, 1998). A written informed consent was obtained from them. The caregivers were asked by the author to participate. Confidentiality is guaranteed, since fictional names are used in the thesis, all data has been kept confidential, and only the research team has had access to it. The security of the data was assured by locking it in a filing cabinet. The Regional Research Ethics Committee at Huddinge University Hospital, Sweden, approved all the studies (Protocol numbers 239/95, 246/96, 106/03).

FINDINGS

Music events

In **Study I**, most of the patients and caregivers participated once or a couple of times. On almost every occasion (34 out of 35 events), patients left before the music event started or at the beginning of the event, and at times other patients joined in. During the music events, personnel participated and facilitated patient singing, playing simple instruments, exercising, dancing, and talking about the current season of the year. When the group sang familiar songs, most patients seemed to enjoy singing, and some of them expressed that they experienced the return of some distant memories. Occasionally, personnel and patients who were foreign-born and raised outside of Sweden participated. Many of them seemed to enjoy participating, but they were unable to sing along. Sometimes these patients sang a song in their native language. While exercising, many patients said it was fun, and often times they laughed and expressed their sense of humor. Personnel and patients danced in pairs. When helping the patients to recall the current season, items such as berries, flowers, leaves, illustrations, and photos were used. A music event lasted for roughly 40 minutes. The music leaders had determined that the patients had enough strength for approximately that length of participation.

Directly after the music events, the patients seemed to exhibit an enhanced attention span, and seemed to be full of vitality and fun. About 15 minutes after the music events had concluded, however, the patients had usually forgotten that they had participated. As for the personnel, they experienced that the participating patients were easier to care for since they became calmer and happier—moods that lasted for several hours or even for the rest of the day. The personnel also felt that something happened inside them. When interacting with the patients during music events, the staff experienced a deepening of feelings for the patients. They felt that the dividing line between themselves and the patients was eliminated, and that a spirit of togetherness and bonding had developed. The personnel felt they had something in common with the patients, which they were able to capitalize on in other contexts. Hence, for the personnel, the music events created connections and new dimensions in their relationships with the patients, which lasted long after the music events ended.

In **Studies II-IV**, results will be reported as the characteristics of the perspectives on verbal communication, body movement, sensory awareness, and vocally expressed emotions in each morning care session (i.e., the usual morning care session, with background music playing, and with caregiver singing). An overview of all the subthemes and themes in **Studies II-IV** are displayed in Table 5.

Table 5. An overview of the subthemes and themes formulated in Studies II–IV

USUAL MORNING CARE SESSIONS							
THEMES	Caregivers toil to create a comprehensible situation for the patients	Balance and sensory awareness	Physical strength, body symmetry	Use of space	Caregiver helping patients to live in their bodies	Emotions/moods and vitality contribution	
SUBTHEMES	Caregivers' understanding of confused patients Caregivers' understanding of mute patients Caregivers' understanding of resistant patients Caregivers' understanding of screaming patients	Flaccid, unbalanced bodies with subdued awareness	Physical weakness, asymmetric and fragmented actions	Living in a limited space	Helping patients living in stiff, unbalanced, bodies	Dominance of positive emotions and moods in varying vitality	Dominance of negative emotions and moods in varying vitality
BACKGROUND MUSIC PLAYING MORNING CARE SESSIONS							
THEMES	The creation in cooperation of an understood context	Balance and sensory awareness	Physical strength, body symmetry	Use of space	Caregiver helping patients to live in their bodies	Emotions/moods and vitality contribution	
SUBTHEMES	Increased patient cooperation and understanding Silent patients' ability to express their wills and opinions Decreased resistance by patients Decreased disruptive screaming by patients	Lengthen bodies, improved balance, stimulated senses	Increased physical strength, more symmetric actions, and a tendency to complete tasks	Living in an expanded space	Helping patients living in a flexible, partly balanced body	Enhanced dominance of positive emotions and moods while having fun in shared vitality	Dominance of negative emotions and moods in shared vitality
CAREGIVER SINGING MORNING CARE SESSIONS							
THEMES	Musical mutuality in a comprehensive context	Balance and sensory awareness	Physical strength, body symmetry	Use of space	Caregiver helping patients to live in their bodies	Emotions/moods and vitality contribution	
SUBTHEMES	Increased patient competence Implicit understanding without words Elimination of patient resistance Enhanced cooperation without disruptive screaming	Straight, balanced bodies, alert senses	Physical strength, symmetric actions, and completed tasks	Living in a greatly expanded space	Helping patients living in flexible, balanced bodies	Positive emotions and moods while being sincere in shared vitality	Negative emotions and moods in shared vitality

The usual morning care session (no music)

In **Study II**, the examination of verbal communication revealed that all patients expressed themselves verbally with confusion, aphasia, resistance, and one patient was screaming. He who screamed also spoke threateningly. Another patient expressed resistance by continuously using violent aggression, such as beating, pushing away, and pinching the caregiver. Most likely because of their cognitive decline, the patients seemed to have difficulty understanding what the caregivers talked about. At the same time, the caregivers seemed to have difficulty understanding what the patients talked about, and it seemed as if the caregivers often times were left to guess and interpret what the patients said. Thus, despite the fact that the caregivers worked hard to create a comprehensible situation for the patients, it seemed that they encountered obstacles when talking which probably hampered mutual understanding.

While communicating verbally, they moved and used their sensory awareness according to the actions taking place (**Study III**). The patients acted with flaccid, unbalanced bodies. They leaned forward with drooping posture and curved backs. Their balance was wobbly and unsteady, their gait faltered, and their movements were slow, small, and shaky. All patients had similar facial expressions: drooping faces with stiff or no expression. Simultaneously, their sensory awareness seemed to be subdued. They demonstrated their visual awareness by looking downward, and when lifting their gaze, it was done slowly. Sometimes when they lifted their gaze, it seemed as if it was not fixed, and that the patients were staring into empty space. Their hearing ability seemed to be impaired because they often did not react when the caregivers spoke, nor did they respond to questions. Regarding the patients ability to experience touch, it seemed as if the patients had a reduced level of feeling. They usually did not react when their clothes were put on, or disliked having their clothes put on. When performing tasks, they did so with physical weakness: asymmetric and fragmented actions with bent arms and cupped or closed hands. The patients washed one side of their body in an asymmetric and unilateral way, and the actions were executed weakly, fragmentedly, and aimlessly. The other side of their body was washed to an even lesser degree, or they left that part unwashed. Furthermore, the patients seemed to live within a limited space, since they seemed to have difficulty recognizing and understanding the environment. Most patients usually found it difficult to find equipment such as toilets, mirrors, towels, and clothes. When aggression was communicated, (beating, hitting, pushing the caregiver away), the patient could probably not understand and misinterpreted the caregiver's movements.

When caring for their patients, the caregivers helped them to live in their stiff and unbalanced bodies. The caregivers used their own bodies, and took great pains when supporting and reducing the patient's balance problems. The caregivers helped the patients to wash their entire body, and demonstrated for the patients how to use items and how to get dressed. Usually they tried to help the patients to look at themselves in the mirror.

At the same time, the caregivers and patients expressed emotions and moods vocally (**Study IV**). The emotions/moods were interwoven in the way the caregivers and patients expressed their vitality. In communication between eight patients and five caregivers throughout the entire morning care session, the caregivers expressed zealous vitality by using strong voices and expressing positive emotions and moods. The patients responded with subdued vitality by speaking weakly in thin, flat and monotonous voices. In their weakened condition, the patients expressed emotions fragmentarily, or for shorter durations than what is regarded as "normal" in verbal communication between human beings. Even though the patients presented weakened conditions, it seemed as if they were able to express positive as well as negative emotions. However, probably because of their weak and dull way of expressing themselves, it was often difficult to hear, interpret, and describe their emotions at all. It seemed as though the patients could not express that they were experiencing a mood state.

In one situation, the caregiver expressed mostly negative emotions and moods in an animated way, and the patient responded negatively in a weak and fragmented manner.

Playing background music during morning care sessions

Compared to the results of the usual morning care sessions, the verbal communication of **Study II** was altered in character: the caregivers decreased the number of verbal instructions. At the same time, it seemed as if the patients expressed an increased ability to understand the verbal messages. The patients also seemed to be partially released from their aphasia; they gained an enhanced ability to speak and to express their will and options. The patients also decreased their resistance; no patient used aggression. Although one patient screamed, he did so in a diminished way. Communicating verbally with background music playing seemed to contribute to ameliorating the situation, since the patients seemed to understand the context.

With preferential background music, it seemed to create a comprehensible context for the patients.

While the altered verbal communication was taking place, there was also an alteration in movement, action and sensory awareness (**Study III**). The patients communicated with an altered way of expressing their balance. Their postures were elongated and their backs were not bent. The patients stood steadier and wobbling was considerably reduced. Their movements seemed to mirror the rhythm of the music. Movements were faster, broader and more extensive; at the same time they were livelier, less stiff and less shaky. When in use, their hands were open with the fingers elongated and separated. The patients demonstrated concentration, vigilance, interest, happiness and satisfaction with lively facial expressions. The patient's sensory awareness seemed to be aroused. When gazing, they looked up and looked around. Their hearing seemed to improve, as they responded in an approving way to the caregiver's comments and questions. They also seemed to hear and be aware of the music being played, and some of them hummed the melody or sang short passages. The patients seemed to have an aroused level of physical sensitivity, using their hands to adjust the sleeves of their garments to fit better. When performing tasks, the patients displayed increased strength and an ability to direct their movements while using their hands either together or alternately. Their movements seemed more powerful and distinct, and they had a tendency to wash both sides of their body. All patients washed a larger area of their body and face compared to the usual caregiving routine, e.g., their entire face, including the neck, was washed all at once. Some patients buttoned their blouses and shirts spontaneously, something they did not do during usual morning care sessions. The patients seemed to use space in an expanded way. They seemed to have an enhanced awareness of their environment. They looked around the room and seemed to recognize different objects. They moved with a steady gait from the toilet to the sink as if implicitly understanding the spatial trajectory involved in making the movement. The patients seemed to know the mirror's location in the facility, and could look at themselves in the mirror with a definite sense of self-recognition.

In the caregiving process, the caregivers helped the patients to live in their flexible and partly balanced body. During the background music care session, the caregivers posture and movements were altered. They stood with straighter backs and their movements were extended and agile. They touched the patients and grooming items with open hands and with elongated and separated fingers. Their facial expressions were changed: they looked more

alert, and most of them smiled and laughed. The patients seemed to have ameliorated balance and strength. The caregivers responded to the patients' balance and strength by not twisting and bending their bodies in the extreme manners that were common during the usual caregiving situation. Thus, the caregivers were able to work with improved balance. When caregivers helped patients to walk, they did not need to offer the same amount of support.

When talking and moving they concurrently expressed emotions and moods vocally (**Study IV**). Their emotions and moods continued to be interwoven into the way they expressed their vitality, but in an altered way. Between the same five caregivers and eight patients as described during the usual morning care session, expressing a dominance of positive emotions and moods, background music seemed to relieve the caregivers of using as much energy as they did in the usual care sessions for prompting and creating positive moods. At the same time, it sounded as if the patients left their state of weakness and dullness as expressed during the usual morning care sessions, and they sounded revitalized. Caregivers and patients spoke with warmer and more sonorous voices. Especially the patients spoke with ameliorated variations in their tones. During the usual morning care sessions it was difficult to hear if the patients expressed moods. During the care sessions with background music, it sounded as though they expressed such abilities; it seemed as if the patients lived in a state of moods. Many of the patients also sang along energetically. It sounded as if patients and caregivers shared and contributed vitality in an almost equal way. During extended periods, only the music was heard, and they communicated and cooperated with pleasant moods. Caregivers and patients continuously expressed humor and playfulness; moods of fun seemed to prevail during the whole session.

However, in one caregiver and patient—the same two described as expressing a dominance of negative emotions and moods during the usual morning care session—negative emotions and moods were expressed in an enhanced way while the background music was playing. In this session, the caregiver and patient seemed to share their vitality in similar manners as the previous caregivers and patients described while listening to background music. The caregiver initially sounded as if she was expressing positive emotions and moods, but as the session continued, she started expressing negative and unpleasant emotions and moods. The patient being cared for responded to these emotions in a similar manner. She expressed negative and unpleasant emotions.

Caregiver singing during the morning care session

When the caregivers sang, both the caregivers and patients expressed an additionally altered way of communicating as compared to the two previous care sessions. In **Study II**, during caregiver singing for or together with the patients, there was a paradox in the verbal communication. No patients expressed aggression or screaming. Narrations of the actions taking place and descriptions of the objects being used ceased almost entirely. Instead, they sang well-known children's songs, popular songs about nature, love, etc. The sound of the caregivers' singing voices, now and then in duets with the patients, were heard instead. When a caregiver sang for or together with the patient, a kind of musical mutuality emerged in their interaction, and it seemed as if they lived in a mutually comprehensive context.

When focusing on the perspective of body, movement and sensory awareness (**Study III**), it was found that when caregivers sang to patients, the patient's body language had different characteristics compared to the previous two sessions. The patients had upright posture with relaxed, straight shoulders. They moved in a calm, smooth and harmonious manner. When looking at something, their eyes looked bright. Facial expressions shifted in a smooth, easy way. All patients demonstrated seriousness and concentration. Most of them demonstrated warm, smiling, and blissful facial expressions; only one showed anger. When caregivers sang, the patients swayed their bodies while beating the rhythm of the music with their hands. Sensory awareness seemed further aroused. Patients were bright-eyed and gazed around attentively, mostly looking at the caregivers, with whom they had continuous eye contact. Their hearing seemed to be further sharpened, since they seemed to be highly attentive to the caregiver's singing, thereby demonstrating an increase in arousal and vigilance. Patients could demonstrate an understanding of a song by nodding when caregivers finished singing a given line from a song or completed singing the song. It seemed as though the patients acquired renewed physical awareness because they immediately seemed to react when their clothes were put on. The patients stood up solidly, and their bodies moved smoothly. Compared to when they were listening to background music, they seemed to perform tasks with enhanced decisiveness, drive, and completeness. They worked calmly and methodologically with two arms, and their hands were held open with the fingers elongated and together. Patients washed more parts of their body, e.g., the face, the neck, and upper body. Their ability to dress themselves also appeared to be enhanced. Patients checked the way in which a blouse or a shirt should be held before accurately slipping their arms into the sleeves. They buttoned the buttons and, without looking at the blouse or shirt, they used their fingers as guides in finding

the location of the buttons and buttonholes. When caregivers sang, the patients appeared to live in an greatly expanded space. It seemed that without any type of coaching by the caregiver, patients could seat themselves, stand, walk around the room and look at themselves in the mirror. Caregiver singing seemed to stimulate a great deal of awareness. The patients seemed to be aware of where the caregiver was standing, and, as a rule, turned toward the caregiver during these sessions.

When caregivers cared for the patients, it seemed as if they helped the patients to live in flexible, balanced bodies. The caregivers seemed to be influenced by their own singing. They stood upright with a relaxed posture, and they moved calmly, smoothly and harmoniously. They kept their hands and their fingers straight and together. When moving, it looked like the caregiver no longer needed to use their bodies to guide the patients in a specific direction. Extreme twisting and bending movements were eliminated. Most caregivers had friendly, sincere, and peaceful facial expressions when standing beside the patients and singing. When caregivers washed and dressed the patients, they worked with smooth, cautious movements.

When talking, moving and using their senses, emotions and moods were expressed vocally (**Study IV**). Caregiver singing seemed to alter the characteristics of the emotions and moods of both the caregivers and patients in comparison to the two previous sessions. No patient expressed aggression or screaming. During caregiver singing, the same eight patients and five caregivers who expressed positive emotions and moods during the two previous care sessions, continued to do so in an altered way. They seemed to express in a balanced way that they shared and contributed vitality that was interwoven with emotions and moods of sincerity. When the caregivers expressed sincerity, it was done with openness, defenselessness, nearness, and peacefulness. When listening to the caregiver's singing, patients seemed to listen attentively and responded expressing sincerity, delight, and wonder. When patients spoke, their voices sounded relaxed and calm. As a whole, prevailing moods during caregiver singing sessions were solemn, serious, and sincere.

However, during these caregiver singing morning care sessions, as in the two previous sessions, the same caregiver and patient communicated with negative emotions and moods. During the whole session, when singing as well as talking, the caregiver sounded irritated, firm and tense. The patient responded immediately, appearing vitalized and expressing

emotions and moods of anger and despair at the same time as she seemed to express an enhanced ability to understand what was going on.

The phenomena discovered during caregiver singing: Music therapeutic caregiving

Study V involves developing a new concept based on the phenomena discovered during caregiver singing in **Studies II-IV**. The concept, called *music therapeutic caregiving* (MTC), is most likely be used in clinical practice, primarily in communication between caregivers and patients in dementia care. The method consists of caregiver singing for or together with the patients during everyday caregiving. The results presented in this thesis reveal that caregiver singing prevented a caring situation that is known to be very stressful for caregivers: patient aggression and screaming. Principally, MTC is a receptive form of singing when seen from the perspective of the patient, although patients may certainly engage in singing during this process, and it had a major influence on the attachment of the patients to their caregivers. Therefore, it is argued that in educating caregivers responsible for the care of persons with dementia, elementary music training, especially vocal training, should be an integral part of the educational regimen. It is suggested that MTC is an inexpensive and simple way to improve the quality of dementia care and whose benefits could be wide-ranging.

REFLECTIONS ON THE FINDINGS

The overall aim of these studies is to illuminate the impact of music and singing on persons with dementia and their caregivers, and to describe a concept based on caregiver singing. It was found that the music and singing seemed to have mutual positive influences on both patients and caregivers. It is quite likely that music particularly influences persons with dementia in a favorable way compared to other sensory stimulation such as touch and showing objects (Norberg, Melin & Asplund, 1986). Using the results of Norberg *et al.* as a foundation, it can be suggested that staff be encouraged to use music when caring for persons with severe dementia (Norman, 2003). It can be stated that **Studies I-V** further explored the use of music in dementia care by now separating music events, the playing of background music and singing, and focusing on patients and caregivers.

Usual morning care sessions (no music)

In **Studies II-V**, the initial situation was the *usual morning care session*, which served as a control situation to describe what happened during an everyday situation. Later on, it was compared to what happened when music and singing was used in the everyday caregiving. First, the findings of the *usual morning care session* in **Studies II-V** will be discussed. It is essential to note that the data collection was done on an SCU for patients with severe dementia, and the caregivers were skilled in caring for the patients. It probably facilitated the patients to display a rich pattern of cognitive and emotional reactions and enhanced abilities (*c.f.* Kihlgren *et al.*, 1996). In the communication between patients and caregivers, it was found that language, movements, sensory awareness, and emotions were interwoven (Watzlawick, Beavin Bavelas & Jackson, 1967). According to the philosopher Merleau-Ponty (1962), a person is always acting as a body in an *intentional arc* that consists of the units of cognition, senses, sensitiveness and movements. When a person becomes ill, the *intentional arc* becomes flaccid, influencing the units described above in a harmful way. The patients had diminished cognition, aphasia, apraxia, agnosia and disturbances in executing actions, which confirmed previous research (DSM-IV, 2002). When the patients communicated, they seemed to be embodied with their flaccid *intentional arc* and impaired cognition, senses and movements (Merleau-Ponty, 1962). When caregivers cared for the patients, they also embodied their language, movements, senses, and emotions in both their being and doing. According to Benner (2000), embodied caring practices meet the needs of, comfort and empower those who are vulnerable. In **Studies I-V**, the patients' mode of communication put

great demands on the caregivers to understand and interpret the vulnerable patients' needs and desires. It is crucial to understand that caring for persons with dementia is regarded as one of the most challenging and difficult tasks facing a caregiver. Regardless of the fact that the caregivers were skilled and experienced, it seemed impossible for them to influence patients to stop being aggressive and screaming (**Studies II-V**), which confirms previous research saying that there are situations that cannot be solved (Graneheim, Norberg & Jansson, 2001). In the mutual relationship between caregivers and patients in dementia care, it is very challenging for caregivers to create an I-You relationship (Buber, 1990a-b). It seemed as if the caregivers did their best to create such a relationship. The patients probably did their best to open up and contribute to this relationship also.

Background music playing

When looking at the two interventions conducted in **Studies II-V** during the usual morning care sessions - *background music playing* and *caregiver singing for and together with the patient* - they can be seen as a continuum with two emerged dimensions. *Background music playing* seemed to open up and alleviate patient and caregiver communication. The patients seemed to communicate with improved cognition, language and physical ability while their resistance diminished and aggression ceased. They appeared to express their needs, desires and body capacity in an enhanced and vitalized way that led to their communication being ameliorated and understood. Their *intentional arc* (Merleau-Ponty, 1962) seemed strengthened and healed during the care sessions, and units of cognition, senses and movements improved. Background music playing helped the patients to regain abilities thought to be worsened by the dementia disease. The results confirmed an abundance of previous studies which state that persons with dementia can be temporarily released from their subdued and often troublesome and difficult way of communicating when listening to music (Snyder & Chlan, 1999; Aldridge, 2001). Perhaps it also helped the caregivers to alter their approach to caregiving (Benner, 2000), and might have influenced them to use their sensitivity for the patients, which could lead to improved dimensions in the I-You relationship (Buber, 1990a-b). It is plausible that the patients participated in an aroused way to create an enhanced symmetric I-You relation.

Caregiver singing

Particularly during the sessions in **Studies II-V** when *caregivers sang for or together with the patients* during the course of morning routines, the patients seemed to further enhance their verbal communication, movements, sensory awareness, and vitality in their emotions. It is suggested that the outcomes of these sessions should be taken advantage of during everyday caregiving. In the philosophy of Merleau-Ponty (1962), it can be described as if the *intentional arc* of the patients was further strengthened and healed, if only when the sessions took place, giving them an opportunity to show altered and improved sides of their units of cognition, senses, sensitiveness and movements. Most of the burdens of the caring situations that took place during the usual morning care session (without music or singing) seemed to be resolved (e.g. patient impaired cognition, patient aggression and screaming, patients' weak, unbalanced, and flaccid bodies, and stiff and shaky movements when performing asymmetric actions). Caregiver singing seems to influence the patients to show and interact with more of their true personalities, allowing them to participate in an enhanced, active way in an I-You relationship with the caregiver (Buber, 1990a-b). The caregivers were most likely able to use more of their skills, giving them the opportunity to, in a deeper way, practice good caregiving (Benner, 2000). In **Study I**, the results revealed that music events created connections and new relationships with the patients, which lasted long after the music events. Perhaps, if caregivers communicate by singing for or together with their patients in everyday caregiving (**Study V**), they might become more deeply connected to them. At the same time, a patient might contribute and communicate with more of their true personality, and more independently participate in using their body in tasks necessary and valuable for everyday life. It is possible that caregivers as well as patients might alter and thus improve their being and doing, and the results could fit well in dementia care education (Kihlgren, 1992). It is, however, crucial to note that **Studies I-V**, as far as it is known, are the first to integrate caregiver singing during everyday caregiving. Further research is needed to discover if the positive influence on patients and caregivers found in Studies **I-V** could be transferred to other dementia care contexts.

Reflections on the influence of music and singing

When trying to understand and explain music's influence on human beings, some authors suggest that music might *distract* people (*c.f.* Tabak, Ehrenfeld & Alpert, 1997; Gregory, 2002). The word *distract* has various meanings: mental turmoil, an obstacle to attention,

drawing someone's attention away from something, entertainment that provokes pleasant interest and distracts you from worries and vexations (Wordweb, 2003). It can be suggested that music, singing, and being sung to (**Studies I-V**) aroused distraction in its favorable sense: it seemed to provoke mostly pleasant reactions and perhaps distracted the patients from worries and vexations. However, when understanding the word *distract* in its more unfavorable sense (mental turmoil, obstacle to attention, drawing someone's attention away from something), the results revealed a reversed impact, as music and singing influenced the patients and caregivers to become *focused and collected*. This was clearly shown when patients used their language in an improved way. Concurrently, they implicitly understood what was going on when the caregiver sang songs instead of talking about the task to be performed. Their gestures were also more composed. Particularly during caregiver singing, patients and caregivers moved with their symmetric bodies in their body's middle line, which may have helped them to orient themselves in space, to move with good body balance, and to be more deeply and emotionally connected to each other (Rosberg, 2000).

Music and singing's long-term, positive impact on persons with dementia has often been discussed. In **Study I**, the music events were an ongoing activity for eight years preceding the study. During these years, it seemed easier to care for patients during the rest of the days that they participated in the music events. Similar impacts were suggested by Olderog Millard & Smith, 1989; and Brotons & Pickett-Cooper, 1996. Because of the patients' dysfunctional brains, the positive influence of music and singing will probably last only a short amount of time. It is probable that if caregivers sing and hum for the patients every time they are close to the patient, the positive influence emerging in **Studies I-V** will probably occur continuously. Perhaps caregiver singing could be compared to pharmacotherapy. Such treatments are usually given many times a day to relieve symptoms. It is possible that caregiver singing could provide powerful relief of dementia symptoms if the patients were continuously exposed to the caregivers' singing voices in ongoing, everyday life situations.

Music therapy sessions led by a music therapist take place often in dementia care. The author of this thesis is a strong supporter of such therapy, and suggests that in these therapies the influence of music and singing on persons with dementia will probably correspond to what was found in **Studies I-V**. It is suggested that regardless of who it is that communicates through music (music therapist, family caregiver, professional caregiver, etc.), the outcomes of **Studies I-V** can be transferred to other situations where music and singing are part of the communication between persons with dementia and other people. Referring once again to

Norberg *et al.* (1986), who found that listening to music seemed to provide a favorable impact that other sensory stimulation methods such as touch and showing objects failed to give, it is thought that music therapy sessions might currently be a preferable, assessable way to facilitate persons with dementia to temporarily relieve their BPSD and show more of their true personality. It is suggested that the openness to being sung to, as one might sing to an infant (Trehub, 2000), may exist in human beings regardless of age, and that people keep their ability to be musical. They may have a cognitive ability where music can create memories, associations and narratives throughout their entire life span (Ruud, 1997). It is further suggested that caregiver singing can be an adjunct to music therapy, and that the two musical approaches should be used in different situations. It is also suggested that when educating professional and family caregivers, a music therapist interested in teaching singing to caregivers should be involved. There may be other suggestions on how to use music and singing in dementia care as well. According to Vink, Bruinsma & Scholten (2003), a review of music therapy in the care of people with dementia will be published at the end of this year. This review might give other conclusions and new insights about how different kinds of music therapy in dementia care might be used.

Singing and other contexts

In this thesis, the participants were persons with dementia and their caregivers. The patients can be regarded as human beings with a dysfunctional brain, and the caregivers represent the healthy human being. Another issue that should be considered is if the findings on the influence of listening to music and singing (**Studies I-V**) could be transferred to other contexts than dementia care situations. In **Study III** it was found that music, and particularly singing, brought symmetric movements to the human body. The Roman mathematician and philosopher Boëtius (480-526) wrote about *Musica Humana*: the human music. He experienced that music gave the human being an inner harmony, it gave the limbs symmetry, and body and soul became interwoven (Benestad, 1978). Perhaps **Studies I-V** can become a part of the discourse that has taken place since ancient times on how music and singing influence people. In **Study I**, patients were easier to care for after music events and at the same time the caregivers felt more closely connected to the patients. The results may give ideas that active participation in singing could alleviate depression, increase self-esteem, improve social interaction skills and induce cognitive stimulation (Bailey & Davidson, 2002). Perhaps music and singing might facilitate rehabilitation in persons with brain injuries such as

hemiplegia, because according to Mauritz (2002), these patients in gait rehabilitation improved their velocity, symmetry, and stride length when background music was playing as compared to traditional therapy with no music. At the same time, the patients had fun. Patients with brain injuries and in coma appear to hear singing. Gustorff (2002) found that when singing for these patients, some of them turned their head toward the therapist. Some opened their eyes or grabbed the therapist's hand. These patients also stretched out their whole body or tried to grope with their limbs, which in some cases were thought to be paralyzed. In **Study V**, *Music therapeutic caregiving* was suggested as a useful means of communication for caregivers in practice outside dementia care. Perhaps it could be incorporated into caring for persons with brain injuries. In nursing research, it would be valuable to investigate if caregiver singing could be beneficial when helping persons with stroke to regain their skills, in order to help them to live their everyday lives as independently as possible.

METHODOLOGICAL CONSIDERATIONS

A number of issues on the use of methods must be scrutinized in order to guarantee the trustworthiness of data collection, analysis and interpretation of the qualitative studies.

Trustworthiness in research using qualitative methods

When presenting qualitative research, validity can be judged by the continuity of the research and whether this continuity is visible throughout the descriptions. In this way the reader can follow how the study was conducted and it can alleviate the need to replicate parts of the study that might confirm or reject the results (Kvale, 1996). In **Studies I-IV**, an attempt was made to give rich descriptions of the steps of each process in the analysis.

Trustworthiness in choosing participants

In **Study I**, an opportunistic sampling method was used (Patton, 2002). The available patients and caregivers were chosen, and the staff decided which patients and caregivers should participate in each music event. Even though the staff exclusively invited patients who were thought to suffer from dementia to the music events, when the data collection took place it was not known whether all of them fulfilled the criteria for the diagnosis of a dementia disease. It might have been the case that some of the patients did not have dementia, but most participating patients had a diagnosis of dementia. However, there might have been patients who did not fulfill the criteria represented in the results. The caregivers were representative of

ordinary human beings and were thought to represent how people could be influenced by the music events being investigated.

In **Studies II-V**, a purposeful sampling method was used. In such sample, the subject should be particularly knowledgeable concerning the issue being investigated (Polit & Hungler, 1999; Patton, 2002). In the **Studies II-V**, all patients on the ward had experience in living with severe dementia. The patients participating in the research were suggested by the head nurse of the ward. She knew the patients well, and she was informed that the author wanted to explore music and singing during the course of morning routine. Perhaps the head nurse chose patients who enjoyed listening to music. However, it is important to note that to be able to participate, a relative or a trustee gave permission. They all confirmed that the participating patients enjoyed music. Hence there might be a bias that the patients were in favor to listening to music. However, as it seemed as all patients on the ward liked to listen to preferred music, it probably had been difficult to find patients who disapproved to listening to such music. One patient who liked music dropped out because she did not want to be filmed. According the patient, there were other reasons for her decision to discontinue than listening to the music. The caregivers were chosen because of their long time of interaction with the patients, and agreed to participate in the research. According to them, they all enjoyed music. When collecting the data, they were not able to choose what music to be listened to, however they chose what songs were sung. Their choices might have influenced the communication between them and the patients. It is anyhow difficult to gauge if other songs would have influenced the caregiver' and patients' communication in an altered way than what was found in the results.

In the findings three different aspects, verbal communication; body movements and sensory awareness; and emotions and moods were investigated in **Studies II-IV**. It can be seen as a triangulation, as the findings might mirror and strengthen each other (*c.f.* Polit and Hungler, 1999).

Trustworthiness in data collection

When participants are unable to verbally report their behavior and experiences observational methods are suggested (Bottorff, 1994; Mullhall, 2003). In **Study I**, *participant observations* were conducted by taking notes. In **Studies II-V**, *video recording* was used. When being

observed, the subject could be influenced to act in a more appropriate way that could give biased data. However, if the observations continue for quiet a while, the researchers usually get the impression that the natural behaviors is occurring (Bottorff, 1994; Mullhall, 2003). In **Study I**, the data collection lasted about nine months, and in **Studies II-V**, the data collection time lasted about five months. Such a long time period gave the impression that the participants acted naturally. Additionally, using videos as a method to collect data removes some of the accusations of researcher bias, as data can be played and replayed as often as needed; it is considered to produce powerful research (Spiers, Costantino & Faucett, 2000).

Trustworthiness in interpretation

According to (Ricoeur, 1976), a text has a surplus of meaning. Although the author endeavored to conduct the most probable interpretation, another researcher with a different pre-understanding, might have presented other results (Dahlberg, Drew & Nyström, 2001). However to guarantee the trustworthiness in interpretation in **Study I**, during the period of analysis and writing, the participating personnel discussed the result with the author and gave opinions about the interpretation. In **Studies II-IV**, co-assessments were performed to ensure the credibility of the results and to diminish the possible biasing effects on the interpretations done by the author. Additionally, in **Studies I-IV**, excerpt and descriptions were used to further guarantee trustworthiness.

Trustworthiness of the descriptions and interpretations has also been obtained through presentations to, and discussions with experienced staff caring for persons with dementia. In **Studies II-IV** the staff agreed to the findings during usual morning care. Some have also been singing for patients during course of caring. Many of the staff confirmed the findings reported during caregiver singing.

Trustworthiness in describing a new concept

In **Study V**, a new concept was described, grounded in the results in **Studies II-IV**. According to Morse *et al.* (1997), new concepts should not be rated negatively to quickly simply because they fail to meet all the rigor criteria for concept analysis. All concepts are not instantly and equally mature: full maturity is archived only over time, with continued use and refinement. They should be considered in the light of their potential contribution (ibid).

Further research focusing on caregiver singing in dementia care situations will help to reveal how refinement should be done.

Transferability

The goal of qualitative research is to get in-depth understanding and knowledge of particular phenomena, and not to produce generalizations. Therefore the results in Studies **I-V** can not be generalized, however probably transferred in other dementia care contexts. However, it would be interesting to investigate if the influence of caregiver singing in Studies **II-IV** could be transferred and applied in other caring contexts as well.

CONCLUSIONS

The results of this thesis reveal that the use of music – caregiver singing, listening to background music, and music events during care sessions – has a positive impact on both patients and caregivers. During the usual day-to-day morning care situations, the patients' characteristic way of talking, using their bodies and senses, and expressing their emotions and moods, put great demands on the caregivers when helping the patients. When the patients were aggressive and screamed, the situations seemed problematic and impossible to solve. However, these situations seemed to abate when listening to background music and when the caregivers sang. Particularly during caregiver singing there were favorable impacts. The patients' ability to use their vitality, cognition, language, posture, sensory awareness, body movements, and also their task execution, understanding of space, and emotions and moods seemed to be enhanced. At the same time, none of the patients were aggressive or screamed. The caregivers also seemed to experience a favorable impact, and perhaps while singing, they became more skillful in their caregiving.

The findings may be useful in the education of all caregivers, so it is suggested that these ideas be implemented in the supervision and curricula of professional caregivers and in the education of family caregivers living with persons with dementia. Further studies are necessary in order to find out if the positive impacts can be transferred to other everyday dementia care situations, and if the suggested brief, favorable impact could be prolonged if caregiver singing were to occur as a common means of communication in everyday dementia care.

ACKNOWLEDGEMENTS

I would like to express my deepest gratitude to the many people who have contributed to this thesis. Without their efforts and support this thesis would not have been possible.

First of all, I would like to express my deepest gratitude to all the patients and caregivers who participated, and to the head nurses, Lisbeth Björling and Wiveca Vall.

I would like to express my very special and sincere thanks to the following people:

To my supervisor, Professor Sirkka-Liisa Ekman, for her openness in scientific thinking, for giving me the freedom to decide which perspective to investigate in the rich data collection, and for giving excellent support when I struggled to learn qualitative methods.

To my supervisor, Steven Brown, Ph.D., for bringing aspects of music's influence on human beings and interdisciplinary thinking into my research, and his encouraging support in helping me discover things I could not see myself. With his excellent editing and writing, the published articles kept a high standard.

To Professor Bengt Winblad, for supporting dementia care research and making nursing research an important contribution to the field of science.

To the doctoral students and Ph.D.s at the Center of Excellence in Elderly Care Research (CECAR), for their bright minds and valuable viewpoints in the seminars, which were absolutely necessary for me in accomplishing the goals of this thesis. In alphabetical order: Els-Marie Andrée Sundelöf, Britt Ebbeskog, Azita Emami, Ingegerd Fagerberg, Birgitta Gustafsson, Görel Hansebo, Kristiina Heikkilä, Wallis Jansson, Inger Karlsson, Annika Larsson Mauleon, Margareta Nilsson, Liisa Palo-Bengtsson, Ingrid Randers, and Helena Sunvisson.

To Cindy Olsson and Judy Peterson for their excellent English linguistic revisions.

To my family:

First of all to Rolf Bornbäcken, my beloved life companion for many years. Thanks for all the support during the time I was writing my thesis.

To my sister, Maria Götell, for generous support, and for painting the picture on the cover of the thesis.

To my stepdaughter, Matilda Linder, for warm support in my life, and for using her skills in graphic design when helping me to design one of the tables in the thesis.

To my mother Birgitta, siblings and in-laws: Pontus, Pia, Pelle, Anneli, Peter, Helena, my nieces Anna and Petra, my sister-in-law Ann-Kerstin, and my brother-in-law Lars for giving support and showing interest in my research.

This thesis has been supported by grants from (in alphabetical order):

Blekinge Institute of Technology, The County Council of Stockholm, The Foundation for Biomusicology and Acoustic Ethology, Gun och Bertil Stones stiftelse, Karolinska Institutet, KP Pensions & Försäkring, The National Board of Health and Welfare (Socialstyrelsen), Johanniterorden i Sverige, The research program “Arts in Hospital and Care as Culture”, The Swedish Association of Health Professionals (Vårdförbundet), Uppsala Sjuksköterskehems Sjuksköterskeförening, Vårdalsstiftelsen.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Sång, bakgrundsmusik och musikstunder i kommunikationen mellan personer med demenssjukdom och deras vårdare.

För närvarande lever det ungefär 150 000 personer med demenssjukdom i Sverige, och ca 50 procent av dem lider av Alzheimers sjukdom (AD). Att vårda personer med demenssjukdom har ibland beskrivits som bland det svåraste en vårdare har att göra. Det anses bero på att de demenssjuka har ändrad förmåga att kommunicera. De kan ha minnesnedsättning, minskad verbal förmåga (afasi), minskad förmåga att känna igen föremål och personer med synen (agnosi), och minskad förmåga att utföra viljemässiga rörelser (apraxi). Dessutom utvecklar de i hög grad tillstånd som kallas för beteendemässiga och psykologiska symtom hos demenssjuka (BPSD). Symtomen brukar visa sig som bl.a. aggression, skrikande, rastlöshet, oro och vandringsbeteende. Inom medicinsk behandling finns det för närvarande endast symtomlindrande läkemedel för personer med AD. Detta gör att det i dagsläget saknas läkemedelsbehandling för 50 procent av de demenssjuka angående deras demenssjukdom. Inom demensvården anses det att i första hand skall vården innehålla interventioner som syftar till att hjälpa de demenssjuka att leva ett så gott liv som möjligt. Tidigare forskning visar på att demenssjuka personer reagerar på musik på ett intresseväckande sätt. I denna avhandling genomfördes interventioner när patienter och vårdare kommunicerade via musik och sång. Projektets övergripande syfte var att belysa musikens och sångens inverkan på personer med demenssjukdom och deras vårdare samt beskriva ett begrepp som är baserat på ”vårdarsång”.

I artikel I formulerades syftet: att belysa betydelsen av musikstunder och patienters och vårdares reaktioner och sociala interaktioner, före, under och efter dessa musikstunder. Etnografisk metod användes. Patienter med misstänkt eller diagnostiserad demenssjukdom och deras personal medverkade. Resultaten visade, att patienterna hade förmåga att sjunga, spela på instrument, röra på kroppen, och skämta under musikstunderna. När de sjöng sånger som de var förtrogna med, upplevde en del patienter att vissa minnen återkom. Minnena upplevdes behagliga. Personalen upplevde, att patienterna som deltog i musikstunderna blev lättare att vårda under resten av den dag som musikstunderna ägde rum. Personalen upplevde också att de påverkades. De vågade göra bort sig, och kände en särskild kontakt med de medverkande patienterna.

I artiklarna **II-V** användes samma datainsamling, nämligen, videoinspelningar av morgontoaletter mellan patienter med grav demenssjukdom och deras vårdare. Tre olika morgontoalettsituationer inspelades. Den ”vanliga” morgontoaletten var utgångspunkten (1). Morgontoaletten gjordes sedan med sina vanliga rutiner, och som första intervention spelades bakgrundsmusik som patienterna tyckte om, samtidigt som morgontoaletten pågick (2). I den andra interventionen sjöng vårdarna för eller tillsammans med patienterna, samtidigt som sedvanliga morgontoalettbestyr pågick (3).

I Artikel **II**, var syftet att belysa den verbala kommunikationen mellan personer med grav demenssjukdom och deras vårdare under de tre ovan beskrivna morgontoaletterna. Fenomenologisk-hermeneutisk metod användes. Resultaten visade, att under den vanliga morgontoaletten uppstod svårigheter för vårdare och patient att förstå varandra. Vissa patienter reagerade med aggressivitet och skrikande. När morgontoaletten skedde under bakgrundsmusik talade vårdaren mindre, samtidigt som samarbetet ökade. Patienterna talade med längre meningar och i ökad utsträckning. Ingen patient reagerade med aggressivitet. Samma patient som skrek under det första tillfället (1), skrek också när de lyssnade på bakgrundsmusik. När vårdaren sjöng för eller tillsammans med patienten verkade patienten i hög grad förstå vad som pågick, och vårdaren och patienten talade i princip inte om vad som hände under morgontoaletten. Likafullt pågick morgontoalettens sedvanliga omvårdnad. Vårdaren sjöng eller nynnade, och patienten verkade förstå och samarbetade aktivt. Ingen patient reagerade med aggressivitet eller skrikande.

I artikel **III** var syftet att belysa hur patienterna och vårdarna förmedlade sig med sina kroppar och sinnen under de tre ovan beskrivna morgontoaletterna. Kvalitativ innehållsanalys användes. Under den vanliga morgontoaletten såg det ut som att patienterna hade en hopsjunkna kroppshållning och de verkade ha dämpade syn-, hörsel- och känselsinnen. De verkade ha svaga kroppskrafter, och de arbetade i asymmetriska och fragmentariska handlingar. De verkade också som de hade begränsad förmåga att uppleva och förstå rummet. Vårdarna anpassade sig till patienternas sätt att använda sina kroppar. Vårdarna hjälpte därför patienterna att leva med sina obalanserade och stela kroppar och sinnen i det begränsade rummet. Bakgrundsmusiken och vårdarsången förändrade såväl patienternas som vårdarnas kroppar och sinnen. Speciellt under sång såg det ut som att patienterna verkade leva med rakryggad kropp och alerta sinnen. De verkade ha starka kroppskrafter, de arbetade symmetriskt och utförde hela handlingar. De verkade också ha återfått förmågan att förstå

rummet och dess innehåll. Kanhända när patienterna förstod sin omgivning (rummet), upphörde de att visa aggressivitet och skrikande. Vårdarna påverkades också av sjungandet. De visade liknande kropps- och sinnespåverkan som patienterna. Vårdarna arbetade med och anpassade sina kroppar och sinnen, när de hjälpte patienterna att leva i smidiga och balanserade kroppar och sinnen.

I artikel **IV** belystes känslorna och sinnesstämningarna som uttrycktes i den verbala kommunikationen under de tre morgontoaletterna. Kvalitativ innehållsanalys användes. Resultaten visade att känslor och sinnestillstånd var sammanbundna med förmågan att visa vitalitet (kraft). Under samtliga situationer under den vanliga morgontoaletten utan musik (1) var det skillnad på hur känslorna uttrycktes. Vårdarna uttryckte vitalitet (kraftfullhet), medan patienterna uttryckte bristande vitalitet (kraftlöshet, håglöshet). Under bakgrundsmusiklyssnande (2) och under vårdarsång (3) verkade patienterna återfå vitalitet (kraft) och använde den. Vårdarna verkade bli avlastade att använda sin vitalitet (kraft) och de verkade uttrycka och använda den i mindre utsträckning. Under alla morgontoalätter uttryckte både patienter och vårdare rikligt med känslor och sinnestillstånd. Dessa uttrycktes på två olika sätt under alla morgontoalättsituationer. I en grupp bestående av åtta patienter och fem vårdare så dominerade positivt uttryckta känslor/sinnestillstånd från början under situation 1. De positiva känslorna/sinnestillstånden tilltog under bakgrundsmusik och under vårdarsång verkade endast positiva känslor/sinnestillstånd uttryckas.

I en annan grupp och under de tre morgontoaletterna där samma vårdare och patient kommunicerade, verkade mestadels negativa känslor/sinnestillstånd uttryckas under den vanliga morgontoaletten. Under bakgrundsmusiklyssnande tilltog de negativa känslorna/sinnestillstånden, och under vårdarsång uttrycktes uteslutande negativa känslor/sinnestillstånd.

Resultaten i artiklarna **II-IV** låg till grund i artikel **V** där begreppet ”*music-therapeutic caregiving*”, (*MTC*), beskrevs och diskuterades i ett tvärvetenskapligt sammanhang. Begreppsbeskrivningen innehåller vad som händer under ”vårdarsång” (*MTC*) och föreslår hur metoden bör användas i vårdarbetet. Begreppet kan förmodligen integreras i teoribildning inom demensvård.

De sammanfattande resultaten visar att musik och sång under omvårdnadssituationer förmodligen är en användbar intervention i kommunikationen mellan vårdare och demenssjuka personer. Musikstunder där patienter och vårdare medverkar kan eventuellt förbättra demensvården. I kommunikationen mellan personer med grav demenssjukdom och deras vårdare föreslås att vårdaren sjunger och nynnar för patienten under omvårdnad. Särskilt under vårdarsång verkar den verbalt förmedlade kommunikationen bli förståelig. Vidare förmodligen särskilt under vårdarsång kan patienter uttrycka sig med sina kroppar och sinnen så att omvårdnadssituationerna eventuellt blir ”enklare” att genomföra. Dessutom verkar det som patienter och vårdare har förmåga att känslomässigt förmedla sig under alla undersökta morgontoaletter. Känsloerna kan förändras när bakgrundmusik och sång finns med i kommunikationen. I de allra flesta situationer kan känsloerna förmodligen ändras på ett positivt sätt. Emellertid, för att underlätta att ”positiva” känslor skall kunna upplevas och uttryckas, föreslås att vårdaren blir undervisad och bli handledd i hur vårdarsång bör kunna användas.

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