Long-term ongoing structured support in early stage of dementia:
A family affair

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ISSN 1652-893X,
Mid Sweden University Doctoral Thesis 197
ISBN 978-91-87557-76-7
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Printed by Mid Sweden University, Sundsvall, Sweden, 2014
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ABSTRACT

Dementia disorders affect more than 35 million people around the world, which will double every twenty years. Dementia is a global disruption of intellectual functioning; there is a decrease of memory ability and other intellectual abilities such as orientation, visuospatial- perceptive ability, language, thinking, executive abilities, problem solving, apraxia and agnosia. These symptoms are often followed by behavioral changes and changes in the personality, such as loss of initiative, emotional instability, irritation, apathy, coarse social behaviour and mood changes. The most frequent symptoms were apathy, depression, irritability, and agitation. About 25,000 persons are diagnosed with dementia each year in Sweden. Today, estimates are that 160,000 persons in total are suffering from dementia in Sweden. In Sweden, most diagnoses are done in the primary health care setting by general practitioners and are based on the person’s own history, interviews with next of kin and an Mini Mental Score Evaluation- Swedish Revision (MMSE-SR) along with blood work and a brain scan to rule out any other diseases.
After diagnosis the next of kin often have many questions about the coming lifestyle changes and ways to handle the personality changes that the person suffering from dementia may go through. Previous studies show that in many cases these questions are left unanswered, because it is difficult to get a follow up with a physician and there are few countries where support after diagnose is common.

In 2009, the Swedish Parliament passed a new law that states that support is to be given to persons caring for people with chronic illnesses, elderly people, or people with functional disabilities. There was, however, no detailed description of the extent or kind of services to be provided, and the municipalities had extensive freedom in implementing the legislation. In the autumn of 2013 the Swedish National Health Board therefore, issued guidelines where eight to ten meetings during a three- to six-month period with information and social support were recommended. A municipality in northern Sweden have a long term ongoing support to persons with dementia and their next of kin since 2006. A close collaboration with the geriatric clinic and private health centers has resulted in support being offered within 4-6 weeks after diagnose.

The overall aim of this thesis was to explore experiences of living with dementia both as a sufferer and as a next of kin; and being part of a long-term ongoing support group, the longest for four years.

Interviews were done with persons with dementia and their next of kin. Results showed that couples who had been the longest in a support group felt great comfort and support. They experienced that their knowledge about the disorder was good and that they could prepare for the changes to come.
Results also showed that to be an adult child of a person with dementia disease means being burdened with the responsibility to act on behalf of the diseased parent despite a deep sense of grief and loss, which leads to frustration with the situation.

Relationships within the family can sometimes change when a family member is affected by dementia. Sometimes for the better; where the family rallied to support the affected member and sometimes for worse; where the relationships were strained when pressure became too much. The persons with dementia who participated in the support groups experienced a great sense of coherence and felt that life was manageable, comprehensible and meaningful. Their healthy partners experienced less comprehensibility and manageability and the adult children more meaningfulness.

The results of the thesis have founded a model for support called PER-model®; Pedagogical, Emotional and Relationship based model of support.

Nyckelord: Dementia, Next of kin, Relationships, Support group.
SAMMANDRAG

Demenssjukdomar drabbar mer än 35 miljoner människor världen över, en summa som kommer att fördobblas vart tjugonde år.

Demens är en global störning av intellektuella funktioner: förmågan att minnas försämras, och förmågor som att orientera sig i tid och rum, språklig förmåga, tankeprocesser som att gå från tanke till handling, problemlösande, utföra saker praktiskt och känna igen föremål. Symtomen följs ofta av förändringar i beteende och personlighet, som låg initiativförmåga, irritation, grovt socialt beteende och humörsvängningar. I Sverige diagnostiseras 25 000 personer per år, totalt så lever 160 000 personer med sjukdomen i Sverige idag. I Sverige ställs diagnosen ofta utifrån blodprover, hjärnröntgen och Mini Mental Score Evaluation-Swedish Revision tillsammans med personens sjukdomshistoria.


Sverige har sen 2009 lagstiftat om rätten till stöd till anhöriga och närstående med demessjukdom eller andra kroniska sjukdomar med funktionshinder. Typen av stöd som ges skiljer sig däremot åt, Socialstyrelsen kom därför hösten 2013 ut med riktlinjer för hur stödet bör se ut för att vara effektivt: 8-10 träffar under 3-6 månader med information och socialt stöd till anhöriga.

En kommun i norra delen av Sverige har gett långvarigt stöd till personer med demessjukdom och deras anhöriga sen 2006.
Ett nära samarbete med Landstinget i regionen och på senare tid även privata vårcentraler i området har lett till att stöd kan erbjudas i direkt samband med diagnostillfället. Personerna deltar ofta i stödgrupp inom ca 4-6 veckor efter sin diagnos. Avhandlingens syfte var att fördjupa kunskapen om personernas upplevelse av att vara i stödgrupp under lång tid; den längsta i 4 år. Intervjuer gjordes med anhöriga och personer med demenssjukdom.

Resultaten visade att de par som varit med längst i stödgrupp kände sig trygga, de upplevde att de fick god kunskap om demens och var förberedda på den förändring som skulle komma. Resultaten visade också att vara vuxet barn till en person med demens innebar att vara tyngd av ansvar för att agera i den sjuka förälderns intresse trots en djup känsla av sorg och förlust vilket ofta leder till frustration med situationen. Relationerna inom familjen kan förändras efter demens diagnosen både till det bättre; att man slutar kring den demenssjuke föräldern men också till det sämre; att familjen splittras då relationerna utsätts för påfrestningar. Personerna med demenssjukdom som deltog i stödgrupperna upplevde och skattade sin känsla av sammanhang högt; att livet var meningsfullt, begripligt och hanterbart. Deras friska partner upplevde mindre begriplighet och hanterbarhet och de vuxna barnen mer meningsfullhet.

Avhandlingens resultat har legat till grund för en modell för stöd till personer med demenssjukdom och deras anhöriga kallat PER-modellen®; Pedagogisk, Emotionell och Relationsbaserad modell för stöd.

Nyckelord: Anhöriga, Demens, Relationer, Stöd grupp
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List of papers

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


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Terminology

Abbreviations

CT- Computer tomography
G8 - The Group of Eight (G8) was the name of a forum for the governments of eight leading industrialised countries, which was originally formed by six leading industrialised countries and subsequently extended adding two additional members. Russia, which was invited to join as the last member, was excluded from the forum by the other members on March 24, 2014, as a result of its involvement in the 2014 Crimea crisis in Ukraine. Thus the group now comprises seven nations and will continue to meet as the G7 group of nations. The included nations are: Canada, USA, France, Germany, United Kingdom, Italy and Japan. The European Union is also represented.
NCD – Neuro Cognitive Disorder
MMSE-SR – Mini Mental Score Evaluation- Swedish Revision
PwD – Person with dementia
SBU - Swedish Council on Health Technology Assessment
SOC- Sense of Coherence
WHO – World Health Organization
Preface

My theoretical foundation and experience as a registered nurse and later as a specialist nurse in elderly care has given me the opportunity to provide expert care to the frailest members of our society: the elderly. The frailest of them all are those elderly who have been diagnosed with dementia and suffer from cognitive disorders that change their perception of reality leaving them without a sense of coherence. Dementia is a disease that increases with age, and at the age of 80 years, approximately 50% suffer from a dementia disorder. My intention is that this thesis will present a model to give care and support to individuals with dementia and their next of kin from a holistic salutogenic nursing approach.
BACKGROUND

According to WHO’s estimates, the number of persons 60 and older will reach 1.2 billion in developed countries by 2025. Marc Wortmann, executive director of Alzheimer Dementia International, said, “Around the world a new case of dementia arises every four seconds. Our current health systems simply cannot cope with the explosion of the dementia crisis as we all live longer” (WHO, 2012). In December 2013 the G8 countries consisting of France, Italy, Japan, Canada, Great Britain, Germany, Russia and the US had a summit in the UK where they declared that they would cooperate in order to find a cure or disease-modifying treatment. The aim is to identify a cure or a disease-modifying therapy for dementia by 2025 and to collectively and significantly increase the amount of funding for dementia research to reach that goal. The G8 summit also encouraged countries to strengthen health and social care systems to improve care and services for people with dementia. This thesis will present one potential way of caring and supporting people with dementia and their next of kin.

Dementia

Dementia is a global disruption of intellectual functioning; there is a decrease of memory ability and other intellectual abilities such as orientation, visuospatial-perceptive ability, language, thinking, executive abilities, problem solving, apraxia and agnosia. These symptoms are often followed by behavioral changes and changes in the personality, such as loss of initiative, emotional instability, irritation, apathy, coarse social behaviour and mood changes (Marcusson, Belonnow, Skoog & Wallin, 2011). These neuropsychiatric symptoms are present in a majority of patients with mild to moderate Alzheimer’s disease. The most
frequent symptoms were apathy, depression, irritability, and agitation (Karttunen et al., 2011). In the new DSM5 criteria for diagnoses, there is an overall criterion for mild or major neurocognitive disorder (NCD). The term dementia is not precluded from use in the etiological subtypes where that term is standard. In DSM-5, major or mild vascular NCD and major or mild NCD due to Alzheimer’s disease have been retained, whereas new separate criteria are now presented for major or mild NCD due to frontotemporal NCD, Lewy bodies, traumatic brain injury, Parkinson’s disease, HIV infection, Huntington’s disease, prion disease, and multiple etiologists (APA, 2013). This thesis will focus on patients with major or mild vascular neurocognitive disorder or Alzheimer’s disease or frontotemporal disease, and their next of kin.

Dementia in Sweden

About 25,000 persons are diagnosed with dementia each year in Sweden (SBU, 2007), approximately 68 people per day. Today, estimates are that 160,000 persons in total are suffering from dementia in Sweden. In Sweden, most diagnoses are done in the primary health care setting by general practitioners and are based on the person’s own history, interviews with next of kin and an MMSE-SR along with blood work and CT of the brain to rule out any other diseases. There are guidelines for treatment and care of persons with dementia provided by the National Board of Health and Welfare (Socialstyrelsen), a government agency in Sweden under the Ministry of Health and Social Affairs. A review of the guidelines in 2013 showed that fewer than half of the individuals diagnosed in primary health care settings get a complete diagnostic investigation, and almost half receive an unspecified diagnosis of dementia. The number of registered investigations and the prescriptions for dementia medication differ greatly among different areas of the country. Among individuals with low education levels and individuals born outside of Scandinavia, there are fewer who are treated with dementia medication.
They are instead treated with antipsychotic medication. The review also stated that there needs to be a structure to educate and guide personnel in dementia nursing care. The number of sheltered accommodation places has increased but still differs greatly among municipalities in Sweden (Socialstyrelsen, 2014).

**Perspective of the person suffering from dementia**

Persons suffering from dementia usually gradually realise something is wrong. They experience loss of short term memory, difficulties communicating, loss of control, autonomy and independence. They express losing the ability to perform normal everyday activities as well as their work. Relations with others are important, even though they realise that others experience of one’s abilities differs from their own (de Boer et al., 2007). Others’ opinions have great impact; many are worried about what is going to happen if others find out they have dementia. Feelings of insecurity, fear, confusion, humility, and even isolation can occur in these persons. They expressed concern about being a burden to others (de Boer et al., 2007).

Persons affected by dementia indicated in discussion how they spend their day, seeking for structure and meaning; stating that they liked having something to do. Others felt that being at the day care centre was like being at work; keeping busy, while others occupied themselves with household chores (Gilmour, Gibson & Campbell, 2003). The quality of life depends on participation in activities with friends and feeling a connection to others or events. Most felt a quality of life in connecting to others and a sense of being useful. Different coping strategies, such as avoidance or denial, normalization, fighting against the disease and continuing to live or different types of compensation were used to cope with the effects of the disease (de Boer et al., 2007). Persons with dementia feel the need for daily
activities and company, but psychological distress was rated the most unmet need by the persons with dementia (Miranda-Castillo, Woods & Orrell, 2013).

Social contacts and the feeling of being useful have been shown to have importance on the level of quality of life for persons with dementia. Feeling useful can also be expressed by participating in research projects (de Boer et al., 2007). Social relations are of great importance to persons with dementia and networks where they can exchange experiences about weird things happening in everyday life, such as losing things just to find them hours later (Clare, Rowlands & Quin, 2008). Social groups are, therefore, an important social activity for persons with dementia living in the community. To have availability to these groups is important for the person’s well-being and social experience (Hochgraeber, Riesner & Schopppmann, 2013).

**Dementia and Family**

Dementia’s impact affects people with the disorder and those in their social networks, most notably, their families (Orange, 1991; Small, Geldart, & Gutman, 2000; Brewer, 2005; Savundranayagam, Hummert, & Montgomery, 2005). Roach and Keady (2008) reported that, following an extensive review of the literature, they could only find one study where the researchers looked at the experience of dementia as part of a family system. Others have compared family caring across these different types of family relationships (MacRae, 2002; Lee & Smith, 2012).

Garwick, Detzner and Boss (1994) described the search for stability and meaning for multigenerational families as a crucial marker in understanding and absorbing dementia into the family identity; it is not one person’s problem, but a collective responsibility that depends on invisible strings of support within and among family members. Vellone et al. (2011) found that caregivers’ quality of life was an
important predictor of both positive and negative outcomes of caregiving and improving caregivers’ quality of life should be a priority. A negative effect was the social restrictions imposed by the caregiving situation, and action should be taken to avoid caregiver isolation (Vellone et al., 2011). Some caregivers seem to re-draw relational boundaries, positioning dementia at the heart of their definition of relationship. They felt that their spouse was not the same person anymore (Walters, Oyebode & Riley, 2010). A case study by Hellström, Nolan and Lundh (2005) showed that a spouse gave support to his wife in a way that would never undermine her self-esteem, which had taken a blow since the diagnosis. Instead he actively built on her residual strengths and worked hard to help her sustain her links with her past, whilst also looking forward to the future. A larger study based on 150 interviews showed three themes in couples affected by dementia: “sustaining couplehood” which captured the efforts made by both spouses to maintain, and, whenever possible, enhance the quality of their lives together for as long as possible. The second theme was “talking things through”, which reflected patterns of communication within relationships and highlighted the importance of both spouses to maintain open channels of communication and discussion to reach a shared understanding and agreement. The third and last theme showed that in addition to excellent communication, many of the relationships between the couples were characterised by “bonds of affection and appreciation” that both spouses worked hard to maintain (Hellström, Nolan & Lundh, 2007).

However in some families the strain of the personality changes created accusations of neglect, exploitation, lack of communication or sequestration of the person with dementia. This suggests that when there are cracks in the family solidarity, dementia can divide the family (Peisah, Brodaty & Quadrio, 2006). The changes in the sufferers’ personality after the diagnosis were especially hard for the next of kin to handle. Family members usually longed for the previous relationship they
had to the sufferer and mourned the loss. Many felt regret and guilt because they had not been supportive enough or had not had enough patience with the sufferer. They also felt socially isolated since they were always working, both in their day job and in taking care of their next of kin suffering from dementia. Longing for freedom and escape as well as a sense of being restricted was common (Sanders, Ott, Kelber & Noonan, 2008).

Clearly disease and illness in a family member affects the whole family in one way or another and also the family as a whole (Benzein, Hagberg & Saveman 2008; Wright & Leahey, 2009). A Swedish report published in 2014 showed that next of kin often took sick leave, lessened time at work or early retirement to take care of their diseased parent or spouse (Szebehely, Ulmanen & Sand, 2014).

**Adult child**

The term “adult child” can carry a double meaning: the adult who is trapped in the fears and reactions of a child, and the child who was forced to be an adult without going through the natural stages that would result in a healthy adult (Henman, 2003, p. 55.). The term “adult child” can, however, have a different meaning according to the context. In this thesis the term is used to describe the relationship of parent-child and how this relationship is constant during childhood and adulthood. You are always your parent’s child regardless of age. Our adult child participants are between the ages of 35-65; however, as one of the participants stated, “We are all in the same boat regardless of other circumstances—we all have a parent with dementia” (II).
The term “adult child” in this thesis is used to express that the “children” are adults above the age of 18 and to describe the relationship among participants. It has no other implications. Adult children to persons with dementia in research are often viewed as caregivers and, therefore, studied together with other caregivers (Betts Adams, 2006; Laakkonen et al., 2008; Sanders et al., 2008; Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006). This makes it hard to find previous research regarding what it means to be an adult child of a person with dementia. However, it is clear that the role for the next of kin changes to one of supervision and decision making. Feelings of frustration, sorrow, and distance were common as well as feelings of affection and benevolence towards the person suffering from dementia (Betts Adams, 2006; Laakkonen et al., 2008). In one study the adult children expressed concern for the sufferer and the problems of daily life regarding falls, handling money, cooking, traffic safety and getting lost when going for a walk. Despite these concerns many felt that the sufferer would be better off at home and did everything they could to make the environment safe for them, such as selling the car and installing different safety features on the heater, stove and other devices (Gilmour, Gibson & Campbell, 2003).

Our proposition is that personality changes offer a great challenge to the adult children. To see your father turning into a little boy or your mother into a schoolgirl has an impact on the lifeworld of the adult children. In order to elucidate the situation for adult children of persons with dementia and help fill the knowledge gap that we feel exists, it is important to explore adult children’s life situation from their perspective, i.e., having a parent affected by dementia.
**Need of support**

After diagnosis the need for support is high, but next of kin often feel abandoned and in need of emotional support (Sanders et al., 2008; Neufield & Eastlick Kushner, 2009; Lakkonen et al., 2008). They may also have the need for information and conversation about the coming lifestyle changes and ways to handle the personality changes that the person suffering from dementia may go through (SBU, 2006; Strang et al., 2006; Harman & Clare, 2006; Laakkonen et al., 2008; Lilly et al., 2012). The care-giving next of kin described needing two types of information: that relating to typical manifestations of dementia and practical information about health, social and financial support (Stokes, Combes & Stokes, 2014). Next of kin also recognised that if they were to continue caring, their own support needs required more recognition. In particular, they would have valued a confidant, someone that they could talk to about delicate issues within the safety of a confidential and established relationship (Ericson, Hellström, Lundh & Nolan, 2001).

Some previous research regarding experiences does not separate the spouse or cohabitants from the adult children, but regards all next of kin involved in the everyday care of the person suffering from dementia as caregivers (Vernooij-Dassen, Derksen, Scheltens & Moniz-Cook, 2006; Betts Adams, 2006; Sanders, Ott, Kelber & Noonan, 2008; Laakkonen et al., 2008). There is also an increased health risk for stress symptoms among care-giving spouses, such as depression, anxiety and fatigue (Donaldson, Tarrier & Burns, 1998; McConaghy & Caltabiano, 2005; Sanders, 2005; Schoenmakers, Buntinx & Depeleire, 2010).

In 2009, the Swedish Parliament passed a new law that states: “Municipalities are obliged to offer support to persons caring for people with chronic illnesses, elderly people, or people with functional disabilities” (Swedish Social Services Act, 2009).
There was, however, no detailed description of the extent or kind of services to be provided, and the municipalities had extensive freedom in implementing the legislation (Johansson, Long & Parker, 2011). In the autumn of 2013 the Swedish National Health Board (Socialstyrelsen), therefore, issued guidelines where eight to ten meetings during a three- to six-month period with information and social support were recommended (Socialstyrelsen, 2013). According to the Swedish National Audit office (2014) support, in most municipalities, consists of groups for next of kin and individual conversations.

**Support Groups**

Studies show that support to caregivers can alleviate stress and increase psychological well-being (Coen et al., 1997; Jegermalm, 2003). There are different models of structured support groups worldwide, including the Memory Club (Gaugler et al., 2011) and Circle of Care (Goldsilver & Gruneir, 2001). In both models the groups are closed and timed with weekly meetings running over a course from 8 to 13 weeks. A meta-analysis of quantitative studies by Chien et al., (2011) show that support is most beneficial to caregivers when given for more than eight weeks. Clinicians and researchers worldwide have devised many methods for trying to help caregivers, such as education and training programmes, support groups and counseling.

Successful interventions have been reported to reduce caregiver distress, depression, and psychological morbidity; to delay nursing home admission of patients; and to improve patients’ psychological well-being (Brodaty, Green & Kochera, 2003). A meta-analysis on 127 intervention studies from 1982 to 2005 showed that psycho educational interventions that require active participation of caregivers had the broadest effect. The active participation could consist of role playing or applying new knowledge to individual problems. The most effective
interventions must also be tailored to the individuals’ specific needs (Pinquart & Sorensen, 2006).

Characteristics of effective caregiver interventions include programmes that are administered over long periods, interventions that approach dementia care as an issue for the entire family, and interventions that train dementia caregivers in the management of behavioural problems (Logsdon RG, McCurry & Teri, 2007; Logsdon, 2008; Zarit, 2009; Mittelman, 2013). Multidimensional interventions for dementia caregivers have also been shown to prevent or delay nursing home admission (Brodaty, Green & Koschera, 2003; Smits, de Lange, Droes, Meiland, Vernoij-Dassen & Pot, 2007; Olazarán et al., 2010). The support groups studied in this thesis are located in a municipality in northern Sweden, which has offered ongoing municipally-organised support since 2006, and the support has no end. The participants just change support group together with their partner; depending on the changes in their functional level of dementia.
Aim of the thesis
The main aim of this thesis was to explore experiences of living with dementia both as a sufferer and as a next of kin; and being part of a long-term ongoing support group in a municipality in northern Sweden.

The specific aims were to explore:
- couples’ experiences of a long-term ongoing structured support group with participants in early stages of dementia and their partners. (I)
- what it means to be an adult child of a person with dementia. (II)
- experiences of family relationships when a family member has dementia. (III)
-- how participants in support groups score on the Sense-of-Coherence scale and what they perceive as contributory factors to a meaningful, manageable and comprehensible everyday life in the presence of dementia. (IV)
Material and methods

Context
In the municipality in the north of Sweden the support centre offers different kinds of assistance to their citizens, individual support or together with a spouse. The municipality offers next of kin groups, support groups, education, voluntary work, social meeting arenas, preventive house calls as well as day care facilities to persons with dementia and their next of kin. The services are offered through the Unit for Support of next of kin. A unique cooperation between the local geriatric clinic and the Unit of Support has lead to a referral time from four to six weeks between diagnosis and entering a preferred kind of support. In the early stage of dementia the support consists of structured support groups where the participants receive information about the disease, medication, progression of the disease as well as practical ideas for everyday life at home. The groups are divided by level of function, one for MMSE-SR ≥ 20 and one <20 MMSE-SR. After <20 the persons with dementia are offered day care and their next of kin goes to a support group for family. This support continues even after admittance to sheltered accommodation or specialized care units for dementia sufferer so the support has no end. The adult children also continue in their group for as long as they feel the need of support. Since 2006 there have been 25 people with dementia in municipal support; 3 have moved on to sheltered accommodation. One of them has since died; one has stayed for four years and one for one year. The rest still live at home and one of them has home care four hours a week.

Sample
Those diagnosed through the geriatric clinic or health care centres who were receiving support through the support unit as well as living in the area were our potential research participants. The targeted participants were also those who were part of a support group for persons suffering from dementia or next of kin to
persons suffering from dementia disease, during the research period from the beginning of 2011 through the end of 2013. A preparatory MMSE-SR was done for participants with dementia in spring 2011 in preparation for the first study regarding experience of long-term ongoing support for couples. According to the Swedish Dementia Centre, the different stages of dementia as shown through MMSE-SR are 25-20 for mild dementia, 19-10 for moderate dementia and 9-0 for severe dementia (Swedish Dementia Centre, 2008). A limit of 20 MMSE-SR points was set as a cutoff point for participants to agree to be part of the study. Anyone with fewer than 20 MMSE points was not asked to participate to make sure that we did not put undue pressure on the participants with dementia. If participants scored lower than 20, they were not approached for consent.

Signed written informed consent forms were asked of the participants prior to interviews or questionnaires.

**Setting**

Support groups met every other week for couples (twice a month) and once a month for adult children at the Municipal Support Centre and lasted between 90-120 minutes. All information remained confidential, and members were reminded of this at the beginning and end of the group meeting. The group had coffee and cake together enjoying each other’s company at the beginning of the meeting. Then the persons with dementia met together with a moderator to discuss their issues and engage in memory training and reminiscences therapy. Here they were asked to tell stories from their lives, write their life stories or just play games aiming to support their sense of self and self-worth. Meanwhile, the partners discussed their issues together with a moderator and received information about dementia disease, information about services provided by the municipality and information about financial issues or whatever else they felt was important to discuss. In the beginning of the semester the participants of the group were given a list of topics
ranging from pathology in different dementia diseases to help and support accessible from municipal care. The participants decided which topics should be covered by the moderators of the group at each meeting, depending on the information they deemed important at the time. The adult children received information once a month about dementia disease, municipality support and financial issues and practical advice in caring for a parent with dementia. They were also given a choice of topics that could be approached by the moderators giving the participants control of the content. This support group is open, and adult children may continue to participate for as long as they need. Some participants have been attending for five years, and feel their experiences are beneficial to the newcomers.

The support for those with dementia and their partners was divided into Support Groups 1 and 2. Those in Support Group 1 had an MMSE-SR 20 and above; those in Support Group 2 had an MMSE-SR below 20. The activities in the groups differed in that the persons with dementia in Group 2 had more social activities and less memory training. Their partners had more information about economics, day care centers and municipal service. When this was no longer sufficient for the persons with dementia, they were moved to day care centres and their partners continued in a support group for next of kin that met at the same time in the day care centre. This means that the support is long term and it continues for as long as the participants require support. The different support groups were also complemented by an open house meeting on Mondays every week for all and are a more informal gathering with no structured information. Many next of kin has moved on to become volunteers at the day care centres and open house meetings. The support centre is located in a building that also houses a restaurant, so no one knows that you are going to a support group; you could just be going out for lunch.
or coffee. This is something that is highly appreciated by the participants, as there is no stigma involved in attending the support groups.

The research results in this thesis have been used to improve and develop the support groups for the benefit of the participants. This has resulted in a trademark protected model of support called the PER-model. PER stands for Pedagogical, Emotional, Relationship based support as described above.

**Procedure**

Contact with participants was achieved through the author attending a support group meeting and introducing the project. Written information with consent forms and prepaid envelopes were distributed at the same meeting. Data was collected by the author, and no unauthorized persons had access to the data apart from the author and her supervisors. The author reviewed the data together with her supervisors and the data was kept in a safe to which the author had the only key. The official Swedish Secrets Act (2009:400) was applied. The material will be kept safe for a minimum of ten years. All material was collected after ethical approval from the Medical Faculty in Umeå.

**Ethical considerations**

Studies including vulnerable subjects, such as persons suffering from a dementia disease require great demand for thought regarding ethical considerations. The need and well-being of the diseased person must outweigh the need for research, and the utmost consideration must be taken to assure that the vulnerable subjects are not compromised in any way. Subjects will not be dependent on research for anything, and they can leave the study at any time without consequences. This is in accordance with WMA, Helsinki Convention of 1964, Articles 6, 11 and 18. Participants were asked for permission for interviews and questionnaires orally and by written consent. They were also informed at the start of all interviews and
asked for permission to continue with the interview. They could at any time refuse participation.

Interviewing vulnerable subjects such as those with dementia can cause emotional upset for the individual suffering from dementia. Cognitive decline during dementia can be measured using an instrument such as the Mini Mental Score Evaluation (MMSE), which measures different aspects of cognitive function such as orientation, memory, and attention (Folstein et al., 1975; Guerrero-Berroa et al., 2009). This was done in preparation of the studies as a means to ensure cognitive level. However an MMSE does not say anything about the individual’s personality and two persons with the same MMSE points can differ greatly in their perception of reality and emotions in the interview situation thereby questioning if the consent is informed as shown by Hellström, Nolan, Nordenfelt and Lundh (2007).

The researcher should feel a moral obligation and sensitivity to the participants with dementia to view them in a holistic manner in a social context of the support group and their healthy partner.

Also all interviews were conducted at the support centre with staff members on hand, who were familiar to the participant and able to take care of any problematic situations if and when they occurred. As an example, one of the participants in our case study (I) was very upset during the interview but insisted on continuing. The reason she gave for being upset was that she no longer remembered anything, saying the upset feelings started the day before. However, she was adamant about being interviewed, since she felt it was important. After the interview one of the staff members at the centre had coffee and cake with her, and they talked about her garden while her husband was interviewed. She left the centre with her husband after the interviews and was smiling as they departed.

However, interviewing can also cause emotional upset for the next of kin as well; therefore, those interviews took place in an open and non-judgmental atmosphere. Pauses for crying or having a glass of water were fine. We also got approval from
the head of the Municipal Counsel on Social Care, which enabled us to inform s and recruit participants in the ongoing support group as well as use the facilities for interviews. Personnel at the centre were also on call for emotional backup after the interview should the interviewees need it.

**Methodology**

The thesis consists of four papers; three are qualitative, and one uses a mixed method with both quantitative and qualitative findings. Since there are several quantitative studies that show the positive effects of support groups, we wanted to explore the participants’ experiences in qualitative studies. A case study, for instance, allows investigators to retain the holistic and meaningful characteristics of real-life events (Yin, 2009). Therefore, a case study design (I) was chosen to explore how couples experience being part of an ongoing long-term support group, especially the experiences of the spouse with dementia. We also used a lifeworld approach in order to explore the experiences of adult children to persons with dementia (II). The lifeworld is our basic reality and the world shows itself to our consciousness and is inexplicably linked to the perceiver of that reality (Bengtsson, 2001; Dahlberg, Dahlberg & Nyström, 2008). To understand what shows itself to our consciousness (phenomenology), it has to be interpreted (hermeneutics); that is, there is no understanding without explanation. Therefore, to increase the understanding of being an adult child to a person with dementia, the present study used phenomenological hermeneutics for the analysis (Lindseth & Norberg, 2004).

The third study was also a qualitative study; it explores the experiences in the family. The study explores changes within the different roles of the family, and also the situation for persons lacking family around them in the early stage of dementia. The data consists of previously transcribed material from Studies 1 and 2, material not already analyzed of 17 participants totaling 21 interviews. The
interviews are with those with dementia disease, healthy partners and adult children. The material was analyzed using a qualitative method (Patton, 2002).

The fourth study is a mixed method study with volunteer participants from all support groups at the Municipal Support Centre, in total 31 participants. The instrument used in the quantitative part was Antonovsky’s Sense of Coherence scale (Eriksson & Lindström, 2006; Sarvimäki & Stenbock-Hult, 2000). The scale was used to measure sense of coherence in all 31 volunteer participants. The questionnaire was completed anonymously at a support group meeting; only a code for group is noted on the questionnaires: A for adult children, B for partner and C for diagnosed with dementia. The questionnaires were then mailed to the researcher free of charge. Analysis was made using SPSS for Windows, version 21.

The qualitative part explored interviews using comprehensibility, manageability and meaningfulness as categories (Elo & Kyngäs, 2008).

**Analysis**

The case study (I) was analyzed by content analysis inspired by Graneheim and Lundman (2004). The interviewer transcribed each interview verbatim, using comments regarding laughter or body language added to the transcript for clarification. Notes regarding body language during the interview were written in private following each interview and added to the transcripts. The transcribed interviews were read through several times to obtain a sense of the whole. Text from all participants relating to their experiences regarding the support group was extracted and combined into one file. This text was divided into meaning units that were condensed, abstracted, and labeled with a code to reflect the content.

Coding was done as close to the interviewees’ meaning as possible being careful not to destroy the meaning of the data through intensive coding (Miles & Huberman, 1994). The codes were then compared and, depending on content,
sorted into sub-categories that were then abstracted and finally merged into three main categories describing content present in three cases. One case was assigned its own category. The short diary notes featured in the article (I) were not analyzed but used to give everyday context to our participants regarding activities and social interactions only.

In order to interpret and illuminate what it means to be an adult child of a person with dementia as experienced by our respondents in the second study, a phenomenological hermeneutical research that was influenced by Paul Ricoeur (1976) and described by Lindseth and Norberg (2004) was used. The lived experience remains private, but its meaning can be made visible. To make the meaning visible requires an interaction between the text and the reader where the reader interprets the text. Interpretation is a special form of understanding; it is based on all forms of written expressions of life. The text remains mute, and an asymmetrical relationship evolves where only one speaks and the author’s intention is unclear for the reader. By understanding and interpreting the text, the reader is allowed to access all possible worlds and a possibility to orientate oneself in those worlds (Ricoeur, 1976).

The analysis began with a naïve reading, progressed to explanatory structural analysis, and ended in a new understanding or comprehension. During the naïve reading, the whole text was read in order to grasp a first understanding, verbalized as a naïve understanding of what it means to be an adult child of a person with dementia. The first interpretation during the naïve understanding can be seen as pure guesswork (Ricoeur, 1976), and the structured analysis viewed as a validation of the guesswork and a way to explain the text (Lindseth & Norberg, 2004).

The whole text was then structurally analyzed with the naïve understanding in mind. The whole text was divided into meaning units. The meaning units were condensed and compared with respect to differences and similarities, and they
were finally abstracted into subthemes and themes. The themes and subthemes were then reflected upon against the naïve reading to validate the findings. Finally, the naïve reading, structural analysis, relevant literature, and authors’ pre-understandings were brought together to develop a new comprehensive understanding of what it means to be an adult child of a person with dementia. The authors’ pre-understandings consisted of working as registered nurses in dementia care as well as previous studies in dementia care settings. However, Lindseth and Norberg (2004) state that the pre-understanding is not bracketed but rather our judgment about the factual, about what is the case, in order to become open to our own experience and to the understandable meaning implicit in this experience (Lindseth & Norberg, 2004).

In the third study the previously collected data were analyzed by content analysis inspired by Patton (2002). Researchers used transcribed interviews with comments regarding laughter or body language added to the transcript for clarification. Text from all participants relating to family experiences regarding changes in family relationships when a member was affected with dementia was extracted and combined into one file. This text was divided into meaning units that were condensed, abstracted, and labeled with a code to reflect the content. Then the codes were compared and, depending on content, sorted into sub-themes that were abstracted and merged into themes. Themes were identified that described the underlying meaning of the content (Ryan & Bernard, 2003).

In the fourth study using a mixed method all questionnaires were filled in anonymously at a support group meeting with a code for each group: 1 for PwD, 2 for partner and 3 for adult children. The questionnaires were then mailed to the researcher free of charge. Analysis was made with SPSS for Windows, version 21. Descriptive analysis means that a total score and Std were used.
For the qualitative content, interviews with four couples where one of the partners suffered from dementia disease and nine adult children, (in total 17 participants) were analyzed in a deductive manner (Elo & Kyngäs, 2008) using meaningfulness, comprehensibility and manageability as categories to explore the data regarding sense of coherence in everyday life as a participant in a support group. The text was divided into meaning units regarding categories and then condensed. The condensed meaning units were then divided into subcategories under the main categories.

For logistical reasons the qualitative data, the interviews, were collected in autumn 2011 and spring 2012. The quantitative data collection was done in January 2012 (For overview of studies, se Table 1, p 24).
Table 1. Overview of studies

<table>
<thead>
<tr>
<th></th>
<th>Paper I</th>
<th>Paper II</th>
<th>Paper III</th>
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<tr>
<td><strong>Aim</strong></td>
<td>to explore couples’ experiences regarding long-term ongoing structured support group with participants in early stages of dementia and their partners.</td>
<td>to explore the meaning of being an adult child to a person with dementia.</td>
<td>To explore what family means in early stages of dementia.</td>
<td>-to explore how participants in support groups score on the Sense-of-Coherence scale and what they perceive as contributory factors to a meaningful, manageable and comprehensible everyday life in the presence of dementia.</td>
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<tr>
<td><strong>Design</strong></td>
<td>qualitative</td>
<td>qualitative</td>
<td>qualitative</td>
<td>mixed method</td>
</tr>
<tr>
<td><strong>Participants</strong></td>
<td>4 couples (8 participants)</td>
<td>9 adult children</td>
<td>13 participants</td>
<td>31 participants</td>
</tr>
<tr>
<td><strong>Methods</strong></td>
<td>Interviews and non-participant observation</td>
<td>interviews</td>
<td>interviews</td>
<td>interviews and questionnaires</td>
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Theoretical Framework

The ontological position of the author is naturalistic, which means that reality exists as a construction of individuals, within a context, and many constructions are, therefore, possible. If there are multiple interpretations of reality that exist in people’s minds, then there is no way by which the ultimate truth or falsity could be determined. Epistemologically, knowledge is maximised when the researcher is close to the participants and their voices and interpretation of reality is the guide to understanding a phenomenon (Polit & Beck, 2004). A science that has lost its connection to the lifeworld loses its significance to the ordinary individual; it will alienate rather than increase understanding or liberate as stated by Hussler.

Bengtsson (2001) describes that according to Hussler there is an intimate connection among life, science and philosophy. All meaning has its source in the lifeworld. The duty of science is to explore the lifeworld and bring it to a theoretical expression, and philosophy’s task is to finally justify the knowledge gained (Bengtsson, 2001). According to Beyer (2013), Husserl’s notion of lifeworld can be looked upon as the rational structure underlying an individual’s lifeworld that consists of the beliefs against which an individual’s everyday attitude towards one self, the objective world and others receive their ultimate justification, which are open for revisions should the need arise.

A single community of subjects can be described as the system of senses or meanings that constitutes their common language or “form of life” given that they conceive of the world and themselves in the categories provided by this language. Subjects belonging to different communities can still share a common lifeworld as the general framework or “a priori structure” of senses or meanings that allows for the mutual translation of their respective languages (with their different associated “homeworlds”) into one another (Beyer, 2013).
This means that while “my” lifeworld is unique, it is still translatable to others in the similar belief, cultural or social lifeworld.

As a registered nurse working with older persons and those with dementia, the lifeworld concept is always present in the nursing activities as a means of making sense and interpreting actions by older individuals and persons suffering from dementia. Understanding someone’s lifeworld also make it easier to help them to interpret their surroundings and make sense of what they are experiencing as a means to enhance their psychological well-being. According to Antonovsky’s salutogenic model (1979, 1987) which proposes that physical and mental health i.e. psychological well-being are primarily determined by sense of coherence, defined as ‘a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one’s internal and external environments are structured, predictable and explicable (comprehensibility). The resources are available to one to meet the demands posed by these stimuli (manageability). Meaningfulness means that these demands are challenges worthy of investment and engagement (Antonovsky, 1987, p. 19).

Therefore, this thesis is also inspired by the nursing theorist Travelbee, founder of the interaction theory, “interpersonal aspects of nursing” (1971). Travelbee states, “The professional nurse practitioner must be prepared to assist individuals and families not just to cope with illness and suffering but to find meaning in these experiences. This is a difficult task of professional nursing and it cannot and must not be evaded” (Travelbee, 1971, p 13). Her interaction theory serves as an aid to the professional nurse who wants to help individuals arrive at meaning. She stresses that it is only within a context of human-to-human relationships that a nurse can do that. A registered nurse, social worker or a next of kin caregiver all have a human-to-human relationship to the individual suffering from dementia.
For the social worker or registered nurse a human-to-human relationship is within the scope of their profession, but for a next of kin caregiver it is within their already established relationship as family.
Results

Paper 1: “Experiences of long-term ongoing structured support in early stage of dementia–a case study”

The qualitative findings showed that participants experienced kinship through shared experiences in social relations as well as understanding and sympathy towards each other in the support group. “I do hope it will continue because we have so much fun together in the group”. They gained knowledge about the disease through information and learning from each other’s experiences. “I mean you know what is going to happen, how it will be worse”. However the persons with dementia were not interested in the information but rather the social interactions during the support group meetings. “Because Alzheimer’s, that sounds as though I am sick, and I am not, I can do a lot of things.”

The participants also had a great sense of comfort and support, which was clear from the analysis, and this comfort increased over time, as shown by the couple who participated for four years and felt great comfort and retained abilities to a high degree. “There is somewhere to go...You are not left in the forest. That is very important...not that we have any problems, but you know where to go”.

There was one couple who struggled with the diagnosis and did not feel that they belonged in a support group. However, they longed for kinship but felt too shy to connect. “I think we are supposed to talk more with each other and take part in each other’s experiences, but that hasn’t really happened. I guess we are just shy.” The participants in support groups should be divided, and participants should receive information according to their needs or interests focusing on social interactions for persons with dementia.
Paper 2: “What it means to be an adult child to a person with dementia”

In the naïve reading an adult child of a person with dementia was understood to mean that they were compelled to take the parental role vis-a´-vis their mother or father with all that this entails: personal hygiene, economy, and safety. At the same time, they mourned the loss of that parent and longed for them to return and to feel close to them again. They were also faced with working double shifts to take care of their parents’ household as well as their own, making sure that the healthy parent was coping with all the extra chores and helping out with cleaning, washing, and care whenever possible. There was a sense of powerlessness, abandonment, and loneliness but also anger against the demented parent at how they changed and all the crazy things they did. There was also a presence of fear: fear of inheriting the disease. Additionally, there was longing for what had been (the previous relation) and the way in which they communicated with the parent before the disease.

The structural analysis revealed three themes: being frustrated, feelings of loss and being burdened as well as 14 subthemes. In being frustrated the adult children expressed how they felt powerless in the changes taking place due to the disease in the parent and in their personal life; they could only look on as the person changed. “I brought things to stimulate her memory, but she didn’t remember.” The frustration also meant wanting at times to dissociate oneself from the diseased parent; when things got too crazy. “She does some weird things, like putting a napkin over a cup and trying to drink through it. Why would you do that?”

In feelings of loss the adult children expressed how they missed their parent. “It’s a great loss; it’s like it’s not my mother. It feels like where did you go?” Feelings of loss also meant profound feelings of sorrow, i.e., mourning the loss of the parent and missing having them in their life. “The hardest part is that you lost a parent; still exists but lost. I don’t know if it would be easier if she was dead.”
The changes in the parent’s personality are hard for them to witness. “Sometimes I feel like it would be for the best if she died, but you don’t want that either. You just want her to be released from this demeaning transformation.”

Being burdened meant that the adult children felt compelled to take responsibility for the diseased parent and the situation, and that no one else did. “Dad had not been diagnosed until mum got sick and ended up in hospital, and then I had to take over.” The adult children often felt worn out due to overworking, by taking care of their parents’ household as well as their own, helping out as best they could. “When mum got sick, my life was really busy with a fulltime job; taking the kids to different sporting events in my spare time. It was like being on a treadmill.” The adult children were also burdened by having to assume a parent’s role for their parent. “This has been a weird journey; she is like a little kid again. Mum, she says to me. Yes, I say, I am your mother now. It’s easier that way (to get along), so you just accept it.”

The comprehensive understanding showed that to be an adult child of a person with dementia disease means being burdened with the responsibility of acting on behalf of the diseased parent despite a deep sense of grief and loss, which leads to frustration with the situation. The adult children needed support to accept the loss of a parent who was still alive and to redefine that relationship. The support group acted as an extended family giving them a safe haven where they could express themselves.

Paper 3 “Experiences of family relationships when a family member has dementia”. The experiences of family relationships can be said to be twofold: on one hand the relationships changed with participants’ experiencing longing, lost closeness, loneliness and changed sibling relationships.
Longing was expressed as, “Her sister gets upset and sad every time she comes. I tell her not to come if it upsets her. It’s hard for her, since she sees the difference clearer when she only visits a few times a year.” In lost closeness the adult children expressed how the relationships changed between the grandchildren and their mother: “It’s just awful really…how everything can be erased… before, she knew all the birthdays of all her children and grandchildren. No, no and it’s like she doesn’t even care now. Before she always got them something or just some money in an envelope, but now nothing… so it’s sad in a way.”

Adult children without siblings expressed their loneliness by wishing they had siblings to share the experience with and with whom they could share decision making. They said they felt truly alone for the first time in their life. “Of course if you have siblings, you have someone to share the experience with emotionally but if you’re an only child…you’re alone.”

In changed sibling relationships the adult children expressed jealousy towards one of their siblings who, in their mind, had a better or closer connection with the affected parent. “My sister has a better hand with mother. Whenever I do something she can swear and curse, but with my sister she never does that.”

On the other hand the family relationships could be supportive to family members expressing kinship, shared responsibilities and love and appreciation to each other. The adult children described their aunts and uncles as supportive and helping out when needed. “It was lucky that my aunt and uncle could come up and help. If they hadn’t done that, then…” and “It’s so important to have good family. It’s important to have someone to talk to and to help guide you in your decisions…They are amazing that way.”
In experience of shared responsibilities the adult children expressed that they helped each other out in keeping the family together and facilitating contacts between their diseased parent and their children—grandchildren to the diseased. “I usually call my son or daughter when I am at Mother’s so she could talk to them” and “We usually go and see mother together now, me, my daughter and her kids. She finds it too hard to speak to mother on her own.”

In experience of love and appreciation the dementia sufferer and partner said that they looked forward to hearing from children and grandchildren and seeing them again. “We have always got along fine. We have three girls and there were never any problems. He is still over the moon every time they come home.”

The relationships within the family could be supported within the context of a support group where participants could act as support teams to each other and also as family to participants without siblings, and in a sense relieve the loneliness for those participants. It seems to be easier to cope with the changes in the relationships and create supporting relationships in larger families where there are more family or team members around the diseased. Single children with no siblings struggle more with the situation and feel the need for sibling support or support from kin in their decision making process.

Paper 4 “Sense of Coherence in persons with dementia and their next of kin—a mixed method study”.

This mixed method study with findings from both quantitative and qualitative data generated a deeper understanding of a sense of coherence within the different participants in the support groups, healthy partner, persons with dementia and adult children. All participants had high global ratings for Sense of Coherence (SOC) with persons with dementia (PwD) slightly higher than the other groups of participants.
However, comparing the subsections in SOC showed that meaningfulness was low in PwD and high among adult children. The high score for PWD was instead generated by high score in comprehensibility and manageability. The persons with dementia expressed that their memory was broken and that they had to keep from stressing. “Yeah, well my memory has been broken; I forget a lot.” Comprehensibility was expressed by partners as: “It’s just after taking part in the support group that we really got an explanation and understood dementia.”

The category meaningfulness was analyzed using the definition by Antonovsky (1987) that meaningfulness is the extent to which an individual believes that life makes sense emotionally and that one possesses the motivation and desire to cope with encountered stimuli. This was expressed by the persons with dementia as: “I forget easily, but I have to say I find this interesting and I enjoy coming here and meeting others.” The adult children found it meaningful to be part of the support group and to help each other. “It’s good to be part of the support group. I’ve been coming five to six years now and hearing the others; giving advice makes me happy.”

The partners scored slightly lower than the adult children and PwD in meaningfulness and comprehensibility and expressed that it felt good to talk to others in the same situation and that learning about dementia was helpful in dealing with everyday situations. “If I hear others are going through the same thing, it just makes it easier.” This suggests that healthy partners were struggling more with the situation than both adult children and PwD. The findings in this mixed method study provides a deeper understanding into what participants perceive as important to enhance the sense of coherence within the support group context, thereby giving insight into what should be incorporated into support groups for persons with dementia and their next of kin.
Discussion

The main aim of this thesis was to explore experiences of living with dementia both as a sufferer and as a next of kin as well as being part of a long-term ongoing support group. All four studies in the thesis show that next of kin find it hard to cope with dementia and that support from others in the same situation as well as information about dementia and practical tips for making everyday life work help to build a sense of comfort and support. It also helps persons with dementia to manage their disease and understand their condition making it comprehensible, manageable and meaningful by participating in support groups focused on social interaction and activities.

In the first study (I) participants in the long-term ongoing support groups expressed a sense of kinship through shared experiences. They also indicated that receiving information about dementia gave them knowledge about the disease and how to manage it on a daily basis. They expressed a sense of comfort and support gained through participation in the support group, and this increased by number of years of participation. Stokes, Combs and Stokes (2014) showed in their study that next of kin were unprepared for the pervasive impact of dementia, even after receiving a formal diagnosis with precise terminology (e.g. Alzheimer’s disease). In addition, they were unprepared for the progressive nature of the condition, as well as the behavioural, psychological and physical manifestations (Stokes et al., 2014).

The ongoing long-term support groups seemed to prepare the next of kin and the sufferer for each step of the journey with dementia. The healthy partners express that they know that it is going to be worse and prepare for that scenario making the progression more manageable to increase their sense of coherence according to Antonovsky (1987).

The findings in Study II suggest that adult children of people with dementia are in need of support for a substantial period of time in order to adapt to the fact that they have lost a parent who is still alive.
Seeing the personality changes is difficult. The second study also showed that to be an adult child of a person with dementia means being burdened with the responsibility to act on behalf of the diseased parent despite a deep sense of grief and loss, which leads to frustration and despondence. It is clear from this that support should also be given to adult children regardless whether they are the primary caregiver or not. The stress posed by this situation and the struggle to regain equilibrium takes its toll on the individual as well as on society in large by loss of income as suggested by Szebehly, Ulmanen and Sand (2014).

However, dementia disease affects the whole family. In the third study (III) the results indicated a duality in the family relationships after diagnosis. The participants experienced longing, lost closeness, loneliness and changed sibling relationships. They also experienced supportive relationships within the family, such as kinship, shared responsibilities and love and appreciation. This indicated that some families were divided by diagnoses of dementia and others pulled together. This is also expressed in a study of McGovern (2011) where some life partnerships affected by dementia experienced growth, renewed commitment, and satisfaction from the care process, despite the broad perception that caregiving for someone with Alzheimer’s is vastly depleting emotionally, physically and financially (McGovern, 2011).

Having social support is related to a sense of coherence and a generalized stress resistance resource (Antonovsky, 1987). Support groups have been shown to lower stress levels and the physical effects of stress (Coen et al., 1997; Jegermalm 2003; Chien et al., 2011) thus increasing manageability and comprehensibility in the situation. Support from trained facilitators, such as social workers or registered nurses, can also increase the possibilities of handling the situation in a more positive manner and finding meaning in the experience.
Finding meaning has a positive effect on mental health in caregivers as well (McLennon, Haberman & Rice, 2010). Meaning can arise from a belief that the caregiver is reciprocating past help from their relative and from their family appreciating the care they provide (Quinn, Clare & Woods, 2013). Study IV showed that adult children found their situation more meaningful than partners or persons with dementia (PwD). However the PwD had the highest overall score of SOC which gives some indication of the success of the support groups presented in this thesis for persons with dementia.

As a registered nurse, Travelbee’s interaction theory can serve as an aid in helping individuals arrive at meaning. Travelbee stresses that it is only within a context of a human-to-human relationship that a nurse can do this (Travelbee, 1971, p. 167). Human relationships are at the heart of supporting another human being in difficult times. Relationships can take time to evolve insofar as everyone feels safe in expressing their feelings and fears. In the first study (I) there was one couple who expressed a longing for kinship and felt shy participating in the group. They were also the newest members in the group and were struggling with the diagnosis.

The long-term ongoing support success in this thesis could be based upon the fact that time was given to evolve and create a relationship with others in the group. In addition, the moderators of the group were responsible for the success, since the participants were part of the support group for several years. It takes time for the participants to feel safe and trust the moderators and others in the group. The group also helped to support the spouses’ relationship; they could share experiences with others in the groups and with each other. They were provided something that they could participate in together, where no one feels left out, and this helped in strengthening their relationship.
Telling stories from their lives and having fun together strengthened the bond of human relationships within the group. Support groups should be structured so that those with dementia disease have as much social interaction as possible, thus enhancing the healthy aspects of their personality. The moderators should enhance the salutogenic perspective for participants, making the situation more meaningful, comprehensible and manageable. The next of kin should be given an opportunity to talk and ask difficult questions of the moderators without their diseased spouse present. In this way the next of kin is empowered to take care of their spouse, and the strategy also empowers the spouse with dementia; their value as a person is enforced.

As Travelbee states to help an individual create meaning in their experience can be done simply by showing that the nurse is concerned. Knowing that he or she cares for and about the ill person may suffice and enable the individual to cope with distress (Travelbee, 1971, p. 172). A study by Miranda-Castillo, Woods and Orrell (2013) showed that the most frequent unmet needs reported by people with dementia, caregivers and professionals were in the areas of daytime activities, company, and psychological distress; however, people with dementia rated psychological distress as the most common unmet need. A salutogenic approach as presented in the ongoing long-term support groups described in this thesis can help alleviate this psychological distress making the situation more manageable with high scores of sense of coherence as seen in Study IV.

Being part of a support group with others also shows the humanness in the experience of dementia—it could affect anyone. Travelbee (1971) thought that the caring situation could help, encourage and support individuals by stimulating health recovery and rehabilitation.
In dementia recovery is not possible but enhancing the salutogenic approach to life can provide individuals with a sense of coherence and meaning, thus helping them achieve a higher quality of life, i.e., to be seen and acknowledged as a whole person and treated with dignity not just an object, as described by Kitwood (1997). His approach focused on and provided strategies for, enhancing the ‘personhood’ of individuals with dementia in close, respectful relationships (Kitwood, 1997; Kitwood & Bredin, 1992).

To be part of a support group means that the person’s identity and social dignity is supported. An environment that is affirmative for a person with dementia, which acknowledges their life story, is also supportive to that person’s identity and sense of self-esteem. According to Nordenfelt (2004), the dignity of personal identity relates to a person’s integrity, autonomy, life history and relationships with other people. This dignity may vary depending on the attitude of others towards an individual, and consequently, it is influenced by changes to an individual’s body and mind (Nordenfelt, 2004). Dignity is usually experienced in relation to others. If someone is not allowed to participate in a relationship, it becomes an instrumental instead of an interactive relationship, which Skjervheim (1996) calls the instrumental mistake. Instead an ‘authentic partnership’ should be established, one that actively incorporates and values diverse perspectives and includes all key stakeholders’ voices directly in decision making (Dupuis et al., 2012). The support groups are there to support and give participants the means to control their own lives and situations, making the best of what is. Their active involvement is crucial for successful support.
Methodological considerations

There is a growing body of work regarding the effect of support and support groups with a quantitative approach, evaluating the effectiveness of interventions. However, in this thesis the main aim was to explore experiences of living with dementia both as a sufferer and as a next of kin, and being part of a long-term ongoing support group in a municipality in northern Sweden. To explore these experiences, a qualitative approach was used to come as close to the participants' experiences as possible, using their own words to describe their experiences. The lifeworld perspective was used to gain a deeper understanding of the participants' everyday life with dementia. Their own words enhanced the experiences they conveyed of being part of a long-term ongoing support group and what that meant for their everyday lives with dementia. The experiences were both positive and negative as seen in Study III, but what became apparent was the comfort and support that the participants in the support groups felt, which increased over time as seen in Study I. The inclusion of persons with dementia was an easy decision, as all participants' experiences should be involved to complete the whole picture. However, this also raised concerns regarding persons with dementia as vulnerable subjects in research, and great care was taken to ensure that they were volunteering participants.

The reaction from one participant in Study I showed how important participation could be for them. It gave them a sense of value, enhancing their dignity and sense of worth. These individuals were in an early stage of dementia, living at home without home care. They usually drove themselves to the support group meetings, which is not in line with how persons with dementia are normally viewed in literature.
This only shows that there is generally a lack of knowledge about living with dementia in its early stages, and that experiences expressed by the people that know is vital in understanding dementia and the impact it has on everyday life after diagnosis. Dementia affects relationships within the families as shown in Study III. Again, using the participants’ own words to describe these changes makes it more comprehensible to the reader. In the fourth study a mixed method was used to enhance the quantitative SOC scale with the participants’ own words to describe their sense of coherence and what made everyday life dementia meaningful, manageable and comprehensible for them. This would not have been possible using only a quantitative perspective.

**Conclusions**
Support given soon after diagnosis enhances the understanding of dementia and how this affects everyday life by giving the next of kin a sense of control. The longer this support continues, the stronger the sense of comfort and support for all of the participants. Participation also enhances a sense of coherence, especially in persons with dementia, giving them a meaningful, comprehensible and manageable everyday life. Support is also needed for the whole family as adult children struggle to cope with the loss of a parent who is still alive and the effect it has on their family.

**Implications for practice**
Participation in support groups should be offered as soon as possible after diagnosis or at the same time that the diagnosis is given and continue for as long as the participants feel the need of support.
Support groups should be structured according to the functional level of participants with dementia but also give participants a sense of control where they can actively decide what is discussed from a list of subjects at each support group meeting.

**Implications for further research**

Further research is needed to verify the effects in a more statistically significant result that could be generalized to a broader population of persons with dementia and their next of kin using larger groups or groups in different municipalities using the same model of support. Also larger quantitative studies using control groups to verify the results or larger interview studies combining quantitative methods to triangulate the research question could be used. Singles who have no family, live alone and are diagnosed with dementia have become more common in today’s society. To be able to give them flexible and individual support, more research into their specific situation is also needed.
ACKNOWLEDGEMENTS

I wish to convey my deep felt appreciation for all the participants in the studies. Your open, honest and interested attitude towards me and my questions were truly inspiring. I hope you will enjoy the result.

I also would like to thank my excellent supervisors: K-G Norbergh and Ove Hellzen, for never wavering support, interesting discussions and laughs. I also apologize afterwards for being such a nuisance at times, pestering you with questions and wanting quick replies. Despite your workload you always did your best to fit me and my questions into your busy schedule and I thank you from the bottom of my heart. My mother always said I could do with a little more patience, again sorry for that.

To Professor Emeritus Kenneth Asplund who encouraged me to apply for doctoral studies and supported my application. You were always ready to answer any question and discuss research with me; ever calm and kind, thank you.

I would also like to thank the local authorities in the municipality where the research took place for their support during and after the research period and their interest of the result.

The personnel at the support centre deserve a special mention; Pär, Barbro and Marie, thank you for all the support and help through this project. Without your work and input this thesis would not have been the same.
Thanks also to all my colleagues in Sundsvall and Östersund for interesting discussions, whether it be in seminars together with fellow doctoral students or at coffee breaks and lunches. Your support was valuable and you all made this journey enjoyable. I especially would like to thank Barbro Dahlbäck, for being an excellent travel companion and peer; you are always encouraging, insightful and helpful.

Dr Erling Englund for statistical support; you always make things seem so easy and clear. I thank you for that, it’s entirely my fault that it doesn’t stick to my memory.

I also thank all of you who I have met over the years; all of you have contributed to shaping me and my work into what it is today. Even if I don’t remember you all by name and mention you here; you are all in my heart and know that I will carry you with me always.

To my brothers Eje and Kristoffer and their families; I thank you for your interest, support and appreciation during my work on this doctoral thesis. I always enjoy your company and I do hope you will enjoy the result of this thesis.

I would also like to thank my mother for believing in my abilities and her unwavering support since my birth. Despite a failing memory you always ask how the thesis is going. This is for you, Mom.
Last but not least, I would like to express my deep love and affection to my husband since 25 years; Peter, you are the rock in my world! Your unwavering support and love through the years still amaze me to this day, I don’t know what I did to deserve this much love. Without you this thesis would not have been possible; you took care of our home, pets and made sure I ate, slept and took time out to have some fun during intense analysis periods. I look forward to the next 25 years of our marriage.
REFERENCES


