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For better and for worse, till death do us part

*Support needs of persons caring for a co-habitant
spouse or partner with dementia*

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Dissertation presented at Dalarna University to be publicly examined in lecture hall 105 (Fö 5), campus Falun, Friday, 19 April 2024 at 09:00 for the Degree of Doctor of Philosophy. The examination will be conducted in Swedish. Opponent: Associate Professor Marie Ernsth-Bravell (School of Health and Welfare, Jönköping University).

Abstract

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Background: Caring for a partner with dementia is typically stressful and challenging. Such carers can become overwhelmed by their responsibilities, neglecting their personal needs as well as their need for support as a carer. Receipt of support is low among spouse carers, while the support received may not be appropriate for their needs. More research is required to develop effective support for this important group of carers.

Overall aim: To explore the life- and caring situation of spouses caring for a partner with dementia and to increase the understanding of their needs and experiences of support.

Methods: This thesis consists of four papers (I-IV): I, Analysis of data on informal carers of persons with dementia (n=330) from a cross-sectional survey of a stratified random probability sample of adults in Sweden (N=30 009); II and III, a cross-sectional survey of a convenience sample of people aged 65 years or older caring for a partner with dementia (N=175). Hierarchical regression models explored positive and negative aspects of caring (II), and principal component analysis examined carers' perceptions of support (III); IV, a thematic analysis of semi-structured telephone interviews with 24 spouse carers, exploring their caring experiences.

Results: Compared to other carers, spouses of persons with dementia received less support from family or local authorities, while experiencing more negative impact from caring (I). Negative impact from, and positive value of, caring among spouses, were associated with different aspects of their situation (II). Support was perceived as important, yet spouses may not perceive support to themselves as more important than support to their partner (III). Spouse carers experienced a loss of self and felt confined in their situation, finding it hard to distinguish between their needs and those of their partner (IV).

Conclusion: Compared to other carers, spouses are more exposed to the negative aspects of caring, while being less supported. Support to spouse carers should focus on strengthening the positive aspects of caring to mitigate the negative aspects. As a spouse's needs are conditioned by their partner's, support should focus on spouses' personal needs and their partners' care needs.

Keywords: Informal care, spouse, dementia, support, needs, experiences

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Liksom det intet tyngre ges än att förbli stilla och överksam, när man hör berättas om andras tunga olyckor, så skänkes den största lycka och ett ljuvt lugn åt var och en, som i den allra minsta mån försöker avhjälpa dem.

Selma Lagerlöf (1933). *Levnadsvishet*. I V. Olander (Red.)

Mårbackablomster. Åhlén & Åkerlund

List of Papers

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

- I. Johansson, M. F., McKee, K. J., Dahlberg, L., Williams, C. L., Summer Meranius, M., Hanson, E., Magnusson, L., Ekman, B. & Marmstål Hammar, L. (2021) A comparison of spouse and non-spouse carers of people with dementia. A national descriptive analysis of Swedish national survey data. *BMC Geriatrics*, 21(1):1–11
- II. Johansson, M. F., McKee, K. J., Dahlberg, L., Summer Meranius, M., Williams, C. L. & Marmstål Hammar, L. (2022) Negative Impact and Positive Value of Caregiving in Spouse Carers of Persons with Dementia in Sweden. *International Journal of Environmental Research and Public Health*, 19(3): 1788
- III. Johansson, M. F., McKee, K. J., Dahlberg, L., Williams, C. L. & Marmstål Hammar, L. (2023) Perceived Importance of Types and Characteristics of Support to Informal Caregivers Among Spouse Caregivers of Persons with Dementia in Sweden: A cross-sectional questionnaire based study. [Submitted for publication]
- IV. Johansson, M.F., Marmstål Hammar, L., Dahlberg, L., McKee, K. J., Williams, C. L. & Summer Meranius M. (2023) Exploring the Experiences and Needs in Everyday Life of Spouse Carers of Persons with Dementia. [Manuscript in preparation]

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Abbreviations and translations

| | |
|-----------------|---|
| HSL | Hälsa- och sjukvårdslag (2017:30) [Eng. Health and Medical Services Act (2017:30)] |
| KL | Kommunallag (2017:725) [Eng. Swedish Local Government Act (2017:725)] |
| Nka | Nationellt kompetenscentrum Anhöriga [Eng. Swedish Family Care Competence Centre] |
| PCA | Principal Components Analysis |
| Prop. | Proposition [Eng. Government bill] |
| PWD | Person with dementia |
| SCB | Statistikmyndigheten SCB [Eng. Statistics Sweden] |
| Socialstyrelsen | [Eng. The National Board of Health and Welfare] |
| SoL | Social Service Act (2001:453) [Swe. Socialtjänstlag (2001:453)] |

Preface

When I started my training as a social worker at the then Ersta Sköndal University College, now Marie Cederschiöld University College, I never intended a career in academia. I had my mind set on getting a degree so I could secure a white-collar job after working as a janitor and cook in different childcare facilities and residential care facilities for older adults. My ambition fell somewhere between aspirations of changing the world and providing support to people in need. I thought about the possibility of a career as a manager in the care of older adults or maybe as a hospital social worker.

My journey into academia can only be described as a sequence of unforeseen events and opportunities, which were presented at the right time and under the right circumstances, piquing my interest and curiosity. It all started when I got the opportunity to do my fieldwork semester as part of a research project run by Prof. Magnus Karlsson, a chance I could not resist. After its completion, he asked if I would be interested in continuing with the project; another opportunity that I immediately accepted. To make a long story short – I stayed on working part time as a research assistant for one year and 11 months, during which time I graduated as a social worker and finished my Master of Arts in Social Work (60 credits). One month after receiving my Master's Degree, Assoc. Prof. Magdalena Elmersjö, my thesis supervisor, called me to ask if I would be interested in working as a substitute teacher in social work. While I realised that this would be challenging, it was another opportunity that offered me the chance to develop my academic and pedagogical skills.

Somewhere along the way, my mission as social worker changed, from the social services to academia – and that is how I ended up in Falun as a PhD-student in care sciences. I still want to change the world... well maybe not the world, but at least try to change the welfare system for the better. Over the last five years I have accepted that my thesis might not completely overthrow the current support systems in place for spouses caring for a partner with dementia, but I believe that the research presented in this thesis will make an important contribution to the development of evidence-based support to a group of individuals that our welfare state depends on.

Marcus Falk Johansson, Falun 2024-02-15

Introduction

Dementia is recognised as a leading cause of dependency among older adults, impacting an estimated 150,000 individuals in Sweden. The majority of those affected live in the community, relying on informal carers – most often a spouse – for help and support (Bökberg et al., 2018; Socialstyrelsen, 2012, 2022; World Health Organization, 2017). These are often called spouse carers. In this thesis, the terms ‘spouse’ and ‘spouse carer’ encompass all individuals in marriage-like relationships with someone with dementia, not only those formally married to their partner. Spouses caring for a partner with dementia may experience a substantial negative impact on their life situation due to the care they provide, however, caring experiences may also be experienced as positive (Lindeza et al., 2020; Macdonald et al., 2020). To alleviate any negative impacts and create opportunities to foster wellbeing for spouses navigating their partner’s dementia, it is important that they are supported (Tolhurst et al., 2019; Whitlatch & Orsulic-Jeras, 2018). In Sweden, informal carers have had the right to receive support from local authorities since 2009 (Johansson et al., 2011). However, support tailored to informal carers needs to be further developed and additional research is needed to address their diverse needs (Socialdepartementet, 2022; Socialstyrelsen, 2022; Takter, 2020). This thesis focuses on spouses caring for a partner with dementia in Sweden, looking into their everyday lives, caring situations, and exploring their needs and experiences of support.

The thesis was conducted within a doctoral program in care sciences, in the area of Health and Welfare, with a focus on evidence-based practice. Care sciences, as an interdisciplinary field of research, addresses research questions focusing on health promotion and disease prevention, the care and support of persons with illnesses, and those caring for them. Additionally, it encompasses the rehabilitation and habilitation of persons with illnesses and disabilities to promote health and wellbeing (Vetenskapsrådet, 2012). In this thesis, the term ‘care’ has been operationalised to encompass a wide range of concepts including hands-on assistance directly linked to an individual’s illness, loss of function, or old age, which may also include informal care. Informal care encompasses any unpaid help or service being provided on a regular basis by a family member or other next of kin (Aneshensel et al., 1995; Jegermalm & Torgé, 2021; Swartz & Collins, 2019). Thus, the term ‘care’ covers both formal

health and social care for individuals living with dementia and the unpaid care, help, and support provided by informal carers. Further, the support provided by health and social care professionals to spouses and other informal carers providing care, help, and support to a person with dementia could be incorporated within the broader concept of care.

The area of the doctoral program, *Health and welfare with a focus on evidence-based practice*, concerns the development of knowledge or evidence to inform practice and promote evidence-based practice within health and social care (Högskolan Dalarna, 2019). Evidence-based practices incorporate research findings, professional expertise, individual views, and contributions from clients or users, incorporating their knowledge, preferences, and attributes. Each source is given equal value as evidence to guide practice (Gilgun, 2005; Rycroft-Malone et al., 2004). In Sweden, the National Board of Health and Welfare (Socialstyrelsen, 2020) provides guidance to how health and social care should interpret evidence-based practice; emphasising the integration of the best available evidence, users' experiences, wishes, and attributes, as well as contextual situations, as part of policy. Professional expertise and judgement also play a crucial role in this integration.

This thesis contributes to the development of evidence-based support for spouses caring for a partner with dementia. It adds further knowledge by looking into not only their situation and attributes, but also by shedding light on their perceived needs and their perceptions and experiences of support and how it meets or does not meet their needs.

Background

Informal care

The term ‘informal care’ covers the provision of care, help, and support provided by a non-professional carer on a regular, unpaid basis. Informal care may involve hands-on care directly related to a person’s disability, illness, or advanced age, or help and support with everyday activities, such as transportation, supervision, or social stimulation (Aneshensel et al., 1995; Swartz & Collins, 2019). Informal carers are individuals who provide this kind of care. They may be defined based on their relationship to the person they care for, help, and support. This implies that anyone who provides unpaid care, help, and support on a regular basis to a family member, friend, or other individual in their social network, whether inside or outside their household, can be considered an informal carer (World Health Organization, 2021).

Informal carers are an essential source of care for individuals of advanced age or with long-term care needs on a global scale, emerging as the source of care in most countries within the Organisation for Economic Co-operation and Development (OECD) (OECD, 2021). Within the European Union, estimates suggest that informal carers provide 80% of all care for persons with long-term care needs (European Commission, 2021b; Zigante, 2018). The estimated percentage of the population engaged in informal care varies between countries, but it has been estimated that an average of 13% of individuals aged 50 or older provide informal care at least once a week in the OECD (World Health Organization, 2021). In the EU, the corresponding estimates range from 12-18% of the population aged between 18 and 75 years old (European Commission, 2021b).

As the population continues to age, estimates indicate an increasing proportion of the population will need long-term care, including persons with dementia. Research has highlighted that health and social care providers are already struggling to meet long-term care demands, and that there will be an escalating need for informal carers due to a greater number of individuals needing health and social care (Costa-Font & Raut, 2022; OECD, 2018). The effects of this trend have been explored, and it has been suggested that informal care can reduce public expenditure on formal care (Bremer et al., 2017). The European Commission has assessed the relationship between informal care and formal

care expenditure, revealing that if only 1% of the proportion of adults being cared for by informal carers were to transition into formal care each year, public expenditure on long-term care would increase by 109% over a 10-year period (European Commission, 2021a). While acknowledging the financial benefits that informal care brings to health and welfare systems, it is important that these are weighed against the potential detrimental impacts informal care may have on the physical, mental, and social wellbeing of the informal carers (Verbakel et al., 2017).

Regarding dementia, global estimates show that, on average, each person with dementia receives approximately six hours of support with activities of daily living and supervision from an informal carer daily, totalling up to 2089 hours annually. This translates into a global total of a staggering 82 billion hours (Wimo et al., 2018). It is also important to note that most informal carers for persons with dementia are women (Wimo et al., 2018; World Health Organization, 2022), with spouses being the largest proportion of primary informal carers (Wimo et al., 2018).

Informal care in Sweden

The responsibility for providing care to individuals of advanced age and those with disabilities differs between countries (Tokovska et al., 2022). Sweden has become the typical example of the Scandinavian (social democratic) welfare regime, characterised by a universal and de-familiarized welfare model (Esping-Andersen, 1990, 1999). In Sweden, the responsibility to provide care and welfare services rests with local authorities (Socialtjänstlag, SoL [2001:453], 2 kap. 1 §; Hälso och Sjukvårdslag, HSL [2017:30], 5 kap. 1 §) along with the right to levy taxes for its financing (Kommunallag, KL [2017:725], 1 kap. 3 §, 2 kap. 4§). However, the division of responsibility between the state, the market, and the family, a fundamental principle of the Scandinavian welfare regime, has undergone significant changes since the 1980s, resulting in a shift in the welfare state (Jegermalm & Sundström, 2017; Sivesind, 2016). This shift has led to a significant reduction in the state's provision of care for older adults, accompanied by an increase in informal care in recent decades (Dahlberg et al., 2018; Ulmanen & Szebehely, 2015).

According to estimates, approximately 725 million hours of informal care and support, in their broader definition, are provided by informal carers to individuals in need of long-term care due to illness, disability, or advanced age in Sweden alone. This equates to SEK 193.6 billion in formal care costs annually (Ekman et al., 2022; Ekman et al., 2021). Estimates related to informal care should be read with some caution due to variations in the definitions of what constitutes informal care as well as who informal carers are. However, when

considering help and support, it is suggested that approximately 15% of the adult population serves as informal carers (Ekman et al., 2022). Other estimates suggest a slightly higher figure, stating that 21% of the adult population provides care to individuals with needs related to prolonged illness, disability, or advanced age (Jegermalm & Sundström, 2017). There is a difference in the provision of care between informal care provided to individuals within and outside the carer's household, with cohabitant family carers, typically spouses, often spending more hours each month providing care and being more engaged in hands-on personal care (Jegermalm & Torgé, 2021).

With this broad definition of informal care, individuals in the age group of 45-64 emerge as the largest segment of informal carers, most often children providing care, help, or support to a parent (Nationellt kompetenscentrum Anhöriga, Nka 2014). However, in terms of time spent on caring, the age group 65-80 years old makes the greatest contributions (Nka, 2014). The individuals in this older age group also most often tend to be spouses and cohabitants of the person they care for (Jegermalm & Torgé, 2021). While most informal carers in Sweden are part of a caring network where responsibilities are shared with other informal carers, as well as health and social care providers, cohabitant carers, such as spouses, receive the least amount of support in their caring roles. Almost a third of cohabitant carers are alone in their caring responsibilities (Jegermalm & Sundström, 2017; Jegermalm & Torgé, 2021).

Dementia

Dementia, a term often used colloquially as an umbrella term, is not a specific disease but rather a syndrome commonly associated with, but not limited to, memory loss (Breitner, 2006; Gauthier et al., 2021). Dementia can be caused by a range of different diseases, each with their own distinct symptoms. Nonetheless, they are all generally characterized by a gradual, progressive deterioration of cognitive functions (Breitner, 2006; Gao et al., 2019). Common difficulties faced by persons with dementia include memory difficulties, confusion, difficulties with time management and problem solving, as well as impacted executive and visuospatial functions. Furthermore, persons with dementia may experience emotional symptoms, including anxiety and depression. They may also display behavioural symptoms such as personality changes, inappropriate behaviours, and social and relationship withdrawal. While these are common symptoms, different types of dementia disorders may exhibit differently (Gauthier et al., 2021; Serge et al., 2022; World Health Organization, 2017).

Dementia is recognised as a leading cause of disability and dependency (Prince et al., 2015; World Health Organization, 2017), affecting over 57 million individuals worldwide (GBD Dementia Forecasting Collaborators, 2022), including between 130,000 to 150,000 in Sweden. The progression of dementia is typically divided into stages, ranging from mild cognitive impairment to severe or major cognitive impairment. In the early stages, characterised by mild cognitive impairment with few cognitive functions impaired, individuals may function relatively independently in their daily lives. However, as the condition advances into the later stages, severe cognitive impairment emerges, affecting multiple cognitive functions. At this point, individuals may require extensive support in their daily lives or become dependent on specialized care (Knopman & Petersen, 2014; World Health Organization, 2017).

Persons with dementia may experience changing and extensive care and support needs in a range of aspects of their lives. Examples of such needs include home and personal safety (including home adaptations or assistive devices), support with daily activities (including personal hygiene and incontinence management), and support to manage neuropsychiatric and cognitive symptoms (Black et al., 2019; Serge et al., 2022; World Health Organization, 2017).

The care needs of persons with dementia may be extensive, depending on the severity of impairment. While professional health and social care are essential, research also suggests that being cared for in the familiar home environment is an essential part of good care practice for persons with dementia (Poole et al., 2017; Serge et al., 2022), with dementia care policies often aiming to delay admission to residential care (Wang et al., 2022).

Informal care of persons with dementia

The majority of persons with dementia reside in the community rather than in residential care settings, and both national and international studies emphasise the crucial role of informal carers, most often spouses or daughters, in the care of persons with dementia (Bremer et al., 2017; Bökberg et al., 2018; Chiatti et al., 2018; Verbakel et al., 2017). Most informal carers of persons with dementia are women (Wimo et al., 2018; World Health Organization, 2022), with spouses being the largest proportion of primary informal carers (Wimo et al., 2018). The involvement of informal carers in the care of persons with dementia has been argued to benefit them (Lepper et al., 2020; World Health Organization, 2017). This trend can also be seen in Sweden, where the national strategy on dementia care states that informal carers should be more engaged in the planning and delivery of care (Socialstyrelsen, 2018, 2022).

Motivations to care for a partner with dementia

Caring for a partner with dementia is seldom a discrete choice for the person providing care; rather it is a slow transition into a caring role (Aneshensel et al., 1995; Steinfeldt et al., 2021). In some instances, individuals may feel obliged to provide care due to statutory regulations (Spasova et al., 2018). However, more often, the decision to care for a partner with dementia is influenced by multiple and inter-related personal, social, and cultural norms, expectations, and motives (Greenwood & Smith, 2019; Zarzycki et al., 2023). Spouses may choose to take on a caring role due to a lack of appropriate formal dementia care or the belief that being cared for at home by a family member is superior to professional dementia care (Greenwood & Smith, 2019; Tyrrell et al., 2019). Social or cultural pressure may also play a role, stemming from religious or cultural beliefs (Greenwood & Smith, 2019). Additionally, expectations to provide care may come from other family members and health and social care providers (Cash et al., 2019; Macdonald et al., 2020).

Caring for a partner with dementia can also be driven by a sense of responsibility for their partner's wellbeing (Greenwood & Smith, 2019). Other motives may arise from a sense of reciprocity, mutuality, and commitment to their relationship, coupled with love for their partner and a fear of losing them to dementia (Greenwood, Pound, & Brearley, 2019; Greenwood & Smith, 2019; Swall et al., 2019). Furthermore, studies have shown that motivations for caring for a person with dementia may differ between spouses and other informal carers. For example, children may be motivated to care for a parent with dementia as it provides an opportunity to maintain their relationship with their parent and simultaneously support their other parent in their caring role (Dombestein et al., 2020).

Consequences of caring for a partner with dementia

The contribution made by spouses caring for a partner with dementia comes with significant personal costs. They often face unpredictable and demanding situations relating to both the care they provide and the challenges associated with the care recipient's dementia. The situation is typically stressful and may have a considerable impact on various aspects of the carer's physical, mental, and social wellbeing (Allen et al., 2017; Alzheimer's Disease International, 2019; Steinfeldt et al., 2021; Walter & Pinquart, 2020).

The negative biopsychosocial response to caring is sometimes described as carer stress or burden (Aneshensel et al., 1995; Montgomery et al., 2016; Zarit et al., 1986). The degree of burden experienced by carers is influenced by several different factors, and its causes are seldom straightforward. However, the nature of the relationship between the carer and person with dementia has

been shown to influence the perceived burden of care. Spouses caring for a partner with dementia may be particularly vulnerable to certain negative consequences of caring. Examples of negative outcomes of care include poorer physical and mental health (Allen et al., 2017; Kirvalidze, Beridze, et al., 2023).

Spouses caring for a partner with dementia not only face a higher risk of adverse consequences than other carers of persons with dementia, but research also suggests that they are more vulnerable to specific negative outcomes than those caring for a partner with different conditions or non-carers of a similar age. Examples of negative consequences include depressive symptoms, loneliness, and social exclusion (Adams, 2008; Beeson, 2003; Hajek et al., 2021; Victor et al., 2020). The caring experience for spouses caring for a partner with dementia is unique, as they are tasked with an overwhelming caring responsibility for a life companion with whom they often reside. Simultaneously, they are also more likely to be older and have their own health concerns (Macdonald et al., 2020; Rigby et al., 2019). Spouses may experience their caring role more intensely than other carers, feeling that they are not only losing their partner to dementia, but also losing themselves to the demands of the care role (Macdonald et al., 2020; Steinfeldt et al., 2021). Spouses caring for a partner with dementia have also been found to face difficulties navigating their own personal needs and interests alongside their caring responsibilities and the needs of their partner. As their partner's needs may be perceived as more important than their own, carers sometimes neglect their own needs and interests (Lee et al., 2022; Lee et al., 2019; Tatangelo et al., 2018).

While the negative consequences of caring for a partner with dementia dominate the literature on spousal care of persons with dementia, there is a growing body of research focusing on the positive caring experiences among couples living with dementia (Lindeza et al., 2020; Lloyd et al., 2016; Macdonald et al., 2020). Positive experiences of caring include a sense of personal growth and accomplishment in managing their situation while also being able to provide value for their partner with dementia (Macdonald et al., 2020; Quinn et al., 2022). The positive aspects can also be related to the relationship with the partner with dementia, and through caring they can experience glimpses of who their partner used to be prior to dementia. Additionally, spouses may also experience that caring brings the couple closer and provides a sense of purpose in their lives (Greenwood & Smith, 2016; Polenick et al., 2019; Quinn et al., 2022; Wadham et al., 2016).

Spouses' needs in the caring situation

Ideally, support for carers should be tailored to their needs based on their specific situation. However, research on carers' needs often lacks a specific focus

on the different needs in carers with distinct relationships to the person they care for (Queluz et al., 2020; Tookey et al., 2021). Despite the limited number of comprehensive studies on how needs differ between spouses and other carers, based on the available literature it is reasonable to assume that support needs differ between spouses and children caring for a person with dementia. Research has shown that spouses have unique needs, and that carers with different familial relationships to the person with dementia perceive the caring situation and their support needs differently (Dang et al., 2022). Often, spouses have support needs beyond the practical or instrumental aspects of caring for a person with dementia. These may include the need to redefine their spousal role and relationship (Atoyebi et al., 2022; Dang et al., 2022; Duggleby et al., 2017; Statz et al., 2022).

Spouses caring for a partner with dementia often report needs related to their own personal health, information, or education about their partners dementia, as well as information on available support and preparedness for caring activities (Hammar et al., 2019; Mansfield et al., 2023; Soong et al., 2020; Tookey et al., 2021). Additionally, spouses may have social needs such as the desire to spend time with others beyond their partner with dementia, and the need for respite from their caring responsibilities (Steenfeldt et al., 2021).

However, research tends to focus on the needs related to the care that spouses provide, while less attention is given to the existential and emotional aspects associated with their caring situation. Existential needs for spouses can involve not knowing what the future holds, a shift in self-perception, questions regarding how and when they need to let go, and concerns about how they will manage in a post-caring situation (Høgsnes et al., 2014; Stefánsdóttir et al., 2022; Thorsen & Johannessen, 2021). Their emotional needs are often associated with experiences of loss and grief, but may also be related to feelings of loneliness, shame, guilt, as well as anger and frustration related to their partner's dementia. However, further research is needed on these issues in order for them to be comprehensively understood (Fowler et al., 2022; Hammar et al., 2019; Tyrrell et al., 2019; Van Aerschot et al., 2022).

Support to spouses caring for a partner with dementia

The consequences of informal care for persons with long-term care needs and those with dementia, along with their support needs, have become an urgent public health matter, highlighted by the World Health Organization (World Health Organization, 2017, 2022). Support for carers of persons with dementia is sometimes divided into instrumental, emotional, and informational support. Instrumental support involves helping with everyday activities in the household, emotional support involves managing uncertainty, stress, anxiety etc., and informational support involves professionals or peers who have their own

experiences of caring under similar circumstances providing information (Brodaty & Donkin, 2009). It has also been reported that there is an increasing number of countries that have adopted strategies to support informal carers (OECD, 2018; Rocard & Llana-Nozal, 2022; Tokovska et al., 2022). However, the uptake of services for informal carers of persons with dementia tends to be low, and challenges exist regarding the content and delivery mode of support services (OECD, 2018; Zwingmann et al., 2020).

Studies suggest that despite policies being put in place, spouses caring for a partner with dementia sometimes experience difficulties in accessing support. These can be caused by a lack of sufficient information about available services, or constraints in their life due to the care they provide, such as not being able to engage in social functions. It has also been argued that spouses, in particular, may not perceive services as helpful, or that they do not recognise their need for support due to their lack of focus on their own needs (Bieber et al., 2019; Jiménez et al., 2022; Macleod et al., 2017; Tyrrell et al., 2019; Zwingmann et al., 2020). Additionally, studies suggest that spouse carers may experience that available support services are not equipped to meet their often multifaceted needs (Fowler et al., 2022; Hammar et al., 2019; Tyrrell et al., 2019). In comparison, research argues that the availability of and positive experiences with formal care may promote the use of carer support among spouses caring for a partner with dementia (Macleod et al., 2017; Zucchetto et al., 2022).

There is an extensive body of evidence on specific interventions for informal carers in general, including informal carers of persons with dementia (Cheng & Zhang, 2020; Kirvalidze, Abbadi, et al., 2023). However, as noted by Gaugler et al. (2017), there is inconsistency in the categorization of support interventions. Furthermore, research on carer support interventions has been characterized by broad heterogeneity in outcome or efficacy measurements, as well as the context and content of the interventions. Additionally, there is often a lack of distinction between carers with different kinship to the care recipient (Cheng & Zhang, 2020; Kirvalidze, Abbadi, et al., 2023; Oliveira et al., 2022). With this perspective, most of the common carer support interventions demonstrate mixed or inconclusive evidence regarding their effectiveness, often showing low to moderate effect sizes (Kirvalidze, Abbadi, et al., 2023; Walter & Pinquart, 2020; Williams et al., 2019). However, studies suggest that interventions may still be effective in supporting spouse carers, especially when tailored to meet specific needs or address the consequences of caring for a person with dementia (Abrahams et al., 2018; Cheng & Zhang, 2020).

Some argue that support services that prepare spouses for caring, such as psychoeducational support, may be beneficial as they reduce the negative consequences of caring (Steenfeldt et al., 2021; Tookey et al., 2021; Wawrziczny et al., 2018). The transition into caring may also result in feelings of no longer being married as their partner's dementia progresses. The impact on the relationship is sometimes attributed to a loss of communication and no longer being able to maintain a reciprocal relationship. While the relationship often encompasses other qualities, some studies suggest that increased communication between spouses may be beneficial for both the spouse and the partner they care for. Additionally, studies have found that dyadic support, such as joint exercise, may improve the psychosocial and health situation of spouse carers (Doyle et al., 2021; Monin et al., 2019; Steinfeldt et al., 2021; Whitlatch & Orsulic-Jeras, 2018).

Spouses may also experience their caring responsibilities as overwhelming, resulting in the neglect of their own personal interests and feelings of being trapped in their caring situation. Research has shown that respite care may be beneficial in meeting their need for rest (Steenfeldt et al., 2021; Vandepitte et al., 2016; Williams et al., 2019). However, respite services outside of the household, such as short-term residential care, seem to have double-sided effects. A recent review by Steinfeldt et al. (2021) noted that carers may experience ambivalence towards separation, and this may contribute to their burden. Similar findings regarding day care services have previously been reported (Vandepitte et al., 2016).

Social support for spouse carers has also been suggested as a way to alleviate burdens and facilitate carer abilities, foster resilience against negative consequences of care, and also ease experiences of becoming isolated in the carer role (Abrahams et al., 2018; Carter et al., 2020; Donnellan et al., 2017; Rigby et al., 2019). The term 'social support', however, seems to be used inconsistently, sometimes referring solely to support from friends or family, and at other times referring to more structured peer-support programs or support groups, and vice versa.

The existing literature highlights that carer support may be beneficial, however, when examined on an aggregated level, such as in a review and meta-synthesis, the qualitative value – providing a sense of affinity or a sense of coherence, for example – for the individual may diminish. It further argues the need for individualized support and that there is no one-size-fits-all solution.

Policy development on support to informal carers in Sweden

For the majority of the 20th century, informal carers have been relatively neglected in the care of older adults, including those with impairments such as dementia. This oversight is based on an informal understanding of the division of provision of care that is shared by civil society and public providers, where the state is seen as the primary provider of health and social care, while civil society and family are merely seen as a complement to this (Dahlberg, 2006; Jegermalm & Sundström, 2017; Johansson et al., 2011).

The Social Service Act of 1982 did not mention informal carers, however, it marked a shift in the long-term care of individuals in need and older adults by highlighting that all care of older adults should be based on principles of autonomy, independence, and ageing in place. In the following years, a government review was initiated to investigate necessary changes in the care of older adults for the upcoming decade (Johansson et al., 2011). The review resulted in the Government's Bill 1987/88:176 on eldercare for the 1990s. This bill formalised the policy that the state has the primary responsibility to meet the care needs of older adults, with informal care being regarded as a complement (Johansson et al., 2011). Additionally, the bill proposed that individuals choosing to care for a family member should be provided with a public allowance to enable them to be absent from work for up to 30 days a year. The bill also recommended that municipalities develop support for informal carers such as 'respite and other personal support' (Prop. 1987/88:176).

In the following decades, the Social Services Committee, which was commissioned in the early 1990s to review and suggest amendments to the Social Service Act, repeatedly advocated for increased support to informal carers. This resulted in legislative changes, with the first being a paragraph in the Social Service Act that came into force in 1998 stating that 'Social services should support and provide relief to those who care for a next of kin with chronic illness, elderly people, or people with disabilities.' The paragraph, however, was framed as a recommendation rather than an obligation to support carers. The legislative changes sparked discussions that a right to support might impede the view that informal care is a voluntary complement to formal care, and that the best support for informal carers was a well-functioning system of care for older adults (Johansson et al., 2011).

Almost a decade after the initial paragraph came into effect, a Government bill (2008/09:82) was introduced, containing changes in chapter 5, paragraph 10 of the Social Service Act. The key modification was a heading being changed from "Informal carers" (Anhörigvårdare) to "Persons caring or sup-

porting a next of kin” (Personer som vårdar eller stödjer närstående). The revised paragraph that came into effect in 2009 stated that “Social service shall provide support to facilitate for persons caring for a next-of-kin with a chronic illness or elderly people or who support a next-of-kin with a disability” (Prop. 2008/09:82; SoL (2001:453)). While this meant that municipalities were obligated to provide support to individuals caring for a next-of-kin, the term ‘relief’ was omitted from the new paragraph (Johansson et al., 2011).

While the new paragraph in the Social Service Act gave informal carers the right to receive support, the specific content or quantity of this support was left to the discretion of individual municipalities. This resulted in a wide array of different solutions for carer support. The National Board of Health and Welfare (Socialstyrelsen, 2012, 2014, 2016, 2018), interest organisations (Takter, 2020), and scholars (Jegermalm, 2004; Wimo et al., 2002) have repeatedly expressed concern about the varied support needs, consequences of caring, and the availability of support.

Following a report from the Swedish Family Care Competence Centre that suggested the need for a national strategy on informal care in Sweden (Magnusson et al., 2018), a government bill was presented in 2019 (Socialdepartementet, 2019), proposing the development of a national strategy. Consequently, the first strategy for supporting informal carers was adopted in 2022 (Socialdepartementet, 2022; Socialstyrelsen, 2022). The strategy maintains the principle that informal care should be voluntary but places emphasis on supporting carers through a well-functioning health and social care system for individuals in need. It also added that health and social care should be delivered with a carer perspective, making sure that informal carers are involved and informed. The strategy also highlights that informal carers may have needs of their own, that are unrelated to their care-receiving next of kin. It also states that support to carers needs to be individualized to meet their unique needs. Additionally, the strategy acknowledges the need for further knowledge on what being an informal carer entails and how the condition or disability of the care-recipient may impact the support needs of informal carers (Socialdepartementet, 2022).

Scientific and theoretical points of departure

View on knowledge

I base my understanding of knowledge not as an objectively measurable reality but rather as our collective, socially constructed understanding of reality. In the seminal work *The Construction of Social Reality* by Searle (1995), he presents a multi-layered ontology, making a crucial distinction between brute objects and social or institutional objects. Brute objects exist regardless of social interactions; they are objects or facts that cannot be disputed. On the other hand, social objects are generated through interactions and social activities. Thus, a social object is based on our shared, collective understanding of a brute fact within a specific context (Searle, 1995). In a correspondence between Smith and Searle (2003), Smith contests the necessity of brute facts in the construction of social objects. In response, Searle argues that to the contrary there is no requirement for a real observer-independent truth about social facts. Rather, social facts are built on our social activities, proving an institutionalized meaning to brute facts. Once the social fact is established, the brute fact is no longer necessary. Similar arguments have been proposed by Bourdieu et al. (1991), advocating for an epistemological understanding where social facts should be treated as things. In research, we apply our understanding of reality. In this thesis the items, measurements, and concepts used are all constructed and labelled by individuals: they are not brute facts but social facts.

Moreover, I would argue that while quantitative methods have often been perceived as positivistic, relying solely on quantifiable observations and objective, measurable truths, this is a misconception. As Zyphur and Pierides (2020) ascertain, statistics have always been value-laden, and the very concept of objective facts or truth is, and always has been, shaped by how social groups of researchers attribute value and arrange their discourses and study objects. This is also present in this thesis. For example, participants' 'health' is measured using a single item for self-rated health, where a five signifies excellent health. While this is seen as a true observation, it is, in fact, an institutionalized or social fact, based in the research context where the numerical value of 'health' is seen as the truth without considering measurements of disease or disability. Additional examples of this can be found in the notion of p -values, where the arbitrary threshold of 0.05, with a 5% risk that the null hypothesis cannot be

rejected, is widely accepted as the limit for deeming an association or test significant and as a representation of reality. Consequently, I cannot claim that the findings presented in this thesis are objectively true or a presentation of brute reality. Instead, they should be regarded as social facts, representing the social reality of the participants and interpreted through scientific methods to generate knowledge on the social reality. It is important to acknowledge that the quantitative findings are interpreted within the context of the 5% margin of error that has come to be accepted in our social context.

Theoretical perspectives

There are several theories and frameworks that can be applied to expand the understanding of informal care, with some theoretical perspectives having had a deeper impact on the research area than others. Examples of theories that have had a profound influence include the concepts of carer stress and burden, as claimed by Zarit et al. (1986) and Aneshensel et al. (1995). However, in this thesis, I have tried to move beyond burden as the principal theoretical paradigm in research into informal care. While theories of carer stress, burden, and coping have proven to be useful, providing research with insights and understanding of informal carers' needs and support, the dominance of burden and stress tends to put emphasis on the negative aspects of caring and caring relationships. In doing this, it obscures the potential positive aspects that caring may have on an individual's life.

Spousal care and caring relationship dynamics are complex, involving aspects beyond stress, burden, and responses to such stimuli. This section will present concepts and perspectives that I believe can contribute to a deeper understanding of the findings presented in this thesis.

In Papers II and III, the concept of mutuality has been used to assess relationship quality as well as a point of departure in the discussions in paper II that explore reciprocal patterns within caring relationships. Meanwhile, caregiver identity theory explores the transition into caring, primarily used as a tool to explore and understand participants' experiences of losing their sense of self within the caring role, as described by participants in Paper IV.

Mutuality

The concept of mutuality in caring relationships has been widely used as a measurement for assessing the quality of caring relationships as well as a predictor for strain in individuals caring for a family member (Archbold et al., 1990; Park & Schumacher, 2014; Streck et al., 2020). Archbold et al. (1990) defined mutuality as 'the positive quality of the relationship between caregiver

and care-receiver’ (p. 376), proposing four theoretical dimensions of the concept: love, shared pleasurable activities, shared values, and reciprocity. However, researchers have argued that despite being widely used, the concept of mutuality lacks clarity, and is being used with different conceptualizations, emphasizing the need for a more precise definition in the context of family carer-receiver relationships (Park & Schumacher, 2014; Streck et al., 2020). Streck et al. (2020) constructed an updated conceptual definition for mutuality: ‘a phenomenon of shared experience and reciprocity resulting in a strengthened caregiver-receiver relationship,’ based on a concept analysis of 79 articles (Streck et al., 2020).

While acknowledging the original theoretical attributes of mutuality – love, shared pleasurable activities, shared values, and reciprocity – proposed in the development of the mutuality scale, Streck et al. (2020) argue that there is a lack of empirical referents to use these domains at a general level for all caring relationships or dyads. Rather, they present a conceptualization of mutuality with three antecedents, attributes, and consequences related to carer-receiver mutuality (Streck et al., 2020). Figure 1, adapted from Streck et al. (2020), presents the components of mutuality. The antecedents can be seen as prerequisites preceding mutuality in the relationship. Firstly, there must be a dyad with a carer and care-receiver, and this dyad needs to be communicating within an environment that allows continuous communication. The defining attributes of mutuality, according to Streck et al. (2020), are positive relationship quality, reciprocity, and shared experience. If the antecedents are fulfilled, and once the attributes are present, mutuality may occur in the carer-care receiver relationship. This results in the carer-receiver dyad experiencing a stronger relationship, with increased levels of empathy between the carer and the recipient. Additionally, there is increased trust, closeness, and warmth, as well as a sense of fulfilment in the relationship.

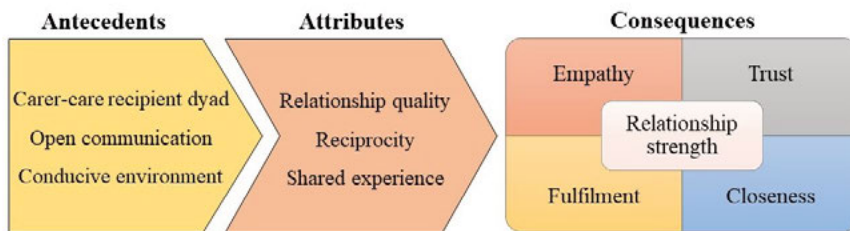


Figure 1. Components of mutuality adapted from Streck et al. (2020).

Caregiver identity theory

Caring for a next of kin or family member has profound impacts on the perception of self and the perceived identity of the carer, leading to alterations in the familial role concerning the care-recipient. The development of carer identity and the acquisition of a carer role have been conceptualized in caregiver identity theory by Montgomery and Kosloski (2009). A carer identity emerges from the pre-existing familial role or identity a person has in their relationship with the person being cared for. Therefore, caregiver identity theory is based on the fundamental observation that there is no generic carer role or identity (Montgomery & Kosloski, 2013; Montgomery et al., 2016).

The development of a carer identity builds on three key premises. Firstly, becoming a carer is a systematic process. Secondly, the process of caring is dynamic and changes over time. Lastly, the individual who takes on the role of carer experiences that their relationship with the care recipient changes and their identity changes as a result of the changes in this relationship (Montgomery & Kosloski, 2013). While the process of becoming a carer rests on these premises, it is also influenced and guided by the individual's previous familial role, personal experiences, social and cultural norms, and the dynamic and unpredictable nature of the caring situation. (Montgomery & Kosloski, 2013).

Montgomery and colleagues (2016) argue that the transition into being a carer causes an unconscious conflict between the perceived familial role, such as spouse or partner, and the carer role. To resolve this conflict, individuals becoming carers are forced to renegotiate their identity to accommodate caring tasks. This transition may be experienced as more or less stressful depending on the individual's previous familial role or responsibilities in their relationship with the person being cared for. If caring in general or if specific tasks are compatible with their previous familial role, they might cause less stress, and the carer may be able to incorporate these responsibilities or tasks without feeling burdened. However, on the other hand, overwhelming needs of the person being cared for, or caring responsibilities that are conflicting with previous familial responsibilities or that exceed the capabilities of the carer, may result in burden, as the carer may not be able to incorporate the carer role into their identity (Montgomery & Kosloski, 2009; Montgomery et al., 2016).

Rationale

It is well established in existing literature that the care provided by informal carers may concern all areas of life, from supervision to hands-on personal care. It is also acknowledged that caring for a person with dementia is generally a stressful experience but may also have positive aspects for the carer providing help and support. However, the caring situation differs between individuals with different familial roles or kinship to the person with dementia, meaning that their needs for support will also be different. Further research is needed to better understand how the provision of care and the caring situation differ between spouses caring for a partner and those with other types of kinship to the person with dementia.

In Sweden, spouses are the primary providers of informal care for persons with dementia. Since 2009, they have had the right to receive support from local authorities, ideally with the support offered corresponding to their individual needs. However, research has shown that the support provided is most often generic and lacks consideration for the familial role or relationship with the care-recipient. Additionally, the support tends to focus on addressing the negative effects of caring or care-related tasks. Thus, the support offered may not be adequately tailored to meet the individual and evolving needs of spouses as their partners' dementia progresses. There is a further need to explore not only the needs related to the negative consequences of caring but also how to further promote the positive aspects of caring. Furthermore, how spouses caring for a person with dementia perceive and experience support should be examined. More knowledge is needed to better understand the plethora of needs experienced by spouses caring for a partner with dementia. This includes how they perceive support, not only in relation to the care they provide, but also concerning their own individual circumstances. Such insights can provide a point of departure for the development of future evidence-based support tailored to the challenges faced by spouses in their caring role.

Aims

The aim of this thesis was to explore the lives and caring situations of spouses caring for a partner with dementia and to increase understanding of their needs and experiences of support.

The specific aims of the four papers in this thesis were as follows:

- I. To describe the care situation of spouse carers of persons with dementia in Sweden in comparison to other informal carers by analysing data from a population-based national survey.
- II. To investigate which factors are associated with the negative impact and positive value of caring in spouse carers of persons with dementia in Sweden.
- III. To explore the perceived importance of types and characteristics of formal support among spouse caregivers of people with dementia and examine how perceived importance is associated with factors related to the caregiver, the caregiving situation and the relationship between the spouse caregivers and the person with dementia.
- IV. To describe the life and caring situation of spouse carers of persons with dementia and explore their experiences and needs in everyday life.

Methods

Design

This thesis comprises four papers (I-IV) based on three different studies (1-3), using both qualitative and quantitative methodologies. The first study (Paper I) is based on a cross-sectional national survey conducted in 2018. The second study (Papers II & III) is based on a cross-sectional questionnaire-based survey of a convenience sample of spouse carers of persons with dementia, conducted in 2019-2020. The third study (Paper IV) is a descriptive qualitative study employing semi-structured individual phone-interviews with spouse carers of persons with dementia, conducted in 2020-2021. An overview of the methodology employed in the included studies and papers is presented in Table 1.

Methodological considerations

In all papers presented in this thesis, efforts were made to increase the overall understanding of the caring situation for spouse carers of persons with dementia in Sweden. The studies aimed to systematically explore the caring situations and support needs of spouses caring for a partner with dementia. As a point of departure, there was a need to describe the target population (Paper I), and further explore factors that may influence the caring situation (Paper II), and, employing novel approaches, try to understand how support could be tailored to the preferences of spouses (Paper III). The final study aimed to deepen the understanding of their experiences and needs in their everyday life as carers of partners with dementia (Paper IV).

Table 1. Overview of the methodology used in the included studies and papers.

| Study | Paper | Design | Sampling method | Participants | Data collection | Data analysis |
|-------|-------|--|--|--|---|---|
| 1 | I | Cross-sectional questionnaire-based survey | Stratified random probability sampling | Informal carers of persons with dementia (n = 330) | Questionnaire and register data | Descriptive statistics; Pearson's Chi Square; Spearman's rank correlation; Partial Spearman's rank correlation |
| 2 | II | Cross-sectional questionnaire-based survey | Convenience sampling | Spouses caring for a partner with dementia (n = 163) | Questionnaire | Descriptive statistics; Pearson's product moment correlation; Hierarchical regression models |
| 2 | III | Cross-sectional questionnaire-based survey | Convenience sampling | Spouses caring for a partner with dementia (n = 163) | Questionnaire | Descriptive statistics; Stuart-Kendall Tau-c; Pearson's product-moment correlation; Principal Components Analysis |
| 3 | IV | Descriptive qualitative study | Purposive sampling | Spouses caring for a partner with dementia (n = 24) | Semi-structured, individual, phone interviews | Thematic analysis |

Participants and data collection

Study 1

Study 1 (Paper I) was based on a cross-sectional national questionnaire-based survey conducted in 2018 by Statistics Sweden (Statistikmyndigheten SCB) on behalf of the Swedish Family Care Competence Centre. The survey used a stratified random probability sample of 30,009 individuals aged 18 years or older, drawn from the Total Population Register managed by Statistics Sweden. Stratification was employed to ensure an equal representation of individuals from each region in Sweden. The questionnaire was distributed by mail along with instructions informing participants that they could complete the questionnaire either on a web-based platform or by returning the printed version by mail. Participants were instructed that the questionnaire should not be completed by proxy. After two reminders, 11,168 individuals had completed the questionnaire. In the introduction of the questionnaire, an informal carer was defined as an individual who regularly provides care, help, or support to a family member, or someone they were in a close relationship with, such as a friend, neighbour, or co-worker, in a personal capacity due to physical or mental illness, disability, or advanced age. It was also stated that the questionnaire did not pertain to the care provided as part of one's occupation, nor did it cover parental care of a child with special needs.

Study 1 focused on a sub-sample of informal carers specifically caring for persons with dementia. To identify this sub-sample, filter questions were used. Firstly, participants were asked if they regularly provided care to one or more persons, and secondly, how often they provided care to the person or persons. Participants who responded 'no' or 'less often than once a month' were excluded based on the study's inclusion criteria defining an informal carer as someone regularly providing care at least once a month. Thirdly, a filter question on the primary cause of the care-recipients' need for care, help, and support was used, where participants who gave the response 'dementia disorder, memory difficulties' were included in the sub-sample.

Of the initial 11,168 respondents, 1,638 participants met the study's inclusion criteria by signifying that they were an informal carer regularly providing care at least once a month. Informal carers of persons with dementia were selected for further analyses, resulting in an analytical sample size of $n=330$. This subset constituted 20.1% of the total number of informal carers included in the study.

Study 2

In Study 2 (Papers II & III), a convenience sample of individuals aged 65 years old or older who provided care for a cohabitant spouse or partner with dementia was recruited. The recruitment process involved sending invitations through professional networks to organisations with a focus on dementia care, care for older adults, and carer support. In response, 37 health or social care organisations and two civil society organisations expressed interest in assisting with the recruitment of participants.

The organisations were given specific instructions to identify potential participants based on the definition of spouse carers as individuals “who provide care, help, or support to a cohabitant spouse or partner with, or under evaluation for, a dementia disorder.” The term “care, help, or support” was further defined as “efforts a person makes on a regular basis, such as personal care, supervision, household activities and maintenance, transportation, or contacts with services, which can include supporting the care-recipient’s personal economy, paying invoices etc.” Once potential participants were identified, organisations were further instructed to provide them with written study information along with an enclosed envelope containing the questionnaire, consent form, and response envelope.

Information on the study was also made available through different media outlets and Dalarna University’s webpage. Participants could choose to either complete the questionnaire by returning the printed copy by post, by using the web-based version, or by phone-interview. A total of 175 respondents completed the questionnaire, of which 12 were excluded as they did not meet the inclusion criteria, resulting an analytical sample of $n = 163$.

Study 3

In Study 3 (Paper IV), participants were recruited from individuals who had provided consent in Study II to be contacted for further research. Potential participants were contacted and provided with information on the study. Out of the 76 individuals who had provided contact information, 24 expressed continued interest and were interviewed. Data for Study 3 were collected through qualitative semi-structured telephone interviews, lasting between 25 and 131 minutes. Participants had the option to skip questions or end the interview at any time.

Measurements

Study 1

The questionnaire for this study was developed by the Swedish Family Care Competence Centre and was based on the questionnaire used in the 2012 study on informal care in Sweden developed by the National Board of Health and Welfare and the Unit for Measurement Technology at Statistics Sweden (Socialstyrelsen, 2012; Statistikmyndigheten SCB, 2019). The questionnaire comprised a total of 29 questions and underwent quality assessment by the Department of Development of Process and Methods at Statistics Sweden. The assessment covered aspects such as the wording and formatting of questions and response options, face validity, and other factors. The questionnaire was also subjected to pilot testing that was conducted by the Swedish Family Care Competence Centre. In addition to the questionnaire, data on the participants were obtained from Statistics Sweden's registers on the following variables: gender, date of birth, nationality, municipality and region of residence, educational level, income, occupational status, and industry (Statistikmyndigheten SCB, 2019).

The following questions and items from the questionnaire were used for the thesis:

Background information: Relationship to care-recipient, gender, age, accommodation of the care-recipient, cohabitation status, primary cause of the need for care, and support in the care-recipient.

Before you received this questionnaire, did you have knowledge of the ordinance in the Social Service Act (Chapter 5, 10 §) that states that carers who care, help, or support a next of kin shall be offered personal support? With response options 'yes' and 'no'.

Do you provide care and support for one or a few persons with everyday activities, personal care, or other types of support due to physical or mental illness, disability, or age? With five response options ranging from 'No' to 'Yes, more than three persons'.

Think about the total care and support you provide (to one or several people), how often do you provide it? With five response options ranging from 'Every day' to 'Less than once a month'.

How many hours in an average week do you provide care and support? With five response options ranging from 'Less than one hour' to '60 hours or more'.

Have you been offered support from the municipality to you personally in your role as a carer (e.g. information, advice, counselling, information on support groups, education, or other support)? With three response options indicating whether the respondent had received support from the municipality, and whether the respondent was satisfied, dissatisfied, or rejected support, followed by three response options indicating that the respondent had not been offered support, with response options for not receiving support including denied application, lack of need of support, or lack of knowledge of available support.

Below is a list of different types of support for carers. Please indicate for each type of support to what degree it applies to you? Followed by a list of 10 different types of support. Response options: ‘Yes, I have been offered/received this type of support’, ‘No I have not been offered/received this type of support but would like to receive this type of support,’ and ‘No, and I am not interested in this type of support’.

Below are some examples of activities and other things that the person you care and support may need help with. Mark the response that best reflects the needs of the person you care for and support. Followed by a list of 10 different activities with six response options. Five response options indicated supported care and support provision, ranging from ‘I care alone’ to ‘Others provide all care and support,’ and one response option indicating no need for support in the care-recipient.

To care and support means that... mark one response option for each statement. Followed by a list of nine different implications that caring may have on the participant’s situation. With four response options ranging from ‘Always/almost always’ to ‘Rarely/Never’.

Does it feel demanding to provide care and support? With four response options ranging from ‘Always/almost always’ to ‘Rarely/Never’.

During an average week, how much or little would you estimate that your sleep is disturbed because of the care and support you provide? With five response options ranging from “Not at all” to “Every night”.

Study 2

A questionnaire was developed by the research team, incorporating validated Swedish items and instruments whenever possible. In cases where no Swedish versions were available, items were translated by the research team with back translations being conducted by external researchers. The following items and instruments from the questionnaire are presented in this thesis:

Background information: Spouse carer gender and age; care-recipient gender and age, municipality of residence, type of accommodation, length of relationship, length of cohabitation, years as a carer, years since partner received dementia diagnosis, type of dementia diagnosis.

The *COPE Index* (Balducci et al., 2008; McKee et al., 2003) is a 15-item measurement tool of the carer's perception of their caring situation, comprising three sub-scales: Negative impact of care (7 items), Positive value of care (4 items), and Quality of support (3 items). All items have response options ranging from "Never" to "Always."

Behavioural and instrumental stressors in dementia (BISID) (Keady & Nolan, 1996) is a measurement tool assessing the carer's reporting on a) the frequency of and b) the level of stress experienced by the carer on 12 different behavioural and instrumental difficulties associated with dementia in the care-recipient. In a sub-section, BISID contains further items concerning faecal and urinary incontinence during the day and night separately. In the study, these were consolidated into two items: faecal incontinence (day and night) and urinary incontinence (day and night).

How many hours in an average week do you provide care and support? With an open-ended response option.

Single item measure of self-rated health (Bowling, 2005). The item contains the question "In general, how would you rate your health?" with five response options ranging from "Excellent" to "Very bad."

During an average week, how much or little would you estimate that your sleep is disturbed because of the care and support you provide? with a five-point response scale ranging from "Not at all" to "Every night."

6-item De Jong Gierveld Loneliness Scale (Gierveld & Tilburg, 2006). This scale comprises two subscales, social and emotional loneliness, with response options "No", "More or less" and "Yes" for each item.

Presence of Meaning subscale from the *Meaning in Life Questionnaire* (Steger et al., 2006). The subscale (5 items) measures the extent to which the respondents feel their lives are meaningful, with response options ranging from "Absolutely untrue" to "Absolutely true".

The Mutuality Scale (Archbold et al, 1992) is a 15-item scale measuring four dimensions of mutuality: love and affection, shared pleasurable activities, shared values, and reciprocity. Response options use a four-point scale ranging from "Not close at all" to "Very close."

Change in emotional closeness due to partner's dementia is measured using a single-item scale designed for this purpose, posing the question "How emotionally close do you feel to your partner today compared with before she/he developed dementia?" Response options are on a three-point scale ranging from "Less close" to "More close."

Change in satisfaction with intimacy due to partner's dementia is assessed using a single-item scale designed for this purpose. The question posed is "How satisfied are you with your physical intimacy with your partner compared with before she/he developed dementia?" Response options are on a three-point scale ranging from "Less satisfied" to "More satisfied."

The perceived importance of support was measured using items adapted from the EUROFAMCARE project (McKee et al., 2008). The carer's perceived importance of support is measured based on two aspects of formal support: types of support (17 items) and characteristics of support (12 items). Response options are provided on a four-point scale ranging from "Not important" to "Extremely important."

Study 3

For the purpose of this study, an interview guide was developed, drawing insights from a pilot study conducted in 2018 (Hammar et al., 2019). The interview guide contained a range of open-ended questions divided into four areas: Relationship with partner, Support received and wanted, Health and wellbeing (including social situation), and the Future. Given the nature of semi-structured interviews, the interview guide was developed to provide an overarching structure on key topics the interview aimed to capture, rather than a rigid schedule. This also facilitated the use of probing questions to explore participant responses in more depth.

Analysis

Paper I

In Study 1, an unequal distribution in responses on several demographic variables and region was observed due to the sampling method and internal missing. To compensate for potential biases, a weight based on a combination of the participant's region, gender, age, and education was applied to all analyses.

To examine the distribution between spouse and non-spouse carers, univariate descriptive analyses were performed. Following initial descriptive analyses,

sub-group analyses were conducted to examine associations between spouse and non-spouse carer status and: (i) the amount and frequency of caring, (ii) supported and unsupported caring, (iii) formal support directed to carers, and (iv) psychosocial and health outcomes of caring. Bivariate analyses included Pearson's chi-squared test, Spearman's rank correlation coefficient and partial Spearman's rank correlation. All statistical analyses were conducted using IBM SPSS v.26.

Paper II

In Paper II, scale and sub-scale scores were calculated following standard procedures for the respective scales or instruments. Descriptive statistics were performed on all included study variables to examine central tendencies and dispersion. Bivariate associations between selected independent variables (spouse carer background characteristics, BISID, health, loneliness, presence of meaning, mutuality, and changes in relationship) and dependent variables (COPE Negative Impact of Care and COPE Positive Value of Care) were examined by estimating Pearson's product-moment correlation coefficient.

Hierarchical regression models were developed for the two selected dependent variables, COPE Index components of Negative Impact of Care and Positive Value of Care, respectively. Independent variables were entered stepwise, with the order of entry determined to first control for background characteristics (Model Step 1: gender, years in relationship, years as a carer). Subsequently, known factors influencing negative and positive outcomes of care (carer stress [Model step 2: BISID sub-scales], health and social well-being [Model step 3: Self-rated health, disturbed sleep, social loneliness, emotional loneliness, presence of meaning], and quality of relationship [Model step 4: Mutuality, change in emotional closeness, change in satisfaction with intimacy]) were assessed to see if they would significantly improve the models at each step. Finally, perceived quality of support was included to examine if it would improve the models after the inclusion of all independent variables (Model step 5: COPE Index component Quality of support). All statistical analyses were conducted using IBM SPSS v. 28.

Paper III

Scale and sub-scale scores were calculated according to standard procedure for the respective scale or instrument. To describe the sample and to examine central tendency and dispersion, univariate descriptive statistics were performed as appropriate. Items measuring the perceived importance of types of support and items measuring the perceived importance or characteristics of support were separately subjected to Principal Component Analysis.

To test the suitability for the use of Principal Component Analysis, the Kaiser-Mayer-Olkin measure of sampling adequacy and Bartlett's test of sphericity were examined. Component extraction was determined a priori based on the Kaiser criterion of eigenvalue >1.0 . As it could not be assumed that the underlying constructs in the data were independent, an oblique rotation method was applied to the extracted components. The extracted components were examined for internal consistency reliability using Cronbach's alpha and Average Inter-Item Correlation. Extracted components were discussed within the research team to provide them with interpretive labels describing their content.

Three components were extracted for both Types of support and Characteristics of support. To examine bivariate associations between the components and selected study variables, a mean value score was calculated for each component. Kendall's Tau-c was chosen to estimate bivariate associations between component values and selected study variables, as several of the variables carried a significant skew or kurtosis and were of different scales or levels of measurements. All statistical analyses were conducted using IBM SPSS v. 28.

Paper IV

For Paper IV, the transcribed interviews were analysed following Braun and Clarke's reflexive thematic analysis approach (Braun & Clarke, 2022). Their approach offers structure to explore, analyse, and report themes – that is the constructs with a shared pattern of meaning. The approach is flexible due to it not being restricted by paradigmatic or theoretical underpinnings, and this allows interpretations to be guided by the researchers' expertise, pre-understanding, and semantic understanding of the data content.

At an initial stage, all interview transcripts were read and re-read thoroughly to become familiar with the data. Following the initial read-through, each transcript was re-read and coded, which involved assigning labels to all observations related to the aim of the study. Codes were collated into a separate Word document, organised, and clustered based on patterns of meaning relevant to the study's aim. Codes with similar meanings were modified or merged, resulting in a reduced number of analytical codes. The clusters of codes with similar patterns of meaning (candidate themes) served as a point of departure in the theme development process. This was an iterative and collaborative process, meaning that transcripts were repeatedly re-read, observations were re-coded and re-organised, and discussions took place until the research team reached consensus on the structure and interpretation of the data. Themes were developed to illustrate singular, multifaceted concepts, with subthemes describing specific aspects of each theme. The iterative process provided a

deeper understanding of the overall structure of the data's content and its patterns of meaning. As a result, the initial seven candidate themes were structured into two themes, each with two subthemes, respectively.

Ethical considerations

At all stages, from planning to the execution of each study, the research was conducted in accordance with the Swedish Ethical Review Act (2003:460), the Swedish Research Council Guidelines for Good Research Practice (Vetenskapsrådet, 2017), and the principles for good research and researcher practice as stated in the European Code of Conduct for Research Integrity (All European Academies, 2023). All studies were granted ethical approval prior to commencing data collection. For Study I, ethical approval was granted by the Regional Ethics Review Board (reg. no. 2018/135-31). For Studies 2 and 3, ethical approval was granted by the Swedish Ethical Review Authority (reg. no: 2019-03288; 2020-02987).

In all research concerning individuals, it is necessary to make ethical considerations. This thesis specifically concerns the experiences of older adults who were approached with a request to share their life histories and personal experiences of caring for a partner with dementia. It is important to keep in mind that behind the figures in the datasets and the transcriptions of interviews, there are individuals sharing their life experiences. Furthermore, the inclusion of older adults, carers, and users in research has been a subject of discussion in relation to the ethics and power dynamics of research versus the value added by user participation in research (Gradinger et al., 2015; O’Sullivan, 2018; Read & Maslin-Prothero, 2011). While the carers in this study are older adults and therefore may be viewed as a vulnerable study population, their participation in research may also empower them, providing agency and legitimacy to their experience and expertise (Iwarsson et al., 2019; Malm et al., 2021; O’Sullivan, 2018; Read & Maslin-Prothero, 2011). The exclusion of carers and older adults from research would risk undermining their autonomy and expertise. This has been discussed regarding the thoughtless use of ‘vulnerable’ in relation to older adults, which, when used without reflection, could be regarded as ageism (Langmann, 2023).

Data for the first study were collected by Statistics Sweden on behalf of the Swedish Family Care Competence Centre, and were shared in accordance with the ethical approval. Prior to participation, all potential participants were provided with study information. The information stated that the study was

conducted by Statistics Sweden and Linnaeus University and concerned informal care. It outlined the study's purpose and how it would be conducted. Participants were also informed about how data would be used and the rules governing the processing of personal data as outlined in the EU General Data Protection Regulation (GDPR, [EU] 2016/679), and the Swedish Public Access to Information and Secrecy Act (2009:400). They were also informed about the regulations in the Act (2001: 99) and the Ordinance (2001: 100) of the Official Statistics. The information also stated that participation in the survey constituted their consent, with the understanding that their responses would be used in reports by the Swedish Family Care Competence Centre and Linnaeus University. Additionally, it was explained that their responses might be used in further studies and be featured in scientific articles.

In the dataset provided by the Swedish Family Care Competence Centre, no personally identifiable information, such as contact information or personal identity numbers, was included. However, as the collated information could be used to profile and potentially identify participants, the raw dataset was not made available in a public repository. Instead, a redacted dataset has since been published in a repository by the researchers responsible for the data.

In adherence to ethical guidelines, emphasis on autonomy and informed consent from participants was paramount in studies 2 and 3. All participants were provided with detailed study information prior to participation. The information explained the studies' purpose and how they would be conducted. It clearly stated that participation is voluntary, and that participants needed to give consent prior to participation but maintained their right to withdraw consent at any time without providing a reason. The information also included contact information for the principal investigator (i.e. main supervisor) and the doctoral student, to give participants the possibility to ask questions prior to participation. Participants were also informed that Dalarna University was responsible for processing their personal data, and the regulations for processing data contained in the EU General Data Protection Regulation, and the Swedish Access to Information and Secrecy Act would be strictly followed.

In Study 2, careful considerations were taken into account during the development of the questionnaire to ensure that questions would not be experienced as too private or troublesome. The demanding length of the questionnaire was also considered, and respondents were offered the possibility to respond through a phone-interview. Participants interested in this option were informed that they could choose to be interviewed by a male or female member of the research team.

In Study 3, considerations were made regarding that participants would be asked to disclose possibly sensitive information on their own health as well as

their perceptions of their partner's dementia. During the interviews, they would also be asked about their wellbeing, how they were affected by their partner's dementia, and their intimate relationship with their partner. Several of the questions participants were asked to respond to could be considered as sensitive and an invasion of privacy. To foster a sense of trust and comfort, participants were offered to choose to be interviewed by a male or female member of the research team. Additionally, it was recognised that these questions might cause discomfort to the participants, evoking feelings of sadness and grief and also possibly feelings of resentment towards their partner or their own life situation. Due to this, participants were informed that if they felt a need for help or counselling after participating in the study, they could be assisted by members of the research team in connecting with suitable care or support providers if desired.

While participants in the studies presented in this thesis may not experience any immediate benefits from participation, the potential discomfort associated with participation was considered outweighed by the possible benefits. The knowledge gained from the studies could potentially contribute to a better understanding of how to effectively target support or meet unmet needs in spouses caring for a partner with dementia. However, after the completion of studies 2 and 3, it had become clear that some participants found that the experience had provided them with a sense of empowerment and accomplishment.

Results

This thesis was conducted with the overarching aim to explore the care situation of spouses caring for a partner with dementia and to increase knowledge of their needs and experiences of support. The aim has been addressed in three studies, which are presented in four different papers, each with its own specific aim and objectives. Corresponding with the overarching aim, key findings forming the basis of this thesis have been synthesized and will be presented under the two main headings: *The Care Situation of Spouses Caring For a Partner with Dementia*, and *The Receipt and Experience of Support*.

The care situation of spouses caring for a partner with dementia

Couples living with dementia

Table 2 provides an overview of the sample characteristics of spouses and their care-recipient partners from **Papers I-III**, while Table 3 describes participating spouses in **Paper IV** and their care-recipient partners with dementia. **Paper I** compares spouses and non-spouses caring for a person with dementia regarding the provision and outcomes of care. Findings from **Paper I** showed that spouses caring for a partner with dementia were significantly older than other informal carers of persons with dementia. Moreover, spouses were less likely to be working carers, with only 13.9% compared to 58.3% of non-spouses. Across all studies, the average age of participating spouses was above 70 years (Table 2 & Table 3) and the majority of the participants were female (Table 2 & Table 3). In **Papers II** and **III**, the focus was specifically on spouses caring for a cohabitant partner with dementia, aiming to investigate factors relevant to understanding their caring situation and perceptions of support. Results showed that nine out of ten spouses caring for a partner with dementia were married to the care-receiving partner (91.0%). Additionally, approximately eight out of ten of the partners with dementia were male, with an average age of 78. Furthermore, the participants in **Papers II** and **III** had shared the majority of their adult lives with their partners with dementia, while the duration of the relationships ranged from 8 to 70 years, with the average participant having been in the relationship for nearly 50 years (Table 2).

In **Paper I**, the results showed that participants caring for a partner were predominantly cohabiting with the person with dementia, in contrast to those with other kinships (78.4% vs. 4.5%). In **Papers II and III**, the duration of cohabitation was examined, and on average, the couples had been living together for approximately 46 years, with just over half of them living in a house or townhouse (54.3%). In **Paper III**, the living situation of the couples was further examined by investigating the types of municipalities they resided in. Results showed that approximately four out of ten couples resided in medium-sized towns or municipalities near medium-sized towns (42.3%), while a similar proportion resided in smaller towns or rural municipalities (38.7%). Only two out of ten couples resided in larger cities or municipalities near larger cities (19.0%).

Table 2. Sample characteristics, spouses and care-recipient partners

| Characteristic | Study 1 | Study 2 |
|--|----------------|-------------------------------|
| | <i>Paper I</i> | <i>Paper II and Paper III</i> |
| Age, M (SD) | | |
| Spouse carer | 73.8 (10.7) | 75.3 (5.8), 65–89 |
| Non-spouse carer | 52.9 (14.1) | - |
| Care-recipient | - | 78.2 (6.7), 62–93 |
| Gender % | | |
| Spouse carer, female | 57.3 | 76.6 |
| Care-recipient, male | - | 78.5 |
| Years in relationship, M (SD), range | - | 48.6 (13.4), 8–70 |
| Years as a carer, M (SD), range | - | 4.4 (4.5), 1–43 |
| Hours of care on average/week ^a | | 71.5 (61.6), 1–168 |
| < 1 h | 5.6 | - |
| 1 - 10 h | 21.1 | - |
| 11 - 29 h | 25.4 | - |
| 30 - 59 h | 28.2 | - |
| 60 h or more | 19.7 | - |
| Received dementia diagnosis, % | | |
| Alzheimer's disease | | 49.1 |
| Vascular dementia | | 19.5 |
| Dementia with Lewy Bodies | | 5.7 |
| Frontotemporal dementia | | 3.1 |
| Dementia due to Parkinson's disease | | 1.9 |
| Unspecified or mixed dementia | | 20.8 |

Note: ^a Spouses' hours of care provision per average week, Reported in proportions (%) in Paper I, and with Mean, Standard deviation, and range in Paper III only.

The average participant reported that they had been providing care for their partner for 4.4 years (SD = 4.5), which is almost one year longer than the duration since their partners received a dementia diagnosis (M = 3.2, SD = 2.9) (II). Almost half of the participants reported that their partner had been diagnosed with Alzheimer's disease. This was followed by vascular dementia or an unspecified or mixed dementia, which was reported by approximately two out of ten participants each. Smaller proportions of participants reported

that their partner was diagnosed with dementia with Lewy Bodies, frontotemporal dementia, or dementia due to Parkinson's disease (Table 2).

Table 3. Description of participants and partners with dementia Paper IV (Study 3)

| Gender, spouse | Age, spouse | Gender, partner | Age, partner | Duration of relationship | Dementia diagnosis | Years as carer |
|----------------|-------------|-----------------|--------------|--------------------------|---------------------------|----------------|
| Female | 66 | Male | 68 | 44 | Dementia with Lewy Bodies | 5 |
| Female | 66 | Male | 71 | 47 | Alzheimer's disease | 6 |
| Female | 66 | Male | 67 | 47 | Unspecified | 11 |
| Female | 67 | Male | 74 | 20 | Alzheimer's disease | 2 |
| Female | 70 | Male | 77 | 52 | Alzheimer's disease | 1 |
| Female | 71 | Male | 73 | 47 | Alzheimer's disease | 4 |
| Female | 72 | Male | 74 | 51 | Dementia with Lewy Bodies | 4 |
| Female | 73 | Male | 72 | 50 | Alzheimer's disease | 6 |
| Female | 74 | Male | 73 | 29 | Alzheimer's disease | 2 |
| Female | 74 | Male | 75 | 58 | Alzheimer's disease | 4 |
| Female | 75 | Male | 75 | 9 | Vascular dementia | 5 |
| Female | 75 | Male | 74 | 32 | Vascular dementia | 7 |
| Male | 75 | Female | 73 | 66 | Alzheimer's disease | 7 |
| Male | 75 | Female | 73 | 53 | Alzheimer's disease | 8 |
| Female | 76 | Male | 81 | 43 | Alzheimer's disease | 3 |
| Female | 76 | Male | 76 | 51 | Unspecified | 4 |
| Female | 76 | Male | 82 | 52 | Frontotemporal dementia | 4 |
| Female | 76 | Male | 74 | 41 | Unspecified | 5 |
| Female | 76 | Male | 79 | 54 | Vascular dementia | 6 |
| Male | 78 | Male | 68 | 36 | Alzheimer's disease | 6 |
| Male | 78 | Female | 77 | 58 | Alzheimer's disease | 6 |
| Male | 79 | Female | 82 | 61 | Unspecified | 13 |
| Male | 87 | Female | 89 | 68 | Vascular dementia | 11 |
| Male | 90 | Female | 93 | 64 | Vascular dementia | 8 |

The provision of care

Participants caring for a partner with dementia spent a considerable amount of time on caring in their everyday life. In **Paper I**, three out of four (74.7%) spouses reported that they cared for their partner every day. In **Paper III**, where different factors that may be associated with perceptions of support

were examined, time spent on caring was used as a measure for caring intensity. Results indicated that the average participant reported spending over 70 hours caring for their partner in an average week ($M = 71.5$, $SD = 61.6$). While some participants reported that they spent one hour or less a week on caring on average, others reported providing care around the clock, amounting to 168 hours per average week (III). However, the interviews conducted in **Paper IV** revealed that spouses do not always label the help or support they provide as 'care'; rather, it was more about being a spouse and part of everyday life.

Paper I examined the supported and unsupported care provided by informal carers of persons with dementia. Results revealed that participants caring for a partner with dementia, to a greater extent, reported that they were alone in their caring, while those with other kinships were more often supported in their caring. In **Paper IV**, which described the life situation of spouses caring for a partner with dementia, findings showed that spouses sometimes described feeling alone in their caring, and that they wished that they had someone else to support them. However, the experience of being alone in caring was sometimes more complex. While they described how different circumstances made them feel that they were alone in their caring situation and generated feelings of confinement, they also described how they did not want to burden their children and chose not to engage them further in caring (IV). Furthermore, when examining potential areas where the person with dementia had a need of care or support, a majority of spouses reported that they provided care or support alone (**Paper I**). There may be several reasons why spouses are alone in caring, one may be the need for adequate and good quality dementia care. Spouses describe how they need to feel confident and safe before handing over the responsibility of caring for their partner with dementia, as described in the sub-theme *Needing support suitable for us* (IV). However, in the area of care or support labelled 'social relationships', there was an exception, as a larger proportion of spouses reported having support from others compared to the proportion that reported that they were alone in caring (Figure 2).

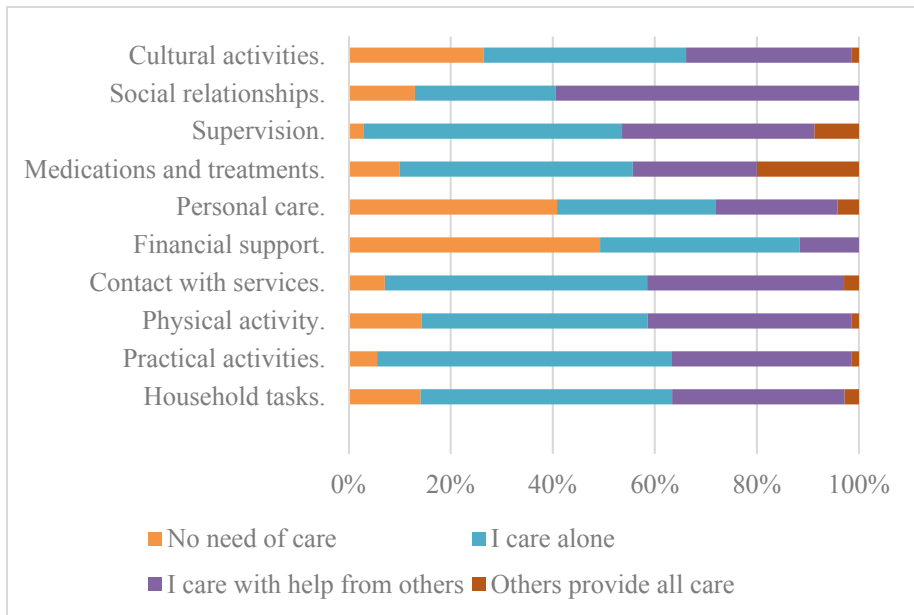


Figure 2. Need for care in partners with dementia, and the extent of support and unsupported care provided by spouses (Adapted from Paper I).

Consequences and impact of care

In **Paper I**, the consequences of caring on participants' lives were examined. Results indicated that caring for a partner with dementia was more psychologically stressful than physically demanding. Spouses experienced more negative consequences of caring than those with other relationships to the person being cared for. The consequences of caring for a partner with dementia was further explored in **Paper II**. On average, spouses reported experiencing some stress due to their partner's dementia, with more stress reported when experiencing a partner's behavioural difficulties related to dementia (e.g. screaming or shouting for no reason, wandering, upsetting behaviours, etc.) than when experiencing instrumental difficulties (e.g. helping with washing, dressing etc.). While **Paper I** showed that spouses experienced more negative consequences than other carers, they also reported a closer relationship with the person with dementia than other carers. These findings are reflected in the results of **Paper II**, where participants reported a negative impact due to caring 'sometimes', while experiencing positive value due to caring 'sometimes' to 'often'.

The duality of the caring situation for spouses caring for a partner with dementia was further examined in **Paper II**. Results revealed a moderate association, with a shared variance of 17%, between the negative impact and positive value of caring at a bivariate level. Furthermore, in multivariable

analyses reported in **Paper II**, other factors known to potentially influence the caring situation were included, revealing that the negative impact and positive value of caring were not moderated by the same factors (**II**). These results suggest that the negative and positive aspects of the caring situation can coexist rather than being at the opposite ends of the same scale.

In **Paper IV**, an exploration of the life situation and needs among spouses caring for a partner with dementia was conducted. The thematic analysis generated two themes, each with two corresponding subthemes (Table 5). Findings reported in **Paper IV** further highlight the complexities of the caring situation, as described in the theme *Being consumed by caring*, which represents spouses' experiences of losing themselves when commencing care, losing their relationship with their partner, and feeling confined in their caring role. These findings align with the results of **Paper I**, where spouses reported finding it hard to find time for personal activities, such as meeting friends, due to their caring responsibilities. Similarly, the subtheme *Feeling confined and forsaking own needs* echoed spouses' descriptions of limited opportunities to tend their own interests and maintain relationships with friends, resulting in feelings of isolation and confinement. Loneliness emerged as a consequence of caring in **Papers II** and **III**, where analyses revealed that spouses caring for a partner may experience both emotional and social loneliness. Emotional loneliness was also significantly associated with negative impacts of caring on both bivariate and multivariate levels (**II**).

Table 4. Themes and subthemes derived from Paper IV.

| Theme | Subtheme |
|---------------------------------------|--|
| Being consumed by caring | Navigating a new role and loss of companionship |
| | Feeling confined and forsaking own needs |
| Longing to be seen and feel supported | Valuing acknowledgment in one's individual situation |
| | Needing support suitable for us |

The theme *Being consumed by caring* generated in **Paper IV**, captures how caring for a partner with dementia has a profound impact on the life situation in the broader perspective, and how caring becomes an integral part of everyday life. In the subtheme *Navigating a new role and loss of companionship*, descriptions of how caring changes spouses' relationships with their partners and their perception of self is presented. The changes in their life were described as burdensome, linked with both their caring responsibilities and the progressive loss of their partner's function due to dementia. As their relation-

ship changed and their life became more about caring for a person with dementia than being a spouse, they expressed how these shifts transformed their roles within the relationship. The transition from being a spouse to a carer while simultaneously their partner transitioned from being a spouse to a care-recipient led to the couple experiencing a decline in equality and companionship. This transition also coincided with a loss of intimacy. In **Paper II**, an examination of factors affecting the negative impact and positive value of caring showed that, on average, spouses experienced reduced mutuality and satisfaction with emotional closeness and physical intimacy due to their partner's dementia. In the bivariate and multivariate analyses, the importance of intimacy for spouses in caring situations was also emphasised, where a loss of intimacy emerged as a significant multivariate predictor for negative impact. However, results also showed that mutuality and emotional closeness were significant factors predicting positive value (**II**).

The receipt and experience of support

Paper I revealed that spouses caring for a partner with dementia were better informed about their right to be supported by local authorities according to the Social Service Act than those with other kinship ties. However, results show that, although a larger proportion of spouses were knowledgeable on their right to receive support, just under half (49.3%) reported being aware of this right.

The support received

Paper I investigated interest in support and how it is received by informal carers of persons with dementia. Results showed that spouses caring for a partner received less support from others in their caring than other individuals with different kinship ties to the care recipient. However, results also revealed that spouses caring for a partner were more frequently offered or receiving formal support than other carers. Figure 3 provides a summary of the findings on support offered, received and spouses' interest in ten different types of support among spouses caring for a partner with dementia as reported in **Paper I**.

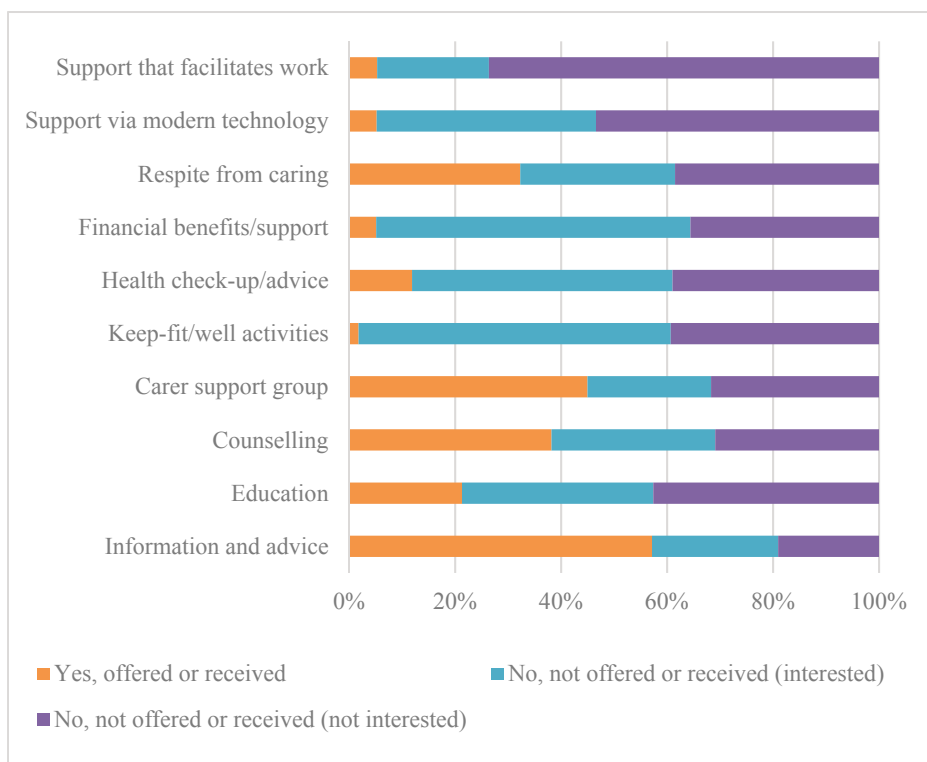


Figure 3. Support offered, received and interest among spouses adapted from Paper 1

In **Paper III**, the study explored the perceived importance of different types of support. The rankings of means, mean values, and standard deviations are summarized in Table 5. The findings in **Paper III** echo those in **Paper I**, with similarities being seen between the reported receipt and interest in different types of support by participants in **Paper I** and how participants in **Paper III** perceived the importance of different types of support.

In **Paper I**, most of the examined types of support had been offered or received by a minority of the participants. The one exception was ‘information and advice’ which had been offered or received by 57.1% of spouses caring for a partner with dementia (Figure. 3). In **Paper III**, the mean value ranking of the perceived importance of different types of support showed that ‘*Information about their partner’s dementia.*’ followed by ‘*Information and advice about type of help and support available and how to access it.*’ had the highest mean rankings.

In **Paper I**, results show that the second most offered or received type of support was ‘support groups’, provided or received by slightly less than half of spouses (45.0%) caring for a partner with dementia. Meanwhile, two out of

ten (23.3%) were not offered but expressed interest in ‘support groups’. Results on the perceived importance among spouses caring for a partner with dementia, as reported in **Paper III**, show that perceptions of the importance of support groups may vary depending on how the support group is organised. Participants’ scores for the support type *The opportunity to attend a carer support group being led by a professional* had the fourth highest mean rank in perceived importance, compared to *Opportunities to attend a carer support group, meeting place for couples in the same situation*, having a mean rank of 10 out of the 17 types of support investigated. In the sub-theme *To be acknowledged in one’s individual situation* (Table 4), the experience of support groups was both positive and negative, with participants often linking the support groups to peer support. Participants also described that there is a specific value in that the carer support group is being led by a professional to provide structure (**IV**).

The third most offered or received support investigated in **Paper I** was counselling, which was offered or received by almost four out of ten (38.2%) spouses caring for a partner (**I**). The importance of receiving counselling or emotional support is evident in several findings reported in **Paper IV**, most predominantly in the sub-theme *Valuing acknowledgment in one’s individual situation* (Table 4), with spouses expressing a need to be acknowledged as individuals with their own needs and not only as carers. The need for professional support or counselling was also linked to not wanting to trouble others, such as children. In **Paper III**, the perceptions of the different types of support that offered opportunities to talk to professionals were also examined. Results on the mean rank of types of support showed that the opportunity to talk to a professional in person had a higher mean rank than talking to a professional online or over the phone (Table 5). These findings are in line with the findings in **Paper I**, which showed that participants reported that support through modern technology was the type of support the largest proportion of spouses caring for a partner reported that they were not receiving and not interested in, with the exemption being support that facilitates work. However, as spouses caring for a partner, on average, were past the age of retirement, this finding was anticipated.

Table 5. Mean value, rank, standard deviation, and range of perceived importance of types of support. N = 163

| Support types | Rank | Mean | SD | range |
|--|-------------|-------------|-----------|--------------|
| Information about the dementia disease my partner has | 1 | 2.1 | .8 | 0-3 |
| Information and advice about the type of help and support that is available and how to access it | 2 | 2.0 | .8 | 0-3 |
| Opportunities to have a holiday or take a break from caring | 3 | 1.9 | 1.0 | 0-3 |
| Opportunities to attend a carer support group close to home lead by a professional | 4 | 1.9 | 1.0 | 0-3 |
| Opportunities to enjoy activities outside of caring | 5 | 1.8 | 1.0 | 0-3 |
| Opportunities for my partner to undertake activities they enjoy | 6 | 1.8 | .9 | 0-3 |
| The opportunity to talk about my problems with a professional as a carer | 7 | 1.8 | 1.0 | 0-3 |
| Training to help me develop the skills I need to care | 8 | 1.7 | .9 | 0-3 |
| Help with planning for the future care | 9 | 1.6 | .9 | 0-3 |
| Opportunities to attend a carer support group meeting place for couples in the same situation | 10 | 1.5 | 1.0 | 0-3 |
| The opportunity to talk online or by phone with a professional about my problems as a carer | 11 | 1.4 | 1.0 | 0-3 |
| Opportunities to spend more time with my family | 12 | 1.3 | 1.0 | 0-3 |
| Help to make partner's environment more suitable for caring | 13 | 1.2 | 1.0 | 0-3 |
| Opportunities to attend a carer support group (online or by phone) lead by a professional | 14 | .9 | 1.0 | 0-3 |
| Help to deal with family disagreements | 16 | .7 | 1.0 | 0-3 |
| More money to help provide things I need to give good care | 17 | .7 | 1.0 | 0-3 |

Note: 0 = not important, 3 = extremely important. Adapted from Paper III.

Results from **Paper I** on the utilisation of and interest in different types of support show that almost a third (32.3 %) of the spouses caring for a partner with dementia were either offered or received respite care, with a slightly larger proportion (38.5%) not being offered or interested in that type of support (Figure 3). In **Paper IV**, findings showed that spouses often felt confined in the caring situation, and expressed a need for rest. However, respite and daycare options seem to be a complex issue. The complexities related to respite care were elaborated upon in the sub-theme *Needing support suitable for us* (Table 4). Some participants described how their partner with dementia was too well to attend respite services, and that suggesting day-care would be insulting. Other participants described how they associated respite with a separation from their partner. Additionally, participants described how they needed to be reassured that their partner would be well looked after to genuinely feel that respite care provides the needed rest. In **Paper III**, the support type *Opportunity to have a holiday or break from care* had the third-highest mean rank in the perceived importance of types of support, while *Opportunities to enjoy activities outside of caring* had a mean rank of five (Table 4). These findings add to the findings described in **Paper IV**, particularly with the theme *Being consumed by caring* (Table 4), where participants described the complexities of the caring situation, highlighting the differences between feeling confined in the situation and needing time to recuperate and engage in enjoyable activities.

In **Paper I**, results indicate that despite only being offered to or received by a small minority of spouses caring for a partner with dementia (1.8%), health advice and opportunities to maintain their own health seem to be of value, with almost six out of ten (58.9%) expressing an interest in support in the form of keep-fit or wellness activities. Additionally, only one in ten (11.9%) had been offered or received health check-ups, while this type of support was of interest to approximately half of the spouses caring for a partner with dementia (49.2%) (Figure 3). Furthermore, in **Paper II**, self-rated health among spouses caring for a partner with dementia emerged as one of the six significant variables in the multivariable model for negative impact of care (**II**).

It is interesting to note that in **Paper I**, almost six out of ten (59.3) spouses caring for a partner with dementia reported that they were not receiving financial benefits or support despite being interested in this type of support (Figure 3). However, results from **Paper III** show that more money used to help provide better care was the type of support with the lowest mean rank among spouses when asked how important they perceived different types of support to be (Table 5).

How they could be supported

In **Paper II**, multivariable analyses on the negative impact and positive value of care were reported. Results indicate that being well supported was a significant predictor for the positive value of care. However, the experience of being well supported did not significantly explain negative impact when controlling for other factors such as gender and age, carer stress, health and wellbeing, and the relationship between the spouse and their partner with dementia. However, in **Paper III**, the associations between negative impact, factors related to a stressful caring situation, and the perceived importance of support were examined. Findings suggest that negative impact and a stressful caring situation on the bivariate level are associated with increased perceived importance for the types of support examined, indicating that while support may not mitigate negative outcomes of care, the negative outcomes may influence how important support is perceived.

Table 6. Mean value, rank, standard deviation, and range of perceived importance of characteristics of support. N = 163

| Support characteristics | Rank | Mean | SD | Range |
|---|------|------|-----|-------|
| Care workers treat partner with dignity and respect | 1 | 2.5 | .6 | 0-3 |
| Your views and opinions are listened to | 2 | 2.4 | .6 | 0-3 |
| The help provided improves the quality of life of partner | 3 | 2.4 | .6 | 0-3 |
| Care workers treat you with dignity and respect | 4 | 2.3 | .7 | 0-3 |
| The help provided improves your quality of life | 5 | 2.3 | .7 | 0-3 |
| Care workers have the skills and training they require | 6 | 2.3 | .8 | 0-3 |
| Help is provided by the same care worker each time | 7 | 2.2 | .8 | 0-3 |
| Help focuses on your needs as well as those of your partner | 8 | 2.1 | .8 | 0-3 |
| Help is available at the time you need it most | 9 | 2.0 | .7 | 0-3 |
| Help arrives at the time it is promised | 10 | 2.0 | .8 | 0-3 |
| The help provided is not too expensive | 11 | 1.9 | 1.0 | 0-3 |
| The help provided fits in with your own routines | 12 | 1.7 | .8 | 0-3 |

Note: 0 = not important, 3 = extremely important. Adapted from Paper III.

In **Paper III**, the perceived importance of different characteristics of support was examined. In Table 6, the mean value and rank of means for the perceived importance of characteristics of support is presented, adapted from **Paper III**. Results from **Paper III** reveal a juxtaposition of the needs of spouses caring for a partner with dementia and their partners' needs for support. When examining the mean rank of perceived importance of characteristics of support, it was noted that characteristics of support focusing on the partner with dementia were often rated higher than the mean rank of those directed to the participant. Examples of this are evident, as out of twelve different characteristics, *Care workers treat*

partner with dignity and respect received the highest mean ranking. In comparison, the characteristic *Care workers treat the carer with dignity and respect* had the fourth-highest ranking. Similarly, the characteristic *Care improves the quality of life of the partner* had a higher mean ranking than *Support that improves the quality of life of the person caring* (Table 6). While this does not imply that spouses do not have individual needs, it shows that they may not necessarily prioritise their own needs over those of their partner. As presented in **Paper III** in the results from the principal components analysis, the perceived importance of different characteristics of support directed to the participant and to their partner with dementia intersect. These findings suggest that the spouse caring for a partner with dementia experiences needs that are entwined with the needs of their partner with dementia.

While findings from all papers suggest that support for spouses caring for a partner with dementia is complex, insights reported in **Paper IV** reveal that spouses and their partners with dementia may have needs that are enmeshed or shared. This can be seen in the theme *Longing to be seen and feel supported*, where spouses seldom single out themselves or their partners as sole recipients of formal care and support; instead the couple is seen as a unit receiving support. However, spouses find it challenging to prioritize their own needs if they did not feel that their partner is well looked after, despite still having their own individual needs. The participants described how it is important for them to be seen as individuals, while also expressing the necessity of good-quality dementia care for them to accept support and to feel adequately supported.

The relationship between the participants and their partners with dementia was a focal point in all papers. In Paper I, participants expressed a close relationship with their partners with dementia. In **Paper II**, variables relating to relationship quality, satisfaction with emotional closeness, and physical intimacy were found to be significant. In this paper, various aspects of the relationship were associated with negative impact and positive value, with mutuality and closeness showing a negative relationship to negative impact and a positive relationship with positive value of caring. This could indicate that support targeting these aspects may be beneficial. In **Paper III**, various aspects of relationship quality, including mutuality, had negative associations with the perceived importance of types and characteristics of support. This indicates that different aspects of the relationship may influence spouses support needs. In **Paper IV**, spouses described how the loss of intimacy and declining relationship quality had a significant impact on their life situation, however, they also claimed that the responsibility they felt for their partners influenced their perspectives on support and their own needs. These findings collectively suggest that the relationship between the spouse caring for a partner with dementia and the partner may be important in shaping the experience of caring, and also how the relationship may influence the development of support mechanisms.

Discussion of results

The overarching aim of this thesis was to explore the life and caring situation of spouses caring for a partner with dementia, and to increase the understanding of their needs and experiences of support. This examination of their life and caring situation went beyond detailing various aspects of their life; it also involved comparing their situations to the situations of others caring for a person with dementia, as well as exploring the inherent dualities of living with a partner with dementia. Additionally, this thesis explores the spouses' perceptions of support and how their relationships contribute to their needs and experiences of support.

Spouses' unique situations

The findings presented in this thesis highlight the unique situations of spouses finding themselves in a caring role for partners with dementia, setting them apart from other carers of persons with dementia. Spouses were generally both older and more likely to be cohabiting with their partners with dementia, most often residing in ordinary housing and receiving less support than other carers (I). None of these findings are surprising, as spouses to a great extent match the profile of cohabitant carers, often being less supported and with more limited involvement in caring networks (Jegermalm & Torgé, 2021). Spouses also provide care to their partners with dementia at a higher frequency and intensity than other carers (I), which is in line with previous research that is generally consistent in indicating that spouses generally shoulder a greater caring responsibility in terms of time spent on caring (Kunicki et al., 2021; McAuliffe et al., 2018; Wawrziczny et al., 2020). Due to spouses engaging in more frequent and intense caring, it would be reasonable to assume that spouses experience greater distress than other carers, and the findings presented in this thesis support this assumption - spouses do indeed experience more negative impacts than other carers (I). However, the existing literature has provided mixed results, sometimes indicating greater distress among adult children than among spouses and vice versa, often focusing on carer burden (Huertas-Domingo et al., 2023; Kunicki et al., 2021; McAuliffe et al., 2018). The differences between spouses and other carers of persons with dementia reported in this thesis (I) might also be understood based on the notion that it

is not solely the degree of negative impact but rather that spouses experience caring differently, which sets them apart. Rigby et al. (2019) argue that there may be differences in the experience of caring for a person with dementia. They suggest that while adult children caring for a parent experience higher distress and lower quality of life, spouses report higher levels of grief as dementia advances. However, it is important to note that variables related to grief or quality of life were not explicitly examined in the comparison reported in this thesis (I). Additionally, other studies have shown that there may be differences in the perception of the carer role and sociocultural obligations to provide care, arguing that these factors may influence the consequences of caring on the carer's life situation (Huertas-Domingo et al., 2023; McAuliffe et al., 2018). This is reflected in the findings in this thesis that spouses do not want to burden their children with caring duties (IV).

The differences in the caring situation, experiences, and consequences of caring between spouses and other carers reported in this thesis (I) play an important role in understanding how support could be targeted. Rather than serving as an argument that one type of carer has a worse or more stressful situation than the other, these findings should be contextualized in relation to previous studies exploring kinship differences. These studies argue that distress is present regardless of the relationship to the person with dementia, but the different features of distress and the experiences of caring impact individuals differently (Conde-Sala et al., 2010; Steinfeldt et al., 2021). Therefore, it is reasonable to assert that spouses do have a unique situation, and their needs for support and their experiences of support will differ from other carers of persons with dementia.

The importance of the spousal relationship

The findings also suggests that spouses may not perceive themselves as carers, but rather they express that caring for their partner with dementia is part of their marital responsibilities (IV). This issue is well known concerning carers, and previous research has shown that this may be influenced by cultural and social norms (Greenwood, Pound, et al., 2019; Zarzycki et al., 2023). Moreover, the fact that spouses may not identify themselves as carers is troublesome, as the use of carer self-identification in research and policy has been problematized as it may exclude those who do not identify as carers or regard their efforts as a form of care both from research and in context of support (Morgan et al., 2021). That carers may not identify or view their efforts as care is also likely to impact how they view their own support needs (Macleod et al., 2017).

The findings reported in this thesis suggest that spouses experienced a close relationship to their partner with dementia (**I**), but they also reported a decrease in mutuality (**II & III**). This decline in mutuality is to be expected according to how mutuality is conceptualized by Streck et al. (2020), and the original theoretical model proposed by Archbold et al. (1990). A common symptom of dementia is impacted memory functions (Knopman & Petersen, 2014), which naturally hinders the exchange of shared experiences and memories to some extent. Additionally, as reported in **Paper IV**, spouses sometimes described a sense of losing themselves, as they transitioned into more of a carer than a spouse, with this impacting on the emotional bond and intimacy they had with their partner. They also described taking on extra tasks and responsibilities to compensate for their partner's loss of function (**IV**). This situation usually impacts the equal, reciprocal exchange, which is a crucial attribute of mutuality (Streck et al., 2020). Furthermore, participating spouses in this thesis had, on average, shared the majority of their adult life with their partner who developed dementia (**II & III**). It would be reasonable to expect that they had developed mutuality over time through shared experiences, especially as findings report them experiencing close relationships (**I**). However, despite the degree of mutuality decreasing with regards to scale midpoint (**II & III**), it is worth noting that spouses had, on average, been caring for their partner with dementia for approximately four and a half years (**I**). Shim et al. (2011) found that the care recipient's functional ability and the duration and experience of caring were significantly associated with mutuality, which could explain why spouses' mutuality was not severely impacted. While mutuality is one aspect of the caring relationship, this study found that mutuality as well as other aspects of the relationship were significantly associated with both negative impact and positive value of caring (**II**). These findings suggest that efforts to strengthen relationships could be a focus of future support to alleviate the negative aspects of care while enhancing the positive ones. Previous research has suggested that such efforts promote health not only among spouse carers but also their partners with dementia (Bielsten, 2020), as well as promoting resilience in both parties (Conway et al., 2020; Donnellan et al., 2015).

Findings presented in this thesis show that spouses may experience needs beyond emotional and instrumental needs that may not be sufficiently met. For example, spouses may feel confined in their caring role, experiencing both social and emotional loneliness, and a sense that they are losing themselves in the caring process (**II & IV**). While this thesis did not explicitly examine the concept of social isolation, findings on spouses' perceptions of confinement in their situation (**IV**) suggest that they might not be as socially connected as they would like to be. This insight may help us understand their experiences of loneliness, based on previous research finding that the experience of loneliness among carers is associated with social isolation (Victor et al., 2020). Moreover, spouses' experiences of loneliness may be exacerbated by feelings

of grief and the perception that they are losing their partner to dementia (Fowler et al., 2022; Greenwood, Pound, & Brearley, 2019). Additionally, spouses' experiences of confinement may be linked to a lack of support from others, which leads to restricted possibilities to enjoy activities outside of caring, including meeting with people other than their partner with dementia (**I & IV**). This has also been seen in previous studies that have found that older spouses are often alone in their caring situations, and that social support from friends is important to aid spouses in their caring situations (Donnellan et al., 2017; Ornstein et al., 2019).

However, losing their partner to dementia was also linked to a loss of self among spouses as they became more of a carer than a spouse (**IV**). The loss of self may be understood within the context of caregiver identity theory (Montgomery & Kosloski, 2009). The acquisition of carer identity implies a transitioning process where a previous familial relationship with the person with dementia is recomposed and substituted with the carer relationship (Montgomery & Kosloski, 2013; Montgomery et al., 2016). As such, it becomes obvious that it is necessary to consider the familial role 'spouse' or 'partner' and the dynamics of the new relationship as a basis to understand the caring situation. The influence of the familial role on the caring situation has also become clear in the findings reported in this thesis, indicating differences in the caring situation between spouses and others caring for a person with dementia (**I**). Similar differences have been previously reported, showing that spouses and children experience the transition into caring differently, leading to different caring situations and support needs (Lee et al., 2019; Steinfeldt et al., 2021). Furthermore, the spouses' experiences of losing their spousal role, as described in this thesis, was impacted by changes in the relationship (**IV**). This suggests that further efforts may be needed to strengthen the relationship between spouses and partners with dementia, as relationship strength and mutuality have been argued to be important mediators of role strain (Archbold et al., 1990).

With an understanding based on caregiver identity theory (Montgomery & Kosloski, 2009), the negative impacts (**I & II**) and the joint needs and experience of confinement (**III & IV**) may be a result of the interpersonal struggles when the role a spouse contradicts the increasing responsibility associated with the role as a carer. Therefore, support that facilitates a role transition may be beneficial in the earlier stages to manage the emotional and existential needs of spouses (Fowler et al., 2022; Lee et al., 2019). However, there are reasons to oppose such support, as it may cause spouses caring for a partner with dementia to further experience existential concerns, especially in a post-caring situation (Fowler et al., 2022; Høgsnes et al., 2014). Instead, findings suggest that spouses may have a need to process their situation, finding counselling important (**III**), as well as expressing worries about their future (**IV**).

There may be a need to process the situation targeting psychosocial needs, not only to ease the transition into the caring role, but also during the entire caring journey, from diagnosis to a post-caring situation. This would also be in line with reports from previous studies on expressed needs of psychosocial support (Van Aerschot et al., 2022), and the potentially beneficial effects of psychosocial interventions for family carers (Teahan et al., 2020).

Facilitating spousal care

While only a minority of carers for persons with dementia were in receipt of support, spouses received less support than other carers (I). There could be several explanations this, one of which is poor knowledge of their right to support (I). Lack of sufficient information and knowledge has been identified as a barrier to support in previous research (Greenwood & Smith, 2015; Macleod et al., 2017; Zwingmann et al., 2020). However, the lack of sufficient knowledge about available support may only be part of the explanation as to why spouses are less likely to access support services. Additionally, as findings suggest that spouses not only lack knowledge about their right to support (I) but also rate informational support as important (III) and express uncertainty on their future (IV), spouses may have further informational support needs that may not currently be met. Other explanations that have been put forward include the idea that the support offered may not be perceived as important, relevant, or aligned to their needs (Potter, 2018; Tyrrell et al., 2019). This may be partly true, as the findings in this thesis suggest that spouses, on average, perceive support as important (III). Furthermore, the low amount of received support reported in the findings of this thesis indicates that this may not be due to low interest, as in many cases spouses caring for a partner with dementia report not receiving support while expressing interested in the type of support relevant for them (I).

Support for spouses must be seen in relation to their complex situation where their own needs are both enmeshed with and conflicting with the needs of their care-recipient partner (IV). A stressful caring situation along with experiencing negative impacts of care was associated with the perceived importance of support (III). However, findings also suggest that spouses may find it hard to focus on their own needs for support in a situation where their partner with dementia has more immediate needs for care (IV). Similar explanations have been reported in the literature, where a stressful caring situation hinders access to support, and spouses caring for a partner experience overwhelming responsibilities, rendering it hard to seek support (Greenwood & Smith, 2015; Hammar et al., 2019; Tatangelo et al., 2018). Therefore, it is not only a matter of providing support; spouses must also be able to access the support offered.

While it is not possible to determine why spouses felt less supported than others based on the findings in this thesis (I), an important aspect seems to lie in the content or quality of support offered and how it is targeted. The findings highlight the importance of adequate and high-quality dementia care, as spouses, on average, rate the most important characteristic of support as care workers treating their partner with dignity and respect (III). Spouses also describe how they need to feel that they can trust health and social care directed to their partner with dementia to feel that they are supported (IV). This aligns with how policy makers in Sweden have discussed carer support in the new carer support strategy adopted in 2022, highlighting that the best support for carers is a well-functioning health and social care system with a carer perspective (Socialdepartementet, 2022). According to the literature, the quality of support, as well as dementia care, is pivotal to increasing support uptake, as a mistrust of services or beliefs that the service is inadequate have been linked to rejecting support, and serve as motivators for spouses to take on a carer responsibility (Chiatti et al., 2018; Greenwood & Smith, 2019; Macleod et al., 2017; Zwingmann et al., 2020).

Moreover, findings suggest that support needs to be accessible and available (III) and should aim to facilitate spouses to maintain and continue their relationship with their partner with dementia (IV). The development of support to meet these needs might require novel approaches to both carer support and dementia care (Gibson et al., 2019; Robinson, 2019). Examples that have been suggested in research include activities for both spouses and partners with dementia, such as exercising together (Doyle et al., 2021). This aligns to some extent with the findings presented in this thesis, where spouses express an interest in keep-fit activities as well as health checkups (I). In order to sustain caring, spouses may also need to focus on their own needs, as research has shown that they might neglect their own health due to the care they provide (Tatangelo et al., 2018).

There is reason to argue for support that aims to maintain the couple unit, forming a caring alliance between professional health and social care, the spouse, and the partner with dementia, as the findings presented in this thesis show that spouses value the relationship with their partner with dementia (III & IV). The need for holistic approaches that build alliances with carers and maintain the couple has also been argued for in research (Gibson et al., 2019; Poole et al., 2017; Robinson, 2019). Examples of such support could include special housing for this group, similar to the dementia villages in Denmark, allowing for continuous relationships and meaningful everyday lives (Peoples et al., 2020).

However, as highlighted in the findings of this thesis, spouses also have a need to engage in activities outside of caring, and to take a break from their caring

responsibilities. In order to experience that they have these opportunities, they also need respite care to be meaningful and safe (**I**, **III** & **IV**). Similar findings have been reported in previous research (Hammar et al., 2019; Morrisby et al., 2019; Tatangelo et al., 2018), indicating that support needs to be both flexible and adaptable. While individualized efforts should be a natural part of the provision of social care (Socialstyrelsen, 2016; SoL (2001:453)), aligning with the ambitions formulated in the national strategy on informal care adopted in 2022 (Socialdepartementet, 2022), there will be a further need to develop support that acknowledges spouses as individuals with their own needs, providing support to both the spouse and their partner with dementia to live up to these ambitions.

The findings reported in this thesis should be considered in relation to the demographics of the participants, as, on average, participants had cared for their partners with dementia for approximately four and half years (**II** & **III**). de Zwart et al. (2017) have reported that the impact of caring on the carer's health and wellbeing is more pronounced in the beginning of caring, with findings that suggest that the impact of caring does not persist over time. This could, to some extent, be related to the perceived support needs among spouses, as the results show that a stressful caring situation is associated with a higher perceived importance of support (**III**). Furthermore, research suggests that support needs alter over time, and that these needs may be most dire in the earlier stages after diagnosis (Lee et al., 2019). As the results reported both in this thesis and in previous research (Hammar et al., 2019; Steinfeldt et al., 2021; Tyrrell et al., 2019), spouses caring for a partner with dementia may have more extensive needs in the earlier stages of their carer journey as they struggle to adapt to their new situation.

This thesis suggests that there may be further steps to consider, one of which concerns the focus of support delivery. The results indicate that positive and negative outcomes of caring are not two ends of the same scale. Findings also demonstrate that the quality of support, on a multivariable level, was associated with the positive value of caring but failed to improve the model for negative value (**II**). Research suggests that support mainly focuses on the negative impacts such as burden (Kirvalidze, Abbadi, et al., 2023; Williams et al., 2019). It may be reasonable to consider that support aiming to strengthen the positive aspects of caring is needed to mitigate the negative consequences. Such suggestions have been put forward previously, suggesting multi-modal support to strengthen resilience not only in the person caring but also in the person with dementia, as well as their surrounding network (Conway et al., 2020; Donnellan et al., 2017; Donnellan et al., 2021). However, this is an area in need of further research.

While there is arguably a range of different support types and interventions available, they have been shown to have limited effect sizes on aggregated levels (Kirvalidze, Abbadi, et al., 2023; Walter & Pinquart, 2020). However, it has been suggested that they might still be beneficial, and that multi-modal support may be a way forward to mitigate distress (Williams et al., 2019). The results on the perceived importance and experience of support give further reason to assume that support may need to have a more holistic approach, targeting not only the spouse caring, but also the partner with dementia to be perceived as meaningful and safe, which is necessary for spouses to feel supported (III & IV).

That spouses feel supported is not only an issue related to the spouses' own situation, health, and wellbeing but also for society at large. Spouses provide significant amounts of care to their partners with dementia (Bremer et al., 2017; Wimo et al., 2018; World Health Organization, 2022), as also shown in this thesis, with spouses providing significantly more care than other carers, reporting a weekly average of caregiving almost double a full-time working week (I-III). The importance of the informal care efforts spouses provide should be considered in the context of the estimated increase in persons with dementia in the forthcoming decades, as well as the increased costs for health and social providers (Costa-Font & Raut, 2022; Meijer et al., 2022; OECD, 2018). As working carers are costly due to loss of productivity and incomes (Costa-Font & Raut, 2022; Ekman et al., 2021; European Commission, 2021b), spouses caring for a partner with dementia will arguably be essential to meet the future needs of an ageing population and increasing rates of dementia, especially since findings show that they are, to a greater extent, past the age of retirement (I).

Methodological discussion

The findings presented in this thesis are based on both quantitative and qualitative methods. This methodological approach may be regarded as a strength, as it enables a deeper understanding of the phenomena under investigation in relation to the overarching aim. It has been argued that the use of different methodologies increases the accuracy and credibility of findings when these are combined, both in the areas of social work (Hussein, 2009) and caring sciences (Foss & Ellefsen, 2002). While methodological triangulation was not applied in any of the papers included here, I believe that by presenting synthesised findings in the result section of this thesis, rather than individually in separate papers, the benefits of combining methodologies becomes apparent. While some have argued against combining methodologies due to differences in epistemological and ontological assumptions (Foss & Ellefsen, 2002), I argue that these differences are not necessarily true. Drawing from my social constructionistic understanding of knowledge, it is unreasonable to argue that it is impossible to synthesize findings from different methodologies. This is a standpoint I share with other scholars arguing for more pragmatic, realist, or constructionist approaches to research (Onwuegbuzie et al., 2009).

Quantitative studies

Designs

Both studies 1 and 2 employ cross-sectional designs. The key limitation of this design is the fact that they render it impossible to conclude on any causal relationships or associations (Bryman, 2016; Polit & Beck, 2016). A second notable limitation of cross-sectional designs is that they only provide a snapshot of a situation. Consequently, these designs make it impossible to examine changes in the care situation over time, preventing any conclusions being made on the potential changing needs for and experiences of support throughout the course of the carer's partner's dementia.

Study 1

Study 1 employed stratified random probability sampling, a method chosen to ensure that the sample distribution corresponds with the target population. However, the high levels of external and internal missing values may affect

the generalizability of study findings. A high level of missing data due to non-response may result in a biased sample, potentially causing underestimations or inflations within specific sub-groups of participants (Bryman, 2016). However, data used for Paper I included both questionnaire data collected for the specific study and registry data. The combination of two data sources helped to reveal biases in the data related to external missing data, and to address this, data were adjusted through the use of weights (Statistikmyndigheten SCB, 2019).

Study 2

For Study 2, a convenience sampling method was employed, where spouses caring for a partner with dementia were recruited based on their availability. This approach means that the sample will probably not be representative of the target population, which affects the generalizability of study findings (Bryman, 2016). Convenience sampling adds to the risk of sampling bias, which is particularly likely in the case of Study 2 due to the sample being rather homogenous, including an overrepresentation of women. Additionally, the study's inclusion criteria, which required proficiency in Swedish, likely resulted in the exclusion of participants from migrant backgrounds or those with poor language capabilities.

Nevertheless, the majority of participants were recruited with the assistance of health and social care providers, as well as civil society organisations focusing on informal carers or dementia. This adds to the overall reliability of the study as it is reasonable to assume that these organisations were able to identify participants meeting the study's inclusion criteria. However, as this mode of recruitment rendered it impossible to calculate a response rate, it was not possible to examine how the convenience sampling procedure may have impacted the sample.

Finally, data collection for Study 2 was terminated in February 2020 due to concerns that the Covid-19 pandemic might impact participant responses. Consequently, the study ended up with a smaller sample ($n = 175$) than initially planned for ($n=200$).

Reliability and validity

Reliability concerns the consistency of measurements, while validity relates to whether a measurement accurately measures the intended concept of an item or scale (Bryman, 2016). In quantitative studies, it is always important to consider both reliability and validity, as they are interdependent. If there is a lack of reliability in measurements, the findings cannot be deemed valid. In both studies 1 and 2, efforts were made to promote reliability in measurements and ensure the validity of study findings.

Study 1

In Study 1, the questionnaire used was developed by the Swedish Family Care Competence Centre and was based on a previous questionnaire used by the National Board of Health and Welfare (Socialstyrelsen, 2012). Due to this, it was possible to review included items and ensure the comparability of results. Prior to data collection, the questionnaire was further appraised for quality by experts in questionnaire development at Statistics Sweden, who provided a comprehensive technical report on the study (Statistikmyndigheten SCB, 2019). During this quality appraisal, the consistency of measurements was examined by experts who also evaluated the validity of the questionnaire. After revisions suggested by Statistics Sweden were made, the Swedish Family Carer Competence Centre conducted pilot testing in a convenience sample of carers, after which some final revisions were made. To ensure the highest standard, the questionnaire was reviewed a final time by Statistics Sweden.

As no multi-item scales were employed, there was no need to examine internal consistency of measurements, and therefore no such tests were conducted or reported. Instead, to determine the suitability of analyses, central tendency and dispersion were examined. Finally, as multiple testing may inflate the risk of type I errors, findings should be interpreted in relation to obtained effect sizes.

Study 2

In Study 2, a questionnaire was developed by the research team, drawing inspiration from the questionnaire used in Study 1. Additional items and scales specific to the overarching aim of the study were incorporated. As far as possible, the questionnaire included items and instruments validated in Swedish. Pilot testing of the questionnaire was conducted to test readability (font-size and layout for example) with a group of people of similar age to the target population.

In instances where there were no validated Swedish translations available, scales or items underwent standard translation-back-translation procedures. External researchers were enlisted to check the equivalence of the translations. This procedure has known flaws, such as the potential for spurious positive agreement between translations due to poor initial translations, however, it is common practice within the research community. The approach may help reveal semantic differences in translations, but should not be regarded as an absolute assurance of quality translations (Behr, 2017). This translation process may have impacted the reliability of the measurements, but reasonable efforts were made to ensure the translations were as reliable and valid as possible. Additionally, all scales used in Papers II and III underwent standard tests for internal consistency, assessed by estimating Cronbach's Alpha. This proce-

ture has some drawbacks, particularly in cases where scales have a low number of items. In cases where Cronbach's Alfa was deemed inadequate, inter-item correlations (Hajjar, 2018) were used.

Finally, as multiple testing may inflate the risk of type I errors, findings should be interpreted in relation to the obtained effect sizes.

Qualitative study

Design

Paper IV adopted a qualitative descriptive design, which was originally planned to be conducted as face-face interviews. However, due to recommendations on social distancing and isolation for older adults in Sweden at the time of data collection, it was necessary to conduct the interviews by phone. While phone interviews have been well established in survey methodology with quantitative approaches, there has been a reluctance to use them in qualitative studies due to concerns such as a potential loss of non-verbal and contextual cues and the risk of verbal data distortion (Novick, 2008). However, as demonstrated by Drabble et al. (2016), phone-interviews are a viable option when faced with restrictions on using face-to-face interviews. They make it possible to get rich and in-depth material, and they may also make it easier for the interviewee to touch on sensitive topics. This has also been reported by Mealer and Jones (2014), who found that it is sometimes easier for the interviewee to talk freely about sensitive or private matters over the phone, although the method does demand more of the interviewer. This was our experience during the data collection for Study 3, where participants were able to talk freely about how they experienced intimacy and the burdens of caring, providing researchers with rich data that were comprehensive in both scope and depth.

Trustworthiness

In qualitative research, it is important to consider trustworthiness throughout all stages, including data-collection, analysis, and the reporting of findings. While some argue that quality in qualitative research concerns rigor and validity, these concepts are not seen as appropriate in constructionist or critical paradigms (Polit & Beck, 2016). As Paper IV adopts an exploratory and interpretive approach, it would be inappropriate to claim that rigor and validity serve as measures of quality. Instead, it is more suitable to use the four criteria of trustworthiness (Bryman, 2016; Polit & Beck, 2016). These are *credibility*, *transferability*, *dependability*, and *confirmability* (Polit & Beck, 2016).

Aligned with Braun and Clarke's (Braun & Clarke, 2006, 2022) six-stage approach to thematic analysis, Nowell et al. (2017) have presented a detailed account of how trustworthiness can be viewed and understood. It is grounded in these criteria that Paper IV will be discussed.

Credibility

Credibility in a study refers to the level of confidence that is found in the truthfulness of the data and the interpretations presented for the study participants. As such, credibility is determined when interpretations are scrutinised by readers, such as fellow researchers, to determine whether they are viewed as believable, which is more likely if they are found to be in alignment with the respondents' views or experiences (Nowell et al., 2017; Polit & Beck, 2016). To increase credibility in Paper IV, the process of generating codes involved peer debriefing as well as discussions on the interpretations of the analytical codes. The analysis was conducted by myself and two of my supervisors, which allowed for interpretations to be made based on different perspectives. As a final step before reporting the generated themes, the interpretations were cross-checked against the interview transcripts to ensure that the themes were not a result of over interpretation. Furthermore, the findings reported in Paper IV were reviewed by co-authors who were not involved in the analysis, to meet the prerequisites for believable interpretations.

Transferability

Transferability refers to the extent to which findings reported in a study are generalizable. However, this only applies to case-to-case transfer, in the sense that the researchers cannot predict which contexts others may want to transfer the findings. To achieve a level of transferability, it is important that findings and methodology are reported with detailed and thick descriptions, to ensure that those wanting to transfer results to another context are able to extrapolate transferability (Bryman, 2016; Nowell et al., 2017; Polit & Beck, 2016). In Paper IV, thick descriptions are provided, including defining care and the context; that is who the participants were and where the research was conducted, if they lived in a community dwelling, were aged 65 or older, and if they were caring for a co-habitant partner with dementia in Sweden.

Dependability

Dependability in research refers to the transparency of the research process, ensuring that it is logical, traceable, and presented clearly. It involves constructing a process that can be audited and should provide readers with the necessary information to examine and determine the dependability of the research. This relates to audit trails, which provide information with evidence on the decisions that were made throughout the research process. The information on these decisions should allow other researchers to come to similar or comparable conclusions. The analysis used to generate themes reported in

Paper IV followed the six-stage approach outlined by Braun and Clarke (2006, 2022). As the analysis followed a step-by-step process, the codes generated were well documented, including the reflections being made and how the researchers laid ground for the interpretations. Furthermore, the process of theme development has been documented, demonstrating the dependability of the research in Paper IV.

Confirmability

Confirmability in research concerns the extent to which interpretations are clearly derived from the data, and it should be apparent that findings are not overly based on the researchers' own agenda or strong theoretical underpinnings. This also relates to the transparency of interpretations and how conclusions were derived from the findings and data. To establish confirmability, it is necessary to have achieved credibility, transferability, and dependability (Nowell et al., 2017; Polit & Beck, 2016). In Paper IV, each sub-theme and theme is supported by several examples derived from the data. This provides readers with the opportunity to examine and understand the relationship between data and the generated themes and sub-themes. While it is unreasonable to assume that any interpretation is completely objective (Bryman, 2016), a presentation of the researchers who conducted the analysis is provided. This information offers insights into their potential pre-understandings that may have influenced the interpretations.

Conclusions

This thesis underscores the pivotal role spouses play in caring for their partners with dementia, and the significant care efforts made by spouses that saves welfare systems substantial sums in long-term care costs. However, it also highlights that their contributions need to be acknowledged in relation to their life and caring situations. Further, this thesis highlight that spouses caring for a partner with dementia face unique situations, in the sense that their situations differ from others caring for persons with dementia. The consequences of caring for a partner with dementia extend across a broad range of areas that are not always directly linked to the stress of caring. While spouses caring for a partner with dementia experience a close relationship with the person who they care for, their relationship is impacted. The loss of intimacy and companionship can lead to spouses experiencing loneliness and a sense of confinement in their caring situation. Importantly, this thesis reveals both the negative consequences and the positive experience of caring, and how the divergent aspects of the caring situation need to be considered when developing support services.

Despite providing care with a greater intensity and frequency than other carers, spouses report being less supported in their situation than others. Only a minority of spouses were receiving support, and nearly half were unaware of their right to be supported according to the Swedish Social Service Act. This lack of awareness might be one of several explanations for the low utilization of support. As such, there is a need to increase awareness among spouses caring for a partner with dementia regarding their right to be personally supported as an individual outside their role as a carer, in order to live up to the ambitions of the national carer strategy.

While spouses recognise that support is important, they may neglect their own needs when their partner's care requirements are not sufficiently met. This is due to their needs for support being interlinked with their partner's care needs. For spouses to be able to focus on their personal needs and feel supported, they need to be reassured that the dementia care put in place for their partners is adequate and of high quality.

In the development of support services for spouses, a holistic approach is necessary, where both the personal needs of the spouse and the formal care needs of their partner are catered for. Support should also acknowledge the relationship between the two parties as the quality of the relationship affects not only the negative aspects of caring but also the positive values of caring.

Implications for policy and practice

- There is a need to further distinguish support efforts provided to carers with different kinships to the person with dementia, as their situations may significantly differ from one other.
- Spouses caring for a partner with dementia experience a close relationship with their partner. However, additional support is needed to maintain this relationship, as this thesis shows that their partner's dementia impacts emotional closeness and physical intimacy.
- Spouses caring for a partner with dementia bear a responsibility for their partner's welfare and may rate support promoting their partner's wellbeing over their own personal needs. As they do not perceive personal support as more important than their partner's dementia-related care needs, support should adopt a holistic approach by forming an alliance with the couples affected by dementia.
- Further efforts should be made to provide opportunities for spouses caring for a partner with dementia to enjoy activities outside of caring. However, there is also a need to provide opportunities for spouses and their partners to maintain their shared interests and enjoy activities together.
- The priority for support should not solely be focused on mitigating the negative consequences of caring, but also on promoting the positive aspects. Such efforts could involve strengthening the relationship and offering meaningful activities for both the spouse and the partner with dementia.
- Lastly, the results of this thesis highlight the need for additional efforts to inform spouses caring for a partner with dementia about their right to receive personal support in their capacity as informal carers.

Suggestions for future research

- Support needs vary among different types of carers. Future research is needed to develop support interventions tailored specifically to spouses caring for a partner with dementia, ensuring that they are accessible and adequately meet their different needs.
- This thesis employs a cross-sectional study design, yet the qualitative study suggests that the situation changes over time. Therefore, further longitudinal studies are needed to explore how the situation changes for spouses throughout the trajectory of their partner's dementia.
- In this thesis, spouses' perceptions of their relationship and intimacy with their partners with dementia were explored. The results show that both factors affect support needs in spouses caring for a partner with dementia, and further research should aim to explore how dementia affects couple intimacy and its relationship to support needs.
- This thesis explored the life situation and support needs of spouses caring for a partner with dementia. There is a need to further explore the situation for spouses caring for a partner with dementia post-caring, both with a focus on the transition of their partner moving into residential dementia care and in the aftermath of their partner's passing.
- Participants in this thesis were predominantly heterosexual and due to the eligibility criteria concerning proficiency in the Swedish language, persons with migrant backgrounds were likely excluded. Thus, the findings presented in this thesis may not be generalizable nor transferable to these groups, and future studies on the caring situation for persons caring for a partner with dementia should aim to include persons from minority groups as well.

Svensk sammanfattning (Swedish summary)

Bakgrund och syfte

I Sverige har kommuner och regioner det formella ansvaret att tillhandahålla stöd och omsorgsinsatser. Sedan 1980-talet har dock äldreomsorgen kraftigt minskat vilket inneburit att anhöriga kommit att ta ett allt större omsorgsansvar för närstående, så kallad informell omsorg. Informell omsorg är ett brett begrepp som innefattar direkta omsorgsinsatser kopplade till en persons sjukdom, ålder eller funktionsnedsättning, men även tillsyn, umgänge och stöd med vardagliga aktiviteter så som beredning av mat, transport, hushållsekonomi med mera.

I Sverige uppskattar man att mellan 15 och 21% av den vuxna befolkningen ger någon form av informell omsorg till en närstående med långvarig sjukdom, hög ålder eller funktionsnedsättning. Den största andelen av befolkningen som ger informell omsorg är mellan 45–64 år, men det är gruppen 65 år och äldre som ger mest omsorg mätt i antal timmar per vecka. Oftast är den yngre gruppen barn som ger stöd till en förälder, medan den äldre gruppen oftast är en make, maka eller sambo som vårdar sin partner.

Merparten av Sveriges cirka 150 000 personer med demenssjukdom bor i det egna hemmet, och oftast är det en make, maka eller sambo som ger vård och omsorg, så kallade partnervårdare. Det är partnervårdarna som står för majoriteten av all vård och omsorg av personer med demenssjukdom i Sverige. Att vårda en partner med demenssjukdom kan ha stor inverkan på partnervårdarens liv och forskning visar att partnervårdare har en ökad risk för fysisk och psykisk ohälsa. Även om vissa partnervårdare upplever att det känns bra att vårda sin livskamrat så är deras tillvaro ofta stressfylld, där hen ställs inför stora osäkerheter kring sin situation och livskamratens demenssjukdom. Samtidigt upplever många partnervårdare sorg kopplat till att förlora att förlora sin livskamrat till demenssjukdom.

För att mildra de negativa konsekvenserna kopplade till att vårda en partner med demenssjukdom kan partnervårdaren behöva stöd, något de har rätt till enligt Socialtjänstlagen (SoL 2010:453, 5:10), men forskning visar att stödet som erbjuds oftast inte är anpassad utifrån partnervårdarens behov. För att

kunna möta partnervårdarens behov så behövs ytterligare forskning om deras situation som vårdare och vilka behov de har.

Det övergripande syftet med denna avhandling att utforska situationen för personer som vårdar en make, maka eller sambo med demenssjukdom och öka kunskaperna om deras behov och upplevelser av stöd.

Metod och material

Avhandlingen består av tre olika delstudier (1–3) där resultaten presenterats i fyra olika vetenskapliga artiklar (I-IV). I delstudierna har både kvalitativa och kvantitativa metoder används.

Delstudie 1 (artikel I)

Den första delstudien har en tvärsnittsstudiedesign där data insamlats med hjälp av en enkät med tillägg av registerdata. Datainsamlingen genomfördes 2018 av Statistikmyndigheten SCB på uppdrag av Nationellt Kompetenscentrum Anhöriga (NKA). Studiens urval bestod av ett nationellt, stratifierat, slumpmässigt urval av 30 009 personer i Sverige över 18 år. Enkäten distribuerades via post och innehöll en instruktion om att besvara enkäten och sända åter via post eller att besvara via web-formulär. Efter två påminnelser hade 11 168 personer besvarat enkäten. I informationen som följde med enkäten definierades anhängigvårdare, och att enkäten inte berörde vård som gavs i deltagarens yrkesutövning eller till ett barn med särskilda behov.

I delstudie 1 analyserades ett underurval av deltagare som gav vård eller omsorg till en person med demenssjukdom. Totalt bestod underurvalet av 330 personer.

Enkäten som användes för datainsamlingen för delstudie 1 utvecklades av NKA i samarbete med SCB. Den innehöll totalt 29 frågor på följande område: Bakgrundinformation, vård- och stödsituation, och konsekvenser av att ge vård. Enkätsvaren kompletterades med information om kön, ålder, och om deltagaren var yrkesverksam eller pensionär från SCB:s register.

Enkätsvaren och registerdata analyserades med hjälp av olika statistiska tester för att undersöka skillnader mellan personer som vårdar en make, maka eller sambo med demenssjukdom, och övriga personer som vårdar en person med demenssjukdom.

Delstudie 2 (artikel II & III)

Den andra delstudien har en tvärsnittsstudiedesign med ett bekvämlighetsurval av personer över 65 som var sammanboende med och vårdade en make, maka eller partner med demenssjukdom. För att rekrytera deltagare kontakades olika nätverk av anhörigkonsulenter, demenssjuksköterskor och anhörigföreningar som ombads att identifiera möjliga deltagare och förse dem med en enkät. Parallellt så fanns även information om studien på internet med information om hur man kunde delta. Totalt besvarades enkäten av 175 personer, varav 163 uppfyllde kriterierna för deltagande.

Enkäten som användes utvecklades av forskargruppen, den bestod av totalt 36 olika frågor och instrument uppdelade på följande områden: Bakgrundsinformation, vård och omsorgssituation, hälsa och välbefinnande, äktenskapet och uppfattningar om stöd.

Enkätsvaren analyserades med olika statistiska metoder för att undersöka samband mellan olika bakgrundsfaktorer och upplevelsen av sin vårdsituation, samt sambanden i uppfattningar om stöd.

Delstudie 3 (artikel IV)

Den tredje delstudien är en beskrivande kvalitativ intervjustudie med ett bekvämlighetsurval bestående av 24 partnervårdare. Deltagarna rekryterades från de deltagare som besvarade enkäten i delstudie 2. För att samla in data utformades en intervjuguide som innehöll fyra olika frågeområden: äktenskapet, uppfattningar om stöd, hälsa och välbefinnande samt framtidsutsikter. Intervjuerna genomfördes semi-strukturerat, vilket innebär att intervjuguiden användes för att få en övergripande struktur till intervjuerna. Det innebar även att det fanns möjlighet för intervjudeltagaren att själv berätta fritt om sin situation och sina upplevelser. Samtliga intervjuer genomfördes per telefon och spelades in på diktafon.

För att analysera intervjuerna skrevs samtliga ut ordagrant. De utskrivna intervjuerna lästes sedan noggrant upprepade gånger. I nästa steg så plockades stycken från intervjuerna ut med specifika betydelser eller som speglade en specifik uppfattning med relevans för studiens syfte. Dessa sorterades sedan in i olika teman för att skapa en övergripande bild av deltagarnas upplevelser och uppfattningar.

Resultat

Resultaten i artikel I visade att personer som vårdar en partner med demenssjukdom var äldre än andra anhöriga till person med demens, de levde även oftare tillsammans med personen med demenssjukdom och gav mer vård och omsorg. Artikel I visade även att personer som vårdar en partner med demenssjukdom i större utsträckning upplever negativa konsekvenser av sitt anhörigskap än andra anhöriga, men även att de upplevde att de hade en närmare relation till personen med demens. Personer som vårdare en partner med demenssjukdom var i större utsträckning ensamma i sitt vårdande, men hade oftare blivit erbjudna stöd än andra anhöriga. Artikel I visade även att det var mindre än hälften av personer som vårdar en partner med demenssjukdom som kände till att de hade rätt att få stöd enligt socialtjänstlagen.

Artikel II undersökte de negativa och positiva upplevelserna av anhörigskapet och vilka faktorer hos personen som vårdar och partnern med demenssjukdom som kunde förklara de negativa och positiva sidorna. Analyserna visade att det var olika faktorer som kunde förklara den negativa och positiva upplevelsen. Tydlig var dock att det fanns ett samband med att uppleva anhörigstress och ha en negativ upplevelse av sin situation, men att även relationen till personen man vårdar spelade in i både en positiv och negativ upplevelse. Analyserna visade också att den positiva och negativa upplevelsen inte varandras motsatser utan två parallella upplevelser.

I artikel III så undersöktes hur viktiga olika typer av stöd och olika egenskaper av stödet uppfattades vara hos personer som vårdade en partner med demenssjukdom. Generellt så upplevs stöd som viktigt, men när samband mellan olika stöd och egenskaper undersöktes så visade resultatet att stöd till personen som vårdar inte var viktigare än stöd till deras partner med demenssjukdom. Bland annat visade resultaten att de viktigaste typerna av stöd berörde information och råd om partners demenssjukdom, men även möjligheter till vila från vårdandet. Den viktigaste egenskapen i stödet var dock att vård och omsorgspersonal behandlade deras partner med demens med värdighet och respekt.

Intervjuerna som analyserades i artikel IV visade att anhöriga ofta upplever att de är fast i sin situation som partnervårdare, där de försakade både sina egna intressen och relationer. Deltagarna beskrev även att de förlorade sin roll som make, maka eller partner och de får en ny roll som vårdare, bland annat då de inte längre kunde utbyta känslor och minnen, men även att de inte längre såg sin partner med demens som en jämlike. Deltagarna beskrev även hur de upplevde att det var viktigt att bli förstådd och bemött som en person och inte bara vårdare. Det framkom även att det var viktigt att deras partner med demenssjukdom fick en god vård och omsorg för att de skulle kunna slappna av.

Slutsatser

Situationen för personer som vårdar en partner med demenssjukdom är unik, den skiljer sig från situationen andra anhöriga till person med demenssjukdom har. Anhörigskapet och vårdandet har konsekvenser för personen som vårdar sin partner med demens som spänner över ett stort antal områden i deras liv. Samtidigt så upplever de en nära relation till sin partner med demenssjukdom, men att relationen är påverkad av demenssjukdomen. Samtidigt så visar denna avhandlings resultat att de negativa och positiva sidorna av anhörigskapet samexisterar. Det finns utifrån forskning även belägg för att om man kan främja det positiva så kan man mildra det negativa då det skapar en motståndskraft.

Trots att personer som vårdar en partner med demenssjukdom ger många timmar vård och omsorg så upplever de i hög grad att de är ensamma i sitt vårdande. Under hälften känner till rätten att få stöd och än mindre mottar eller har blivit erbjudna stöd. Samhället behöver således bli bättre på att informera om vilket stöd som finns att få och hur man kan få stöd i rollen som vårdare av en partner med demenssjukdom. Personer som vårdar en närstående med demenssjukdom känner ett ansvar för sin partner, de kan ha svårt att slappna av om de inte är trygga med demensvården. Därför är det viktigt att demensvården håller en god kvalitet, och i utvecklingen av anhörigstöd och demensvård bör kommuner och regioner ha ett mer holistiskt perspektiv för att stödja inte bara personen med demens eller personen som vårdar utan stödja paret som helhet.

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