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CAREGIVERS' SINGING FACILITATES MUTUAL ENCOUNTER

Implementation and Evaluation of Music
Therapeutic Caregiving in Complex
Dementia Care Situations

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*In memory of my grandmas,
who made me love
and see the importance of working
for the older people in our society.*

Front page picture painted by Maria Götell, 2011.

ABSTRACT

Persons with severe dementia suffer from major cognitive impairment, and are in need of considerable caring services. They commonly react with problematic behaviors, such as resistance and aggression in close care (e.g., morning care situations). Non-pharmacological treatments such as care interventions should be used to enhance mutuality in encounters and minimize problematic behaviors. Music Therapeutic Caregiving (MTC) is one such intervention and involves the caregiver singing for or together with the persons with dementia during caregiving. MTC is proposed to decrease expressions of aggressive behaviors and enhance communication between persons with dementia and their caregivers. In addition, it has been suggested that MTC can enhance the posture and sensory awareness of persons with dementia, as well as alter the characteristics of the emotions and moods of both the caregivers and the persons with dementia.

This thesis was designed with the aim of demonstrating if and in that case how the intervention of using MTC impacted the participants in this study, which included patients with severe dementia and their caregivers. Five studies were included in this thesis, each of which focused on specific aspects of morning care situations with or without the use of MTC. The first study (**I**) aimed to describe professional caregivers' experiences of caring for persons with dementia during morning care situations without and with MTC. The second study (**II**) aimed to present professional caregivers' experiences of persons with dementia during morning care situations without and with MTC. The third study (**III**) aimed to describe how persons with dementia and their caregivers express verbal and non-verbal communication and make eye contact during the caring activity 'getting dressed' during morning care situations without and with MTC. The fourth study (**IV**) was a single case study and described expressed emotions and expressions of resistiveness to care in two nursing home residents with severe dementia, during morning care situations without and with MTC. Study **V** aimed to describe expressions of emotions and resistiveness to care among persons with dementia during morning care situations without and with MTC.

Study **I** revealed that during usual morning care situations (without the use of MTC), the caregivers often had problems reaching the persons with dementia and described a struggle when it was necessary to physically restrain some patients due to aggression and resistance. They found consolation when the persons with dementia showed them affection. In study **II**, the persons with dementia were described as not mentally present during usual morning care situations, and their resistance and aggression lead to difficulties in communicating and cooperating. Study **III** revealed that the caregivers communicated mainly with verbal instructions and body movements, and that they seldom invited the persons with dementia to participate in the communication. The responses of persons with dementia were at times active and compliant, and other times confused, disruptive, resistant and aggressive.

During MTC, the caregivers described a feeling of well-being, as positive emotions seemed dominant for both the caregivers (study **I**) and the persons with dementia (study **II**). The caregivers sense of well-being led to a joyful and positive encounter with the persons with dementia (study **I**). In study **II**, caregivers found the persons with dementia better able to express themselves appropriately. Expressions of positive emotions were dominant amongst patients and they were mainly described as relaxed, self-confident, and pliable. Study **III** also showed that the persons with dementia commonly responded to caregivers' communication in a composed manner, by being active, compliant and relaxed. Study **III** further revealed that the caregivers seemed more interested in communicating with the persons with dementia and solicited mutual engagement. In study **IV**, both residents increased positive expressed emotions, while the negative expressed emotions and resistance decreased. Study **V** also revealed that the positive emotions, such as pleasure and general alertness significantly increased during MTC, while resistant behaviors, such as pulling away, grabbing objects and adduction, were significantly reduced.

From this thesis, it can be concluded that the use of MTC during morning care situations with persons with dementia can increase their positive expressed emotions, decrease their negative expressed emotions and resistance to care, and lead to a more positive interaction for both them and their caregivers. It can also be concluded that MTC can enhance communication between persons with dementia and their caregivers during caring and thus increase the mutuality in the encounter, thereby facilitating an interpersonal relation during morning care situations. More research concerning MTC is needed and should be conducted using larger samples, different data collection and analysis methods, as well as different care situations.

Key words: dementia, caring, caregivers, intervention, music, singing, emotion, aggression, resistance communication, qualitative, quantitative, content analysis, single case, student t-test.

SAMMANFATTNING

Personer med grav demenssjukdom lider av allvarlig kognitiv nedsättning och är därför i behov av omfattande vård. Dessa personer reagerar ofta med beteenden som motsträvighet och aggressivitet under omvårdnad, exempelvis under morgontoalettsituationer. Icke-farmakologisk behandling, så som omvårdnadsinterventioner föreslås användas för att främja ömsesidighet i mötet mellan vårdare och personer med demenssjukdom, samt för att minska problematiska beteenden. Vårdarsång är en sådan intervention, i vilken vårdaren sjunger för eller tillsammans med personen med demenssjukdom under omvårdnad. Vårdarsång har visat sig minska aggressivitet och motsträvighet, samt öka kommunikation mellan personer med demenssjukdom och deras vårdare och även förstärka personer med demenssjukdoms kroppshållning och deras sätt att använda sina sinnen, samt förhöja deras sinnesstämning och känslor, likväl för deras vårdare.

Denna avhandling designades med syftet att demonstrera om och i så fall hur vårdarsång som intervention påverkar deltagarna i denna avhandling, vilka var personer med grav demenssjukdom och deras vårdare. Fem studier är inkluderade; den första (**I**) syftade till att beskriva professionella vårdares erfarenheter av att vårda personer med demenssjukdom under morgontoalett utan samt med vårdarsång. Studie **II** syftade till att presentera professionella vårdares erfarenheter av personer med demenssjukdom under morgontoalettsituationer utan samt med vårdarsång. Studie **III** syftade till att beskriva hur personer med demenssjukdom och deras vårdare uttrycker verbal och icke-verbal kommunikation och ögonkontakt vid aktiviteten påklädnad under morgontoalettsituationer utan samt med vårdarsång. Studie **IV** var en single case studie med syftet att beskriva känslouttryck, samt uttryck av motsträvighet mot omvårdnad för två personer med demenssjukdom under morgontoalettsituationer utan samt med vårdarsång. Studie **V** syftade till att beskriva känslouttryck, samt motsträvighet mot omvårdnad hos personer med demenssjukdom under morgontoalettsituationer utan samt med vårdarsång.

Vårdarna beskrev i studie **I** att de under vanlig morgontoalett (utan vårdarsång) hade problem att nå personerna med demenssjukdom i relationen och en fysisk och mental kamp beskrevs då de var tvungna att bruka tvång för att kunna vårda på grund av aggressivitet och motsträvighet. De beskrev också en känsla av bekräftelse när personerna med demens uttryckte kärlek emot dem. I studie **II** beskrev vårdarna personerna med demenssjukdom som mentalt frånvarande under vanlig morgontoalett, och de hade svårigheter att kommunicera, samt samarbeta och de uttryckte motsträvighet och aggressivitet mot vårdarna. I studie **III** framkom att vårdarna kommunicerade med att ge verbala instruktioner, samt genom kroppsrörelser och de bjöd sällan in personerna med demenssjukdom i kommunikationen. Personerna med demenssjukdom svarade med att vara aktiva och följsamma, men framför allt genom att vara motsträviga och aggressiva, förvirrade och splittrade i sin respons.

Under morgontoalet med vårdarsång beskrev vårdarna känslor av välbehag relaterat till att positiva känslor uttrycktes vara dominerande för både vårdarna själva (I) och för personerna med demenssjukdom (II), vilket vårdarna beskrev ledde till ett glädjefullt och positivt möte med personerna med demenssjukdom (I). I studie II beskrevs att personerna med demenssjukdom uttryckte sig mer adekvat och de beskrevs som avslappnade, självsäkra och följsamma. Även studie III visade att personerna med demenssjukdom mestadels svarade vårdarna genom att vara aktiva, följsamma och avslappnade under vårdarsång. Även vårdarna verkade mer intresserade att kommunicera med personerna med demenssjukdom och ett gemensamt engagemang tycktes uppkomma. I studie IV ökade positiva känslouttryck för båda deltagarna, medan negativa känslouttryck och uttryck för motsträvighet minskade. I studie V ökade positiva känslouttrycken ”pleasure”, samt ”general alertness”, medan de motsträviga beteendena ”pull away”, ”grab object” och ”adduct” minskade.

Slutsats grundat i denna avhandling är att vårdarsång under morgontoaletsituationer med personer med demenssjukdom och deras vårdare kan hjälpa personer med demenssjukdom att öka positiva och minska negativa känslouttryck och minska motsträvighet, samt främja ett positivt möte mellan dem och deras vårdare. Det kan också konkluderas att vårdarsång kan vara ett sätt för personer med demenssjukdom och deras vårdare att öka möjligheten att kommunicera och därmed möjliggöra ett gemensamt möte och en relation under morgontoaletsituationen. Mer forskning gällande vårdarsång behövs och bör innehålla fler deltagare, olika datainsamlingar, analysmetoder och genomföras i olika vårdsituationer.

Sökord: demens, omvårdnad, vårdare, intervention, musik, sång, känslor, aggression, motsträvighet, kommunikation, kvalitativ, kvantitativ, innehållsanalys, single case, student t-test.

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- II. Hammar Marmstål, L., Emami, A., Engstöm, G & Götell, E. (2010) Reactions of Persons with dementia to caregivers singing in morning care situations. *The Open Nursing Journal*. 4, 35-41. Accepted for publication September 29th, 2010.
- III. Hammar Marmstål, L., Emami, A., Engstrom, G., & Götell, E. (2011) Communicating through caregiver singing during morning care situations in dementia care. *Scandinavian Journal of Caring Sciences*. 25, 160-168. Accepted for publication April 5th, 2010.
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LIST OF ABBREVIATIONS

ADL	Activity of Daily Life
AD	Alzheimer's Disease
AN	Assistant Nurse
BPSD	Behavioral and Psychological Symptoms of Dementia
GI	Group Interview
MMSE	Mini Mental State Examination
MTC	Music Therapeutic Caregiving
NA	Nursing Aid
OERS	Observed Emotion Rating Scale
RCT	Randomized Controlled Trail
RTCS	Resistiveness to Care Scale
SBU	The Swedish Council on Technology Assessment in Health Care
VIO	Video observation
VD	Vascular Dementia

1 INTRODUCTION

When thinking about growing old, people might think of quitting work, relaxing, travelling and spending time with family and friends. Most people will indeed have it that way, but some unlucky people will face cognitive decline while growing older. Five percent of 65 years olds are diagnosed with dementia, and the percentage will increase by an aging population.

Dementia is a Latin word derived from the following: ‘de’ - without, and ‘mens’ - soul, literally ‘without soul’ (Midence & Cunliffe, 1996). I do not believe that these words should be taken literary, as I believe that persons suffering from dementia retain much of their personality and abilities inside themselves, though much is lost. I believe that they still have their ‘souls’ and uniqueness as individuals and should be met on those terms.

Older people have always been an important part of my life. I had close contact with my grandmothers, and spent a lot of time with them during summer breaks. They were important parts of my family and I loved to hear them talk about “the old times”. I believe that my contact with my grandmothers was the reason I decided to work in elderly care at the age of 18. I had graduated high school and was given the opportunity to work as a nursing aid during the summer at a nursing home for older people. Among the persons living at the nursing home were persons with dementia. At the end of the summer, I was offered the chance to continue working at the nursing home, which I was happy to accept. I remember thinking it was so much fun and enlightening for me that I wanted to tell everyone about my experiences at work. When I think back, I believe the reason I enjoyed it so much was because I felt important to the persons living at the nursing home and I established relationships with them. I also learned many things from them and I believe that they thought they learned from me to.

The days at the ward were filled with duties; everything from caring tasks, such as morning care and showering, to cleaning, shopping, cooking, and baking. We did as much as possible together with the elderly at the ward. I remember that we listened to a lot of music and we sang a lot during morning care situations. This was a natural thing that many of the staff did with residents who seemed to enjoy it. One lady diagnosed with dementia wanted to sing a special song every morning. One morning while we sang together, she stopped and looked at me and said: “Oh, well! If that singing voice should come from a pig, I wouldn’t want to eat the meat”. We laughed a lot and kept on singing.

After some years, I decided to work as a registered nurse in elderly care. I began studying at nursing school and, when I graduated, I began working at a nursing home for both persons with dementia as well as the elderly with no cognitive decline. The work was certainly interesting and enjoyable, and at the same time stressful, due to feelings of insufficiency from both the elderly and the caregivers. I, as well as other caregivers, experienced problematic situations while caring and communicating with persons with dementia and it was difficult to handle and cope with these situations. After some years as a nurse, I wanted to develop my

skills in order to eventually influence the situations faced by the nurses in elderly care, and I therefore undertook a master's degree in nursing with a focus on elderly care.

When I finished my master's, I was given the opportunity to become a research assistant in the project presented in this thesis. I had no training in music or singing and was unaware of any research in this area when I started the project. As I mentioned earlier, I had sung together with persons with dementia, but I had not reflected upon what took place during the singing or that this might be connected to the singing. I was clearly a novice in this area, but nevertheless rich in experience of caring for persons with dementia as nursing aid and nursing assistant, as well as a registered nurse. However, prior to beginning the studies I completed a course in Music Therapeutic Caregiving (MTC), which I found joyful and instructive. I also found it interesting to hear anecdotes from other participants about the joy of singing during care and how they had be influenced by persons with dementia.

2 BACKGROUND

The background section is divided into six sub-sections. First is a short description of the occurrence of dementia. This is followed by a summary of the research concerning living with dementia, as well as communicating with and caring for persons with dementia. Next, aspects of philosophy, and caring is described followed by treatments, and the use of music in dementia care. Last in the background section is a description of singing during caring for persons with dementia.

2.1 OCCURRENCE OF DEMENTIA

Dementia is primarily a disease of later life and affects 5% of people older than 65 years of age, half of which are over 85 years. The global occurrence of dementia is estimated to be 30 million cases, and by the year 2050 this figure is expected to reach 100 million (Ferri et al., 2006). In the European Union, approximately 5.1 million people live with dementia (Berr, Wancata, & Ritchie, 2005). In Sweden, the occurrence of persons with dementia is estimated to be 148,000 and will also increase in this aging population (Berr et al., 2005; Ferri et al., 2006; The Swedish National Board of Health and Welfare, 2010). The global societal cost of dementia is an estimated 315.4 billion USD (Wimo, Winblad, & Jonsson, 2007); in Sweden alone about 7.2 billion USD (The Swedish National Board of Health and Welfare, 2010). According to the Swedish Council on Technology Assessment in Health Care [SBU] (2008a), Alzheimer's disease (AD) accounts for the largest group of dementia diagnoses in Sweden (50-70% of patients with dementia), and Vascular dementia (VD) is the second largest (20-25%).

2.2 LIVING WITH DEMENTIA

Living with dementia means facing severe challenges in everyday life. Patients commonly suffer from major cognitive decline, including severe memory loss, as well as a decreased ability to judge and value situations, emotional impairments and changes in personality (Volicer & Hurley, 2003). Though these problems are mild in the beginning, they eventually become more severe and the experience of losing cognitive as well as emotional functions is described as terrifying (Tappen et al., 1997). Persons living with dementia suffer (Norberg, 2001) as they face difficulties in daily life; these difficulties can arise from situations that most healthy people take for granted, such as making simple decisions, communicating, eating, or walking (Tappen, Williams, Fishman, & Touhy, 1999).

In early stage dementia, the memory loss of a person with dementia might manifest as forgetting the temporal order of different events in their lives or the names of familiar objects, persons or places. As the disease progresses, increased impairment of cognitive abilities becomes evident. As it becomes more difficult to retrieve memories of recent experiences and disorientation becomes complete, the person with dementia fails to recognize even their relatives (Midence & Cunliffe, 1996). Also increased are difficulties speaking and making purposeful movements, and thereby washing and dressing, as well as recognizing their surroundings and thus orienting themselves (Redfern & Ross, 2006). At this stage, the person

with dementia will be in need of support and professional caring (Tappen et al., 1997). It is common that persons with dementia need to move to nursing homes, as they are not able to care for themselves nor are their next of kin (Margallo-Lana et al., 2001).

Suffering from dementia is described by both Clare (2008) and Redfern & Ross (2006) as losing one's self. Due to cognitive impairment, behavioral changes, depressions or lack of understanding communication, several researchers such as Volicer, Van der Steen and Frijters (2009) and Jervis and Manson (2007), state that persons with dementia commonly express so-called behavioral and psychological symptoms of dementia (BPSD) (Finkel, 2003). BPSD include a wide range of behaviors such as screaming, wandering or pacing, resisting care, verbal and physical aggression, putting on too many layers of clothing or disrobing inappropriately, inappropriate sexual behavior, sleep disturbance, hitting or scratching and psychosocial manifestations such as depression and psychosis (Buhr & White, 2007; Finkel, 2001). As many as 85% of persons with dementia living in nursing homes are reported to demonstrate BPSD (Ballard, Corbett, Chitramohan, & Aarsland, 2009), and aggression, irritability, and resistance are the most frequent behavior (Wetzels, Zuidema, de Jonghe, Verhey, & Koopmans, 2010; Zuidema, Derksen, Verhey, & Koopmans, 2007). Although the cause underlying the expression of BPSD depends of the level of cognitive impairment and anxiety, it can also be influenced by other problems such as infections, anemia, dehydration, hypoglycemia, hypo- or hyperthyroidism, and cardiovascular diseases (Williams, French, & Ferrell, 2006; Volicer, Lane, Panke, & Lyman, 2005).

The concept BPSD is frequently referred to in nursing research as problematic behaviors (Jervis & Manson, 2007), challenging behavior (Almvik, Rasmussen, & Woods, 2006), disruptive behaviors (Han et al., 2010) or demanding behaviors (Skovdahl, Fahlstrom, Horttana, Winblad, & Kihlgren, 2008). These behaviors are commonly thought to be difficult to hinder or deal with in care situations (Georges et al., 2008; Graneheim, Isaksson, Ljung, & Jansson, 2005; Skovdahl et al., 2008). BPSD is commonly expressed in close interaction with others, such as in caring situations. Thus, BPSD and especially expressions of resistance and aggression is common during morning care situations with persons with dementia (Almvik et al., 2006; Cohen Mansfield & Parpura Gill, 2007).

Resistiveness to care, defined as '*behaviors to withstand or oppose the effort of the caregiver during the provision of care*' is another concept used in nursing research to describe problematic behaviors during caring of persons with dementia. Resistiveness to care includes several behaviors, such as screaming, crying, pinching, and clenching of the mouth (Mahoney et al., 1999). The behaviors included in resistiveness to care can also be found in BPSD. In fact, several behaviors included in BPSD can also be referred to as emotional expressions, and although persons with dementia have impaired means of expressing themselves with words, they remain able to express both negative and positive emotions in other ways (Lawton, Van Haitsma, & Klapper, 1996; Phillips, Reid-Arndt, & Pak, 2010). Lawton et al. (1996) states that it is important to acknowledge the expression of positive or negative emotions of persons with dementia as an indicator of the individual's likes and dislikes, given their limited abilities to report on their own internal states.

2.3 PROFESSIONAL CAREGIVERS IN DEMENTIA CARE

Caregivers that experience high job satisfaction in dementia care describe having the perception or reward of delivering individualized care of good quality (Vernooij-Dassen et al., 2009). Additionally, caregivers experiencing an ability to maintain a relationship with persons with dementia and the ability to improve the status and quality of life for persons with dementia have high job satisfaction (Ryan, Nolan, Enderby, & Reid, 2004). Conversely, according to Vernooij-Dassen et al. (2009), job satisfaction is reduced when caregivers' experience an inability to deal problematic behaviors in persons with dementia.

In dementia care, the expressions of BPSD is a significant problem, and in close interaction situations such as the administration of personal care, expressions of BPSD is particularly evident, time consuming and challenging for the caregivers to manage (Åstrom et al., 2004; Isaksson, Graneheim, & Åstrom, 2009; Miyamoto, Tachimori, & Ito, 2010). Aggression towards caregivers can be perceived as violence in the workplace (Pulsford & Duxbury, 2006), and expressions of BPSD, especially aggression, screaming, and low Activity in Daily Life (ADL) levels among residents with dementia are correlated with higher caregiver burden (Vernooij-Dassen et al., 2009). Caregivers that are exposed to aggression from persons with dementia might react with feelings of depression and antipathy (Rabinowitz, Mausbach, & Gallagher-Thompson, 2009; Skovdahl, Kihlgren, & Kihlgren, 2003a), as well as feelings of insufficiency and powerlessness (Sandvide, Åström, Norberg, & Saveman, 2004; Skovdahl et al., 2003b). Sandvide et al. (2004) found that caregivers exposed to violence felt that their personal integrity had been invaded and that they were not respected in their profession. They also described being afraid of losing their job if they did not carry out their duties, as well as feelings of guilt from constraining the persons with dementia. Needham et al. (2005) stated in a review that caregivers' predominant feelings were anger, fear or anxiety, post-traumatic stress disorder symptoms, guilt, self-blame and shame when handling violence. These effects existed despite differing countries, cultures and nursing settings. Onishi et al. (2005) as well as Remington, Abdallah, Melillo, and Flanagan (2006) suggest that there is a clear negative association between a caregiver's burden and BPSD, which can lead to burnout for the caregiver and jeopardize his or her safety and health, and also endanger the level of care for the person with dementia due to constraint or the absence of care. Åstrom et al. (2004) and Sandvide et al. (2004) claim that caregivers exposed to BPSD might react with aggression towards the person with dementia. Graneheim et al. (2005) as well as Morgan et al. (2008) claim that caregivers are compelled to constrain persons with dementia in caring situations when exposed to BPSD. This commonly leads to increased problematic behavior from the person with dementia.

2.4 COMMUNICATION IN DEMENTIA CARE

Gaining mutuality between persons with dementia and caregivers is one of the most problematic aspects in dementia care (Hansebo & Kihlgren, 2002). Since persons with dementia suffer from major cognitive impairments, they have difficulties in recognizing and engaging with others and thus encounters with caregivers are commonly problematic (Buhr & White, 2007; O'Connor, Ames, Gardner, & King, 2009; Penrod et al., 2007; Simard & Volicer, 2009). Interaction with caregivers is crucial during caring, and in these situations

persons with dementia commonly express BPSD, especially resistance and aggression (Buhr & White, 2007; O'Connor et al., 2009). It has been suggested that the aggressive behaviors of persons with dementia are grounded in the difficulties they face in interpreting and expressing verbal and non-verbal communication (Almvik et al., 2006). Linguistic function is typically impaired with dementia, leading to expressions of aggression or resistance when their communications skills fail them (Acton, Yauk, Hopkins, & Mayhew, 2007; Matteau, Landreville, Laplante, & Laplante, 2003). Marshall and Rossman (2006) suggest that communication is a two-way street consisting of give-and-take exchanges; verbal exchanges between a listener and a speaker, or non-verbal exchanges including body movements, eye contact, and eye movements (ibid). As persons with dementia have problems in both interpreting and expressing themselves, mutual communication is hard to accomplish. Caregivers have difficulties addressing the source of the behavior, and for both persons with dementia and caregivers, improving communication in dementia care is crucial to gain mutuality in caring situations.

Several strategies have been investigated in an attempt to facilitate communication and thereby minimize the expressions of BPSD (Small, Gutman, Makela, & Hillhouse, 2003; Vasse, Vernooij-Dassen, Spijker, Rikkert, & Koopmans, 2009). One way to achieve this, according to nursing researchers Normann, Henriksen, Norberg, and Asplund (2005), is for the caregiver to both support the patient and avoid demands in the communication in order to resemble communion or mutuality in the relationship with persons with dementia.

Studies of communication in dementia care generally frame the issue in terms of verbal communication, and have delivered conflicting results. For example, Potkins et al. (2003) suggested that caregivers should speak slowly and in short sentences, ask closed-ended questions, and talk about concrete matters. Small et al. (2003), in contrast, argues that slower speech is ineffective as persons with dementia forget the earlier part of the utterance, and that too much verbal communication and too many demands made by caregivers might be challenging for the persons with dementia, and thereby lead to problematic behaviors. They instead suggest that questions should be asked in a manner that limits demands, and that caregivers should encourage persons with dementia with their speech. Christenson, Buchanan, Houlihan, and Wanzek (2011) recommend using 'alpha commands', which are commands that are clear, concise and feasible and will make persons with dementia more likely to comply during caring activities. Williams and Herman (2011) proposed that caregivers should use an emotional tone of voice that is caring and respectful, and by that decrease expressions of resistance during caring.

Vasse et al. (2009) completed a review of studies focused on communication strategies, including non-verbal communication such as emotion expression, Snoozelen or Validation therapy, and Reminiscence therapy. These therapies showed improvement in communication between caregivers and persons with dementia but were not applied during caring situations. Studies that were focused on improving verbal conversation during activities revealed that persons with dementia had difficulties in performing different tasks, such as those included in ADL or walking while talking. Although BPSD are thought to be rooted in communication

difficulties, the review found only marginal effects in decreasing these behaviors. In fact only 4 out of 19 studies demonstrated positive effects in decreasing BPSD.

2.5 PHILOSOPHY AND CARING PERSPECTIVE

The philosopher Lévinas (1993) described humans as fellow creatures of other humans. When meeting other humans, it is possible to see them in one of two ways. One way is in *totality*; to categorize the other human and see them as objects. Our own thoughts about this human reduce them to the category in which we want to place them, and we are not open to seeing what is new and unique in the other. When we see other people in *totality*, it is possible to tyrannize and have authority over them. To see the other person in *eternity*, on the other hand, is to see the other as something that our own minds cannot understand with our thoughts. In *eternity*, the other person is seen as something bigger and we are thereby more likely to be open to the other person instead of categorizing them. Lévinas (1993) suggested that by truly meeting another human face to face is to meet them in *eternity*, as once we see another's uniqueness it is not possible to tyrannize that person.

The philosopher Buber (2004) described meetings between humans in a somewhat similar way, and claimed that humans are able to meet either as two subjects ("I-Thou") or as subjects and objects ("I-It"). An "I-It" meeting is characterized by objectification, abstraction and categorization of the other. In contrast, an "I-Thou" meeting is characterized by mutuality, equality, and engagement with mutual communication. Paterson and Zderad (1988) interpreted Buber's relation philosophy within the caring context, and suggest that caring should consist of 'doing' and 'being'; that is, caring should not only consist of the practicality of providing care, 'doing', but also involves 'being' with the patient, as one person in relation to another, as in Buber's (2004) description of "I-Thou".

Paterson and Zderad (1988) also influenced nursing theorists Boykin and Schoenhofer (1993) during the development of their theory about caring in nursing. They, as well as Watson (2008), suggested that caring is at the heart of nursing and that it facilitates the maintenance of health and preserves the human dignity of the patient. Watson (2008) further proposed that caring means being in relation to someone which involves grasping and gaining access to each human in order to understand their specific values. Watson (2008) and Boykin and Schoenhofer (1993) stated that caring can only be clearly demonstrated through the interpersonal relationship between nurse and patient, and should involve effective and mutual communication characterized by give and take. Boykin and Schoenhofer (1993) suggested that the caregiving situation should be conceptualized as a shared lived experience in an interpersonal relationship between the nurse and the patient, and this is developed when the two present themselves as wanting to offer and receive professional nursing service. Paterson and Zderad (1988) also argued that the interaction between caregiver and patient is the locus of caring and that the caregiver and the patient are urged to be present in the encounter. However, complete mutuality in the caring relation is not possible as the patient is in need of the caregiver's professional services and thus in a weak position. Watson (2008) stated that there should be a dialogue between caregiver and patient, the caregiver should acknowledge the patient as a whole human being and demonstrate, both verbally and non-verbally, that they are able to listen to the patient.

2.5.1 Caring for persons with dementia

In 1992, research on caring for persons with dementia suggested Goal-directed care, including the five following goals for the persons with dementia during care: feel safe, feel comfortable, experience a sense of control, minimal stress, and have adequate positive stimulation and pleasure. To reach these goals, the caregivers should be relaxed, flexible, smiling, maintaining eye contact, use positive and caring tone, and say positive things about the persons with dementia. Persons with dementia should be given the opportunity to participate to whatever degree they can in their ADL, while not burdening them with too many directions at once (Ryden & Feldt, 1992). Kihlgren et al. (1993) analyzed educational interventions for caregivers and found that caring should promote integrity and enhance the possibility for persons with dementia to take part in decisions and activities. Ekman (1996) and Runci, Doyle, and Redman (1999) suggested that bilingual caregivers speaking the native language of immigrated persons with dementia promoted enhanced care. Consoling care was described by Norberg (2001), who suggested that living with dementia means suffering and persons with dementia therefore need consoling care. The center of consolation is communion, which involves sharing with persons with dementia on an intimate personal level. This provides comfort and consolation and eases the suffering of persons with dementia.

Kitwood (1997) provided a psychosocial perspective on dementia care, and was the first to suggest that caring should be individualized (so called “person centered”). He further emphasized that we do not exist in isolation, but rather each have a ‘context’ in which our personhood is manifested. Persons with dementia should be approached on their own terms and should foremost be seen as human, with a secondary focus on their disease. Kitwood’s definition of “person-centredness” was informed by several philosophies, including Buber (1984). Nursing researcher McCormack (2004) performed a literature review and linked Kitwood’s perspective of person-centredness to caring practice. McCormack (2004) defines person-centered care in terms of four concepts: *being in relation*- the person with dementia exists in relationships with others, *being in social world*- persons are social beings, *being in place*- persons have a context through which their personhood is articulated, *being with self*- being recognized, respected and trusted as a person as they impact their own sense of self. The contents of these concepts are also implicated in many other models of nursing, particularly those with humanistic philosophical underpinning, such as those previously mentioned from Watson (1985) and Boykin and Schoenhofer (1993).

Edvardsson, Winblad, and Sandman (2008), Normann et al. (2006), and Penrod et al. (2007) have supported the person-centered approach for caring and conceptualized this by suggesting that caring should acknowledge each person with dementia for their “personhood”. Edvardsson et al. (2008) pointed out the keystones of person-centered care, and suggested that the personhood of persons with dementia should be considered in all aspects of care. Caring should be characterized by the recognition that the personality of persons with dementia is increasingly concealed rather than lost. Personalization of the persons with dementia care and their environment, and that the persons with dementia should be offered shared decision-making. The behavior of persons with dementia should be

interpreted from the point of view of the person and their relationship with the caregiver, and this should be prioritized to the same degree as the care tasks.

McKeown, Clarke, Ingleton, Ryan, and Repper (2010) suggested that acknowledging the life story of persons with dementia, as done in person centered care, has the potential to enable care staff to see the person behind the patient and to enable the voice of the person with dementia to be heard, verbally and non-verbally. It also enables person with dementia to feel proud about themselves and their lives. Normann et al. (2005) and Normann, Norberg, and Asplund (2002) suggested that person-centered care facilitates communion between caregiver and persons with dementia. When the caregiver has a supportive attitude and avoids making demands in the communication, persons with dementia may express episodes of lucidity (Normann et al., 2006; Normann, Asplund, & Norberg, 1998) by unexpectedly talking or acting in a way that reveals an awareness of their situation. After reviewing the literature, Enmarker, Olsen and Hellzen (2010) suggested that person-centered approaches were the most effective in managing aggressive and violent behaviors and improving communication. Hoeffler et al. (2006) and Rader et al. (2006) suggested that person-centered approaches reduce agitation, aggression and discomfort of persons with dementia during the caring activities showering and bathing.

In their outlines for practicing person-centered care for persons with dementia, the Swedish National Board of Health and Welfare (2010) described person-centered care as having the experiences and reality of persons with dementia in focus, and multi-professional adequately educated staff should work in teams. Expressions of BPSD should be elucidated from the perspective of the person with dementia and the staff should strive to maintain the patient's social network as well as their own relationship with the person with dementia. The self-determinations of persons with dementia should be preserved and they should be seen as active companions in daily care. However, in the articles concerning person-centered care (Edvardsson et al., 2008; McCormack, 2004; McKeown et al., 2010; Penrod et al., 2007; Runci et al., 1999), there was no information about what specific methods are used.

2.6 TREATMENT AND CARING INTERVENTIONS IN DEMENTIA CARE

In dementia care, Ballard, Wait and Birks (2008) point out that pharmacological treatment are often the first line of treatment, and non-pharmacological treatment is next in line. They further suggest that non-pharmacological treatment should be considered first, but that both kinds should be used if necessary.

2.6.1 Pharmacological treatment

Alzheimer's disease is the most common cause of dementia and is associated with loss of cholinergic neurons of the brain. Medications with cholinesterase inhibitors delay this loss. There are conflicting opinions concerning the effectiveness of cholinesterase inhibitors. For instance, Birks (2006) suggested that they increase cognitive and ADL functions, and decreased problematic behaviors for persons with mild to moderate dementia. Gasper, Ott, and Lapane (2005) have suggested that due to the effects of cholinesterase inhibitors, persons with Alzheimer's disease will live longer, while Suh et al. (2011) stated that cholinesterase inhibitors do not prolong the lives of persons with dementia.

Despite evidence of only modest efficacy, pharmacological treatments with antipsychotics are generally the first line of treatment for BPSD. However, these medications are associated with considerable side effects and do not treat the underlying causes of the behavior. They also provide only temporary relief in terms of preventing BPSD (Ballard, et al., 2009; Dettmore, Kolanowski, & Boustani, 2009; Kverno, Black, Nolan, & Rabins, 2009). Antipsychotic medications have a particularly high risk of seriously side effects for persons with dementia and it is recommended that these should be used with extreme caution. Antipsychotics increase the risk for persons with dementia of falling and drowsiness is common in almost all antipsychotics. Additionally, side effects such as tremor, dizziness, reduced well-being, social withdrawal, accelerated cognitive decline, and stroke may occur with antipsychotics. It is nevertheless common that persons with dementia are over prescribed with these medications, and despite the fact that antipsychotics are often prescribed they are not actually licensed for use for people with dementia (Ballard et al., 2008). Persons with dementia are also commonly described as depressive. Although diagnosing depression in persons with dementia can be difficult, due to denial and cognitive impairment, it is nevertheless common that they are prescribed anti depressive medications and it is unclear exactly what kinds of effects these medications have (Bains, Birks, & Denning, 2009).

2.6.2 Non-Pharmacological treatments

Although non-pharmacological treatments are cost effective, they are generally underutilized for persons with dementia, despite their potential to reduce BPSD without the risks associated with pharmacological treatment (Dettmore et al., 2009; Herrmann & Gauthier, 2008). A majority of research concerning the treatment of persons with dementia has found that non-pharmacological treatment should be considered before pharmacological treatment, in order to make life as pleasant as possible, with meaningful encounters between patients and caregivers, by increasing mutual communication and resolving BPSD (The Swedish Medical Product Agency, 2008; Cohen-Mansfield, Marx, Thein, & Dakheel-Ali, 2010; Herrmann and Gauthier, 2008; Kverno et al., 2009; Ballard et al., 2009; Vasse et al., 2009).

A common component of several non-pharmacological treatments is called ‘Care intervention’ (The Swedish Council on Technology Assessment in Health Care [SBU], 2008b), which is an overarching concept including different interventions. Some of these interventions are direct and aim to be incorporated into daily care in order to illuminate or alleviate symptoms. Other interventions are indirect, aiming to create a positive environment at a nursing home or to increase caregivers’ knowledge about caring for persons with dementia (ibid). However, reviews of various care interventions, including Reminiscence Therapy (SBU, 2008b; Woods et al., 2005), Cognitive Rehabilitation Therapy (Clare et al., 2003), Validation Therapy (Neal & Briggs, 2003), Reality Orientation (Spector, Orrell, Davies, & Woods, 2000), Behavioral Therapy, Touch and Massage, and Light Therapy (SBU, 2008b), have found that a majority of both the qualitative and quantitative studies vary in quality, and as none of the studies have been repeated, it is difficult to draw any general conclusions as to their effects.

2.6.3 Music and human beings

All human cultures have some relation to music, and music has been an important part of human lives since as far back as we know about. Music, rhythm, and movements come naturally to humans. A child's joy is awakened by melodies, rhythms, and dancing and music engages humans, irrespective age, and stimulates emotions. Music can be consoling, provoke joy, improve or worsen moods, and even create encounters between people. Everyone is somehow affected by music and has some relationship to music. Music has been a part of human lives from the very beginning to the end thanks to the human brain with its capacities (Fagius, 2001). The sub-section is divided into two parts; the first provides some background information about the effects of music on the various parts of the brain, and the second describes the benefits of music specifically in dementia care.

2.6.3.1 Music and the Brain

Although music has been used as a therapy in many areas, including dementia care, the mechanism behind its healing remains unclear (Lin et al., 2011). Fagius (2001) suggested that every human, regardless of musical training, has the ability to enjoy music in some way, meaning that every human brain has a musical ability. Levitin (2007) and Zatorre and McGill (2005) proposed that musical activity involves nearly every region of the brain, and when some part of it is impaired, humans might perceive musical activity with other regions. Zatorre and McGill (2005) further suggested that when listening to music the inner ear translates the sound waves into neural impulses, which continue through several way stations in the brainstem and midbrain before reaching the auditory cortex in both hemispheres of the brain.

Trying to follow along with familiar music recruits additional regions of the brain, including the hippocampus (the memory center) and subsections of the frontal lobe, particularly the lowest regions called inferior frontal cortex. Tapping along with music, either physically or just mentally, involves the cerebellum's timing circuits. Levitin (2007) suggested that performing music, regardless of which instrument is played or whether the music is sung, engages the frontal lobes for the planning of the behavior, as well as the motor cortex in the parietal lobe and the sensory cortex, which provide the tactile feedback necessary to press the right key on the instrument or to moved the baton in the right way. Zatorre and McGill (2005) stated that listening to or recalling lyrics invokes language centers and the memory center, in the temporal and frontal lobes, respectively. At a deeper level, the emotions experienced in response to music could be seen as the locus, and involve structures deep in the primitive reptilian regions of the cerebellar vermis as well as the amygdala, the heart of emotional processing in the cortex. In addition, Fagius (2001), Levitin (2007), and Zatorre and McGill (2005) have stated that there is no single language center, nor is there a single music center. Rather, there are regions that perform component operations, and other regions that coordinate this information. Stewart, von Kriegstein, Warren and Griffiths (2006) have also argued that music activates different parts of the brain, depending on the many musical elements such as melody, rhythm, accent, and timbre. They further suggest that the combination of language and music, as in singing, offers a greater chance of activating intact neurological pathways than simply using language alone. Singing has been shown to be beneficial in other areas; Wan and Schlaug (2010) focused on children with autism that have

difficulties with speech and in social interactions, and could suggest that singing enhances their ability of interact with others, as well as to communicate both verbally and non-verbally.

2.6.3.2 *The Use of Music in Dementia Care*

The use of music has been suggested to be included in care interventions for persons with dementia (SBU, 2008b; Skingley & Vella-Burrows, 2010). In a review of the use of music in dementia care in which randomized controlled trials were used, Vink, Birks, Bruinsma and Scholten (2007) suggested that though background music can be used for stimulation, no general conclusions or recommendations could be made. Music therapy involves a therapist leading a music session with one or several persons with dementia, and has been recommended as a way for persons with dementia to successfully communicate and socialize with others (Raglio and Gianelli, 2009 and Raglio et al., 2010).

During music therapy, when persons with dementia listen to music, play instruments or sing, their expressions of BPSD decrease (Guétin et al., 2009a; Hulme, Wright, Crocker, Oluboyede, & House, 2009; Ridder & Aldridge, 2005), while engagement (Lin et al., 2011) and expressions of positive emotions increase (Bigand, Filipic, & Lalitte, 2005; Lin et al., 2011). Several studies have revealed that persons with dementia are able to sing and thereby remember song texts even though they rarely speak or form sentences (Chatterton, Baker, & Morgan, 2010; Clair, Mathews, & Kosloski, 2005; Raglio & Gianelli, 2009), and Simmons-Stern, Budson, and Ally (2010) found that persons with dementia remembered lyrics of songs if those lyrics were sung and not if they were read.

In a review of non-pharmacological strategies, Kverno et al. (2009) suggested that live music or preferred music is beneficial and may reduce the expressions of BPSD in persons with dementia. However, the authors concluded that the studies vary in quality and more research is needed that focuses on persons with severe dementia. Furthermore, the meta-summary of nursing studies by SBU (2008b) found that it is possible to communicate and establish positive relationships with persons with dementia and bring out their latent abilities when using music, dancing, and singing. However, none of the studies included in this meta-summary have been repeated and, as they varied in quality, more good quality studies are needed to provide evidence for best practice.

It has been suggest in nursing care that individualized music listening may reduce the expressions of BPSD in persons with dementia (Ragneskog, Asplund, Kihlgren, and Norberg, 2001; Ragneskog, Brane, Karlsson, and Kihlgren, 1996; Gerdner, 2000, 2005), as well as lead to relaxation (Norberg, Melin, and Asplund, 2003). Götell, Brown, and Ekman (2000) found that when caregivers and persons with dementia were participating during music sessions, the caregivers as well as the persons with dementia revealed positive emotions. The caregivers stated that the persons with dementia were easier to care for throughout the rest of the day, though not the day after. However, Thomas, Heitman, and Alexander (1997) argued that the possible influences from music sessions or music listening is only temporary, and when the music session is over, expressions of BPSD might arise once again. It has been argued that BPSD commonly occurs during caring, and therefore future studies should focus on caring

interventions that aim to be implemented during caring situations (Cohen-Mansfield & Parpura Gill, 2007; Kolanowski, Fick, Frazer, & Penrod, 2010; and Kverno et al., 2009).

Although few studies of music during caring have been conducted, Cohen-Mansfield (2007), Hulme et al. (2009), and Thomas et al. (1997) suggested that listening to music during bathing reduces BPSD and relaxes persons with dementia. Even fewer studies have been conducted on singing during caring. Chatterton et al. (2010) concluded that when singing during caring, the caregivers improved caregiving experiences for themselves as well for persons with dementia. The authors suggested that singing seemed to improve quality of life for the persons with dementia, regardless of the qualifications or singing ability of the singer. It appeared that singing during caring was more effective than music therapy. The authors therefore suggested that music therapist should empower caregivers to sing.

2.6.4 Singing during caring for persons with dementia

As a first attempt, Götell (2003) used qualitative methods to analyze video recorded observations (VIOs) focusing on communication between nine persons with dementia and their professional caregivers during morning care situations. Activities were first carried out in 'the usual way', and then with individualized background music listening, and finally when the caregivers were singing for or together with the persons with dementia, so-called 'Music Therapeutic Caregiving' (MTC) (Brown, Götell, & Ekman, 2001). The situations were video recorded and took place one time per person with dementia.

During MTC, the caregivers as well as the persons with dementia expressed an altered way of communicating as compared to the two other sessions. The persons with dementia abated their expressions of aggression and screaming, and the caregivers instructions ceased almost entirely. Instead, the caregivers sang well-known children's songs, popular songs about nature, love etc. The persons with dementia and the caregivers seemed to coexist in a mutually comprehensive context, and their verbal communication was enhanced (Götell, Brown, & Ekman, 2002). Dennis (2011) had similar findings in a study designed as a follow up the study to Götell et al. (2002). Engström, Hammar Marmstål, Williams, and Götell (2010) found increased positive verbal and non-verbal communication and decreased negative verbal and non-verbal communication in a single case study during MTC. When focusing on body movements and sensory awareness, Götell, Brown, and Ekman (2003) found that the persons with dementia had upright posture with relaxed straight shoulders during MTC. They moved in a calm, smooth and harmonious manner, and they had warm, smiling, and blissful faces. They swayed their bodies and hands to the rhythm and were focused on the caregiver, looking into their faces. Some persons with dementia sang along or hummed. Compared to the other sessions (usual morning care and with background music), they seemed to perform tasks with enhanced decisiveness, drive and completeness. Their ability to wash and dress themselves also appeared enhanced, and they needed decreased amounts coaching from the caregivers. In a study focusing on emotions and moods (Götell, Brown, and Ekman, 2009), MTC seemed to alter the characteristics of the emotions and moods of both the caregivers and the persons with dementia compared to previous sessions. Negative expressed emotions, such as aggression or screaming, were largely abated. While the persons with dementia listened to the caregivers' singing, they did so attentively and

responded with sincerity, delight and wonder, and their voices were relaxed and calm (ibid). Several studies have concluded that it was an advantage to use MTC as compared to usual morning care situation (Götell, 2003; Dennis, 2011; Engström et al., 2010). Götell (2003) further suggested that MTC was a way for the caregivers and the persons with dementia to communicate on a mutual basis, leading to cooperation. However, in the studies included in the thesis by Götell (2003), the participating persons with dementia and their caregivers were observed only once during usual morning care, one time during background music, and one time during MTC, and there no repeated studies were conducted. This makes it impossible to draw meaningful conclusions about the value of MTC use in every day dementia care.

3 RATIONALE

The number of persons with dementia is increasing rapidly worldwide, and due to the increased cognitive impairment of persons with dementia, they are in need of professional care. Cognitive impairments, communication difficulties and expressions of BPSD are considered obstacles for gaining mutual togetherness in the caring relationship between persons with dementia and their caregivers, and it has become a serious concern of how to develop care in favor of both the persons with dementia and their caregivers.

It has been suggested that care interventions should be used to decrease expressions of BPSD and to enhance mutuality and communication between persons with dementia and their caregivers. However, studies of care interventions vary in quality and have not been repeated, making general conclusions concerning their efficacies difficult. The intervention involving caregivers singing during caring, so called Music Therapeutic Caregiving (MTC), was found to be a good method for decreasing problematic and enhancing positive behaviors in persons with dementia, and communication in the caring relationship. Due to the considerable positive influences on persons with dementia that have been described, it would be interesting to conduct additional studies to solidify these results. However, in early studies investigating and also discovering MTC, the conclusions drawn by the researchers were solely based on observations. Thus, the caregivers' experiences of caring for the persons with dementia with and without MTC were not elucidated, there were no repeated sessions of MTC, or the intervention did not take place over an extended period of time. Furthermore, no statistical analysis was done of the data. The persons with dementia participated only once during the MTC session and it was not possible to draw any general conclusions as to its effects.

The present thesis was carefully designed with repeated sessions of morning care situations involving persons with dementia and their caregivers, both with or without MTC, and with qualitative and quantitative methods. The positive and negative expressions of the persons with dementia were noted, as well as the quantity of these expressions that occurred during the situations with and without MTC. The caregivers' experiences of the situations were also acknowledged, especially since this had not been done before. The communication between the persons with dementia and their caregivers was also described, as it is considered to be an important part of the interaction.

4 AIM OF THE THESIS

The overall aim of this thesis was to demonstrate if and in that case how the intervention of using MTC impacted the participants of this study, which included patients with severe dementia and their caregivers.

4.1 AIMS OF STUDIES I-V

- Study I:** The aim was to describe professional caregivers' experiences of caring for persons with dementia during morning care situations without and with Music Therapeutic Caregiving.
- Study II:** The aim was to present professional caregivers' experiences of persons with dementia during morning care situations without and with Music Therapeutic Caregiving.
- Study III:** The aim was to describe how persons with dementia and their caregivers express verbal and non-verbal communication and make eye contact during the caring activity 'getting dressed' during morning care situations without and with Music Therapeutic Caregiving.
- Study IV:** The aim was to describe expressed emotions and expressions of resistiveness to care in two nursing home residents with severe dementia, during morning care situations without and with Music Therapeutic Caregiving.
- Study V:** The aim was to describe expressions of emotions and resistiveness to care among persons with dementia during morning care situations without and with Music Therapeutic Caregiving.

5 METHODS

The thesis presents an intervention study in dementia care, using MTC as a caring intervention. Video observation (VIOs) and Group Interviews (GIs) were utilized to conduct the study. The following analysis methods were used to analyze the data: qualitative content analysis, quantitative student t-test, and quantitative single case approach. Thus, the thesis includes three studies with a qualitative approach (study **I**, **II**, and **III**), and two studies with a quantitative approach (study **IV** and **V**).

5.1 CONTEXT AND PARTICIPANTS

The data collections were conducted at two nursing homes (A and B) for persons with dementia located in a medium sized town in an urban area of Sweden. Participants were severe persons with dementia living at the two homes and caregivers working at the homes. The nursing homes were built quite similarly, with about 50 persons with dementia living in each home. The nursing homes were divided into at six different wards, and about six to ten persons with dementia lived at each ward. All persons with dementia had their own room with their own belongings, a small kitchen, and a bathroom. A large kitchen, dining room, and TV-room were located in the middle of the ward. All meals were prepared and eaten in the dining rooms, and the persons with dementia spent most of their time at these public areas of the wards.

All persons with dementia at the nursing homes were diagnosed with severe dementia and therefore considered eligible to participate in the study. However, to limit the number of participants, the head nurses at the homes nominated twelve persons with dementia to participate in the study. These persons lived in two wards in the two respective nursing homes, meaning that two whole wards were selected with six persons with dementia in each ward. The inclusion criteria were that they should be native Swedish speakers and, according to the head nurse's perception, had an extensive history of interaction with the caregivers working at the wards, including during morning care situations.

Of the twelve persons with dementia, two died during the data collection (the data collected, was erased and excluded from the study). Thus, ten persons with dementia participated in the study, six women and four men. According to their medical records, five of the persons with dementia were diagnosed with VD and five were diagnosed with AD. To elucidate cognitive functions of the persons with dementia, Mini-mental state examinations (MMSE) (Folstein, Folstein, & McHugh, 1975) were conducted. The scores were between 12-0, and the mean value was 3.3. The results indicated that all the persons with dementia had severe dementia, and all persons with dementia required considerable help and support in performing ADL. Table 1 provides information of the persons with dementia in this study.

Table 1: Study Participants – Persons with Dementia.

Persons with Dementia	Age	Sex	Diagnosis	MMSE	Nursing Home
1	86	Man	VD	0	A
2	79	Female	AD	6	A
3	66	Female	AD	0	A
4	87	Female	VD	8	A
5	92	Female	AD	12	A
6	88	Female	VD	0	A
7	82	Man	VD	4	B
8	76	Man	AD	0	B
9	71	Man	VD	0	B
10	86	Female	AD	3	B

The head nurses also nominated the participating caregivers based on the criterion that they had been working in dementia care for at least two years, be native Swedish speakers, and have an extensive history of interacting with the participating persons with dementia during morning care situations. Based on those criteria, all ten caregivers working at the wards (all female, five at each ward) were nominated by the head nurses and asked to participate in the study. Of these women, two declined due to health problems, one withdrew her participation, and one terminated her participation when the patient she was caring for passed away (none of these caregivers was included in the data collection). Hence, six caregivers participated in this study, three at each home. They were between 31 and 54 years old, four were educated as assistant nurses (AN) and two were trained as nursing aides (NA). The caregivers were responsible for, among other things, the personal hygiene of the persons with dementia. They had been working in dementia care between 2.5 and 30 years, and were native Swedish speakers. They all had extensive experience with caring for the persons with dementia in the project. Table 2 provides information about the caregivers.

Table 2: Age, sex and education among the participating caregivers.

Caregivers	Age	Sex	Education	Years working in dementia care	Nursing home
1	54	Female	AN	30	A
2	32	Female	NA	3	A
3	31	Female	AN	3	A
4	44	Female	AN	2,5	B
5	49	Female	NA	30	B
6	36	Female	AN	6	B

5.2 RESEARCH SITUATION AND INTERVENTION

The research situation studied was the ‘morning care situation’ with the participating persons with dementia and the caregivers. The “usual” morning care situation (meaning caring was done as they usually do) constituted the baseline situation, and the “intervention” situation (Polit & Beck, 2008) constituted morning care situations with MTC, in which the caregivers sang for or together with the persons with dementia while caring for them.

A typical morning care situation involved the caregiver helping the person with dementia from the bed to the bathroom, where the person with dementia sat down on the toilet and had their nightclothes removed. The patients’ faces and upper bodies were washed and deodorant and lotion were applied. The upper body was dressed and the lower body was then washed (camera directed on upper body). Socks and shoes were put on, and the persons with dementia were led to the sink (three of them in wheelchairs), and directed towards the mirror. While at the sink, their teeth were brushed (four of them by themselves), and their hair was combed (two of them by themselves). The morning care situation ended when the persons with dementia and the caregivers left the bathroom. The caregivers were instructed to communicate verbally and non-verbally as they usual did during morning care situations.

All caregivers were given training in preparation of the MTC situations after participating in the usual morning care situation. They were offered a course in MTC (Music Therapeutic Caregiving I, MKM019), which included theories about MTC, music and health, using body movements to accompany singing, and learning songs from elderly people’s childhood and young adult years. Two of the caregivers completed the course and final exam, while the others were instructed on how to use MTC by the author of this thesis. These instructions included lectures about previous studies of MTC, basic singing techniques, and learning suitable songs. During the interventions, specific songs were sung that the elderly would ordinarily recognize from their past, such as children’s songs, sing-along songs and popular songs from the early part of the 20th century.

5.3 DATA COLLECTION

Data of the project consisted of video observations (VIOs) of the morning care situations with and without MTC and group interviews (GIs) with the caregivers about their experiences of the caring situations with and without MTC. The VIOs provided data for study **III**, **IV** and **V**, and GIs for study **I**, and **II**.

5.3.1 Video Observations

VIOs (Haidet, Tate, Divirgilio-Thomas, Kolanowski, & Happ, 2009; Latvala, Voukila-Oikkonen, & Janhonen, 2000) were used for data collection in an attempt to capture both verbal and non-verbal communication between the persons with dementia and the caregivers (study **III**). VIOs were also used to measure the duration of verbal and non-verbal expressions of emotions and resistance in a single case study (Kazdin, 2003) of two of the persons with dementia (study **IV**), as well as to measure the duration of verbal and

non-verbal expressions of emotions, and resistance for all the persons with dementia (study **IV**). VIOs have been used in several studies in dementia care, such as Hansebo and Kihlgren (2002) and Palo-Bengtsson, Winblad, and Ekman (1998).

The persons with dementia and the caregivers were observed by the author of this thesis while performing morning care routines. The author was with them in the bathrooms and filmed the activities of the persons with dementia and their caregivers. Each patient was observed a total of eight times over eight weeks; once a week per person with dementia during usual morning care situations and once a week per person with dementia during morning care situations with MTC intervention. The data collection involved 80 VIOs, capturing approximately 20 hours of film.

5.3.2 Group Interviews

One GI was conducted in each home as a focus group interview (Côte Arsenault & Morrison Beedy, 2005) with the caregivers following VIOs of the usual morning care situation, in order to ask them about their experiences of the usual morning care situations. After the VIOs of morning care situations with MTC, an additional GI with the caregivers was conducted in each home in order to interview them about their experiences of morning care situations with MTC. The interviews were held in a conference room at the nursing homes where the participating caregivers worked. The GIs were tape-recorded and lasted about one hour each, for a total of about four hours. The interviews were unstructured with open-ended questions and guidelines from the moderator (Polit & Beck, 2008) to encourage discussion in the groups. GIs after the usual morning care situations without singing had one main question: *Could you please tell me about your experiences in caring for the persons with dementia during morning care situations?* This question was followed up with probing questions (Polit & Beck, 2008). The question asked after the intervention was: *Could you please tell me about your experiences in caring for the persons with dementia during morning care situations with MTC?* This question was also followed up with probing questions, and these questions varied depending on the caregivers' answers and discussions. The author of this thesis carried out the GIs and acted as the moderator with assistance from the main supervisor (Eva Götell) in the project. The descriptions of the caregivers' experiences during the two situations constituted data for study **I**, which describes caregivers' experiences of the situations with and without MTC, and study **II**, which describes caregivers' experiences of the reactions of persons with dementia during the situations with and without MTC.

The data collection started in January 2007 and was completed in June 2007. Table 3 describes the order of the data collection in Home A and Home B.

Table 3: Data collection of the two nursing homes

HOME A	HOME B
VIO of usual morning care situation, four weeks	VIO of usual morning care situation, four weeks
GIs	GIs
VIO of intervention (MTC), four weeks	VIO of intervention (MTC), four weeks
GIs	GIs

5.4 DATA ANALYSIS

In studies **I**, **II** and **III**, qualitative content analysis was used when analyzing GIs and VIOs. Qualitative content analysis can be inductive or deductive (Hsieh & Shannon, 2005), though the inductive approach is the most common in health care research (Elo & Kyngäs, 2008). Content analysis could also be latent or manifest, where “latent” refers to the content and underlying meaning (what the text speaks about) (Baxter, 1991; Downe-Wambold, 1992; Krippendorff, 2004, Sandelowski, 2000), and “manifest” describes the visible and obvious components (what the text says) (Baxter, 1991, Graneheim & Lundman, 2004; Krippendorff, 2004). Content analysis aims to make replicable and valid conclusions from data in reference to their context, with the purpose of providing knowledge, new insights, and practical guides to action (Krippendorff, 2004). Content analysis does not urge a pre-existing theoretical or philosophical commitment, in contrast to e.g. phenomenology or ethnography (Sandelowski, 2000), since it is a descriptive analyzing method aiming to describe the phenomenon as it is and to let the phenomenon speak for its self (Lincoln & Guba, 1985).

Qualitative content analysis is a dynamic form of analysis of the verbal and visual that is oriented towards summarizing the contents of the data (Hsieh & Shannon, 2005, Krippendorff, 2004; Neuendorf, 2002; Sandelowski, 2000). It is focused on differences and similarities in the data, which are expressed through analysis in categories or themes (Baxter, 1991; Downe-Wambold, 1992; Graneheim & Lundman, 2004). When creating categories or themes, knowledge about the context is important in order to conduct valid interpretations of the data; thus no parts of the text can be excluded from its context. Content analysis is flexible in terms of design, can be applicable in various depths (Krippendorff, 2004; Neuendorf, 2002), and is suitable when analyzing communication between persons such as in interviews or in observations (Berg, 2004; Elo & Kyngäs, 2008; Graneheim & Lundman, 2004; Sandelowski, 2000).

In this thesis, latent qualitative content analysis, as described by Graneheim and Lundman (2004), was used for studies **I** and **II**. According to Graneheim and Lundman (2008), the epistemological and ontological basis in qualitative content analysis is unclear. However, the authors were inspired by Watzlawick, Beavin Bavelas, & Jackson (1967), who stated that in communication between humans there is an underlying meaning that needs to be interpreted,

and those who communicate are interpreting one another from their own perspectives. Graneheim and Lundman (2004) suggested that texts based on interviews or observations are shaped by an interaction between the researcher and the participants and thereby can be seen as a communicating act in which the messages have been interpreted and described. A qualitative content analysis could be a useful tool for interpreting these kinds of texts. This method has been used in dementia care research by nursing researchers (Erlingsson, Ono, Sasaki, & Saveman, 2011; Isaksson et al., 2009), as well as several researchers in geriatric nursing research (Andersson & Hansebo, 2009; Flackman, Hansebo, & Kihlgren, 2009; Graneheim & Lundman, 2010; Karlsson, 2007; Stenwall, 2009). This method was used to describe caregivers' experiences of caring for the persons with dementia with and without MTC (study **I**) and to describe their evaluations of the reactions of persons with dementia with and without MTC (study **II**). In study **III**, latent qualitative content analysis as described by nursing researchers Elo and Kyngäs (2008) was used to analyze communication between persons with dementia and their caregivers with and without MTC as revealed by VIOs. This method from Elo and Kyngäs (2008) has been used in several studies in nursing research, including Karlsson, Tisell, Engström, and Andershed (2011), and Korkiakangas et al. (2011).

In studies **I**, **II**, and **III**, the focus was on both caregivers and the persons with dementia. In studies **IV** and **V**, the VIOs were analyzed with the focus on the persons with dementia, as the scales were designed to analyze only their behaviors. In study **IV**, a single case design (Kazdin, 2003) was used to evaluate the expressed emotions and resistant behaviors of two of the persons with dementia, as well as the duration of these behaviors during the situations with and without MTC. In study **V**, student's t-test was used to compare mean values of the expressions of emotions and resistance of persons with dementia with and without MTC. The student's t-test is used when the aim is to compare the mean values of variables between groups (Campbell & Machin, 2000), and these groups that were compared in this study (**V**) were the usual morning care situations and the morning care situations with MTC.

5.4.1 Study I

The aim of study **I** was to describe professional caregivers' experiences of caring for persons with dementia during morning care situations without and with MTC. The GIs constituted the data, and qualitative content analysis as described by Graneheim and Lundman (2004) was conducted. A first reading was done to get a sense of the whole of the transcribed texts and two content areas emerged: 'handling resistance', which was based on the GIs concerning the usual morning care situations, and 'handling pliability', which was based on the GIs concerning the MTC situations. Thereafter, the text concerning the usual morning care situation and the text relating to the interviews about the MTC situation were analyzed separately. The texts were broken down into meaning units, which were words, sentences or phrases related to the aim of the study. The meaning units were condensed and labeled with codes, which could be discrete objects, events or other phenomena and were understood in relation to the context. The third step was to continuously compare the codes to identify both differences and similarities. Based on the codes, categories were developed, which were expressions of the manifest content of the text. The fourth step was to compare and critically analyze the categories, and six sub-themes were developed; four based on the analysis of the interviews about the usual morning care situation and two based on the interviews about the

MTC situation. The themes link together the underlying meanings in the categories and represent a red thread throughout the condensed meaning units, codes and categories on an interpretative level and expresses the latent content of the text. Finally, the four sub-themes based on the usual morning care situation were grouped into the first theme, *Struggling for care in communion*, and the two sub-themes based on the MTC situation were grouped into the second theme, *Consolidating care in communion*.

5.4.2 Study II

The aim in study II was to present professional caregivers' experiences of persons with dementia during morning care situations without and with MTC. The focus was on the reactions of the persons with dementia during the situations. The GIs constituted data and qualitative content analysis (Graneheim & Lundman, 2004) was conducted to analyze the resulting transcribed texts. The four GIs were read several times to get a sense of their entirety. Two content areas emerged, 'being in a foreign situation', which was based on the GIs about the usual morning care situations, and 'to recognize the situation', which was based on the GIs about the MTC situations. Henceforth, texts related to the GIs about the usual morning care situation and the GIs about the MTC situation were analyzed separately. The steps in the analysis process followed were those described above in study I, since the analysis also followed the model from Graneheim and Lundman (2004). In this analysis, eight sub-themes were developed; four based on the interviews about the usual morning care routines, and four based on the interviews about the MTC situations. A theme links the underlying meanings in the categories together, and is a red thread throughout the condensed meaning units, codes and categories on an interpretative level, and expresses the latent content of the text. The eight sub-themes formed two comprehensive themes: *Being in a different reality*, which were based on interviews about the usual morning care situations and *Being present*, which were based on the interviews about the MTC situations. An example of the analysis process is shown in Table 4.

Table 4: Example analysis process for study II.

Meaning unit	Code	Category	Sub-theme	Theme
She has an enormous concentration, and she is watching me all the time and is really listening.	Enormous concentration, and watching, and really listens	concentration, and focused on what is going on	Being engaged and empowered	Being present

5.4.3 Study III

The aim of study **III** was to describe how persons with dementia and their caregivers express verbal and non-verbal communication and make eye contact during the caring activity ‘getting dressed’ during morning care situations without and with MTC. The data consisted of 40 video observations (VIO) without MTC and 40 VIO with MTC. In total, the VIOs were constituted approximately 20 hours of film, which was considered to be unmanageable in relation to conducting a well-focused qualitative analysis. After viewing the VIOs several times, the impression was that the sequence ‘dressing the upper body’ involved a large amount of verbal and non-verbal communication between the persons with dementia and the caregivers, and for this reason that sequence was chosen for analysis in all the VIOs. This resulted in about 10 hours of film from the 80 episodes with dressing the persons with dementia’ upper bodies; 40 of usual morning care situations, and 40 of morning care situations with MTC.

The VIOs from the usual morning care situations, and morning care situations with MTC situations were analyzed separately. Verbal communication, non-verbal communication, and eye-movements during the VIO were transcribed into text. Verbal communication included speech, sounds and singing. Non-verbal communication included body movements, eye-movements and eye contact. Qualitative content analysis described by nursing researchers Elo and Kyngäs (2008) was used to analyze the transcriptions. The transcriptions were read thoroughly and coded; content that related to the study’s aim was denoted, first in the margins of the text and then on a coding sheet. The codes were grouped based on differences and similarities, and abstracted under higher order headings into sub-categories. The sub-categories were compared and critically analyzed and grouped with similar events and incidents, and through interpretation generic categories were developed. An example of the analysis process is shown in Table 5. The analysis generated five generic categories for the usual morning care situation and three for the morning care situations with MTC. These are presented in the result section.

Table 5: Example of the analysis process from study III

Transcription	Code	Sub-category	Generic category
Caregiver: “Safer could no one be...” (singing an old psalm). She holds a bra in front of the PWD* so she can put her hands in it. Looks at the PWD’s face as if to attempt to make eye contact. Patient: “...than God’s little children, not the star in the sky...” (singing the psalm). Puts her hands in the bra and helps to pull her arms through it. Looks at the bra, and then at the caregiver.	The caregiver strives to communicate non-verbally by trying to get the PWD to cooperate in the dressing procedure. The caregiver seeks eye contact. PWD responds by being active in the dressing, and by singing. The PWD acknowledges the caregiver’s attempts to make eye contact.	The caregiver invites the PWD to communicate (verbally- singing, and non-verbally), and the PWD responds by returning communication (verbally-singing, and non-verbally).	Caregivers invite communication - PWDs respond actively and comply

* PWD – person with dementia.

5.4.4 Study IV

The aim of study **IV** was to describe expressed emotions and expressions of resistiveness to care in two nursing home residents with severe dementia, during morning care situations without and with MTC. The scales used as instruments were The Observed Emotion Rating Scale (OERS) (Lawton, 1999a) (see appendix 1) and Resistiveness to Care Scale (RTCS) (Mahoney et al., 1999) (see appendix 2). Before deciding to use these scales, an extensive search of scales was done to find those most suitable. However, it became clear that scales focusing on persons with dementia during caring situations were problematic to find, and in addition there were very few scales focusing on expressions of emotions and resistance. Scales in dementia care generally frame the everyday life of the persons with dementia with certain focus, for example, The Gottfries-Bråne-Steen Scale (Bråne, Gottfries, & Winblad, 2001) or The Multi Dimensional Dementia Assessment Scale (Sandman, Adolfsson, Norberg, Nyström, & Winblad, 1988). Although parts of these scales could be useful in this study, the reliability of the scales would of course been questioned. The OERS and the RTCS frame the research question and are suitable to use on caring situations.

The OERS (Lawton, 1999a) was used to score the observations according to the expressions of emotions of the persons with dementia. This scale was used because persons with dementia commonly have greatly reduced cognitive and communicative capacity, though they maintain the ability to express their emotions. The OERS includes five observed expressed emotions for persons with dementia, with two positive and three negative expressed emotions. The positive emotions consisted of pleasure and general alertness, while the negative included anger, anxiety/fear, and sadness. All five expressions are rated for duration during a ten minute observation period. Each variable representing the expressions is scored for duration according to: not in view, never, less than 16 seconds, 16 to 59 seconds, 1 to 5 minutes, and more than 5 minutes. Reliability of the scale was tested with kappas ranging from 0.76 to 0.89. (Lawton, 1999b).

RTCS was the second instrument used (Mahoney et al., 1999), which includes 13 observable behaviors indicating resistiveness to care. The behaviors were rated for duration during a ten minute observation period. The 13 behaviors include to turn away, pull away, push away, push/pull, grab object, grab person, adduct, hit or kick, say no, cry, threaten, scream or yell, and clench mouth. For each variable representing the behaviors, scores of duration can range from none, less than 16 seconds, 16 to 59 seconds, 1 to 2 minutes, and more than 2 minutes. Mahoney et al., (1999) calculated the consistent reliability of this scale with internal consistency established in two long time care dementia populations (Cronbach's alphas 0.82–0.87).

As far as was known during the designing of this study, the scales had never before been used on VIOs with MTC. To test these scales on the data, an analysis on the individual level seemed suitable, and the single case experimental AB design (Kazdin, 2003) was conducted. The two cases constituted two female persons with dementia who were assigned the fictitious names Mrs Andersson and Mrs Jonsson. The inclusion criteria when selecting these persons was that they should have the same sex and the same MMSE score, and that they should be cared for by the same caregiver. Two persons with dementia fulfilled those criteria. VIOs of

the two cases covered eight of the usual morning care situations (four of each case), which constituted the baseline sessions (Kazdin, 2003), and eight of morning care situations with MTC (four of each case), which constituted the intervention sessions (Kazdin, 2003). The scales allowed 10 minute films to be analyzed, and the first ten minutes of the 16 VIOs were chosen. Both instruments, OERS (Lawton, 1999a) and RTCS (Mahoney et al., 1999), were first scored by the author of this thesis, and secondly by another investigator co-supervisor Gabriella Engström, and results were then compared. Any discrepancies were discussed and resolved by consensus. The observed expressions in the OERS and the observable behaviors related to RTCS of the two cases were scored for duration in seconds for each VIO, and the resulting scoring of duration during baseline and during the intervention was presented in a bar chart. The scored variables of the usual morning care situations were compared with the scored variables of the morning care situations with MTC on an individual level for the two single cases.

5.4.5 Study V

The aim of study V was to describe expressions of emotions and resistiveness to care among persons with dementia, during morning care situations with and without MTC. Two scales, The Observed Emotion Rating Scale (OERS) (Lawton, 1999a) and Resistiveness to Care Scale (RTCS) (Mahoney et al., 1999), were used to analyze the VIOs. This study was conducted after having completed the analysis on individual level (study IV), and as the scales seemed to work properly on the data from study IV, they were tested in this study on a group level. The group included all ten persons with dementia, and thus all 80 VIOs. The first ten minutes of the 80 VIOs corresponded to about 13 hours of film, and included the 40 VIOs of the baseline (usual morning care situations), and the 40 VIOs of the intervention (morning care situations with MTC).

Both instruments, OERS (Lawton, 1999a) and RTCS (Mahoney et al., 1999), were first scored by the author of this thesis. A test/retest of reliability was performed whereby the author of this thesis watched all videotapes once again after a period of 10 days. An agreement minus disagreement divided by the total observations was calculated. It yielded a reliability score of 0.97, which was well within the acceptable range for reliability. A second investigator (Co-supervisor Gabriella Engström) also scored all VIOs and the results were compared. Any discrepancies were discussed and resolved by consensus. The observed expressions in the OERS and the observable behaviors related to RTCS were scored for duration in seconds for each observation, and the resulting scoring of duration during baseline and during the intervention was presented in a bar chart.

The student's t-test (Campbell & Machin, 2000) was used to compare the mean scores for baseline and intervention of every variable of the two scales. Statistical analysis was performed with the SPSS (Statistical Package of Social Science), version 17.0. A p-value of <0.05 was considered significant.

5.5 ETHICAL CONSIDERATIONS

Throughout the process of working with the different parts of this research project, ethical considerations (Gustafsson, Hermerén, & Peterson, 2006) have been observed in all steps, and the study was approved by a regional ethical committee (Dnr: 2006/274). All caregivers were informed orally and in writing about the study and research ethics by the first author. The caregivers then signed a written consent. The persons with dementia in the study were fragile persons, and because of their severe dementia they were unable to understand the information given about the study. Therefore, proxy consent (Karlavish et al., 2008) was obtained from their next of kin, who were informed that participation in the study was voluntary and that they could withdraw at any time without experiencing penalties or loss of access to services for their relative. Additionally, the persons with dementia were carefully observed during the observations for any signs that indicated that they objected to participating in the study or that their integrity was being compromised. No such signs were observed. Although the persons with dementia could observe the videotaping equipment, they did not seem to be distracted by it. Confidentiality of all participants was assured by keeping the data and their personal information in a locked safe, and by coding the data when presenting the results.

6 RESULTS

The result section consists of a description of the results of each study, followed by a comprehensive summary that was generated by comparing all results.

6.1 STUDY I

The aim of study I was to describe professional caregivers' experiences of caring for persons with dementia during morning care situations without and with MTC. Analysis of the usual morning care situation (without MTC), led to the formation of the first theme; *Struggling for care in communion*, which consisted of four sub-themes. In the first sub-theme, *Hampered communication*, the caregivers described feelings of being alone in trying to communicate with the persons with dementia. Failing to understand or not being understood led to feelings of powerlessness, and even insufficiency, because they being unable to reach the persons with dementia in the communication.

The sub-theme *Physical and mental struggle with aggression* described the necessity of constraining the persons with dementia in order to care for them. This left the caregivers with feelings of immorality. Although persons with dementia commonly displayed physical and verbal aggression, it was considered both important and energy consuming not to let the persons with dementia see how they felt, though caregivers were not always able to control this. The caregivers explained that they were sometimes afraid of the persons with dementia, due to their physical aggression, and described feelings of sadness and anger when caring for them.

The third sub-theme, *Struggle with ethical demands*, described the caregivers' struggle to maintain good ethics and to respect the self-determination of the persons with dementia. Constraint thereby became an ethical dilemma. The ethical struggle was described as present within themselves when caring for aggressive persons with dementia, who they were compelled to constrain, and also when trying to maintain their mood to ensure a good encounter with the persons with dementia. The caregivers also suggested that they might avoid caring for aggressive persons with dementia because of the immoral use of constraint. To choose not to care for the persons with dementia was described as a struggle too, because in this case they felt that they did not fulfill their duties.

In the *reward - consolation and love* (the fourth sub-theme), the caregivers described that they felt forgiven for constraining the persons with dementia and gained satisfaction from doing their job, because the persons with dementia were mostly satisfied afterwards. The caregivers described a license to constrain due to the patients' inability, and this was their consolation when the constraint contradicted their morals. When caring took place without constraint, the caregivers described feelings of confirmation, because this was considered proof that it is possible to give good care. The love they had for the persons with dementia was described as crucial in their work, and a smile or laughter from the persons with dementia was said to make the caregivers feel appreciated, and could also be taken as a proof that the aggression in the caring situation was not directed against them.

The analysis of the GIs of morning care situations with MTC led to the formation of the second major theme; *Consolidating care in communion*, which consisted of two sub-themes. In the first sub-theme, *Awakening cooperation*, the caregivers described that mutual communication was being awakened and the caregivers suggested that MTC was a possible way to interact with the persons with dementia. While the caregivers sang songs, they felt that they made fewer demands and spoke less, yet this encouraged communication. The caregivers stated that were able to make eye contact with the persons with dementia, and the communication was described as “face to face”. The caregivers also explained that they were able to care for the persons with dementia without constraint. The elements in the caring situation were described as uninterrupted and a nice moment they shared with the persons with dementia, which made them feel close to them.

The second sub-theme, *Feeling of wellbeing*, described singing as making the caregivers feel happy and the persons with dementia seemed to notice this, leading to positive emotions emanating from them, too. Caregivers regarded this as revealing a connection between themselves and the persons with dementia. The caregivers described being happily surprised when they experienced that some persons with dementia started to sing as they seemed present and acted more appropriately in the situation and were able to communicate in a nice way. One of the ten persons with dementia was described as aggressive and resistant during the washing, but in general, the caregivers explained that MTC led to a relaxed atmosphere when caring for the persons with dementia.

6.2 STUDY II

The aim of study **II** was to present professional caregivers’ experiences of persons with dementia during morning care situations without and with MTC. The analysis of the GIs without MTC generated one theme, *Being in a different reality*, and this constituted four sub-themes. The caregivers described it as difficult to connect with the persons with dementia in the morning care situation, making communication and cooperation difficult.

The first sub-theme, *Being aloof*, described persons with dementia as physically, but not mentally, present in the situation, which made communication difficult. Their responses to questions or requests were confused, if they responded at all, when caregivers spoke to them, and they often did not make eye contact. *Showing resistance* reported that the persons with dementia did not want to or were not able to cooperate, and thereby expressed resistance by verbal protests or irritation, and also by reluctant movements. *Showing aggression* was both physical, such as slapping, and verbal, such as cursing and issuing insults from the persons with dementia. Some persons with dementia expressed both physical and verbal aggression, and some were aggressive while getting undressed or washing or in both situations. Aggression commonly escalated while the persons with dementia were being washed. The last sub-theme was *Expressing affection* and reported that the persons with dementia sometimes gently stroked, smiled or said something nice to the caregiver even though they did not realize who they were.

The main theme that arose from the intervention with MTC was *Being present*. The caregivers described their experiences with the persons with dementia differently. During MTC, the persons with dementia expressed themselves more adequately, and communication was enhanced making cooperation possible. This analysis generated in four sub-themes. The first sub-theme, *Being engaged and empowered*, described the persons with dementia as participating in the activity and interested in what was going on. The persons with dementia were also described as responding more adequately and acting more appropriately in the caring activity.

In the sub-theme *Demonstrating episodes of lucidity*, the persons with dementia were described as singing along and thereby remembering lyrics. They spoke more clearly and even continued singing when the caregivers lost the texts. The persons with dementia also seemed to notice things they had not before, such as their reflection in the mirror. Some of them began to wash themselves or tried to undress or dress themselves without being told to do so.

In the sub-theme *Becoming “compliant”*, the caregivers described the persons with dementia as not struggling away or expressing resistance, even if they did not actually cooperate. The caregivers noted that the persons with dementia moved with strength and self-confidence during MTC, and they more easily stood up, walked, and showed purpose in their movements. The pace of the songs was thought to help them walk more easily, with strength in their steps.

In the fourth sub-theme *Expression joy and relaxation*, the persons with dementia were described as looking happy, and even laughed and made jokes. Some sang along and made jokes, and some even made up their own lyrics to the song. The persons with dementia were also described as relaxed in their minds and bodies and also self-confident in their way of acting. One person with dementia was described as aggressive when she was being undressed and washed, but was described as relaxed and happy by the time she was being dressed.

6.3 STUDY III

The aim of this study was to describe how persons with dementia and their caregivers express verbal and non-verbal communication and make eye contact during the caring activity ‘getting dressed’ during morning care situations without and with MTC. The usual morning care situations were characterized by the caregivers leading the task of getting dressed with verbal instructions, including questions, requests or the giving of information about the dressing procedure. Caregivers also used non-verbal communication by acting out the task or instructions; e.g., showing the person with dementia a skirt. They seldom invited the persons with dementia to join in communication or participate in the dressing procedure; instead they seemed to focus fully on the task of getting the persons with dementia dressed. Little eye contact was made, and neither caregivers nor persons with dementia seemed interested in making it.

Data derived from usual morning care situations led to the creation of five generic categories:

1) *Caregivers provide instructions – Persons with dementia respond actively and comply.* The caregivers made requests while simultaneously showing an item of clothing, for example a T-shirt. Some persons with dementia seemed active and cooperated in the dressing procedure by verbally responding correctly to the caregivers' requests and physically cooperating, while others cooperated physically but remained silent.

2) *Caregivers provide instructions - Persons with dementia respond at different paces.* When caregivers instructed persons with dementia by posing questions to them about the dressing procedure, they did not wait for a response, but generally began performing the task while asking the question. The caregivers also commonly interrupted the persons with dementia as they attempted to participate in the dressing procedure, which also made the persons with dementia passive.

3) *Caregivers provide instructions – Persons with dementia respond in an incongruent manner.* The caregivers verbally informed persons with dementia of what they were doing during the dressing procedure or posed questions, and some persons with dementia were able to verbally respond correctly, though they seemed incapable of appropriate non-verbal communication through body movements. The opposite pattern was also detected.

4) *Caregivers provide instructions – Persons with dementia respond with confusion.* The caregivers' verbal or non-verbal communication, or both, led to confusion for the persons with dementia. Some persons with dementia repeated words that the caregivers were saying, spoke incoherently, or displayed passive or inadequate physical responses that were not congruous with their verbal response.

5) *Caregivers provide instructions – Persons with dementia respond with resistance and aggression.* While the caregivers dressed the persons with dementia, they sometimes stated what they were doing while at other times they remained silent. Commonly, the persons with dementia expressed resistance, and their bodies seemed tensed. Resistance was expressed verbally by screaming, crying, grinding teeth, or saying 'no', and also non-verbally through movements, such as holding on to the chair, towel or on to the caregiver.

During the intervention situations with MTC, the caregivers also steered the process of getting dressed. In contrast to the usual morning care situation, however, they invited persons with dementia to participate in the communication. The caregivers seemed interested in the persons with dementia, who seemed relaxed and expressed well-being. Communication consisted of eye contact and non-verbal directions, demonstrated with body movements related to getting dressed. Verbal communication consisted of singing songs about things other than getting dressed; such as dancing, love, sailing, and God. Overall, the persons with dementia responded in a composed manner to the caregivers' communication by being active and compliant as well as relaxed. Frequent eye contact was observed between the caregivers and the persons with dementia.

Data from morning care situations with MTC led to three generic categories:

1) *Caregivers invite communication - Persons with dementia respond actively and comply.* While singing, the caregivers showed persons with dementia the clothing and several persons with dementia responded actively by, for example, lifting their arms or trying to put on a T-shirt. The caregivers invited the persons with dementia to participate by waiting for

them to respond and by seeking eye contact with the persons with dementia. When the caregivers sang, most of the persons with dementia actively participated in verbal communication by singing, humming or whistling along. Some sang a whole song, and at the same time participated non-verbally in getting dressed through cooperative body movements.

2) *Caregivers invite communication – Persons with dementia respond with resistance or in incongruent manner.* In some cases when the caregivers tried to get the persons with dementia dressed, the persons with dementia expressed resistance. Resistance was primarily expressed non-verbally by holding on to the chair or caregiver while getting dressed. While the caregivers sang and non-verbally instructed the persons with dementia, some persons with dementia responded with behavior that was incongruent.

3) *Caregivers and Persons with dementia communicate; mutual relaxation and well-being.* Mutual well-being was expressed by the caregivers and the persons with dementia. When the caregivers sang, the persons with dementia sang along, or hummed and whistled. Some persons with dementia filled in song texts if the caregivers stopped singing. Mutual eye contact was frequent, and some persons with dementia frequently tracked the caregivers' movements with their eyes.

6.4 STUDY IV

The aim was to describe expressed emotions and expressions of resistiveness to care in two nursing home residents with severe dementia, during morning care situations without and with MTC.

6.4.1 Resistant Behavior

For Mrs Jonsson, screaming or yelling was the most common resistant behavior both during baseline and during the MTC intervention. The mean number of seconds in which Mrs Jonsson screamed or yelled decreased by 35% from 149 seconds during baseline sessions to 97 seconds during the intervention sessions. Mrs Jonsson cried during all observations prior to the intervention. During the intervention sessions, she cried in only one session out of four. Although resistiveness to care by pulling away was expressed by Mrs Jonsson both at baseline and at intervention, the duration of this behavior decrease from a mean of 29s during baseline sessions to a mean of 12 seconds during MTC interventions. The duration of grabbing behavior displayed by Mrs Jonsson decreased during MTC intervention; 50% reduction in grabbing objects and 23% reduction in grabbing persons (Table 6).

For Mrs Andersson, clenching her mouth was the most common resistant behavior observed both during baseline and during MTC intervention. Mrs Andersson clenched her mouth during all four observations at baseline, though during the intervention sessions the duration of this behavior decreased from a mean of 226 seconds to a mean of 60 seconds (73% reduction). Screaming or yelling was the resistant behavior that was most dramatically reduced in Mrs Andersson; this behavior was displayed during all baseline observations compared to only one of the intervention observations. Showing resisitiveness to care by grabbing objects was also expressed by Mrs Andersson during all four observations at baseline, with a mean of 8.7 seconds, while only during one intervention session for three seconds (91% reduction). The resistant behavior of saying “no” occurred in two of the four baseline observations for Mrs Andersson, and was not observed at all during the intervention observations. Finally, pulling away decreased for Mrs Andersson by 84% from baseline to intervention (Table 7).

6.4.2 Expression of Negative Emotions

For Mrs Jonsson, an evaluation of the negative expressed emotions showed that anxiety or fear occurred in all observations, though the duration varied; at baseline, anxiety/fear lasted for more than five minutes in three of the four observations, whereas during MTC, three of the four observations showed anxiety/fear for 1-5 minutes. Furthermore, expressions of anger were observed for Mrs Jonsson during three morning care sessions at baseline (less than 16 seconds) compared with one session during intervention (less than 16 seconds). Sadness was expressed by Mrs Jonsson in all observations during baseline, and during the intervention. However, during baseline sadness was expressed during one observation in more than five minutes, while during the intervention sadness was never observed for more than 1-5 minutes. Figure 1 provides a graphical summary of the negative expressed emotions for Mrs Jonsson.

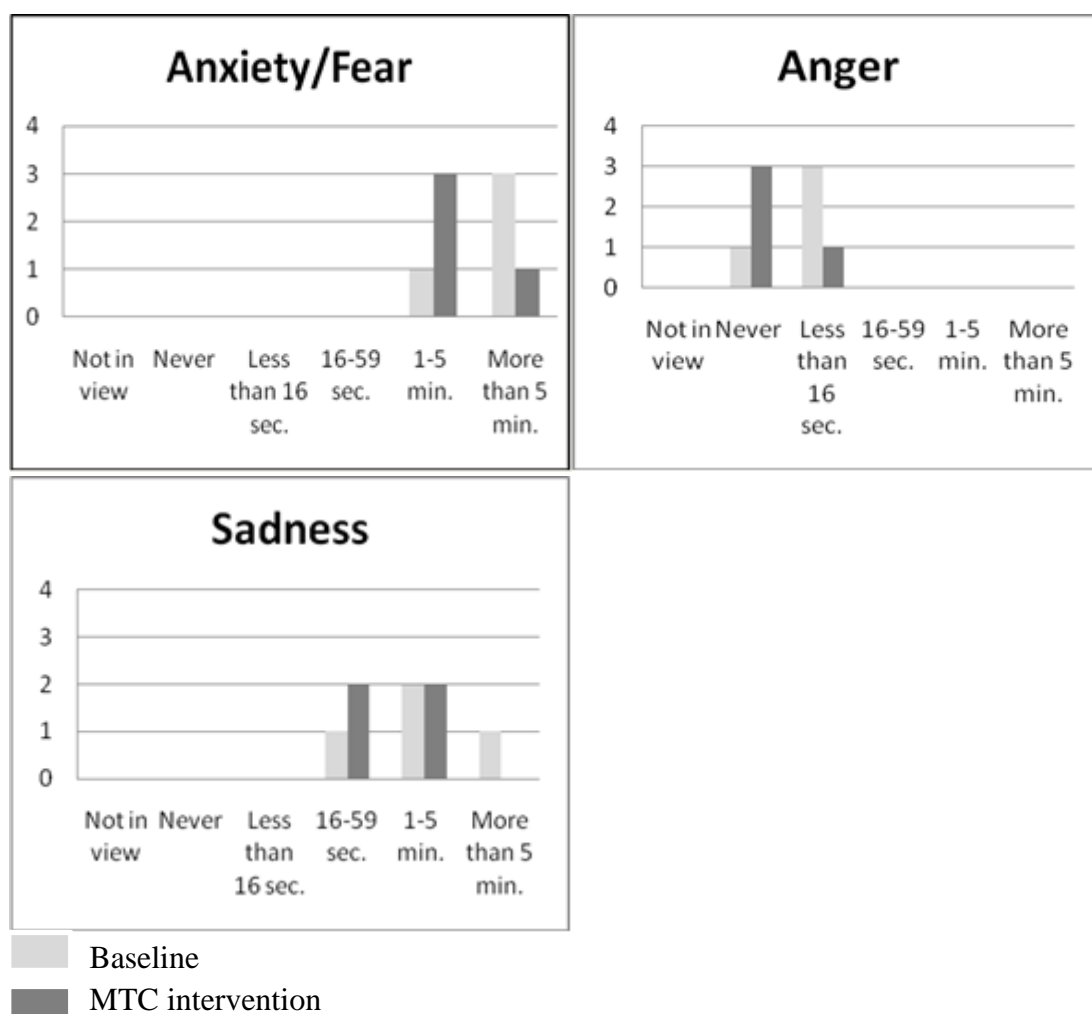


Figure 1. The distribution of negative expressed emotions for Mrs Jonsson at baseline and during MTC according to the OERS.

For Mrs Andersson, negative emotion in the form of anxiety or fear was expressed for more than five minutes during all observations at baseline, compared to 1–5 minutes during intervention. Negative emotion in form of anger was expressed at baseline in all

observations for 1-5 minutes, whilst during the intervention it was expressed for 1-5 minutes in only one observation, for 16-59 seconds in one observation, and 0-16 seconds in the remaining two observations. Sadness was expressed by Mrs Andersson during baseline in one observation for 1-5 minutes. During the intervention, sadness was not shown in any of the observations. Figure 2 provides a graphical summary of the negative expressed emotions for Mrs Andersson.

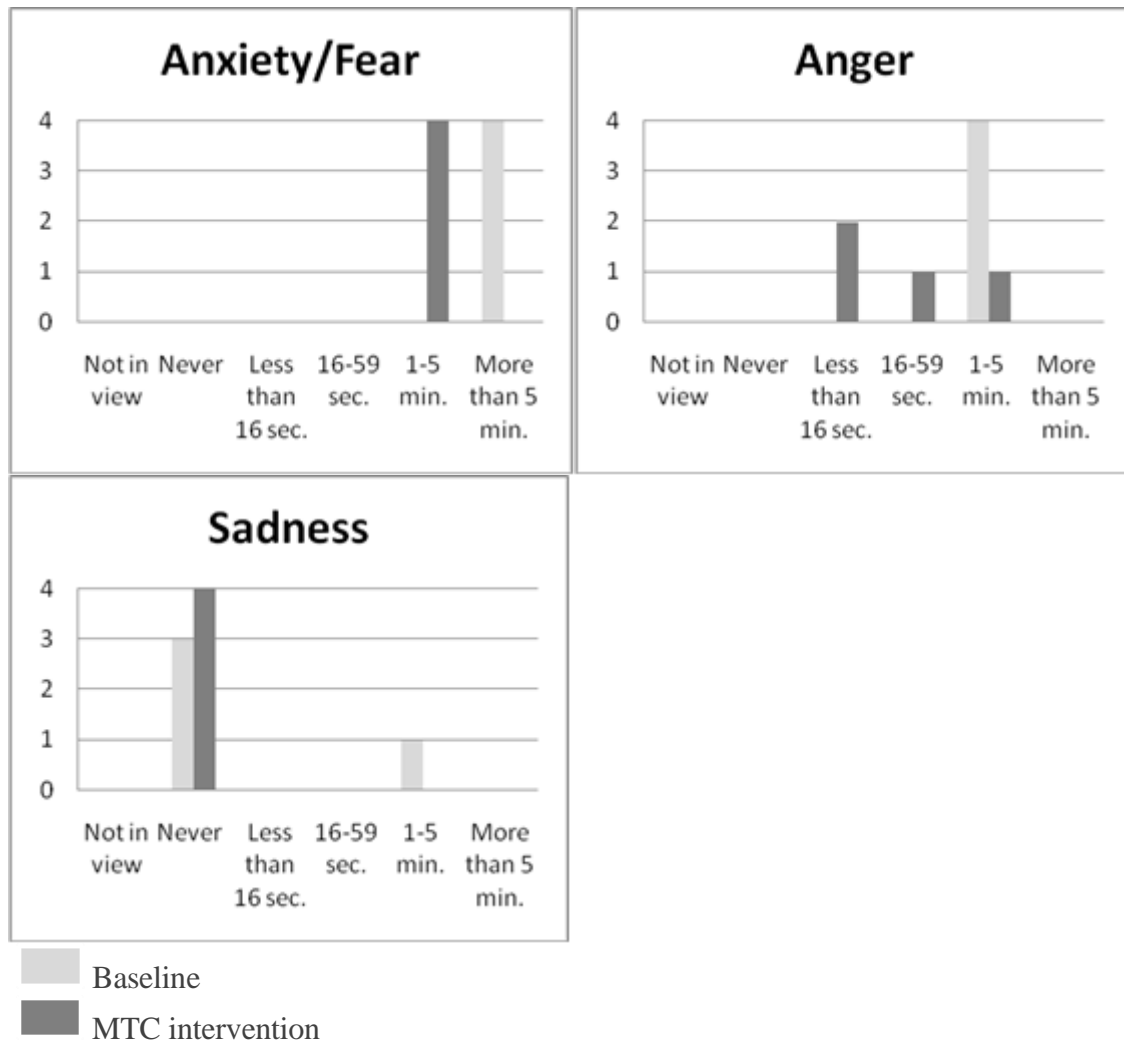


Figure 2. The distribution of negative expressed emotions for Mrs Andersson at baseline and during MTC according to the OERS.

6.4.3 Expression of Positive Emotions

In terms of positive expressed emotions, pleasure was observed for Mrs Jonsson during three baseline observations for less than 16 seconds each, and during three intervention sessions; one session for less than 16 seconds, and two sessions for 16 to 59 seconds. General alertness was observed to the same extent in both baseline and intervention sessions with Mrs Jonsson. Positive expressed emotions for Mrs Jonsson are displayed in Figure 3.

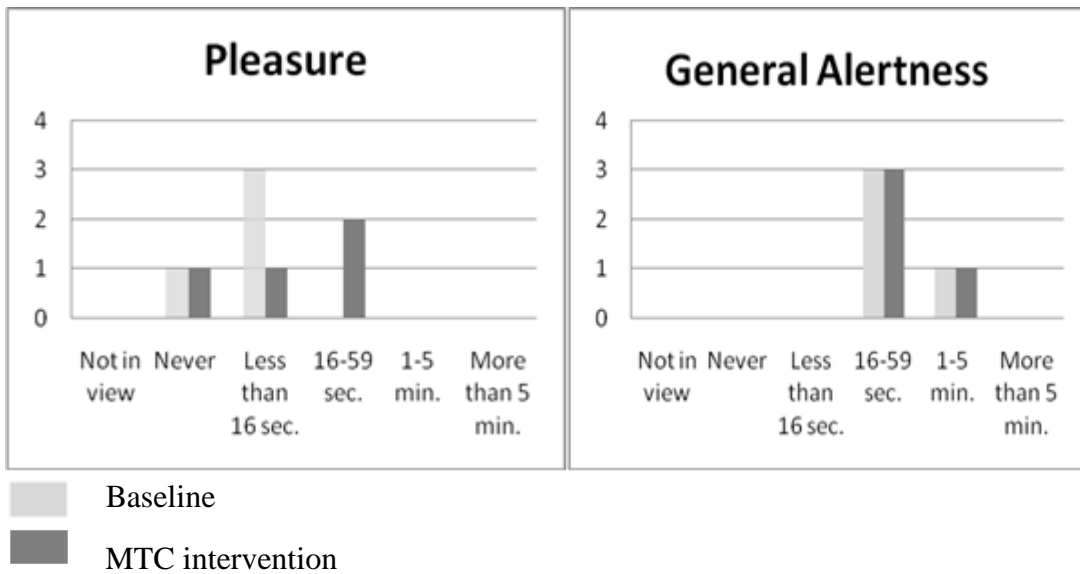


Figure 3. Time distribution of positive expressed emotions for Mrs Jonsson observed during video observations at baseline and during intervention according to the OERS.

Positive expressed emotions increased for Mrs Andersson during MTC intervention. Mrs Andersson only showed pleasure during the intervention sessions; two observations of less than 16 seconds and one of 16 to 59 seconds. General alertness was seen during all sessions; one to five minutes in one baseline observation and more than five minutes in the remaining three baseline observations, and for more than five minutes in all intervention observations. Positive expressed emotions for Mrs Andersson are displayed in Figure 4.

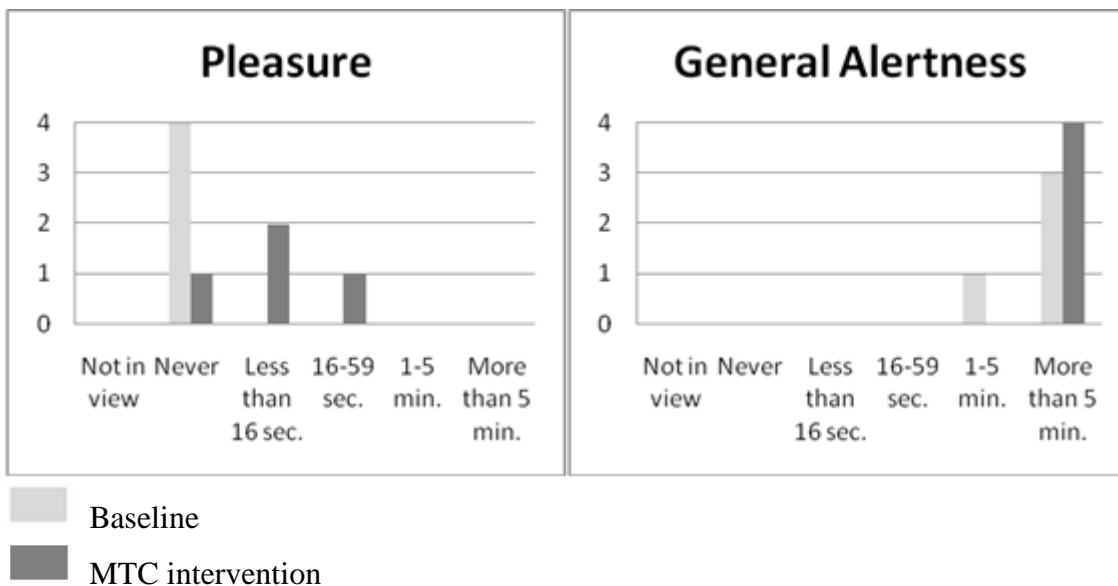


Figure 4. Time distribution of positive expressed emotions for Mrs Andersson observed during video observations at baseline according to the OERS.

6.5 STUDY V

The aim of study V was to describe expressions of emotions and resistiveness to care among persons with dementia during morning care situations without and with MTC. The distribution of observed resistant behaviors, as measured with the RTCS, was seen at different levels of duration during baseline and intervention situation (Table 8). The resistant behaviors *pulling away*, *grabbing objects* and *adduction* decreased to a significant degree during the intervention. Pulling away was observed both during baseline and intervention. During baseline, pulling away was observed for an average of 149 seconds in 65% of the 40 observations compared to an average of 49 seconds in 47% of the 40 observations during MTC intervention. Grabbing objects (for less than 59 seconds) was observed in 52.5% of the 40 baseline situations, in contrast to 35% of 40 intervention situations. Furthermore, adduction was observed both during baseline and MTC intervention for less than 59 seconds. During baseline, adduction occurred for an average of 78.5 seconds in 52.5 % of the 40 observations compared to an average of 30.8 seconds in 47.5 % of the 40 observations during MTC intervention.

The distribution of observed expressed emotions measured with the OERS during baseline and the intervention is presented in Table 9. In terms of positive expressed emotions, pleasure and general alertness significantly increased during the intervention. During baseline, pleasure was observed for an average of 282 seconds (4.7 minutes) in 65% of the 40 observations compared to 1388 seconds (23 minutes) in 83 % of the 40 observations during MTC intervention. General alertness was observed in 97.5% out of the 40 baseline observations with an average of 2010 seconds (33.4 minutes) compared to in all 40 observations with an average of 2703 seconds (45 minutes) during the intervention.

Table 8: Number (%) of observations per score level of RTCS during morning care without (40 VIOs) and with MTC (40 VIOs)

Number (%) of observations per score level during baseline								Number (%) of observations per score level during intervention							
	None	<16 sec	16-59 sec	1-2 min	>2 min	Mean sec	SD	None	<16 sec	16-59 sec	1-2 min	>2 min	Mean sec	SD	p
Pull away	14 (35)	8 (20)	17 (43)	1(2)	0	148.8	15.480	21 (53)	16 (40)	3 (7)	0	0	49.3	6.929	0.013
Grab Object	19 (47.5)	11 (27.5)	10 (25)	0	0	81.3	10.139	26 (65)	12 (30)	2 (5)	0	0	32.7	5.397	0.020
Adduct	19 (47.5)	13 (32.5)	8 (20)	0	0	78.5	9.769	21 (52.5)	17 (42.5)	2 (5)	0	0	30.8	5.013	0.037
Turn away	36 (90)	4 (10)	0	0	0	4.0	0.852	40 (100)	0	0	0	0	0	0	0.172
Push away	37 (92.5)	3 (7.5)	0	0	0	18.0	5.692	35 (87.5)	5 (12.5)	0	0	0	10.3	2.907	0.407
Pull/Push	25 (62.5)	7 (17.5)	8 (20)	0	0	55.5	8.999	27 (67.5)	11 (27.5)	2 (5)	0	0	21.8	4.375	0.097
Grab Person	21(52.5)	7(17.5)	9(22.5)	3(7.5)	0	142.5	25.612	24(60)	8(20)	8(20)	0	0	64.3	10.820	0.180
Hit/Kick	31 (77.5)	6 (15)	3 (7.5)	0	0	20.0	5.397	33 (82.5)	7 (17.5)	0	0	0	9.3	2.309	0.308
Say No	18 (45)	17 (42.5)	4 (10)	1 (2.5)	0	73.3	14.626	25 (62.5)	13 (32.5)	2 (5)	0	0	23.3	4.287	0.179
Cry	34 (85)	5 (12.5)	0	1 (2.5)	0	32.5	7.878	37 (92.5)	2 (5)	1 (2.5)	0	0	14.8	3.606	0.221
Threaten	37 (92.5)	3 (7.5)	0	0	0	2.5	0.635	38 (95)	2 (5)	0	0	0	1.5	4.743	0.168
Scream	18 (45)	12 (30)	7 (17.5)	1 (2.5)	2 (5)	205.8	45.664	26 (65)	11 (27.5)	1 (2.5)	1 (2.5)	1 (2.5)	104.5	30.449	0.079
Clench Mouth	32 (80)	1 (2.5)	3 (7.5)	0	4(10)	261.0	71.094	32 (80)	0	7 (17.5)	1 (2.5)	0	95.3	20.944	0.343

Table. 9. Number (%) of observations per score level of OERS during morning care without (40 VIOs) and with MTC (40 VIOs)

Number (%) of observations per score level during baseline									Number (%) of observations per score level during intervention								
	Not in view	Never	< 16 sec	16-59 sec	1-5 min	>5 min	Mean sec	SD	Not in view	Never	< 16 sec	16-59 sec	1-5 min	> 5 min	Mean sec	SD	p
Pleasure	0	14 (35)	8 (20)	10 (25)	8 (20)	0	281.8	37.022	0	7 (17)	6 (15)	7 (18)	14 (35)	6 (15)	1387.5	151.948	0.016
General alert	0	1 (2.5)	10 (25)	10 (25)	4 (10)	15 (37.5)	2010.2	221.636	0	0	4 (10)	7 (17.5)	11 (27.5)	18 (45)	2703.3	212.850	0.042
Anger	0	11 (27.5)	4 (10)	13 (32.5)	9 (22.5)	3 (7.5)	776.0	108.828	0	15 (37.5)	11 (27.5)	7 (17.5)	7 (17.5)	0	308.3	41.363	0.078
Anxiety/ Fear	0	15 (37.5)	5 (12.5)	7 (17.5)	6 (15)	7 (17.5)	1161.0	190.441	0	17 (42.5)	8 (20)	3 (7.5)	11 (27.5)	1 (2.5)	564.0	86.949	0.118
Sadness	0	30 (75)	4 (10)	3 (7.5)	2 (5)	1 (2.5)	222.8	60.073	0	34 (85)	1 (2.5)	3 (7.5)	2 (5)	0	114.5	34.403	0.219

6.6 SUMMARY OF THE RESULTS

6.6.1 Usual morning Care Situations

During the usual morning care situations, study **I** revealed that the caregivers had problems to connect with the persons with dementia, and struggled with the aggression and resistance expressed by the persons with dementia, as well as with ethical dilemmas. They did, however, describe a consolation when they were able to fulfill their duties and when the persons with dementia showed affection. Study **II** focused on the caregivers' experiences of the reactions of persons with dementia, and described them as physically though not mentally present during usual morning care situations, they had difficulties in communicating and cooperating, and they expressed resistance and aggression, but also affection, towards the caregivers. Study **III** revealed that the caregivers commonly lead the persons with dementia by verbal instructions and body movements, and seldom invited them to communicate or participate in getting dressed. The responses of persons with dementia were at times active and compliant, and at others resistant and aggressive, confused, and disruptive.

6.6.2 MTC Intervention in Morning Care Situations

During MTC, the caregivers experienced that cooperation was improved, as they were able to connect with the persons with dementia and communication was described as 'face to face'. The caregivers described feelings of well-being because positive emotions were dominant for both the caregivers (study **I**) and the persons with dementia (study **II**), which led to a joyful and positive encounter with the persons with dementia. Study **I** also revealed that MTC allowed the caregivers to connect with the persons with dementia and the caregivers were emotionally affected by the improved awareness of the persons with dementia. The positive effects on the persons with dementia were seen by caregivers as a confirmation of their work and feeling appreciated increased their feelings of well-being. Study **II** revealed that the caregivers found that the persons with dementia expressed themselves more appropriately, which made cooperation possible. The expression of positive emotions was dominant, and persons with dementia were described as relaxed, self-confident, and pliable, though also at times resistant and aggressive. Study **III** also revealed that the persons with dementia tended to respond to caregivers' attempts for communication in a composed manner, by being active, compliant and relaxed, although verbal communication consisted of singing about things other than getting dressed, such as dancing, love, sailing, or God. Additionally, study **III** indicated that the caregivers were more interested in communicating with the persons with dementia, and solicited their mutual engagement. However, resistance and aggression were also observed during MTC. In study **IV**, both cases demonstrated an increase in some positive expressed emotions and a decrease in some negative expressed emotions and resistance. Study **V** revealed similar results, with the significant increases in pleasure and general alertness and significant reduction in resistant behaviors (pulling away, grabbing objects and adduction). Study **I-III** found that the interaction between caregivers and persons with dementia seemed improved during MTC, though problematic behaviors, such as resistance and aggression, were still observed in all studies (**I-V**) during MTC.

7 DISCUSSION

The discussion is divided into two sections; an evaluation of the methods used for each study, including reflections upon the strengths and weaknesses of the studies and thesis, and specific reflections of the results.

7.1 METHODOLOGICAL CONSIDERATIONS

While discussing the rigor of research findings, the qualitative paradigm uses one set of terminology while the quantitative paradigm uses another. This is problematic when using both methods in the thesis. However, some researchers, including Downe-Wambold (1992), Sandelowski (1995), Whittemore, Chase, and Mandle (2001), as well as Golafshani (2003) have argued that it is possible to make use of the more traditional quantitative concept even when conducting qualitative research. In this thesis the concepts of validity and reliability will be explored when reflecting upon the rigor of the methods used, independent of their particular paradigms.

The overall aim of this thesis was to demonstrate if and in that case how the intervention of using MTC impacted the participants of this study, which included patients with severe dementia and their caregivers. The qualitative approach was chosen because, according to Polit and Beck (2008), it enables researchers to observe participants' actions and/or hear their voices, in order to reach an in depth understanding of the research question. Furthermore, Creswell (2007) argued that qualitative approaches provide options for accomplishing a complex and detailed understanding of an issue, and that level of detail can be established by either talking directly to the participants or observing them. Thus, the qualitative GI technique was used to study caregivers' experiences of caring for the persons with dementia with and without MTC (study **I**), and their impressions of the reactions of persons with dementia during morning care situations with and without MTC (**II**). Additionally, qualitative VIO was also used in order to study the communication between persons with dementia and their caregivers (study **III**). For studies **IV** and **V**, a quantitative approach was chosen as it provides information about the frequency or degree to which the investigated problem occurs (Halcomb & Andrew, 2005; Polit & Beck, 2008), and was thus used to describe expressions of resistance and emotions of persons with dementia either with or without MTC.

7.1.1 Internal Validity

Using both qualitative and quantitative methods in a research projects has the potential to enrich the study, since qualitative findings can generate hypotheses that can then be tested quantitatively, and quantitative findings can be further understood through a qualitative in-depth probing (Morse, 2003; Polit & Beck, 2008). In this research project, qualitative findings from studies **I** and **II** provided the foundation for study **III**, and the qualitative findings of studies **I**, **II** and **III**, formed the basis for the design of the quantitative study **IV**,

which in turn provided the basis for study V. Therefore, the qualitative findings from the early studies generated the need for quantitative measurements in later studies.

7.1.1.1 Pre-understandings

The internal validity of data analysis in qualitative research must include a discussion about pre-understanding, a well-known concept in hermeneutics that is applicable to all qualitative research when discussing validity. The concept of pre-understanding was described by the philosopher Gadamer (2004) in his ideas about the interpretation of texts and suggests that every interpretation of an action or a text is assumed to be included, and earlier understandings are therefore not unprejudiced. Thus, pre-understandings cannot be excluded and should rather be acknowledged in order to perform a high quality analysis. However, pre-understandings must be controlled for, otherwise the uniqueness and the potential new findings in the material might get lost as the researcher is steered by he or she already knows (their pre-understanding).

The author of this thesis has shed some light of her pre-understanding in the introduction section of the thesis. To have knowledge about caring for persons with dementia and the behaviors that might be problematic, as well as the research literature concerning dementia care, can be seen as strength when interpreting the GIs with the caregivers (studies I and II), as well as the VIOs (study III). It is also important to have knowledge about previous research concerning MTC, the limitations of that research and the possible influences this knowledge might have on the current research. This was kept in mind during the design of the thesis, collection of the data, and the analysis procedure.

Patton (2002) argued that when analyzing qualitative data it might be problematic to ‘control’ the pre-understanding, and it is common to have several researchers audit the process. The pre-understanding of the author of this thesis was controlled by letting the analysis process in all studies be audited by the supervisors (Eva Götell, Azita Emami, Gabriella Engström). As neither Azita Emami nor Gabriella Engström had previously participated in studies about MTC, they were perhaps best able to critically audit the analysis in all studies.

7.1.1.2 Design and Participants

Previous research concerning MTC (Götell, 2003) was conducted with other objectives in focus, and was solely qualitative in nature and did not include repetitive measurements or analyses. We therefore designed this intervention study to conduct both qualitative and quantitative analysis based on several observations of both persons with dementia and their caregivers during morning care situations. It is also considered important to acknowledge the experiences of the participants in our target situations, and thus the participating caregivers’ experiences were analyzed.

In this thesis, as well as in previous research about MTC (Götell, 2003), the research situation selected was morning care, and the results might have been different if another caring situation had been chosen. Various situation-specific factors could influence the results, including the time of the day and the architecture of the room (e.g., in the bathroom there are

various objects that indicate what to do). If the research situation used had been bed time, only the bed could indicate what to do and thus the results may have been different.

In this research project, data was collected from two different nursing homes for persons with dementia in urban areas of Sweden. Selecting two different homes could be seen as a strength, as it minimizes the risk of displaying results based on only one particular nursing home which might have its own 'culture'. The nursing homes were located in different parts of the city, in order to minimize the risk of cooperation among the caregivers or the nursing homes. The head nurse at each nursing home suggested a ward (one ward at each home) with persons with dementia, and the patients and caregivers in these two wards were asked to participate in the studies. The selected wards were chosen solely due to the head nurse's perception of a stabile ward, meaning that the persons with dementia were well known by the caregivers. The next of kin to the persons with dementia signed consent for the persons with dementia and were therefore those who agreed that they could participate. All correspondence with the next of kin was done by the author of this thesis. No next of kin said no, which could imply that they knew "their" person with dementia liked singing and this may have influenced the findings of MTC.

The selection of the two persons with dementia in study **IV** was done with regards to them having the same score of MMSE (zero) and the same sex (female). Another criterion was that they were cared for by the same caregiver, as this minimized the potential impacts of different caring styles from different caregivers. Naturally, the interaction between the caregiver and each of the two persons with dementia was not identical, as the patients were two different persons with their own unique personalities. Additionally, if another caregiver of other persons with dementia had been selected for this single case study (study **IV**), the results would probably have been somewhat different. However, the two selected cases were the only ones that fulfilled all inclusion criteria.

The participating caregivers signed consent confirming their participation. Since the caregivers were selected by the head nurses at the nursing homes solely based on the criterion that they had an extensive history of interacting with the participating persons with dementia, and all agreed to participate, we do not believe that the sample was biased towards either those who do or do not enjoy singing. However, it should be kept in mind that those who agreed to participate may have done so because they liked singing. This was not elucidated prior in the project. However, one caregiver terminated her participation without given any reason. This might have had to do with her not being willing to sing during the intervention.

The participating persons with dementia were not selected due to their specific diagnosis (e.g., Alzheimer's disease or vascular dementia). Furthermore, it was not elucidated whether any particular diagnosis was correlated to differences in the caregivers' experiences of the reactions of persons with dementia (study **II**), their way of communication (study **III**) or the expression of emotions or resistance (studies **IV** and **V**).

The fact that the persons with dementia and their caregivers served as their own controls is, in quantitative terms, known as “Cross over design” (Brown & Prescott, 2006). It could be argued that this is a strength of the design, as the use of matching control groups might be problematic when observing human behaviors, especially in persons with dementia. O’Connor et al. (2009) argued that Randomized Controlled Trial (RCT) studies are considered as ‘golden standard’, due to their high quality and potential to generalize findings. However, Murfield et al. (2011) suggest that RTC studies could be problematic to conduct in dementia care; it is almost impossible to find control group to match the intervention group (Murfield et al., 2011), as even patients with the same diagnosis demonstrate different behaviors from one person to the next. The same could be argued for the caregivers, as caring is demonstrated differently from one caregiver to another and this would most likely have caused mismatch with a control group (Kazdin, 2003; Polit & Beck, 2008). High staff turnover might also be a problem that could affect both the persons with dementia and the study.

Many RCT studies take place over an extended period of time. Murfield (2011) further stated that the level of cognitive decline, acute illness, the presence of BPSD, or death might affect the intervention, and thereby make it difficult for the persons with dementia to complete the study. In this thesis, the participating persons with dementia had all severe dementia and participated in data collection once a week for a relatively short period of about two months. During this process, we did not observe any major differences in the behavior of the persons with dementia or the caregivers. The choice to limit time period for data collection to two months per patient was not only done for financial reasons, but mostly with the rationale that they had severe dementia and there was a high risk that their disease would progress or that they would pass away (as two patients did), which could thereby influence the findings. Furthermore, due to ethical matters, it could be demanding for both caregivers and the persons with dementia to participate in a research project that are over a long period.

Another strength of the design is that the persons with dementia were always cared for by the same caregiver. This excludes the chance that different caregivers and persons with dementia would work differently together. However, if the persons with dementia had been cared for by different caregivers, their particular reaction may have led to different results. By having familiar caregivers administer care to the persons with dementia was deemed both ethically sound and beneficial for the quality of the study, as possible problems in the caring interaction may have been avoided.

Although all participating caregivers were offered a course in MTC, only two of them had the opportunity to take it. The four remaining caregivers were given instructions in how to use MTC by the author of this thesis, who is certified in MTC. It should be kept in mind that this might have influenced how the caregivers acted during the intervention, as they did not have the same extensive education in MTC. This might have influenced their way of communicating (study **III**), or how they experienced the situations with or without MTC with focus on themselves (study **I**) or on the caring for the persons with dementia (study **II**).

7.1.1.3 Data Collection

Data was collected by conducting GIs (Côte Arsenault & Morrison Beedy, 2005) with the participating caregivers (studies **I** and **II**), and by conducting VIOs (studies **III**, **IV**, and **V**) of morning care situations with the persons with dementia and the caregivers.

The use of GIs as a data collection method for studies **I** and **II** seemed suitable, as it is an appropriate method when the researcher wants to gather a group's experiences of a certain subject. One benefit of this data collection method is that people often need to listen to the opinions and understandings of others in order to form their own. This makes the content of the interview rich and therefore GIs are suggested to be a suitable data collection method as they facilitate open discussions among the participants (Côte Arsenault & Morrison Beedy, 2005).

Studies **I** and **II** used focus group interviews, as inspired by Côte Arsenault and Morrison Beedy (2005). It is often suggested that the number of participants in each focus group should be at least five (Jamieson & Williams, 2003) or sometimes even six (Kreuger & Casey, 2000). Due to drop out of caregivers, having at least five participants per interview was not possible. The interviews were therefore named GIs, since the criterion for forming a group is at least three participants with something in common, such as their work (Cambridge, 2008). Nevertheless, the GIs followed the key components of focus group interviews that Côte Arsenault and Morrison Beedy (2005) described. It should be noted that the variations of the caregivers' descriptions may have been greater if there had been more participants in the interviews.

One possible strength of studies **I** and **II** is that the GIs were conducted in two different and independent nursing homes that were not in cooperation with each other, and yet the GIs seemed to be in agreement with each other. An alternative method considered was to conduct individual interviews with the caregivers, which could have produced different results. However, after the author of this thesis spent approximately one month at each nursing home recording VIOs, the choice to conduct GI was made on the rationale that the groups of caregivers seemed to interact well with one another and to be open minded to each other. Côte Arsenault and Morrison Beedy (2005) and Webb and Kevern (2001) suggested that the interaction among participants in GIs is of great importance because the participants need to feel free to speak their minds in order to enrich the interview. In these GIs, the participants' discussions were dynamic, and agreements and disagreements emerged throughout the conversation, which was deemed to enrich the interview.

One potential disadvantage of GIs is that the participants knew each other well and might not have dared to be honest in their descriptions. The dominant impressions, however, were that the GIs were characterized by openness and lively descriptions of both situations (usual morning care situations and morning care situations with MTC), and the interviews from each nursing home seemed to reveal quite similar experiences in both situations. In addition, the author of this thesis conducted the GIs for studies **I** and **II**, recorded the VIOs for studies **III**, **IV** and **V**, and instructed the caregivers in the use of MTC interventions, and therefore spent a fair amount of time in the nursing homes and became familiar with the caregivers. This

familiarity might have influenced the caregivers' descriptions in the GIs, a situation that could have been prevented if some other researcher had carried out the GIs. However, Côte Arsenault and Morrison Beedy (2005) claimed that it is of uttermost importance that the participants in GIs feel comfortable to speak their mind. Given this, it was considered to be the most suitable way to have the author of this thesis act as the moderator of the GIs, and this might even enriched the interviews.

It is well known that caregivers have to face BPSD from persons with dementia, which is very stressful (Almvik et al., 2006; Åström et al., 2004; Morgan et al., 2008). Caregivers in dementia care, as a group, do not get very much recognition for their job, nor do they get many opportunities for continuing education to develop their skills. Thus, being asked to participate in a research project may have given the caregivers recognition for their work, and thereby encouraged them to openly tell about their problems in their work; this could have influenced the caregivers' descriptions during the interviews.

Additionally, the caregivers found the singing intervention very joyful, and this may have made them search for an effect of MTC on the persons with dementia, which they later described in the interviews. The caregivers were also somewhat familiar with earlier research about MTC (Götell, 2003), either from their participation in the course Music Therapeutic Caregiving I (MKM019) or the instruction in MTC by the author of this thesis. This awareness might have made them consciously look for an effect while they were singing, which could thereby have led to unconscious changes in their behavior during MTC sessions. Although this might have influenced the findings in all studies (studies **I-IV**), some of the findings of studies **I**, **II**, and **III** were confirmed by the quantitative findings concerning emotions and resistance in studies **IV** and **V**.

VIO is considered to be an appropriate data collection method because they provide the opportunity for both qualitative and quantitative analysis (Haidet et al., 2009; Latvala et al., 2000). In dementia care research, VIOs have commonly been used for data collection (Hansebo and Kihlgren, 2002; Kihlgren et al., 1993; Palo-Bengtsson et al., 1998). Due to the permanence and richness VIOs offer, they enable researchers to capture complex behaviors of interest and give the possibility to repeatedly review the recordings during the analysis of the material. As such, VIOs are a kind of recorded reality and facilitate analysis by all researchers involved in the project (Latvala et al., 2000; Spiers, Costantino, & Faucett, 2000). Marshall and Rossman (2006) supported this by suggesting that audio-video recordings offers rich information that often exceeds other kinds of data because of its ability to capture both verbal and non-verbal expressions. Additionally, when participants not are able to report their own behaviors or experiences, observational method is suggested (Mulhall, 2003). Furthermore, VIOs give the opportunity to catch behaviors that the participants might not notice themselves and therefore cannot report in interviews. VIO therefore proved to be a suitable data collection method for studies **III**, **IV**, and **V**, since the purpose was to catch both the verbal and non-verbal communication between the persons with dementia and their caregivers (studies **III**), the verbal and non-verbal expressions of resistance and emotions of two persons with dementia on individual level (studies **IV**), and also all the verbal and non-

verbal expressions of resistance and emotions of the persons with dementias on a group level (V).

7.1.1.4 Data Analysis

The data collected from the studies was the determining factor when choosing the analyzing method. As the studies used different data collection methods, and these methods provide data with certain limitations, the methods used to analyze the data differed among the studies.

7.1.1.4.1 Studies I and II

In studies **I** and **II**, GIs were used to collect data about caregivers and persons with dementia in morning care situations with and without MTC. The aim of study **I** was to describe professional caregivers' experiences of caring for persons with dementia during morning care situations without and with MTC, and thus had its focus on the caregivers themselves. The aim of study **II** was to present professional caregivers' experiences of persons with dementia, and was thus focused on the reactions of the persons with dementias during morning care situations without and with MTC. As GIs represent a kind of data collection that does not generally give in-depth information about the participants, content analysis as described by Graneheim and Lundman (2004) was considered to be a suitable method, because it can be applied to data with variable depths. It is the data, however, that is the determining factor of how deep the analysis can go. Latent content analysis was conducted in studies **I** and **II** in order to reach the full depths that the data from the GIs could offer. The analysis method was helpful in structuring the text and gave the opportunity to move back and forth between the material as a whole and specific parts of the material at different levels of abstraction. Due to the clear differences between descriptions of the usual morning care situation and the MTC intervention situation in studies **I** and **II**, it was considered important to perform such pendulation between the transcribed interviews in order to not lose the content of the text, and thereby confirm the analysis. Quotations were included in the results sections of the articles in order to confirm the themes that evolved from the analysis. Internal validity was also increased by performing the analysis in cooperation with supervisors Eva Götell, Azita Emami, and Gabriella Engström, in particular with Azita Emami and Gabriella Engström as they did not have previous experience in research about MTC and likely had less of a pre-understanding than Eva Götell. Data analysis for studies **I** and **II** was also critically discussed in a scientific group. Moreover, the caregivers were shown the transcribed texts of the interviews, as well as the findings (**I**, **II**), for confirmation.

7.1.1.4.2 Study III

The aim of study **III** was to describe how persons with dementia and their caregivers express verbal and non-verbal communication and make eye contact during the caring activity 'getting dressed' during morning care situations without and with MTC. The objectives that grounded the analysis in study **III** were generated from the findings from studies **I** and **II**, because it became clear that many of the problems described were linked to communication difficulties. With that in mind, as well as the clear differences described between usual morning care situations and morning care situations with MTC, it was considered interesting to analyze the VIOs in order to elucidate if the caregivers' descriptions of the situations were

in line with the results brought from the analysis of the VIOs. Qualitative content analysis, as described by nursing researchers Elo and Kyngäs (2008), was performed on the VIOs from study **III** by focusing on communication.

Although it was considered important to include all 80 VIOs, the large amount and the many hours of VIOs made it impossible to do a well-focused qualitative analysis of the entire VIO collection in its full length. After reviewing the VIOs several times, a decision was made to select the sequence “getting dressed” with rationale that it involved a large amount of verbal and non-verbal communication (the focus of the study). If another sequence had been chosen or if the VIOs had been analyzed in their full lengths, the communication might have been described in a different way. Other factors could also influence the analysis, such as selecting a shorter sequence, including fewer VIOs, or using another analysis method, which might eventually offer the possibility of a deeper analysis. It is also important to keep in mind that what happened shortly before the chosen sequence “getting dressed” might influence the communication that took place while “getting dressed”.

One characteristic of qualitative content analysis is that it can be applied at different depths (Downe-Wambold, 1992; Elo & Kyngäs, 2008). The process of content analysis described by Elo & Kyngäs (2008) provides a description of how to practically conduct either an inductive or a deductive content analysis, starting with the same departure point. The decision to conduct the inductive or the deductive approach comes first after the transcribed text has been read to ‘get a sense of the whole’. This was particularly suitable in this study, as it was first thought that a deductive analysis should be used to arrange the data and thereby put the text into an analysis matrix (Elo & Kyngäs, 2008), based on the concept of communication. However, after making ‘sense of the whole’ of the transcribed VIOs, the text seemed to offer more levels than could be reached with the deductive approach, thus making the inductive analysis described by Elo and Kyngäs (2008) more suitable. Sandelowski (2000) described that this is often the case when starting the analysis with a pre-existing coding system, because it limits the analysis (ibid), as in deductive analysis (Elo & Kyngäs, 2008). In order to be able to carefully describe the steps in the analysis based on the above considerations, and to be concise about the literature used in the analysis, the Elo and Kyngäs (2008) interpretation of this type of content analysis was selected for study **III**. It should be noted that if another description of content analysis from other research areas had been chosen (e.g., Baxter, 1991; Berg, 2004; or Downe-Wambold, 1992), the results from the analysis might have been different.

As previously mentioned, the steps in the analysis process described by Elo and Kyngäs (2008) allow the movement between the analysis of the material as a whole and focusing on particular sections of the transcribed text at all levels of abstraction. Thus, the abstractions and eventually the findings were confirmed by constantly going back to original data and viewing the VIOs and reading the transcriptions. Because both the usual morning care situations and those morning care situations with MTC involved the expression of both positive and negative emotions, it was considered impossible to reach the highest level of abstraction in categories described. However, Elo & Kyngäs (2008) stated that the analysis process should continue as far as reasonable or possible. Additionally, in order to increase

internal validity the steps in the analysis were discussed by the authors of the corresponding publication (Eva Götell, Azita Emami, Gabriella Engström), and extracts of the transcriptions were included in the presentation of results in order to confirm the categories of the analysis. The manuscript was also discussed in scientific groups.

7.1.1.4.3 Studies IV and V

The VIOs were analyzed quantitatively to describe expressed emotions and expressions of resistiveness to care in two nursing home residents with severe dementia, during morning care situations without and with MTC in a single case design (study **IV**) and of all the persons with dementia during baseline and intervention (study **V**), and the OERS and RTCS were used to analyze the recordings in both studies. In study **IV**, the design of single case experimental AB design was chosen because this analysis aims to elucidate the exact effect of an intervention on the individual level (Kazdin, 2003) and it would have been preferable to use several more scales in order to even more precisely describe the two cases. However, since validated scales were hard to find and the OERS and RTCS were suitable for answering the studies' aims, they were considered sufficient for both studies **IV** and **V**.

The OERS and RTCS allowed 10 minutes film to be analyzed, which means that of the 16 VIOs included in study **IV** and the 80 VIOs included in study **V**, only the first ten minutes of each VIO was analyzed. In study **IV**, the morning care situations were almost completed within the first 10 minutes in all VIOs. In study **V**, however, some VIOs were about 20 minutes long whereas others were just a couple of seconds longer than 10 minutes, which means that in some VIOs the persons with dementia had completed the morning care situation while some were only half completed. This might have influenced their expressions of resistance and emotions.

The use of two score scales could be problematic, as the procedure for defining the variables may vary from person to person. However, both scales had pre-defined variables (see Appendix for scales and definitions of the variables). In addition, a second investigator (Gabriella Engström) also scored the scales independently of the author of this thesis and the discrepancies, though minimal, were resolved by consensus. As Kazdin (2003) suggested, the reliability of the findings increases when the analysis is performed several times by several different investigators.

In study **V**, the Students t-test (Campbell & Machin, 2000) was used as it is considered to be suitable for testing differences between two groups; in this case, the two groups included all VIOs of baseline compared to all VIOs of the intervention.

7.1.2 Reliability

The moderator (the first author of this thesis) of the GIs had taken a research course in how to conduct GIs, and the GIs for studies **I** and **II** were conducted with the assistance of a second investigator, Eva Götell, in order to make notes and suggest probing questions that a single moderator might miss. This might strengthen the studies' reliability because it might have extended the GIs and minimized the risk that a single researcher's pre-understanding and

capabilities would limit the content of the GIs. In GIs, as in all interviews, the interviewers must be objective (Kvale, 2009), and the purpose of the interview should be clear, the interviewer focused (Côte Arsenault & Morrison Beedy, 2005), and the risk that the interviews will be steered in such a way that the researcher gets the answers he or she prefers should be minimized. This is easier to control when the interviews are conducted by a moderator and an assistant, as in the GIs conducted in this thesis. Reducing the effects of objectification and pre-understanding was a high priority during the interviews for studies **I** and **II**.

VIOs were chosen as the data collection method for studies **III**, **IV** and **V**. As Polit and Beck (2008) point out, the researcher should keep in mind that participants might change their behavior when they know that they are being observed. However, Latvala et al. (2000) and Haidet et al. (2009) stated that a participant acclimates to the presence of the video camera and starts to behave as if they are not being filmed. The general perception was that although the persons with dementia could observe both the person conducting the VIOs (the author of this thesis) and the videotaping equipment, they did not seem to be distracted by them; indeed, they seemed to forget that the camera and the observer were there. Since the caregivers were observed a minimum of eight times, they also appeared to acclimate themselves to having the camera and the observer present.

The scales that measures expressions of emotions (OERS) and resistiveness to care (RCTS) used in studies **IV** and **V** are valid instruments used in research on persons with dementia. However, both scales could be considered inadequate for the analysis of the time between the expressed behaviors. RTCS includes approximately one minute in the same score, and has an upper range of two minutes; there is no additional scoring for expressions of behavior that last for longer than 2 minutes. OERS has a range of four minutes in the same score, and was limited to expressions of less than five minutes; no additional scoring for expressions of behavior longer than 5 minutes. This means that persons with dementia that expressed anger for one minute would be scored the same those that expressed anger for five minutes, thus making exact measurements in either of the scales problematic.

To increase inter-rater reliability in studies **IV** and **V**, a test/retest was performed to demonstrate the stability of a measurement over time, whereby all videotapes were watched once again by the author of this thesis after a period of 10 days. An agreement minus disagreement divided by the total observations was calculated. It yielded a reliability of 0.97, which is well within the acceptable range for reliability. However, it should be kept in mind that the possibility to accomplish this high number in the test/retest was because the scales were rough in construction, which means that even if the number of seconds differed in the retest, they generally fell into the same categories of the scales. Only one disagreement occurred during the retest.

7.1.3 External Validity

In qualitative research, the possibility for generalizing the findings is determined by the reader. However, a rich description of the context and characteristics of participants, data collection and process of analysis, as well as a vigorous presentation of the findings and

appropriate use of quotations, will enhance the possibility to generalize the results to different situations and contexts (Patton, 2002). In this thesis, generalization of the findings might be possible to other settings involving persons with dementia. However, based on the qualitative nature of the studies in this thesis, the small number of participating caregivers, and the focus on morning care situations, conclusions based on the caregivers experiences (studies **I** and **II**) and the communication patterns displayed in study **III** could only be drawn for these participants. Thus, in order to generalize the findings concerning MTC, more research is needed that includes other and/or more participants, different settings, contexts, and caring situations, as well as different methods and study designs.

While focusing on quantitative studies, the single case design of study **IV** does not facilitate generalization, which could be seen as a limitation of the study. The results may not be generalized to other situations than morning care or other individuals with dementia. It would be interesting in future research about the effect of MTC to include larger samples and include other caring situations in order to allow for generalization. However, such studies do not offer the same opportunity to elucidate possible effects on individual levels, as in the Single Case design (Kazdin, 2003).

In the study on group level (study **V**), the sample consisted of 10 persons with dementia who were video observed 8 times each, for a total of 80 times. The number of persons with dementia participating in this study was too low and cannot represent the general population of persons with dementia, and it is therefore not possible to generalize these findings. It can be concluded that further research about the effects of MTC should involve larger samples to quantitatively generalize research findings.

7.2 REFLECTIONS ON THE RESULTS

The overall aim of this thesis was to demonstrate if and in that case how the intervention of using MTC impacts the participants in these studies, including patients with severe dementia and their caregivers. Since the two research situations were usual morning care and morning care with MTC, they will be discussed separately. In the section focused on usual morning care situations, mainly studies **I-III** will be discussed, while all five studies will be discussed in the section focused on MTC. This is because the value of the results of studies **IV** and **V** can only be appreciated after comparing the variables of the usual morning care situations with the MTC situations.

7.2.1 Usual Morning Care Situations

Results from the usual morning care situations generally framed the difficulties the caregivers faced in encountering the persons with dementia (study **I**), and described the persons with dementia as aloof and expressing resistance and aggression, which made communication and cooperation difficult (study **II**). Communication difficulties were also displayed in study **III**, in which the caregivers led the persons with dementia with verbal instructions and body movements, though they seldom invited the persons with dementia to communicate or participate in getting dressed. The persons with dementia did respond with resistant and disruptive behaviors, but also by being active and comply.

7.2.1.1 Toiling during Caring: the Stress on Caregivers

The expressions of aggression from the persons with dementia seemed to cause considerable stress for the caregivers, according to both the caregivers' descriptions (studies **I** and **II**) and the analyzed VIOs (study **III**). The results from study **I** outlined the caregivers' experiences the caring situations and revealed that cooperation was difficult or even impossible during usual morning care situations, due to expressions of BPSD, mostly resistance and aggression, and confusion on behalf of the persons with dementia. In study **II**, caregivers also described the persons with dementia as aloof and physically, but not mentally, present; this could be related to what Finkel (2003) called apathy or psychotic behavior, which is included in the concept BPSD. The expressions of BPSD by the persons with dementia, especially aggression and resistance (studies **I-V**), could in part be due to the research situation selected; during morning care situations, in which caregivers and persons with dementia interacted very closely with one another in ways that could involve the caregivers intruding on the patient's personal space. Brodaty and Low (2003) suggested such responses are natural from persons with dementia when someone invades their personal space.

The interaction between persons with dementia and caregivers is crucial in caring situations. The usual morning care results revealed that communication and cooperation seemed to be a significant problem (studies **I-III**), and the persons with dementia commonly expressed resistance, confusion, and aggression in response to the caregivers. McDaniel, Edland, and Heyman (1995) suggested that expressions of BPSD are grounded in the patient's problems in relating to themselves, to others, and to the world, and thus interacting with caregivers or others commonly becomes problematic and evokes expressions of BPSD. Graneheim et al. (2005) and Skovdahl et al. (2008) suggest that these problematic situations occur because the underlying causes of BPSD are seldom solved.

The caregivers in study **I** indicated that aggression and resistance from the persons with dementia was particularly difficult to cope with. Onishi et al. (2005) and Remington et al. (2006) claimed that being compelled to deal with BPSD can lead to negative stress symptoms. This can in turn lead to burnout for the caregiver and thereby jeopardize the safety and health of the caregiver as well as the care for the person with dementia. The caregivers described in study **I** also described being compelled to constrain the persons with dementia due to aggression and resistance, and although this contradicted to their own morals it was seen as a necessary solution when nothing else worked. When the use of constraint contradicted to their morals, the quality of care might suffer; this dilemma of using constraint versus 'doing their duties' was also found in a study by Sandvide et al. (2004).

It is important to discuss the impact of caring interactions on the caregivers. Pulsford and Duxbury (2006) suggested that aggression towards caregivers can be perceived as violence in their workplace, and Needham et al. (2005) stated in a review that caregivers' predominant feelings in response to these situations were anger, fear or anxiety, post-traumatic stress disorder symptoms, guilt, self-blame and shame. In dealing with such problematic behavior from persons with dementia, Skovdahl et al. (2008) also suggested that the considerable pressure on caregivers may ignite feelings of antipathy (Åström et al., 2004; Skovdahl et al.,

2003), which in turn might lead to impassivity (Pulsford & Duxbury, 2006) towards the person with dementia.

Since previous research offers no general solution for handling situations in which expressions of BPSD occur (Åström et al., 2004; Morgan et al., 2008; Skovdahl et al., 2003a), caregivers must face these situations in their everyday job. In dementia care, the caregivers are in charge during caring situations and are thus responsible for finding the tools to minimize the expression of BPSD, especially aggression, during caring. This could be seen as an unfair pressure. Study I revealed that caregivers often tried bribing and coaxing in order to avoid the need to constrain the persons with dementia, which was most often unsuccessful. It is important to note that although caregivers must be extreme flexible and creative in order to come up with solutions, each person with dementia is unique; what works one day with one patient might not work on another (study I).

Nevertheless, the caregivers in study I described a consolation in their work; the love the persons with dementia showed the caregivers made them feel appreciated and needed. This love was often reciprocal, and one caregiver even called the persons with dementia 'her other family'. Sung Chang and Tsai (2005) found similar results while interviewing nursing aids and stated that although working with persons with dementia is considered stressful due to their unpredictable behaviors, caregivers considered their work satisfying because they were able to provide empathetic care. Additionally, caregivers were described as having developed strong emotional attachments after caring for the residents for a long period of time, which were possibly tied to feelings of being needed and worthwhile.

7.2.1.2 Hampered Communication Leads to Failed Mutuality

Difficulty communicating with persons with dementia was commonly described by caregivers (studies I and II) and was also revealed in study III. In study I, communication was even described as a one way (from the caregivers to patients) during usual morning care situations, and cooperation difficulties were thought to be rooted in the patients' difficulties in interpreting and expressing communication. This is supported by several researchers in the field, suggesting that caregivers commonly try to communicate, while the persons with dementia mostly lack the ability to respond adequately (Acton et al., 2007; Almvik, Woods, & Rasmussen, 2007; Cohen Mansfield & Parpura Gill, 2007). This could be interpreted as a struggle for the caregivers, as they are alone in trying to facilitate a caring relation. However, in contrast to the results from study I in which the caregivers described trying to communicate, study III revealed that the caregivers tended to exclude the persons with dementia from the communication and perform the dressing themselves. Thus, it could be argued that both parties (persons with dementia and their caregivers) are involved in these communication problems.

Studies II and III, as well as previous research (Almvik et al., 2006), revealed that persons with dementia have severe problems in both interpreting and expressing verbal and non-verbal communication, and thus may find the caregivers' approach to communication confusing. Sandvik et al. (2002) discuss the importance of 'give and respond' models of

verbal or non-verbal communication between two persons. 'Give' should be seen as an invitation, which in this case would be the caregivers' attempts to communicate. 'Respond' should be seen as an acknowledgement of an invitation, which would come from the persons with dementia. In studies **I-III**, the persons with dementia seemed to lack the ability to respond to the caregivers' instructions, which in turn might have reinforced the caregivers' tendency to not invite the persons with dementia to communicate (study **III**). However, it could also be argued that this lack of response was a natural consequence of the caregivers' lack of invitation (Marshall & Rossman, 2006).

Watson (1999) claimed that the caregiver must have the strength to cope with patient encounters in order to create a caring relationship. The caregivers described encounters with the persons with dementia as very stressful, and according to the caregivers' own descriptions (studies **I** and **II**) and the analysis of communication (study **III**) it seems as though the caregivers did not have the strength to cope with these encounters and thus could not develop the necessary caring relationship. Further factors affecting the caring relationship are discussed below.

Persons with dementia seemed to be excluded from communication during usual morning care situations (study **III**). Caregivers rarely sought eye contact and seemed focused on the task of dressing the persons with dementia, without cooperating them. One way to interpret this lack of 'invitation' is that the expressions of aggression and resistance, as described in study **I**, was highly stressful for the caregivers and caused them to focus on their tasks rather than communication and cooperation. Alternatively, the caregivers' communication strategy in study **III** might have been a result of habituation, in which they know the persons they care for so well and since they 'know' that a response is unlikely they have stopped their attempts to communicate.

The lack of invitation and cooperation, such as that seen in study **III**, was nevertheless discussed by Paterson and Zderad (1988), who suggested that caring should consist of 'doing' and 'being'; both the practicality of providing care ('doing') and meaningful and confirming encounters with the patient ('being'). The caregivers in study **III** seemed to be focused of the 'doing' rather than 'being' with the person with dementia during the caring situation, which could have a negative influence on the caring relation. Nursing theorists Boykin and Schoenhofer (1993), as well as Watson (2008), have suggested that caring can only be effectively demonstrated through the interpersonal relationship between nurse and patient and should involve effective communication characterized by give and take between the two. However, the persons with dementia were described as absent minded (study **II**) and it seemed likely that the caregivers had somewhat given up on communicating with them and therefore no longer tried to connect with them (study **III**). It therefore seems unlikely that a 'give and take' relationship, which is described by Watson (2008) and Boykin and Schoenhofer (1993) as a necessity in a caring relationship, is problematic to accomplish during the usual morning care situation (studies **I-III**).

The persons with dementia seemed to lack the ability to express their wishes and to be present in the encounter (studies **II** and **III**), which left the caregivers somewhat alone in the

encounter. Several researchers have commented on the necessity for reciprocity in the caring relationship. For instance, Boykin & Schoenhofer (1993) stated that a caregiving situation should be conceptualized as a shared lived experience between the nurse and the patient, and is developed when the two present themselves as wanting to offer and receive professional nursing service. Paterson and Zderad (1988) also argued that the interaction between caregiver and patient is the locus of caring, and that both are urged to be present in the encounter. Watson (2008) stated that it should be a dialogue between caregiver and the patient, and that the caregiver should be able to listen to and interpret the patient. Based on the analysis of the usual morning care situations in studies **I-III**, it can be concluded that the optimal caring relationship described by Boykin and Schoenhofer (1993), Watson (2008), and Paterson and Zderad (1988) is hard to accomplish when the persons cared for have severe dementia and are not able to focus or be ‘mentally present’.

7.2.1.3 *Persons with Dementia as the ‘Others’*

Based on the caregivers’ descriptions in studies **I** and **II**, as well as the analysis of their communication strategies during usual morning care situations in study **III**, it was revealed that situations became problematic due to a combination of the cognitive impairments of the persons with dementia, and thus low communication skills, and the caregivers communication strategies. Perhaps caregivers consider persons with dementia as what the existential philosopher Gadamer (2004) calls ‘the others’; something unlike themselves as caregivers and as humans. The caregivers might not have had the strength to be open to the uniqueness of the persons with dementia and instead saw through their diagnosis as ‘the others’ (studies **I-III**). Gadamer (2004) further suggest that to reach beyond the otherness, the individuality of that person needs to be recognized and only when we retain respect for their uniqueness can we begin to understand them. In nursing care, this understanding of the patient and participation in the caring relationship is the best we can strive for. This description of ‘the other’ has also been seen in other context in caring science, one example is Rydlo (2010) with the description of student nurses as ‘the others’ while growing in caring.

As discussed in the previous section, the difficulties in communicating and cooperating with the persons with dementia may lead to the exclusion of patients from communication and participation in caring activities. If persons with dementia are not given the chance to communicate, this would reduce the opportunity for caregivers to see their uniqueness as human beings and increase the chance of focusing on their impaired cognitive abilities, and consequently see them as objects. This interaction could be characterized as an objectifying subject-object interaction, what Buber (2004) called an I-It meeting and Lévinas (1993) called *totality* (see section 1.5 Philosophy and Caring Perspective for details). In both the I-It and *totality* meetings, mutuality between two people is not possible and they cannot grow together in this type of relationship. To improve this situation, the persons with dementia and their caregivers should meet in *eternity* (Lévinas, 1993) or as I-Thou (Buber, 2004), if the caregivers have the strength needed to accomplish this encounter.

As the caregivers described, although they tried many different methods to improve this encounter, nothing seemed to work (study **I**). It could therefore be interpreted that they did not have the strength to try or even the belief that such an encounter is possible with persons

with dementia. In order to get through the morning care situation and fulfill their duties, the caregivers may have needed to ‘shut off’, to be in a position of authority over the persons with dementia. This could be interpreted as a way to tyrannize the other, as in *totality* (Lévinas, 1993), in which the persons with dementia are seen as ‘the other’ instead of the unique person they still are despite their dementia diagnosis. However, it could also be questioned if it is even possible to have an encounter in I-Thou or *eternity* with persons with dementia, because it necessitates the presence of both parties and this seems problematic based on the cognitive impairment of the persons with dementia.

The caregivers nevertheless reacted positively when they had a connection or a compliment from the persons with dementia (studies **I** and **III**), and they described the love they felt for them (study **I**). This indicates that they probably want to meet the persons with dementia as whole human beings, open to them as unique persons, as in *eternity* (Lévinas, 1993), and with focus on mutuality, equality, and engagement in the encounter, as in I-Thou (Buber, 2004). A lack of the necessary strength or the tools to accomplish this may inhibit such encounters.

7.2.2 Morning Care Situations with MTC

Based on all studies in the thesis (studies **I-V**), the situations with MTC produced different results and were seen as beneficial in comparison to the usual morning care situations. The caregivers described mainly positive influences on both themselves (study **I**) and the persons with dementia (study **II**). Furthermore, communication was in general enhanced (study **III**), and the expressions of resistance decreased and expressions of positive emotions increased among the persons with dementia (studies **IV** and **V**).

7.2.2.1 Predominantly Enhanced Wellness

Surprisingly, in contrast to the interviews based on the usual morning care situations, the caregivers spoke very little about expressions of BPSD during morning care situations with MTC (studies **I** and **II**). Instead they describe joy and a greatly improved level of communication with the persons with dementia (study **I**) and the persons with dementia were described as happier and more responsive towards the caregivers (study **II**). Positive emotions and adequate communication were demonstrated by the persons with dementia and the caregivers seemed to have gained an additional strategy for caring and invited the persons with dementia to communicate (study **III**). Resistant behaviors, which were only minimally described in studies **I** and **II**, were present in somewhat reduced severity in study **III** and in frequency in studies **IV** and **V**. Of the two single cases in study **IV**, negative expressed emotions was shown to decrease, with one exception in which anxiety-fear was seen in one of the cases. In study **V**, the mean number of seconds in which patients displayed resistant behavior was lower, with significant decreases observed for the variables pulling away, grabbing objects, and adduction. These tendencies support the previous research that suggests that MTC decreases resistance and aggressive expressions (Dennis, 2011; Götell et al., 2009). In other caring interventions involving music listening during different activities, including during bathing (Cohen Mansfield & Parpura Gill, 2007), the expression of negative emotions such as aggression and agitation has also been found to decrease during music listening (Gerdner & Schoenfelder, 2010; Guetin, Souza, Voiriot, Picot, & Herisson, 2009b; Sung &

Chang, 2005; Svansdottir & Snaedal, 2006). Similar findings have also been discovered in the field of music therapy in dementia care, where resistant behaviors were reported to decrease and engagement to increase when playing instruments, listening to music or singing (Berger et al., 2004; Clair et al., 2005; Raglio et al., 2010).

In the field of dementia care research, resistance is a commonly expressed behavior by persons with dementia during caregiving and has been a major focus of research concerning dementia care during the last decades (Buhr & White, 2007; Chou, Kaas, & Richie, 1996; Rossby, Beck, & Heacock, 1992; Skovdahl, Kihlgren, & Kihlgren, 2003a). Resistant behaviors are an expression of objection by persons with dementia, and during caregiving this commonly results in an inability to perform caregiving without physical (Morgan et al., 2008) or pharmacological (Bains et al., 2009) restraints. In studies **I** and **II**, the caregivers did in contrast described that caring was easier to perform during morning care situations with MTC. The results from study **V** indicate that this might have to do with the significant decrease in the expression of negative emotions and increase in the expression of positive emotions, such as general alertness, by persons with dementia. General alertness, which includes participating in the task, making eye contact, looking around the room and responding, was also seen increase in one of the cases in study **IV**. Similar results were found in studies **II** and **III**, in which the persons with dementia appeared more responsive and active during caring with MTC. The expression of pleasure, another positive emotion, also increased during MTC in both cases in study **IV**, and the increase in study **V** was significant. Pleasure included singing, whistling, smiling and laughing, and was also found in the qualitative studies **I-III**. Together, the increase in both general alertness and pleasure might insinuate that the persons with dementia were more responsive and susceptible towards the caregivers during caring, making the caring duties easier to perform (study **I**). Götell et al. (2003, 2009) also suggested that MTC makes persons with dementia more engaged and interested in what is going on in the caring activity and evokes enhanced sensory awareness. Spiro (2010) and Cuddy and Duffin (2005) suggested that music listening might activate abilities and affect specific processes, making persons with dementia increase their level of activity in different tasks during these music events.

In all studies (**I-V**), the expression of positive emotions seemed to be increased while the negative emotions decreased. This supports previous findings of MTC (Dennis, 2011; Götell et al., 2002, 2009) suggesting that persons with dementia expressed positive emotions and moods during morning care situations with MTC as they sang along, smiled, and laughed with the caregiver. This might insinuate that MTC is a way for persons with dementia to experience caring in a less problematic way, as they express less resistance to it. Also nursing researchers Gerdner and Schoenfelder (2010) have suggested that music listening reveals expressions of pleasure and creates positive emotional states for persons with dementia. It should be noted, however, that negative emotions were nevertheless described by caregivers in studies **I** and **II** and displayed during MTC in study **III**, though in reduced severity.

The connection between music and emotions has been discussed by several researchers. Bigand et al. (2005) suggested that basic emotions, such as happiness, anger, fear, and sadness can be recognized in and induced by musical stimuli, and further stated that emotion

is at the core of musical experiences. Lawton et al. (1996) underlined the importance of acknowledging the expressions of emotions by persons with dementia, as these emotions can act as indicators of their likes and dislikes in those patients who are unable to report their internal states. In addition Molnar-Szakacs and Overy (2006) explains expressed emotions by stating that music has the ability to trigger memories, and that emotion is awakened through these memories. Music that is recognized spontaneously transports the mind back in time to memories and that is why different emotions might be evoked by it. In all studies (I-V) it was also found that persons with dementia were able to remember songs and sing along during MTC. In relation to Molnar-Szakacs and Overy (2006), it can be speculated that MTC awakens the memories of the song texts and thereby makes patients sing along with the caregivers. This tendency could also be linked to Levitin (2007), which shed light on what happens in the human brain when listening to music and suggested that listening to or recalling lyrics invokes both the language and memory centers and it becomes natural to start to sing. The emotions evoked in response to music could be seen as the locus of it. Furthermore, neuroscientists Stewart, von Kriegstein, Warren and Griffiths (2006) argued that music allows access to different parts of the brain and based on the many elements involved in music, such as melody, rhythm, accent, and timbre, they suggest that combining language and music, such as in singing, offers a greater chance of activating intact neurological pathways than using language alone.

Additionally, the singing of the persons with dementia could be discussed with several music therapists such as Cuddy and Duffin (2005) and Ridder & Aldridge (2005), who have stated that persons with dementia are able to remember song texts and to sing songs, and that emotions are expressed through these mechanisms. The songs chosen for this MTC intervention (studies I-V) were songs from the patients' youth. This type of selection is supported by Spiro (2010), who suggested that singing familiar old songs with persons with dementia seems to act as a memory trigger and encourage feelings of connectedness to past events and awaken the emotions associated with them. Cross (2006) and Cuddy and Duffin (2005) also suggest that these type of songs are suitable, since singing represents important cultural events from early life that may be spared in dementia.

The benefits of MTC were not only seen on the patients, but also the caregivers. Although it was not the focus of this research, it can be speculated that the caregivers experienced higher job satisfaction during MTC, as the expressions of aggressiveness and resistance decreased and positive expressed emotions increased in the persons with dementia (studies II-V), the caregivers expressed positive emotions (studies I and III) and described morning care routines as less stressful and easier to perform (study I). Although more research is needed to confirm this speculation, it is interesting to note that previous research by Vernooij-Dassen et al. (2009) suggested that job satisfaction is reduced by caregivers' experiences of inability to deal with problematic behaviors from persons with dementia. In addition, Remington et al. (2006) suggested a clear negative association between a caregiver's burden and expressions of BPSD. The results from studies I-III revealed that positive emotions were dominant for both the caregivers and the persons with dementia during MTC, leading to a joyful and positive encounter, which likely results in higher job satisfaction. Additionally, the caregivers were emotionally affected because the persons with dementia seemed more aware

and capable in their speech and movements (studies **II** and **III**), and the expressions of positive emotions from the persons with dementia were seen as a confirmation of the caregivers' work and made them feel appreciated (studies **I** and **II**). Previous research by Sung et al. (2005) concerning job satisfaction for caregivers in dementia care also stated that developing a relationship with the patients is a major factor in job satisfaction among nurses. Perceiving one's work in a positive light and feeling confirmed in what one is doing are important in job satisfaction, according to (Vernooij-Dassen et al., 2009).

7.2.2.2 *Enhanced Mutual Communication*

During MTC, the quality of communication between the persons with dementia and their caregivers seemed to increase (studies **I-III**). This is in agreement with Engström et al. (2010), who found that positive communication increased while negative communication decreased during MTC. The results from study **III** further suggest that the communication skills of persons with dementia were enhanced during MTC, and they seemed more aware of the situation and responsive to caregivers (both verbally and non-verbally) during the activity of getting dressed.

The positive impact of MTC on persons with dementia was seen in studies **II-V**; for example, in studies **II** and **III** the persons with dementia were seen as present, focused, and more purposeful in movements during the morning care situation, and they demonstrated increased general alertness in study **V**. The increased focus on the situation, as described by caregivers, made communication between them and the persons with dementia possible (study **II**), and tends to confirm previous findings (Götell et al., 2002). In addition, the persons with dementia remembered song texts and were able to sing along, and could even instruct the caregivers about how they wanted things to be done during the morning care situations with MTC (studies **II** and **III**).

This increased awareness and performance ability was also found in previous research about MTC (Dennis, 2011; Götell et al., 2002), as well as in the field of music therapy in which persons with dementia were able to remember all the words to a song though they rarely spoke or were able to put sentences together (Ridder and Aldridge, 2005). Findings from studies **II** and **III** showed that the persons with dementia not only remembered song texts and sang along, in some cases they were also able to correctly perform different parts of the caring activity, and were more cooperative, even though the songs were focused on subjects other than the caring activity, such as love, summer, God, and sailing. This adequateness from the persons with dementia might be understood as what nursing researchers (Normann et al., 2006; Normann et al., 1998) described as expressions of 'episodes of lucidity', in which the person with dementia suddenly speaks or acts in a way that surprises the caregiver because the person with dementia seems more aware than usual. Additionally, Normann (2006) stated that it is possible to provoke these episodes of lucidity when communion between caregivers and person with dementia is reached. In order to reach communion in the encounter, the caregivers and the persons with dementia must communicate as whole human beings and avoid making demands. One interpretation of the caregivers' descriptions of the persons with dementia (study **II**) and the communication between them (study **III**) is that

during MTC the two parties were working in communion, and thus could communicate and sometimes even cooperate during the morning care situation.

MTC seemed to have influenced the caregivers' way of communicating as well, and study **III** revealed that they approached the persons with dementia in a different way during MTC. In contrast to the usual morning care situation, caregivers seemed to have more energy and be interested in communicating and cooperating with the persons with dementia. Studies **II** and **III** revealed that verbal communication was not as necessary during MTC, and although caregivers gave less instructions, the persons with dementia were more compliant and some were even able to cooperate. These findings support previous research by Götell et al, (2003, 2009). In study **II** the persons with dementia were described as present, inviting, and willing to interact with the caregiver. In turn, they were able to cooperate to a greater extent (studies **I-III**), which made it easier to carry out care work (studies **I** and **II**); similar results were found by Götell et al. (2000, 2002, 2003). Additionally, caregivers used traditional speech less and instead sang with the persons with dementia during MTC (studies **I-III**). This could explain the reduction in the expressions of BPSD; as Small et al. (2003) suggested, too much verbal communication and too many demands made by the caregivers might be challenging for persons with dementia to handle, and thereby lead to increased problematic behaviors. Ekman (1996) and Normann et al. (2002, 2005) also suggest that too much verbal communication and too many instructions might be challenging for persons with dementia to handle, and that avoiding demands and seeing the persons with dementia as whole human beings, not merely objectifying them in terms of their diagnosis, resembles communion in the encounter.

7.2.2.3 *Facilitating an Interpersonal Relationship*

During MTC, the persons with dementia and the caregivers seemed to more easily connect to each other in the encounter (studies **I-III**). This might be caused by the decreased expression of negative emotions and resistance and increased positive emotions among persons with dementia (studies **IV** and **V**), as well as their increased general alertness (study **V**). It could also be due to the caregivers' use of another strategy when approaching the persons with dementia (study **III**). Their invitation to the persons with dementia seemed to declare that they were seen as a competent communication partner, and not as a person with decreased cognitive abilities. Kitwood (1997) suggested that seeing the human and not the diagnosis, and thereby practicing individualized care, is of utmost importance when practicing person centered care. Similarly, Edvardsson et al. (2008), Normann et al. (2006), and Penrod et al. (2007) stated that caring for persons with dementia should be conceptualized by acknowledging the persons with dementia, as the person they are (their personhood).

During MTC, the persons with dementia expressed themselves through skills that even the caregivers thought were lost, some by singing, humming, speaking or participating in the activity (studies **I-III**). The caregivers were also more patient and invited the persons with dementia to participate in the dressing procedure (study **III**), which seemed to encourage their participation in the activity, both verbally and non-verbally. This could be in agreement with previous research focused on person centered care, in which the personality and the abilities of the person with dementia should be regarded as increasingly concealed rather than

lost (Edvardsson et al., 2008 and McKeown et al., 2010). By singing familiar songs and inviting the persons with dementia to cooperate and communicate (study **I-III**), it could be interpreted that their personalities and abilities were being acknowledged.

Allowing persons with dementia to participate in the caring and the decisions made (study **III**) could also be linked to what Kihlgren et al. (1993) describes as important in so called integrity promoted care, a component acknowledged in person centered care. Study **III** further revealed that the caregivers used eye contact in to a greater degree during MTC than during usual morning care. They smiled and laughed a lot, had a positive and caring tone through singing, and allowed the persons with dementia to participate (studies **I-III**). This seemed in turn to make the persons with dementia more comfortable and self-confident (studies **II** and **III**), and they expressed more pleasure than during usual morning care (studies **II-V**). This is in line with goal directed care (Ryden & Feldt, 1992), in which the caregivers should be flexible, smile, maintain eye contact, and use a positive and caring tone in order to successfully interact with persons with dementia during care situations.

It could be reflected on that during MTC, the persons with dementia were seen by the caregivers as unique whole human beings, and not in the objective (their diagnosis) (studies **I-III**). This seemed to facilitate the connection between caregivers and persons with dementia within the encounter, making the persons with dementia more active in both getting dressed and communicating. Nursing researcher McCormack (2004) shed light on this by describing person centered care as caring that should be seen from the viewpoint of the person with dementia and that the relationship is as important as the care tasks. Paterson and Zderad (1988) suggested that caring should consist of both 'doing' (providing care) and 'being' (spending time with the patient). During MTC, the caregivers seemed able to simultaneously 'do' the task of getting the persons with dementia dressed and washed and 'be' with them in the encounter (studies **I-III**). This became clear as the caregivers' described a face-to-face encounter (study **II**), as well as enhanced verbal and non-verbal communication (studies **I** and **II**), which was also displayed in the communication patterns (study **III**).

Paterson and Zderad (1988) has influenced nursing theorists Boykin and Schoenhofer (1993) in the development of their theory about caring in nursing. They, as well as Watson (2008), suggest that caring may only be effectively demonstrated through the interpersonal relationship between nurse and patient and should involve effective communication characterized by give and take between the two. This interpersonal relationship is displayed in the studies **I-III**, as both caregivers and the persons with dementia seemed present and willing to verbally and non-verbally communicate during MTC, and this communication was even occasionally introduced by the persons with dementia. The relationship between the persons with dementia and their caregivers during MTC (studies **I-III**) could further be evaluated according to Boykin and Schoenhofer (1993), who stated that the caring relationship should be conceptualized as a shared lived experience between the nurse and the patient, and this is developed when the two present themselves as wanting to offer and receive professional nursing service. In studies **I-III**, the caregivers invited the persons with dementia to cooperate and those who were able participated and answered this invitation

during caring, which was also validated by study **V** in which persons with dementia demonstrated increased general alertness.

MTC could thereby be considered a way to facilitate a caring relationship, as it seems to offer a greater chance for persons with dementia to express themselves through emotions and actions (studies **I-V**) and thereby achieve communion with their caregivers (studies **I-III**). Interestingly, the verbal communication during MTC comprised of singing about things that did not concern the caring activity (studies **I-V**); the caring relation seemed to be accomplished anyway. This seems to be in contrast to what previous research (e.g., Ekman, 1996; Normann et al., 2002) has suggested, namely that verbal communication is a potentially important component when one aims to facilitate a caring relation between persons with dementia and their caregivers. Additionally, in all studies (studies **I-V**), the persons with dementia were more present during MTC, and this could be seen as one of the ways in which to develop the caring relationship between the persons with dementia and their caregivers during MTC. As Paterson and Zderad (1988) argued, the interaction between caregiver and patient is the locus of caring and both caregiver and patient are urged to be present in the interaction to encounter.

7.2.2.4 The Persons with Dementia as Equals in the Encounter

As previous mentioned, it seemed possible to establish a caring relationship between the persons with dementia and their caregivers during MTC, which might be grounded in the following factors: the decreased expression of negative emotions and resistance, the increased expression of positive emotions (studies **IV** and **V**), which included increased general alertness (study **V**), and enhanced mutuality in the interaction (studies **I-III**). However, as it was the caregivers who were steering the situations, it could be argued that the caregivers' strategies for communicating are important and that while singing the caregivers seemed more interested and willing to cooperate in the persons with dementia (study **III**). As highlighted in communion (Normann et al., 2002; 2005) and person centered care (Kitwood, 1997) caregivers avoided demands, did not use traditional verbal communication (speech), and potentially saw the persons with dementia as competent human beings able to communicate. In contrast to the usual morning care situations, in which the caregivers seemed to meet the persons with dementia from an "I-It" perspective (Buber, 2004), "I-Thou" seemed to predominate during MTC.

However, as communication is a two-way street and urges give-and-take exchanges; verbal exchanges between a listener and a speaker, or non-verbal exchanges including body movements, eye contact, and eye movements (Marshall & Rossman, 2006). The persons with dementia therefore have an important role in establishing mutual communication as in I-Thou. In study **I-III**, the persons with dementia seemed more able to acknowledge the caregivers' invitations (verbal or non-verbal), by cooperating, singing, or laughing. This seemed to validate the communication strategies from the caregivers, who in turn continued with singing as a way of communicating. This linked to Bubers' (2004) philosophy stating that an I-Thou encounter between people involves communication in the form of a dialogue, characterized by equality, mutuality, personal presence and engagement; they meet as subjects, not objects. Such a meeting urges true presence. During MTC the caregivers and the

persons with dementia seemed occasionally truly present both physically and mentally in the situation, and occasionally meet as I-Thou.

Also the philosopher Lévinas (1993) explained that humans are fellow creatures of other humans, each with a feeling of responsibility for others incorporated into them, and this responsibility does not require any reciprocal gain. Lévinas also stated that another human's face encourages us to take responsibility for them, and in doing so it is not possible to objectify and categorize the other (ibid). The caregivers (studies **I-III**) seem to feel this responsibility for the persons with dementia, both as their caregivers and as fellow humans, and this was expressed to a greater degree during MTC. The caregivers literally met the persons with dementia 'face-to-face' and seemed to aim to encounter them in the communication (studies **I-III**), what Lévinas (1993) names *eternity*, rather than to objectify or categorize them.

The caregivers seemed to recognize the persons with dementia as unique individuals with competent skills in communication and cooperation (study **III**), which led to enhanced cooperation, and togetherness during morning care situations. This may correspond to theory from the existential philosopher Gadamer about 'the other', which states that in order to reach beyond the otherness, the individuality of that person needs to be seen, and this implies looking beyond the former in order to more fully understand the other person. By participating with the other and to be a part of the other is the most and the best we can strive for and accomplish. It is only possible to gain an understanding of the "other" if we retain respect for the thing, or more precisely, for its "otherness" (Gadamer, 2004). It seems that during MTC the caregivers were able to recognize and appreciate 'the others' (the persons with dementia) and to look beyond their diagnosis and impaired cognitive skills, and thereby gained a better understanding of them. This in turn might have allowed the persons with dementia feel more confident in their communication, and in addition, thanks to feeling confirmed and recognized as whole humans by the caregivers, they might have felt free to express themselves (studies **I-V**).

8 CONCLUSIONS AND IMPLICATIONS

The results of the usual morning care situation from studies **I** to **V** tend to confirm previous research in the area of dementia care; namely that in the usual morning care situations expressions of BPSD, particularly resistance and aggressiveness, were described by the caregivers (studies **I** and **II**) and observed in the VIOs (study **III**) and found to be problematic in the encounters between the persons with dementia and their caregivers. It also seemed to be difficult for the caregivers to find ways in which to achieve mutuality in these encounters. During the situations with MTC, however, it seemed as though the persons with dementia and their caregivers were able to facilitate mutuality in the encounter and thereby build an interpersonal relationship. It can be speculated that this was the result of decreased expressions of negative emotions and resistance by the persons with dementia, as well as their increased expression of positive emotions. In turn the caregivers seemed to approach the persons with dementia in a different way and consider the persons with dementia as competent while communicating with them.

The results of this thesis and other studies concerning MTC (e.g., Dennis, 2011; Engström et al., 2010; Götell et al., 2000, 2002, 2003, 2009) may contribute to dementia research by increasing awareness about MTC as a possible intervention for facilitating mutuality in the encounter between persons with dementia and their caregivers. However, these studies all have their weaknesses and more research about MTC is needed using larger samples, different methods and data collection strategies, as well as different contexts, such as in home care settings or during different caring situations (e.g., meal time or bed time). The relative importance of MTC research is indicated not only by its uniqueness, but also by the fact that MTC is implemented during a care situation in which persons with dementia and their caregivers interact, and thus where the most problematic situations occur. If MTC has the possibility to facilitate positive encounters in these situations, it could be seen as an area to prioritize in dementia care research.

MTC is fairly easy to implement in the context of dementia care directed towards personal needs, as in morning care situations. However, it should be noted that in this thesis all participants were native Swedish speakers and thus the caregivers were well acquainted with the songs and the persons with dementia seemed, in many cases, to acknowledge these songs. It could be problematic if, for example, the caregivers were foreign and did not know the Swedish songs. One solution might be to teach caregivers these songs. Alternatively, whenever possible, persons with dementia should be cared for by caregivers speaking and singing in their language, whether in Swedish or another language.

Singing is widely enjoyed as a means of expression across most cultures and geographic regions, which makes MTC globally relevant. A main advantage of MTC over several other kinds of musical intervention is that it requires no special equipment other than the singing voice. It can also easily be individualized to accommodate the preferences of each individual person with dementia, which might encourage them to join the singing, hum along or whistle, and thus becoming an active participant instead of a passive listener. It is important that the education in MTC includes training on how to effectively use singing as a tool during

caregiving. Chatterton (2010) argued that without knowledge of correct technique, singing while performing care can be demanding for the caregivers and it could be optimal if training in singing is provided by professionals such as music therapists or well-trained singing instructors. If MTC is to be included in dementia care, it should be implemented from a management level in order to ensure appropriate organizational structures that support the caregivers in carrying it out.

9 FUTURE RESEARCH

Future research about MTC should include studies during different care situations, such as meal time or bed time. Different research designs and methods should also be included. Research concerning the applications of MTC should also be conducted in other areas of research, such as physical therapy, which includes mobilization. Another area of interest could be the working environment and job satisfaction of the caregivers.

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