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**CARERS TO PEOPLE WITH  
LEWY BODY DEMENTIA AND  
ALZHEIMER'S DISEASE**

**EXPERIENCES AND COPING  
STRATEGIES**

Ellen J. Svendsboe



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# **Carers to people with Lewy Body dementia and Alzheimer's Disease**

## **Experiences and coping strategies**

THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

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## **DEDICATION**

I would like to thank all the carer's to people with dementia, living around the world, for doing an important job! This is a study describing parts of your situation that aims to give better conditions for each of you.

This study is dedicated to my mother Mally Johanna Svendsbø, the greatest carer of them all!



## ABSTRACT

The overall aim of this thesis was to investigate and describe the experience of carers to people with different types of dementia, in particular Alzheimer's disease (AD) and dementia with Lewy bodies (DLB), and how they cope with their situation. The project comprises four studies. Study I is a systematic review of peer-reviewed articles retrieved from MEDLINE, PSYCINFO and EMBASE through OVID, using PRISMA guidelines, to explore the association between neuropsychiatric symptoms (NPS) in people with dementia and carer stress. Study II and III are cross-sectional (Study II) and longitudinal (Study III) studies, with data from carers to persons with mild dementia recruited from out-patient clinics in the Western part of Norway who were followed annually for up to three years (2005-2013). The aim was to study the differences and the level of carer reported distress in mild dementia, especially in dementia with Lewy bodies (DLB) and Alzheimer's disease (AD). The analysis of study II was performed by using regression analysis, first unadjusted, then adjusted, and presenting descriptive data. Study III used a mixed model regression analysis, in addition to present descriptive data. Study IV comprised focus group interviews with adult carers, spouses, children and grandchildren to persons with DLB and AD. The data from this study were analysed using systematic text condensation. Main findings from study I were that the most important NPS associated with carer burden were irritability, sleep disturbance, and anxiety. Further, from study II, the carers to people with AD and DLB experienced moderate to high level of burden in an early stage of dementia. NPS, motor symptoms and activities of daily living scores were significantly associated with higher carer burden, based on scores on the Relative Stress Scale. Main findings from study III were that distress in carers of persons with mild dementia increases over time. This increase was noted in carers of persons with AD, whereas distress in carers to people with DLB was high at baseline, but remained relatively stable over time. One possible explanation for the lack of increase in carer stress to people with DLB, was that many DLB patients were admitted to nursing home during the first year, which likely reduced the burden of carers. In study IV, the experiences of carers to people with DLB and AD were divided into two categories, different diagnoses-different experiences of symptoms, and coping strategies. Symptoms like sleep disturbance, fluctuations, hallucinations, appetite changes, swallowing problems and change in day-to-day functioning were challenges in DLB and deficit in short-term memory and delusions for carers to people with AD. The second category, coping strategies were divided into emotional- and problem focused strategies. Individual strategies both varied and were common for the carers of the two groups of dementia. Common strategies were getting knowledge, using humour and always hope, and including the need for time to themselves. In summary, the four studies provide new information about the

association between specific symptoms in dementia and carer stress, disease-specific carer challenges over time, and specific experiences and coping mechanisms used by the carers. The differences inherent in the caring role for people caring for persons with DLB and AD requires tailored and targeted support and knowledge, both for the person with dementia, but also for the carers.



## LIST OF SCIENTIFIC PAPERS

- I. Terum, T. M., Andersen, J. R., Rongve, A., Aarsland, D., Svendsboe, E. J., & Testad, I. (2017) The relationship of specific items on the Neuropsychiatric Inventory to caregiver burden in dementia: a systematic review. *International Journal of Geriatric Psychiatry*. 2017; 32(7):703-717.
- II. Svendsboe, E., Terum, T., Testad, I., Aarsland, D., Ulstein, I., Corbett, A. and Rongve, A. (2016) Caregiver burden in family carers of people with dementia with Lewy bodies and Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 31(9), 1075-1083.
- III. Svendsboe, E. J., Testad, I., Terum, T., Assmus, J., Corbett, A., Aarsland, D., Rongve, A. (2018) Patterns of carer distress over time in mild dementia. *International Journal of Geriatric Psychiatry*. 2018; 33(7):987-993.
- IV. Svendsboe, E. J., Stenwall, E., Corbett, A., Rongve, A., & Testad, I. Perceived symptoms and coping strategies in carers to people with Lewy Body dementia and Alzheimer's Disease. (In writing).



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## LIST OF ABBREVIATIONS

AD	Alzheimer's Disease
ADL	Activities of Daily Living
AIC	Akaike Information Criterion
BPSD	Behavioural and psychological symptoms of dementia
CDR SB	Clinical Dementia Rating Scale, Sum of Boxes
CIRS	Cumulative Illness Rating Scale
CT	Computed Tomography (scan)
DAT	Dopamine transporter
DLB	Dementia with Lewy Bodies
DSM-4	Diagnostic and Statistical Manual for Mental Disorders, 4 <sup>th</sup> edition
FTD	Frontotemporal Dementia
ICD-10	Tenth Revision of the International Classification of Diseases
NDR	The Norwegian Dementia Register (NorCog)
(N)LME	(Nonlinear and) Linear Mixed Effects model
NPI	Neuropsychiatric Inventory
NPS	Neuropsychiatric symptom
MADRS	Montgomery and Aasberg Depression Rating Scale
MMSE	Mini-Mental State Examination
MRI	Magnetic Resonance Imaging
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RBD	REM-sleep Behaviour Disorder
REK	Regional Etisk Komite (Regional committee of ethics, Norway)
REM	Rapid Eye Movement
RDRS-2	Rapid Disability Rating Scale-2
SPSS 21	Statistical Package for social sciences (version 21)
STC	Systematic Text Condensation
UPDRS	The Unified Parkinson's Disease Rating Scale
VaD	Vascular Dementia
WHO	World Health Organisation
ZBI	Zarit Burden Inventory



# 1 INTRODUCTION

It is estimated that there are about 47 million people living with dementia worldwide (2015), and this number is expected to increase to 66 million by the year 2030. The most common cause is Alzheimer's Disease (AD), followed by vascular dementia and Dementia with Lewy Bodies (DLB) (Aarsland et al., 2008; Barker et al., 2002; Livingston et al., 2017; Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016; Wimo et al., 2017). The global cost of dementia is estimated to US \$ 818 billion (Prince et al., 2015) with nearly 85% related to family and social expenses, rather than medical care. The prevalence of dementia in Norway is estimated to be 78.000, which is 1.5% of the total population, and according to the Norwegian Directorate of Health there are approximately 350 000 cares to people with dementia in Norway (Health & Services, 2016). The cost of dementia in Norway is estimated to be €3.02 billion a year (Engedal & Haugen, 2004; Prince et al., 2015; Vossius et al., 2015). Being a carer to a person with DLB or AD is in many ways a challenging situation. The last decades have revealed a clearer picture of how it is being a carer to a person with dementia, regarding experiences, what kind of knowledge they need, what kind of resource the carers can act as, and to some extent, how the professional health care could provide the carer with useful help. Even though most of these diseases are not yet curable, the course might be modifiable with good care, and available interventions and coping abilities may improve the trajectory of symptoms (Livingston et al., 2017).

Mr. Karl Deter, known as husband of Auguste Deter (1850-1906), was the first known carer of a person with dementia, described in the modern part of the history. He worked as a railway clerk, in Frankfurt, Germany, where he married (in 1880) and lived together with Mrs. Auguste Deter. They gave birth to one daughter, and Mrs Deter was only 51 years old when she was admitted to a mental institution in Frankfurt, Germany (1901). Her husband told that he had recently noticed a gradual functional decline in his wife. In the last 8 months she had been developing progressive changes in her personality. She had symptoms of dementia with rapidly worsening memory and pronounced psychosocial impairment. He told that she had become jealous and that she sometimes felt that someone wanted to kill her, and thereby she began to shout wildly. She was examined by the now famous Alois Alzheimer (1864-1915), and he found her to be both disorientated to time and place and confused. About 5 years later, April 8<sup>th</sup>, 1906, she died from a septicaemia resulting from a decubitus ulcer. She had over time generally worsened, and her speech was described as completely unintelligible together with apathy, and she spent her last time in bed with her legs pulled up. Alois Alzheimer never forgot this patient, and even if he did not work at this institution at the time of Auguste Deter's death, he asked for her records and brain to be

sent to him post mortem. He then found the histological features, extracellular amyloid plaques and intraneuronal neurofibrillary tangles in addition to the loss of brain tissue, that are today associated with Alzheimer's disease (Cipriani, Dolciotti, Picchi, & Bonuccelli, 2011; Toodayan, 2016). Alzheimer's disease as a term, was first introduced by Emil Kraepelin, in a chapter of his Handbook of Psychiatry, called Senile and Presenile Dementias (7<sup>th</sup> chapter, 2<sup>nd</sup> volume), after the death of Alzheimer, and is known today as the most common neurodegenerative disease (Cipriani et al., 2011; Ferri et al., 2005).

During the last 20-30 years of studying experiences of the carers to people with dementia as well as the person directly affected by the disease, researchers have found that carers report strain, stress, mental and health problems, family conflicts and burden due to their duties as a carer for a person living with dementia (Armstrong, Gitlin, Parisi, Roth, & Gross, 2018; Ornstein et al., 2013; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Working as a Registered Nurse (RN) in psychiatry, nursing homes, and in home care, often gave me a chance to reflect over the situation of the carers. Many seemed severely exhausted, and performed tasks 24 hours a day, without any possibility to get help, other than help aiming directly at the person with dementia. They often cried, when I talked to them, and they were obviously affected both mentally and physically, by their burden of being a carer. I often found poorly cooperation and communication between the professionals and the carer. There was a clear gap between the need of the carers and the support provided by the health professionals. The communication platform was often missing, and the carers reaction and care were seldom a part of the work tasks of the nurses, more than a given momentary understanding and random support. These experiences and the inadequacy feeling, led me, in turn, to reflect on carers involvement and their needs being a carer, and how I, as a professional nurse, can meet them, and help them cope with their situation.



## **2 BACKGROUND**

A brief outline of the Norwegian health care system will be provided in order to obtain an understanding of conditions for carers in Norway. Thereafter, the two key disorders for this thesis, DLB and AD, will be introduced, with core symptoms and disease development. Next, the term carer and how it is used in this study will be explained and defined. The term “burden” is used frequently in previous research and will be defined regarding conception and understanding. The background section will end with a review of previous research on carers to persons living with DLB and AD.

### **2.1 HEALTH CARE IN NORWAY**

The group of carers of people with dementia is a fast growing population worldwide, with specific needs to their own health. Norway has a population of 5.3 million inhabitants and the percentage over age 65 is 15.2% and life expectancy is 81.4 years (Thomson, Osborn, Squires, & Jun, 2012) according to Statistics Norway (Norway, 2015). Healthcare is governed and financed nationally, and social security is financed through national and municipal taxes and covers public retirement funds, and sick leave payment. More and more long-term care is provided within the home (Holm, Mathisen, Sæterstrand, & Brinchmann, 2017); and a political goal is to have “the ability to live in one’s own home and community safely, independently, and comfortably, regardless of age, income, or ability level”. (Organization, 2001). In Norway, the new European policy framework, Health 2020, and the Norwegian Public Health Act aim to improve health services by addressing health disparities and public health problems for equitable access to care (Organization, 2015). The Care Plan 2020 concludes that users of health care resources and the health- and care professionals must join forces in the municipalities to create health and care services that have a high level of professional expertise and broad interdisciplinary competency (Health & Services, 2016). Norway has various levels of health care, primarily divided in primary and secondary health care. Primary health care is the responsibilities of the municipalities, by providing primary health care and the ministry plays a more indirect role, mainly through legislations and funding mechanisms. Secondary healthcare is the responsibility of the central state authorities, providing specialist healthcare (Steihaug, Paulsen, & Melby, 2017; Thomson et al., 2012). Primary health care is provided both in home care, all hours a day, 7 days a week, or in local health institutions like nursing homes and home for the elderly. Long-term care is provided, both in institutions and in private homes, but more and more long-term care is being provided as home-based care. There is an annual limit for many cost-sharing requirements, above which there is a set out-of-pocket cost (Thomson et al., 2012). A portion of the national taxes is transferred to local

government municipalities, which provide primary healthcare, and the municipalities spend almost ¼ of their total expenditures on health care (Romøren, Torjesen, & Landmark, 2011). It is stated in the Norwegian law that the municipality shall offer through the General Practitioner, named “fastlegen”, a thorough consultation, possible diagnosis and treatment through the course of the disease. The law further acknowledged that anyone who needs long-term coordinated services is entitled an “individual plan”. The patient and/or the carer have the right to participate in drawing up this plan (named individual plan), which is arranged by the municipality assigning a coordinator. In order to get primary healthcare, an application for services is sent to the purchaser office in their own municipality. If the application is granted, an order for the service consented is sent to the provider, with decision about the amount of time and services that the purchaser office offer (Steihaug et al., 2017). The Norwegian Ministry of Health and Care Services wants to create a health and care service centred on and influenced by users and patients. The purpose of their plan, called Dementia Plan 2020, which is developed in cooperation with people who themselves have dementia and their carers, is to build a more dementia-friendly society. This will require openness and knowledge about dementia in society in general and in the health and care services in particular. The plan states that people with dementia and their families will need support and respite care. By providing necessary help, people with dementia and their carers need to be involved in the planning of the services, but also have a continuing dialog that makes sure that there exists real user involvement with real influence of the services at system level and in individual level (Health & Services, 2016; Klug, Halaas, & Peterson, 2014). For the moment, the municipal health and care services are not sufficiently adapted to these needs of both the people with dementia and their carers, and claim that they need to make great changes in the delivery of care in the future. These changes need to be addressed towards the organisation of the services, their competence and expertise, and the design of the physical environment of people with dementia, and their carers (Health & Services, 2016).

## **2.2 CARER**

The term carer (or caregiver in the United States of America and Canada ) is often used in health-research and practice (Fine, 2004), and has developed from “one who cares” meaning a person who is a worrier (1691-1850), through the model of the burden of individual care to a more social conception of care<sup>1</sup>. One of the consequences of the emergence of the concept of “carers” has been the calls to accord it greater social recognition and make the effort more visible (Fine,

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<sup>1</sup> OED Online (<http://dictionary.oed.com/cgi/entry/>), accessed June 2003.

2004). A previous study explored the process through which people identify themselves as a carer by adopting the notion of caring as a “position” rather than a “role”. This was in order to highlight the fluctuating nature of the phenomenon of being a carer and its difficulties. For example, by being described as a carer when they do not define themselves as a carer, especially when their actions are described in terms of their relationship and not by determined tasks (i.e. spouses) (Molyneaux, Butchard, Simpson, & Murray, 2011; O’Connor, 2007).

By defining the roles as carer and the one being cared-for, can create, according to O’Connor (2007) and Molyneaux, Butchard, Simpson, & Murray (2011), a division between people who might otherwise work naturally together. Not only can it make a discriminated application on the one being cared-for, but it could also create a rift for those in receipt of care, which are left increasingly vulnerable to neglect or abuse (Calderbank, 2000).

This thesis will use the term “carer”, (although the term “caregiver” has been used in paper 2) where “carer” as a noun means that there is a person giving care, and a person receiving care, as opposed to a task that are being performed. According to the Norwegian law, the patient’s carer is the one the patient wants to be her/his carer, to be involved in health care plans or health services delivery. Usually the next of kind is the spouse, child, grandchild, sister/brother in law, but it does not exclude friends or neighbours as listed carer. General rule is that the patient her/himself, if he/she has the cognitive/mental capacity, defines whom the carer should be (Services, 2013).

## **2.3 EMPOWERMENT**

Empowerment was one of the seven guiding principles when The World Health Organisations (WHO) defined health promotion through the Ottawa charter (1986). To clarify the understanding of the concept in this study, a brief characterisation will be provided. The WHO definition of empowerment is understood (glossary 2011) as:

“ Empowerment is a multidimensional social process that enables people to gain control over their lives.  
(WHO, 2011)

This definition, according to WHO, challenges existing power allocations and relations to give disadvantaged groups more power. The possibility of enabling someone to make decisions about their own health is a primary goal (Organization, 2011). Further this power and control may manifest itself at

macro, meso and micro levels. The Norwegian Ministry of Health and Care Services (2016), provided guidelines to the municipalities of how to take care of carers to persons with dementia. They stated that the person with dementia and their carers are the experts on what their needs are, and must be empowered by making them take an active part of the decision-making progress in every level of empowerment. The first level (Tones & Green, 2004), defined as micro-level, which is individually or at small groups, means that everyone have an influence at their own life situation and what kind of health care offers that should be offered. Second, at meso-level, the carer's needs to meet, share experiences and act together with other carers in similar positions. At this meso-level power might refer to power exerted by organizations or communities. Third, at macro-level, influence from the carers should direct national policy, where carers should be involved and participate through user-representations and ongoing dialogues (Health & Services, 2016; Tones & Green, 2004).

## **2.4 BURDEN, STRESS AND STRAIN**

The concepts of burden, strain and stress are frequently used in research regarding carers of people with dementia and other chronic diseases, and are mainly used to measure the experiences of carers and determine physical, emotional, negative feelings, and social failure or inability to meet the unwritten expectations in the community (Leggett, Zarit, Taylor, & Galvin, 2011; Sales, 2003; Teschendorf et al., 2007). The meaning of these concepts may vary, and sometimes even overlap, but they do have an underlying meaning of despair, frustration and negative loaded emotions in almost every study (Chappell, Dujela, & Smith, 2014; Chappell & Reid, 2002). To clarify the underlying research, which give this study a platform, a summarized description of earlier studies with use of these three terms will be provided.

### **2.4.1 Burden**

One of the most studied variables over years has been burden, defined in 1986 as “the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning” (Zarit, Todd, & Zarit, 1986). More recently, a study from 2011 claims that there are three dimension of burden for carers; role strain, personal strain and worry about performance. Recurrent behavioural and emotional problems, ADL disability, isolation, carer's age, and the persons with dementias gender were significantly associated with burden. They defined the term “burden” as subjective outcome of the interplay of stressors and resources that the carer might use to manage those stressors. Further, they stated that subjective burden would be expected to increase as stress such as behaviour problems and activity

of daily living (ADL) deficits increased (Leggett et al., 2011). An internet-based survey (2010), including 962 carers to people with DLB, investigated carers burden and needs. They found that carer burden mostly correlated with mood (depression, anxiety, and apathy), and sleep disturbance in the person with DLB. This increased burden led to feelings of social isolation, but also lack of understanding and adequate support from family, friends, or providers (Galvin et al., 2010). Another study claims that carer burden is preponderantly used as an indicator of carer experiences, but points out that much disagreement remains on what the term really entails. The authors divide the term burden into subjective and objective burden, and argues that discussions tends to overlook the unique correlates and consequences of each dimension. Further, the multiple conceptualizations of carer burden can make research in the field uninformative, and there is a need of understanding research in context, by meaning theory in the context of stress and role theory (Bastawrous, 2013).

As described later in this thesis, different types of dementia, such as AD and DLB, have different clinical symptoms which may pose specific and different challenges for the carer. There are however few longitudinal studies investigating differences between carers of people with DLB and AD, mostly they are divided into longitudinal studies of people with unspecified *dementia, AD or Vascular Dementia (VD)*, or have very few participants. One longitudinal study compared carers of people with AD, VD and “other types of dementia, and they suggest that burden is a here and now experience of caregiving. This study compared the correlates of carer burden for spouse and adult child, at two points, first six months after prescribed cholinesterase inhibitors (Aricept, Reminyl and Exelon), and then again 18 months after medication started. They found that adult children experienced more burden than spouses at both measures points did. Aspects that supported this were the facts that adult children are more likely to have multiple demands of home, interest, and work that contributed to their burden. Further, particular for the spouses, disease characteristics (agitation, sleep problems, more formal services) and their prior relationship with the care recipient were related to carer burden (Chappell et al., 2014). In a study by Razani et al., 2014, they looked into which changes in carer burden over a year can be predicted by the functioning of the person with dementia, measured by the carers’ psychological stress. They found that baseline patient functioning predicted overall changes in carer burden, but that increases in psychological symptoms of carer, such as depression, anxiety, and hostility were the best predictors for specific types of increased carer burden, such as social, developmental, or physical burden. (Razani et al., 2014) There are many studies published during the last 20-30 years that aim to describe what carers to people with dementia experience. However, only a few of them differentiate between carer’s experiences and the different diagnosis of dementia. A recent study done by Liu et al., (2016),

looked into which Behavioural and Psychological symptoms in persons with dementia (BPSD) that have the highest impact on burden in carers for people with Frontotemporal Dementia (FTD), DLB and AD. Carer burden was assessed using Zarit Burden Inventory (ZBI)(Zarit, Orr, & Zarit, 1985). They found that there was a difference between the carer burden between the types of dementia, which was related to specific symptoms including aberrant motor behaviour in FTD, hallucinations in DLB and apathy in AD. Furthermore, they found that the extent of BPSD significantly correlated with carer burden. People with AD and DLB and their carers had similar scores at Neuropsychiatric Inventory (NPI) total score and ZBI scores, people with FTD and their carers had the highest scores at NPI and ZBI (Liu et al., 2017). In addition to psychiatric and behavioural challenges related to carer burden, a study by Mazaheri et al., (2013) describes carers to people with AD or VaD living in Iran, and the financial burden. The persons with dementia suffer from losing their role as financial provider, which can cause problem for their role and damage self-dignity concerning their senior position in their family system. In our multinational community, this is an important finding that can contribute to the development of appropriate dementia care (Mazaheri et al., 2013).

## **2.4.2 Stress**

Seyle (1956) is known to be the one originating the concept of stress from his work with animals. The definition of stress was as non-specifically induced changes within a system and as sum of all non-specifically induced changes in a biological system. Or explained with other words, “stress is the nonspecific response of the body to any demand made upon it”. (p.137). Seyle states that all living beings are constantly under stress and anything, pleasant or unpleasant, that speeds up the life, causes a temporary increase in stress. He further states that both pain and passion could be equally stressful, meaning that stress is not simply nervous tension nor the result of damage, but above all, it is not something to be necessarily avoided. It is associated with the expression of all our innate drives, and complete freedom from stress is death (Serban, 2012). In contrast, Lazarus and Folkman (1984) defined psychological stress as “the 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” (p.21) (Lazarus & Folkman, 1984). This means that there is no illness solely caused by an external organism, whether or not illness occurs, depends also on the organism’s susceptibility. One has to emphasize the relationship between the person and environment, which takes into account characteristics of the person and the nature of the environmental event (Lazarus & Folkman, 1984). Risk factors for carer burden include female sex, low educational attainment, residence with the care recipient, high number of hours spent caregiving, and lack of choice

in being a carer according to a recent review (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). Another study, which compared caregiving to people with DLB with AD, reported that overall carer distress was higher in persons with DLB than in persons with AD. They stated that persons with DLB have a different neuropsychological profile, more psychiatric symptoms and more serious functional deficits than AD in early cognitive decline. One limitation of this study was the low number of participants, only 12 carers to persons with AD and 16 carers to persons with DLB were included. However, the high degree of carer distress in DLB suggests that psychological and behavioural disorders aggravate distress, and were related to symptoms such as hallucinations, anxiety, apathy and delusions (Ricci et al., 2009). Studies comparing distress between carers to people with AD and DLB, found that caring for people with DLB was associated with significantly more distress, than caring for people with AD (table 1). Consistent with increased burden of caring for people with DLB were factors like behaviours, psychosis, cognitive fluctuations, daytime somnolence and mood abnormalities, while burden of caring for people with AD were associated with mood abnormalities, heightened memory impairment and repetitiveness in conversation. As nonpharmacological treatment, they suggest minimizing the risk of falls, to use ramps, and to prevent stress education given to carers in addition to monitoring their carer burnout, especially for carers to people with DLB. There were slight differences about cognition in these studies, were some found that cognitive activities did not have any effect at carer burden, whilst some argued the opposite, especially regarding fluctuations in people with DLB (Lee, McKeith, Mosimann, Ghosh-Nodyal, & Thomas, 2013; Mohamed, Rosenheck, Lyketsos, & Schneider, 2010; Zupancic, Mahajan, & Handa, 2011). Further context of Lazarus and Folkman's term stress in relationship to coping will be discussed in chapter 4.1.1.



**Table 1.** Overview of studies including burden in carers to people with DLB compared to carers to people with AD.

<b>Authors</b>	<b>Setting</b>	<b>Sample size</b>	<b>Assessments</b>	<b>Findings</b>
Lowery et al, (2000)	England	25 with DLB 75 with AD	Depression measured by Montgomery Asberg depression rating scale and Geriatric Mental State Schedule	Association between carer depression and severity of problem behaviour in people with DLB and AD. Sign. Association between depression in DLB carers and depression in patients.
Berger et al, (2005)	Germany	1 with DLB 32 with AD 4 with VaD 4 with FTD 2 with Mixed 2 with unknown	Caregiver Burden Interview (BI)	Subjective burden on carers remained stable, but still affected the carer's wellbeing. The increase of dementia severity and deterioration of patient's symptoms, and the association of these variables with carer burden became stronger.
Lee et al, (2013)	England	29 with DLB 30 with AD 30 with VaD 32 with PDD	NPI, Dementia Cognitive Fluctuations Scale (DCFS), Unified Parkinson's Disease Rating Scale (UPDRS) II & III, and The Cambridge Assessment for mental disorders in the elderly (CAMCOG)	Caring for people with DLB or PDD was associated with more stress, than caring for people with AD or VaD. This stress was associated with higher levels of psychosis, mood disturbance, daytime sleep and cognitive fluctuations. Age, gender and severity of cognitive impairment did not.
Liu et al, (2016)	England	22 with DLB 110 with AD 82 with FTD	MMSE, Montreal Cognitive Assessment, Clock Drawing test, NPI, ZBI.	Differences was found between the types of dementia, which included aberrant motor behaviour in FTD, hallucinations in DLB and apathy in AD. Furthermore, the extent of BPSD significantly correlated with caregiver burden. DLB and AD patients had similar scores at NPI total and ZBI scores, FTD patients had the highest score at NPI and ZBI



<b>Authors</b>	<b>Setting</b>	<b>Sample size</b>	<b>Assessments</b>	<b>Findings</b>
Ricci et al, (2008)	Italy	16 with DLB 12 with AD	NPI, ADL, IADL,	Overall carer distress was higher to people with DLB compared to people with AD. People with DLB have different neuropsychological profile, more psychiatric symptoms and more serious functional deficits than AD in early cognitive decline. This high degree of carer distress in DLB suggests that psychological and behavioural disorders aggravate distress, and are related to symptoms as hallucinations, anxiety, apathy and delusions.
Brodsky, 2015	Australia	10 with DLB 344 with AD 33 with VaD 24 with FTD 76 with mixed dementia 27 other dementia	NPI, over 3 years.	DLB was associated with greater frequency and severity of hallucinations, and displayed less appetite disturbances at baseline than other types of dementia. Male patients with dementia displayed higher levels of delusions, agitation, apathy, disinhibition, irritability, and night-time behaviour, and females tended to display more depression. 75% of patients had three or more symptoms at the end of the study, indicating the challenge many caregivers face in managing multiple symptoms. Different symptoms have different trajectories and baseline characteristics of patients, including sex and dementia type, can predict the subsequent course of symptoms.

### **2.4.3 Strain**

Pearlin et al., (1990) defines strain both as a stressor and as perceived stress. Others have described strain as the effects of caregiving on the carer (Ory, Hoffman III, Yee, Tennstedt, & Schulz, 1999; Pearlin, Mullan, Semple, & Skaff, 1990). In a study by Leggett et al., (2011) they found that there are three dimensions of burden for the carers defined as role strain, personal strain and worry about performance. The term strain and burden seems to share some of the content in what it defines (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005; Amanda N Leggett, Zarit, Taylor, & Galvin, 2010). Leggett et al. (2011) claims that the dimensions of social consequences and psychological burden conceptually represent the same constructs as role strain and personal strain and include similar items. This study further reports that recurrent behavioural and emotional problems, ADL disability, isolation, carer's age, and patient gender were significant predictors of burden to carers to people with DLB (Leggett et al., 2010). Berger et al. (2014) studied the course and severity of dementia-related symptoms and their relationship to carer's subjective burden and depression, and found that subjective burden on carers remained stable, over the 2 years, but still affected the carer's wellbeing. The increase of dementia severity and deterioration of patient's symptoms were associated with carer burden. This was a study comparing carers to persons with AD, DLB, VaD, FTD and mixed Dementias, however only with few participants in each group (Berger et al., 2005).

## **2.5 THE RELATIVES' STRESS SCALE**

Measuring caregiver burden, distress or experiences can be done in different ways. The assessments used in the quantitative part of this thesis is based on the Relatives' Stress Scale, a widely used assessment, and first known in Europe by the study of Greene et al., (1982). They constructed a scale (Relatives' Stress Scale) for evaluation of the strain put upon the caregivers to elderly people with dementia. The relatives' ratings of the behaviour and mood of the patient were registered, and the caregivers own ratings of the degree of stress and upset arising from having to care for the patient. Subscales were produced with the use of a factorial method, tapping different aspects of the patient's behaviour and the caregivers reactions. These aspects of burden were grouped into 3 items. Personal distress, experienced in relation to the person with dementia, and Life Upset/domestic Upset, produced by having to care for the person with dementia in social settings. Third, negative feelings associated with the patients and carers behaviour. However the relationship between the degree of stress reported by carers and possible causal variables including the patient's behaviour seemed to be modest and only 38 carers were included (Greene, Smith, Gardiner, & Timbury, 1982).

Ulstein et al., (2007) wanted to identify caregiver and patient characteristics associated with various aspects of burden of care, using and testing the Relatives' Stress Scale (RSS), in addition to patient cognitive function assessments, NPI (Neuropsychiatric Inventory), BPSD (Behavioural and psychological symptoms) and DAD (Disability Assessment for Dementia). The data came from 196 carer-patient dyads, in Norway, where the persons with dementia and the caregivers were living at home. The self-administered RSS is a useful instrument to measure the strain put on the caregivers. They found that being a carer with daily contact with the patient, high scores on the NPI, and decline in ADL-function, together with the time spent caring, resulted in high level of social distress. Emotional distress was strongly associated with level of BPSD, the hours spent caring per week and the carer being a female. The variable negative feelings differed from those explaining emotional and social distress, with low patient age and high NPI score as the only significant explanatory variables, with being a wife as most important characteristic (Ulstein, Bruun Wyller, & Engedal, 2007).

Another study by Ulstein et al., compares the scores RSS with those on the General Health Questionnaire (GHQ) and Geriatric Depression Scale (GDS), and sets an optimal cut-off for psychiatric morbidity in the carers themselves. 194 carers and persons with dementia were included, all living at home and had a weekly face-to-face contact with their carer. They did a two-step cluster analysis to distinguish between carers with low vs. a high probability of psychiatric morbidity. Carers scoring RSS  $\leq 23$  should have ordinary follow up and be referring to an educational program in the community. If they scored from 23 to 30 points on the RSS they should be observed in case of depression. To prevent such problems they may benefit from psychosocial interventions such as individual counselling or participation in problem-solved groups for carers. If carers scores more than 30 they should be referred for psychiatric assessment and treatment when required. The weakness in this study is that data came from only one clinical and one non-clinical setting, in addition the sample conducted a lower percentage of female patients than expected (Ulstein, Wyller, & Engedal, 2007).

## **2.6 DEMENTIA**

### **2.6.1 Definitions**

The word dementia derives from the two Latin words *de* (out of) and *mens* (mind). It is known that cultural beliefs about dementia such as it being a punishment or a curse, has led doctors to avoid diagnosing dementia, because of fear of stigmatising (Livingston et al., 2017; Mukadam & Livingston, 2012). In contrast to mild cognitive impairment (MCI) and subjective cognitive decline (SCD), characterised by objective or subjective cognitive decline from a previously attained cognitive level and normal ADL, dementia is defined as a cognitive

decline that affects activities of daily living or social functioning (Organization, 2016). It is important to include a medical and family history, when searching for a diagnose, which obtains both psychiatric, behavioural and cognitive changes, both declared by the patient him/her selves, but also the conceptions of carers in the same areas (Association, 2017). Dementia is a syndrome with the characteristic symptoms like difficulties with memory, language, problem-solving and other cognitive skills that affect a person's ability to perform everyday activities. These difficulties appears when nerve cells (neurons) in parts of the brain involved in cognitive function have been damaged or destroyed (Association, 2017). Different causes of dementia are related with distinct symptom pattern, especially those in older age groups may have brain abnormalities associated with more than one diagnosis of dementia (Schneider, Arvanitakis, Bang, & Bennett, 2007) The World Health Organization (WHO) describes dementia as:

“Dementia is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation”(Organization, 2016).

## **2.6.2 Assessment and diagnosis**

National guidelines in Norway recommend that people with suspected dementia should be investigated by the General Practitioner (GP) in primary health care. If the GP is in doubt of what kind of diagnose it is, he/she could seek assistance from the secondary health care, named the “specialist care”. A systematic approach is recommend, including history taking from the patient and carer, review of medical history and medication, structured cognitive assessments, blood test, and structural imaging. The blood test are to reveal comorbid illness, whose treatment might improve cognition, and the rare reversible causes of dementias, as those caused by hypothyroidism, infection (e.g. Syphilis or HIV) among others (Kambugu et al., 2016; Livingston et al., 2017). Imaging with CT or MRI has its purpose to exclude treatable causes, for example normal pressure hydrocephalus, and elucidate a possible dementia diagnosis (Livingston et al., 2017). Further, there are many short validated cognitive test, but the most commonly used test is the Mini-Mental State examination (MMSE) (Folstein, Folstein, & McHugh, 1975). However, MMSE lacks sensitivity in patients with high premorbid educational attainment and suspected early impairment, (Martin & O'Neill, 2009). Montreal Cognitive Assessment are known to be effective in detecting DLB, and there is now a new guideline for diagnosing DLB from 2017 (McKeith et al., 2017) (Nasreddine et al., 2012).

## 2.7 DEMENTIA WITH LEWY BODIES

During research on parkinsonism in 1912, Fritz Heinrich Lewy (1885-1950) discovered what is now known to be Dementia with Lewy Bodies (DLB). However, it was first in 1958, when Okazaki described the clinical symptoms of disorientation, hallucinations and profound motor symptoms with rapid progression that DLB became an independent neurodegenerative entity. The autopsy also showed the distinguished presence of cortical Lewy bodies, which were different from those seen in the brains of persons with Parkinson's disease (Holdorff, 2002; Okazaki, Lipkin, & Aronson, 1961). An essential requirement for a DLB diagnosis is progressive cognitive decline of sufficient magnitude to interfere with normal social or occupational functions, or with usual daily activities (McKeith et al., 2017). The core clinical features are, according to the fourth consensus report of the DLB Consortium (McKeith et al., 2017) fluctuation in cognition, recurrent visual hallucinations, REM sleep behaviour disorder and one or more spontaneous cardinal features of parkinsonism (bradykinesia, rest tremor, or rigidity), and occurs early and may continue throughout the disease. The cognitive fluctuation may appear as delirium-like, as spontaneous alterations in cognition, attention and arousal (McKeith et al., 2017). People with DLB may have variable attention, altered consciousness, waxing and waning episodes of behavioural inconsistency and incoherent speech (McKeith et al., 2017). Further, these fluctuations may not reliably discriminate DLB from AD, but questions about daytime drowsiness, lethargy, staring into space, or episodes of disorganized speech do (McKeith et al., 2017). Complex visual hallucinations occur in up to 80% of persons with DLB. These hallucinations are typically well-formed, featuring people, children, or animals, sometimes accompanied by related phenomena including passage hallucinations, sense of presence, and visual illusions (McKeith et al., 2017). Parkinsonism occurs in over 85% in persons with DLB, and is defined as bradykinesia in combination with rest tremor, rigidity or both. The last clinical core feature is REM sleep behaviour disorder, which is a parasomnia manifested by recurrent dream enactment behaviour that includes movements mimicking dream content and associated with an absence of normal REM sleep atonia. Supportive clinical features are clinical features that are commonly present, but lack diagnostic specificity. These symptoms may indicate DLB, particularly when they continue over time, or if several occur in combination (McKeith et al., 2017; Rongve, Boeve, & Aarsland, 2010), and include features such as severe sensitivity to antipsychotic agents; postural instability; repeated falls; syncope or other orthostatic hypotension; urinary incontinence; hypersomnia; hyposmia; hallucinations in other modalities; systematized delusions; apathy, anxiety, and depression (McKeith et al., 2017).

Clinical signs and symptoms are weighted as core or supportive, and biomarkers as indicative or supportive. This supportive evidence is often valuable in clinical

decision-making, acting as signposts to or adding evidence for a DLB diagnosis. The spatial and perceptual difficulties of DLB often occur early, like problems with coping figures, size matching tasks or perceptual discrimination, e.g. incomplete letters. Memory and object naming seems to be less affected in DLB. If one or more of indicative biomarkers is found, associated with one or more clinical core features, this indicates DLB, but should never be diagnosed on the basis of biomarkers alone (McKeith et al., 2017). To distinguishing DLB from AD, the utility of DAT imaging has 78% sensitivity and 90% specificity (McKeith et al., 2007).

## **2.8 ALZHEIMER'S DISEASE**

Alzheimer's disease (AD) is a progressive degenerative disease, and counts for 65-77% of all people that are affected by dementia (Association, 2017; Barker et al., 2002). There is no single test for diagnosing AD, instead a variety of approaches and tools can help to make a diagnosis, as mentioned in chapter 2.6. Typically, initial symptoms of Alzheimer's disease are memory loss that disrupt daily life, not being able to recall recently learned information, or important dates, or events, and consequently asking for the same information repeatedly. Further, a challenge in planning or solving problems are often seen, like their ability to develop and follow a plan or work with numbers. Familiar recipes might suddenly be a problem to follow, or keeping track of monthly bills. People with AD often find it hard to complete daily tasks, like driving to a familiar location, or managing a budget. In addition the confusion with time or place, keeping track of seasons or forgetting where they have put things and their ability to retrace steps. Other core symptoms are trouble understanding visual images and spatial relationships, and having problems with understanding or formulating words in speaking or writing. As the disease develops symptoms like decreased or poor judgement can be prominent, in addition to a change in mood and personality. This could make their participation in hobbies, social activities, work or sports, or other social settings difficult (Association, 2017).

In 2011 there was a slight change in the diagnostic guidelines for Alzheimer's disease. These revised guidelines of 2011 encompasses an entire continuum from the initial pathological changes in the brain before symptoms appear through the clinical dementia stage caused by the accumulation of brain changes. This means that it does not only includes those with dementia due to the disease, but also those with mild cognitive impairment due to Alzheimer's and asymptomatic individuals who have verified biomarkers of Alzheimer's. Under these 2011 guidelines it is more accurately labelled as "dementia due to Alzheimer's" or "Alzheimer's dementia"(Association, 2017). However, in this thesis the term Alzheimer's disease will be used, as most of the earlier studies are referred to

this disease as Alzheimer's disease, and the diagnoses of Alzheimer for the DemVest study was made according the "The National Institute of Neurological and Communicative Disorders and the Stroke-Alzheimer's Disease and Related Disorders Association" (McKhann et al., 1984).

## **2.9 ETHICS**

By involving human beings in this study, the relevant ethical guideline as proclaimed in the Declaration of Helsinki has been followed ("Declaration of Helsinki: ethical principles for medical research involving human subjects," 2013). Research studies in Norway, shall get approval from regional committees for medical and health research. The ministry of Norway have establish such committees by dividing the country into north, west, south and east part of Norway. This PhD study has it approval from REK-west, id 2010/633 (qualitative part, paper 4), 167.04 (quantitative part DemVest, paper 2 & 3) and REK-east, id 2009/1953 (quantitative part HUKLI, paper 2). The participants provided written consent after the study procedures were explained in detail to the person with dementia and carer, which were spouse, child, or grandchild, all adults. Only people with dementia of mild degree of dementia were included in study II & III, and thus capacity for consent was retained, as judged by an experienced clinician who was a licenced specialist of geriatric medicine, psychiatry, or neurology. Their carers have also acted as consultees in cases where capacity to give informed consent from the person with dementia was lacking (Study II and III). Carers provided written consent for their involvement in the study (study II, III and IV).

In paper 2 & 3, data was analysed from a file with stored data, and all of the informants were anonymous, identified by numbers. The key of identifying numbers with names, were stored at a separate office from the PhD candidate, in another research partners office, in locked cabinets. The audiotape of the focus group interviews from study IV, were also locked in a cabinet at the office, after the digital files achieved were stored safely in a password-computer, intended only for use during the research project. All transcribed materials and field notes were kept in binders in locked cabinets in Western Norway University of Applied Sciences, Stord, Norway. When transcribing and analysing data from study 4, details and names from informants were coded, such as names, and place of residents. As the background of whom the carers were related to, namely people with DLB or people with AD, in addition to age of the carer, are of importance, we decided to keep this information as it was. In study 4, it was not possible to ensure the participating carers totally confidentiality from the other participants. However, we strongly argued, in front of and after every interview, to keep their shared stories within their group. Other possible challenges reflected on in front



of our focus group interview, were the vulnerability of discussing economic perspectives, different time spent with the person with dementia, use or not use of genetic test for predicting dementia, and perhaps the carers started feeling inadequate or more distressed. By contacting outpatient clinics, in these districts, both moderator and co-moderator discussed these challenges with these clinics, supervisors and colleagues, and possible ways of handling them, in front of the interviews were considered. My own preconception of the investigated field has been under consideration in every step of this study. My previous experience as a RN for people with dementia and their carers, have provided me with a previous understanding and knowledge about health care settings, and may coloured my understanding of the data collection, analysing and reporting. However, by being aware of this, I would consider it to be a resource, giving my understanding and experience, reflecting at my own involvement, this could lead to a broader understanding of the carer's situation.

Considering the sensitivity of the carer situation, a contact with the professionals at the geriatric outpatient clinic were offered after the interviews. Speaking of sensitive and personal matters, may extract questions or feelings that someone with professional knowledge could answer (Polit & Beck, 2014). None of the carers used that service. Further descriptions of ethical considerations will be included in methods and result, as every step of this study needs to take account for possible ethical challenges from the start to the end.

Regarding integrity, my supervisors and myself, have followed the standards for good routines that prevent dishonesty and promote honesty. Implication for good standards will be good reference practice in both presentation and papers, and don't steal content from the works of other writers and researchers, and not publish it as one's own, but cite it as source (plagiarism). The results are and will be reported in academic scientific journals, with all of the standards of good reference practice. Further the supervisors and myself have read the presentation of this study, in example the different paper versions and analyses, to provide negative criticism by guidelines by NESH (Kalleberg et al., 2006). When performing research my supervisors and I will not take part in processes that involve approving, funding or judging our own research, but strive for openness and discussion concerning impartiality.



### 3 RATIONALE

Previous research shows that being a carer to a person with DLB or AD are associated with stress, burden, and depression. It involves a high risk of getting psychiatric disorders, decreasing the possibilities of a social life, is physical demanding, and emotional challenging. There are few studies with a low number of participants that differentiate between the diagnosis of DLB and AD (table 1), and they indicate that carers to people with DLB are more distressed and burdened comparing carers to people with AD. There seems to be no clear understanding of how the health care system may ease the burden of these carers. Several interventions have been proceeded, but the effect seems to be unclear and not as good as hoped for (Rokstad et al., 2014). Earlier studies have shown that nursing home admittance seems to be earlier for a person with DLB compared to a person with AD, but also a higher frequency of neuropsychiatric symptoms, including sleep problems, a more rapid cognitive decline, and shorter survival in people with DLB compared to people with AD (Aarsland et al., 2008; Oesterhus et al., 2014; Rongve et al., 2010; Rongve, Vossius, Nore, Testad, & Aarsland, 2014). Effects of nursing home admittance, the effect of specialized education according to dementia have some impact on carer's situations, but nevertheless, not yet given the whole solution how to relieve the carer's depression, burden and stressful situation. Few studies describes effective interventions and to our knowledge, very few studies differentiate between the experiences of carers to people with DLB and AD. Regarding the DemVest unique database, there are strengths like a high numbers of carer to people with DLB and AD, both at starting point and in annual follow-up measurements. The diagnostic procedures were rigorous, and high accuracy was demonstrated in the 56 cases with neuropathological diagnosis (Skogseth et al., 2017)

The overall aim of this thesis is to analyse and describe how the carers to people with mild dementia, in particular AD and DLB, experience their life as a carer. The focus is on carers and their involvement, studied from different perspectives.

More specifically, to define and describe what carers, meaning adult children, grandchildren and spouses to persons with DLB and AD experience at the time of diagnosis, then during 3 years, and finally to interview carers about their experiences and coping mechanisms, and see if they differ between the carers of people with DLB and AD.

### *Objectives*

In order to achieve this aim, this study will have following objectives:

1. Conduct a systematic review to identify published studies that evaluate associations between carer distress and neuropsychiatric symptoms in people with dementia.
2. Analyse data from DemVest and National Dementia Register to define and compare the experiences of carers of people with AD and DLB at the time of diagnosis.
3. Analyse data extracted from the DemVest study to longitudinally describe distress in carers of people with mild dementia, particular to people with DLB and AD, over a three-year period.
4. Conduct focus group interviews to describe the caring experience for carers of people with DLB and AD, and explore how coping strategies may be applied to support these carers.

In order find answers, this thesis will look into the possibilities of finding different experiences by the carers to people with DLB compared to carers to people with AD, both in tendency and in depth. By doing this, it will provide knowledge to be used by the professional health care, making a better day for the carers and the person with DLB or AD.

## 4 THEORETICAL FRAMEWORK

In the Norwegian ministry of Health's guidelines for Norwegian municipalities where this study took place, an emphasis is made on the need for special care and supervision for carers to people with dementia to meet their day-to-day demanding situations (Health & Services, 2016; omsorgstjenesteloven, 2011). Further, the Official Health Service acknowledges the experiences and knowledge of the carers and support them by giving information, offering education and support like day care centres for the person with dementia, and economic compensations. These guidelines state that knowledge about coping strategies is important for both the carer, but also for the person with dementia, and for the relationship between the carer and the person with dementia. In this chapter theories of stress and coping and choice of methods to meet the overall aim of understanding how the carer's can manage challenging and stressful events that evolves in their lives as carers, will be presented.

### 4.1 THEORY OF STRESS AND COPING

To provide a framework for understanding the perspective of carers to people with DLB and AD, the theory of stress and coping by Lazarus and Folkman (1984), has been used in this study (Lazarus & Folkman, 1984).

Their definition of coping is:

...a constantly changing cognitive and behavioural effort to manage specific external and/or internal demands, that are appraised as taxing or exceeding the resources of the person. (Lazarus & Folkman, 1984, p.141)

Their definition of coping, relates to the situation of carers to people with DLB and AD, as it is process-oriented rather than trait-oriented, as reflected in the words *constantly changing*, and *specific* demands. The definition also implies a *distinction between coping and automatized adaptive behaviour*, by limiting the coping to demands appraised as taxing or exceeding a person's resources. By defining coping as *efforts* to manage, it does not exclude anything, regardless of how well or badly it works. By using *manage*, it also avoids equating coping with mastery (Lazarus & Folkman, 1984).

Coping as a process can be seen when stress has a long duration, as in grieving over a lost person, or situations where the disease is chronic, or last over a longer period of time, such as learning that your loved one is diagnosed with dementia. The shock or the efforts to deny the statement of the diagnosis at first, but then slowly accept the situation and reengage in the stressful situation, and thereby finding coping strategies in their situations as carers. The appraisal phase when

stress occurs, is divided in primary- and secondary, where the primary phase is assessed to determine if this phase is being stressful or not, and in the secondary phase there is a judgement of what might be done to improve the situation. This process may last several years, or only for months, depending on the persons resources, but it is characterised by multiple ways of coping. Changes in coping may occur for hours, days, weeks or even years, as in grieving, and there is always an unfolding, shifting pattern of cognitive appraisal and reappraisal, where problem strategies and emotional strategies shifts (Lazarus & Folkman, 1984). It is also important to remember that coping involves much more than problem solving. A coping function refers to the purpose a strategy serves, which have a given function. Thereby this distinction is consistent with the definition of coping in that it is independent of outcome (Folkman & Lazarus, 1988).

The appraisal of coping is related to which strategies the persons use to deal with their situation. Emotion-focused coping is one of two coping strategies, according to Lazarus and Folkman (1984), and the other one is problem-focused coping. Emotion-focused coping arises when we need to lower the emotional discomfort, as a solution of a situation we cannot manage or have the opportunity to change. Emotional-focused coping can be actions like making a distance towards the “problem”, like denial of the situation or selective attention for a while. This could give the person a chance to adapt with the situation that might not be changeable. Another example of emotional focused coping could be performing physical activities, or abuse of alcohol or drugs.. Common for these strategies are that they make us able to be in a situation we cannot change or need some time to find good strategies to manage/cope and can be useful and necessary at the start of a crisis or situation that seems uncontrollable. A problem-focused coping is known by one’s ability to find initiatives/actions that solves the crisis/problem, aiming at lowering the stress. Example could be seeking help from others, change routines, lifestyles or reduce causes of stress, or more inner centred strategies like lower your own expectations, getting new knowledge, seek information and other similar actions (Lazarus & Folkman, 1984; Renolen, 2008). By trying to reduce the stress/crisis, there is no clear solution that guides everyone, meaning which coping strategy is best. The stressful situation is constantly changing, involving both the environment and social interactions in the person’s life. Problem-focused coping and emotional coping are both important for coping with a stressful situation.

## **4.2 MULTI METHODS DESIGN**

The basic idea of every research is to get a deeper and broader understanding of the research field (Polit & Beck, 2014) and this thesis uses both quantitative and qualitative methods, in order to give an answer to the aim of this study.

Combining quantitative and qualitative research methods is debated, understood and communicated in multiple ways, and has even been called a third methodological movement (Hall, 2012). There is an ongoing discussion of what the title of this methodology should rightfully be named (Creswell & Clark, 2007; Greene, 2007; Tashakkori & Teddlie, 2010) and one way of defining the method using both qualitative and quantitative data is by calling it multi methods. Others defining using two methods, which are both complete in themselves and can be published in separate papers, as multiple methods (Morse, 2010).

Quantitative method is an investigation of a phenomena, with precise measurement and quantification, often involving a rigorous and controlled design (Polit & Beck, 2014). According to Sale, Lohfeld et al. (2002), the earlier position of the quantitative paradigm is that there is only one truth, objectively investigated. This “truth” exists independent of human perception, and the researcher and the research object are independent, with no influence at each other (Sale, Lohfeld, & Brazil, 2002). In lead of the investigation of the perception of a value-free framework, a measure and analysing process without personal affection was highly recommend. Randomized control trials, blinding, written or orally administered questionnaires with a degree structured response form were the “golden standards”, with a large proposition of participators defining it as representative (Sale et al., 2002). According to Johnson and Onwuegbuzie (2004) a quantitative researcher believe that social observations must be treated as entities in the same way as the physical scientists treat physical phenomena. The researcher should be objective and remain emotionally detached with the object of the study. Another way of illustrating quantitative researchers are that they are using a formal writing style, using the impersonal passive voice and describing social laws as the major focus (Tashakkori & Teddlie, 1998). According to this philosophy, the researcher and the object studied are independent entities, and examines the nature of knowledge (Guba & Lincoln, 1989). The goal is to measure and analyse causal relationships between variables, with techniques to ensure this including randomization, blinding, highly structured protocols, and questionnaires with predetermined responses, with a larger sample than qualitative research (Guba & Lincoln, 1989; Sale et al., 2002). The aim of our study requires a method which describes carer stress to people with DLB and AD, and identifies which disease specific symptoms impacts carer stress the most.

Qualitative method is defined as an investigation of a phenomena, through the collection of rich narrative materials, like using in depth interviews, focus group interviews, or observation (Polit & Beck, 2014). In this study the method gives the carers an opportunity to express themselves more extensively about their own caregiver situation. The use of focus group interviews as a method is chosen to get a variety of perspectives and increase confidence in the patterns

that emerges. The strength of using this kind of method instead of personal interviews, observational studies, or, is that focus group participants get to hear other's responses and thereby make additional comments beyond their own original responses (Patton, 2005). The participants don't need to agree or disagree with the group, but rather consider their own views and knowledge in the context of view of other (Patton, 2002). The focus group interviews are led by moderator (who is responsible for the study), and the task is to guide and focus the interview and encourage discussion between participants (Malterud, 2012a). To understand the result of this qualitative part of the study, a systematic text condensation (STC) has been chosen as procedure to interpret the interviews (Malterud, 2012b). Using this method, gives us the opportunity to understand the experience and coping strategies of carers to people with DLB and AD, as expressed by themselves, without exploring possible underlying meaning of what was said. STC holds an explorative ambition to present examples from the carer's life, and not to cover the full range of potential available phenomena. STC thereby implies analytic reduction, changing between decontextualization and recontextualization of data. The theoretical perspective are applied in an editing analysis style, and is elaborated by Giorgi's principles, which includes four steps of analysis (Malterud, 2012b).

#### **4.2.1 Multi methods as a bridge builder**

The use of multiple methods in this thesis, is viewed as a bridge builder for getting a deeper understanding of how it is being a carer to a person with dementia, in particular to people with DLB and AD. In order to analyse, define and describe this experience, there is need of a quantitative measurement, and qualitative method, to label, enrich and describe the carer's situation. This means that each method requires their own research question (objectives), and thereby never give the same answers (Creswell, 2013). Creswell and Clark (2007) defined using two or more methods in a research project, as *mixed methods*, meaning including both qualitative and quantitative data in a single study. However, when using the concept of mixed methods, the data needs to be collected concurrently or sequentially, in priority, and involve the integration of the data at one or more stages in the process of research (Creswell & Clark, 2007). Another definition of using different methods, is the use of one solid dominant and complete method and one additional component, but that never the less, stands alone to answer each research objective. The supplementary component provides explanation or insight within the context of the core component, and cannot be interpreted or utilized alone (Morse & Niehaus, 2007; Morse, 2010). Morse (2010) further argues that this should be referred to as multiple methods and not mixed methods (Morse, 2010).

Using different methods makes the results more robust, gives a more complete picture of the phenomenon, and is an attempt to answer objectivities rather than restricting or constraining researchers' choices. In our study it gives us the opportunity to see the tendency of perceived carer stress, and identify differences and associations between diagnose specific symptoms and carer related stress. However, this study also finds possible explanations of what carers to people with DLB and with AD identifies as diagnose specific symptoms, meaning symptoms both appearing as cognitive and physical symptoms, and coping strategies related to these symptoms. Creswell further points out that a person's method is tied to that persons philosophy, where the design is framed within a larger philosophical foundation (Creswell & Clark, 2007; Abbas Tashakkori & Teddlie, 2010). My own background as a nurse in nursing homes and home care with a lot of contact with carers to people with dementia, is a central part of how this thesis is constructed. It also affects how the results of the four studies have been interpreted and presented, even if I have tried to set my preconceptions aside, so that new knowledge from the interviews can be found and presented as they are (Malterud, 2011).

Cartwright and Runhardt (2014) states that there is no correct answers, because it depends on the aim of the study. Further they argues that to serve all the different purposes, we should construct more and more different measures surrounding the same basic idea, in order to gain more accuracy (Cartwright & Montuschi, 2014). It could be argued that many ways of measures could be confusing and lead to less clarity. To accumulate knowledge when social science use different measures, makes it difficult to make genuine comparisons since different measures can give different verdicts (Cartwright & Montuschi, 2014). Even if the methodologies can be considered as opposites, the aim is to answer research questions through empirical observations, descriptions of data and discussions of the results, to minimize confirmation bias or other validity issues (Johnson & Onwuegbuzie, 2004). Jong (2003, in Johnson & Onwuegbuzie, 2004) specified that social and behavioural science not only tried to describe the many different phenomena like intentions, experiences, attitudes, but also more reductive phenomena as macromolecules, nerve cells, micro-level homunculi and biochemical computational systems. There is room for both social and more clearly material reality, and rather ask when the method is the most helpful and when/how and if they should be mixed or combined to get a deeper understanding of the research (Johnson & Onwuegbuzie, 2004). By combining both tendency and in-depth methods this study provides not only the differences of the experiences of the carers but also explanations of these experiences. This could be seen as a bridge builder between the two methods, and give a deeper understanding of the research field.





## 5 MATERIAL AND METHODS

### 5.1 METHODS

This PhD-study is based on four papers addressing the carer's experiences by being a carer to a person with DLB or AD. Study II and III contain quantitative data, with a cross-sectional study and a longitudinal study. Study I is a review conducted with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, Altman, & Group, 2009). Study IV is a qualitative study, using focus group interviews as method.

**Table 2.** Overview of papers in this study.

Paper	Design	Data collection (years)	Participants	Data collection	Analyses
1	Review	1990-2017	13 studies (of 1344 in total)	Peer-reviewed, full text articles, in English. Informal carers, provided care for people with dementia, AD, DLB, or FTD, and association between all 12 NPSs and carer burden was studied using the NPI.	The findings in each paper were standardized and graded on a 12-point scale, with 12 indicating the symptom with the most impact on carer burden.
2	Cross-sectional study	2005-2013	186 carers, spouses and children.	Descriptive data of person with AD and DLB, Carer stress (RSS), NPI, RDRS-2, MMSE, CDR SB, UPDRS-3, MADRS.	Linear regression analyses, first unadjusted and then in stepwise-adjusts.
3	Longitudinal study	2005-2013	223 carers to persons with mild dementia, 63 with DLB, and 97 with AD, 63 with other dementia types.	At baseline, until 2 and 3 years follow-up. Carer stress (RSS), descriptive data of the persons with mild dementia, DLB or AD, MMSE, duration of symptoms prior to inclusion, admission to a nursing home.	Linear mixed effects model.
4	Qualitative interview study	2017	21 adolescents, spouse or child, divided by diagnoses (DLB and AD) into 4 groups.	Focus group interviews .	Systematic text condensation.

### 5.1.1 Paper I

The main objective in this paper was to identify whether individual NPSs in people with dementia are associated with carer burden. This paper is a systematic review of peer-reviewed articles retrieved from MEDLINE, PSYCINFO and EMBASE through OVID, and followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (January, 2017) (Moher et al., 2009). 13 studies are included, of these five studies identified people with AD, in one study Parkinson's disease Dementia, and the others did not differentiate between dementia subtypes. The including characteristics were: The participants were informal carers. The carers provided care for people with mild and moderate dementia, AD, DLB, or FTD. The association between all 12 NPSs and carer burden were studied using the assessment Neuropsychiatric Inventory (NPI, description at 5.1.2, Assessments). Further this study only included studies that investigated the strength of the association between individual NPSs and carer burden, and determined whether the association between individual NPSs and carer burden was statistically significant. A set of 1344 unique abstracts and papers were reviewed, and of them, 13 studies were included. Many concepts are used in an attempt to grasp the emotional demands of caregiving, but this review includes studies using valid and reliable measures of carer burden and distress. The guidelines for quality assessment of observational cohort and cross-sectional studies published by the National Institutes of Health<sup>2</sup>, were followed to assess quality, and the authors of the studies were contacted for additional information, when needed. The findings in each of the papers were standardized and graded on a 12-point scale, with 12 indicating the symptom with the most impact on carer burden. This ranking was based on the size of the different types of coefficients or proportions. In studies of measuring association between individual NPSs and the level of burden, mean scores were calculated across studies for each symptom. For studies looking at the association between individual NPSs and carer burden sum score, stepwise regression models were typically applied, and coefficients were only provided for the individual NPSs that were retained in the models. For these outcomes, it was calculated the proportion of studies with a standardized individual NPS score  $\geq 9$ . My own contribution to this study was to discuss the aim, with the first author, discussing limitation and inclusion/exclusion criteria's. Further we discussed the use of the assessment NPI, different use of carer reported assessment, and critically revised the paper for content and approved the final version for submission.

#### *Exclusion criteria*

Studies were excluded if they assessed carer burden using tightly defined measures of psychiatric morbidity, were descriptive or studied group differences instead of the relative effect of individual NPSs.

## 5.1.2 Paper II

This paper studied and analysed similarities and differences between the experiences of carers to people with AD and DLB at the time of diagnosis, from the dataset DemVest, a prospective cohort study from Western Norway (2005-2013, n=266), and the National Dementia Register (NDR total=2220), established in 2009. The NDR cohort consist of people with dementia or mild cognitive impairment living at home who were referred to memory clinics in Eastern, Southern and Western of Norway. From the NDR study, 17 persons with DLB were included. Eight persons with DLB were excluded due to missing data. In the DemVest-study, 169 persons with carers were included (100 AD and 69 DLB).

In the DemVest cohort the diagnoses were made according to the Diagnostic and Statistical Manual for Mental Disorders, 4<sup>th</sup> edition (DSM-IV), AD was diagnosed according to The National Institute of Neurological and Communicative Disorders and the Stroke-Alzheimer's Disease and Related Disorders Association (McKhann et al., 1984) and DLB according to the revised published consensus criteria (McKeith et al., 2005). For the NDR participants the diagnoses were made according to the ICD-10 research criteria (McKhann et al., 1984), and all had completed a standardized comprehensive assessment, including a medical history and informant interview. All NDR participants (n=17) were diagnosed with DLB, and also had a physical and psychiatric examination data available, collected with the use of standardized assessment scales, and structural brain imaging data (CT or MRI)(Nåvik, Engedal, & Ulstein, 2014).

The participants from the DemVest cohort and their carers were identified by screening all referrals to out-patient clinics between 2005-2008, followed by a further recruitment phase to selectively identify persons diagnosed with DLB and their carers, up to the end of 2013 (Aarsland et al., 2008). People with mild or probable DLB or AD, living at home with a carer who was either a spouse or a child, were included in this study. The clinicians and nurses that collected the data participated in several training sessions before the beginning of the DemVest-study, and training was repeated bi-annually. The person with dementia was first seen by a clinician who performed a structured clinical interview to collect demographic data, medical history, and drug history. The nurse performed the carer interviews and the neuropsychological tests.

Exclusion criteria were acute delirium or confusion, terminal illness, recently diagnosed with a major somatic illness, previous bipolar disorder or psychotic disorder. Persons that did not fulfil the criteria for probable or possible DLB or AD, or did not have a carer who was spouse or child, were also excluded in this study, because of the unknown time spent with the persons with DLB or AD.

### *Assessments*

The caregivers completed the Relatives' Stress Scale (RSS), developed by Greene (Greene, Smith, Gardiner, & Timbury, 1982) to measure caregiver burden for persons caring for individuals with dementia, and further developed and tested in Norway, for use as a screening instrument for psychiatric morbidity in the carers and for establishing an optimal cut-off point for such a purpose (Ulstein, Bruun Wyller, & Engedal, 2007).

The RSS has 15 different questions, each scored 0-4 (0 = never/not at all, 1 = rarely/a little, 2 = sometimes/moderately, 3=frequently/quite a lot, 4 = always/considerably perceived burden), with a total score range of 0-60. Higher scores reflects a higher reported caregiver burden (Ulstein et al., 2007). RSS can also be used as identifying carer and patient characteristics associated with various aspects of burden. RSS can be divided into three subgroups: Emotional Distress (ED question 1-6), Social Distress (SD, question 7-11, 13 ) and Negative Feelings (NF, question 12, 14-15 ) to give an opportunity to differentiate between different patterns of distress (Ulstein et al., 2007). The emotional distress section includes questions like: Do you ever feel you can no longer cope? Do you ever get depressed by the situation, or do you worry about accidents happening to the patient? Social distress ask about how the caregivers social life has been affected, if there has been any household routine changing, difficulties on getting away on holiday. Negative feelings ask about the frustration, anger and embarrassment by being a caregiver (Ulstein et al., 2007).

The Relative Stress Scale is translated and adapted for the Norwegian language and culture, with a Cronbach's  $\alpha$  of 0.91 and a factor analysis gave three factors that had an eigenvalue higher than 1.0 and accounted for 62% of the total variance. Six items were clustered into a group called "emotional distress", six items into a group called social distress and the three remaining items into a group called "negative feelings". Cronbach's alpha was 0.84, 0.86 and 0.70 respectively (Ulstein, Bruun Wyller, & Engedal, 2007). In north of Europe the Relative Stress Scale (RSS) is widely used in clinical praxis and research for evaluation of the carers' burden (Brækhus, Øksengård, Engedal, & Laake, 1999; Greene, Smith, Gardiner, & Timbury, 1982; Thommessen et al., 2002).

### *Rapid Disability Rating Scale-2 and the Neuropsychiatric Inventory*

The level of Activities of Daily Living (ADL) functioning was rated by the Rapid Disability Rating Scale-2 (RDRS-2)(Linn & Linn, 1982) and the Neuropsychiatric Inventory (NPI)(Cummings et al., 1994). RDRS-2 exists in two versions, both a 19-item version and a 21-item version, and Z-scores were applied to compare the scores form different persons with DLB and AD from the

two versions of the scale. RDRS-2 is divided into three domains, namely activities of daily living, degree of dependence and cognitive impairment. Activities of daily living contains the ability of walking, eating, bathing, mobility, dressing, toileting, grooming and adaptive tasks. Degree of dependence is measured by communication, hearing, sight, diet, tendency of staying in bed during the day, incontinence, and medication. The last area, cognitive impairment, measures the mental confusion, uncooperativeness, and depression. They are ranked as 0=best function and 3=worst function. According to the results, elderly people with minimal disability are those who do not require a lot of care, the moderately disabled are those who might require some form for treatment or hospitalizations, and the severely disabled are the people who need to be transferred to nursing home or other institutions (Linn & Linn, 1982). To identify the neuropsychiatric symptoms (NPS), the assessment Neuropsychiatric Inventory (NPI) was used. It is a structured interview with a carer and the patient, and contains 12 psychiatric and behavioural symptom items, with scores that range from 0-36, with a higher score indicating more severe symptoms (Cummings et al., 1994). The NPI is a carer based evaluation, reporting whether an individual NPS is present or not, during the last 4 weeks. Thereby the carer rates each item for frequency and severity. The amount of carer stress associated with each symptom is also registered. The 12 symptoms in NPI are: delusions, hallucinations, agitation, dysphoria, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behaviour, night time behaviour disturbances, and appetite/eating abnormalities (Cummings, 1997).

### *Cognitive measurement*

Cognition was measured by Mini Mental State Examination (MMSE), an established cognitive test with 20 items, and with a max score of 30. A higher score indicates better cognitive function (Folstein et al., 1975). In addition, the dementia severity was measured through the Clinical Dementia Rating scale, sum of boxes (CDR-SB). This is a global cognitive and functional measurement tool, with sub-items for memory, orientation, judgement and problem solving, community affairs, home and hobbies and personal care. The CDR-SB score is obtained by summing each (total of 6) of the domain box scores, with scores ranging from (0, 0.5, 1, 2 and 3) with sum scores from 0 to 18 (Morris et al., 1997; O'Bryant et al., 2008).

Socio-demographic variables like age, gender, education, social status, duration of dementia symptoms prior to diagnosis were registered from the people with dementia. Further the only variable registered from the carer, was type of carer, meaning spouse, child, or others.

Regarding study 2 and 3, they may have potential bias regarding referrals of primary care patients, which may have led to an increased number of people with complicated dementia or NPS. However, General Practitioners were invited to refer any patients with suspected dementia, and the people with dementia were included from psychiatric, neurologic, and geriatric clinics. The accuracy of diagnostic procedures was demonstrated in the 56 cases with neuropathological diagnosis (Skogseth et al., 2017).

### 5.1.3 Paper III

**Table 3.** Descriptive analysis of patient variables at baseline.

	Mild Dementia n=223	AD n=97	DLB n=63	p-value
Gender (women) <sup>1</sup>	156 (58.6%)	78 (71.6%)	36 (48.6%)	0.002
Carer (spouse) <sup>1</sup>	91 (49.7%)	53 (48.6%)	38 (51.4%)	0.764
Age (years) <sup>2</sup>	75.7 (7.6)	75.7 (7.6)	75.8 (7.2)	0.808
Duration of symptoms (years) <sup>2</sup>	2.8 (2.2)	2.4 (1.9)	3.0 (1.9)	0.010
MMSE total <sup>2</sup>	23.7 (2.7)	23.6 (2.5)	23.1 (3.2)	0.301
Years of education <sup>2</sup>	9.8 (3.0)	9.7 (3.0)	9.5 (2.8)	0.623
RSS-total <sup>2</sup>	18.2 (10.8)	15.6 (10.1)	18.6 (10.8)	0.082

<sup>1</sup> n (%), Fisher's exact test.

<sup>2</sup> Mean (SD), Mann-Whitney Test. MMSE: Mini-Mental State Examination. RSS: Relative Stress Scale.

The third paper analyses the longitudinal course of perceived distress in carers to persons with DLB and AD, over a three year period based on data from the DemVest-study. It includes 162 people diagnosed with mild dementia and of these 97 people are diagnosed with AD, 63 people are diagnosed with DLBs and registered with a carer, and living at home at baseline measurements. The recruitment of participants, diagnostic work-up and exclusions criteria are the same as described in paper 2. Carers being a child or spouse were included in this analyse. In 56 of the DemVest DLB patients the clinical diagnosis were confirmed neuropathologically, with sensitivity, specificity, positive predictive value, and negative predictive values for probable DLB to be 73%, 93%, 79% and 90% (Skogseth et al., 2017). Patients and carers were seen annually for the full study period.

## *Assessments*

Relative Stress Scale was used and are described in 2.4 and 5.1.2.

Trained nurses and clinicians conducted cognitive assessments, by using the Mini Mental State Examination (Folstein et al., 1975), neuropsychological tests, other standardized clinical instrument and biomarkers as previously described in addition to paper II, in this method section. The nurses and clinicians screened the people with dementia and their carers at baseline, one year later, two years later and three years later.

Sociodemographic variables were age, gender, education, social status and duration of symptoms prior to diagnosis for the person with dementia. Time of admission to a nursing home were also recorded. Carer information was status regarding role, in this study either as a spouse or as a child.

### **5.1.4 Paper IV**

This paper aims to describe the different experiences of carers to people with DLB and AD, and explore how coping strategies may be applied to support these carers. 21 persons in total four focus groups were recruited for this part of the study, conducting 4-6 carer in each group including spouses, adult children and grandchildren. Two of the groups consisted carers to people with DLB (n=5+4) and the two other groups consisted of carers to people with AD (n=6+6). Variation in gender, relationship, living condition, type of care and stages of dementia were represented within both groups of dementia, with 4 men and 17 women. This variation was in order to achieve greater variation in settings and participants, obtaining varied descriptions of data, by purposeful sampling principles. The carers were recruited by written letters send by nurses at out-patient clinics in western part of Norway. One reminder letter was sent out after a month by the same out-patient clinic nurses. A text message, with a reminder of the interview where and when, was sent the day before the interviews, when contact was established and written acceptance of being interviewed was signed by the carers. The frequency and quality of the relation between the carer and the person with dementia was not defined, but all of the carer confirmed that they had close contact.

The interviews started with a brief information about the study and by explaining the purpose of the study. The interviews lasted from 60-90 minutes, and were audio-recorded. The interviews had a semi structured interview guide (appendix 1), based on open-ended questions from previous findings from the quantitative part of my study, and earlier studies regarding carer to persons with dementia and their experiences. The interviews were transcribed and quotations were

translated to English from Norwegian. Participants signed an informed consent form ahead of the interviews, after receiving both written and oral information about the study. All of the steps in this part of the study were discussed with the supervisors and the candidate, all of them with experience within geriatric, psychiatric and caring fields of healthcare.

Systematic Text Condensation (STC) was used to analyse the qualitative part of the study. This approach presents the experiences as the informants presents themselves, rather than looking after an underlying meaning. STC is an elaboration of Giorgi's principles, and further developed by Malterud (2012). This method offers the researcher a process of intersubjectivity, reflexivity, and feasibility, while maintaining a responsible level of methodological rigour. Phenomenological philosophy is not as explicitly stated in STC as in Giorgi's analysis, but still shares the foundations of life-world experiences as valid knowledge (Giorgi, 2009; Malterud, 2012b). STC involves four steps in the analyse process. The first step was to read all of the transcribed interviews, both myself and the supervisors (I.T and E.S). This was to obtain an overall impression and identify preliminary themes, while constantly reminding ourselves that our professional background, clinical experience, interests or gender dominate the understanding of the themes. We created a semi-structured interview guide, to ensure that every group answered the same questions (appendix 1). We identified meaning units representing different way of caring, and organised them into coded groups. A meaning unit is a text sentence or part of a text, giving some information about the research question. We identified, classified and sorted meaning unites by the earlier coding, and debated often and changed the coded groups, finding these groups to be similar with another group, or representing two or more distinct phenomena in the same group. A creative debate between the supervisors and myself lifted the interviews in several direction, regarding discussion about having preconceptions or not, but also discussing which criteria we used while including or excluding meaning units into each code group. The third step was to organising the meaning units, condense the contents of each coded group. By reducing the content into a condensate, we identified it with an authentic illustrative quotation. By reviewing each of the subgroups within the same code group, it lead us to the results of three subgroups under each meaning units. Finally, the content of each code group were summarised and described, as sections of the results paragraph. The category heading was chosen to provide brief and expressive statements of our most important findings and the sub categories were named and placed under each main categories.



## 5.2 STATISTICS

Statistical analyses were performed with SPSS version 21 (paper II and III) and R 3.3 (Team, 2016) with the package nlme 3.1 (paper 2) (Pinheiro, Bates, DebRoy, & Sarkar, 2014). Descriptive analysis were performed to assess the characteristics of the sample in the quantitative part (paper 1 & 2), by reporting means and standard deviations of demographic data for all carers and people with dementia. For data not normally distributed, differences between groups were tested with nonparametric tests. For not normally distributed data, differences were tested by using nonparametric test.

Linear regression analyses were applied, in paper II, first unadjusted and then stepwise adjusted. RSS total, which was normally distributed in both groups, was used as the dependent variable, and demographic and clinical variables as independent variables. Variables with a p-value of 0.2 or lower in the unadjusted analyses were then entered into an adjusted linear regression applying the enter mode in SPSS. Linear regression models are used to study multifactor data, and adjust for predictors that leads to an improvement in precision of the estimated effect (Steyerberg, 2008). Further, by using linear regression the Standard Error (SE) effect of this study, measured in Stress (RSS), is smaller, because adjusted linear regression provide more power to the analysis compared to the unadjusted analysis (Steyerberg, 2008) In paper III, associations between RSS during three years after baseline and diagnosis were assessed by a linear mixed effects (LME) model including RSS-total as dependent variable, with the diagnosis, time and the interaction between time and diagnosis as independent variables. A linear mixed effects model is used to study longitudinal continuous data, where random effects serve to model the between-individual correlation structure (Verbeke & Lesaffre, 1996). We estimated the model both for linear and simple contrasts in time. The model estimated both unadjusted and adjusted for age, sex, duration of disease, type of carer, admission status (admitted to nursing home at the time point, yes/no), and MMSE-total scores. The final set of adjustments was defined based on the results of the single adjustment models (Akaike information criterion, AIC) and clinical considerations. Additionally, we used graphical methods to illustrate the development of RSS-total over time in relation to time of nursing home admission of DLB and AD patients (figure 1). The significance level was set to 0.05.

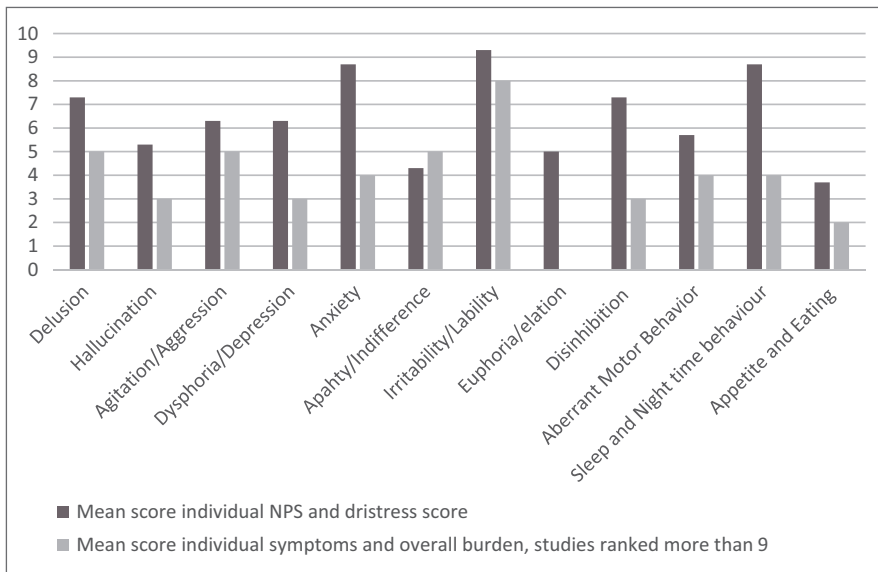
All of the statistical analyses were performed together with a statistician and supervisors (A.R. and D. A.), and discussed frequently, meaning both methods and results, and finally coming to a conclusion.



## 6 RESULTS

### 6.1 PAPER I

The major part of carers were women (70.4%) as children (53.8%), or spouses (36%) or other close relatives or “other” (e.g. siblings or children in-laws). When synthesizing the findings, the studies were divided into two groups, one investigating association between individual NPSs and distress scores (n=3), and the other one investigating association between individual symptoms and overall burden (n=10). 10 studies diagnosed dementia using on a standardized assessment program, whilst 3 did not specify. The MMSE score varied from 13.8 to 23, however in three studies the MMSE scores were not presented, but instead CDR were reported as mild to moderate dementia, which can be compared as the same stages for the others measured MMSE. Level of burden associated with specific neuropsychiatric symptoms (using NPI) indicated that irritability agitation/aggression, sleep disturbance anxiety apathy, and delusion influenced the carer burden most. The symptoms with weakest impact on carer burden were appetite and eating disorders and euphoria. However, heterogeneity in the sample size and analyses makes it hard to draw firm conclusions.



**Figure 1.** Mean scores ranking neuropsychiatric symptoms in studies exploring association between NPI and carer burden

## 6.2 PAPER II

Carer distress was measured by RSS, and divided into subgroups, and mean score for RSS total for all carers was 17.3 (SD=10.6). RSS total score, in addition to the subgroups Emotional Distress (ED), Social Distress (SD) had a significantly higher mean score by carers to people with DLB compared to carers to people with AD (table 4). When differentiating into three risk groups of psychiatric morbidity (Ingun Ulstein et al., 2007), low risk (0-22 ), intermediate risk (23-29), and high risk ( $\geq 30$ ), we found that the overall scores of carer distress were high in both carers to people with DLB and AD, with 15.1% having an intermediate and 11.3% a high risk score. However, there was a higher proportion of DLB carers in the intermediate risk group ( $p=0.030$ ). This means that 15.1% of the carers already at baseline, should be observed in case of depression, and 11.3% of the carers should be referred for psychiatric assessment and treatment. NPI intensity, UPDRS-3, and RDRS-2, mean total scores were significantly higher to people with DLB compared to people with AD (table 4). This means that caring for a person with DLB who is likely to develop NPS earlier, where daily activities are more severely impaired early on, have more challenges than a carer caring for a person with AD.

**Table 4.** Carer reported stress.

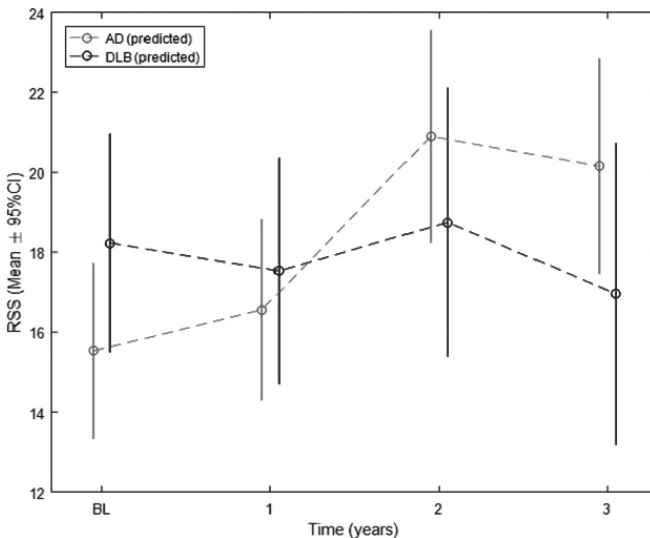
	ALL	AD	DLB	p-value <sup>1</sup>
RSS total mean, SD	17.3 (10.6)	15.0 (9.7)	19.9 (11.2)	$p=0.005$
RSS, Emotional distress, mean, SD	7.2 (4.9)	5.9 (4.2)	9.03 (5.3)	$<0.0005$
RSS, Social distress, mean, SD	6.7 (5.1)	5.7 (4.6)	8.1 (5.6)	0.006
RSS, Negative feelings, mean, SD	3.2 (2.1)	3.1 (2.0)	3.5 (2.2)	0.258
NPI intensity, mean, SD	7.5 (5.5)	6.1 (5.1)	9.1 (5.7)	$<0.0005$
UPDRS-3 total, mean, SD	6.9 (10.8)	1.7 (3.0)	14.1 (13.5)	$<0.0005$
RDRS-2, z-score, mean, SD	-0.1 (1.0)	-0.4 (0.8)	0.2 (1.2)	0.008

<sup>1</sup> Mann-Whitney Test

RSS = Relative Stress Scale, NPI = Neuropsychiatric Inventory, UPDRS-2 = The Unified Parkinson's Disease Rating Scale-2, RDRS-2 = Rapid Disability Rating Scale-2, AD = Alzheimer's disease, DLB = Dementia with Lewy Bodies, SD = Standard Deviation.

### 6.3 PAPER III

This paper reports the findings of carer reported distress, with measure points at baseline, one, two and three years follow-up, in mild dementia. There were more female patients (71.6%), and a shorter mean duration of symptoms before baseline for people with AD compared to people with DLB, but otherwise there were no significant differences regarding age, duration of symptoms prior to diagnosis, MMSE total or years of education. Carer distress measured by RSS increased significantly over time in mild dementia, however, carer distress increased more from baseline until 2 (p=0.047) and 3 years (p=0.019) for those carers caring for people with AD. RSS total score for carers to people with DLB was initial high at baseline, and had little variance across the 3 year period. Another interesting finding, was that carers to people with DLB had a significant lower (p=0.002) RSS score during the first year from baseline if the person they cared for was admitted to a nursing home, compared for those still living at home. This was not observed in carer to people with AD, however the number of spouses or children reported at RSS, was highly reduced after the person with dementia was admitted to a nursing home. By calculating a linear mixed effects model, we adjusted for age, gender, duration of symptoms prior to inclusion, type of carer (spouse/child), admission to nursing home, and MMSE total score. Change of diagnosis effect (AD vs DLB) was the only significant finding, in the adjusted model, with B=0.18 (p=0.016), meaning that our findings illustrate that the difference of the carer reported distress is influenced by the diagnosis of dementia (DLB and AD).



RSS = Relative Stress Scale, CI = Confidence Interval.

**Figure 2.** Carer distress in DLB and AD over a 3-year period.

## 6.4 PAPER IV

The results from the focus group interviews came up with two main categories. The first category was named “Different diagnosis – different symptoms”. The main findings were that carers to people with DLB and AD have some common, but also different experiences, regarding symptoms to the person with DLB and AD (table 5). Particular for carers to people with DLB were symptom described as fluctuations, hallucinations, agitation, eating and swallowing problems, daily functioning, and short term memory, mapped both through diagnosis specific symptoms, but also which symptoms the carer experiences as difficult to handle. Next category was coping strategies, divided into two sub-groups called emotional focused strategies and problem focused strategies. This section includes what the carers mentioned to be their way of dealing with the situations, and what kind of strategies they preferred, as a carer to a person with a degenerative illness, as dementia is.

**Table 5.** Overview of main and sub categories.

Carers stated:	DLB and AD	AD specific	DLB specific
<b>1. Symptoms</b>	Delusions, loss of words, sleeping disturbance.	physical agitation, deficits in short term memory.	Fluctuations, hallucinations, change in appetite, swallowing problems, variation in day-to-day functioning.
<b>2. Coping strategies:</b>			
Emotional focused strategies	Using humour, having hope, having leisure time, being despaired, learning being patience, get angry, ignoring unimportant issues, and having time for physical activity.	Need of fighting, screaming, and claiming their rights, need of grieving, but also live your own life.	Don't win every discussion, motivate the person with DLB, seeking support from family and friends, having hope, escape from threatening situations and upsetting situations with families, friends or colleagues.
Problem focused strategies	Getting knowledge, using the knowledge, sharing the knowledge, have a work or hobby, getting a good night sleep, following earlier routines.	Good communication with health professionals, take on challenge at the time, accept that we are all different.	Ability to put themselves aside, priority the person with DLB, trust their own knowledge, relaying their own judgement, hiding medicines.

## 7 DISCUSSION

In this section, the findings in this study will be discussed according to previous research and linked to the theoretical perspective of coping and coping strategies. In the end of this discussion a methodological strengths and weakness will be accounted for.

Our main findings in this thesis were that

- 1) The neuropsychiatric symptoms of the person with dementia that exert the most impact on carer burden are irritability, agitation, sleep disturbances, anxiety, apathy, and delusions.
- 2) Caring for people with DLB and AD is challenging and can lead to mental health burden and create increased risk of psychiatric disorders in the carers, already in an early stage of the disease, with a higher risk for carers to people with DLB compared to carers to people with AD.
- 3) Caring for people with mild dementia over time is associated with increasing distress, and particularly for carers to people with AD. Carers to people with DLB remain relatively stable at a high level of distress, from time of diagnosis and over a three year period. Admission to a nursing home, during the first year, was associated with a reduction in distress for carers to people with DLB compared with those caring for a person with DLB living at home.
- 4) Being a carer to a person with DLB or AD requires attention to diagnosis specific symptoms, and coping strategies.

### 7.1 DIFFERENT DIAGNOSES

Findings from paper II and paper III shows that being a carer to a person with DLB can create different and higher distress than for a carer for a person with AD, already in an early stage of the disease. Further, our longitudinal study showed that as time went by, the carers to persons with DLB remain at the same high level of distress, whilst the carer to persons with AD increased their distress from an initial low level. In paper IV we asked the carers to people with DLB and AD what they experienced as a carer. They described symptoms that differed between the diagnoses as sleep disturbances, delusions, hallucinations, fluctuations, change in appetite and changes in day-to-day functioning. From paper I, the main findings were that irritability, agitation, sleep disturbance, anxiety, apathy and delusion seems to impact carer burden most.

In the following section, these findings will be discussed in relation to previous research and perspectives of Lazarus and Folkman's theory of coping (Lazarus & Folkman, 1984).

### 7.1.1 Symptoms

Many studies have consistently found neuropsychiatric symptoms (NPS) to be among the most disturbing factors distressing carers to people with dementia, meaning increasing their carer burden (Gallagher, Fischer, & Iaboni, 2017). Especially, long-term or longitudinal studies have shown that NPS early in the course of dementia (Gaugler, Kane, Kane, & Newcomer, 2005), as well as subsequent increases in NPS later in the disease course, were most predictive of increases in carer burden over time. Further, NPS are referred to be unpredictable, disruptive, difficult to manage, potentially embarrassing or abusive, and sleep depriving for the carers (Gaugler, Davey, Pearlin, & Zarit, 2000; Gaugler et al., 2010; Shim, Kang, Kim, & Kim, 2016). In Study II (Svendsboe et al., 2016), a cross-sectional study including people with mild dementia only, we found that carers to people diagnosed with DLB experienced moderate or high caregiver burden with an increased risk of psychiatric disorders, already in an early stage of dementia. This stress was measured by the Relative's Stress Scale (RSS) (Greene et al., 1982), and was significantly associated with the level of Neuropsychiatric symptoms as measured by NPI. A recent study reports that physicians and other primary health care providers need to be aware of the psychosocial benefits for family carers of people receiving a timely diagnosis of dementia. This benefit were related to relief, validation and improved access to services by the carers (Morgan et al., 2014). According to Lazarus and Folkman (1984) the adaption to stress is mediated by appraisal of that stress, in this situation, carer distress. The coping is defined as cognitive and behavioural efforts to manage this stress, perceived as taxing or exceeding the resources of the carers. Further, coping strategies like problem-focused coping is about defining and resolving situations. Management of the problem that is causing the distress could be by generating alternative solutions, getting knowledge, weighting the alternatives, getting social support and by acting (Folkman & Lazarus, 1988). Earlier studies are inconsistent in findings of the effect of using problem-focused strategies for carers to people with dementia, but concludes that it is likely to be an advantageous (Huang et al., 2015; Kneebone & Martin, 2003). A possible explanation could be that the degree of control by the carer is low when caring for a spouse or parent, defined as a dependent elderly person (Rodríguez-Pérez, Abreu-Sánchez, Rojas-Ocaña, & del-Pino-Casado, 2017). Some of the participants in our qualitative study talked about increased nightmare, and hallucinations at night time as challenging to handle, which also other studies have reported (Lee et al., 2013; Liu et al., 2017). Our carer stated further that they were frightened in these situations, and that this change in sleep pattern by the person with dementia also affected their own sleep quality. Regarding Lazarus and Folkman (1984) emotional-focused coping describes processes, primarily cognitive, that aims to ease or manage emotional distress. Strategies like avoidance, distancing, selective attention is often chosen as attempts to resolve difficult situations. The participants in our



study described how they solved situations temporarily by escaping from the situation, or giving it selective attention. Other studies show that problem-focused strategies which intend to confront the reality, and managing unknown consequences, create a more tolerable situation and greater resilience for the carers to people with dementia (Almberg, Grafström, & Winblad, 1997; Wilks, Little, Gough, & Spurlock, 2011). However, using a mix of these two strategies seems to be a necessary way of coping for the carers in our study. One of the main findings from paper IV was that carers to people with DLB struggled with symptoms like hallucinations, delusions and nightmares which the person with DLB lived out, even after waking up. The carers in our study told that this was difficult for them to handle, and made them angry, impatient and worried. A study by De Vugt et al. (2004) reported that changes in the patient's behaviour are influenced by the carer's management. Carers that did not understand or accepted the behaviour told about more patient hyperactivity, than those who used supportive strategies. Their study concluded that the carers' impatience, irritation or anger might result in higher neuropsychiatric symptoms in the person with dementia (De Vugt et al., 2004). Another recent study reports that carer burden is a mediating factor between depressive symptoms and neuropsychiatric symptoms, and carers with higher levels of depressive symptoms are the ones who are most burdened (Delfino, Komatsu, Komatsu, Neri, & Cachioni, 2018).

According to McKeith et al. (2017) fluctuations, daytime drowsiness, lethargy, staring into space, or episodes of disorganized speech are typical in DLB (McKeith et al., 2017). This is consistent with our findings, however, carers to people with DLB stated that day time drowsiness was hard to cope with, whilst carers to people with AD talked about night time sleep disorder. It is known that carers to persons with dementia often require support services to help ease the challenges of providing care. Evidence indicating which types of interventions that are most efficient, seems to lack both in dementia general, but also when differentiating the diagnoses of dementia, and the caregiving following the diagnoses (Gilhooly et al., 2016; Quinn, Clare, & Woods, 2010). When searching for studies which differentiate between experiences of carers to people with DLB and AD, a limited number of studies were found and most of the studies have few participants. However, one study found that the severity of behavioural disturbance was associated with carer depression in DLB carers, and the DLB carers were significantly more likely to experience a major depressive disorder (Lowery et al., 2000). This is consistent with our paper II, which finds an association between carer distress and impaired activities of daily living and neuropsychiatric symptoms. Our study III shows that over time, caring distress for those with AD increased, whilst with an initial relative high level of caring distress by carers for those with DLB remained stable. A possible explanation could be that the symptoms of AD starts with "common" dementia symptoms, like forgetfulness,

disorientation and forgetting names. These symptoms are common knowledge and this predictability makes the situation more manageable and stress occurring in these situations could be addressed with a problem focused strategy. The initial symptoms of DLB includes hallucinations, fluctuations and delusions, which are less familiar symptoms of dementia. They represent a major shift in the behaviour and together with less predictability, this causes extra distress for carers to people with DLB, and an emotional focused strategy is more likely to occur in this situation. As described in study IV, a wife's solution when getting attacked by her husband due to him hallucinating, was to fight and escape from the situation. This was an emotion-focused coping as a solution to a situation she did not have the opportunity to change there and then. Another emotional coping strategy used was keeping a distance to others, like finding other places to shop for avoiding meetings with friends and families. Thus, they did not bare to confront this situation, and dealt with the stress by using emotional coping strategy aimed at regulating and reducing the emotional stress in their situation. When the carers to people with DLB told about fluctuations that made their friends and family doubting the carer's statements of the symptoms of the persons with DLB, made them sometimes stop arguing or explaining about their situations, and made the feel guilt and insufficient. . Change in behaviour such as being attacked or accused of lying, causes a higher level of distress than change in behaviour such as forgetting names, disorientation and so forth. When AD progresses, symptoms as hallucination, fluctuations and delusions, and reduced ADL function often occur. This could explain our findings in study III with high level of carer distress to people with DLB in an early stage of the disease, whilst carer distress to people with AD had lower distress in an early stage, which increased over the time.

These results show that carers to people with AD and DLB, need different, targeted support and knowledge at different stages of the disease. Previous studies suggest that carer interventions overall are ineffective, with no clear strategy to help to ease this burden. Considerations for the potentially different experiences and stressors for carers, both at the time of diagnosis and over time, are rare. (Cheng, 2017; Dauphinot et al., 2015; Hasegawa et al., 2014; Pinquart & Sorensen, 2006). Psychoeducational interventions are most effective at improving carer knowledge, reducing burden and depression symptoms, and increasing subjective wellbeing and satisfaction, even if the effects are medium to small (Gitlin & Hodgson, 2015; Pinquart & Sorensen, 2006). None of these studies differentiated between the diagnoses, which would be important to explore further in future studies.

## 7.2 MANAGING THE SYMPTOMS

Results from papers I, II, III and IV all pinpoint the fact that there is a change in the relationship between the person with dementia, and their carer, when he or she is diagnosed with dementia, in particular DLB or AD. This change affects the carer in several ways, as in taking over responsibilities their spouse or parent used to have, giving them a new role as “information link” to friends and family, dealing with their own grief and having to cope with the fact that their loved one has a degenerative mortal disease. As much as the carers in our study wanted a cure for the disease, they all were realistic about the situation. Using problem-focused coping strategies, the carers were not passive in their situation, they reported social contacts, with families, friends and neighbors, and how they made themselves small attainable goals that would engaged their focus, giving them a feeling of mastery and control. This concept of understanding the situation or stressful event is important for coping, and to further identify efforts can managing the problem causing distress (Folkman et al., 1994). In study IV, carers told about their confusing situation regarding role conceptions both when the person with dementia was living at home, and even when he/she was admitted to a nursing home. The unknowing content of their role as a carer to a person with a complicated disease, was disturbing both when the person with dementia lived at home, but also when admitted to a nursing home, and led to despair. Study III showed that for carers to people with DLB, an admission to a nursing home during the first year after diagnosis, was associated with a significantly lower reported carer distress. One of the important finding in paper II, was that impaired ADL function was associated with carer distress. One of the core clinical features of DLB is one or more spontaneous cardinal features of Parkinsonism (bradykinesia, rest tremor, or rigidity), which often occur early and may continue throughout the disease (McKeith et al., 2017). This symptom of DLB, in addition to disruptive behaviors like agitation, aggression, disinhibition, delusion and mood disturbance, may demand more physical help from the carers, compared to carers to people with AD, that don't have this initial symptoms (Cheng, 2017; Terum et al., 2017; Zupancic et al., 2011). Timely diagnosis allows the carers and the people with dementia to plan for the future, make adjustments like role- changing decisions together in front of the necessary role changes (Killen et al., 2016). The frustrations and crises may be reduced both for the carer and the person with dementia, in this role changing situation, and thereby contribute to reduce burden at the carer.

According to Norwegian Ministry of Health and Care Services guidelines (2016), empowerment is a core issue on how to provide best care and support for people with dementia and their carer (Health & Services, 2016). At every level, micro-, meso-, and macro, both the person with dementia and their carer should be enabled to get as much control over their lives as possible, through

support from the health care and their municipality. To achieve the goal of the guidelines, carer needs both to be asked and accounted for, in every stage and development in their role as a carer for a person with dementia. This study, has shown that enabling people with dementia and their carers, requires not only knowledge about the specific disease, but also about coping strategies attached to symptoms shown. This is important for the carer themselves on a micro level, for the health care professionals in order to provide proper support on a meso level, and finally for the policymakers on a macro level, when developing guidelines.

## **7.3 METHODOLOGICAL CONSIDERATIONS**

To assess the quality of these four studies, evaluation of the conceptual and methodologic decisions we made will be provided. A presentation of the reliability and validity of study I, II, and III will follow, in addition to the trustworthiness of study IV, which encompasses dependability, confirmability, credibility, and transferability (Polit & Beck, 2014)

### **7.3.1 Reliability**

The consistency of information and the accuracy are often referred to as the reliability of the study. This refers to the probability that the same result would be obtained in another similar study, meaning that the result could reflect a wider group than the participants of our study (Polit & Beck, 2014). Both qualitative and quantitative research includes a cluster of aspects of methods, designs, methodologies, epistemological and ontological assumptions. The discussion between proponents of different approaches is often not in the nature of data being used, but in bigger issues as views about the nature of reality, the limits of knowledge, purpose and politics of research. (Biesta, 2010). Morse and Niehaus (2007) discussed that one should give attention to the theoretical drive of the study, which informed the type of design used. Meaning that theoretical drive reminds the researcher of the overall direction of the project, and help the researcher to remain consistent with the principles of induction and qualitative inquiry (for qualitative projects), or with deduction and quantitative inquiry (for quantitative projects). They defined the theoretical drive of a study as the core methods component in a study, and indicates that researchers could identify this component by whether their study was approached inductively or deductively. Thus, they saw all designs having one core component and one supportive component (Morse & Niehaus, 2007) These considerations are discussed and taken account for in every step of this study, together with my supervisors, colleagues, and professors at Karolinska Institute and at Western University of Applied Sciences.

In study I, the review is limited to determining the strength of the association between individual NPSs, assessed using the NPI, and carer burden, and excluded 1306 articles because they studied the association between carer burden and the NPI scores for the total NPSs or the NPI scores for NPS clusters. This limitation was made to investigate the effect of individual NPS, even if it excludes studies assessing NPS with different assessment tools or studying different outcome measures. If we had included these articles a broader description would probably appear, but most certainly clouded the main objective, namely identify individual NPSs associated with carer burden. Another limitation of this review, is that unpublished reports are not included, and that there might be an under-representation of nonsignificant findings in the published literature, however the transparency of the process using PRISMA checklist and flowchart, provides the reader with knowledge of what papers the results are based up on (Polit & Beck, 2014). 11 papers included in this review included samples from no European countries. A recent study reported that the mean portion of people with dementia residing at home is higher in low-income or middle income countries than in high income countries (Wimo et al., 2017). The articles country's economic status and how it impact the carer burden are not addressed in this review.

In study II and III, regarding reliability, it is worth mentioning that from 2008 until 2013, only participants with the diagnosis of probably or possible DLB were recruited. This skewness in the group could have a random bias effect regarding the findings from the total dementia group, but would likely not influence the findings in the AD and DLB groups separately. However, many of the carers experiences are likely to be the same, and this was also taken into considerations when choosing the variables and analysing the data. Further this study are performed in Norway, which is an industrial high income country, with a social welfare construction which middle or low income countries don't have. The carers in Norway are not uniform, but still have the opportunity to get help from a community based welfare system, with both a physical, psychological and economic help and guidance if needed. The unique group of DLB carers in these studies makes it possible to explore and report carer's experiences from an effect of a diagnosis that has barely been studied earlier. Findings may be of great importance for further care, but because of the effect of these symptoms on carers to people with DLB.

### **7.3.2 Validity**

Validity can broadly be defined as concerning the soundness of the study's evidence, meaning whether the findings are unbiased, cogent, and well-grounded (Polit & Beck, 2014) In paper 1 the search for relevant studies were performed in major bibliographic databases, like MEDLINE, PSYCINFO, and EMBASE

through OVID. In addition manual searches were performed in the references lists of the retrieved studies. The search strategy as described in the paper, is limited to full text articles written in English, published in 1990 or later. Inclusion and exclusion criteria are described in detail. A table and description of the graded quality of the findings is presented in the review, to provide information on the quality of the individual studies. Bias was considered by two of the authors (Terum and Andersen), and were identified in articles with lack of control of potentially confounding variables in addition to sample size justification and power estimates, with dyads of 100 or less, which limiting the ability to detect smaller effect sizes (6 articles). All of the studies in this paper were cross-sectional, four studies examined the association using the Spearman rank correlation test, while three used Pearson's correlation test, five used multiple regression analyses, and one used the chi-squared test. The carer burden were reported by using NPI Caregiver Distress Index (Cummings, 1997), Zarit Burden Interview (Zarit et al., 1985), Caregiver Burden Inventory (Caserta, Lund, & Wright, 1996), and Caregiver Burden Scale (Novak & Guest, 1989), which are all valid and reliable instrument for identifying carer burden. A heterogeneity in assessment tools could have made the summary of these data problematic and of uncertain validity. By narrowing the inclusion criteria in our study, and thereby eliminate some of the heterogeneity, we argued for a respectable interpret of the findings. This study used the Preferred Reporting Items of Systematic reviews and Meta-Analyses (PRISMA). This guideline is constructed to address the quality of systematic reviews, in especially to assess the strengths and weaknesses. PRISMA checklists has 27 items pertain to the content of the reviews, which includes the title, abstract, methods, results, discussion and funding. The PRISMA flow diagram shows the flow of information through the different phases of a systematic review, and gives a clear picture of number of included and excluded papers, and the reason for exclusion.

Validity can broadly be defined as concerning the soundness of the study's evidence, meaning whether the findings are unbiased, cogent, and well-grounded (Polit & Beck, 2014).

In front of our analysis of paper 2 and 3, our preliminary calculations were that we included 122 AD and 71 DLB and found significant differences in the RSS scores between groups,  $p > 0.001$ . For the given effect size (population mean of 15.3 vs. 19.8 AD vs. DLB), SD (9.9 vs. 11.4), sample sizes (122 and 71) and alpha (0.050, 2-tailed) power is 0.817, or 81.7%. This means that 82% of studies would be expected to yield a significant difference between groups, rejecting the null hypothesis that the two population means are equal. We recruited more people and an additional 17 DLB data sets from the National Norwegian Memory Register, and therefore our planned calculations for this study had higher power

than in our preliminary results. We attempted to control for additional known and possible confounding factors like the stage of disease, admittance to nursing home and burden of medical illness. Co-variables that were included in secondary analyses are data from the person with dementia, not variables from caregivers themselves. The variables from the persons with dementia are degree/stage and type of dementia, age, sex, family relationships, medical co morbidities, education, social status, type of work/occupation, limitations in daily activities and specific sleep disturbances. A limitation of these studies were the limited socio-demographic data on the carers, the missing gender of the carers, and that the number of carers of patients declined with time, mainly due to nursing home admittance for the person with dementia, or death of one of them. Spouses and children were analyzed in the same group, both in paper 2 and in paper 3. This could have clouded the findings, when spouses most probably lives together with the person with dementia, and may have the carer role constantly. In the other hand, being carer as a child could also be extra stressful, especially if they have their own family to take care of, and don't have the opportunity to be present with the person with dementia as much as they want.

The supervisors and my own background is central in finding variables, selecting analyses, and at last, presenting the results. This may have been different if we have other occupational groups involved, or with a representative from the carer group. However, the instruments and assessments used are widely used and validated, which increase the reliability.

Sale et al. (2002) asks if it has been a growing trend of quantifying qualitative research as a direct result of mixing quantitative and qualitative approaches. It could be a result of researcher from the two paradigms attempting to work together, or the desire for qualitative research to be "taken seriously" in the world of positivist research, such as is commonly found in medicine. They further states that mixing research methods across paradigms, often diminishes the value of both methods, pressure is being exerted from the quantitative camp for qualitative research to "measure up" to its standards without understanding the basic premises of qualitative investigations (Sale et al., 2002) Focus group interviews provides detailed descriptions of experiences and beliefs by the carer. This methodology capitalizes on skills and abilities that nurses possess in their experience by gathering detailed, objective and sensitive information by using therapeutic communication and techniques. Further, as being a qualitative technique, it subscribes to the tenet that people can provide information by reporting their thoughts, feelings, and experiences. Focus group interviews maximize the collection of relevant, high-qualitative data regarding the research question (Morrison-Beedy, Côté-Arsenault, & Feinstein, 2001).



In study IV the informants were recruited through out-patient clinics in western part of Norway. An invitation letter was sent from two different regions, by nurses from these clinics. When the participants accepted the invitation, they signed and reposted the letter to the out-patient clinicians, and finally, I received the signed confirmations. This was done to protect the information about the carers, and to make sure that they did not feel any pressure to participate. In every step of this part of the study, we discussed whom the participants were, and if we could refer the results to be an accurate reflection of a wider group than those who participated in this study (Polit & Beck, 2014). Regarding the reliability of interpreting the results of these interviews, there were two supervisors, with different kind of nursing background, in addition to myself, in constant discussions in every steps of the analysis and in the writing process.

Reflecting on the relevance of the questions in the Relative Stress Scale (RSS) (Greene et al., 1982) answering the aim and objectives in this study, led to several discussion with my supervisors. In a study aiming to identify if the RSS is a useful instrument to identify various aspects of carer burden in dementia, they concludes that RSS offers an opportunity to differentiate between different patterns of distress. Even if the cohort in this study consisted of carers to people with the syndrome dementia, and not diagnose specific, they found that tailored intervention aimed at symptoms could reduce the strain of caring (Ulstein et al., 2007) By studying the RSS it seems possible to separate them into problem focused or emotional focused coping questions (Lazarus & Folkman, 1984). Typical examples that could reflect at emotional focused coping are questions like no 1: do you ever feel you can no longer cope with the situation? Or question 6: Do you ever feel that there will be no end to the problem? Compared to this emotional focused coping questions, there is also questions aiming towards problem focused coping, like question 10: Is your sleep interrupted by the person with dementia? Or question 7: Do you find it difficult to get away on holiday? However, it is worth mentioning that in my opinion the majority of the questions in RSS are emotional focused coping questions, with several question asking about negative loaded coping situations, like question 12: Do you ever feel embarrassed by...? This may interrupt the results by giving an undifferentiated picture of how the carers find positive coping strategies and use their positive coping mechanisms to enhance their caring situation. In addition, the very first question could affect the state of mind of the carers for the rest of the questions, starting out with an overall question regarding their control over the situation. However, this study reveals the different experiences being a carer for people with DLB compared to people with AD, and the negative and burdened element is an important part of their situations that also needs attention.



The use of focus group interviews as a method is chosen to get a variety of perspectives and increase confidence in the patterns that emerges. The strength of using this kind of method instead of in example one to one interviews, is that focus group participants get to listen to other's responses and thereby make additional comments beyond their own original responses. It is also a positive effect that the participants don't need to agree or disagree with the group, but rather consider their own views and knowledge in the context of view of other (Patton, 2002). Focus group can also be seen as a comforting situation for people in a carer situation with the same type of symptoms. Further the extent to if there is a relatively consistent, shared view or great diversity can be quickly assessed. The limitation might be that the available response time for each participant can be restricted, and thereby the number of question also needs to be restricted (Malterud, 2012a).

Credibility of qualitative studies depends on three elements stated by Patton (2002): Rigorous methods for doing fieldwork that data are systematically analysed with attention to issues of credibility. The credibility of the researcher, meaning experience, training for the task, track record, status and presentation of self is important in deciding credibility (Patton, 2002). By judging the credibility of data using focus group interviews, this study has the limitation that these interviews can be dominated by some of the participants, and that confidentiality cannot be assured, and thereby risk that some don't speak up freely (Patton, 2002). But on the other hand, the interviews are hold by two health-educated and well experienced nurses, with the ability to partly ask every participant to answer.

### **7.3.3 Trustworthiness**

In study IV trustworthiness, including credibility, dependability and transferability, were considered. Regarding credibility, the participants were selected to have different gender, age and roles (spouse and child) in order to get varied experiences. However this might also cloud the findings, and further studies should aim for both gender and age specific experiences. The focus groups consisted of 4 men and 17 women, which could discriminate information from the men. However both moderator and co-moderator made sure that all of the participants answered the questions, with rounds around the tables and similar initiatives. In the focus groups, there were no limitation regarding the stage of development in DLB or AD. Witnessing statements from carers to people with DLB or AD in moderate or severe stage could be frightening and upsetting for carers to people with mild DLB or AD. In the invitation letter, and at the setting of the focus group interviews, every carer were offered to talk to a nurse/geriatrician after the interviews, if needed. None of them used that offer. This offer could have made them secure to speak out more freely, knowing that their strong

and emotional stories could upset them, but still have this offer to talk with someone after. Reflecting over the group of interviewed carers, it is likely that these carers have strengths that not every carer may possess. However, their unique descriptions might be helpful for every carer. All the interviews were recorded and transcribed verbatim. Through the analysis period, the authors discussed the different steps of the analysis process, in according to reach agreement. The discussions between the authors also helped being more cautious about whether the final themes covered all data and decreased the risk of excluding some data. The most suitable meaning units were chosen, and the process of developing the theme and subthemes was documented. Representative quotations from the transcribed text were selected to illustrate the theme and subthemes. Among the authors, there is a broad experience both in geriatric nursing, medicine and in qualitative content analysis. Dependability was handled by asking the same questions in every interview in addition to having an open dialogue within the research team. Regarding transferability, efforts were made to give clear descriptions of the context, participants and recruitment phases and finally by describing analysis and results presentations with quotations (Malterud, 2011).

The quantitative part of the study was analysed and performed in front of the qualitative part of the study, meaning that the results of the quantitative study were published first. Thereby the reflection over the focus group interview guide was thorough consider, both regarding the questions from RSS, and the search of given a broader answer to the research aim. The focus group interviews were performed with a semi structured interview guide, and the participants talked relatively freely about their experiences, with some additional questions from me as an interviewer. The questions in the qualitative part are more positive directed, like: If you receive help from home care or others, could you describe what you think is positive about this help? Or: if you reflect on your role as a carer, what gives you the strength being in that role, and has this role changed you? Given all the burden and stress reported from earlier studies, it is important to investigate how the carers can cope with their situation and how they make the best of the situation. This approach will most likely interfere with the answers and results, and needs to be taken into account when analysing, as in example missing out the negative coping strategies, like abuse of alcohol and medicines.

## **7.4 FUTURE PERSPECTIVES AND INVESTIGATIONS**

In a report from The Ministry of Health in Norway, 2014, the authors conclude that interventions supporting carers of people with dementia only have small effect on carer burden (Dalsbø, Kirkehei, & Dahm, 2014). Results from this study brings up the important aspects of getting knowledge both of the specific disease, but also how and what coping mechanism might support the carers to

people with DLB and AD . Regarding common knowledge of dementia, the symptoms of AD have often been presented and acknowledged as the “rightful” symptoms of dementia, like problems with short term memory, forgetting names and problems with performing everyday tasks, as preparing meals, vacuuming and similar activities. The core symptoms of DLB are hallucinations, fluctuations, and impaired ADL functioning, occurs in an early stage of the disease. DLB accounts for 15% to 26% of all cases (Aarsland et al., 2008; Prince et al., 2015) and few carers knows what kind of symptoms DLB consists of, and there is an urgent need to be provided with more knowledge of this. Furthermore, studies of how best to support carers to people with DLB, with information, education, and other types of help, are needed. Individual support, as to what kind of assistance they can be provided with, and how coping strategies might help them to manage difficult situations is important to map, when the specific diagnosis of dementia is given. Regarding the difficulty of measuring and pre-suming/predicting the level of stress, and how to ease this burden, interventions with diagnosis specific initiatives should be taken. Measuring the experiences in direct diagnose specific education for the carers to people with DLB and AD in separate groups, using RSS and interviews, could reveal further important knowledge to ease the burden of theses carers.

The carers in this study divided their experiences into different aspects, like knowledge of the development, symptoms and life expectancy. Some carers questioned the knowledge and experience of the professional health care workers, especially regarding the DLB symptoms and development, which also a recent study reported (Killen et al., 2016). Mapping the knowledge of the professionals and provide them with education, in home care and nursing home, with further intention to strengthening this knowledge of DLB (and AD), could assure that all of the professionals had the basic knowledge of these diseases. This knowledge could increase an adaptive coping style by gaining a knowledge of the diseases symptoms and development. The function of problem-focused coping, like getting knowledge, is to manage the problem causing the distress (Folkman & Lazarus, 1988). An intervention like this, could enhance knowledge and adaptive coping in response to the challenges experienced (Killen et al., 2016).



## **8 CONCLUSION**

Being a carer to a person with dementia requires knowledge, coping strategies and professional health resources. A main finding in this study, is that differentiating between diagnoses of dementia is important for the carers coping strategies, and the understanding of the diseases symptoms and development. Further, awareness, knowledge, and support from the health care regarding symptoms, coping strategies in the nearest family of people with dementia diseases must have priority already in an early disease stage.



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