

From DEPARTMENT OF NEUROBIOLOGY, CARE
SCIENCE AND SOCIETY
Karolinska Institutet, Stockholm, Sweden
and
Sophiahemmet University, Stockholm, Sweden

**“BEING IN THE PRESENT”
THE MEANING OF THE INTERACTION BETWEEN
OLDER PERSONS WITH ALZHEIMER'S DISEASE
AND A THERAPY DOG.**

Anna Swall



**Karolinska
Institutet**

Stockholm 2015

All previously published papers were reproduced with permission from the publisher.

Published by Karolinska Institutet.

Printed by Eprint AB 2015

© Anna Swall, 2015

ISBN 978-91-7549-847-8

“Being in the present”
The meaning of the interaction between older
persons with Alzheimer’s disease and a therapy dog.

THESIS FOR DOCTORAL DEGREE (Ph.D.)

by

Anna Swall

Principal Supervisor:

Professor Ingegerd Fagerberg
Ersta Sköndal University College
Department of Health Care science

Co-supervisor(s):

PhD Carina Lundh Hagelin
Sophiahemmet University, and
Karolinska Institutet
Department of Learning, Informatics,
Management and Ethics

PhD Britt Ebbeskog
Karolinska Institutet
Department of Neurobiology, Care Sciences
and Society, Division of Nursing

Opponent:

Associate Professor David Edvardsson
Umeå University
Department of Nursing

Examination Board:

Associate Professor Helle Wijk
Gothenburg University
Department of Care Science and Society

Professor Lena Borell
Karolinska Institutet
Department of Neurobiology, Care Science and
Society
Division of Occupational Therapy

Professor Kenneth Asplund
Mid Sweden University
Faculty of Human Sciences
Department of Human Science

*Defence of thesis will be conducted Friday the 17th of April 2015 at 9.00. Karolinska
Institutet, Alfred Nobels Allé 23, Huddinge H3 blå.*

*Imagine if I one day
do not remember you,
if I your precious face
no longer can perceive.
You take my hand
and put it at your heart,
see I'm right here
with you.
I see you with empty eyes
you are my beloved one
but I do not know it anymore.*

Birgitta Ögneloo Wiklund

To Michael, Anton and Moa.

You are my life, my world, my everything.

Front page picture painted by Maria Götell, 2015.

ABSTRACT

The number of persons with Alzheimer's disease is increasing world-wide and the disease affects the persons, their families, the health care system and the economy within society worldwide. The symptoms and behaviours caused by Alzheimer's disease may be difficult to manage for the person and their caregivers. Alternative methods are recommended before pharmacological treatment. The presence of a therapy dog has been described as beneficial, in for instance increasing well-being and alleviating symptoms and dementia behaviours. The overall aim of this thesis was to gain a deeper understanding of the influence of therapy dogs on persons with Alzheimer's disease from the person's and the dog handler's perspectives. Further, adopting a longitudinal perspective, the study investigates the therapy dog's influence on activity and sleep for persons with Alzheimer's disease. Video observations of five persons with Alzheimer's disease interacting with a therapy dog (**I**, **II**), as well as interviews with nine dog handlers (**III**) were gathered and transcribed. Data was analyzed using a phenomenological hermeneutical method (**I**, **II**, **III**). Registration of activity and sleep was conducted over a period of 16 weeks using an Actigraf that generated curves, and were then analysed using descriptive statistics (**III**). The time spent with the dog revealed memories and feelings resulting in existential thoughts of oneself and life, which then connected to the present situation (**I**). Distancing oneself from the symptoms of the disease when interacting with the dog showed a person functioning in the present with the dog, striving for the dog's best and putting the dog before and above oneself (**II**). The therapy dog's presence showed no pattern of effect on the patients' daytime activity and sleep. The findings instead pointed to a great variety of possible different effects, bringing about increased activity at different time points, for example during night-time sleep (**III**), creating a respite from illness and contributing wordlessly to an existence but thoroughly directed by the dog handler, where the person was comfortable and took the initiative (**IV**). In conclusion, the therapy dog team's presence with the person with Alzheimer's disease induced meaning that allowed the person's hidden qualities and abilities to develop and, when observed from a person-centred perspective, also brought out the individual in each person.

Keywords: Animal-assisted therapy, Alzheimer's disease, Descriptive statistics, Lifeworld, Memories, Person-centred care, Phenomenological hermeneutics, Therapy dog,

LIST OF SCIENTIFIC PAPERS

- I. Swall, A., Ebbeskog, B., Lundh Hagelin, C., & Fagerberg, I. (2014) Can therapy dogs evoke awareness of one's past and present life in persons with Alzheimer's disease? *International Journal of Older People Nursing*. doi:10.1111/opn.12053
- II. Swall, A., Ebbeskog, B., Lundh Hagelin, C., & Fagerberg, I. 'Stepping out of the shadows of Alzheimer's disease' - A Phenomenological hermeneutic study of older persons with Alzheimer's disease caring for a therapy dog. (*resubmitted*)
- III. Swall, A., Fagerberg, I., Ebbeskog, B. & Lundh Hagelin, C. (2014) A therapy dog's impact on daytime activity and night-time sleep for older persons with Alzheimer's disease – A case study. *Clinical Nursing Studies*. 2(4). doi: 10.5430/cns.v2n4p80
- IV. Swall, A., Ebbeskog, B., Lundh Hagelin, C., & Fagerberg, I. 'Bringing respite in the burden of illness ' – Dog handlers experience of visiting older persons with dementia together with a therapy dog. (*submitted*)

CONTENTS

1	Introduction	1
2	Background	2
2.1	The human being - The person	2
2.1.1	Being in the world.....	3
2.2	Dementia - Disease and health.....	3
2.2.1	Life with Alzheimer’s disease	4
2.2.2	Life with Alzheimer’s disease- Life with health and illness	6
2.3	Caring for persons with Alzheimer’s disease and other dementias ..	6
2.3.1	Person-centred care	7
2.4	Environment; Humans and animals.....	8
2.4.1	Animal-Assisted Therapy	9
2.4.2	Therapy dogs.....	10
3	Rationale.....	12
4	Aims.....	13
5	Methods	14
5.1	Design	14
5.2	Participants and setting.....	15
5.2.1	Therapy dog teams.....	17
5.3	Data collection.....	18
5.3.1	Video observations (VIOs).....	18
5.3.2	Actigraf 7.....	18
5.3.3	Interviews	18

5.4	Analysis	19
5.4.1	Phenomenological hermeneutics	19
5.4.2	Case study	21
5.5	Ethical considerations	22
6	Findings	24
6.1	Study I.....	24
6.2	Study II	25
6.3	Study III.....	26
6.4	Study IV.....	28
7	Discussion of findings.....	29
7.1.1	The person and person-centredness.....	29
7.1.2	To become present and mindful	33
7.1.3	Lack of person-centredness	35
8	Methodological considerations	38
8.1	Design	38
8.1.1	The lifeworld approach.....	38
8.2	Participants	38
8.3	The therapy dog team.....	39
8.4	Data collection and analyses	40
8.4.1	Video observations (I, II).....	40
8.4.2	Interviews (IV).....	40
8.4.3	Case study	43

9	Conclusions and implications	45
10	Future research	46
11	Acknowledgements	47
12	Swedish summary	50
13	References	52

LIST OF ABBREVIATIONS

AAA	Animal Assisted Activity
AAI	Animal Assisted Interventions
AAT	Animal Assisted Therapy
BPSD	Behavioural and psychological symptoms of dementia
EL	Episodes of Lucidity
MMSE	Mini-mental State Examination
VIOs	Video observations

1 INTRODUCTION

Ever since I was a little girl growing up in close contact with my grandmothers I have always looked up to and been inspired by older people and their life experience. In my work as a Registered Nurse caring for the old this interest developed and an eagerness to improve care became my focus.

“If I ever forget you or your name, please promise me that you won’t visit me again...”(Aina)

These words of my grandmother left their mark on me, and I can understand her fear of developing memory loss, and of changing in front of her family. Caring for older persons with dementia is challenging in many ways. During my years caring for the old, the most challenging moments came when caring for persons with dementia and their relatives. You need to be inventive, try to manage to see the person behind the illness and at the same time include their relatives who are slowly watching their family member change. Many times I found comfort when some of those with dementia were calm and satisfied in their situation despite their memory loss. But more often I felt helpless when the person showed anxiety when crying, screaming, wandering around and sometimes agitating. My training as a Registered Nurse oddly enough involved very little education on persons with Alzheimer’s disease and dementias. The longer I worked in the field the more I understood the importance of research into the care of persons with dementia. These insights led to the opportunity to teach students about caring for older persons with dementia. In my work as a teacher at the University I think it important to talk about the situation for the person with dementia but also to teach the importance of person-centred care.

2 BACKGROUND

The background will present from a nursing metaparadigm perspective: Human Being, Health, Caring and Environment (Fawcett, 1996, 2013; Roy, 2007; Thorne et al., 1998).

2.1 THE HUMAN BEING - THE PERSON

A human being is more than just a body. As human beings we have the ability to feel deep emotions and analyze events connected to ourselves, as well as to communicate and create meaning in life. “Being a person” has several dimensions and could be described as being conscious, embodied and reflective; the centre of something, the centre of social communication and subjectively experienced one becomes a person (Smith, 2011). As human beings we rely on our body to give us information about the world so that we can sense it, adjust to it and to different situations, and thereby give life meaning (Corbin, 2003). A person is a biological, social, psychological and spiritual individual (McCormack, 2003); a complex organism with more than just a body, that is, with the body and spirit linked together, and with self-reflective abilities (Marcel, 2001); and with a unique value that cannot be reduced (Smith, 2011). An even broader description might be a union of body and spirit embodying the person, meaning the requirement for not just the subject and mental aspects of the human, but also a connection to the body, in order to fully become a person (Smith, 2011). The person is a conscious being while an object does not have consciousness; the person is still a person even in the event of falling into unconsciousness, such as when in a coma.

When illness is prominent it involves more than just a suffering body it also influences us emotionally because of our suffering self (Corbin, 2003). This may include getting old and vulnerable when we are afflicted with illness, and what Frank (2013 p. 1) would call “losing the destination and the map of life”. According to Kleinman (1978), Lupton (2012) and Thorne et al. (1998) illness is understood as the social and lived experience of suffering a disease as a human being. It is hard to handle not being able to recognize one’s body, and to manage to take care of oneself in a situation. The future suddenly becomes uncertain and social life often fades away when one struggles with an uncertainty that brings a

fear of being in the world, a fear of existing (Frank, 2013). Existentially suffering from an illness is also connected with “myself” (Kristensson Uggla, 2014). The mind is never disconnected from the body, but is confused over the changes in the body through the stages of an illness (Frank, 2013).

To experience the world through our senses is to feel the world through the body, through “I” (Marcel, 2001). Being human, and being a person means to participate in a lifeworld observing and encountering one’s own life events and situations (Smith, 2011).

2.1.1 Being in the world

As human beings we live in our lifeworld, and that lifeworld embraces all humans who live in the world where our life constantly goes on and where meaning is experienced (Dahlberg, Dahlberg & Nyström, 2008). Husserl (1992) does not distinguish between body and soul, but considers them as one in the lifeworld. He further argues that the lifeworld is the absolute presence in the real world without neither distance oneself from it nor objectify it. This can be contrasted with Descartes’ description of dualism when the body and soul are separated, the world and the consciousness, the object and the subject (Husserl, 1992). Our consciousness is intentional, meaning that it is turned to something that has meaning to us. We experience things in our lifeworld through our senses that are meaningful, and with more experience of meaningful things, the horizons in our experience through life are broadened (Husserl, 2004). As persons we share our lifeworld with other human beings, and we see, understand, touch and imagine what other human beings think and feel. We have feelings on different levels that allow us to survive; feelings that induce joy and distress, hope and fear, feelings that make us decide and act. By using our feelings and applying our perception we find our way to what has meaning in our lifeworld (Husserl, 2004), though we can never escape from the lifeworld, because it is taken for granted and connected to everything we do in life. As persons we live as subjects in our lifeworld, where our experience has meaning (Dahlberg et al., 2008) and our life in both health and illness goes on.

2.2 DEMENTIA - DISEASE AND HEALTH

Dementia as a concept embraces several dementia diagnoses and is on the increase with 35.6 million people in 2010 living with the disease worldwide. The

risk of developing dementia increases with age and doubles every fifth year after the age of 65 (Prince et al., 2013; Prince et al., 2009). The number of people with dementia is increasing and is expected to nearly double every 20 years with 65.7 million expected in 2030, and 115.4 million in 2050 (Prince et al., 2013). The disease affects the sufferers, their families, the health care system and the economy within society worldwide (Allergi et al., 2007; Hugo & Ganguli, 2014; Schaller et al., 2015). Age is the greatest risk factor, and women have a higher prevalence because women live longer (Hugo & Ganguli, 2014). Alzheimer's disease is a neurodegenerative condition and also the most common form of dementia making up 50-70% of all dementias (Chouraki & Seshadri, 2014). Alzheimer's disease is characterized by the loss of neurons, synapses and the accumulation of plaque, and has an average duration of 10 years until death (Hugo & Ganguli, 2014). Antipsychotic medication is prescribed worldwide, but Guthrie, Clark and McCowan (2010) suggest that alternative strategies are needed, due to the relatively small benefits derived from this type of medication.

2.2.1 Life with Alzheimer's disease

Ageing is something that comes with life, leaving its mark externally on our bodies, and the brain. Every day is a challenge for persons with Alzheimer's disease, as they try to live and handle all aspects of everyday life when suffering from the illness (Clare et al., 2008), feelings of fear and insecurity (Beattie et al., 2004; De Boer et al., 2007; Derksen et al., 2006) losing meaning, feeling empty (Graneheim & Jansson, 2006) and trying to preserve their identity (Nygård & Borell, 1998), autonomy and private sphere (Graneheim, Norberg & Jansson, 2001). The first common symptom is stated as memory loss (Clare, Roth, & Pratt, 2005; Cotrell & Hooker, 2005; Harman & Clare, 2006) with difficulty remembering the names of people and objects (Kitwood, 1997), followed by difficulties in organizing, planning, following directions and performing everyday chores (Hugo & Ganguli, 2014), which also involves a personal adjustment to any situation (Ekman, Robinson & Giorgi, 2012). According to Sabat (2006) persons with Alzheimer's disease may retain their rehearsed memories (implicit memory), but have difficulty talking about them (explicit memory). According to Sabat (2006) these implicit memories are not always expressed explicitly, and if the memory is still there,

the implicit memory is manifested in behaviours like crying and sadness if the individual is insulted or disrespected. The emotion is present, but the memory of the situation inducing these emotions is gone (Sabat, 2006). Changes in behaviour, as well as cognitive decline (Ballard et al., 2009; Finkel, 2001), personality change, loss of empathy, inappropriate behaviour and loss of judgment are noted as the disease progresses (Hugo & Ganguli, 2014).

Anxiety can arise, manifested in screaming, reluctance, aggressiveness and wandering behaviours, summarized in other disciplines as the Behavioural and Psychological Symptoms of Dementia (BPSD) (Ballard et al., 2009; Cohen-Mansfield, Marx & Dakheel-Ali, 2010; Finkel, 2001; Hugo & Ganguli, 2014; Jervis & Manson, 2007; Kverno et al., 2009; Vasse et al., 2010). These will be further described in the thesis as Symptoms and Behaviours of Alzheimer's disease. These situations are difficult to handle for both the person and the caregiver (Almvik, Rasmussen & Woods, 2006; Gates, Fitzwater & Succop, 2003; Georges et al., 2008; Graneheim et al., 2005; Pulsford & Duxbury, 2006; Skovdahl et al., 2008). According to Graneheim and Jansson, (2006) sometimes feelings of homesickness arises, which leads to an attempt to find the way home, resulting in doors having to be locked (Halek, 2011). Often pharmacological treatment, such as the use of neuroleptics, is administered in order to minimize these symptoms and behaviours; side effects often occur and the pharmacological treatment provides only temporary relief (Guthrie et al., 2010; Huybrechts et al., 2012; Kales et al., 2012; Treloar et al., 2010). Wandering behaviours could be life-threatening for the person due to the risk of wandering away from home (Halloran, 2014). Symptoms of paranoia, with suspiciousness and loss of control are described by Kitwood (1997) as fearful experiences. Live in denial of the pending disease, and try to hang on to something familiar, which induces a copying style of words or behaviours triggered from the environment (Kitwood, 1997). In the later stage of the disease symptoms like depression, apathy and agitation and disturbed sleep (Hugo & Ganguli, 2014) due to difficulties coping with external stimuli in the evening are common (Bliwise, 2004; Greenblum & Rowe, 2012; McCurry et al., 2000), as well as dysphagia, incontinence, myoclonus and seizures (Hugo & Ganguli, 2014). However, despite the severe symptoms and behaviours of dementia, life with Alzheimer's disease can be experienced individually, and according to

Sabat (2001) and Kitwood (1997) care should be adapted to the individual's experience of his/her illness.

2.2.2 Life with Alzheimer's disease- Life with health and illness

Life with Alzheimer's disease involves moments of both health and illness. Persons may sometimes act independently, but at other moments not have the ability to realize their own shortcomings, like needing help to take the initiative to manage their own hygiene (Kitwood, 1997). As the illness progresses the person may experience speech impairment, with difficulty finding the right words, reading, talking with other people and following a shifting conversation (Kitwood, 1997). According to Kitwood (1998) feelings of having no power over one's own life occur. Life with dementia has been described as wanting to be included and supported in activities, being loved and cared for, being appreciated and respected to preserve one's dignity (Tranvåg, Petersen & Nåden, 2013); feeling unsure in an unfamiliar world (Phinney, 1998); being different in the eyes of others, longing to be a valuable person with the right to make one's own decisions (Mazaheri et al., 2013). Fearing one's future self as described by Cotrell and Hooker (2005) could influence the person's emotions. Living with Alzheimer's disease has been described as longing to be treated as an equal human being (Tranvåg et al., 2013), striving to participate to preserve one's dignity in daily life (Helgesen, Larsson & Athlin, 2014) and to preserve one's sense of "self" (Hedman, 2014). Despite the symptoms of the disease that may influence the person's daily life, studies show that episodes of lucidity occur (Normann et al., 2005; Normann, Asplund & Norberg, 1998; Normann, Norberg & Asplund, 2002). These moments appear in a present state of mind, the presence is present and the person talks and acts in a more adequate way. These moments are often in connection with person-centred conversations between the person and a caregiver (Normann et al., 2005; Normann et al., 2002) that increase the person's human self worth by acknowledging them as a person and enhancing their sense of dignity (Tranvåg et al., 2013).

2.3 CARING FOR PERSONS WITH ALZHEIMER'S DISEASE AND OTHER DEMENTIAS

Non-pharmacological treatment, like psychological and other supportive therapies (Halloran, 2014; Herrmann & Gauthier, 2008; Hogan et al., 2008;

Hugo & Ganguli, 2014; Kverno et al., 2009; Treloar et al., 2010) is preferred before the use of pharmaceuticals (Fiju, Butler & Sasaki, 2014; Guthrie et al., 2010) to minimize the symptoms and behaviours of Alzheimer's disease. Cohen-Mansfield (2013) suggests that behaviours caused by the symptoms of dementia are due to the lack of fulfilled needs when in care. Caring interventions aim to interact with the person's life to provide an environment with a positive atmosphere, as well as to decrease symptoms and behaviours that are difficult for the person and the caregiver to handle (Gates et al., 2003; Pulsford & Duxbury, 2006). According to Fitzsimmons, Barba and Stump (2014) therapy intervention should be based on the needs, preferences and abilities of the person. Examples of alternative methods used include tactile stimulation (Skovdahl, Sörlie & Kihlgren, 2007), caregivers singing (Hammar et al., 2011a; Hammar et al., 2011b) therapeutic and (Tappen et al., 1997; Tappen et al., 2001) person-centred conversations (Hedman et al., 2013; Hedman et al., 2014; McEvoy, 2014), validation therapy (Neal & Briggs, 2003; Soderlund, Norberg & Hansebo, 2012) and snoezelen therapy (Staal et al., 2007). These methods are often linked to reminiscence, a so-called memory trigger (Woods et al., 2005), and have been shown to strengthen the person's identity (Crichton & Koch, 2007; Normann et al., 2005). However, the Swedish Council on Health Technology Assessment (SBU) (2006) states that therapies have just a temporary effect. In addition Fiju et al. (2014) state that symptoms like anxiety and delusion, could be signs of worry and irritability, which could decrease if care focused on the person's emotions, and one were to induce sympathy and create calm instead of focusing on current symptoms. Further, Cohen-Mansfield (2013) states that persons with dementia react most commonly to pain and distress, and need social contact, support and stimuli to reduce boredom. The treatment and care around the person with dementia should be based on the person's experience of illness (Kitwood, 1997).

2.3.1 Person-centred care

According to McCance, McCormack and Dewing (2011) person-centred care aims to reduce the imbalance between medical care and a holistic, focused and collaborative care. The concept of person-centred care has developed into an approach where the lived experience of the person with dementia is taken into consideration, including every human uniqueness, worth as equals in the center of caring (Edvardsson, Winblad & Sandman, 2008). McCormack (2003, pp.

203-204) describes the meaning of person-centredness as “a way of reaching decisions which are truly one’s own, decisions that express all that one believes important about oneself and the world, the entire complexity of one’s values”. A high level of person-centredness is related to participating in meaningful activities that are important to the individual, e.g. watering plants, making coffee or going to church, all of which can increase the quality of life and the cognitive ability for persons with dementia (Edvardsson, Fetherstonhaugh & Nay, 2009; Edvardsson et al., 2013; McCormack & McCane, 2006). According to Edvardsson et al. (2013), Edvardsson et al. (2008), McCormack and McCane (2006) these activities can reaffirm and strengthen the person, and have been successful when using person-centred care for persons with Alzheimer’s disease. Person-centredness is also associated with a greater ability to take part in daily life (ADL) as well as an overall higher quality of life, (Edvardsson et al., 2013; Sjögren, 2013), and less use of pharmacotherapy (Kontos & Naglie, 2007). A person-centred perspective creates positive care for the patient, enhances the caring climate, reduces the stress of conscience in caregivers (Edvardsson, Sandman & Borell, 2014), as well as showing the person with dementia as someone of value (Edvardsson, Varrailhon & Edvardsson, 2014). In addition, caregivers felt better prepared for challenging issues when guidelines for person-centred care were introduced at a nursing home (Vikström et al., 2015).

2.4 ENVIRONMENT; HUMANS AND ANIMALS

From an historical point of view, Florence Nightingale (1859/2013), early in the history of nursing, stated that a pet could be an excellent companion to the sick, especially to those suffering from chronic illness. The human-animal bond has been known about since humans first started to domesticate animals for farming (Fine & Beck, 2010) with both species needing each other (Nordenfeldt, 2006). The relationship between humans and animals is described as special, with both being deeply rooted to each other (Holmberg, 2009; Fine & Beck, 2010). The bond needs engagement from both species, with the animal recognizing and trusting the human, who in turn needs to be caring and understand the needs of the animal for the enhancement of mutual well-being (Beck, 1999; Nordenfeldt, 2006). According to Beck (1999) a pet can have a positive impact on a human’s loneliness and often increase the opportunities for meeting people. In addition, studies show effects on human-animal interaction such as increased trust,

empathy (Hergovich et al., 2002), social interaction with increased verbal activity (Fick, 1993), increased physical (Edwards & Beck, 2002) and mental health and reduction of stress-related parameters on hormones and heart rates (Beetz et al., 2012). Nowadays animals are common in health care, and they can increase meaning in the care of older persons with dementia (Motomura, Yagi & Ohyama, 2004).

2.4.1 Animal-Assisted Therapy

Animals can benefit humans in different health care settings, such as psychiatric care, paediatric care and palliative care, by encouraging increased social behaviours, reducing pain and anxiety, as well as lowering blood pressure and pulse rates (Beck, 1999; Cherniack & Cherniack, 2014). However, less positive results such as grief at loss of one's pets has been identified (Cherniack & Cherniack, 2014), as well as increased agitating behaviour (Filan & Llewellyn-Jones, 2006). Animal-Assisted Intervention (AAI) has many definitions for different professions, but may be defined as; "an intervention that involves an animal that aims to step in and interfere in any affair, to affect its course or issue" (Kruger & Serpell, 2010, p. 36). Included in AAI are activities like Animal-Assisted Activity (AAA) and Animal-Assisted Therapy (AAT) (Horowitz, 2010; Kruger & Serpell, 2010). Activities like AAA have no specific goals other than to provide motivational, educational and recreational benefits to enhance quality of life. This intervention is mainly about activity in general (Strang, 2007), but with the underpinning factor that the animal and its handler are both trained to carry out the activity AAA (Kruger & Serpell, 2010). AAT therapy is also referred to as Pet therapy (Horowitz, 2010), and is a specific goal-directed intervention (Horowitz, 2010) where a trained animal (usually a dog) and handler are integrated into and engaged in a treatment process in a controlled situation (Buettner & Fitzsimmons, 2011) for a specific purpose aligned to the particular person in need of the treatment (Williams & Jenkins, 2008). The handler is a specialist and possesses expertise as a professional handler within the field of his/her own profession in health care (Kruger & Serpell, 2010). The purpose of AAT is mainly to promote cognitive, emotional and social abilities within the person with dementia (Horowitz, 2010).

AAT includes a variety of animals in service in health care, as well as in controlled situations in the care of older person with dementias (Buettner & Fitzsimmons, 2011), who with their handlers can decrease the symptoms and behaviours of illness (Cohen-Mansfield, 2013) reduce anxiety and sadness (Mossello et al., 2011) and increase quality of life (Bernabei et al., 2013; Marx et al., 2010). A review by Cherniack and Cherniack (2014) shows that animals that contribute towards successful AAT can include birds, fish, cats and dogs. The benefits of AAT for persons with dementia have been described as increased social behaviour showing increased speech and joyfulness, and relief of loneliness and boredom. Increased food intake in the presence of aquarium fish with increased weight as a result was also found (Cherniack & Cherniack, 2014). As well as reduced wandering behaviour (Edwards & Beck, 2002). However, Williams and Jenkins (2008) point out that consideration must be given to those who are not interested in animals or are afraid of them.

2.4.2 Therapy dogs

Therapy involving dogs in the care of the old and of persons with dementia has increased with the dog being described as being able to read non-verbal communication and not judging the person or their inabilities (Strang, 2007). According to Baton et al., (1998), Filan and Llewellyn-Jones (2006), Mossello et al. (2011), Perkins et al., (2008), (Richeson, 2003) and Sellers (2005) therapy dogs have been shown to increase social behaviour and to increase interaction between persons with dementia. Further, Baun and McCabe (2003), Churchill et al., (1999) and McCabe et al., (2002) suggested that the presence of a therapy dog reduces the problematic symptoms and behaviours of dementia. Moretti et al. (2011) state that the presence of a therapy dog has been shown to decrease signs of depression, and to minimize agitating outbursts (Fritz et al., 1995). Studies also show that a therapy dog's presence influences the physical capacity of persons with dementia (Nordgren & Engström, 2012), and quality of life, as well as reducing agitating behaviours, aggression and apathy (Motomura et al., 2004; Nordgren & Engström, 2014; Richeson, 2003). When in contact with the dog, the persons with dementia seem to become less anxious and the social behaviour between them improves (Bernabei et al., 2013; Churchill et al., 1999; Filan & Llewellyn-Jones, 2006; Kantamori et al., 2001; Marx et al., 2010; Perkins et al., 2008; Sellers, 2005). In addition, in one study the therapy dog was

described as possibly complementing pharmaceutical treatment for persons with dementia (Nordgren & Engström, 2014). However, in the studies mentioned data was gathered over a relatively short period of time, and according to Bernabei et al. (2013); Churchill et al. (1999); Richeson (2003); Sellers (2005); The National Board of Health and Welfare (2014); Williams and Jenkins (2008) few studies have been conducted to elucidate the possible impact of animals over the course of several sessions for a suitable group of people.

3 RATIONALE

With people living longer than before the number of persons with Alzheimer's disease is increasing at faster rate. Pharmacological treatments aimed at reducing or minimizing the symptoms and behaviours are now common. However, the side effects are severe and their usefulness therefore becomes questionable. Instead, alternative treatments that facilitate interaction and provide direct support to the person are suggested as a first option. One alternative method is AAT with a therapy dog team, where previous research suggests a positive influence on the persons with Alzheimer's disease and other dementias with decreased symptoms and behaviours, and increased activity and quality of life. The use of therapy dog teams in the care of persons with dementia is increasing. However, there is a lack of knowledge regarding earlier studies on the therapy dog visits and their impact on persons with Alzheimer's disease. Earlier studies were based on short observations of reactions in dementia patients. In addition, previous studies have not focused on the possible influences over a longer period of time, nor on the person's individual experience of the interaction with the dog over several sessions. Neither have dog handlers with their unique experience from two professions been the subject of any previous study.

4 AIMS

The Overall aim was to gain a deeper understanding of the therapy dog's influence on persons with Alzheimer's disease, from the person and the dog handler's perspective. In addition, a longitudinal perspective was adopted to study the therapy dog's influence on activity and sleep for persons with Alzheimer's disease.

The aim of the four studies were:

Study I. To illuminate the meaning of the lived experience of encounters with a therapy dog for persons with Alzheimer's disease.

Study II. To illuminate meanings of the lived experience of older persons with Alzheimer's disease caring for a therapy dog.

Study III. To investigate how continuous and scheduled visits by a prescribed therapy dog affected the daytime and night-time activity for persons with Alzheimer's disease.

Study IV. To illuminate meanings of dog handler's lived experiences of visiting older persons with dementia with their therapy dog.

5 METHODS

The thesis presents four studies adopting a longitudinal perspective for persons with Alzheimer’s disease, where three different data collections and two different analytical methods were used (Table 1).

5.1 DESIGN

An explorative design with a lifeworld approach was used to gain a deeper understanding of the phenomenon studied in the thesis, the therapy dog’s influence on older persons with Alzheimer’s disease and other dementias, and to investigate how the therapy dog impacted the activity of persons with Alzheimer’s disease. The thesis comprised four studies (**I-IV**) with both qualitative (**I, II, IV**) and quantitative (**III**) methods used, as shown in Table 1.

Table 1. Overview of the studies included in the thesis.

Study	Aim	Method	Data	Findings
I	To illuminate the meaning of the lived experience of encounters with a therapy dog for persons with Alzheimer’s disease.	Transcribed video recordings were analyzed using phenomenological hermeneutics	Video observations	Aware of one’s past and present existence. In harmony with the dog’s presence. Present with the dog in communion and understanding. Balancing between memories and reality
II	To illuminate meanings of the lived experience of older persons with Alzheimer’s disease caring for a therapy dog.	Transcribed video recordings were analyzed using phenomenological hermeneutics	Video observations	To care for the dog by using own resources and abilities as a human being. Being loving and caring. Being close and at a distance.

III	To investigate how continuous and scheduled visits by a prescribed therapy dog affected daytime activity and night-time sleep for persons with Alzheimer's disease.	Descriptive statistics. Mean value (m) and standard deviation (SD) of collected counts/minute	A case study	No clear pattern of effect on individual persons' daytime activity and sleep when interacting with a therapy dog was noted. The results instead pointed to a great variety of possible different effects that resulted in increased activity at different stages, for example during night-time sleep.
IV	To illuminate meanings of dog handler's lived experiences visiting older persons with dementia with their therapy dog.	Transcribed interviews were analyzed using phenomenological hermeneutics	Interviews	Respite from the burden of illness for persons with dementia. Being an unintended listener and using one's skills. Being responsive to an emotional existence for persons with dementia. Creating an existence free from illness for persons with dementia.

5.2 PARTICIPANTS AND SETTING

The AAT team included in the project for studies **I**, **II**, **III** had been established for two years at the nursing home where the study took place. The dog handler was a Registered Nurse, and had undergone specialist education in both care of persons with dementia and dog handling. The trained therapy dogs were a Labrador (11 years old) and occasionally an apprentice dog a dachshund (7 years old). The dog handler controlled the dogs and ensured that only one dog at a time interacted with the person during the visits. The visits took place in a room specially adapted with toys for dogs, pictures of dogs, and where activities included throwing balls, giving sweets, as well as cuddling and talking to the dog. The dog handler was present at all times and encouraged the persons with Alzheimer's disease to give the dog commands to perform and do tricks, or just to cuddle with the dog.

The participants for Studies **I**, **II**, **III** (Table 2) were recruited from a municipal nursing home in a metropolitan area in Sweden. They all were diagnosed with Alzheimer's disease and had never had therapy dog visits before. The persons had all been prescribed therapy dog visits by the Registered Nurse working on

the ward. Five persons with Alzheimer’s disease participated in the research project and were prescribed scheduled AAT team visits with a therapy dog team over a period 10 weeks (**I, II**). Study **III** took place in parallel with the therapy dog visits and registered activity and sleep over 16 weeks, including a baseline week before the start of the visits, and a five-week follow-up after the visits had come to a close. Study **I, II** and **III** were carried out at the nursing home on four inpatient wards for persons with Alzheimer’s disease. One inclusion criterion was that the persons with Alzheimer’s disease should not have previously had therapy dog visits. One man and four women aged 89-95 years were included. Their Mini-mental state examination (MMSE) scores varied between 1-17 p, which indicated medium to severe Alzheimer’s disease. One person was excluded from the project due to strong negative reactions to the dog.

Table 2. Study participants, persons with Alzheimer’s disease, Studies I, II and III.

Participant	Age	Gender	Initial MMSE
Person 1 (Mrs. Anderson)	95	Female	9
Person 2 (Mrs. Brown)	89	Female	9
Person 3 (Mrs. Carlson)	95	Female	1
Person 4 (Mrs. Daniels)	91	Female	17
Person 5 (Mr. Edgar)	89	Male	14

MMSE scores for each person one week before initiating therapy dog visits.

The dog handler participants for Study **IV** were recruited using a convenience sample method (Polit & Beck, 2012) by the founder of one therapy dog school in Sweden, which ensured that the dog handlers had all had the same education with their dog at this particular therapy dog school. They had all also specialized in visiting persons with dementia. A snowball sampling (Polit & Beck, 2012) was initiated but no additional participants were recruited. The interviews were conducted between April and June 2014. Nine dog handlers participated in interviews at their work place at eight different nursing homes in a metropolitan area in Sweden. The dog handlers were all women and had worked visiting persons with dementia with their dog for between three and seven years. Two handlers were Registered Nurses, one was an Occupational Therapy Assistant

and six were Assistant Nurses. Their ages were between 43 and 65 and they had worked in care of the old for between 20 and 37 years.

5.2.1 Therapy dog teams

The only current therapy dog school in Sweden was established in 2008. According to the school (Swedish Standards Institute, 2008) the therapy dog's main tasks are to promote human welfare, and to stimulate the training of physical, psychological, social, emotional and cognitive functions. The education is continuously reviewed by the Swedish National Board of Health and Welfare to ensure that the required standard and quality of the education are maintained, and also that the guidelines for health care, regarding for instance allergies, are followed. The dogs are thoroughly tested and examined by a veterinary surgeon to ensure that they are functionally suitable for therapy dog work. The dog handlers are required to have care of the old as their normal job. e.g. a Registered Nurse, Physiotherapist, Occupational Therapist or Assistant Nurse, with experience of caring for persons with dementia for a minimum of two years. The dogs are tested during their training to see if they function well in encounters with persons with Alzheimer's disease and other dementias, and to cope with the possible symptoms and behaviours that might arise. The prescriptions for each person are drawn up by a Registered Nurse, an Occupational Therapist or a Physiotherapist at the establishment where the old person lives. A prescription presents the rationale behind and the purpose of proposed therapy, e.g. to increase activity and alertness, or to reduce anxiety, agitation, pain and depression. Each visit has a specific purpose in support of the individual and follows a prescribed schedule. Unlike an untrained dog, the trained dog knows how to approach the person in a gentle and soft manner. The visit can include close contact, touching the dog's coat, talking and cuddling, throwing balls or searching for hidden sweets. The activities can vary for each visit depending on the person's prescription. All visits and contacts are evaluated by the handler in line with the establishment's routines (Swedish Standards Institute, 2008).

5.3 DATA COLLECTION

5.3.1 Video observations (VIOs)

VIOs (I, II) took place at the municipal nursing home between January and September 2011, comprising four in-patient wards for older persons with dementia. Through VIOs it is possible to observe human experiences and behaviours in daily life (Latvala et al., 2000). Data consisted of VIOs capturing the interaction of persons with Alzheimer's disease with a therapy dog and its handler. Each person had therapy dog visits once a week for 10 weeks, and every visit was videotaped, totalling 50 sessions, and 25 hours of video recorded data was gathered. Observation focused on the interaction between the person with Alzheimer's disease and the therapy dog. At the end of each visit the participating person was asked what the visit was like. This enabled the person to talk about their experience of the visit in their own words. The answers were analyzed together with the texts from the VIOs.

5.3.2 Actigraf 7

The Actigraf 7 was used to follow each person's daytime and night-time activity over a period of 16 weeks, comprising a baseline week before the therapy dog visits started, the scheduled therapy dog visits (10 weeks) and a follow-up period of 5 weeks after the visits had ended. At baseline MMSE was measured for each person. Each person wore an Actigraf 7 (Actiwatch[®]; Cambridge Neurotechnology, Cambridge, UK) on their non-dominant wrist, day and night for a total of 16 weeks. The Actiwatch has been used in several studies (Eggermont & Scherder, 2008; Martin & Hakim, 2011; Nagels et al., 2006; Someren, 2007), and has an accelerator that registers the intensity and speed of arm movement. The registration of activity and sleep was set at 1 minute (one epoch), where a mean value of counts/minute was registered and formed curves, when transported the data into software and then further into Excel[®].

5.3.3 Interviews

The narrative interviews (IV) took place between April and June 2014, and lasted between 22-96 minutes. The participants were asked to narrate their experiences with older persons with dementia interacting with a therapy dog. According to Quinn Patton (2002) questions should be asked in an open-ended

way, which encourages people to answer in their own words. Two open ended questions were asked: “Could you please tell me about a situation when visiting a person with dementia with your therapy dog that you experienced as positive?” and “Could you please tell me about a situation when visiting a person with dementia with your therapy dog that you experienced as less positive or negative?” Occasional follow-up questions were asked like; “Could you please tell me more about...” and “You mentioned something about...” or “Could you please tell me what happened then...” The participants were informed about the study in writing through email, and were then briefed orally before the start of the interview. Twelve dog handlers were asked to participate, and nine accepted and signed an informed consent. The interviews were audiotaped and transcribed verbatim. During the interview the participant was given the opportunity to talk with minor interruptions in line with Cresswell (2007).

5.4 ANALYSIS

5.4.1 Phenomenological hermeneutics

The lifeworld approach enables the researcher to enter the lifeworld as a subject to gain insight of the context of the phenomenon studied (**I, II, IV**), and experience what reveals itself as something new (Husserl, 1992; Lindseth & Norberg, 2004). The researcher needs to have open-mindedness to the lifeworld, meaning that the world is the sender of events and the researcher the receiver with an open mind (Dahlberg & Drew, 1997). According to Ricoeur (1976) a human’s experience cannot directly become another person’s experience, the lived experience is always private, but its meaning can become public through speech. The phenomenological hermeneutic method was developed by Lindseth and Norberg (2004), further described by Fagerberg and Norberg (2009), and inspired by the philosophy of Paul Ricoeur, and facilitates the capture of the meanings of the lived experience of being in the world. The method has been used in several studies by, amongst others, Fischer et al.(2008), Johansson, Bergbom and Lindahl (2012) and Kneck, Klang and Fagerberg (2012). The process of interpretation consists of a constant circular movement between the parts and the whole of the text, and between explanation and understanding to grasp not only what the text says, but what it is talking about (Ricoeur, 1976). This movement involves ontological as well as epistemological assumptions and

is referred to as interpretation (Ricoeur, 2007). Ricoeur (1998) argues that hermeneutics is the theory behind understanding in relation to interpretation. The movement towards meaning is performed by “bracketing” the judgment about the factual - what the interpreter “takes for granted” about the studied phenomenon. Further to which the researcher becomes open to the meaning of the experience narrated (Dahlberg et al., 2008; Lindseth & Norberg, 2004) through e.g. VIOs or interviews. The researcher needs to have an open mind to what is revealed as something new. By accomplishing bracketing, or what Husserl (2004) would have called “epoché”, and switching from a natural to a phenomenological attitude during the analysis, a deeper understanding is reached (Lindseth & Norberg, 2004). VIOs were conducted to capture the interaction in the encounters between the person with Alzheimer’s disease and the therapy dog at each visit (10 visits/person once a week) (**I**, **II**). This resulted in 50 videos producing 25 hours of data for analysis. Narrative interviews were conducted (**IV**) with nine dog handlers in order to grasp an understanding of their lived experiences of visiting persons with dementia with their therapy dog. The narratives and the VIOs were transcribed into a text without interpretation, in order to form an autonomous text (Ricoeur, 1976), a text that expressed its own meaning (Lindseth & Norberg, 2004). The video observations were transcribed to form a text from verbal and non-verbal expressions (Hammar et al., 2011a; Latvala et al., 2000; Soderlund et al., 2012) to capture every possible expression and emotion, such as laughter, smiles, eye-contact and crying from the persons with Alzheimer’s disease. Several studies have used the phenomenological hermeneutics method when analysing VIOs (Ekman et al., 1995; Hansebo & Kihlgren, 2002; Kihlgren et al., 1996).

Table 2. Example of transcribed text from the VIOs for study I. P = Participant, DH = Dog Handler.

<p>P: Well hello! The therapy dog approaches her (participant), and rubs his head against her legs, she stretches her hand towards the dog, smiling and caressing P: Hello! Hey hey, do you remember me? Looking at the dog, looking out into the room P: Yes, maybe you do? P leans forward slightly in the wheelchair, looking down at the floor DH comes forward and sits down next to her squatting on the floor DH: Take the ball to M! (talking to the dog) Come, come! P follows the dogs with her eyes DH gives the ball to P, Here! Come on (talking to the dog)! P looks at the dog as DH talks to the dog off-screen, P smiles, the dog brings the ball DH: Ah! you can have a piece of sausage because you are so clever (DH gives the dog some sausage, P looking at the dog) DH puts a big ball in the arms of P, P looks down towards the floor, holding the ball in her arms DH leans closer to D and whispers in her ear DH: Here are some dog treats (pointing at a plastic cup) P: Oh well? DH: He can have some, if he sits nicely (pointing to the dog). DH puts dog treats in P’s hand, P stretches her</p>

The interviews (**IV**) were also transcribed verbatim into a text. The analysis of the text consisted of three steps; naïve reading, structural analysis and finally comprehensive understanding. To be able to grasp a first understanding, the text was read through several times to understand what the text was saying, and what the text was talking about in order to induce meaning (Lindseth & Norberg, 2004; Ricoeur, 1976). The naïve reading was written down to form a first naïve understanding (Lindseth & Norberg, 2004). The next step was the structural analysis where meaning units were divided and organized in line with the aim of the study. The meaning units were then condensed and further abstracted into sub-themes and a theme (**IV**), and in Studies **I** and **II** into themes and a main theme. The naïve understanding was reformed several times and finally validated against the structural analysis (**I, II, IV**). The main theme, the themes and the sub-themes were then reflected upon in relation to the research question, the naïve understanding, the authors' pre-understanding and the study context referring to both philosophical (**I**) and theoretical literature (**II, IV**). From critical reflection a deeper and a comprehensive understanding about the phenomenon emerged. The awareness of the meaning both broadened and deepened (Lindseth & Norberg, 2004).

5.4.2 Case study

The case study design (Yin, 2009) used in study **III** has been used in several studies, e.g. Borley, Sixsmith and Church (2014) and Normann, Henriksen, Norberg and Asplund (2005) and the study put the case itself in central (Polit & Beck, 2012) and reveal information about a more general phenomenon (Yin, 2009). A case study seemed appropriate if knowledge was to be collected about each person's activity and sleep pattern in connection with the therapy dog visits. Individual activity levels and characteristics were recorded, and measured as a mean value (m) and standard deviation (SD) of collected counts/minute per week day and night, including the baseline week. The activity curves were then transferred to the Actiwatch software and further analyzed using descriptive analysis with Excel[®] software. The activity was measured throughout the whole 16 weeks, including baseline and follow up, for one hour before the visit, during

the 30 -45 minute visit, and for one hour after each visit, to be able to investigate the effect on activity of the AAT team visit. Data was also compared with the VIOs at every visit for each person to understand what kind of activity the visits mostly contained. Daytime activity and night-time sleep were separated for each person and analyzed separately including sleep onset and cessation. Day and night beginning and end were based on activity curves, where activity lower than 40 counts/minute indicated sleep (Camtech User Manual, 2008).

5.5 ETHICAL CONSIDERATIONS

The research project was approved by the Regional Board of Research Ethics (2010/220-31/1). During the research project the ambition to maintain an ethical approach and consideration in line with World Medical Association (World Medical Association, 2014) were carefully been taken into account. Three studies (**I, II, III**) were conducted at the same nursing home involving the same five participants in all three studies. The therapy dog team was already established at the nursing home and the research project was designed to align with the current practice of the therapy dog team's ongoing work. Information about the research project was given to the caregivers and Registered Nurses. Contact with the next of kin of the person with Alzheimer's disease was established by the Registered Nurse on the ward. When the person's next of kin accepted they were contacted and an individual meeting took place where they were given oral and written information about the study project. Persons with dementia have a reduced decision-making capacity, and Karlawish et al. (2008) suggest that the next of kin for persons with dementia should choose the best option for participation in research projects for the person with dementia as long as it would benefit the person's best interest and well-being. All next of kin were assured that the therapy dog visits would stop if any discomfort was expressed by the patient. They all accepted participation for their close ones, which both strengthened the project and was in the person's best interest. However, each person with Alzheimer's disease participating in the project was asked about participation before every visit with the therapy dog took place. Research is not just about finding new methods or medication to improve something, but also about finding values and qualities that can contribute to society to demonstrate the benefits of the research (The Research Council, 2011). During the research project the benefits and risks of the project were constantly discussed and

evaluated. According to Svanström and Johansson Sundler (2013) the inner life of persons with dementia needs to be understood for them to feel safe and secure. The persons were observed during the VIOs and the situation critically reflected upon for signs that might indicate discomfort for those being filmed, but no signs were shown. Occasionally the persons looked at the camera during the VIOs, and I then stepped in front of the camera waving and smiling, to reveal myself as a non-threat. For study **IV** contact information for 13 dog handlers was provided by the founder of the therapy dog school. The participants were contacted by email with information about the study and the research project, and were further informed orally before the interview. The interviews included nine dog handlers, and the participants were informed that the interviews would be audiotaped and they could withdraw their participation at any time without indicating their reason. The audiotaped recordings, the VIOs and the transcriptions were stored in a safe to which only the research group had access. Ethical considerations were further considered regarding the participants and possible discomfort when sharing their lived experiences. A few of the participants in study **IV** occasionally cried when narrating situations about themselves, the person with dementia and the therapy dog. However, the situation during the interview never needed to be interrupted, because the dog handlers were content to continue.

6 FINDINGS

The findings for each study are presented separately.

6.1 STUDY I

The meaning of the lived experience of encounters with a therapy dog for persons with Alzheimer's disease was to be **Aware of one's past and present existence** which was understood as being aware of one's senses and memories when inspired by the closeness of the therapy dog. Moments of temporary presence of mind were revealed in memories from stories told of the past and present, in close contact with the dog. This presence of mind also presented the challenge of interpreting what was real and true in connection with one's memories. **In harmony with the dog's presence** meant that the interaction was grounded in strong feelings for the dog when playing, cuddling and talking to the dog during the visits. These moments resulted in memories with feelings and existential thoughts told of oneself and the earlier life and one became aware of these thoughts being connected to their present situation. **Present with the dog in communion and understanding** tells of the current situation and the hard life on the ward, where the dog's presence means an escape from the present, to a moment filled of meaning with a friend. **Balancing between memories** and reality meant a struggle between moments of temporary presence of mind and memories of past and present life and living, trying to be sure of what was reality and what was not. Remembering sad and joyful memories, but taking strength from the presence of the dog the memories of earlier relationships with dogs became clearer. In communion with the dog one can express and understand the reality of one's life and living, and one's desire to be with the dog, and one tells the dog clearly about this. Being aware of one's feelings through words and one's body when the dog was close, e.g. by showing affection for the dog in harmony and communion, through the laughter and sadness brought on by memories.

6.2 STUDY II

To give of one's own resources and abilities as a human being by using one's hidden resources and ability to be the person one possibly was before the disease, and distance oneself from the symptoms of the disease in the present situation with the dog. To show an autonomous person who is significant and important for the moment and decide what is best for the dog. **Letting one's feelings lead the way for the dog's best** was to show caring with love, reassuring safety and security for the dog. Bringing memories and experience from life when caring for dogs. Being empathic and affectionate towards the dog by understanding, respecting and having insight for the dog and its situation. Believing that one understand the dog's wishes, as well as how to respect the dog by treating it like a living creature of value. Striving for the dog's best in every situation and putting the dog before oneself. The symptoms of the disease dwindle and one picks up past memories from life, which enables one to protect the dog in the moment. Caring by protecting and understanding that one cannot take care of the dog in one's present condition, but instead understanding how the dog should be taken care of as well as how important the dog is. Protecting and expressing concern for the dog about things in the environment that can harm the dog. **Being close and at a distance** was to create a special relationship with the dog, and in closeness and quietness the dog and oneself understand each other by existing in close proximity, but at the same time one distances oneself the moment the dog comes too close. Quietly caring for the dog when playing, and repeating procedures several times, in mutual understanding between oneself and the dog without commands or control from the handler. To distance oneself from the dog in the moment, demonstrating one's own integrity and setting limits for oneself when the dog is too close. Being emotional, stating that one wishes to be left alone, and just observing the dog quietly from a distance without further explanation. Preserve oneself and one's emotions by distancing the dog in situations where one thinks it is best for the dog to be alone.

6.3 STUDY III

The findings of how continuous and scheduled visits by a prescribed therapy dog affected daytime activity and night-time sleep for persons with Alzheimer's disease show no clear pattern of effect. The findings instead show a great variety of possible different effects that result in increased activity at different time points, for example during night-time sleep.

The findings are presented for each person (five cases) according to the individual AAT prescription. For **Mrs. Anderson** the purpose was to increase activity during daytime and decrease her activity at night. Mrs. Anderson's daytime activity showed an increased activity from baseline and during the period of the therapy dog visits, which decreased after the visits ended (Figure 1). At night the purpose was to decrease activity and increase sleep (Figure 2), and an increase in activity during the period of therapy dog visits was shown. Mrs. Anderson decreased her activity one hour after each visit. The aim for **Mrs. Brown** was to decrease daytime activity due to her daily anxiety. Mrs. Brown's daytime activity decreased from baseline and during the period of the therapy dog visits, and further decreased over a period of five weeks after the visits ended (Figure 1). Her activity at night decreased from baseline, during the weeks of therapy dog visits and during the follow-up weeks after the visits ended (Figure 2). After 8 of 10 therapy dog visits Mrs. Brown had increased her activity one hour after the therapy dog had left. For **Mrs. Carlson** the purpose was to increase activity. Mrs. Carlson daytime activity was reasonably steady during baseline and the weeks of therapy dog visits, but the activity increased slightly during the follow-up weeks after the therapy dog visits ended (Figure 1). At night Mrs. Carlson activity decreased from baseline and during weeks of the visits, but increased during the follow-up weeks (Figure 2). After each therapy dog visit Mrs. Carlson decreased her activity one hour after each visit. The aim for **Mrs. Daniels** was to increase activity during daytime. Mrs. Daniels' daytime activity decreased from baseline and during the weeks of therapy dog visits (Figure 1), but she increased her activity during the follow-up weeks. Mrs. Daniels' activity at night decreased from baseline and during the weeks of the visits (Figure 2), but increased during the follow-up weeks. After each therapy dog visit Mrs. Daniels had decreased her activity one hour after each visit. For **Mr. Edgar** the purpose was to maintain activity. Mr. Edgar's daytime activity

decreased from baseline and during the weeks of therapy dog visits, and further decreased during the follow-up weeks after the visits ended (Figure 1). Mr. Edgar’s activity at night decreased from baseline and during the weeks of visits but increased during the follow-up weeks (Figure 2). After each therapy dog visit Mr. Edgar had decreased his activity one hour after each visit. The registered activity levels for the persons with Alzheimer’s disease varied both between persons and within the individual person. This was found to be the case both during the day and at night.

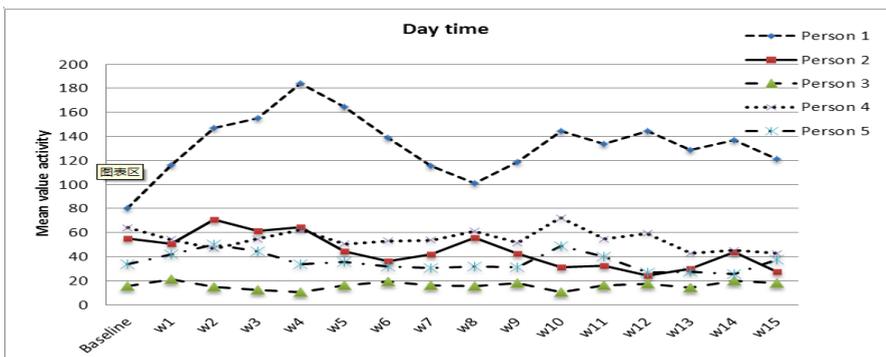


Figure 1. Daytime activity for participants study III
Swall, A., Fagerberg, I., Ebbeskog, B. & Lundh Hagelin, C. (2014) A therapy dog’s impact on daytime activity and night-time sleep for older persons with Alzheimer’s disease – A case study. *Clinical Nursing Studies*. 2(4). doi: 10.5430/cns.v2n4p80, page 10.

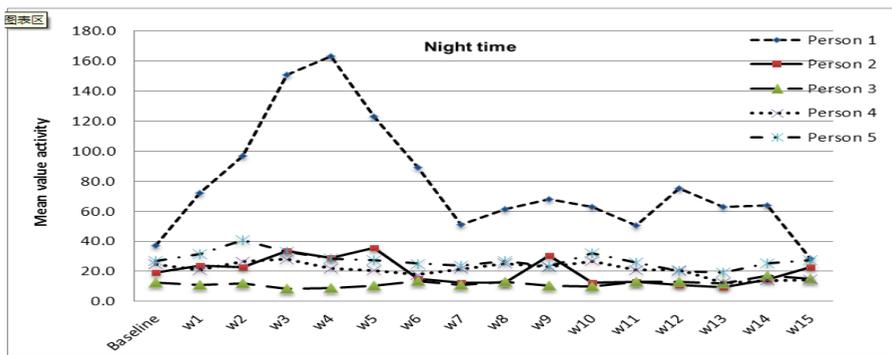


Figure 2. Night-time activity for participants study III
Swall, A., Fagerberg, I., Ebbeskog, B. & Lundh Hagelin, C. (2014) A therapy dog’s impact on daytime activity and night-time sleep for older persons with Alzheimer’s disease – A case study. *Clinical Nursing Studies*. 2(4). doi: 10.5430/cns.v2n4p80, page 10.

6.4 STUDY IV

Respite in the burden of illness for the persons with dementia was understood as the dog handler and dog providing relief and creating a situation where the person with dementia could get away from their illness for just a moment, guiding them to a place where they were comfortable, take the initiative and express wishes, desires and requests that they otherwise would not do. As a dog handler contributed silently but completely controlled the situation, inducing well-being in body and mind for the person and being privileged to create freedom from the burden of illness, as an act of caring. **Being an unintended listener and using one's skills** was to listen to stories about the persons with dementia and their life, and to become overwhelmed by the sad and joyful moments told in words and shown in emotions. Based on information gained using one's skills to develop a plan to either increase or decrease visits in the future. Being insightful and making ethical decisions about whether or not the therapy dog visits need to come to a close, or instead let the dog visit a person until the end of life. **Being responsive to an emotionally existence for person with dementia** was listening to existential thoughts and feelings about life and death, and at the same time respectfully withdrawing for a moment to give the person with dementia some privacy with the dog. To impart meaningfulness by taking note of the person's bodily reactions and behaviours when close to the dog. Being surprised and overwhelmed when the person with dementia acts in a healthy way, as well as when physiological changes at the end of life occur. **Bringing an existence free from illness for persons with dementia** by promoting a moment where one's presence with the dog influences the person's behaviour in a healthy way. Attentively adapting the visits individually to each person with dementia to reduce problematic behaviours, which in turn increases meaningfulness and allows treatment free of antipsychotics for several weeks. Being surprised to see the person act, as one has never seen them act before. To realize that every decision one makes has consequences for the persons with dementia, and that problematic behaviours would result and pharmacological intervention would be needed if one decided to end the visits for the person.

7 DISCUSSION OF FINDINGS

The overall aim was to gain a deeper understanding of the therapy dog's influence on persons with Alzheimer's disease, from the person and the dog handler's perspective. In addition, a longitudinal perspective was adopted to study the therapy dog's influence on activity and sleep for persons with Alzheimer's disease. The results from the four studies (**I**, **II**, **III**, **IV**) could be seen as four intertwined dimensions that create a state where the person becomes present with their memories (**I**), in their person (**II**) and with their individuality (**III**), all realized when the dog handler promotes a meaningful moment (**IV**). This can be understood as the therapy dog team creating meaning for the person with Alzheimer's disease. The person interacts with the dog and becomes free of illness and enjoys health and wellbeing for the moment. The discussion of findings is presented under the following headings; "The person and person-centredness", "To become present and mindful" and "Lack of person-centredness".

7.1.1 The person and person-centredness

When the dog is present, the persons move to a place where they find peace of mind, remember and use their own resources to find something familiar to hold on to, silently steered by the handler (**IV**). For some persons the dog creates meaning and occasional relief from the symptoms of illness, momentarily connecting its presence with the individual person. In a life with Alzheimer's disease or other dementias things may be experienced as chaotic, scary, confusing and frightening (Clare et al., 2008) all connected to the symptoms of the disease, described by Graneheim and Jansson (2006) as "being in a muddle". The current existence may present a struggle to try to grasp something, to reach somewhere familiar. Therapy dog teams are used to promote human welfare, and to stimulate the training of physical, psychological, social, emotional and cognitive functions (Swedish Standards Institute, 2008). This could be to decrease anxiety, wandering, apathy or to increase activity. When living with Alzheimer's disease one tends to be stigmatized by the surroundings (Thorton, 2011), as a result of one's inability to act and function as before (Behuniak, 2011). However, when the persons in the studies (**I**, **II**, **III**) interact with the therapy dog, their inabilities are no longer present. Instead they show abilities that the dog handlers have never been seen before (**IV**). The moment with the

dog could be understood as a person-centred act of caring that McCormack (2004) describes as ; existing in relation to other persons, being a social being, one's personhood taking a place in one's current context, and being recognized and respected. Further, this has an impact on one's sense of self, as well as guarding one's rights as a person, and preserving one's authentic values, values that are important to oneself in all aspects of life (McCormack, 2003). It may be that the presence with the dog enables the person to exist and be social with others, thus becoming respected and recognized by the dog and handler in this context (IV), which in turn may induce person-centredness. Respecting the person and seeing beyond their difficulties creates a better relationship between the person and others (Kontos & Naglie, 2007). The presence of the dog evoked awareness shown in a joy for life and in the situation, when the person with dementia comprehended their life situation with the disease and managed to act within and control the situation by using their memories of how to care for a friend (I, II). The result could be understood as bringing a moment of health and lack of suffering (Eriksson, 1992), for the person with Alzheimer's disease when the dog is present. The person gains reprieve from the burden of illness (IV), is present through memories (I) and is a person with the symptoms of illness put aside. Memories together with the dog may bring on the behaviour of a healthy person full of confidence for the moment. The persons seem to have developed abilities such as leading, deciding and acting in ways to benefit the dog (II). However, memories of sadness and grief that are difficult to handle for the person in the moment also arise (I). According to McCormack (2004) one important aspect in person-centred care is the relationship between the person and the caregiver, but it is also important to know about the person's social context and about the others that are important in the person's life. Further, McCormack and McCance (2010) describe person-centredness as getting to know the person and his/her life plan, which includes striving to know their innermost thoughts, dreams and hopes. The relationship with the dog may have become important and grown even deeper during the period of visits. The person possibly shows their 'innermost self' when the dog is close, including emotions of sadness based on memories from life and possibly from one's life plan. However, allowing the person to express their inner feelings may strengthen the person's self (Hedman, 2014) and in turn decrease the symptoms of illness. The use of person-centred care is grounded in the idea that each individual is a

“person” with experiences, and can experience life and relationships despite the pending illness (Edvardsson et al., 2008; Kitwood, 1997; Penrod et al., 2007). This seems to be the case when the person interacts with the therapy dog. The person tells of their memories of life, as well as moments when life is reflected upon and expressed in a way appropriate to existential thoughts (**I**) and where the person shows her/himself and life through memories.

According to Ricoeur (2005) the miracle of memory is afforded by recognition. A picture, a face or a lost proficiency can change to a state where recognition is present. He further states that life history is connected to the memory and that, despite the loss of memory when the illness progresses, the memory enables the person to still preserve their identity (Ricoeur, 2005). The memories evoked in connection with the dog bring recognition of a life with dogs, people, feelings and experiences, which are reflected upon and told about in words and emotions (**I, II**). In turn these memories induce the behaviour of a person with confidence using their own abilities for the moment with the dog, which could be understood as a preservation of the person’s own identity (**II**) in line with Ricoeur’s (2005) theory. Aspects such as in-depth knowledge about a person’s life and meaningful activities, family and occupations are an important part of person-centred care (McKeown et al., 2010; Thorton, 2011). It could be suggested that person-centred care is achieved when the dog is close (**I, II, III**). The therapy dog visits could also be seen as a tool to increase understanding and knowledge about the person’s “person”. The individual with Alzheimer's disease needs to be seen as a “person”, as being conscious, embodying the centre of something, a centre of subject experience (Smith, 2011). This could be achieved for example by socializing with others in a social, undemanding environment (Edvardsson et al., 2008), and the person is thus perceived as an independent person by others, with rights, values and beliefs (Edvardsson et al., 2008; McCormack & McCane, 2006). The person manages to act as a healthy human being with the symptoms of the illness put aside, perhaps in an undemanding environment for the moment, managing to use one’s abilities such as leading and acting in the dog’s best interest (**II**) guided by the dog handler (**IV**). The connection with the dog may induce a value in the person, a worthiness to be special and chosen to meet the dog (**II**) and do good things for the dog, for one’s friend (**I, II**). Studies show that a person with Alzheimer’s disease has a hidden

personhood, not a lost one (Edvardsson et al., 2008; Kitwood, 1997; McCormack, 2004; The National Board of Health and Welfare, 2010). By being special and chosen to interact with the dog may strengthen the persons “personhood”, and feelings of being the centre of one’s own subject experience might arise, of how to be a person (Marcel, 2001; Smith, 2011).

For a human to feel “I” one is in need of senses to feel, smell and hear in order to make the body function. The ability to feel like “I” is a fundamental thing in life, and the person experiences the phenomenon in life through their “I”(Marcel, 2001). Persons with dementia need support to be a “person” and to feel “I”, with a normal life grounded in life history, interests, needs, meaningful activities and being in an environment that is personalized (Edvardsson et al., 2009). It may be that the dog evokes memories from their life history with interests, as well as a meaningful activity interacting with the dog. The handler brings respite from illness (**IV**) when bringing the dog. This helps the person to find meaning through bodily closeness, which in turn may connect with their life history evoking joyful and sad memories that tell something about the person (**I,II**) which makes the moment between the person and the dog meaningful, and the dog handler can then withdraw temporarily (**IV**).

For some persons increased activity at night during the period of visits occurred (**III**). Persons with dementia often suffer from disturbed sleep at night and anxiety during the latter part of the day, so-called sun-downing (McCurry et al., 2000). One person was more awake at night during the period of the therapy dog visits (**III**). Perhaps emotions from the visits remained. It could be that the dog’s impact on the person’s activity only had effect for a short time, as discussed by SBU (2006), where caring interventions for persons with dementia are not expected to have a prolonged effect on the patient. However, according to Edvardsson et al. (2008) person-centred care is rooted in the lived experience of life, which indicates that each person may be influenced by the therapy dog individually. The impact of the therapy dog’s presence on activity and sleep has been shown to influence each person individually by both day and night (**III**). When a prescription for the therapy dog team is drawn up for a specific purpose, it may be that night-time activity, or night-time habits for the person are not taken into consideration. The person-centred perspective (Edvardsson et al., 2008; Kitwood, 1997) may not be fully adapted for the person at night.

According to the dog handlers, they sometimes make ethical decisions about whether or not the visits should continue, based on the person's reactions to the dog's presence (IV). Further, the dog handlers' use their skills to listen silently and observe the person, and in some situations the dog's visits result in reduced symptoms of illness for several weeks negating the need temporarily for antipsychotics (IV). This could reinforce a person-centred perspective, where knowledge of life and the person is crucial (Thorton, 2011), where the perspective of the person with dementia symptoms and the person's experience of reality is taken into consideration (The National Board of Health and Welfare, 2010), and attention is paid to the dog's influence on the person's life in the longer term and not just for the moment (III, IV).

7.1.2 To become present and mindful

Each person is unique and their reaction to dogs may be considered individual (III) whatever the lived experience of dogs in their lives. The dog handlers' experience of visiting person with dementia with their therapy dog showed that their visits resulted in persons behaving in a more healthy way, as well as creating well-being in body and mind (IV). In some cases the dog handlers' experiences made them decide that the dog should follow the person to the end of life because the dog brought such an improvement to the life of that particular person. There were times when the visits needed to stop due to the discomfort the person experienced with the dog (IV). Parse (1992) describes health in a person as an equilibrium of aspects such as being able to choose meaning in the moment for oneself, and mental, social and spiritual well-being, which in turn evokes equilibrium in body, mind and soul. The dog handler brings an existence free from illness (IV) where the persons with Alzheimer's disease care for the dog. They might experience the moment with the dog to be one of well-being and being "I", being a person (II), with the symptoms of the disease dwindling for a moment. Normann et al., 2005, Normann et al., 1998 and Normann et al., 2002, describe the concept of Episodes of Lucidity (EL) in persons with dementia. It is possible that the person may experience EL in the present when memories arise that make the person act and care for the dog in its best interests (I, II).

The dog's presence seems to evoke something in the person that often creates a peaceful and calm moment, but occasionally a moment with feelings that are difficult to handle (I). In moments where peace of mind is noted, this could be understood as moments of mindfulness. Mindfulness is described as a healing intention where the person with illness can find acceptance, mindfulness, love and an awareness connected to oneself (Schmidt, 2004). As stated earlier, the person expresses joy, love and evoked memories (I, II). The patients act in ways that possibly shows the inner person, where they manage to make decisions about the dog and tell the handler how the dog should be taken care of (II). The concept of mindfulness is described as an equilibrium between the person's outer and inner life (Schmidt, 2004). The dog's presence may increase the person's self-esteem in these situations. The person becomes aware of the situation (I) and manifests a healthy behaviour (II), which is also emphasized by the handler (IV). The salutogenic perspective, where the purpose is to feel a "sense of coherence", to have health despite the pending illness (Antonovsky, 1996; Costa Oliveira, 2014; Eriksson & Lindström, 2008), can be seen as the visits strengthen the persons' "self" in their interaction with the dog, which is also shown when persons with Alzheimer's disease participate in group conversations (Hedman, 2014). The therapy dog does not demand an answer or an explanation, and does not require anything from the person. The situation and the interaction between them are unconditional and encourages the persons to act in ways they are comfortable with, which in turn may evoke abilities that they have not demonstrated earlier during the pending illness (I, II, IV). According to Antonovsky (1996) the salutogenic perspective focuses on health promotion rather than illness prevention, based on seeing the healthy aspects in a person instead of the ill. Living with Alzheimer's disease may induce feelings and thoughts of having no meaning to others, which may result in loss of identity (Svanström & Johansson Sundler, 2013). When the dog is present, the person may find comfort and meaning in life, a moment of peace with mindfulness, as well as a strengthened "self". Taken together the persons show their behaviour from a salutogenic perspective, where health is primary and well-being is created.

The persons with Alzheimer's disease engaged with the dog through physical closeness, caressing and talking, revealing feelings (I, II) and memories from life in the past and the present time (I). According to Holst and Edberg (2010) a

person with dementia seems to become more “negative” in their state of mind when the illness progresses, e.g. developing depression with an attendant boredom and loss of well-being. The dog handler with their skills created distance from the burden of illness (**IV**) as the dog interacted with the person. In a study Öhlén et al. (2014) describe at-homeness metaphorically and philosophically as feelings of being at home despite suffering from illness. To feel at-homeness includes an awareness of the self being recognized and experiencing a temporary familiarity. The dog handlers bring the dog as a tool to enable self-esteem where at-homeness (Öhlén et al., 2014) as well as mindfulness (Schmidt, 2004) may be present. For a moment the person has the ability to put the symptoms of illness aside and possibly experience a moment of health despite illness, as described in the Salutogenic perspective (Antonovsky, 1996).

7.1.3 Lack of person-centredness

The persons with Alzheimer’s disease show strong feelings, e.g. joy with laughter, words and body language, care for the dog and make decisions for the dog’s best (**I, II, III, IV**). When using the validation method persons with dementia become calmer, joyful, more open and interested in their surroundings (Söderlund, 2013). However, variation in activity and sleep is shown between and within each person (**III**), revealing that every person is unique and reacts in an individual and unique way. According to earlier studies (Bernabei et al., 2013; Churchill et al., 1999; Filan & Llewellyn-Jones, 2006; Kantamori et al., 2001; Marx et al., 2010; McCabe et al., 2002; Motomura et al., 2004; Nordgren & Engström, 2012; Perkins et al., 2008; Richeson, 2003; Sellers, 2005) AAT with a therapy dog is said to influence persons with dementia by minimizing anxiety and agitating behaviours such as apathy and aggression, increasing their physical capacity and quality of life and improving social behaviours between persons. However, Filan and Llewellyn-Jones (2006) found in their review that for some persons with dementia a therapy dog may have a negative influence such as causing agitation. The dog handlers often make an ethical decision to end the visits based on the person’s reactions to the therapy dog (**IV**). The therapy dog occasionally evoked existential thoughts with feelings that were difficult for the person to handle (**I**). A person with dementia suffers from memory loss at varying levels, but may also have the implicit memory and the feelings left,

(Sabat, 2006). It may be that moments with the dog may remain longer afterwards, which may enable the person to remember how to caress the dog, but leave them unable to talk about the feeling that arise. This can give rise to both positive and negative feelings depending on the event experienced. They remember moments in the present and the past both with and without dogs (**I**). These memories also induce sadness and grief in the moment, and it may be possible that these feelings remain in the person as an implicit memory with feelings of sadness, but that the person can no longer remember what induced the feelings that occurred during the visit (explicit memory) (Sabat, 2006). According to McCormack and McCane (2006) the purpose of interaction in person-centredness, among other things, is that the person as well as the caregiver experience increased well-being in their shared decision-making. It is possible that despite the fact that the person agrees on in a shared decision making, it may be possible that the person does not wish to have the feelings of sadness that might remain a while after the end of the visit as an explicit memory. In connection the person may not have the ability to understand or interpret why these feelings arise or how to handle them. This could be considered a lack of person-centredness. According to The National Board of Health and Welfare (2010) a person-centred perspective in the care of the person should be more personal and understanding and pay attention to the person with dementia's symptoms. According to descriptions of person-centredness, the caregivers should embrace the reality as it is experienced by the person with dementia (The National Board of Health and Welfare, 2010), placing the person in the centre of the caring process, fully taking them into consideration and ensuring that they are understood, heard and included (Burton, 2007). Therapy dog visits may not be suitable for everyone despite the person's own wishes to meet the dog, and what the caregivers believe is a person-centred perspective. In addition questions can be raised on what the effect on the person with Alzheimer's disease would be if the dog became ill or died, or if the dog handler decided to change work place. The persons may possibly be used to having their lives improved by the dog's visits. This could result in a life situation where symptoms of the disease again become present when the dog stops visiting. In turn this might necessitate an increase of pharmacological treatment with the risk of side-effects (Treloar et al., 2010). The dog handlers are attentive and adapt to each situation individually (**IV**) and to each person, and sometimes adjust the

visit schedule to the person's needs, e.g. extending the visit period. However, this might affect others that might need therapy dog visits, despite the dog handler's desire to do what is best. From a person-centred and salutogenic perspective and with the aim of promoting health and well-being for the person, therapy dog visits may be introduced gradually and then evaluated by the Registered Nurse and the dog handler treating each person individually.

8 METHODOLOGICAL CONSIDERATIONS

Methodological considerations include design, participants, data collection, analysis and measures and are discussed below.

8.1 DESIGN

The overall aim of the thesis was to gain a deeper understanding of the therapy dog's influence on persons with Alzheimer's disease, from the perspective of both the person and the dog handler. In addition, a longitudinal perspective was adopted to study the therapy dog's influence on activity and sleep for persons with Alzheimer's disease. The lifeworld approach using qualitative (**I, II, IV**) and quantitative (**III**) methods has been useful to gain a deeper understanding of the therapy dog's influence on persons with Alzheimer's disease and other dementias.

8.1.1 The lifeworld approach

Lifeworld research is characterized by openness to meaning where the goal is clarification and deeper levels of the meaning given (Dahlberg et al., 2008). Openness to the epistemological and ontological assumptions has been established by increasing understanding of the philosophy based on the lifeworld and interpretation of the text. This thesis comprises three qualitative studies (**I, II, IV**) and one quantitative study (**III**) that complement each other towards a deeper understanding of the lifeworld of the persons' with Alzheimer's disease and other dementias, and is seen as a strength of the thesis. The lifeworld approach with its philosophy may be difficult to understand, and occasionally it was a challenge to incorporate philosophical thinking. However, the lifeworld approach has provided an understanding of how caring research could be linked to philosophy to gain a deeper understanding of the phenomenon under study.

8.2 PARTICIPANTS

In order to recruit participants for Studies **I, II** and **III** the manager and one dog handler were contacted at a nursing home. The nursing home was suitable because it comprised several wards of persons with dementia, and two

established therapy dog teams. Five persons with Alzheimer's disease were eligible for participation. There were many more persons that would have been eligible but due to the therapy dog's deteriorating health only five persons were able to receive visits before the dog died. One other possibility would have been to recruit participants from other nursing homes where therapy dog teams were established. However, the research team decided that the five selected persons with Alzheimer's disease were enough, and that the richness and variation of data from both VIOs (**I**, **II**) and the Actiwatch (**III**) were deemed satisfactory. The recruitment for study **IV** involved dog handlers from different municipal nursing homes in a metropolitan area in Sweden. Also only one dog handler had participated with her dog in Studies **I**, **II** and **III**. The dog handler contact information was collected from the founder of the therapy dog school in Sweden. It may be seen as strength that all but two dog handlers were from different nursing homes, thus they were not influenced by a particular "culture" of one nursing home. Four dog handlers did not want to participate and in the end a total of nine dog handlers accepted the invitation to participate. According to Dahlberg et al. (2008) and Walsh and Downe (2005) richness and quality is preferred before quantity, and the data for study **IV** is considered to provide both richness and variation.

8.3 THE THERAPY DOG TEAM

The therapy dog team (**I**, **II**, **III**) consisted of a trained therapy dog, a Labrador (11 years old) and, occasionally, an apprentice dog, a dachshund (7 years old), and the trained dog handler. The dog handler controlled the dogs and ensured that only one dog at the time interacted with the person during a visit. It is possible that the switch between dogs could have affected the persons with Alzheimer's disease in a negative or confusing way. However, it seemed that the persons were able to separate them and talk about them individually. When a person with Alzheimer's disease (**I**, **II**, **III**) and other dementias (**IV**) is prescribed therapy dog visits, the person often has a connection in some way to dogs earlier in life (Swedish Standards Institute, 2008). This means that persons without a connection to dogs in life miss out on this opportunity. When living with Alzheimer's disease the disease progresses as neurons are lost (Hugo & Ganguli, 2014), and one's experience of the dogs may also change as a result of the disease. One person who had experience of dogs in life accepted the

therapy dog visits, but was then excluded from the project when expressing strong negative reactions on meeting the dog.

8.4 DATA COLLECTION AND ANALYSES

8.4.1 Video observations (I, II)

The VIOs were recorded in a specially adapted room where the visit took place, and focused on the interaction between the person with Alzheimer's disease and the therapy dog. Previous studies (Hammar, 2011a; Hansebo & Kihlgren, 2002; Soderlund et al., 2012) have used VIOs in a similar context, which is suitable with its rich data that includes both verbal and non-verbal communication (Marshall & Rossman, 2006). It was possible that the persons' behavior would change when they were aware of being filmed (Haidet et al., 2009; Polit & Beck, 2012). However, it was found that the persons interacting with the therapy dog only had eyes for the dog. Occasionally they looked at the camera, but ignored it as a non-threat when I revealed myself in front of the camera. According to Haidet et al. (2009) one important aspect when video filming persons with dementia is to look for both positive and negative signs because of their inability to express themselves verbally. Throughout the period of therapy dog visits signs were looked for that could reveal both positive and negative reactions in the patients, but no signs of discomfort were observed. The VIO sessions ended with asking the participant about the current visit. It is possible that interviews instead of VIOs would have revealed a different result. On the other hand a form of interview was performed by asking the person with Alzheimer's disease about the visit on camera. This was also included in the analysis. During the VIOs non-verbal communication, which would not had been recorded in interviews, was taken into consideration. Nevertheless, the VIOs made it possible to repeatedly view data which Latvala et al. (2000) suggests increases credibility.

8.4.2 Interviews (IV)

The narrative interviews were conducted between April and June 2014 with participants selected by convenience sample (Polit & Beck, 2012) by the founder of the therapy dog school. A snowball sampling (Polit & Beck, 2012) was initiated but did not result in more participants. To illuminate meanings of the

lived experience, narratives about the phenomenon are needed (Lindseth & Norberg, 2004). To create a comforting atmosphere interviewers may start with “small talk” about the project and themselves before the interview (Hannabuss, 1996). This is done to provide information about the background to the project and the study aim. In an open dialogue interview, the interviewee and the interviewer share a dialogue of experiences. However, in a research dialogue the interviewer is not willing to share his/her opinions of the phenomenon in focus (Dahlberg et al., 2008). During the interviews the dialogue flowed, but as an interviewer, the focus was to make the participant reflect upon the phenomenon through their experiences. The dog handlers had few “minor positive/negative” experiences to talk about. It could be questioned whether their attitude to therapy dog visits in general was positive, since handlers take their private dog to their job. Perhaps a generally positive attitude would have influenced the results in this study (IV), which would then have been a limitation. However, despite the interviews being designed to let the dog handlers talk without too much interruption (Polit & Beck, 2012) the narratives were steered towards situations where the visits had to end for some reason, or when aggression or sadness were expressed during the visits. This was in order to try to capture a variation in the lived experiences. However, the lived experience can never be completely narrated, only aspects of it (Lindseth & Norberg, 2004). One interview lasted for 22 minutes which could be seen as a short time. Despite the lack of minor positive/negative experiences expressed the findings of Study IV in some way confirmed Studies I and II in aspects such as; evoked past and present memories (I), and expressions of caring for the dog as the act of a confident person (II). This may have strengthened the results in the thesis. Hannabuss (1996) describes the importance of exploring each issue during an interview before moving to the next. Occasionally issues that had been explored needed further exploration, and the interview was then steered back to the subject, and often other experiences were related. This was done in accordance with the ideas of Dahlberg et al. (2008, p. 185) who state that “the interview must be directed towards the phenomenon at which the understanding aims”. One important technique during the interview is knowing when not to interrupt and when to let silence work as narration (Hannabuss, 1996). Often the beginning of the interviews were a bit tentative, but more often than not after a while the participants told of their experiences without problems. As an interviewer I remained silent when the

participant shared their experiences, which was occasionally difficult. However, during the data collection of the interviews, the rehearsed silence became easier to manage, and the interviews were improved.

8.4.2.1 Analysis VIOs and interviews - Phenomenological hermeneutics

The phenomenological hermeneutical method (Lindseth & Norberg, 2004) was used to gain a deeper understanding of lived experiences (**I, II, IV**). The researcher need to be familiar with the context around the phenomenon (Drew, 2001; Husserl, 1995; Lindseth & Norberg, 2004) and pre-understanding is a presumption to raise the quality of the result (Lindseth & Norberg, 2004). The experience of working with older persons with Alzheimer's disease could be seen as strength in all three studies (**I, II, IV**) with knowledge of how to approach the person with Alzheimer's disease during VIOs, as well as in the analysis process when interpreting the data. According to Drew (2001) the phenomenon under study gives information of how the researcher is connected to the things studied. With pre-understanding and awareness of the context for persons with dementia and the dog handlers (Registered Nurses, Assistant Nurses, and Occupational Therapy Assistants) the meanings in the lifeworld emerged and were explained (**I, II, IV**). However, there is never only one meaning, other interpretive meanings are possible (Ricoeur, 1976). To gain self-awareness (Drew, 2001) is to restrain one's judgment about the factual (epoché) and become open for what reveals itself (Husserl, 2004). To become self-aware and restrain the judgment about the factual, all studies were thoroughly discussed in research seminars, as well as critically reviewed during the analysis process by the research group.

To gain trustworthiness and credibility it is necessary to thoroughly describe the analytical process (Cope, 2014; Rolfe, 2006), to establish confidence in the findings (Koch, 1994; Polit & Beck, 2012), and self-awareness in the analysis (Koch, 1994). To achieve dependability the steps in the analysis have been described (**I, II, IV**), as moving back and forth, where the naïve understandings were reformulated several times, before the naïve understanding finally could be validated against the structural analysis. Through the process the findings were thoroughly scrutinized and reflected upon in research seminars, as well as illustrated through quotations in the findings in the articles (**I, II, IV**) in order to

increase confirmability (Cope, 2014; Koch, 1994; Polit & Beck, 2012). By interpreting the findings using philosophical and theoretical literature, the understanding deepened further. During the interpretation the pre-understanding was revised, and the text suddenly interpret the researcher (Lindseth & Norberg, 2004), which became more apparent the longer and deeper the analysis continued. In turn this could be seen as the circular movement (hermeneutic circle) that eventually reveals something new, when the horizons of knowledge are broadened and pre-understandings change.

It is possible that other analytical methods might have been suitable for Studies **I, II, IV**. However, the phenomenological hermeneutical method is suitable when illuminating meanings of the lived experience of being in the world, where the findings are formulated in “everyday words” with the aim to affect people (Lindseth & Norberg, 2004). Dahlberg et al. (2008) suggest that lifeworld research may be generalized, but this is dependent on the context, phenomenon and study. The findings in Studies **I, II** and **IV** may be generalized and transferred to similar contexts, settings and groups (Cope, 2014; Koch, 1994) regarding therapy dog visits. By imply how the findings in qualitative studies could be useful in other or similar contexts where they were originally inferred, generalization could be achieved (Finfgeld-Connett, 2010). However, the findings are based on persons with dementia that had a close connection to dogs earlier in life, which needs to be taken into consideration before transferring the findings to others and similar contexts.

8.4.3 Case study

8.4.3.1 Measures (III)

The Actigraf 7 was considered an appropriate method for measuring the activity of persons with AD (Martin & Hakim, 2011). However, the long recordings (every minute for 16 weeks) gave a large amount of data to handle, which sometimes showed low activity (0 counts/minute) for several minutes. But it was important to follow the person both day and night during these weeks and be able to separate day and night-time activity. The Actigraf 7 has been tested for both reliability and validity (Eggermont & Scherder, 2008; Someren, 2007), meaning that the watch measures the speed and intensity of arm movement

objectively with no possibility of human interference, which may be seen as a strength in support of both reliability and validity (Polit & Beck, 2012), for observation of activity and sleep, where bias might have been present (Drew, 2001). However, low activity under 40 counts/minute, which indicates sleep, cannot be guaranteed with certainty without being confirmed by for example observation.

Mini-mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) was used to measure the cognitive level in the persons with Alzheimer's disease. However, Hellström et al. (2007) found that persons with dementia that go through the MMSE may feel insulted by the questions asked. If the project were to be repeated, another measurement for cognitive decline would probably be used, to ensure that the persons would not feel uncomfortable. When the project was carried out the MMSE was the one test that was most frequently used.

8.4.3.2 *Validity and generalizability*

A case study (III) was performed to gain knowledge of the therapy dog's impact on activity and sleep for persons with Alzheimer's disease. The description of a case study can often provide implications on a more general phenomenon (Polit & Beck, 2012; Yin, 2009). Despite the low number of participants to allow for more advanced statistical analysis, the results showed a variation of each person's activity during the therapy dog visits and follow-up. This could be interpreted as the general implication of a phenomenon (Yin, 2009), meaning that the dogs impact on the person revealed varying individual activity curves, which also was dependent on the prescriptions for each person, thus increasing validity of the findings (Polit & Beck, 2012). However, if a larger number of participants had been recruited perhaps a different result would have been revealed with statistical differences. Nevertheless, this study is the first of its kind to measure activity by day and night related to therapy dog visits for a total of 16 weeks, which strengthened insight into the need for individual adaption during the period of visits. The study inspires further research into the activity of people with dementia and particularly sleep in this context. The study cannot contribute to generalization but instead creates a possible precondition for designing further studies regarding the therapy dog's impact on the activity and sleep of persons with dementia.

9 CONCLUSIONS AND IMPLICATIONS

The therapy dog visits can be seen as a tool to draw out the hidden qualities and abilities of the person with Alzheimer's disease, which in turn brings out the individual in each person. The interaction between the therapy dog and the person creates moments of opportunity for caregivers and dog handlers to reach the person in a person-centred way. The therapy dog's presences might in some situations impart a feeling of safety and encourage the person to reveal important information about their lives and about themselves that could be of importance for the caregivers closest to the person. The person with Alzheimer's disease shows signs of presence of mind, with the illness momentarily put aside when the dog is close, and where well-being is noted for the moment. In addition, the frequency of the therapy dog visits may be individually adapted to each person taking into consideration activity, signs of well-being and the memories aroused, and it is possible that some persons with Alzheimer's disease will need more frequent contact with the therapy dog team. The dog handler has an important role together with the dog. The dog handler has skills that can be seen as the "link" between the dog and the person that forms the therapy, which strengthens the assumption that therapy dog teams are to be preferred before ordinary domestic dogs visiting the ward.

Therapy dog visits may however not be suitable for everyone despite the person's own desire to meet the dog. This underlines the importance of evaluating each visit for each person for both day and night from a person-centred perspective to ensure it is right for each individual. It is also possible that certain persons should not be prescribed therapy dog team visits because of increased anxiety afterwards. The care of each person needs to be properly considered and be responsive to possible signs of discomfort associated with therapy dog visits.

10 FUTURE RESEARCH

Therapy dog visits have been shown to influence each person individually by creating positive well-being in varying levels for persons with Alzheimer's disease. However, the research around persons with Alzheimer's disease and other dementias and the use of therapy dog teams needs further investigation.

Areas for future research could focus on;

- the verbal communication of persons with severe dementia in interaction with a therapy dog.
- the emotional expressions of persons with severe dementia in interaction with a therapy dog.
- the final hours at the end of life for persons with severe dementia in interaction with a therapy dog.
- more extensive longitudinal studies into the interaction between the person with dementia and the therapy dog focusing on activity and quality of life.
- investigating if the therapy dog's presence has a longer term impact on the well-being of the person with severe dementia.

11 ACKNOWLEDGEMENTS

Many people have contributed to this thesis in many ways, and without their support and effort, it would have been difficult to complete my thesis.

Firstly, I would like to express my deepest gratitude to the persons with Alzheimer's disease and the dog handlers that participated in this research project. Without you this thesis would not have been possible.

Further I would like to thank the following for financial support: Sophiahemmet University, Sophiahemmet Research Foundation, Agria Insurance, SKK Research Foundation, King Gustav V's and Queen Victoria's Foundation, the Dementia Foundation, the Ragnhild and Einar Lundström Foundation and the Queen Silvia Fund for Education and Research.

I would also like to express my special gratitude to:

The Karolinska Institutet, Department of Neurobiology, Care Sciences and Society (NVS) for giving me the opportunity to conduct my doctoral studies.

My supervisors:

Professor Ingegerd Fagerberg for believing in me and sharing your scientific knowledge, and for encouraging me and being supportive along the way. I am grateful to you for "hiring" me as the doctoral student for this project. You have always had the time for me and my questions and challenged me to take the next step.

Britt Ebbeskog, for your scientific knowledge and guidance and support during this journey, and for your letters with research articles now and then.

Carina Lundh Hagelin, for your scientific knowledge and support, and for always having the time for me and my questions. For always listening when I need to talk.

I also want to express my special gratitude to:

Jan Åke Lindgren, Dean at Sophiahemmet University for support and providing excellent research conditions.

Pernilla Hillerås, director of research and graduate education, Sophiahemmet University. For your support and understanding during my doctoral studies.

Maria Kumlin, former director of research, Sophiahemmet University. For support and encouragement.

Ann Lundén, director of education, Sophiahemmet University, for your support over the years.

Susanne Georgsson Öhman, my mentor, for your hugs, your support and understanding, and for being a wonderful person in every situation. For being my inspiration to become a researcher.

To the doctoral students, Professor Per-Olof Sandman and other participants at the research seminars at KI, NVS for increasing my scientific knowledge through interesting discussions.

To researchers and doctoral students at Sophiahemmet University for interesting research seminars initiated by Pernilla Hillerås and Carina Lundh Hagelin.

To researchers and doctoral students at Ersta Sköndal University College for interesting research seminars initiated by Professor Ingegerd Fagerberg.

To my colleagues and doctoral “fellows” in “Soffan-gruppen” Åsa Craftman, Karin Bergkvist, Anna Klarare and Inger Wallin Lundell at Sophiahemmet University. Thank you for being there all these years, for needed talks and breaks during this period of our lives.

To fellow doctoral students over the years, Agneta Breitholtz, Gunilla Martinsson, Åsa Kneck, Mats Holmberg and Lena Axelsson for support.

To Sophiahemmet University Library for all your help, and a special thanks to Eva Unemo Wahlfridsson for help with the references in this thesis.

To Michael Cole for linguistic revision for manuscripts and the final thesis.

To Sara Runesdotter for statistical support.

To my friends and family who have supported me all the way:

To my mother-in-law Monica, and Björn for letting me stay at your house whenever I need to. To my father-in-law for your interest in my research.

A very special thanks to my beloved sister Lena Marmstål Hammar. You are my best friend and my biggest supporter. I am so blessed to have you in my life, and especially during this journey. To your husband Thomas Hammar and your beloved boys Elmer and Edvard. Love you!

To my beloved parents Jan and Birgitta Marmstål for always believing in me, for giving me the best opportunities in life. Thank you for your never-ending love, and always being there in all situations. Love you!

My beloved children Anton and Moa. You remind me of what is important in life, and your energy gives me the strength to continue. Your curiosity with questions about older persons with dementia, and what memory loss is. Your cute messages on the white board in my office which have given me the strength to finish this thesis. I love you with all of my heart!

My deepest thanks to my beloved husband Michael Swall. Over the years you have endured a roller coaster of emotions from me. But you have nevertheless always adapted yourself and our family to give me the best possible working atmosphere and to allow me to go into my “bubble”. During the last couple of months I have unintentionally neglected you and our family to finish writing my thesis. I am grateful that you have given me the time and opportunity. You are my everything and I am eternally grateful. Love you!

12 SWEDISH SUMMARY

Personer med Alzheimers sjukdom ökar i världen och sjukdomen har inflytande på personerna, deras familjer, hälsovårdssystemet och ekonomin i samhället världen över. Personer med Alzheimers sjukdom uttrycker sig ibland genom symtom och beteenden som är svåra att hantera för dem själva och vårdarna närmast dem. Alternativa metoder före farmakologisk användning rekommenderas för att minska dessa symtom och beteenden. Närvaron av en vårdhund har visat sig vara till nytta när till exempel det gäller att öka välbefinnande och minska symtom och beteenden grundat i demenssjukdom. Det övergripande syftet med avhandlingen var att få en djupare förståelse för vårdhundens inflytande på personer med Alzheimers sjukdom, inom personens och hundförare perspektiv. Vidare att under ett longitudinellt perspektiv undersöka vårdhundens inflytande på aktivitet och sömn för personer med Alzheimers sjukdom. Video observationer genomfördes med fem personer med Alzheimers sjukdom som interagerar med en vårdhund (**I, II**), samt intervjuer med nio hundförare (**III**) genomfördes och transkriberades. Data analyserades med fenomenologisk hermeneutisk metod (**I, II, IV**). Registrering av aktivitets och sömnkurvor genomfördes under en tid av 16 veckor med hjälp av en Actigraf, vilka sedan analyserades med beskrivande statistik (**III**). Stunden med hunden avslöjar minnen och känslor, vilket leder till existentiella tankar, och berättelser om sig och livet, i både nutid och dåtid (**I**). Man distanserar sig från symtomen av sjukdomen, när man interagerade med hunden. Man visar en person som fungerar i den nuvarande situationen med hunden och strävar efter hundens bästa i situationen samt sätter hunden framför sig själv (**II**). Vårdhundens närvaro visade inga specifika mönster av effekt gällande aktivitet dagtid för varje person. Resultaten pekar istället på en rad möjliga aktivitetseffekter vid olika tidpunkter som t.ex. under natten (**III**). Som hundförare tillför man en stunds andrum från sjukdomen för personer med demens, när man kommer med hunden. Man bidrar också till en tillvaro där personen känner sig bekväm att ta egna initiativ (**IV**). Sammanfattningsvis, vårdhundteamets närvaro med personen med Alzheimers sjukdom inger mening, som tar fram personens dolda egenskaper och förmågor, men som också lyfter

fram varje person individuellt. Vårdhundbesök för personer med Alzheimer's sjukdom kan eventuellt ses som ett personcentrerat alternativ för några personer.

13 REFERENCES

- Allergi, R. F., Butman, J., Arizaga, R. L., Machnicki, G., Serrano, C., Taragano, F. E., . . . Lon, L. (2007). Economic impact of dementia in developing countries: an evaluation of costs of Alzheimer-type dementia in Argentina. *International Psychogeriatrics*, *19*(4), 705-718. doi: 10.1017/S1041610206003784
- Almvik, R., Rasmussen, K., & Woods, P. (2006). Challenging behaviour in the elderly—monitoring violent incidents. *International Journal of Geriatric Psychiatry*, *21*(4), 368-374. doi: 10.1002/gps.1474
- Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International*, *11*(1), 11-18. doi: 10.1093/heapro/11.1.11
- Ballard, C. B., Gauthier, S., Cummings, J., Brodaty, H., Grossberg, G., Robert, P., & Lyketsos, C. (2009). Management of agitation and aggression associated with Alzheimer disease. *Nature Reviews Neurology*, *5*(5), 245-255. doi: 10.1038/nrneurol.2009.39.
- Baton, K., McCabe, B. W., Baun, M. M., & Wilson, C. (1998). *The effect of a therapy dog on socialization and physiological indicators of stress in persons diagnosed with Alzheimer's Disease*. CA: Thousand Oaks: Sage.
- Baun, M. M., & McCabe, B. W. (2003). Companion Animals and persons with dementia of the Alzheimer's type: therapeutic possibilities. *American Behavioural Scientist*, *47*(1). doi: org/10.1177/0002764203255211
- Beattie, A., Daker-White, G., Gilliard, J., & Means, R. (2004). 'How can they tell?' A qualitative study of the views of younger people about their dementia and dementia care services. *Health and Social Care in Community*, *12*(4), 359-368.
- Beck, A. M. (1999). Companion animals and their companions: Sharing a strategy for survival. *Bulletin of Science, Technology & Society*, *19*(4), 281-285. doi: 10.1177/027046769901900404
- Beetz, A., Uvnäs-Moberg, K., Julius, H., & Kotrschal, K. (2012). Psychosocial and psychophysiological effects of human-animal interactions: The possible role of oxytocin. *Frontiers in Psychology*, *3*, 234 doi: 10.3389/fpsyg.2012.00234

- Behuniak, S. M. (2011). The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society*, 31(1), 70-92. doi: 10.1017/S0144686X10000693
- Bernabei, V., De Ronchi, D., La Ferla, T., Moretti, F., Tonelli, L., Ferrari, B., . . . Atti, A. R. (2013). Animal-assisted interventions for elderly patients affected by dementia or psychiatric disorders: A review. *Journal of Psychiatric Research*, 47(6), 762-73. doi:10.1016/j.jpsychires.2012.12.014
- Bliwise, L. D. (2004). Sleep Disorders in Alzheimer's Disease and Other Dementias. *Clinical Cornerstone. Neurodegenerative Diseases*, 6, 16-28.
- Borley, G., Sixsmith, J., & Church, S. (2014). How does a woman with Alzheimer's disease make sense of becoming cared for? *Dementia*. Advance online publication. doi: 10.1177/1471301214561647
- Buettner, L. L., & Fitzsimmons, S. (2011). Animal-assisted therapy for clients with dementia. *Journal of Gerontological Nursing*, 37(5), 10-14. doi: 10.3928/00989134-20110329-05
- Buron, B. (2007). Levels of personhood: A model for dementia care. *Geriatric Nursing*, 29(5), 324-332. doi: 10.1016/j.gerinurse.2007.11.001
- Camtech User Manual (2008). The Actiwatch User Manual. CamNtech Ltd, Cambridge. Version 7.2, No 30096. 1-67.
- Cherniack, E. P., & Cherniack, A. R. (2014). The benefit of pets and animal-assisted therapy to the health of older individuals. *Current Gerontology and Geriatrics Research*. Retrieved from: <http://www.hindawi.com/journals/cggr/2014/623203/> doi: org/10.1155/2014/623203
- Chouraki, V., & Seshadri, S. (2014). Chapter Five – Genetics of Alzheimer's disease. *Advances in Genetics*, 87, 245-294. doi: 10.1016/B978-0-12-800149-3.00005-6
- Churchill, M., Safaoui, J., McCabe, B. W., & Baun, M. M. (1999). Using a therapy dog to alleviate the agitation and desocialization of people with Alzheimer's Disease. *Journal of Psychosocial Nursing*, 37(4), 16-22.
- Clare, L., Roth, I., & Pratt, R. (2005). Perceptions of change over time in early-stage Alzheimer's disease implications for understanding awareness and coping style. *Dementia The international journal of research and practice*, 4(4), 487-520. doi: 10.1177/1471301205058304

- Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008). The experience of living with dementia in residential care: An interpretative phenomenological analysis. *The Gerontologist*, 48(6), 711-720.
- Cohen-Mansfield, J. (2013). Nonpharmacologic treatment of behavioural disorders in dementia. *Current Treatment Options in Neurology*, 15, 765-785. doi: 10.1007/s11940-013-0257-2
- Cohen-Mansfield, J., Marx, M. S., Thein, K., & Dakheel-Ali, M. (2010). The impact of past and present preferences on stimulus engagement in nursing home residents with dementia. *Aging Mental Health*, 14(1), 67-73.
- Cope, D. G. (2014). Methods and Meanings: Credibility and trustworthiness of qualitative research. *Oncology Nursing Forum*, 41(1), 89-91
- Corbin, J. M. (2003). The body in health and illness. *Qualitative Health Research*, 13(2), 256-67. doi: 10.1177/1049732302239603
- Costa Oliviera, C. (2014). Suffering and salutogenesis. *Health Promotion International*. Advance online publication. doi: 10.1093/heapro/dau061
- Cotrell, V. & Hooker, K. (2005). Possible selves of individuals with Alzheimer's disease. *Psychology and Aging*, 20(2), 285-294. doi: 10.1037/0882-7974.20.2.285
- Cresswell, J. W. (2007). *Qualitative inquiry & research design. Choosing among five approaches*. USA: Sage Publications Inc.
- Crichton, J. & Koch, T. (2007). Living with dementia curating self-identity. *Dementia*, 6(3), 365-381.. doi: 10.1177/1471301207081570
- Dahlberg, K., Dahlberg, H., & Nyström, M. (2008). *Reflective lifeworld research*. Lund, Sweden: Studentlitteratur.
- Dahlberg, K., & Drew, N. (1997). A lifeworld paradigm for nursing research. *Journal of Holistic Nursing*, 15(3), 303-317.
- De Boer, M. E., Hertogh, C., Dröes, R.-M., Riphagen, I. I., Jonker, C., & Eefsting, J. A. (2007). Suffering from dementia – the patient's perspective: a review of the literature. *International Psychogeriatrics*, 19(6), 1021-1039. doi: 10.1017/S1041610207005765
- Derksen, E., Vernooij-Dassen, M., Gillissen, F., Rikkert, M. O., & Scheltens, P. (2006). Impact of diagnostic disclosure in dementia on patients and

carers: Qualitative case series analysis. *Age & Mental Health*, 10(5), 525-531. doi: 10.1080/13607860600638024

- Drew, N. (2001). Meaningfulness as an epistemologic concept for explicating the researcher's constitutive part in phenomenologic research. *Advances in Nursing Science*, 23(4), 16-31.
- Edwards, N., & Beck, A. M. (2002). Animal-assisted therapy and nutrition in Alzheimer's disease. *Western Journal of Nursing Research*, 24(6), 697-712. doi: 10.1177/019394502320555430
- Edvardsson, D., Fetherstonhaugh, D., & Nay, R. (2009). Promoting a continuation of self and normality: Person-centred care as described by people with dementia, their family members and aged care staff. *Journal of Clinical Nursing*, 19(17-18), 2611-2618. doi: 10.1111/j.1365-2702.2009.03143.x
- Edvardsson, D., Peterson, L., Sjögren, K., Lindkvist, M., & Sandman, P. O. (2013). Everyday activities for people with dementia in residential aged care: associations with person-centredness and quality of life. *International Journal of Older People Nursing*, 9(4), 269-76. doi: 10.1111/opn.12030
- Edvardsson, D., Sandman, P. O., & Borell, L. (2014). Implementing national guidelines for person-centred care of people with dementia in residential aged care: Effects on perceived person-centredness, staff strain, and stress of conscience. *International Psychogeriatrics*, 26(7), 1171-1179. doi: 10.1017/S1041610214000258
- Edvardsson, D., Varrailhon, P., & Edvardsson, K. (2014). Promoting person-centredness in long-term care: An exploratory study. *Journal of Gerontological Nursing*, 40(4), 46-53. doi: 10.3928/00989134-20131028-03
- Edvardsson, D., Winblad, B., & Sandman, P. O. (2008). Person-centred care of people with severe Alzheimer's disease: Current status and ways forward. *The Lancet Neurology*, 7(4), 362-367.
- Eggermont, L. H. P., & Scherder, E. J. A. (2008). Ambulatory but sedentary: Impact on cognition and the rest-activity rhythm in nursing home residents with dementia. *Journal of Gerontology: Psychological sciences*, 63(5), 278-287. doi: org/10.1093/geronb/63.5.P279

- Ekman, S.-L., Robins Wahlin, T.-B., Norberg, A., & Winblad, B. (1995). Dimensions and progression in the interaction between bilingual/monolingual caregivers and bilingual demented immigrants: Analysis of video-recorded morning care sessions in institutions coded by means of the Erikson theory of "eight stages of man". *International Journal of Aging and Human Development*, 41(1), 29-45.
- Ekman, S.-L., Robinson, P., & Giorgi, B. (2012). The lived experience of early-stage Alzheimer's disease: A three-year longitudinal phenomenological case study. *Journal of Phenomenological Psychology*, 43(2), 216-238.
- Eriksson, K. (1992). The alleviation of suffering – the idea of caring. *Scandinavian Journal of Caring Science*, 6(2), 119-123.
- Eriksson, M., & Lindström, B. (2008). A salutogenic interpretation of the Ottawa Charter. *Health Promotion International*, 23(2), 190-9. doi: 10.1093/heapro/dan014
- Fagerberg, I., & Norberg, A. (2009). "Learning by doing" - or how to reach an understanding of the research method phenomenological heremenutics. *Nurse Education Today*, 29(7), 735-739. doi: 10.1016/j.nedt.2009.03.010.
- Fawcett, J. (1996). On the requirements for a metaparadigm: An invitation to dialogue. *Nursing Science Quarterly*, 9(3).
- Fawcett, J. & Desanto-Madeya, S. (2013). *Contemporary nursing knowledge: Analysis and evaluation of nursing models and theories* (3rd ed.). Philadelphia: F.A. Davis.
- Fick, K. M. (1993). The influence of an animal on social interactions of nursing home residents in a group setting. *American Journal of Occupational Therapy*, 47, 529-534.
- Fiju, M., Butler, J. P., & Sasaki, H. (2014). Emotional function in dementia patients. *The Official Journal of the Japanese Psychogeriatric Society* 14(3), 202-9. doi: 10.1111/psyg.12059
- Filan, S., & Llewellyn-Jones, R. (2006). Animal-assisted therapy for dementia: A review of the literature. *International Psychogeriatrics*, 18(4), 597-611.
- Fine, A. H., & Beck, A. (2010). Understanding our kinship with animals: Input for health care professionals interested in the human/animal bond. In A. H. Fine (Ed.), *Handbook on Animal-Assisted Therapy. Theoretical*

foundations and guidelines for practice (3rd ed.; pp. 3-15). London: Elsevier.

- Fingeld-Connett, D. (2010). Generalizability and transferability of meta-synthesis research findings. *Journal of Advanced Nursing*, 66(2), 246-254. doi: 10.1111/j.1365-2648.2009.05250.x
- Finkel, S., I. (2001). Behavioural and psychological symptoms of dementia. *Clinics Psychiatry*, 62(Suppl.21), 3-6.
- Fischer, R. S., Norberg, A., & Lundman, B. (2008). Embracing opposites: Meanings of growing old as narrated by people aged 85. *International Journal och Aging and Human Development*, 67(3), 259-271.
- Fitzsimmons, S., Barba, B., & Stump, M. (2014). Sensory and nurturing nonpharmacological interventions for behavioural and psychological symptoms of dementia. *Journal of Gerontological Nursing*, 40(11), 9-15. doi: 10.3928/00989134-20140923-01
- Folstein, M., Folstein, S., & McHugh, P. (1975). Mini-Mental State: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12(3), 189-198. doi: org/10.1016/0022-3956(75)90026-6
- Frank, A. W. (2013). *The wounded storyteller: Body, illness and ethics* (2nd ed.). Chicago: The University of Chicago Press.
- Fritz, C. L., Farver, T. B., Kass, P. H., & Hart, L. A. (1995). Association with companion animals and the expression of noncognitive symptoms in Alzheimer's patients. *The Journal of Nervous and Mental Disease*, 183(7), 456-459. doi: org/10.1097/00005053-199507000-00006
- Gates, D., Fitzwater, E., & Succop, P. (2003). Relationships of stressors, strain and anger to caregivers' assaults. *Issues in Mental Health Nursing*, 24, 775-793.
- Georges, J., Jansen, S., Jackson, J., Meyrieux, A., Sadowska, A., & Selmes, M. (2008). Alzheimer's disease in real life--the dementia carer's survey. *International Journal Geriatric Psychiatry*, 23(5), 546-551. doi: 10.1002/gps.1984
- Graneheim, U., Isaksson, U., Ljung, I., & Jansson, L. (2005). Balancing between contradictions: the meaning of interaction with people suffering from dementia and "behavioural disturbances". *International Journal och Aging and Human Development*, 60(2), 145-157.

- Graneheim, U., Norberg, A., & Jansson, L. (2001). Interaction relating to privacy, identity, autonomy and security: An observational study focusing on a woman with dementia and 'behavioural disturbances', and on her care providers. *Journal of Advanced Nursing*, 36(2), 256-265.
- Graneheim, U. H., & Jansson, L. (2006). The meaning of living with dementia and disturbing behaviour as narrated by three persons admitted to a residential home. *Journal of Clinical Nursing*, 15(11), 1397-1403.
- Greenblum, C. A., & Rowe, M. A. (2012). Night time activity in individuals with dementia: Understanding the problem and identifying solutions. *Journal of Gerontological Nursing*, 38(5), 8-11. doi: 10.3928/00989134-20120410-02
- Guthrie, B., Clark, S. A., & McCowan, C. (2010). The burden of psychotropic drugs prescribing in people with dementia: A population database study. *Age and Ageing*, 39(5), 637-642. doi: 10.1093/ageing/afq090
- Haidet, K. K., Tate, J., Divirgilio-Thomas, D., Kolanowski, A., & Happ, M. B. (2009). Methods to improve reliability of video-recorded behavioural data. *Research in Nursing & Health*, 32, 465-474. doi: 10.1002/nur.20334
- Halek, M. B. (2011). Description of the behaviour of wandering in people with dementia living in nursing homes – a review of the literature. . *Scandinavian Journal of Caring Science*.(DOI: 10.1111/j1471-6712.2011 00932.x.), 404-413.
- Halloran, L. (2014). Behavioural and psychological symptoms of dementia. *The Journal for Nurse Practitioners* 10(8), 625–626. doi: 10.1016/j.nurpra.2014.06.012
- Hammar, L. M., Emami, A., Engström, G., & Götell, E. (2011a). Communicating through caregiver singing during morning care situations in dementia care. *Scandinavian Journal of Caring Sciences*., 25(1), 160-168. doi: 10.1111/j.1471-6712.2010.00806.x.
- Hammar, L. M., Emami, A., Götell, E., & Engström, G. (2011b). The impact of caregivers' singing on expressions of motions and resistance during morning care situations in persons with dementia: An intervention in dementia care. *Journal of Clinical Nursing*, 20(17-18), 969-978.
- Hannabuss, S. (1996). Research interviews. *New Library World*, 97(5), 22-30. doi: org/10.1108/03074809610122881

- Hansebo, G., & Kihlgren, M. (2002). Carers' interactions with patients suffering from severe dementia: A difficult balance to facilitate mutual togetherness. *Journal of Clinical Nursing*, *11*, 225-236.
- Harman, G., & Clare, L. (2006). Illness representations and lived experience in early-stage dementia. *Qualitative Health Research*, *16*(4), 484-502. doi: 10.1177/1049732306286851
- Hedman, R. (2014). *Striving to be able and included*. (Doctoral dissertation, Karolinska institutet).
- Hedman, R., Hansebo, G., Ternestedt, B.-M., Hellström, I., & Norberg, A. (2013). How people with Alzheimer's disease express their sense of self: Analysis using Rom Harre's theory of selfhood. *Dementia*, *12*(6), 713-33. doi: 10.1177/1471301212444053
- Hedman, R., Hellström, I., Ternestedt, B.-M., Hansebo, G., & Norberg, A. (2014). Social positioning by people with Alzheimer's disease in a support group. *Journal of Aging Studies*, *28*, 11-21.
- Helgesen, A. K., Larsson, M., & Athlin, E. (2014). Patient participation in special care units for persons with dementia: A losing principle? *Nursing Ethics*, *21*(1). doi: 10.1177/0969733013486796
- Hellström, I., Nolan, M., Nordenfeldt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, *14*(608). doi: 10.1177/0969733007080206
- Hergovich, A., Monshi, B., Semmler, G., & Zieglmayer, V. (2002). The effects of the presence of a dog in the classroom. *Anthrozoos*, *15*(1), 37-50.
- Herrmann, N., & Gauthier, S. (2008). Diagnosis and treatment of dementia: Management of severe Alzheimer disease. *Canadian Medical Association Journal*, *179*, 1279-1287.
- Hogan, D. B., Bailey, P., Black, S., Carswell, A., Chertkow, H., Clarke, B., ... Thorpe, L. (2008). Diagnosis and treatment of dementia: Nonpharmacologic and pharmacologic therapy mild to moderate dementia. *Canadian Medical Association Journal*, *179*(10), 1019-1026.
- Holmberg, T. (Ed.). (2009). *Investigating human/animal relations in science, culture and work* (Skrifter från Centrum för genusvetenskap, Uppsala universitet, 10). Uppsala: Centrum för genusvetenskap, Uppsala universitet.

- Holst, G., & Edberg, A.-K. (2010). Wellbeing among people with dementia and their next of kin over a period of 3 years. *Scandinavian Journal of Caring Science*, 25(3), 549-557. doi: 10.1111/j.1471-6712.2010.00863.x
- Horowitz, S. (2010). Animal-assisted therapy for inpatients, tapping the unique healing power of the human-animal bond. *Alternative and Complementary therapies*, 16(6), 339-343. doi: 10.1089/act.2010.16603
- Hugo, J., & Ganguli, M. (2014). Dementia and cognitive impairment: Epidemiology, diagnosis, and treatment. *Clinical Geriatric Medicine*, 30 (3), 421-42.
- Husserl, E. (1992). *Cartesianska meditationer: En inledning till fenomenologin* [Cartesian meditations: An introduction to phenomenology] (D. Birnbaum & S.-O. Wallenstein, Trans.). Göteborg: Daidalos.
- Husserl, E. (1995). *Fenomenologins idé* [The idea of phenomenology] (J. Bengtsson, Trans.). Göteborg: Daidalos.
- Husserl, E. (2004). *Idéer, till en ren fenomenologi och fenomenologisk filosofi*. [Ideas: General introduction to pure phenomenology] (J. Jakobsson, Trans.). Stockholm: Thales.
- Huybrechts, K., Gerhard, T., Crystal, S., Olfson, M., Avorn, J., Levin, R., . . . Schneeweiss, S. (2012). Differential risk of death in older residents in nursing homes prescribed specific antipsychotic drugs: Population based cohort study. *BMJ*, 344, e977. doi: <http://dx.doi.org/10.1136/bmj.e977>
- Jervis, L. L., & Manson, S. M. (2007). Cognitive impairment, psychiatric disorders, and problematic behaviours in a tribal nursing home. *Journal of Aging and Health*, 19(2), 260-274. doi: 10.1177/0898264306297191
- Johansson, L., Bergbom, I., & Lindahl, B. (2012). Meanings of being critically ill in sound-intensive ICU patientroom - A phenomenological hermenetical study. *The open Nursing Journal*, 6, 103-111.
- Kales, H. C., Kim, H. M., Zivin, K., Valenstein, M., Seyfried, L. S., Chiang, C., . . . Blow, F. C. (2012). Risk of mortality among individual antipsychotics in patients with dementia. *American Journal Psychiatry*, 169(1), 71-79.
- Kantamori, M., Suzuki, M., Yamamoto, K., Kanda, M., Matsui, Y., Kojima, E., . . . Oshiro, H. (2001). A day care program and evaluation of animal-assisted therapy (AAT) for the elderly with senile dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 16(4), 234-239.

- Karlawish, J. (2008). Measuring decision-making capacity in cognitively impaired individuals. *Neurosignals*, 16(1), 91-98. doi: 10.1159/000109763
- Karlawish, J., kim, S. Y., Knopman, D., van Dyck, C. H., James, B. D., & Marson, D. (2008). The views of Alzheimer disease patients and their study partners on proxy consent for clinical trial enrollment. *American Journal of Geriatric Psychiatry*, 16(3), 240-247.
- Kihlgren, M., Hallgren, A., Norberg, A., & Karlsson, I. (1996). Disclosure of basic strengths and basic weakness in demented patients during morning care before and after straff training in integrity promoting care. Analysis of video recordings by mean of the Eriksson theory "eight stages of man". *International Journal of Aging and Human Development*, 43, 219-233.
- Kitwood, T. (1997). The experience of dementia. *Journal of Aging & Mental Health*, 1(1), 13-22. doi:10.1080/13607869757344
- Kitwood, T. (1998). Toward a theory of dementia care: Ethics and interaction. *The Journal of Clinical Ethics*, 9(1), 23-34.
- Kleinman, A. (1978). Concepts and a model for the comparison of medical systems as cultural systems. *Social Science & Medicine*, 12(2-B), 85-93.
- Kneck, Å., Klang, B., & Fagerberg, I. (2012). Learning to live with diabetes – integrating an illness or objectifying a disease. *Journal of Advanced Nursing*, 68(11), 2486-2495. doi: 10.1111/j.1365-2648.2012.05947.x
- Koch, T. (1994). Establishing rigour in qualitative research: The decision trail. *Journal of Advanced Nursing*, 19, 976-986.
- Kontos, P. C., & Naglie, G. (2007). Bridging theory and practice: Imagination, the body, and person-centred dementia care. *Dementia*, 6(4), 549-569. doi: 10.1177/14713012070084394
- Kristensson Uggla, B. (2014). Personfilosofi: Filosofiska utgångspunkter för personcentrering inom hälso- och sjukvård. In I. Ekman (Ed.), *Personcentrering inom hälso- och sjukvård: Från filosofi till praktik* (pp. 21-68). Stockholm: Liber.
- Kruger, K. A., & Serpell, J. A. (2010). Animal-assisted interventions in mental health: Definitions and theoretical foundations. In A. H. Fine (Ed.), *Handbook on animal-assisted therapy: Theoretical foundations and guidelines for practice* (3rd ed.; pp. 33-44). London: Elsevier.

- Kverno, K. S., Black, B. S., Nolan, M. T., & Rabins, P. V. (2009). Research on treating neuropsychiatric symptoms of advanced dementia with non-pharmacological strategies, 1998-2008: A systematic literature review. *International Psychogeriatrics*(IPA), 1-21.
- Latvala, E., Voukila-Oikkonen, P., & Janhonen, S. (2000). Videotaped recording as a method of participant observation in psychiatric nursing research. *Journal of Advanced Nursing*, 31, 1252-1257.
- Lindseth, A., & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences*, 18(2), 145-153.
- Lupton, D. (2012). *Medicine as culture. Illness, disease and the body* (Vol. 3). Chennai, India: Sage Publications Ltd.
- Marcel, G. (2001). *The mystery of being: Vol 1: Reflection & mystery* (G. S. Fraser, Transl.). South Bend, IN: St. Augustine's Press. (Original work published 1950).
- Marshall, C., & Rossman, G. B. (2006). *Designing qualitative research* (4th ed.) Thousands Oaks, California: SAGE.
- Martin, J. M., & Hakim, A. D. (2011). Wrist actigraphy. *American College of Chest Physicians*, 139(6), 1414-1527. doi: org/10.1378/chest.10-1872
- Marx, M. S., Cohen-Mansfield, J., Regier, N. G., Dakheel-Ali, M., Srihari, A., & Thein, K. (2010). The impact of different dog-related stimuli on engagement of persons with dementia. *American Journal of Alzheimer's disease & Other Dementias*, 25(1), 37-45.
- Mazaheri, M., Eriksson, L. E., Heikkilä, K., Nasrabadi, A. N., Ekman, S. L., & Sunvisson, H. (2013). Experiences of living with dementia: Qualitative content analysis of semi-structured interviews. *Journal of Clinical Nursing*, 22(21-22), 3032-3041. doi: 10.1111/jocn.12275
- McCabe, B. W., Baun, M. M., Speich, D., & Agrawal, S. (2002). Resident dog in the Alzheimer's special care unit. *Western Journal of Nursing Research*, 24(6), 684-696. doi: 10.1177/019394502236641
- McCance, T., McCormack, B., & Dewing, J. (2011). An exploration of person-centredness in practice. *The Online Journal of Issues in Nursing*, 16(2), 1. doi: 10.3912/OJIN.Vol16No02Man01

- McCormack, B. (2003). A conceptual framework for person-centred practice with older people. *International Journal of Nursing Practice*, 9(3), 202-209.
- McCormack, B. (2004). Person-centredness in gerontological nursing: An overview of the literature. *Journal of Clinical Nursing*, 13(3a), 31-38. doi: 10.1111/j.1365-2702.2004.00924.x
- McCormack, B., & McCance, T. (2010). *Person-centred nursing theory and practice*: Wiley-Blackwell.
- McCormack, B., & McCance, T. V. (2006). Development of a framework for person-centred nursing. *Journal of Advanced Nursing*, 56(5), 472-479. doi: 10.1111/j.1365-2648.2006.04042.x.
- McCurry, S. M., Reynolds, C. F., Ancoli-Israel, S., Teri, L., & Vitiello, M. V. (2000). Treatment of sleep disturbance in Alzheimer's disease. *Sleep Medicine Reviews*, 4(6), 603-628. doi: 10.1053/smr.2000.0127
- McEvoy, P. (2014). Dementia communication using empathic curiosity. *Nursing times.*, 110(24), 12-15.
- McKeown, J., Clarke, A., Ingleton, C., Ryan, T., & Repper, J. (2010). The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing*, 5, 148-158. doi: 10.1111/j.1748-3743.2010.00219.x
- Moretti, F., De Rochi, D., Bernabei, V., Marchetti, L., Ferrari, B., Forlani, C., . . . Sacchetti, C. (2011). Pet therapy in elderly patients with mental illness. *Psychogeriatrics*, 11, 125-129.
- Mossello, E., Ridolfi, A., Mello, A. M., Lorenzini, G., Mugnai, F., Piccini, C., . . . Marchionni, N. (2011). Animal-assisted activity and emotional status of patients with Alzheimer's disease in day care. *International Psychogeriatrics*, 23(6), 899-905. doi: 10.1017/S1041610211000226
- Motomura, N., Yagi, T., & Ohyama, H. (2004). Animal assisted therapy for people with dementia. *Psychogeriatrics*, 4, 40-42.
- Nagels, G., Engelborghs, S., Vloeberghs, E., D, V. D., Pickut, B. A., & De Deyn, P. P. (2006). Actigraphic measurement of agitated behaviour in dementia. *International Journal of Geriatric Psychiatry*, 21(4), 338-339. doi: org/10.1002/gps.1483

- Neal, M., & Briggs, M. (2003). Validation therapy for dementia. *Cochrane database of systematic reviews*, (3), CD001394. doi: .1002/14651858.CD001394.
- Nightingale, F. (1859/2013). *Notes on nursing what it is, and what it is not*. New York: Barnes & Noble.
- Nordenfelt, L. (2006). *Animal and human health and welfare: A comparative philosophical analysis*. Biddles. Wallingford: CABI.
- Nordgren, L., & Engström, G. (2012). Effects of animal-assisted therapy on behavioural and/or psychological symptoms in dementia: A case report. *American Journal of Alzheimer's Disease & Other Dementias*, 27(8), 625-632. doi: 10.1177/1533317512464117.
- Nordgren, L., & Engström, G. (2014). Effects of dog-assisted intervention on behavioural and psychological symptoms of dementia. *Nursing Older People*, 26(3), 31-8. doi: 10.7748/nop2014.03.26.3.31.e517.
- Normann, H. K., Asplund, K., Karlsson, S., Sandman, P. O., & Norberg, A. (2005). People with severe dementia exhibit episodes of lucidity: A population-based study. *Journal of Clinical Nursing*, 15(11), 1413-1417. doi: 10.1111/j.1365-2702.2005.01505.x.
- Normann, H. K., Asplund, K., & Norberg, A. (1998). Episodes of lucidity in people with severe dementia as narrated by formal carers. *Journal of Advanced Nursing*, 28(6), 1295-1300.
- Normann, H. K., Henriksen, N., Norberg, A., & Asplund, K. (2005). Lucidity in a woman with severe dementia related to conversation: A case study. *Journal of Clinical Nursing*, 14(7), 891-896.
- Normann, H. K., Norberg, A., & Asplund, K. (2002). Confirmation and lucidity during conversations with a woman with severe dementia. *Journal of Advanced Nursing*, 39(4), 370-376.
- Nygård, L., & Borell, L. (1998). A lifeworld of altering meaning: Expressions of the illness experience of dementia in everyday life over 3 years. *The Occupational Therapy Journal of Research*, 18(2), 109-136.
- Parse, R. R. (1992). Human becoming: Parse's theory of nursing. *Nursing Science Quarterly*, 5(1), 35-42. doi: 10.1177/089431849200500109

- Penrod, J., Yu, F., Kolanowski, A., Fick, D. M., Loeb, S. J., & Hupcey, J. E. (2007). Reframing person-centred nursing care for persons with dementia. *Research Theory Nursing Practice*, 21(1), 57-72.
- Perkins, J., Bartlett, H., Travers, C., & Rand, J. (2008). Dog-assisted therapy for older people with dementia: A review. *Australasian Journal of Ageing*, 27, 177-182.
- Phinney, A. (1998). Living with dementia from the patient's perspective. *Journal of Gerontological Nursing*, 24(6), 8-15. doi: 10.3928/0098-9134-19980601-06
- Polit, D. F., & Beck, C. T. (2012). *Nursing research: Generating and assessing Evidence for nursing practice* (9th ed.). Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C.P. (2013). The global prevalence of dementia: A systematic review and metaanalysis. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 9(1), 63-75. doi: 10.1016/j.jalz.2012.11.007.
- Prince, M., Ferri, C., Sousa, R., Albanese, E., Riberio, W. S., & Honyashiki. (2009). Alzheimer's disease international world Alzheimer report 2009. London: Institute of Psychiatry, King's College.
- Pulsford, D., & Duxbury, J. (2006). Aggressive behaviour by people with dementia in residential care settings: A review. *Journal of Psychiatric and Mental Health Nursing*, 13, 611-618.
- Quinn Patton, M. (2002). *Qualitative research & evaluation methods*. USA: Sage Publications Inc.
- Richeson, N. E. (2003). Effects of animal-assisted therapy on agitated behaviours and social interactions of older adults with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 18(6), 353-358.
- Ricoeur, P. (1976). *Interpretation theory: Discourse and the surplus of meaning*. Fort Worth, Texas: Texas Christian University Press.
- Ricoeur, P. (1998). *Hermeneutics and the human sciences: essays on language, action and interpretation*. Cambridge: Cambridge University Press.

- Ricoeur, P. (2005). *Minne, historia, glömska* [Memory, history, forgetfulness] (E.Backelin, Trans.).(2nd ed.). Göteborg: Diadlos.(Original work published 2000).
- Ricoeur, P. (2007). *From text to action, essays in hermeneutics, II*. Evanston, Illinois: Northwestern University Press.
- Rolfe, G. (2006). Validity, trustworthiness and rigour: Quality and the idea of qualitative research. *Journal of Advanced Nursing*, 53(3), 304-310.
- Roy, C. (2007). Update from the future: thinking of theorist Callista Roy. *Nursing Science Quarterly*, 20(2).
- Sabat, S. R. (2001). *The experience of Alzheimer's disease, life through a tangled veil*. Massachusetts, USA: Blackwell Publisher Inc.
- Sabat, S. R. (2006). Implicit memory and people with Alzheimer's disease: Implication for caregiving. *American Journal of Alzheimer's Disease and Other Dementias*, 21(11), 11-4. doi: 10.1177/153331750602100113
- Schaller, S., Mauskopf, J., Kriza, C., Wahlster, P., & Kolominsky-Rabas, P. L. (2015). The main cost drivers in dementia: a systematic review. *International Journal of Geriatric Psychiatry*, 30, 111-129. doi: 10.1002/gps.4198
- Schmidt, S. (2004). Mindfulness and healing intentions: Concepts, practice, and research evaluation. *Journal of Alternative and Complementary Medicine*, 10(Suppl.1), S7-14.
- Sellers, D. M. (2005). The evaluation of an animal assisted therapy intervention for elders with dementia in long-term care. *Activities, Adaptions and Aging*, 30(1), 61-67. doi:10.1300/J016v30n01_04
- Sjögren, K. (2013). *Personcentrerad vård i särskilda boenden för äldre* [Person-centred care in nursing homes for older persons]. (Doctoral dissertation, Umeå universitet).
- Skovdahl, K., Fahlström, G., Horttana, B., Winblad, B., & Kihlgren, M. (2008). Demanding behaviours and workload in elderly care in Sweden: occurrence at two time points within a decade. *Scandinavian Journal of Caring Science*, 22(3), 323-330. doi: 10.1111/j.1471-6712.2007.00500.x.
- Skovdahl, K., Sörлие, V., & Kihlgren, M. (2007). Tactile stimulation associated with nursing care to individuals with dementia showing aggressive or restless tendencies: an intervention study in dementia care. *International*

Journal of Older People Nursing, 2(3), 162-170. doi: 10.1111/j.1748-3743.2007.00056.x.

Smith, C. (2011). *What is a person: Rethinking humanity, social life, and the moral good from the person up?* Chicago: University of Chicago Press.

Socialstyrelsen [The National Board of Health and Welfare]. (2010). *Nationella riktlinjer för vård och omsorg vid demenssjukdom 2010* [National guidelines for health and social care for persons with dementia]. Stockholm: Socialstyrelsen. Retrieved from: <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/18012/2010-5-1.pdf>

Socialstyrelsen [The National Board of Health and Welfare]. (2014). *Vårdhund för äldre i särskilt boende: En systematisk översikt om effekter och vetenskapligt stöd* [Therapy dog for older persons in municipal care]. Stockholm: Socialstyrelsen. Retrieved from: <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/19340/2014-1-25.pdf>

Someren, E. J. V. (2007). Improving actigraphic sleep estimates in insomnia and dementia: how many nights? *Journal of Sleep Research*, 16, 269-275. doi: org/10.1111/j.1365-2869.2007.00592.x

Staal, J. A., Sacks, A., Matheis, R., Collier, L., Calia, T., Hanif, H., & Kofman, E. S. (2007). The effects of Snoezelen (multi-sensory behaviour therapy) and psychiatric care on agitation, apathy, and activities of daily living in dementia patients on a short term geriatric psychiatric inpatient unit. *International Journal of Psychiatry in Medicine*, 37(4), 357-370. doi: 10.2190/PM.37.4.a

Statens beredning för medicinsk utvärdering [The Swedish Council on Health Technology Assessment]. (2006). *Sammanfattning av SBU:s rapport om demenssjukdomar: En systematisk litteraturoversikt* [Summary of the report from SBU on dementia diseases: A systematic literature review] (SBU-rapport, 172). Stockholm: SBU.

Strang, P. (2007). Djur som "terapeuter" i vården [Animals as therapists in health care]. In B. Beck-Friis, P. Strang & A. Beck-Friis (Eds.), *Hundens betydelse i vården: Erfarenheter och praktiska råd* [The dog's meaning in health care] (pp. 85-87). Stockholm: Gothia förlag.

- Swall, A., Fagerberg, I., Ebbeskog, B., & Lundh Hagelin, C. (2014). A therapy dog's impact on daytime activity and night-time sleep for older persons with Alzheimer's disease: A case study. *Clinical Nursing Studies*, 2(4). Advance online publication. doi: 10.5430/cns.v2n4p80
- Svanström, R., & Johansson Sundler, A. (2013). Gradually losing one's foothold: A fragmented existence when living alone with dementia. *Dementia*. Advance online publication. doi: 10.1177/1471301213494510
- Söderlund, M. (2013). *Förhållningssätt och kommunikation i mötet med personer med demenssjukdom. Utvärdering av ett träningsprogram med validationsmetoden.* (PhD), Karolinska Institutet, Eprint AB, Stockholm.
- Söderlund, M., Norberg, A., & Hansebo, G. (2012). Implementation of the validation method: Nurses' descriptions of caring relationships with residents with dementia disease. *Dementia: The International Journal of Social Research and Practice*, 11, 569-587. doi: 10.1177/1471301211421225.
- Tappen, R. M., Williams-Burgess, C., Edelstein, J., Touhy, T., & Fishman, S. (1997). Communicating with individuals with Alzheimer's disease: Examination of recommended strategies. *Archives of Psychiatric Nursing*, 16(5), 249-256.
- Tappen, R. M., Williams, C. L., Barry, C., & DiSesa, D. (2001). Conversation intervention with Alzheimer's patients: Increasing the relevance of communication. *Clinical Gerontologist*, 24(3/4), 63-75.
- The Research Council, V. (2011). Good Research Practice ,God Forskningssed. In G. Hermerén (Ed.). Bromma.
- Swedish Standards Institute. (2008). *Vårdhundsteam inom äldreomsorg, demensvård och rehabilitering för vuxna efter förvärvad hjärnskada : Krav på utbildning* (Svensk Standard 876000). Stockholm: SIS.
- Thorne, S., Canam, C., Dahinten, S., Hall, W., Henderson, A., & Kirkham, S. R. (1998). Nursing's metaparadigm concepts: Disimpacting the debates. *Journal of Advanced Nursing*, 27, 1257-1268.
- Thorton, L. (2011). Person-centred dementia care: An essential component of ethical nursing care. *Canadian Nursing Home*, 22(3), 10-14.
- Tranvåg, O., Petersen, K. A., & Nåden, D. (2013). Relational interactions preserving dignity experience: Perceptions of persons living with

dementia. *Nursing Ethics*. Advance online publication. doi:
10.1177/0969733014549882

- Treloar, A., Crugel, M., Prasanna, A., Solomons, L., Fox, C., Paton, C., & Katona, C. (2010). Ethical dilemmas: Should antipsychotics ever be prescribed for people with dementia? *The British Journal of Psychiatry*, *197*(2), 88-90. doi: 10.1192/bjp.bp.109.076307
- Walsh, D., & Downe, S. (2005). Appraising the quality of qualitative research. *Midwifery*, *22*(2), 108-119. doi: 10.1016/j.midw.2005.05.004
- Vasse, E., Vernooj-Dassen, M., Spijker, A., Rikkert, M. O., & Koopmans, R. (2010). A systematic review of communication strategies for people with dementia in residential and nursing homes. *International Psychogeriatrics*, *22*(2), 189-200. doi: 10.1017/S1041610209990615
- Vikström, S., Sandman, P. O., Stenwall, E., Boström, A.-M., Saarnio, L., Kindblom, K., . . . Borell, L. (2015). A model for implementing guidelines for person-centred care in a nursing home setting. *International Psychogeriatrics*, *27*(1), 49-59. doi: 10.1017/S1041610214001598
- Williams, E., & Jenkins, R. (2008). Dog visitation therapy in dementia care: a literature review. *Clinical research, nursing older people*, *20*(8), 31-35.
- Woods, B., Spector, A., Jones, C., Orrell, M., & Davies, S. (2005). Reminiscence therapy for dementia : Review. *Cochrane database of systematic reviews*, (2), CD001120. doi: 10.1002/14651858.CD001120.pub2
- World Medical Association (1964/2013). *WMA Declaration of Helsinki: Ethical principles for medical research involving human subjects*. Retrieved from <http://www.wma.net/en/30publications/10policies/b3/>
- Yin, R. (2009). *Case study research, design and methods* (4th ed.). Thousand Oaks, California.: Sage.
- Öhlén, J., Ekman, I., Zingmark, K., Bolmsjö, I., & Benzein, E. (2014). Conceptual development of “at-homeness” despite illness and disease: A review. *International Journal of Qualitative Studies on Health and Well-being*, *9*, 23677. doi: org/10.3402/qhw.v9.23677