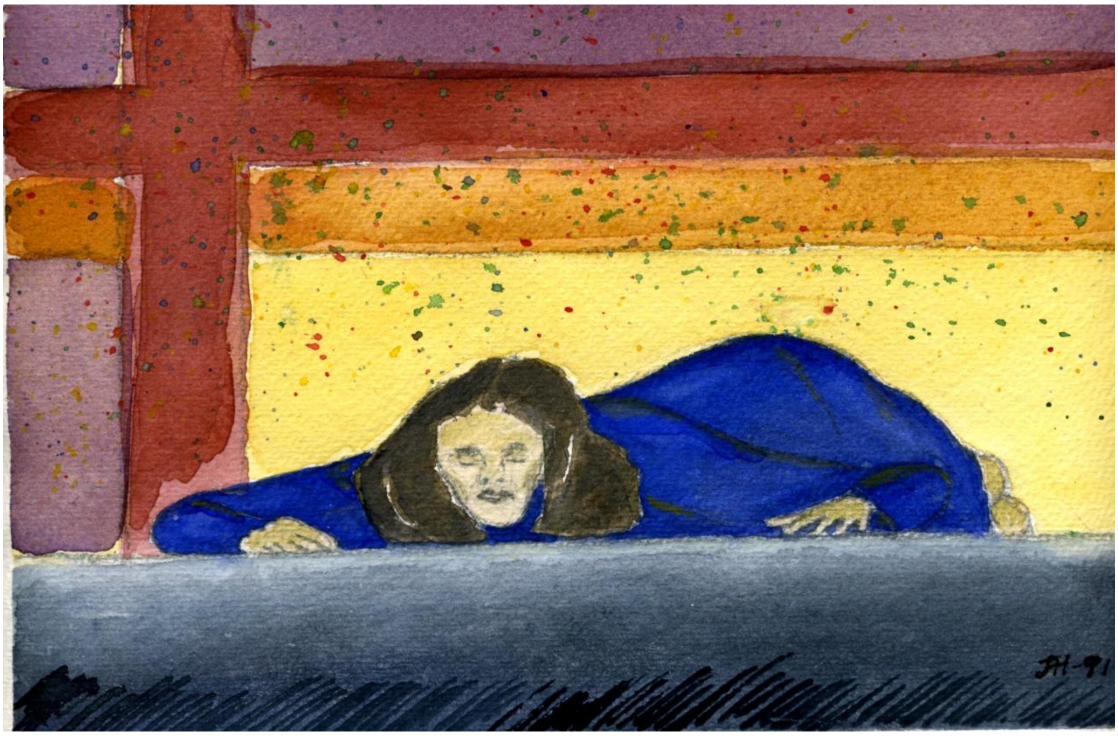
Public Health and Dementia- with focus on access to society



“Struck down” Hunderi, 1991”

Aud Johannessen

norden
Nordic School of Public Health
NHV

Isolation

She felt insecure
Afraid, confused
Didn’t understand what happened to her.
Therefore, she built walls around herself.
Old friends were locked out,
But she let me in.

Hunderi, R. I. A., & Hunderi, O. (2009).

Abstract

Aim: The overall aim of this thesis is to learn more about how to contribute to improving the daily lives of persons with dementia and those of their carers, and to increase these people's participation in society.

Methods: The thesis comprises four studies carried out between 2003 and 2011. Study I was based on qualitative interviews with 20 persons with early-onset dementia living in the Southern Norway. Study II was a qualitative study with interviews of 19 support contacts, from the Southern Norway. Study III was also based on interviews, in this study with 35 administrators in local authorities, from 32 Norwegian rural and urban local authorities. Study IV was an evaluation study of an intervention for carers of people with dementia and data were obtained in three steps; (1) a self-derived questionnaires with space for comments, completed by 45 carers after the intervention and 12 months after the starting point of the intervention; (2) interviews with 13 carers 12 months after the starting point of the intervention and analysed together with the comments from the evaluation questionnaires; and (3) a new intervention for carers of younger persons with dementia was developed based on the findings from the two first steps. The new intervention was evaluated with a self-report questionnaire completed by the carers with space for comments based on the findings from the two first steps. The questionnaire was completed by 48 carers after the new intervention and 12 months after the starting point of this intervention.

Main findings: Study I describes how people with dementia experience living with dementia, their experiences of the process towards a dementia diagnosis and their descriptions of how they try to maintain their "quality of life". Study II describes how support contacts perceive their work in dementia care. The study also shows the support contacts' motives for becoming a support contact and their encouraging and discouraging experiences while being a support contact. Furthermore, Study III describes the variation in the process that leads or does not lead to the use of support contacts as a service offered to families with dementia. The administrators' skills, the accessibility and management of the service are factors that influence this process of offering families with dementia a support contact. Study IV shows that carers rated the original intervention as being beneficial for them, a benefit that remained. These findings correspond with the findings from the interviews. Study IV also shows that the carers of younger persons with dementia benefited from the new intervention aimed at carers of younger people with dementia, a benefit that remained. The carers had valuable proposals for further interventions.

Conclusion: This thesis shows us that the opinions of these families, their supporters and those of other health personnel should not be overlooked when developing services in order to facilitate the provision of the chance to participate in society to families with dementia.

Keywords: accessibility, dementia, health promotion, services, Universal Design

Sammendrag

Mål: Hovedmålet med denne avhandlingen er å få mer kunnskaper om hvordan man kan legge til rette for å bedre hverdagen til personer med demens og deres pårørende, samt hvordan man kan bidra til å øke deres muligheter til deltagelse i samfunnet.

Metode: Avhandlingen består av fire studier som ble gjennomført i tidsrommet 2003 - 2011. Studie I var basert på kvalitative intervjuer med 20 personer som hadde fått diagnosen demens før de fylte 65 år, som kom fra Sør-Norge. Studie II var en kvalitativ studie hvor 19 støttekontakter ble intervjuet, også disse ble inkludert fra Sør-Norge. Studie III baserte seg på intervjuer, hvor 35 ledere fra 32 norske kommuner ble inkludert. Disse kommunene representerte store og små byer og bygder. Studie IV var en intervensjonsstudie for pårørende til personer med demens, og data var innhentet gjennom tre steg; (1) et selvutfyllende spørreskjema med plass til kommentarer, som ble fylt ut av 45 pårørende etter intervensjonen og 12 måneder etter oppstart av intervensjonen; (2) intervjuer av 13 pårørende 12 måneder etter oppstart av intervensjonen, og analysert sammen med kommentarer fra spørreskjemaene; og (3) basert på funnene i de to første stegene ble en ny intervensjon for pårørende til yngre personer med demens (< 65 år) utviklet. Evalueringsskjemaene til denne nye intervensjonen ble utviklet på bakgrunn av funn fra de to første stegene i Studie IV. Skjemaene ble fylt ut av 47 pårørende etter intervensjonen og 12 måneder etter oppstart av intervensjonen. Disse skjemaene hadde også plass til kommentarer.

Hovedfunn: Studie I beskriver hvordan mennesker med demens opplever å leve med demens og deres erfaringer knyttet til prosess som leder til å få stillet en demens diagnosen. Studien viser også hvordan de forsøker å opprettholde livskvalitet i det daglige. Studie II beskriver hvordan støttekontakter opplever deres arbeidsoppgaver i demensomsorgen. Studien viser også støttekontaktenes motiver for å bli støttekontakt, og motiverende og demotiverende erfaringer knyttet til det å være støttekontakt. Studie III beskriver variasjonen i prosessen som leder til eller ikke leder til at støttekontakt tjenesten blir tildelt familier med demens. Lederes kunnskaper, organisering av kommunene og tilgjengelighet av tjenesten er variasjoner som påvirker tildelingen av en støttekontakt. Studie IV viser at pårørende hadde nytte av den opprinnelige intervensjonen og effekten forble. Disse funn samsvarer med funn fra intervjuene med pårørende. Studien viser også at den nye intervensjonen for pårørende til yngre personer med demens var nyttig for disse pårørende og denne effekten forble. Pårørende forbedret intervensjonene og de hadde verdifulle forslag til videre utvikling av intervensjonene.

Konklusjon: Denne avhandlingen viser at disse familiene, støttekontaktene og annet helsepersonells meninger ikke må bli oversett når en skal utvikle tjenestetilbud og tilrettelegge tjenester slik at det er mulig for familier med demens å delta i samfunnet.

Nøkkelord: tilgjengelighet, demens, helsefremmende arbeid, tjenester, Universell Design

CONTENTS

Abbreviations

ADL	Activities of daily living
BPSD	Behavioural and psychological symptoms of dementia
EOD	Early-onset dementia
IQR	Interquartile range
MMSE	Mini-Mental State Examination
Nor-DIF study	The Norwegian multicentre intervention study
PSI	Psychoeducative interventions
RCT	Randomized controlled trial
SOC	Sense of Coherence

LIST OF ORIGINAL PAPERS

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

I: Johannessen, A., & Möller, A. (2011). Experiences of persons with early-onset dementia in everyday life: a qualitative study. *Dementia,* doi: 10.1177/1471301211430647

II: Johannessen, A., Hallberg, U., & Möller, A. (2012). Motivating and discouraging factors with being a support contact in the dementia care sector: a grounded theory study. *Scandinavian Journal of Disability Research,* doi: 10.1080/15017419.2012.667000

III: Johannessen, A., & Möller, A. Accessibility of support contacts for families with dementia: a qualitative study. *Nordic Journal of Social Research,* Submitted.

IV: Johannessen, A., Haugen, P. K., Kirkevold, Ø., Ulstein, I., & Möller, A. The value of integrating carers' view when evaluating and developing interventions for families of people with dementia: a qualitative and quantitative study. In progress.

INTRODUCTION

Improved health among the general population and better health care services in Western countries have resulted in longer life expectancy and consequently a higher prevalence of dementia (Alzheimer's Disease International, 2009). The majority of people with dementia in Scandinavia live in their own homes until the later stages of the disorder with assistance from close family members and some additional formal help from the social services (SBU, 2006). Persons with dementia suffer as their coping capacity and ability to function in daily life gradually decreases, and more and more activities become too much to cope with (SBU, 2006; Engedal & Haugen, 2009). Today we also know that caring for a family member with dementia is associated with a well-documented risk of developing health problems of one's own (Schulz, O'Brian, Bookwala & Fleissner, 1995; Ulstein, Bruun Wyller & Engedal, 2007a; Brodaty & Donkin, 2009). Thus, dementia affects not only the individuals themselves but the entire family, which means that it involves a large group of people, giving rise to the need for a public health perspective. Also the World Health Organization and the Alzheimer's Disease International emphasize that dementia must be a public health priority (WHO, 2012).

Therefore, the starting point for this thesis is the question of what kind of social services, seen from a public health perspective, families with dementia need to be able to maintain their health in the early and moderate stages of the dementia disorder. The focus of this thesis is on how to make these services accessible to families with dementia and through these services to contribute to making society accessible to persons with dementia and their primary family carers, using the help of a support contact. These ideas are linked to the concept of Universal Design as described by Story, Mueller and Mace (2001), also focused on in the reports from the Ministry of Health and Care Services (HOD, 2005-2006; 2008-2009)

My own experiences as a professional psychiatric nurse working at a hospital and in a non-specialist residential home for the elderly showed me how people with dementia and their carers and families struggle with the disorder of dementia in their everyday life. My research experiences while studying for a master's degree in public health focused also on the dementia disorder and additionally from a public health perspective. Through these experiences and other projects that I, together with colleagues, undertook, we started to realize that there was much more to do in this field for families with dementia as well as for those families experiencing dementia before the age of 65 years. Also, my teaching experiences and encounters with different types of health professionals in Norway made me realize that the concept of accessibility is a relevant theme in the dementia care sector. I became aware of the fact that there is a lack of knowledge and understanding of the concept of accessibility. Understanding to what extent the environment is accessible to people can be divided into three dimensions, physical access to the environment, access to information, and access to social activities and services. However, the most common way of discussing issues focusing on accessibility is to look at it from the dimension of the physical environment and the demand for access to it. The other dimensions are often omitted (Iwarsson & Ståhl, 2003). Accessibility to social activities and services of different kinds in the dementia care sector in Norway are often neglected. There is a need for more knowledge about why as we know from a survey study (Westerberg, 2009) that the accessible services certainly vary, in quality as well as quantity, and the provision does not seem to have changed significantly in recent years (Eek & Kirkevold, 2011). With these aspects in mind, this thesis, therefore, looks at different ways of making services more accessible and through this to make society more inclusive towards people with dementia and their primary family carers. The thesis comprises four studies, which mainly apply qualitative approaches. Focuses in the studies are perceptions of living with dementia (Study I), perceptions of being a support contact (Study II), arguments from local authorities in using support contacts or not to support persons with dementia and their carers (Study III), and finally an evaluation of interventions to help families to learn to live with dementia in the family (Study IV).

A brief introduction to public health

The expectations we have of the health care system and what rights and obligations we have with respect to health can be mirrored in words used in the media. These words have changed in the Norwegian welfare state during the past couple of decades. Words related to health care used in media today reflect ideologies; words that hardly existed two decades ago, such as ‘services’ and ‘clients’ (Blakar, 2006).

In previous decades public health was considered as collective action taken by society to prevent disease, prolong life and promote the health of populations, but this concept has changed in rich countries over the past decades (Beaglehole & Bonita, 1999). Many poor countries are still fighting the infectious diseases that are the major causes of morbidity and mortality, but in rich countries the disease patterns have changed as a consequence of the causes of the diseases having changed (Beaglehole & Bonita, 1999). The diseases and the demand for treatment in these rich countries focus on individual lifestyles and environmental elements. The demand is focused on diseases such as cancer, mental diseases, auto-immune and metabolic disorders.

The Ottawa Charter (WHO, 1986) pointed out that health concerns the individual, but that public health is the health of society or the population at large. The World Health Organization (WHO) in its document *Health 21 – health for all policy* (1998) point out the importance of equity. By 'equity' WHO mean that, when improving the health of the entire population, the focus must be on reducing social and economical inequity, and also that there should be equality of access to services. Furthermore, it is stated that everyone should be ensured access to appropriate health care and that good health is a fundamental right of human beings. If these aspects are taken into account, the demands in a public health perspective are enormous, when it comes to supporting these persons with dementia and their primary family carers.

BACKGROUND

Dementia

Social political reforms, modern medical treatment, environmental factors and lifestyle factors contribute to people reaching old age with better health. The incidence of the disease known as dementia increases with advanced age as the main risk factor for dementia is advanced age. The prevalence of dementia doubles roughly every five years after the age of 65 (Alzheimer's disease International, 2009). This will lead to an increasing number of persons with dementia in all populations over the whole world. Over the last decades researchers have also been made aware that dementia can occur before the age of 65 (Harvey, Skelton-Robinson & Rossor, 2003), a disability often referred to as 'young people with dementia', 'younger people with dementia' or 'early-onset dementia' and the abbreviation of this last term, EOD, will be used henceforth in this text.

Furthermore, dementia is a collective term for various organic brain diseases and the most common are Alzheimer's disease type, vascular dementia, dementia with Lewy bodies and frontotemporal dementia (Alzheimer's Disease International, 2009). The diseases are described and classified in the International Statistical Classification of Diseases and Health Related Problems – 10th edition (ICD-10) (2004) and in the American Diagnostic and Statistical Manual of Mental Disorder (DSM- IV-TR) (1994). Dementia is a progressive syndrome that embraces various symptoms including a deterioration of memory and cognitive disabilities such as loss of judgement, executive function and general information processing (Alzheimer's Disease International, 2009). The dementia disease often causes behavioural and psychological symptoms (BPSD), such as sleep disturbance, depression, anxiety, confusion and hallucinations (Alzheimer's Disease International, 2009). The available drug treatments for the person with dementia seem to have various and sometimes sparse to moderate effect on these different BPSD symptoms (Selbaek, Kirkevold & Engedal, 2007; Ballard & Corbett, 2010; Seitz et al., 2011). Also the BPSD symptoms seem to be more frequent among people with EOD than among older patients (Luscombe, Brodaty & Freeth, 1998; Harvey et al., 2003). Awareness of the person with dementia's need for help is reduced, but later studies also claim that people with dementia can express their needs and their voice must not be overlooked (Rymer et al., 2002; Allen, Oyebode & Allen, 2009; Westius, Andersson & Kallenberg, 2009; Bakker et al., 2010; Baalen van, Vingerhoets, Sixma & Lange de, 2010; Vogel, Waldorff & Waldemar, 2010).

The course of the disease may last 10 to 12 years from start to finish and the need for help in everyday life increases gradually as the disease progresses (SBU, 2006; Engedal & Haugen, 2009). The Mini-Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975) is one of the international screening instruments developed to assess cognitive function among the elderly and to capture orientation, memory loss, language problems and visuo-constructive abilities (Engedal & Haugen, 2009). The test scores are put into a context to illuminate the degree of dementia very roughly in relation to the functioning and care needs of the person with dementia, as is illustrated in figure 1. Age and education will affect the MMSE score, as does the type of dementia. People with frontotemporal dementia will be able to score highly on the MMSE, but be greatly disabled when it comes to daily living. People with Alzheimer’s disease and vascular dementia score lower than individuals with frontotemporal dementia, but cope better with the activities of daily living (Engedal & Haugen, 2009).

Therefore, the MMSE score, as described in figure 1, gives only a rough overview of trends in the disease and the needs that will eventually arise for the persons affected and their families. It, therefore, only provides a visual picture of the challenges to health care in general that can be associated with the development of dementia, even though there will be individual circumstances and coping levels that must be accounted for in the assessment of assistance needs. The establishment of a support contact might be a positive service for a person with dementia through a long stretch of the disease (Figure 1), but no research studies were available. A study of the carers found such service of utmost value (Bjørge, 2004).

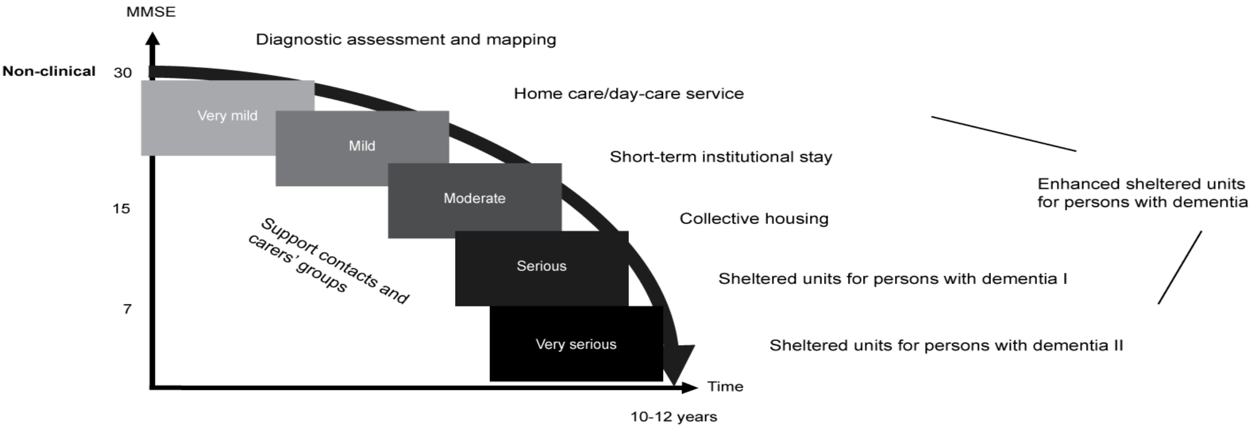


Figure 1. The need for different services throughout the progress of the disease (Modified and translated from Engedal and Haugen (2009): Permission has been granted by the author and publisher.)

Dementia from a public health perspective

It was estimated in 2005 that about 25 million people had dementia worldwide and that the number of sufferers might double every 20 years. Currently there are 4.6 million new cases over the entire world every year (Ferri et al., 2005). According to a newly published report by WHO and Alzheimer's Disease International (2012) there are today approximately 35.6 million people living with dementia worldwide. This number is estimated to double by 2030 and more than triple by 2050. In Scandinavia there were about 350,000 people with dementia (110,000 male and 240,000 female) in 2005 and the prevalence of people with dementia over 65 years in Norway will be 1.8% for women and 1% for men over 65 years today (Dementia Care in the Nordic Countries, 2005). It has also been estimated that 3% of all persons with dementia are under 65 years of age, meaning that up to 1,400 Norwegian citizens under 65 years of age suffer from dementia. This estimate was based on the work of Harvey et al. (2003), because no prevalence study has been carried out in Norway. Furthermore, there are approximately 71,000 people with dementia in Norway, also these estimates are based on Harvey and others (2003) today, and 50% of those suffering from dementia live in their own homes and are cared for by primary family members with some additional formal help. Of those who live in a nursing home in Norway today, 70 - 80% of them have a dementia disorder (Engedal & Haugen, 2009).

In recent decades, the focus has been on the fact that dementia can lead to unemployment and financial worries for these families and also affect children: children who, in some cases, are still dependent (Skovdal et al., 2007; Allen et al., 2009; Svanberg, Stott & Spector, 2010). It is also important that social services and different kinds of support are individually adapted in a gender perspective and also to fit each family's needs (Schulz, Martire, Julie & Klinger, 2005; Parker, Mills & Abbey, 2008; Brodaty & Donkin, 2009; Moniz-Cook & Mansthorp, 2009; Baker, Robertson & Connelly, 2010). With this in mind, there will be a high level of demand linked to the establishment of dementia care services in the coming years to prevent illness among the increasing number of individuals in families containing a person with dementia and also to cope with the high costs linked to this.

The accessibility of suitable care in nursing homes, short-term care homes and day care does not match the number of people with dementia in the Norwegian local authorities. In the county of Vestfold, which is representative of the counties of Norway, there are now roughly 3,300 people with dementia; half of them live at home and of these individuals there are about 800 that are in need of an organized day care service. These 800 individuals compete for a place in the 50 day care places available in the county (Bering, 2006). The conditions are similar on a national basis (Eek & Nygård, 2006; Eek & Kirkevold, 2011). According to

Norwegian legislation, everyone in need of practical or personal support in their daily life because of disabilities, diseases, age or other causes has a right to obtain this kind of help through support contacts or domiciliary care (HOD, 2006). However, this service is rarely used in the Norwegian dementia care sector, according to a survey performed by Westerberg (2009). Only a third of the Norwegian local authorities offered this service to persons with dementia and that proportion does not seem to have changed since 2009 (Westerberg, 2009; Eek & Kirkevold, 2011). Insufficient services constitute a burden for carers. People with dementia also suffer because they realize they are a burden to their carers (Kabel, 2001; Krüger, 2003). There is also still a stigma linked to the disorder (Johnstone, 2011)

That persons affected by dementia gradually lose the ability to function so as to safeguard their own health and, at the same time, the carers are at risk of developing their own health problems due to their carer obligations are known facts (Schulz et al., 2005; Brodaty & Donkin, 2009). Studies show that between 15% and 50% of primary family members can become depressed as a result of the prolonged isolation and stress associated with carer obligations, and depression is also an accompanying symptom of dementia (Schulz et al., 2005; Ulstein et al., 2007a; Brodaty & Donkin, 2009; Engedal & Haugen, 2009). The incidence and deterioration of existing somatic diseases also increase in primary carers of persons with dementia. Informal carers of persons with dementia have a higher consumption of drugs, as well as more sick leaves, if they are in work (Schulz et al., 2005; Brodaty & Donkin, 2009; Engedal & Haugen, 2009).

Factors affecting the carers' health are related to the dementia symptoms of the person with dementia (BPSD), and of other reasons such as: the other family members, the relationship, age, gender and the level of activities of daily living (ADL) that the person with the disorder can perform (Riedijk et al., 2006; Vugt de et al., 2006; Zarit & Femia, 2008; Brodaty & Donkin, 2009). The relationship affects the carer's experience of the necessary tasks. If the care recipient is considered a valuable person, and not just as a problem, there will also be positive experiences associated with being a care provider (Haaning, 2002; Dulin & Dominy, 2008; Shim, Barroso & Davis, 2011).

From a public health perspective, it is important to find proper methods and treatments to help the increasing number of families who are affected by dementia, so as to maintain and improve health and add years to life (Alzheimer's Disease International, 2009). This includes children in some affected families (Mæland, 1999; Allen et al., 2009; Svaneberg, Stott & Spector, 2010). In their study, Alzheimer's Disease International (2009) pointed out that interventions with information about services in the local authority targeting primary family members do improve public health among the elderly population and add years of life for these people. It is, therefore, important to give families and individuals with dementia knowledge about the disorder and the services that are accessible for everyone or 'universal', so that they can be helped to cope with everyday life, and thus achieve better health (Moniz-Cook & Mansthorp, 2009; Brodaty & Donkin, 2009; Shim et al., 2011). One such Norwegian service is laid down in the health legislation. This legislation gives people with disabilities, regardless of age, the right to apply for assistance for the family and/or the persons suffering from dementia themselves (HOD, 2006), and this could promote health in families with a person with dementia. Another method of promoting health is to include the potential users themselves in the design of treatment and services. Norwegian regulations on individual care plans and Norwegian legislation on patient rights have set the framework for the inclusion of people with dementia and their families in treatment (HOD, 2004; 2009).

There is broad agreement that carers of people with dementia benefit from knowledge about the disorder and the caring person's role (Brodaty & Donkin, 2009). It is also agreed that carers find information about the resources available in the local authority beneficial and that people with dementia benefit from individual or group intervention (Green & Brodaty, 2002; Beattie, Dark-White, Gilliard & Means, 2004; Parker et al., 2008; Moniz-Cook & Mansthorp, 2009). Failing to help carers of people with dementia will thus have an impact on both the individual with dementia and his/her carer and viewed in a broader perspective, will affect the health of the elderly population. Dementia contributes to disability and dependency among affected people and causes significantly more illness among their formal carers and higher mortality and loss of years of life in the dementia-affected families. To promote health via information and social and medical support of different kinds is, therefore, a big challenge for all parts of society (Alzheimer's Disease International, 2009). In order to reduce the harm and suffering, it is necessary to involve and include both the person with dementia and their families in the treatment. It is also important to help them to gain power over the situation. This includes encouraging them to choose to act independently to influence and take control over the determinants in their own life situation. Furthermore, this control can increase their chance of improving their health and well-being in a responsible manner. This means encouraging the involvement of the person and their family in the treatment, making them part of it (Tones & Tilford, 2001). The term “empowerment” can, therefore, be associated with this encouraging process of including the people with dementia and their carers as a means of promoting their health. Furthermore, health professionals should throughout the period of support and education show them how to manage their life situation and help them to look after themselves, as well as to clarify their needs and present them with opportunities for participation in the treatment.

Health

According to the WHO in 1946, health is a state of complete physical, mental and social well-being and not only the absence of disease and infirmity (WHO, 2006) and health should then be viewed in a holistic way. Following a holistic way of looking at health from a humanist perspective, Medin and Alexandersson (2002) see individuals as playing an active part in this context and everyone has a chance of achieving their goal depending on their resources and the environment. Others also argue (Tones & Tilford, 2001) that the medical way of looking at health often ignores the psychosocial aspects of health, and they claim that to promote health it is important to consider a change from the traditional top-down perspective to a bottom-up view, so as to include individuals and promote empowerment.

Furthermore, Antonovsky’s ‘salutogenic’ views on health, Lazarus’s theory of stress and coping (Lazarus, 1993), as well as Karazek and Theorell’s model for the relationship between the demands of and control of work (Karazek, 1990) constitute an understanding of how we can contribute to promoting health. This understanding constitutes a basis for the promotion of health within the families studied in this thesis.

Health promotion, the new public health

The concept of promoting public health has changed in the course of the past decades. The new way of understanding how to promote health changed so as to focus on ‘empowerment’ and ‘population participation’, keywords in the new alternative way of thinking to prevent diseases (Andrews, 2003). One of the main strategies within health promotion work is, therefore, to create environments that provide opportunities for each individual to promote their own health (Haglund & Petterson, 1998). To establish and contribute to developing services as the focus of this thesis, it can be looked at from the point of view of Health Promotion or *"the new public health"* perspective to promote health (Andrews, 2003), providing the families with dementia support to promote their health.

Rootman and others (2001) have pointed out seven principles within health promotion and these are: empowerment, participation, holism, intersectoral, equity, sustainability and a multi strategy plan to promote health. Also in a document and in the new health reform published by the Norwegian Ministry of Health and Care Services (HOD, 2011) these seven principles are mentioned and the concept of "user participation" will be crucial in the current facilitation of medical services to promote health. In promoting the individualized services which should be accessible for all, this document, the new health reform and the new act for health care services for local authorities' focuses on close cooperation between the users (who participate in their own treatment plan), the carers and the local authorities (HOD, 2006; 2008-2009; 2011).

This thesis addresses some important topics related to public health and health promotion, focusing on the increasing number of persons with dementia and carers having a family member with a chronic disorder that causes more disability, dependency and mortality within these families (WHO, 2004; Alzheimer's Disease International, 2009). Furthermore, this thesis focuses on services that are meant to be accessible to all who are in need of the service in a society that claims to be inclusive, and will be described in more detail in their respective sections in the following text.

Salutogenic views on health

The theory and doctrine of salutogenesis was introduced by Antonovsky, a medical sociologist (Antonovsky, 1991). His approach was based on what he called a salutogenic perspective of health, that is, one that studies the cause of health and what promotes it in contrast to a pathogenic perspective, which studies what makes people sick. He introduced the concept 'sense of coherence' (SOC) to explain why some people become ill under stress while others do not and remain healthy (Antonovsky, 1987). He defined it as a "global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence”. The concept has three components: comprehensibility (the extent to which stimuli from one’s external and internal environment are structured, explicable and predictable), manageability (the extent to which resources are available to a person to meet the demands posed by these stimuli) and meaningfulness (the extent to which these demands are challenges worthy of investment and engagement). Furthermore, Antonovsky (1991) did look upon good health and bad health as opposites, he meant that these opposites of continuous variables may vary over the course of life, and it is not so that you either have bad health (ill), or good health (not ill) for your whole life. They depend on the three different components moving towards different dimensions of health. The SOC can vary from high to low. A high SOC implies a greater degree of ability to meet challenges and the stress of life in a way that preserves health. Antonovsky (1991) also pointed out that: “Man has free will but her/his ability to cope, understand and feel a sense of the outside world depends on their life experiences” (Antonovsky, 1991). The concept of SOC can be seen in the context of coping when the components are seen as internal and external resources in an individual who can be reinforced or reduced (Medin & Alexanderson, 2000). It is also important to understand that Antonovsky’s SOC is about a basic attitude in every individual and that it should not be regarded as a coping strategy in the same way that, for example, Lazarus uses the term. Seen from a salutogenic perspective, humans thus have opportunities to cope in new situations and health is not static, but can be affected by new knowledge and experiences which shed light on these definitions. Overall, the SOC is a fundamental attitude found in every human being.

Stress and Coping

Historically, the word “stress” has been used since the fourteenth century, though at that point it was not used in connection with humans (Lazarus, 1993). It was only after the Second World War that it became common to talk about stress in connection with stresses in life or as caused by a disorder among humans. Initially, only physiological reactions to stress were studied (Selye, 1978). In the 1950s, scientists began to talk about stressful situations having a psychological aspect, and that stress had individual manifestations (Selye, 1978; Lazarus, 1993). Today, it is agreed that coping processes in relation to stressful situations are individual, different in relation to different situations and that they change over time. Lazarus defines stress as:

> “a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus, 1975).

When it comes to studying how people cope with a disorder, it is important to discern which personal measures are the most beneficial, to find individual measures that are adapted to the individuals’ coping skills where and when needed and related to the situation and problem (Ringsberg, Alexandersson, Borg & Hensing, 2001a; Möller & Nyman, 2003; Gallagher-Thompson, 2007). Being able to cope with stressful situations means having the ability to think constructively, to be resolute, to have hope, to have learnt to be creative and optimistic, to have courage, confidence and a sense of context (Lazarus, 1993). Lazarus defines coping as:

> “Constantly changing cognitive and behavioural efforts to manage, reduce or tolerate external and/or internal demands (or conflicts between them) that are appraised as taxing or exceeding the resources of the person” (Lazarus, 1984).

Throughout life we all encounter situations that require different coping strategies and how we approach these situations varies, as does how it affects our health when the situation requires more of us than we initially believed we had the capacity to cope with. The emotions that arise associated with stress and coping are individual and can be experienced as anxiety, anger, guilt, shame, sadness and jealousy (Lazarus, 1993).

Furthermore, one method of understanding how we react in different situations and how this affects our health can be illustrated through a model created by Karazek and Theorell (1990). In this model they look at requirements, control and the ability to make decisions and, moreover, the relationship between demands and control. Their model is a multidimensional one that examines the relationship between person and environment with a particular focus on this interaction in the work situation. The model utilizes two dimensions or constructs, namely decision-making and demands, which focus on explaining the development of stress on the individual at work. The model illustrates how requirements and decision-making opportunities in a job situation change as pressure increases or opportunities for decision making are restricted, and major decision-making opportunities and low demands result in a relaxed state. If there are few opportunities for decision making and low demands, this will lead to passivity, though high demands and few opportunities for decision-making might lead to tension (Figure 3).

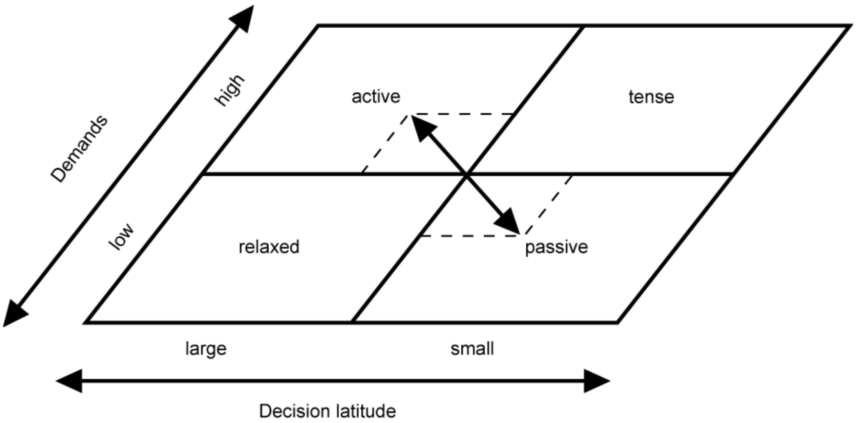


Figure 3. A Model of the relationship between demands and control. Following Karazek and Theorell's model (Karazek, 1990) (Translated by the author AJ)

The model is applicable also to informal carers of people with dementia. It highlights how the demands, control and ability to make decisions can change for carers over the duration of the dementia disorder as the person with dementia begins to be in need of more help and the demands increase. When carers realize the person with dementia is demonstrating higher levels of BPSD, they may feel more locked up in their homes, and because the behaviour is of such a nature that it cannot be changed, carers find that the demands increase. On this basis, the decision-making opportunities will be limited because the tasks are too demanding and too difficult. Options with respect to making decisions are small. According to the model by Karazek and Theorell (1990), such a situation will lead to tension. An individual's demands in relation to the opportunity to take decisions together influence the ability to cope (Figure 3) (Karazek, 1990). To ease such situations it is important to provide these carers and the persons with dementia with services of various kinds and with knowledge.

Accessibility

The extents to which the environment is accessible can be divided into four dimensions: access to the physical environment, to information, to social activities and to services. So far the most common way of discussing accessibility is to look at it from the dimension of physical environments and demands. The other two dimensions are often omitted (Iwarsson & Ståhl, 2003), but in a report by the Norwegian Ministry of Health and Care Services (HOD, 2005-2006) these dimensions are included.

Creating a society that takes into account that there are an increasing number of elderly citizens with reduced mental capacity and people with dementia and their primary family carers will also be useful to others. To adapt society to as many as possible, regardless of disability, is a challenge and goal that appears in several official Norwegian documents (NOU, 2005; NMR, 2005; BLD, 2009; HOD, 2005-2006; 2008-2009).

The United Nations' standard rules on the Equalization of Opportunities for Persons with Disabilities (WHO, 1999) highlighted the fact that people with disabilities must be given the same rights and obligations as others in society. Furthermore, Norwegian society also has speeded up its efforts to make everything accessible to all (NOU, 2005; NMR, 2005).

People with dementia will experience this lack of accessibility to varying degrees related to everyday life in the public arena and also in their own home. This lack of accessibility can be reduced by facilitating optimal indoor and outdoor environments. We also know that if the environment is adapted for people with dementia, this seems to have a positive effect on the person's activities of daily life (ADL) and can reduce BPSD as well (Engedal & Haugen, 2009). Providing an accessible environment will thus reduce the carers' strain and stress. Interaction with a person who has a high level of BPSD is even more demanding than when the person with dementia can function more calmly (Engedal & Haugen, 2009). Persons with dementia do gradually develop greater functional failure and this increases the need for adapted communication and structure in everyday life, throughout the course of the disorder. Confusion and forgetfulness are parts of human experience in general; so designing the

environment in a manner that facilitates orientation in public spaces will be essential and useful even for those who do not have a dementia disorder (Blackman et al., 2003).
Blackman et al. (2003) and Brorsson, Öhman, Lundberg and Nygård (2012) show in their studies that access to public spaces and the physical environment is often reduced for those with dementia experiencing difficulties with spatial recognition. Furthermore, these difficulties may lead to social isolation for persons with dementia and their primary family carers. This isolation may affect the carers as well as the person with dementia as time goes on. To promote health in these families with dementia it is important to prevent social isolation (Holley, 2007).

Information is one of the dimensions of accessibility, and modern society requires skills not all of us have. In contemporary society, we use IT as an instrument, which makes information accessible speedily and easily for many of us. However, this development of IT also leads to many people finding that a significant amount of information is becoming less and less accessible, for example, tickets that can only be purchased online and bills that can likewise only be paid online. The demand for knowledge, activity, speed and orientation required in order to be able to get to, go to or do various things in everyday life has changed. These types of demand are also linked to accessible services and information offered by local authorities, and quite often these services are only accessible online. These days it might also be difficult to orientate oneself in a bus/railway station because completing one’s travel requires specific kinds of knowledge and alertness. The discrepancy in culture between urban and rural areas, or between countries, may influence these matters. The environment in all these matters will make society less accessible for people with cognitive impairment. People with a cognitive impairment or dementia of some kind do have a residue of experience-based knowledge from before they developed cognitive impairment, but it is not easy to acquire new knowledge when their mental capacity is slowly being reduced (SBU, 2006; Engedal & Haugen, 2009). One example of this is that the person with dementia does manage to use a well-known old coffee machine, but it might be difficult for him or her to use a new one that looks different, if the old one breaks down. Another example is that they do not manage to learn new technology familiar to the younger generation today. Most of the time, the persons with dementia will have difficulty coping in an IT society where many of the tasks once learned do not exist anymore and most of this old knowledge has only limited value in the coping process today with the current demands society makes on us. As a result, society may become less accessible to people with dementia and the elderly, which is doubly problematic because we already know that the elderly population will continue to increase during the next couple of decades.

A Swedish research study describes ‘digital discrepancy’ in contemporary IT-society and shows that people over 65 years use IT less than those under 65 years. The study also shows that there is a gender perspective in the use of IT as women use IT less than men, though this will probably be changed in the future as the gender gap in IT use narrows (Andersen, 2004). In today’s society, people have to be able to acquire new knowledge to maintain activity linked to technology or transport, and the speed associated with this has increased, which makes life difficult for people with dementia.

Even if great efforts are made to increase accessibility for all in the different parts of society – physical, social, cultural and informational – there are situations when individuals cannot manage their everyday life by themselves. In such situations they need help or assistance from society and from other persons. One example of support is the support contact recommended by Norwegian Directorate for Health and Social Affairs (HOD, 2006; 2011) (see page 18).

Perceptions of living with dementia

Only a few international studies that shed some light on what it is like to live with a dementia disease have been published recent (Steeman, Dierckx de Casterle’, Godderis & Grypdonck, 2006; Harris & Keady, 2012). Hardly any such study has been about the Norwegian population. To bring a subjective understanding of experiences linked to living with a dementia disease, the term ‘disorder’ will be used in the following text in this thesis. Krüger (2003) has summarized how a woman with a dementia disorder experienced living with it, and how she expressed it: she felt relieved when she was diagnosed with Alzheimer’s, because it meant that she and her husband understood the reason for all the changes they had experienced. The Dementia Medical Care Service helped her to live a better life, and enabled her to cope better with various activities. Still, many things in everyday life were difficult to interpret, for example, time, such as “quarter to twelve”, make no sense. Therefore, when spending time outside the home, she tended to have difficulties with appointments. In traffic, she also has problems, because sometimes, in the middle of a cross road, she does not know how to deal with the traffic lights. Such situations make her stressed and she becomes unsure of herself. When she is in a shop, she can open her wallet but have no idea what money is. Confusion like this may be only momentary, and she may be able to continue after a while. She says that many people around her do not understand that she is sick, because she is so vigorous physically. To cope, she is dependent on peace and structure in her daily life. She has experienced much grief and feels as if something is constantly being lost. Impressions and events are sliding away. The process of developing the disorder is a lonely one and she believes it would be nice to be able to talk to others who are in the same situation.

In another study with interviews of ten persons suffering from dementia, Wogn-Henriksen (1997) states that many people with dementia feel that they receive sporadic or little information about the disorder. In the same study, it furthermore appeared that everyone who was interviewed also experienced changes in cognitive abilities. They described feeling that there was something wrong with their heads and that they were forgetting things. It was difficult for them to find words, communicate with others, and understand what was happening around them, recognizing people, environments and objects. They all had a feeling of being “stupid” and experienced emotional changes such as a greater degree of sadness. They felt that they became tired more quickly. The experience of loneliness and various losses was also important throughout the development of the disorder. Experiences and feelings associated with loss of the driving licence and work were also described. Some were distressed that they sometimes told lies or became angry, because they did not know what to say in a particular situation. Wogn-Henriksen’s (1997) interpretation was that all the interviewees experienced a clear sense of change associated with the failure of and loss of behavioural control. The study revealed that many of the persons with dementia had a loss of awareness of their need for help. Denial can also be seen as a protective factor. Various benefits associated with the disorder were also described in the study, expressed in terms of fellowship and companionship working as protection against the loneliness of living in an institution. The interviewed mentioned that it was good to be able to take it easy. They felt more secure because of the help they had received (Wogn-Henriksen, 1997). Later studies confirm Wogn-Henriksen (1997) and Krüger’s (2003) findings, and these studies indicate that the majority of people with dementia are able to articulate their experiences and needs in an insightful manner (Kabel, 2001; Beattie et al., 2004; Roach, Keady, Bee & Hope, 2008; Westius et al., 2009). This is also shown in paintings performed by people with dementia, see the picture painted by Hunderi in 1996 (Hunderi & Hunderi, 2009), the frontispiece to this thesis. Permission has been granted by the author and publisher to use the painting and poetry in this thesis.

Support contacts

According to the recommendation of the Norwegian Directorate for Health and Social Affairs (HOD, 2005-2006) and the Goverments's plan (HOD, 2008), a strategy is needed to develop services to make society more inclusive for people with dementia. This can be done via activities, adopted by the local authority, either in their homes, in nursing homes or at day care centres. It is also stated in the legislation relating to Social Services §4-2 (HOD, 2006) that anyone who has special needs for assistance because of disease, disability, age or for other reasons can be assigned to receive information, advice, guidance and support from society to prevent social problems or contribute to solving social problems through a support contact (the abbreviation "supporter" will be used in this thesis). The service can also be offered to carers of persons with dementia who have a particularly stressful carer obligation, and this does apply to families which include a person with dementia (Engedal & Haugen, 2009). Furthermore, the service can also be offered to people who have been given a placement in a residential or day care institution. There is no official time limit on the service, but usually this support is allocated for a limited period and is supposed to have the following function: to help the supported person to participate in social, cultural and sport activities, to be a social contact or someone to talk to, or to go shopping with, and can also contribute to respite for carers. Supporters are a "non-treatment service" and require no formal qualifications. They are usually hired on a self-employed basis, often part-time, by the local authorities and must agree to maintain professional confidentiality. In literature that describes the supporters' work, emphasis is placed on interpersonal communication and issues that deal with working with another person (Westergård, 1999). Other literature describes how the environment affects people with dementia and the environment impact on their functional levels and psychiatric symptoms (Blackman et al., 2003; Engedal & Haugen, 2009; Brorsson et al., 2012).

The legislation that grants the right to be assigned with a supporter is more or less the same across the Scandinavian countries. The differences relate to age; in Norway and Denmark there is no age limit on the person being assigned with this service particularly, but in Sweden there is a maximum age limit of 65 years, except for those aged above 65 years who were offered this service before the age of 65, and who are entitled to that service as long as they need it (Svensson, Ekvall & Storfält, 2007). In Norway they are hired by the local authorities on a self-employed basis to work as a "paid friend" with a low salary and their role can be compared with that of respite carers, voluntary workers, befrienders or domiciliary homecare in Norway and other Western countries.

In their role as supporters in dementia care, they are responsible for the task of organizing the social environment and stimuli for the person with dementia. Therefore it is natural to give them the opportunity to gain knowledge and guidance about how to do this so as to develop their "sense of coherence", understanding and control of the role (Antonovsky, 1991; Tones & Tilford, 2001). The use of supporters in dementia care may provide people with dementia and their primary family carers an opportunity of greater participation in society, meaning that each individual is given the opportunity to improve their health by avoiding isolation (Wilkinson, 2001; Johannessen, 2009; Brodaty & Donkin, 2009; Engedal & Haugen, 2009). Supporters may be the link for people with dementia, by making the community more accessible or inclusive and improving the opportunities to participate (physically, culturally and socially) in society. This can be compared with the function "command lines" have for the blind and those visually impaired using computer programmes. A supporter can also help to reduce "technological barriers" as described on page 15. The task of designing an indoor environment to make it suitable for people with dementia is something we know about and have access to, but in outdoor spaces, both public and private, this is more difficult to arrange (Blackman et al., 2003; Brorsson et al., 2012). One reason for this is that different kinds of disabilities require different solutions. The supporter can be used in this context and can give relief to family members and provide them with respite. Seen from a public health perspective, this will affect many people, because most people with dementia live in their own homes (Dementia Care in the Nordic Countries, 2005; SBU, 2006). As people with dementia will develop disabilities in many areas related to the physical and social environment and will need individualized services throughout the course of the disorder (as described in Figure 1), the supporters could be of great importance. However, this kind of service traditionally is relatively rarely used. According to a survey study, only one third of Norwegian local authorities offer this service to persons with dementia or to their carers (Westerberg, 2009) and this proportion does not seem to have changed significantly since then (Eek & Kirkevold, 2011). Very little is known as to why this service is so rarely used in the dementia care sector, what it is like to be a supporter and also whether it is a beneficial service for families with dementia. A literature study by Johannessen (2009) has shown that it is difficult to recruit supporters in the dementia care sector, they tend to quit after a short time and they need knowledge about the dementia disorder and continuous counselling from health personnel. Most of them are also women (Johannessen, 2009).

Learning to live with dementia in the family

Psychoeducative intervention is a method that falls within the category of psychosocial interventions. Psychoeducative interventions directed at carers aim to help people to understand a disorder, the progression of it, in this case that of the one afflicted with dementia. The intervention is also intended to help carers understand and cope with their own emotional reactions, as well as providing an opinion as to how to understand the behaviour of the person with dementia and what can have an influence on that behaviour. The intervention is intended to give families tools to cope with life in a better way and also to provide them with knowledge about various services within health care and carer's rights. There are studies in that also recommend individual psychoeducative interventions for people with dementia or group-based interventions (Dröes, Meiland, Vernooij-Dassen, Lange de & Tilburg van, 2006; Moniz-Cook & Manthorp), but there has been a lack of focus on organizing such interventions for people with dementia (The National Board of Health and Welfare, 2010; Eek & Kirkevold, 2011), as well as their inclusion in the decisions relating to themselves (Beattie et al., 2004; Parker et al., 2008; Moniz-Cook & Mansthorp, 2009).

There is broad agreement among researchers that giving family members structured and systematic education about the disorder may increase their ability to discover tools to cope with the challenges they face as carers and help them find solutions that can increase their chances of living active and participatory lives. This also has a positive impact on the persons with dementia (Mittelman, Ferris, Schulman, Steinberg & Levin, 1996; Marriott, Donaldsson, Tarrier & Burns, 2000; Brodaty, Green & Korchera, 2003; Schulz et al., 2005; Parker et al., 2008; Brodaty & Donkin, 2009). The intervention must include methods that provide carers with the opportunity to practise how to deal with the demands of everyday life to reduce stress. This includes providing carers with the means of obtaining knowledge about how to gain more formal assistance and at what time, to provide them with relief and also to make society more accessible for them and the person with dementia. Using a problem-solving method in the interventions to help carers has been shown to be positive (Green & Brodaty, 2002; Brodaty et al., 2003; Schulz et al., 2005; Parker et al., 2008; Brodaty & Donkin, 2009). Problem-solving as a method has also been used in other groups dealing with a specific disease, such as asthma (Ringsberg & Timpka, 2001b).

Psychoeducative intervention can be successful and is a method that health professionals can use to reduce stress and the burden of care, as well as to increase the use of coping strategies among carers of people with dementia in order to promote health in all these families (Parker et al., 2008; Brodaty & Donkin, 2009; Moniz-Cook & Mansthorp, 2009). Psychosocial interventions for carers can be successful, i.e. education about dementia, communication skills, training and problem-solving, are all considered to be promising approaches. Still, the results after such interventions diverge and show sparse to moderate effects on measurements like stress and burden of care among the carers, but researchers confirm that this type of intervention is helpful for the carers (Green & Brodaty, 2002; Brodaty & Donkin, 2009; Moniz.Cook et al., 2011). In Norway a short-term intervention (Nor-DIF) was set up (Ulstein, 2007b) and resulted in the development of a new intervention programme for carers of EOD. These two psychoeducative intervention programmes are applied in this thesis and the abbreviation of this term, PSI, will henceforth be used and described in the following text.

The intervention programmes

The intervention programmes as applied in this thesis, aim to contribute to changing a situation. The intervention programmes in this thesis included two elements.

The first element was a three-hour lecture focusing on education about dementia, provided by a psychiatrist or a psychologist. The carers were taught about the symptoms and the normal course of dementia as well as drug treatment strategies and were given a short introduction to the intervention approach. The carers received hand-outs from the lecturers so that they would have an accurate record of the educational part of the interventions. The carers were also given a handbook about dementia for carers (National Public Health, 2000) in the original intervention for carers of persons with dementia in general. Copies of relevant literature and legislation about health care services were distributed in the new intervention which only included carers of people with EOD.

The second element of the intervention programmes consisted of seven group meetings and lasted for four and a half months in the original intervention and six months with eight meetings in the new intervention. Each meeting was of two hours' duration, aiming to teach about communication techniques and structured problem-solving so as to provide carers' with knowledge that would give them tools to cope with everyday challenges (Text box 2).

Text box 2. Structured problem solving

1. Definition of a problem (as concrete as possible)
2. Brainstorming; all proposals to be recorded
3. Discussing the proposed solutions, pro and con
4. Choosing a solution or a combination of solutions
5. Detailed preparation of how to carry out the chosen solution
6. Evaluation at next meeting

(Ulstein, Sandvik, Wyller and Engedal, 2007c: Permission to reproduce has been granted by the author and publisher.)

There was a two-week interval between the first two group meetings, while the remaining meetings were evenly distributed. The meetings started with a few minutes "small talk" before evaluating the problem solving exercises from the previous meeting. Sometimes the problem solving had failed. Possible reasons for failure could be insufficient exploration of the problem or inappropriate planning of how to carry out the chosen solution. Then a new problem to explore was chosen from the problems with which the group members were struggling. The group leader always took responsibility for unsuccessful problem solving. The group leaders focused on problems that were of interest to all the participants, or at least most of them. In the original intervention groups there was one leader and in the new intervention there were two group leaders for each group. The group leader was the administrative leader, i.e. responsible for preparing the group's room with respect to equipment (flip-chart, chairs, table) and keeping to the schedule. The structure of the group is shown in Figure 4.

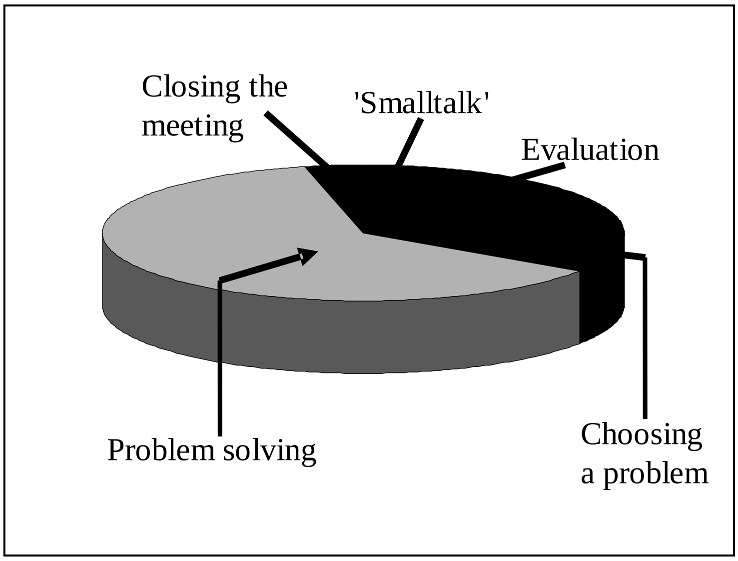


Figure 4. Structure of the group meetings (Ulstein et al., 2007c: Permission to reproduce has been granted by the author and publisher.)

The main topics in all the groups were about how and when to get formal help from the local authority with the activities of daily living, how to handle BPSD and how to encourage the person with dementia to accept the formal help offered. The group leaders used cognitive techniques (James, Powell & Reichelt, 2001) to help the carers to gain more realistic expectations about the ability of the persons with dementia to function in everyday life. In the interventions there were five to nine carers in each group.

AIMS OF THE THESIS

The overall aim of this thesis is to learn more about how to contribute to improving the daily lives of persons with dementia and those of their carers, and to increase these people’s participation in society.

The aims of the studies included in this thesis can be summarised as follows:

Study I: To study how people with dementia perceive living with dementia.

Study II: To find out how the supporters perceive their work.

Study III: To find out why some local authorities allocate supporters to persons with dementia and their family carers and others do not.

Study IV: To evaluate the consequences of the interventions as subjectively rated by the carers and, if possible, to make proposals on how to improve interventions.

METHODS AND METHODOLOGICAL CONSIDERATIONS

This thesis includes four studies carried out between 2003 and 2011 (Table 1).

Table 1. Overview of the included studies

Study	Design	Data collection	Participants
I	Qualitative	Qualitative interviews	20 persons with EOD Four hospitals
II	Qualitative	Qualitative interviews	19 supporters 12 local authorities
III	Qualitative	Qualitative interviews	35 administrators in the dementia care sector 32 local authorities
IV	Intervention	Questionnaires/comments Semi-structured interviews	45 persons with dementia and 45 of their carers 13 carers Six hospitals 48 carers of persons with EOD Four hospitals

Overall study design

In this thesis all the studies are of persons with dementia and their carers from accessibility perspective, focusing on services in the Norwegian dementia care sector.

- Study I is a study using data based on interviews of people with EOD. The study aimed to find out how people with dementia perceive living with dementia with the hope of being able to suggest some improvement of treatment in further development of social services.

- Study II is a study of how the supporters perceive their work. It uses data based on interviews with supporters in the dementia care sector. The data came from supporters drawn from local authorities in both urban and rural areas of Norway.

- Study III is a study using data based on interviews with administrators in the dementia care sector. The study aimed to find out why some local authorities allocate supporters to persons with dementia and their primary family carers and others do not.

- Study IV is an intervention study and comprises data from the Nor-DIF multicentre study, the original intervention study, which asked carers to rate the intervention subjectively by means of a self-derived evaluation questionnaire and from interviews with carers from the Nor-DIF study and their comments from the open questions on the self-derived questionnaire. Based on these findings a new intervention was developed aimed at carers of persons with EOD. The data from this new intervention were collected by means of self-derived questionnaires developed after the evaluation of the original intervention of this study, for the evaluation of the new intervention. These evaluation questionnaires also included comments from the open questions on the questionnaires. The study aimed to evaluate the interventions further, if possible, and to improve interventions, comparing the later results with the former measurements.

Qualitative and quantitative research approaches

The various methods that have been used in this thesis are presented here. Research applying qualitative approaches used in science focusing on the association between disorders and health behaviour and the impact of social and environmental determinants on health may be described as explorative, descriptive or inductive (Bowling, 2004). The strength of qualitative studies lies in their ability to present a description of people's experiences in their daily lives and thereby enable an understanding of society and the social world in which they live (Karlberg, Hallberg & Sarvimäki, 2002; Bowling, 2004). Qualitative methods may also generate hypotheses (Karlberg, et al., 2002). In Study I, II and III qualitative interviews were used to develop a new understanding with the aim of learning more about experiences of different kinds with the hope that this knowledge will lead to further developments in health care. In order to search for a wider understanding, both quantitative and qualitative research methods were used in Study IV. According to Bowling (2002) public health science uses both qualitative and quantitative methods in order to create new knowledge and generate research questions and the kind of information that is sought should control the methods. All the methods also have their own problems and limitations, but sometimes using more than one method can be beneficial for the understanding of the research questions (Malterud, 2001; Bowling, 2004). Karlberg and others (2002) have considered it important to use a variety of methods within public health research. Quantitative methods are usually used to test hypotheses and to evaluate outcomes of interventions (Bowling, 2004).

Psychoeducative evaluation studies, as applied in this thesis in Study IV, aim to contribute to changing a situation; and also to the development of the quality of the interventions so as to improve treatment or services (Bowling, 2004). Several studies (Moniz-Cook et al., 2011) have shown that it has been difficult to measure the outcome and identify the effect or benefit of an intervention and of its different parts. Therefore, it may be important to evaluate the interventions using different approaches, as in Study IV in this thesis and also described by others (Ringsberg et al. 2001a; Bowling, 2004; Möller & Nyman, 2005; SBU, 2006; Borg, 2007; Gallagher-Thompson, 2007).

Participants

Study I: The 20 participants with EOD were recruited by health professionals from four different memory clinics in Southern Norway. They were recruited from three months to one year after the persons with dementia had received the diagnosis.

Study II: In Study II, administrators from the dementia care sector in 12 different local authorities' recruited participants. The 19 participating supporters were open and strategic selected. The data came from supporters drawn from local authorities in both urban and rural areas of Norway.

Study III: An open and strategic selection was used in Study III with the 35 participating administrators in the dementia care sector representing 32 different local authorities covering rural and urban areas in Norway. They were phoned and asked to participate by the author (AJ).

Study IV: Participants with different kinship to the person with dementia were included in Study IV. In Study IV the carers of a person with dementia participating in the original intervention in Study IV came from various regions of Norway other than the northern parts. They were recruited from nine of the last randomly composed groups included in the Nor-DIF study (Ulstein et al., 2007c). The participants in the interviews representing the original intervention of Study IV were strategic selected from three of the last groups at three different hospitals. In the new intervention or the last section of Study IV, the participating carers were recruited by health personnel from four memory clinics, covering four counties in various regions in Southern Norway.

Data collection

Study I, II and III: In these studies qualitative interviews were used, because very limited previous research existed within those three fields. A qualitative approach can describe the subjects' perceptions of life and work in their own words and was therefore applied in these three studies.

Study IV: The data in Study IV were collected using various methods: questionnaires with some open space for comments in the first and second part of the study and semi-structured interviews in the second part. The variety of methods was chosen in order to supplement and validate the findings in the different interventions of Study IV. Furthermore, from the participants in the original intervention of Study IV, details of age, kinship and duration of the dementia disorder were also collected.

Interviews and questionnaires

Unstructured or open interviews follow an interpretive approach, and allow the individuals to tell their own stories with their own words. The aim of this approach is to get an in-depth understanding of phenomena to allow analysis of peoples' understanding of their own social world or situation. The interview guide, therefore, comprises few specific questions. By using an open interview approach the questions are asked and formulated in an open-ended manner. Based on these specific questions, follow-up questions are formulated and asked in a conversational form. The quality of the data is, therefore, influenced by the relationship between the informant and the researcher. Most frequently the sample size in this type of study is such that the collection of data from the subjects can continue until no further themes, stories or information emerges (Bowling, 2004).

Structured interview forms can be filled in by an interviewer or be completed by the subject. Both methods present possible demands and problems. Detailed instructions are required to the interviewer. The questions must also be without ambiguity or uncertainty so that the answers can be given on the questionnaire. In the interview with structured questionnaires difficulties and questions may arise, because the interaction between the informant and the interviewer in the formulation of the questions can influence the answers. The understanding and the meaning of questions may also contribute to have an effect on the answers (Bowling, 2004).

Qualitative research interviews

Study I: An open interview was used in Study I, lasting about one hour and a half. An interview guide was used and concerned the subjective meaning of "What is it like to have dementia?"

Study II: This study was carried out in the same way as Study I, and the interviews lasted from half an hour to one hour. In this study the questions focused on the experience of being a dementia care supporter. A conversational approach encouraged participants to offer reflections on their experiences.

Study III: In Study III a guide was used that comprised thematic questions focusing on the administrators in the dementia care sector and their experience of what kind of service families with dementia need during the entire progress of the disorder. Questions were also put related to what the local authorities' duties are towards these families and how the local authority carries out these duties. These interviews were carried out in a conversation-based format by one of the authors (AJ), and lasted for about 45 - 55 minutes. (However, one interview lasted for only 10 minutes owing to the informant's lack of experience).

Depending on the answers and reflections, new ideas presented by the informants raised further questions and were asked in order to obtain additional information in Studies I, II and III. The interviewing in Studies I, II and III continued until no further themes, stories or information emerged (Glaser & Strauss, 1967; Bowling, 2004). In Studies II and III, the interviewer was neither known to the informants nor to any of the health personnel staff recruiting to these two studies. The interviewer was not known to the informants in Study I but did know some of the health personnel staff who had recruited the informants. The engaged and active involvement of the researchers and the informants in responding, clarifying the themes and sorting out possible misunderstandings is required during the interviews. It is also important to be aware that the relationship between the researcher and the informant during the interview process may have an influence on the data. The informants were given the opportunity to raise questions of relevance to the interviewer. During the process, data was created (Kvale & Brinkmann, 2010). The interviews were transcribed and analyzed within a few days after the interviews had been carried out in Studies I, II and III.

Study IV: In the second part of Study IV semi-structured interviews were used, asking thematic questions focusing on the informants' perception of significance of the original intervention. The themes focused on the overall significance of the intervention and the value of the education about dementia, the course compendium, the group discussions and the benefit of meeting other carers. Two themes focused also on whether they managed to cope better and had found better ways of meeting demands made upon them as a result of participating to the course. Further questions were also asked in order to obtain additional information. Nine of the interviews in Study IV were carried out by the author of this thesis (AJ), and a project assistant trained in interviewing carried out the remaining four, because the interviewer was, in these cases, one of the group-leaders of the original intervention groups in Study IV. Data collection in this part of Study IV was conducted 12 months after the starting point of the original intervention and transcribed within a few days after the interview had been carried out.

The self-derived questionnaires

Questionnaires were developed for the evaluation of the original interventions and the new intervention for carers of persons with EOD in Study IV. The questionnaires were conducted immediately after the interventions and 12 months after the start of the interventions. The participants were also asked to comment on the intervention programme in an open space for comments in both of the self-derived evaluation questionnaires on both evaluation occasions.

The questionnaire in the original intervention of Study IV consisted of questions covering themes to reveal how much they had valued the intervention. These questions could be answered; “no benefit”, “some benefit” and “great benefit”. Also questions were asked to reveal if the carers cope better and have found better ways of meeting demands made up on them as a result of participating to the course. The alternative answers were; “worse”, “no change”, “sometimes better” or “better”. The questionnaire was filled in anonymously by the carers.

In the new intervention of Study IV the evaluation questionnaire was developed based on the results gathered from the original evaluation of the intervention, to explore whether a recorded benefit would last or not. The questionnaire consisted of 10 questions measuring carers’ evaluation of the degree to which they benefitted from the intervention.

The questionnaires were answered by the carers and distributed and collected anonymously by the leaders of the intervention programme for carers of persons with EOD groups.

Data analysis

Qualitative analysis

Study I and II: These studies were based on interviews analysed by means of grounded theory (Corbin & Strauss, 2008).

Grounded theory

Grounded theory has been applied in Study I and II. The aim of the grounded theory method is to generate theoretical frameworks which explain the collected data. Classical grounded theory, as developed by Glaser and Strauss (1967) stresses that a theory emerges from empirical data during the analysis of the basic area. This grounded theory method strives to generate substantive theories valuable in clinical practice. Classical grounded theory developed by Glaser and Strauss (1967) has been viewed as abstract and theoretically diffuse, and so other researchers have developed and described ways of understanding grounded theory that go beyond classical grounded theory. During the process of developing and demystifying classical grounded theory, Strauss, together with Corbin has developed the "Reformulated grounded theory" (Corbin & Strauss, 2008). They have introduced new procedures to be used in analysing the data in terms of open, axial and selective coding, intending to make the emerging theory dense, complex and precise. The difference between these two directions in grounded theory has been illustrated by Dellve, Abrahamsson, Trulsson and Hallberg (2002) in the following questions asked by the researcher when analysing data: in classical grounded theory you analyse the data by looking for strategies humans use in a situation and asking "What do we have here?", and in the reformulated grounded theory by looking for social processes or causes of contexts by asking the data "What if?"

The grounded theory in this study is based on the reformulated grounded theory (Corbin & Strauss, 2008). The reformulated grounded theory method is found to be easier and more pragmatic than the classical version. The method based on reformulated grounded theory studies people's lives through processes and social interactions, making it appropriate as the chosen method (Corbin & Strauss, 2008). Therefore, it was suitable in Studies I and II as the approach can give new information about the experience of living with EOD, so as to assess the implications for practice and the development of further services for these people and to learn how the supporters perceive their work. This approach is likely to provide new information about how people with dementia perceive their lives.

A third grounded theory has also been developed by Charmaz (2000) and is called 'constructivist grounded theory'. Charmaz introduces subjective and objective aspects of theory, and analyses the data more freely. According to Charmaz (2000), the power of grounded theory methodology is that it gives tools for understanding subjects' meanings of the reality or the image of reality, rather than seeking the truth or the "real truth". According to Charmaz (2000), constructivist grounded theory allows for more flexibility than does the applications of static procedures and rigid perceptions.

The interviews in both Studies I and II were audio-recorded and transcribed verbatim. In the following steps the transcribed interviews were analysed in line with the reformulated grounded theory method (Corbin & Strauss, 2008). With the use of this method, the aim was to generate conceptual categories or models. The transcribed verbatim interview protocols were subjected to three types of coding processes: open, axial and selective coding (Corbin & Strauss, 2008) and the process consisted of hierarchical analysis. In the open process the data were examined sentence by sentence and coded; the codes with similar content were then grouped together into concepts at a higher, more abstract level. As the interviews progressed, the comparison techniques allowed categories to be constructed. A process of axial coding occurred at this point, whereby the identification of links and dimensions developed each category systematically. Upon further data collection, additional categories and subcategories were subsequently explored (Corbin & Strauss, 2008).

All the categories were saturated in both studies and core categories were identified. Constant comparison was made between different parts of the data, different subjects and different categories to ensure that all the categories were grounded and saturated, over the entire process. An important property of the conceptualization of data is that the latent patterns in the data are identified as categories and that these concepts are abstracts with respect to time, place and people (Glaser, 2002). As few categories as possible should be generated without losing too many variations in the data (Glaser, 1978).

The results are presented as categories describing the experiences in terms of processes related to everyday life for persons with early-onset dementia in Study I. In Study II the categories covered sets of dimensional experiences, expressed as opposite pairs of words showing dimensions representing a continuum where experiences can vary for persons working as supporters.

Study III and IV: The interviews in Study III were also based on interviews and were analysed by means of qualitative content analysis. In Study IV, the interviews and the data gathered from the open-ended questionnaire were analysed by means of qualitative content analysis.

Content analysis

Content analysis may be done whether a quantitative method or a qualitative method is employed. The quantitative method is often used in media research (Blakar, 2006). The qualitative method used in this thesis is often used within education, nursing and social work research. The method is used to reveal themes or patterns, and gestalt social phenomena in interviews, papers of different kinds and all sorts of observations (Graneheim & Lundman, 2004). Content analyses reveal or identify certain consistencies, themes or patterns after the text has been sifted. A theme is likely to take a categorical form and a pattern is more of a descriptive finding (Patton, 2002). Content analysis has also been described as a method to make data systematically more comparable (Berg, 2004). The analysis may include the understanding of the meaning in the latent content as well as the manifest content of the text. Both manifest and latent content analysis comprise understanding, but these may vary in terms of degree of abstraction and depth (Graneheim & Lundman, 2004). The method described by Graneheim and Lundman (2004) with manifest content analysis was used to perform the analysis and was carried out in the following steps in Studies III and IV:

- The texts were carefully read in a holistic manner, with openness to the material and its contents so as to gain an overall impression
- Words, phrases and sentences that conveyed the same meaning were grouped together and a central meaning (meaning units) for that group was identified
- Data were systematically condensed without changing the original meaning
- The meaning units were labelled with a code to represent their content
- The thematic statements or meaning units were then grouped together into categories. These categories consisted of groups of codes according to the themes of the comments provided in the questionnaires. During the process of analysis, the comments in Study IV collected immediately after the interventions and those made 12 months after the start of the interventions were separated

Statistical analysis

Only descriptive statistics (mean, range, frequency, median and percentage) were used in Study IV.

Validity

Validity is given high priority through the whole research process and that includes the correct collection of data and its systematic analysis. The research process requires attention and the findings should be grounded in empirical data with an exact description of the process (Kvale & Brinkmann, 2010). Specific guidelines for qualitative research have been laid down, but many argue that qualitative and quantitative research should be subject to the same validity criteria were the objects are able to ask questions about the asked questions (Kvale & Brinkman, 2010). Here, the focus is on the researcher’s ability to convince the reader with a clear impression of the attention to detail and trustworthiness of the process and the conclusions that are derived from it (Graneheim & Lundman, 2004; Kvale & Brinkmann, 2010). The importance of validity applies not only to the methods that are used in the research, but also to researchers themselves, their moral integrity and, particularly, practical prudence at the critical point for the evaluation of the information has been produced. Throughout all the collection of data and the analysis in this thesis, Kvale and Brinkmann’s (2010) guidelines have been followed in order to validate the findings and create trustworthiness.

- The process in the research interviews in I, II and III was open and flexible and aimed at getting spontaneous ‘answers’ to the phenomena studied. The open process therefore, enables statements to be clarified and described in order to ensure and clarify correct comprehension.
- The process in all the research studies was described carefully and the data analysis was performed as soon as possible. In Studies I-II and III, qualitative analysis was discussed and supervised continuously with senior researchers and also all the studies were discussed with colleagues, other health care professionals and senior researchers at seminars.
- Throughout the data collection and analysis, several measures were taken in order to validate the findings and establish trustworthiness in Study IV. The questionnaires in the original intervention in Study IV were constructed so as to evaluate the original intervention and the questionnaire in the new intervention was used after experience had been gained from the evaluation of the original intervention in Study IV. On both questionnaires there was space for the informants to comment freely. In Study IV, the semi-structured interviews and the comments as in the original intervention were also conducted to validate the quantitative data. A trained project assistant performed four of the interviews, after receiving instructions in Study IV, because one of the authors was the leader of one of the intervention groups in which the informants participated. This was done to ensure valid and uniform data collection.
- Extracts are presented in the text relating to all four studies so as to facilitate the reader’s consideration of the validity of the findings.

Pre-understanding in the research process

Kvale and Brinkmann (2010) argue that the validity of a study may depend on the credibility, knowledge and understanding of the researcher's character, moral integrity and execution. The researcher's background and pre-understanding are likely to be revealed by the 'meanings' extracted from the textual data. Therefore, the analysis has to be a careful balance between the text, expressions and the researcher's consciousness of the fact that the understanding of the text can be influenced by his or her own perspective, knowledge or attitudes in the form of a preconception of the content (Graneheim & Lundman, 2004, Kvale & Brinkmann, 2010). The interview process may also be seen as the location for the production of knowledge and understanding. It is a process featuring the exchange of meanings between people and a conversation around themes in the interest of both parties; in fact, an "inter-view" (Kvale & Brinkmann, 2010).

The two faces in Figure 7 depict the interviewer and the informant and the imagined interaction between them. Furthermore, the interaction between the two faces can form the "information", or the weaving shape, and in this picture it has created or can be seen as a vase. Looking at interviews as a method has been done since the time of Socrates (Kvale & Brinkmann, 2010). Another consideration in the preconceptions is background of the researcher (Kvale & Brinkmann, 2010). As an example of this, caring can have different values related to gender and to society. All observations are filtered and selected through the researcher's eyes and what is seen and reported as "findings" depends on how the researcher sees the world (Malterud, 2001). Critical self-reflection is, therefore, necessary in order to avoid bias. My background as a registered psychiatric nurse and dementia educator along with my professional experiences from working with elderly people, dementia patients, psychiatric patients and professionals of different kinds has played a part in forming my preconceptions. Furthermore, my entire private experiences throughout life as a woman, a mother and a participant in a family will have had an influence on my preconceptions and will have formed my way of understanding others, as described in the picture below by Kvale and Brinkmann (2010).

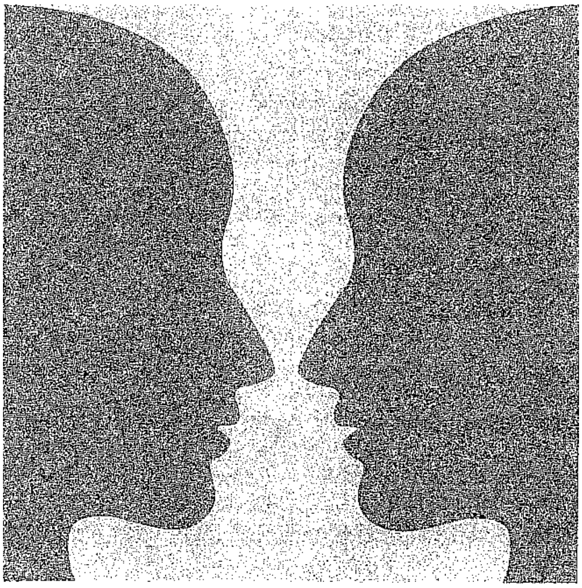


Figure 7. Research interview seen as an Inter-view (Kvale & Brinkmann, 2010).

Ethical considerations

First of all research is important and also necessary for the development of the society, and society and people clearly have the right to demand research on important topics. Furthermore, people also have their right to protection of their integrity and privacy. The statements of ethical principles listed in the Declaration of Helsinki (WMA, 2010) and the interview guidelines from Kvale and Brinkman (2010) are intended to protect people. The principles listed in the statement that include medical research involving human beings state that the most important research considerations are related to the well-being of human beings and should be emphasized and take precedence over the interests of research. These principles are highlighted to protect life, health, the privacy and the dignity of the individuals being studied and are the scientists’ responsibility. The value of the study must, therefore, always be considered and weighed against any harm to the participants.

In order to follow these principles the participating persons with dementia, supporters and administrators in the dementia care sector and carers were all informed in both written and oral form about each study by professional health personnel as well as by the author (AJ), before they were interviewed or the carers were asked to fill in questionnaires. It was stressed in all the studies that participation was voluntary and this was especially emphasized in Study I, because of the participants’ cognitive impairment. Furthermore, health personnel at the various hospitals considered the capacity of the persons with dementia before they were asked to participate.

In Study I and in the original intervention of Study IV the participants’ also gave written consent before they participated in these studies. The participating supporters and administrators in the dementia care sector in Studies II and III and carers of persons with EOD in the new intervention of Study IV gave oral consent to take part.

All the informants were unknown to the author (AJ) except for four informants in the second part of Study IV and some of the carers of persons with EOD. The data from these participants were, therefore, collected by others anonymously.

During the period of time working on this thesis I found that nearly all the participants wanted to participate and they said that they felt it was important to participate if it could help others in the future, and no one withdrew after they had begun to participate. It also should be said that the kind of questions raised in these studies may initiate a process in the minds of the participants, so that it is important to focus on their dignity and well-being during the interview process, and to make sure that they feel good after they have undergone the interview and questionnaire processes (Kvale & Brinkmann, 2010). The ethical concerns relating to the practice of speaking for vulnerable individuals are emphasized by Gillis and Alldred (2002). During my work on this thesis, I have tried to balance my wish to draw attention to the opinions expressed by persons with dementia, carers, supporters and administrators, and my wish to respect the confidentiality of the informants. Therefore, I described the findings in an anonymous way, and a special attention was given to the extracts from persons with dementia, because these participants’ could perhaps more easily be recognized. Furthermore, I took special care to respect the confidentiality of the participants in Studies II and III, so that their opinions could not be recognized. In Study IV I focused on making the extracts unrecognisable when they were evaluating the intervention. Their evaluation of the intervention had no influence on further support or treatment.

Study I, II and III were approved by the Regional Committee for Ethics in Medical Research, Southern Norway. Study IV was already approved by the Committee, because the participants were included from another study.

FINDINGS

Study I

Study I: Persons with early-onset dementia – experiences of dementia in everyday life: a qualitative study.

The informants' stories about their experiences are described through two main categories; the process *towards a dementia diagnosis* and *fighting for dignity* after being diagnosed with dementia.

Towards a dementia diagnosis: This core category describes the experiences of persons with dementia in the process towards a dementia diagnosis and covers their various experiences of life in this situation. The core category is composed of two subcategories, the first describing the *changes* people with EOD experienced after developing the disorder, from the beginning of perceived symptoms and during the process. These changes were described as memory loss, failing to cope with work tasks or being unable to face new tasks. The second subcategory describes their struggle with *being diagnosed*, and how it felt to be given the diagnosis and their feelings in relation to the process of receiving a dementia diagnosis. For some of them the initial diagnosis was not clear cut: they had received other diagnoses.

Fighting for dignity: In this core category the informants describes their efforts to maintain their quality of life after having been diagnosed, knowing that there would be no going back after receiving the diagnosis. The core category covers two subcategories. The subcategory *intrapsychic challenges* describes the difficulties the informants experienced as they developed dementia at a relatively young age, and also their experiences of suffering from a stigmatizing disorder that affected their self-image. Many of the symptoms made them feel stupid, and they said it was difficult to socialize with others. In the subcategory *social* *challenges* the informants talk about the taboo they perceive as surrounding the dementia disorder. They also expressed how they considered the disorder affected other family members.

Study II

Study II: Motivating and discouraging factors with being a support contact in the dementia care sector: a grounded theory study.

The main findings in this study relate to the supporters' motives for becoming a supporter, and their experiences of encouraging and discouraging factors in the process of remaining a supporter in the dementia sector. The interviews revealed four sets of two-dimensional experiences of being a supporter, which may be expressed in pairs of contrasting words: *flexibility vs. rigidity; being compensated vs. feeling used; affiliation vs. abandonment;* and *satisfaction vs. lack of satisfaction.* The participants' two dimensions of motivating factors for becoming a supporter were described as: to provide others with help, while at the same time doing it for personal fulfilment.

Flexibility vs. rigidity concerns the freedom to choose what to do as a supporter, and there were stories about choosing different kinds of activities and the opportunity to select the time and place for being together, but there were also reports of being captured in monotonous activities with little chance of variation.

Being compensated vs. feeling used relates to the participants' feelings about having a salary, and being reimbursed for costs arising from their activities. All the participants stated that the salary was not an important factor in deciding to be a supporter, but they were concerned about the procedure of getting reimbursed for costs arising from their activities.

Affiliation vs. abandonment refers to the supporters' need to belong to the wider staff of the dementia team health professionals and to be informed about the treatment with which these families were being provided. Many described a feeling of abandonment and exclusion from the wider team of professionals. This lack of affiliation and feedback from the local authority on their work reduced their motivation to continue being a supporter.

Satisfaction vs. lack of satisfaction focuses on the personal feelings and experiences of being a supporter. For many of them, becoming a supporter had been something they had undertaken on their own initiative and that in itself constituted a motivating factor. Participants' feelings of uncertainty when the persons with dementia had problems following their guidance in certain activities could discourage them from working as a supporter. Any positive feedback from these families gave them a feeling of being appreciated and was a motivating factor.

Study III

Study III: Accessibility of support contacts for families with dementia: a qualitative study.

This study describes the variations of the process that lead or do not lead to the use of supporters as a service offered to families with dementia by the local authorities. These variations are shown throughout three main categories: *skills, accessibility* and *management* and moreover throughout the subcategories within each main category.

Skills, describes the range of the administrators' experiences, knowledge of dementia and of the legislation concerned with offering families with dementia a support contact, and is described through two subcategories. In the subcategory *formal knowledge,* the informants described a varying degree of formal knowledge about dementia and health care legislations. The informants' formal knowledge influenced the services provided to these families. In the subcategory *experiential knowledge,* all the informants who had experience of using supporters described the service as a valuable one for the care of people with dementia. They stated that these positive experiences made them wish they could develop the supporter service further.

Accessibility, in this main category, the informants described the circumstances that lead to the supporter service being made available to families with dementia. This process is described through variations in the two subcategories. In the subcategory *supplying information,* the informants described how information is provided through various channels about supporters and other available services. Some informants said that they do not provide information about the supporter service, because the local authority focuses on offering day care centre placement. In the subcategory *characteristics of the families,* the informants describe a range of characteristics, some of which were: age, no suitable day care centre available or the carers' need of relief.

Management of services, this main category describes the informants' different ways of managing recruitment and organizing the supporter service. They are described further in the two subcategories that lead to allocation of the service. In the subcategory *recruitment*, many informants cited difficulties when trying to recruit supporters, but the informants who had experience of using supporters stated that it is not so difficult to recruit supporters. In the subcategory *organization*, many informants said that the supporter service was managed by different departments within the local authorities. In their opinion, this way of organizing the supporter service leads to lack of cooperation, and this was one of the reasons why the service was not offered regularly.

Study IV

Study IV: The value of integrating carers' view when evaluating and developing interventions for families of people with dementia: a qualitative and quantitative study.

Evaluation of the original intervention via questionnaires

The responses on the evaluation-questionnaires showed that all the carers experienced benefits from the intervention and found the knowledge they had obtained useful. Participation had helped them in dealing with the demands associated with dementia in a better way, a benefit that was sustained. They found it useful to meet other carers and to participate in the group discussions and this effect also remained up to the final measurement.

Evaluation of the original intervention via interviews

The interviews and the comments on the evaluation questionnaires revealed two main categories in the data, and seven subcategories have been summarized and further described. All the interviewed participants said they had benefited from the intervention and the comments on the evaluation-questionnaire and the interviews revealed information containing suggestions for improvement of the PSI.

In the main category, *Need of support and knowledge,* the carers describe their need in order to be able to cope with the challenges of daily life. These needs may be subdivided into three subcategories. In the subcategory *the disease,* broadly, the carers indicated a need for knowledge about dementia in general, which included topics such as the expected progress and treatment of the disorder. In the subcategory *how to cope with the person with dementia* the carers described a need for knowledge about how to communicate with a person with dementia. Throughout the subcategory *what it is like to be a carer* they expressed a need of more formal help from society. How to solve practical tasks and their feelings about these tasks was something all the carers had in mind.

In the main category, *how the intervention contributed to providing the carers' with support and knowledge,* the carers reported how the intervention had given them useful knowledge, which was further subdivided into three subcategories. In the subcategory *the education,* the carers said they had learnt from the educational part of the intervention as well as from the written information they had received. In addition, they had found the group-discussions useful. According to some carers, under the heading of *the group composition* it was useful when the group consisted of spouses as well as adult children. Others wanted the groups to be more homogeneous in relation to the age of the person with dementia. In the subcategory *the group structure,* the carers stated that learning was a process and emphasised the importance of the clear structure of the group meetings.

The new intervention

The new intervention was based on the findings from the evaluation of the original intervention via evaluation questionnaires and interviews. This intervention was directed to carers of persons with EOD. On the questionnaires regarding the carers' perception of this new intervention, and their degree of benefit from participating in the programme, almost all reported a high level of benefit, a benefit that was sustained after six months for almost all. The comments from the evaluation questionnaire resulted in valuable suggestions for further interventions.

DISCUSSION

The findings show that the accessibility to the dementia care services as perceived by persons with dementia, carers, supporters and administrators in the local authorities can vary and depends on knowledge about the available services, legislations and the dementia disorder. This is not in line with the Norwegian Ministry of Health and Care Services (HOD, 2005-2006; 2011) recommendations and intentions for dementia care in Norway. Neither is it in line with the intentions of the Discrimination and Accessibility Act (BLD, 2009) or the new interaction reform under Norwegian Health Care (HOD 2008-2009) that entered into force in January (2012). The findings are also not in line with the principles of Universal Design (Story et al., 2001). The term "Universal Design" is often used when talking about accessibility for all, but the terms "planning for all" and "design for all" are also used. Universal Design means designing products and environments in a way that enables them to be used by all people, to the greatest extent possible, without the need for adaptations or special designs (Story et al., 2001). The concept of a Universal Design first originated in the United States in the 1980s among designers and product developers. The term was first introduced in an article in 1985 by the architect Ron Mace in Designers West (Story et al., 2001). The connection between society's intentions and the actual services that are provided is described in various documents. Bernler, Möller and Karp (1991) have described one such model, the "top-down" vs. "bottom-up" model. In the top-down perspective the structure of the care services is decided from above. The values in society are demonstrated in the laws and regulations, which in their turn lay down what recommendations, rules and finance shall be given in order to handle the everyday support and care. These intentions do not necessarily meet the basic needs of individuals. The bottom-up perspective means looking at the relationship between the individual and the society's health and social care systems the other way round. Starting with the basic needs of individuals, different ways of meeting these needs, which may be instrumental, relational or existential, are elaborated both informally and formally. In cases where the informal system is not enough, the formal system is activated and developed (Möller, 1998). By using this model we learned, while working on this thesis, several ways of developing and improving services, from the opinions of persons with dementia, from carers, supporters and from administrators. We learned about services that can contribute to empowering these families to promote their own health by maintaining the participation in society of persons with dementia and their carers, which we hope will lead to a better daily life for them.

First of all, by using this “bottom up” model as a focus in this thesis we learned how people with dementia perceive living with dementia and believe that their opinions should be included as an integral part of the treatment plan provided for them, and that their opinions should also be compared with the information provided by other family members. This is something other researchers can confirm (Beattie, Daker-White, Gilliard & Means, 2002; Willis, Chan, Murray, Matthews & Banerjee, 2009; Baalen van et al., 2010; Nowell, Thornton & Simpson, 2011; Pipon-Young, Lee, Jones & Guss, 2012).

Furthermore, we learned that the services offered to help people with dementia in general should focus on those which help to keep persons with dementia connected to others and to society. As a consequence of having dementia, which includes cognitive impairment, these people often lose touch with society as also Brorsson et al., (2012) found in their study. This is important because being part of society and receiving affirmation from others through social interaction in an “I and you” relationship gives meaning to life and is a description of human life itself, as Buber (1923) explained. There is also a lack of studies focusing on the importance of friendship and social contacts among persons with dementia (Medeiros de, Saunders & Sabat, 2011). Blackman and others (2003) have shown in their study that accessibility to public space and the environment is limited for people with dementia. Services should, therefore, be set up to support them in maintaining contact with other people, to activities and in gaining access to public space as also Brorsson and others found in their study (2012). According to Pipon-Young and others (2012), people with dementia need to be provided with information about those in a similar situation to foster a sense of hope and resilience. They also found that people with dementia need a variety of social support and would appreciate the development of a shared social identity focusing on their strength as they have (Pipon-Young et al., 2012). Furthermore, Caddell and Clare (2011) concluded in their review study that it is difficult to draw any conclusions about what interventions aiming at supporting integrity and identity should contain for people with dementia. They highly recommend, therefore, that further investigations should be done (Caddell & Clare, 2011).

From a public health perspective it is also important to provide varied and differentiated support to these families so as to maintain activities, to prevent social isolation and to promote health (Holley, 2007; Brodaty & Donkin, 2009; Hassan & Arentz, 2009; Moni-Cook & Manthorp, 2009). According to the findings in this thesis, both carers and the persons with dementia themselves should be offered interventions along with others in the same situation with a focus on providing them with knowledge and also helping them to find useful coping strategies. These findings are also supported by other studies which used different methods (Lavoie et al., 2005; Moniz-Cook et al., 2011; Pipon-Young et al., 2012) and also the statements from one carer (Brown & Roach, 2010).

Furthermore, in this thesis we have learned from the findings that carers have valuable insights about developing intervention that can contribute to improving their daily lives and their chances of participating in society. In this thesis we used the carers' subjective experiences or the "bottom up" (Möller, 1998) model to evaluate and suggest further development of the interventions. This approach is referred to also as 'recovery research', looking at recovery as a coping process and how professionals can support the individuals in these processes (Borg, 2007). The "bottom up" approach can also be seen in the light of SOC as Antonovsky (1991) pointed out: "Man has free will but her/his ability to cope, understand and feel a sense of the outside world depends on their life experiences", and in this context these carers experiences can be valuable when developing and evaluating interventions to improve the lives of others. Also a study by Lavoie et al. (2005) confirms that this type of approach is important. Lavoie et al. (2005) stated that there are too few studies with this type of approach, which limits progress in the development of effective interventions. The task in the future is to work for improvements, and with further collaboration, to study the effects of these, applying qualitative approaches and using carers' subjective experiences to contribute towards developing interventions further. The intention is to contribute to making society more accessible for families containing a person with dementia in line with recommendations in other studies (Beattie et al., 2002; Möller & Nyman, 2005; Borg, 2007). These tasks focusing on empowerment have also been set out in a manifesto from the European network INTERDEM in order to consolidate the results of research in past decades. The manifesto stated that researchers should continue to focus on empowerment, theory and methods that have been learned and also achieve effects by testing with quantitative approaches (Moniz-Cook et al., 2011).

Different dimensions of accessibility to the environment are presented; 1) accessibility to the physical environment, 2) to information, and 3) to social activities and services. The most common way of discussing issues focusing on Universal Design, or accessibility, is to look at it from the dimension of the physical environment and demands. The other two dimensions are often omitted (Iwarsson & Ståhl, 2003), but in a Norwegian Act of Parliament these dimensions are mentioned (BLD, 2009). Also according to the recommendations of the Norwegian Directorate for Health and Social Affairs (HOD, 2005-2006; 2011) and the Government's Dementia Plan (HOD, 2008), a strategy has been developed in order to make society more inclusive for people with dementia. This can be done through activities, adopted by the local authority, either in the patients' homes, in nursing homes or at day care centres. Another way of supporting persons with dementia and their carers is by the use of supporters, though they are rarely used in dementia care (Westerberg, 2009; Eek & Kirkevold, 2011). There are very few high-quality studies on the benefits of this service for persons with dementia (Lee & Cameron, 2006). Such studies as do ask whether supporters do provide a beneficial service have mainly focused on carers (Lee & Cameron, 2006; Charlesworth et al., 2008). These studies do not find this service effective for carers compared to other services with professional health personnel, but the researchers point out in both studies that there is a need for more research in the field before any conclusions can be drawn. However, our findings from the experiences of administrators in the local authorities and the supporters who themselves had worked with the service in dementia care suggest that the service was positive and of great value for these families, though not in the later stages of the dementia disorder. This was because their experience of the work entailed at that later stage was too ambiguous for a supporter with no formal qualifications about dementia to perform, and for that reason the service could not properly be provided for the later stages of dementia. However, that this might be a valuable service has also been stated by Bjørge (2004) and Jansson, Almberg, Grafstroe & Winblad (1998).

From the supporters we have also learned how to encourage people to become and sustain being a supporter and this adds knowledge to a field where very little is known (Johannessen, 2009). This service is one that could be developed further in order to catch up with the huge demand for support in the future caused by an ever-increasing number of families with a person with dementia, including the families with a person with EOD (Alzheimer's Disease

International, 2009; Harris & Keady, 2009). Moreover, this thesis contributes additional facts about how administrators in the local authorities can contribute to supporting the supporters in their struggle to find a balance between being a professional and at the same time being a friend. This point is also found in Gough and Modig (1996). We have also learned from this thesis that supporters experience their work as meaningful, gratifying and important for the people with dementia and their carers, also giving them a positive feeling when helping others. The positive feeling one gets when helping others has been confirmed by Dulin and Dominy (2008).

The findings from this thesis might be transferrable to other people who also occupy the middle ground between being a professional and being a friend in the role of befrienders, respite carers or voluntary workers, in Norway as well as other Western countries. The supporters expressed more or less the same needs for education as carers of persons with dementia do, as recorded by Moniz-Cook and Manthorpe (2009) and Brodaty and Donkin (2009). Supporters might, therefore, be educated together with carers, as has been suggested by Jansson et al. (1998) and Hotvedt (2011).

Throughout this thesis drawing on four studies we have learned that the administrators in the local authorities must have formal knowledge about dementia and legislation within the health care system as laid down in the new Health Reform Act (HOD, 2008-2009). Complex and multiple needs for differentiated care services in dementia care often have to be addressed, which means that cooperation is essential (Hassan & Arnetz, 2009; Engedal & Haugen, 2009; Brodaty & Donkin, 2009) and the health reforms initiated in 2012 (HOD, 2008-2009) will contribute by stimulating better collaboration between and within local authorities and between local authorities and hospitals.

There is a need for more knowledge among general practitioners about the disorder including the possibility that dementia may occur before the age of 65, in order to reduce the difficulties these families experience in the process towards a dementia diagnosis. These families also need information and support along the way to diagnosis and also afterwards. In spite of the stigma linked to the dementia disorder, as described by some persons with dementia, they do want to know what is wrong and according to a survey by Alzheimer Europe (2011) most people want to see a doctor when they experience memory loss. The survey also confirms that a clear majority in all the included countries, such as the United States, Germany, Poland, Spain and France, favoured greater public investment in the care of people with Alzheimer’s disease, and wanted current spending on the research and care of people with dementia to be increased.

Methodological aspects and future research

The strength of this thesis is that we have used a “bottom up” perspective (Möller, 1998) throughout the planning, implementation and analysis of the findings. Qualitative methods were chosen for this reason. Qualitative methods enable the researchers to focus on the informant’s point of view and the present studies show that the informants’ own descriptions and stories are worth taking into consideration when trying to understand, in Study I, what it is to be a person living with a dementia disorder, and, in Study II, what it is like to be a support contact for a person with dementia, and, in Study III, why the supporter service is not offered more in all local authorities and to more families with dementia, and, in Study IV, how to evaluate and develop interventions for carers of persons with dementia with their subjective experiences of interventions. The process of evaluation of the interventions in Study IV gave us valuable knowledge about developing this service, as had been requested by Lavoie et al. (2005) and in the INTERDEM manifesto (Moniz-Cook et al., 2011). Also, the use of different approaches in the study, such as the open-ended questionnaires with space for comments and the interviews, was valuable (Lunde & Ramhøj, 2001; Bowling, 2004). Using several methods as performed in Study IV may increase the value of social research in a context like that described by Lunde and Ramhøj (2001). Two sources which reveal the same results can confirm, compliment and cross-validate each other. The study design we used in the process of evaluation (Patton, 1990) can be seen as a strength of the study and made it possible to acquire new knowledge and thus to develop the intervention further.

The subjective view of or “the bottom up” perspective on what it is like to be a person with EOD, as well as to be elderly with dementia, at the time this study was performed, had until then been only sparsely explored in the dementia care sciences (Steeman et al., 2006; Harris & Keady, 2012) and, therefore, grounded theory was suitable for generating emerging categories and exploring important aspects. The method was indeed useful in giving glimpses into what it is like to be a person with dementia, living with the disorder in everyday life (Study I) and what it is like to be a supporter caring for those with dementia (Study II).

In Study III content analysis was used to analyse the data and the choice of method was motivated by the variation of the use of supporters in dementia care in different local authorities. The intention was to find out what reasons administrators from different local authorities gave for their opinion on using supporters or not. It was not our ambition to develop a theory. To do that, we should have had to interview considerably more persons in each local authority. The views of each individual administrator were focused, and do not necessarily reflect the views of each local authority and its leaders.

The main limitation of this thesis is what we have not done: we have neither included persons' with dementia and their primary carers nor asked for their opinions of the supporter service or their suggestions for improvement of this service and of other services. Moreover, saturation as used in Study I, II and III, is a critical point in qualitative research and it is closely connected to the sampling process. It is important to obtain heterogeneous informants in order to look for variations in experience, i.e. open sampling and a strategic sampling process (Bowling, 2004). This means that generating categories directly when collecting data leads to discovering what kinds of further questions to ask and this method also allows some comments to be made. A grounded theory study is dependent on wide descriptions (Glaser, 1978) and, as a researcher I am dependent on informative and verbal participants. In the three first studies saturation was reached, but saturation relies on a subjective understanding, meaning that saturation is reached when new data suits the categories already devised (Charmaz, 2000). However, we can never be absolutely sure about what could happen if we were to include more participants. Maybe the very next one could have contributed some new information.

In Study I the informants were persons with a dementia disorder consisting of various cognitive impairments, brain damage and at different stages of the disorder, which meant that they were sometimes less communicative than desired. It is also well known (Engedal & Haugen, 2009) that people with a dementia disorder may have difficulty in expressing themselves or having insight into their entire life situation. To compensate for that, great efforts were made during the interviews to follow the thoughts of the interviewees and to perform the interviews at their pace.

There might also be a risk that the recruitment of very positive and well-functioning informants in Study II by the administrators in the local authorities has affected the findings. But again, in the interview situations it was possible to grasp both positive and negative aspects and to deepen and concretize the discussions.

Also in Study IV content analysis was used on the qualitative data. Evaluations of interventions using carers' subjective experiences expressed in their own words after having worked with an intervention are rare (Lavoie et al., 2005). Dellve et al. (2002) have described how qualitative methods are helpful in adding knowledge of phenomena in areas where little is known.

One methodological limitation in Study IV was the lack of pre-testing before the intervention. Another limitation was the formulations of the self-derived evaluation questionnaires used after both of the interventions, and particularly in the new intervention. In this new intervention in Study IV we wanted to see how we could improve and develop the original intervention further. We focused particularly, therefore, on developing the type of questions used on the self-derived questionnaires after the original intervention. Moreover, this development of the evaluation questionnaire was based on our results from the original intervention, where the carers' would hardly have scored 'no value' or 'no benefit' for the interventions. For that reason we dropped 'no value' from the scale of 1-5, so that 1 indicated "little benefit" and 5 "great benefit". The INTERDEM manifesto also confirms that this type of intervention is beneficial for carers (Moniz-Cook et al., 2011). Historically, intervention groups have shown inconclusive results with carers in this field and we need to think again about how research has been carried out in past decades, as Hornillos & Crespo (2012) point out in their review study. Interviews or focus group discussions could be one such idea in order to get a wider and deeper understanding of how to improve the new intervention in Study IV.

The interviewer and the informant in an interview situation do interact and each brings with them pre-understandings from their own lives. It is possible that gender influences pre-understanding and the interaction process. Therefore, it might be that the informants would have identified or expressed themselves in another way if the interviewers had had the same gender as the informants in all the four studies in this thesis.

Future research

The designs in the four presented studies are explorative. Knowledge about experiences of living with dementia is meagre. Only a few studies have been performed internationally and hardly any about a Norwegian population. To find out about the experiences of the persons in focus in the present dissertation seemed to be a good start when trying to learn more about how to improve those persons' lives. No study has been presented about experiences of being a supporter. One basic assumption in the present work is that supporters can help improve the lives of persons with dementia. From that perspective it is interesting to find out about experiences of those who have worked as supporters. The third study concerns opinions about supporters held by administrators. Since these administrators are central in deciding about allowing supporters or not, their opinions and knowledge are of great importance. In the fourth study finally, there was a lack of agreement between clinical experiences and results from the research that had been performed. This kind of lack of agreement is not an unusual one and it might be that different kinds of questions need to be put in order to reach a fuller, both scientific and clinical, understanding (Möller & Nyman, 2003). Based on the findings from the present studies some ideas about further research can be sketched. In future studies hypotheses can be formulated and tested.

I. From Study I it is clear that persons with dementia themselves have important information to share. Further elucidation of the experiences of the lives of persons with dementia is needed. In such a study persons with dementia of different aetiologies should be separated. The experiences of persons with frontal lobe damage will probably differ from those with Alzheimer's disease and vascular dementia. The experiences of elderly persons will probably differ from those of people with EOD. It might also be interesting to compare persons with dementia who live alone with those having a partner, and perhaps also to include a gender perspective.

II. An analysis of aspects of different kinds of support to persons meriting special help is needed. In the present study supporters of persons with dementia are in focus. There are other groups in society that receive support, such as persons with mobility, psychiatric or intellectual disabilities, immigrants, persons released from correctional institutions and so on. What do these supporters have in common? A literature review of studies of experiences of being a supporter in the above-mentioned fields would be interesting. Another aspect from Study II that should be further developed is that of support for the supporters. The supporters say they would gain from supervision and further education. Some of them also said that they wanted to be more integrated with the ordinary staff than at present. A programme to handle these wishes from the supporters needs to be developed and researched. Both supporters and administrators should participate in such a development.

III. In Study III 35 administrators from 32 local authorities were interviewed. One interesting question is whether these interviews will encourage them to use supporters more in future. Talking about supporters as an alternative and learning something new about legislation and the experiences of other local authorities may have increased their willingness to use this kind of service. This could be studied with quite a simple questionnaire. Also, there could be a study of how closely the 32 studies of local authorities in Norway represented all the 429 that exist in Norway and, additionally, to see how the new legislation encourages them to use supporters in the dementia service.

IV. Evaluations of interventions are always difficult to perform. So many factors contribute to what is happening. The RCT studies that are often presented as the best way of evaluating interventions are frequently impossible to perform and they also quite often miss some aspects of the effects of an intervention. One conclusion from Study IV is that subjective experiences expressed in “own words” must be included in evaluations if we want to learn more about different kinds of effects and if we want information that can help us to improve the method of intervention. It may be some benefit to be gained by using a combination of several methods rather than just one method. However, related to Study IV there is much room for improvement. If questionnaires are to be used, they need to be much more strictly formulated. Qualitative analyses should be performed on a richer material and quantitative and qualitative methods should be more closely synchronized.

Moreover, during work on this thesis research questions in addition to those mentioned above have been raised. In particular, there is a need for further research on how to find different ways of making services more accessible and, through this, to make society more inclusive for people with dementia and their primary family carers. There is also a need for more research:

- To find out whether persons with dementia and their carers value the supporter service and also to find out what proposals they have for the development of the service.

- On the potential for developing the supporter service and other services further in order to stimulate and protect the increasing number of persons with dementia and to help carers with respite. Also to investigate the use of the supporter service in dementia care from a cost–benefit perspective.

- To find out more about what kind of support families with EOD and their children need.

CONCLUSION: CLINICAL IMPLICATIONS

The focus in this thesis has been on how to contribute to improving the daily lives of persons with dementia and those of their carers, and how to increase their chances of participating in society. Moreover, this thesis shows us that these families' opinions and those of their supporters and other health personnel should not be overlooked in the facilitation and development of services. Throughout the analysis clinical implications for practice have been revealed by the data, as follows:

- Group activities need to be organized for persons with dementia together with other people and likeminded persons, to stimulate them and also protect them from social isolation. This is important throughout the entire duration of the disorder.

- The person with dementia and their formal carers should be included in planning how services should be performed and delivered throughout the entire duration of the disorder.

- Persons with dementia and their family carers should be provided in the early stage of the disorder with interventions that include information about the disease, the legislation, communication techniques and what it is like to live with dementia and to be a carer.

- The supporter services have the potential to be used more frequently than they are, and both the supporters and the administrators in the dementia care sector should be included in planning how the service can be developed and evaluated.

- Supporters can be a beneficial service in dementia care, but local authorities need to provide supporters with supervision and training in order to be able to recruit more supporters and retain them in the dementia sector.

- Administrators in the local authorities, general practitioners and other health professionals working in dementia care must have sufficient knowledge about dementia and the relevant health care legislation.

- Better collaboration and organizational structures are needed between the different departments in local authorities and hospitals to provide these families with sufficiently individualized services to stimulate and protect people with dementia and to give respite to their formal carers.

ACKNOWLEDGEMENT

REFERENCES

Allen, J., Oyebode, J. R., & Allen, J. (2009). Having a father with young onset dementia: The impact on well-being of young people. *Dementia, 8* (4), 455-480.

Alzheimer's Disease International. (2009). World Alzheimer Report, Retrieved from www.alz.co.uk

Alzheimer Europe. (2011). Retrieved from Alzheimer Europe http://www.alzheimer-europe.org/Research/Value-of-knowing

American Psychiatric Association. (1994). Diagnostic and Statistical Manual of Mental Disorders (4th ed.), (DSM-IV). Washington DC: APA.

Andersen, A. (2004). *Digitala klyftor – förr, nu och i framtiden* [In Swedish]. Rapport Ju 2002: Stockholm: Justisdepartementet, Arbetsgruppen för IT och demokrati.

Andrews, T. (2003). "Nytt" ideologisk grunnlag for å forebygge helsearbeid [In Norwegian]. *Tidsskrift for velferdsforskning, 6* (1), 30-42.

Antonovsky, A. (1987). *Unravelling the mystery of health: how people manage stress and stay well*. San Francisco: Jossey-Bass.

Antonovsky, A. (1991). *Hälsans mysterium* [In Swedish]. Stockholm: Natur och kultur.

Baalen van, A., Vingerhoets, Ad., J. J. M., Sixma, H. J., & Lange de, J. (2010). How to evaluate quality of care from perspective of people with dementia: An overview of the literature. *Dementia, 10* (1), 112-137.

Baker, K. L., Robertson, N., & Connelly, D. (2010). Men caring for wives or partners with dementia: Masculinity, strain and gain. *Aging & Mental Health, 14* (3), 319-327.

Bakker, C., Vugt de, M., Vernooij-Dassen, M., Vliet van, D., Verhey, F. R. J., & Koopmans, R. T. C. M. (2010). Needs in Early Onset Dementia: A Qualitative Case from the Need YD Study. *American Journal of Alzheimer's Disease and Other Dementias, 25,* 634.

Ballard, C., & Corbett, A. (2010). Management of Neuropsychiatric Symptoms in People with Dementia. *CNS Drugs, 24* (9), 729-739.

Beaglehole, R., & Bonita, R. (1999). *Public health at the crossroads, Achievements and prospects.* Cambridge: Cambridge University Press.

Beattie, A. M., Daker-White, G., Gilliard, J., & Means, R. (2002). Younger people in dementia care: a review of service needs, service provision and models of good practice. *Aging & Mental Health, 6,* 205-212.

Beattie, A. M., Daker-White, G., Gilliard, J., & Means, R. (2004). How can they tell? A qualitative study of the view of younger people about their dementia and dementia services. *Health and Social Care in the Community, 12* (4), 359-368.

Berg, B. L. (2004). *Qualitative research methods for the social science.* Boston: Pearson Education International.

Bering, E. (2006). *Mangler over 500 plasser til demente* [In Norwegian]. Tønsberg: Tønsbergs Blad, 16 Januar.

Bernler, G., Möller, A., & Karp, H. (1991). *Om social omsorg och omsorgsforskning* [In Swedish]. Göteborg: Göteborgs universitet.

Bjørge, T. (2004). *Friminutt for pårørende* [In Norwegian]. Tønsberg: Forlaget Aldring og helse.

Blackman, T., Mitchell, L., Burton, E., Jenks, M., Parsons, M., Raman, S., & Williams, K. (2003). The Accessibility of public Spaces for People with Dementia: a new priority for the "open city". *Disability & Society, 18*, 357-371.

Blakar, R. M. (2006). *Språk er makt* [In Norwegian]. Oslo: Rev. utg., Pax.

BLD, (2009). *Lov om forbud mot diskriminering på grunn av nedsatt funksjonsevne diskriminerings- og tilgjengelighetslove* [In Norwegian]. Barne- likestillings- og Inkluderingsdepartementet. Retrieved from http://www.lovdata.no/all/hl-20080620-042.html

Borg, M. (2007). *The nature of recovery as lived in everyday life: Perspectives of individuals recovering from severe mental health problems.* (Doctoral thesis). Trondheim: University of Science and Technology.

Brodaty, H., Green, A., & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal American Geriatric Society, 51,* 657-64.

Brodaty, H., & Donkin, M. (2009). Family carers of people with dementia. *Dialogues in Clinical Neuroscience, 11,* 217-228.

Brorsson, A., Öhman, A., Lundberg, S., & Nygård, L. (2012). Accessibility in public space as perceived by people with Alzheimer's disease. *Dementia, 10* (4), 587-602.

Brown, A., & Roach, P. (2011). My husband has young-onset dementia: A daughter, wife and mothers story. *Dementia, 9* (4), 451-453.

Bowling, A. (2004). *Research methods in health* (2nd ed.), New York: Open University Press.

Buber, M. (1923). *Ich und Du* [In German]. Leipzig: Insel-Verlag.

Caddell, L. S., & Clare, L. (2011). Interventions supporting self and identity in people with dementia: A systematic review. *Aging & Mental Health, 15* (7), 797-810.

Charlesworth, G., Shepstone, I., Wilson, E., Reynolds, S., Mugford, M., Price, D., Harvey, I., & Poland, F. (2008). Befriending carers of people with dementia: randomised controlled trial. *British Medical Journal, 7* (336), 1295-1297.

Charmaz, K. (2000). Grounded Theory, Objectivist and constructivist methods. In Denzin, N. K., & Lincoln, Y. S. (Eds.), *Handbook of qualitative research* (2nd eds., pp. 509-535). California: Thousand Oaks, Sage.

Corbin, J., & Strauss, A. (2008). *Basics of Qualitative research* (3nd.), Los Angeles: Sage Publications Ltd.

Dellve, L. K., Abrahamsson, H., Trulsson, U., & Hallberg, L. R-M. (2002). Grounded theory in public health research. In Hallberg, L. R-M. (ed.), *Qualitative research methods in public health research* (pp. 137-174). Lund: Studentlitteratur.

Dementia care in the Nordic Countries. (2005). [In Norwegian]. Retrieved from http://www.nordiskdemens.org

Dröes, R-M., Meiland, F., Lange, J., Vernooij-Dassen, M., & Tilburg van, W. (2009). The meeting centres support programme. In Moniz-Cook, E., & Manthorpe, J. (Eds.), *Early Psychosocial Interventions in Dementia* (pp. 201-210). London: Jessica Kingsley Publishers.

Dulin, P. L., & Dominy, J. B. (2008). The influence of feeling positive about helping among dementia caregivers in New Zealand. *Dementia, 7* (1), 55-69.

Eek, A., & Nygård, A. M. (2006). *Lysning i sikte?* [In Norwegian]. Tønsberg: Forlaget Aldring og Helse.

Eek, A., & Kirkevold, Ø. (2011). *Nasjonal kartlegging av tilbudet til personer med demens 2010-2011* [In Norwegian]. Tønsberg: Forlaget Aldring og helse.

Engedal, K., & Haugen, P. K. (2009). *Demens fakta og utfordringer: En lærebok* [In Norwegian]. (5th eds.), Tønsberg: Forlaget Aldring og Helse.

Ericsson, I., & Kjellström, S. (2011). Creating relationships with persons with moderate to sever dementia. *Dementia, 10* (4), 523-538..

Ferri, C. P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M.,…Scazufica, M.(2005). Global prevalence of dementia: a Delphi consensus study. *Lancet, 17*, 366, 9503, 2112-7.

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). Mini-mental state. A practical method for grading the cognitive state of patients for the clinicians. *Journal of Psychiatry Research, 12,* 189-98.

Gallagher-Thompson, D. (2007). Exciting advances in family caregiver research. *Aging & Mental Health, 11* (6), 613-615.

Gillis, V., & Alldred, P. (2002). The ethics of intension: Research as a political tool. In Mauthner, M., Birch, M., Jessop, J., & Miller, T. (Eds.), *Ethics in qualitative research* (pp. 123-145). London: Sage Publications.

Glaser, B., & Strauss, A. (1967). *The discovery of Grounded Theory*. Chicago: Aldin, IL.

Glaser, B. (1978). *Theoretical Sensitivity*. Mill Valley: Sociology Press.

Glaser, B. (2002). Grounded theory and gender relevance. *Health Care Woman International, 23,* 786-93.

Gough, R., & Modig, M. (1996). *Leva med personlig assistans: vårdtagare blir arbetsledare* [In Swedish]. Stockholm: Centrum för utvärdering av socialt arbete.

Graneheim, U., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24,* 105-112.

Green, A., & Brodaty, H. (2002). Caregiver interventions. In Qizilbash, N., Schneider, L. S., Chui, H., Tariot, P., Brodaty, H., Kaye, J., & Erkinjuntti, T. (Eds.), *Evidence-based Dementia Practice* (pp. 764-794). Oxford: Blackwell Science Ltd.

Haaning, M. G. (2002). Familieomsorgsgivning ved demens [In Danish]. *Gerontologi og samfund, 18* (1), 6-9.

Haglund, B. J. A., & Pettersson, B. (1998). Att lära av erfarenheter. Systematisk beskrivning och kritisk granskning, 20 frågor om hälsoprojekt [In Swedish]. *Socialmedicinsk tidskrift, 3,* 106-111.

Harris, P. B., & Keady, J. (2009). Selfhood in younger onset dementia: transitions and testimonies. *Aging & Mental Health*, *13*, 437-444.

Harris, P. B., & Keady, J. (2011). The Journal's 10 year Anniversary – Looking back and moving forward. *Dementia, 10* (3), 3-6.

Harvey, R. J., Skelton-Robinson, M., & Rossor, M. N. (2003).The prevalence and causes of dementia in people under the age of 65 years. *Journal of Neurology Neurosurgery & Psychiatry*, *74*, 1206-1209.

Hassan, H., & Arnetz, J. E. (2009). A comparative study of nursing staff, care recipients' and their relatives' perception of quality of older people care. *International Journal of Older People Nursing, 5,* 5-15.

HOD, (2002-2003). *Nedbygging av funksjonshemmende barrierer* [In Norwegian]. Helse og omsorgsdepartementet. Report NO: 40. Retrieved from http://www.regjeringen.no /Rpub/STM/20022003/040/PDFS/STM200220030040000DDDPDFS.pdf

HOD, (2004). *Forskrift om individuell plan etter helselovgivningen og Sosialhelsetjenesteloven* [In Norwegian]. Helse og omsorgsdepartementet. Retrieved from http://www.lovdata.no/cgi-wift/ldles?doc=/sf/sf/sf-20041223-1837

HOD, (2005-2006). *Mestring, mulighet og mening, framtidas omsorgsutfordringer* [In Norwegian]. Helse og omsorgsdepartementet, Report NO: 25. Retrieved from http://www.regjeringen.no/nb/dep/hod/dok/regpubl/stmeld/20052006/stmeld-nr-25-2005-2006-.html?id=200879

HOD, (2006). *Loven om sosiale tjenester §4-2.* [In Norwegian]. Helse og omsorgsdepartementet. Retrieved from http://www.lovdata.no/all/tl-19911213-081-004.html

HOD, (2008). *Demens plan 2015* [In Norwegian]. Helse og omsorgsdepartementet. Retrieved from http://www.regjeringen.no/upload/HOD/Dokumenter%20KTA/Dementia Plan2015.pdf

HOD, (2008-2009). *Samhandlingsreformen: Rett behandling – på rett sted – til rett tid* [In Norwegian]. Helse og omsorgsdepartementet. St. meld. 47. Retrieved from http://www.regjeringen.no/pages/2206374/PDFS/STM200820090047000DDDPDFS.pdf

HOD, (2009). *The act of patient's right 2004.* The Norwegian Ministry of Health and Care Services. Retrieved from http://www.regjeringen.no/nb/dep/hod/tema/ pasientinformasjon/the-act-of-2-july-1999- no-63-relating-to.html?id=229533

HOD, (2011). *Demensplan 2015, Revidert handlingsprogram 2012-2015* [In Norwegian]. Helse og omsorgsdepartementet. Retrived from http://www.regjeringen.no/ uploud/HOD/Vedlegg/Omsorgsplan_2015/Demensplan2015.Pdf

HOD, (2011). *Lov om kommunale helse- og omsorgstjenester* [In Norwegian]. Helse og omsorgsdepartementet. Retrived from http://www.lovdata.no/all/tl-20110624-030-001.html

HOD, (2012). *Lov om folkehelsearbeid* [In Norwegian]. Helse og omsorgsdepartementet. Retrived from http://www.lovdata.no/ltavd1/filer/nl-20110624-029.html

Holley, U. A. (2007). Social isolation: a practical guide for nurses assisting clients with chronic illness. *Rehabilitation Nursing, 32*, 51-6.

Hornillos, C., & Crespo, M. (2012). Support groups for caregivers of Alzheimer patients: A historical review. *Dementia, 11* (2), 155-169.

Hotvedt, K. (2011). *Tilbud til pårørende- pårørendeskoler og samtalegrupper* [In Norwegian]. Tønsberg: Forlaget Aldring og helse.

Hunderi, R. I. A., & Hunderi, O. (2009). *The road into the Land of Mist*. Tønsberg: Forlaget Aldring og Helse.

International Statistical Classification of Diseases and Health Related problems. ICD-10. (2004). Second Edition. 10th Revision. Geneva: WHO.

Iwarsson, S., & Ståhl, A. (2003). Accessibility, usability and universal design - positioning and definition of concepts describing person - enviroment relationships. *Disability and rehabilitation, 25* (2), 57-67.

Jansson, W., Almberg, B., Grafstroe, M., & Winblad, B. (1998). The Circle Model-Support for relatives of people with dementia. *International Journal of Geriatric Psychiatry, 13*, 674-681.

James, I., Powell, I., & Reichelt, K. (2001). Cognitive therapy for carers: Distinguishing fact from fiction. *Journal of Dementia Care, 9*, 24-26.

Johannessen, A. (2009). *Volunteers in the dementia care.* Retrieved from http://www.alzheimer-europe.org/Conferences/Previous-conferences/2009-Brussels/Abstracts-and-presentations/Oral-poster-presentations/(language)/eng-GB

Johnstone, M. J. (2011). Metaphors, stigma and the 'Alzheimerization' of the euthanasia debate. *Dementia, 10* (2), 149-163.

Kabel, S. (2001). *Mennesket bag demensen, Et personligt portræt af otte tidligt diagnosticerede demente* [In Danish]. Aalborg: Formidlingscenter Nord.

Karazek, R., & Theorell, T. (1990). *Healthy work - stress, productivity, and the reconstruction of working life.* New York: Basic Books, Inc.

Karlberg, I., Hallberg, L. R-M., & Sarvimäki, A. (2002). Introduction and aims of the book – Public Health and Research on Public Health. In Hallberg, L. R-M. (Ed.), *Qualitative Methods in Public Health Research* (pp. 13-34). Lund: Studentlitteratur.

Krüger, R. (2003). Alene i meg selv [In Norwegian]. *DEMENS, 4*, 2-4.

Kvale, S., & Brinkmann, S. (2010). *Det kvalitative forskningsintervju* [In Norwegian]. (2 utg.), Oslo: Gyldendal Norsk Forlag AS.

Lavoie, J. P., Ducharme, F., Lèvesque, L., Hèbert, R., Vèzina, J., Gendron, C.,…Voyer, L. (2005). Understanding the outcomes of a psycho-educational group intervention for caregivers of persons with dementia living at home: A process evaluation. *Aging & Mental Health, 9* (1), 25-34.

Lazarus, R. S. (1975). Coping theory and research: past, present, and future. *Psychosomatic Medicine, 55*, 234-247.

Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal, and Coping.* New York: Springer.

Lazarus, R.S. (1993). From psychological stress to the emotions: a history of changing outlooks. *Annual Review of psychology*, *44*, 1-21.

Lee, H., & Cameron, M. (2006). Respite care for people with dementia and their carers. *The Cohchrane Library*, Issue 1.

Lunde, I. M., & Ramhøj, P. (2001). *Humanistisk forskning indenfor sundhedsvidenskab og kvalitative metoder* [In Danish]. København: Akademisk Forlag.

Luscombe, G., Brodaty, H., & Freeth, S. (1998). Younger people with dementia: diagnostic issues, effects on carers and use of services. *International Journal of Geriatric Psychiatry*, *13*, 323-330.

Malterud, K. (2001). Qualitative research: standards, challenges and guidelines. *The Lancet, 358*, 483-88.

Marriott, A., Donaldson, C., Tarrier, N., & Burns, A. (2000). Effectiveness of cognitive-behavioural family intervention in reducing the burden of care in carers of patients with Alzheimer's disease. *British Journal of Psychiatry, 176*, 557-562.

Medeiros de, K., Saunders, P. A., & Sabat, S. R. (2011). Friendship and social environments of people with dementia: Introduction to the Special Issue. *Dementia, 10* (3), 341-359.

Medin, J., & Alexanderson, K. (2000). *Begreppen hälsa och hälsofrämjande: en litteraturstudie* [In Swedish]. Lund: Studentlitteratur.

Mittelman, M. S., Ferris, S. H., Schulman, E., Steinberg, G., & Levin, B. (1996). A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. *American Medical Association, 276*, 1725-1731.

Moniz-Cook, E., & Manthorpe, J. (2009). Personalising psychological interventions to individual needs and context. In Moniz-Cook, E., & Manthorpe, J. (Eds.), *Dementia Evidence-Based Practice* (pp. 11-39). London: Jessica Kingsley Publishers.

Moniz-Cook, E. Vernooij-Dassen, M. Woods, B. Orrel, M., & Interdem Network. (2011). Psychosocial interventions in dementia care research. The INTERDEM manifesto. *Aging & Mental Health, 15* (3), 283-290.

Möller, A. (1998). Hjälprelationer i omsorg och vård [In Swedish]. Lund: Studentlitteratur.

Möller, A., & Nyman, E. (2005). Why, what and how? – Questions for psychological research in medicine. *Disability and Rehabilitation, 27,* 649-654.

Mæland, J. G. (1999). *Forebyggende helsearbeid i teori og praksis* [In Norwegian]. Oslo: Tano Aschehoug.

National Public Health, (2000). *Å leve med demens: en håndbok for pårørende* [In Norwegian]. Oslo: Nasjonalforeningen for folkehelse.

NMR, (2005). *Design for alle - et nordisk handlingsprogram* [In Norwegian]. Rapport, Forhåndsversjon, 20-21. august. Oslo: Nordisk Ministerråd.

NOU, (2005). *Likeverd og tilgjengelighet, Rettslig vern mot diskriminering på grunnlag av nedsatt funksjonsevne, Bedret tilgjengelighet for alle* [In Norwegian]. Oslo: Norges offentlige utredninger, Statens forvaltningstjeneste Informasjonsforvaltning, NO, 8.

Nowell, Z. C., Thornton, A., & Simpson, J. (2011). The subjective experiences of personhood in dementia care settings. *Dementia,* doi: 10.1177/1471301211430648.

Parker, D., Mills, S., & Abbey, R. N. (2008). Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review. *International Evidence Based Health, 6*, 137-172.

Patton, M. Q. (1990). *Qualitative evaluation and research methods*. California: Newbury Park, Sage Publications.

Pipon-Young F. E., Lee, K. M., Jones, F., & Guss, R. (2012). I'm not all gone, I can still speak: The experiences of younger people with dementia. An action research study. *Dementia, 11* (1), 75-94.

Riedijk, S. R., Vugt de, M. E., Duivenvoorden, H. J., Niermeijer, M. F., Van Swieten, J. C., Verhey, F. R., & Tibben, A. (2006). Caregiver burden, health-related quality of life and coping in dementia caregivers: A comparison of frontotemporal dementia and Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders, 22,* 405-412.

Ringsberg, K. C., Alexandersson, K. A. E., Borg, K. E., & Hensing, G. K. E. (2001a). The Health line- a method for collecting data on self-rated health over time: a pilot study. *Scandinavian Journal of Public Health, 29,* 233-239.

Ringsberg, K. C., & Timpka, T. (2001b). Clinical health education for patients with asthma-like symptoms but negative asthma tests. *Allergy, 56*, 1049-1054.

Roach, P., Keady, J., Bee, P., & Hope, K. (2008). Subjective experiences of younger people with dementia and their families: implications for UK research, policy and practice. *Clinical Gerontology, 18*, 165-174.

Rootman, I., Goodstadt, M., Hyndman, B., McQueen, D., Potvin, L., Springnett, J., & Ziglio, E. (2001). *Evaluation in Health Promotion. Principles and Perspectives.* Copenhagen: WHO Regional Publications Europeans series, no 92.

Rymer, S., Salloway, S., Norton, L., Malloy, P., Correia, S., & Monast, D. (2002). Impaired awareness, behavior disturbance, and caregiver burden in Alzheimer disease. *Alzheimer Disease and Associated Disorders, 16,* 248-253.

SBU, (2006). *Dementia diseases – a systematic review. SBU's summary and conclusions*. Retrived from http://www.sbu.se/sv/Publicerat/Gul/Demenssjukdomar

Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist, 35*, 771-791.

Schulz, R., Martire L. M., Julie, N., & Klinger, M. (2005). Evidence-Based Caregiver Interventions in Geriatric Psychiatry. *Psychiatric Clinics of North America, 28,* 1007-1038.

Seitz, D. P., Adunuri, N., Gill, S. S., Gruneir, A., Herrmann, N., & Rochon, P. (2011). Antidepressant for agitation and psychosis in dementia, Review. *The Cochrane library,* Issue 2.

Selbaek, G., Kirkevold, Ø., & Engedal, K. (2007). The prevalence of psychiatric symptoms and behavioural disturbances and the use of psychotropic drugs in Norwegian nursing homes. *International Journal of Geriatric Psychiatry, 22,* 843-849.

Seyle, H. (1978). *Stress under press* [In Norwegian]. Oslo: Hjemmets Fagpresseforlag.

Shim, B., Barroso, J., & Davis, L. L. (2011). A comparative qualitative analysis of stories of spousal caregivers of people with dementia: Negative, ambivalent, and positive experiences. *International Journal of Nursing Studies, 49* (2), 220-229.

Skovdal, K., Palo-Bengtsson, L., Anttila, S., Hojgard, U., Fredriksson, M., Jonsson, A. K., & Glad, J. (2007). *Yngre personer med demenssjukdom och närstående till dessa personer: en kunnskapssammansettning* [In Swedish]. Stockholm: Institutet for utveckling av metoder i socialt arbete, Socialstyrelsen, No, 112-1.

Steeman, E., Dierckx de Casterlè, B., Godderis, J., & Grypdonck, M. (2006). Living with early-stage dementia: a review of qualitative studies. *Journal of Advanced Nursing, 54* (6), 722-738.

Story, M., Mueller, J., & Mace, R. (2001). *The Universal Design File, Designed for People of all Ages and Abilities.* Raleigh, USA: North Carolina State University.

Svanberg, E., Stott, J., & Spector, A. (2010). 'Just helping': Children living with a parent with young onset dementia. *Aging & Mental Health, 14,* 740-751.

Svensson, C., Ekvall, M., & Storfält, R. (2007). *Kontaktperson – en avlönad vän i behov av stöd?* [In Swedish]. Retrived from: http://gupea.ub.gu.se/dspace/handle/2077/8531

Takai, M., Takahashi, M., Iwamitsu, Y., Ando, N., Okazaki, S., Nakajima, K., & Oishi, S., Miyaoka, H. (2009). The experience of burnout among home caregivers of patients with dementia: Relation to depression and quality of care. *Archives of Gerontology and Geriatrics, 49* (1), e1-5.

The National Board of Health and Welfare, (2010). *Nationella riktlinjer för vård och omsorg vid demenssjukdom.* [In Swedish]. Stockholm: Socialstyrelsen, www.socialstyrelsen.se

Tones, K., & Tilford, S. (2001). *Health promotion effectiveness, efficiency and equity,* (3nd eds.), Cheltenham: Nelson Thorns Ltd.

Ulstein, I., Bruun Wyller, T., & Engedal, K. (2007a). The relative stress scale: a useful instrument to identify various aspects of carer burden in dementia? *International Journal of Geriatric Psychiatry, 22*, 61-67.

Ulstein, I. D. (2007b). *Dementia in the family.* (Doctoral thesis). Oslo: Faculty of Medicine.

Ulstein, I. D., Sandvik, L., Wyller, T.B., & Engedal, K. (2007c). A one-year randomized controlled psychosocial intervention study among family carers of dementia patients - effects on patients and carers. *Dementia and Geriatric Cognitive Disorders, 24*, 469-475.

Vogel, A., Waldorf, F. B., & Waldemar, G. (2010). Impaired Awareness of Deficits and Neuropsychiatric Symptoms in Early Alzheimer's Disease: The Danish Alzheimer Study (DAISY). *The Journal of Neuropsychiatry and Clinical Neurosciences, 22*, 93-99.

Vugt de, M. E., Riedijk, S. R., Aalten, P., Tibben, A., Swieten, J. C., & Verhey, F. R. (2006). Impact of behavioral problems on spousal caregivers: a comparison between Alzheimer's disease and frontotemporal dementia. *Dementia Geriatric Cognitive Disorders, 22,* 35-41.

Westerberg, T. H. (2009). *Gode tilbud i demensomsorgen - demensteam, dagsenter og Pårørendeskoler* [In Norwegian]. Tønsberg: Aldring og helse.

Westergård, B. E. (1999). *Støttekontakt-arbeid* [In Norwegian]. Oslo: Gyldendal.

Westius, A., Andersson, L., & Kallenberg, K. (2009). View of life in persons with dementia. *Dementia, 8,* 481-499.

WHO, (1986). *The Ottawa Charter for Health Promotion.* Copenhagen: World Health Organization. Retrieved from http://www.who.int/hpr/NPH/docs/ottawa_charter_hp.pdf

WHO, (1998). *Health 21 – the introduction to the health for all policy for the European region.* Copenhagen: World Health Organization, Europe.

WHO, (1999). *United Nation's standard rules on the Equalization of Opportunities for Persons with Disabilities*. World Health Organization. Retrieved from http://www.who.int/disabilities/policies/standard_rules/en/index.html

WHO, (2004). *The Global Burden of Disease.* World Health Organization. Retrieved from http://www. who.int/healthinfo/global_burden_disease/2004_report_update/en/ index.html

WHO, (2006). *Constitution of the world health organization.* World Health Organization. Retrieved from http://www.who.int/governance/eb/who_constitution_en.pdf

WHO, (2012). *Dementia: a public health priority.* World Health Organization and Alzheimer's Disease International. World Health Organization. Retrieved from http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html

Wilkinson, H. (2001). Empowerment and decision-making for people with dementia: The use of legal interventions in Scotland. *Aging & Mental Health, 5,* 322-328.

Willis, R., Chan, J., Murray, J., Matthews, D., & Banerjee, S. (2009). People with dementia and their family carers' satisfaction with memory services: A qualitative evaluation generating quality indicators for dementia care. *Journal of Mental Health, 18,* 26-37.

WMA, (2000). *The Declaration of Helsinki.* Helsinki: World Medical Association. Retrieved from http://www.wma.net/en/30publications/10policies/b3/

Wogn-Henriksen, K. (1997). Siden blir det vel verre-? [In Norwegian]. Sem: INFO-banken.

Zarit, S., & Femia, E. (2008). Behaviour and psychological interventions for family caregivers. *American Journal of Nursing, 108,* 47-53.

APPENDICES

Paper I-IV

NHV-Reports