

“Doing things together”

Towards a health promoting approach to couples' relationships and everyday life in dementia

Therése Bielsten



Linköping University Medical Dissertation No. 1729

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Norrköping 2020

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Printed in Sweden by LiU-Tryck, Linköping, Sweden, 2020

ISBN 978-91-7929-910-1

ISSN 0345-0082

To my grandfather Ragnar Bielsten

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ABSTRACT

Background: Most people with dementia live in their own homes, often together with their partners, who become informal caregivers. Relationship quality and sense of couplehood can be threatened as a result of the transition from a mutually interdependent relationship to a caregiver-care-receiver relationship. This, in turn, may lead to many negative consequences for both partners. Support provided for couples is often divided into different types for the person with dementia and for the partner without dementia and lacks couple-based support that targets the relationship, resources and the couple's everyday life together.

Aim: The overall aim of this thesis is to explore couple-centred interventions in dementia and to develop and test a salutogenic, resource-oriented and couple-based intervention among couples in which one partner has dementia living at home.

Methods and findings: This thesis comprises three parts: The first part *Exploring* involves two linked reviews, one narrative review (study I A) and one scoping review (study I B) that aim to identify and describe what previous couple-centred interventions comprised and why they were conducted. The results of the reviews revealed a knowledge gap in and a need for easily accessible support that targets couple relationships, resources and everyday life. The second part *Developing* (study II) refers to the development of an easily accessible resource-oriented couple-management intervention. The first step was to identify priority topics for such an intervention through a co-researcher process with couples living with dementia. This included a comprehensive literature review, interviews with couples in which one partner has dementia, and consultation meetings with expert groups of people with dementia and partners in both Sweden and the UK. The co-researcher process and the expert meetings informed four main themes with corresponding sub-themes that couples with dementia considered as important to their wellbeing in their everyday lives: (1) Home and Neighbourhood, (2) Meaningful Activities and Relationships, (3) Approach and Empowerment, and (4) Couplehood. The themes were further developed and integrated into the multimedia application DemPower, which was developed for the delivery of the intervention.

The third part *Testing and Evaluating* describes a feasibility study (study III) in which the DemPower application was tested for feasibility and acceptability among couples in Sweden and the UK. The results of the feasibility study indicated that the DemPower intervention was feasible and acceptable among couples in which one partner has dementia living at home. The testing and evaluating part also comprise a qualitative study (study IV) that explores the experiences of engaging with DemPower together as a couple living with dementia in Sweden. The findings resulted in the three themes: (1) Growth of the relationship, (2) We are not alone, and (3) Positive approach, which the couples appreciated and associated with the resource-oriented and salutogenic approach

of DemPower. The overall findings of the thesis are presented in a concluding synthesis at the end of the thesis. The concluding synthesis, focused on “*Meaningfulness*”, “*Empowering health promotion*”, “*Normalization*” and “*Transitions and couplehood*”, represents the core findings of this thesis.

What this thesis adds: This thesis contributes to research, healthcare and the public by highlighting the need for a salutogenic approach toward couples living with dementia. The DemPower application, with its focus on couples’ relationships, resource-orientation and everyday life, has proven feasibility and acceptability and has meaningfully addressed a gap in the literature and in practice. As researchers, healthcare professionals and the public, we need to support couples where one partner has dementia to continue to live as normal life as possible. This can best be achieved by focusing on what couples can do, by inclusion and by valuing them as the experts within dementia research and of their life experiences.

Keywords: Couplehood, Dementia, Everyday life, Intervention, Salutogenesis

SAMMANFATTNING

Bakgrund: Majoriteten av personer med demens bor i sitt eget hem och ofta tillsammans med sin partner som blir en informell vårdgivare. Relationens kvalitet och känsla av parskap hotas ofta till följd av övergången från en ömsesidig beroenderelation till en vårdgivare-vårdtagar-relation allt eftersom demenssjukdomen fortskrider. Detta kan innebära många negativa konsekvenser. Stöd för par där ena partnern har demens delas ofta upp i olika former för personen med demens och för partnern utan demens, vilket innebär att det saknas parbaserat resursorienterat stöd med inriktning på att främja parrelationen och parets vardagliga liv.

Syfte: Syftet med denna avhandling är att utforska parcentrerade interventioner inom demens och att utveckla och testa ett parbaserat, salutogent och resursorienterat stöd för par där ena partnern har en demenssjukdom och som bor tillsammans i det egna hemmet.

Metoder och fynd: Denna avhandling består av tre delar. Den första delen *att utforska* inkluderar två länkade litteraturöversikter, en narrativ översikt och en kartläggande översikt (studie I) som beskriver tidigare interventioner för par som lever med demens och varför de genomförts. Resultaten av översikterna visade ett kunskapsgap i, och ett behov av lättillgängligt stöd som riktar sig till parförhållanden, parens resurser och att främja det vardagliga livet. Den andra delen, *att skapa* (studie II) involverar utvecklingen av ett lättillgängligt resursorienterat och parbaserat stöd. Det första steget var att identifiera prioriterade ämnen för en sådan intervention tillsammans med par som lever med demens, genom en så kallad medforskarprocess. Detta inkluderade en omfattande litteraturgenomgång, intervjuer med par där ena partnern har demens, och konsultationsmöten med expertgrupper bestående av personer med demens och partners i Sverige och i Storbritannien. Medforskarprocessen och expertmötena resulterade i fyra huvudteman med motsvarande underteman vilka par med demens ansåg vara viktiga för deras relation och för välbefinnande i vardagen: (1) Hem och grannskap, (2) Meningsfulla aktiviteter och relationer, (3) Förhållningssätt och empowerment och (4) Parskap. Dessa teman vidareutvecklades och integrerades i multimedia-applikationen DemPower, som utvecklades i syfte att erbjuda interventionen till par som lever med demens.

Den tredje delen *att testa och att utvärdera* beskriver genomförbarhetsstudien (studie III) där applikationen DemPower testades med avseende på genomförbarhet och acceptabilitet hos par där en partner har demens i Sverige och i Storbritannien. Resultaten av studien visade att DemPower-interventionen var genomförbar och acceptabel bland par där ena partnern har demens. Denna delen av avhandlingen inkluderar även en kvalitativ studie (studie IV) som undersökte parens erfarenheter av att testa DemPower tillsammans som ett par. De samlade upplevelserna resulterade i tre teman: (1) Utveckling av parrelationen, (2) Vi är inte ensamma och (3) Positivt förhållningssätt. De övergripande resultaten från avhandlingen presenteras även i en konkluderande syntes i slutet av

avhandlingen. Den konkluderande syntesen med fokus på *Meningsfullhet*, *Empowerment*, *Normalisering* och *Parskap* representerar kärnan i denna avhandling.

Avhandlingens slutsatser och kunskapsbidrag: DemPower-applikationen med fokus på parförhållanden, hälsofrämjande resurser och vardagen har bidragit med ett stöd som vilar på en genuin parbaserad grund tillämpad i det vardagliga livet för par som lever med demens. Denna avhandling bidrar även med kunskap till forskning, vård och allmänheten genom att lyfta fram ett salutogent förhållningssätt till par som lever med demens. Som forskare, vårdpersonal och allmänhet bör vi stödja par där ena partnern har demens för att de ska kunna fortsätta leva ett så normalt liv som möjligt. Detta kan bäst uppnås genom att fokusera på parens resurser, genom inkludering och genom att värdera dem som experter inom demensforskning och i deras livserfarenheter.

Nyckelord: Demens, Det vardagliga livet, Intervention, Parskap, Salutogenes

ORIGINAL PAPERS

This thesis is based on five scientific articles which are presented in four studies. The studies are referred to in the text by their Roman numerals:

- I. Bielsten, T., & Hellström, I. (2019). A review of couple-centred interventions in dementia: Exploring the what and why — Part A. *Dementia: The International Journal of Social Research and Practice*, 18, 2436–2449.
Bielsten, T., & Hellström, I. (2019). An extended review of couple-centred interventions in dementia: Exploring the what and why — Part B. *Dementia: The International Journal of Social Research and Practice*, 18, 2450–2473.
- II. Bielsten, T., Lasrado, R., Keady, J., Kullberg, A., & Hellström, I. (2018). Living Life and Doing Things Together: Collaborative Research with Couples Where One Partner Has a Diagnosis of Dementia. *Qualitative Health Research*, 28, 1719–1734.
- III. Lasrado, R., Bielsten, T., Hann, M., Davies, L., Schumm, J., Reilly, S., Swarbrick, C., Dowlen, R., Keady, J., & Hellström, I. Feasibility and Acceptability of DemPower: A Couple Management App for Couples Where One Partner has a Dementia (submitted).
- IV. Bielsten, T., Keady, J., Kullberg, A., Lasrado, R., & Hellström, I. Couples experiences of using DemPower in everyday life (submitted).

Prior to the feasibility study (study III), a protocol paper with the trial registration number (ISRCTN) 10122979, was published and is attached to the thesis (appendix II):

Lasrado, R., Bielsten, T., Hann, M., Davies, L., Schumm, J., Reilly, S., Swarbrick, C., Keady, J., & Hellström, I. (2018). Designing and implementing a home-based couple management guide for couples where one partner has dementia (DemPower): Protocol for a nonrandomized feasibility trial. *Journal of Medical Internet Research*, 20.

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PREFACE

I have always enjoyed the company of older people, with or without dementia. My mum used to take me to her job when I was a child. She was a manager at a nursing home. When I turned 15, I started working in the cleaning department at the same nursing home during the summer. I talked to the residents, observed the interactions between the residents and the staff and longed to start working there “for real”. And I did, first as a care assistant for a number of summers and then as an assistant nurse after I graduated from upper secondary school. After a couple of years at the nursing home, I wanted to try something else. I spent two years in the restaurant business, first as a waitress and later as the manager of a small restaurant. Through this experience, it became clear to me that my heart belonged to nursing and within the care of older people. So I returned to the nursing home.

I began my life as a nurse 2010 after I graduated from the nursing program at Linköping University. My aim was to nurse older people and people with dementia. After working as a nurse for a couple of years in nursing homes and at a geriatric ward, I started studying to become a specialist nurse in the care of older people. My interest in research came about whilst I was writing my bachelor’s thesis and further developed through my master’s thesis. One year after graduating as a specialist nurse in 2014, I applied for and received the post of PhD student on the Neighbourhoods and Dementia study. However, I never left my clinical work. I have continued to work at nursing homes a few Saturdays each month and for a few weeks each summer.

What struck me relatively early in my PhD studies was that I actually possessed very little knowledge of people with dementia living at home. At the same time, I also gained an awareness that people with dementia are still largely defined on the basis of what they *cannot* do and on their decline trajectory. This can hardly be empowering. I hope that this thesis will contribute to a more balanced view of dementia and that research, healthcare professionals and the public will adopt a more salutogenic approach that focuses on health promotion and on what people with dementia (and partners) *can* do. That narrative turn is so important in paving a way to a new future in dementia studies and care.

1. INTRODUCTION

In line with the increasing number of older people globally, the numbers of people with dementia is also rising. In 2017, it was estimated that 50 million people worldwide were living with dementia and that this figure will further increase to 150 million people by year 2050. In Sweden, the prevalence of dementia was estimated to be about 158,000 people in 2012, and is expected to double over the next 20 years. Two-thirds of people with dementia live in their own homes, which applies to high-income countries worldwide. People with dementia also live for longer periods in their own homes which indicates that an increasing number of people will need specific and tailored support. People with dementia living at home are often supported by a close relative, usually by their partner. This means that people with dementia also need support in the context of a couple-based relationship and in the context of their everyday lives.

Dementia, with its progressive nature, brings about challenges to couples' relationships. For example, it has been argued that the major threat to couples' relationships is when the relationship develops into a caregiver-care-receiver relationship which often has a negative impact on relationship quality. Accordingly, it has been suggested that support targeted at the quality of couples' relationships is a protective factor for their wellbeing. However, there is, at present, a lack of relationship-based support that targets the couple as a unit and place the couple' relationships, wellbeing and everyday lives centre stage. This thesis aim is to explore previous research of couple-centred interventions, and to develop and test a resource-oriented, salutogenic and couple-based intervention where one partner has dementia living at home.

Throughout this thesis I will refer to the person with dementia as "the person with dementia" or "the partner with dementia" and their partner as the "partner without dementia". I refer to the couple as a "couple living with dementia". When I use the term caregiver, it relates to all types of caregivers, including partners without dementia. I will refer to myself as either "I" or "TB" depending upon the particular context of the situation described. The term "expert" refers to people with dementia and relatives to people with dementia because of their personal and relational knowledge which has been drawn on to develop this thesis.

2. BACKGROUND

2.1. People living with dementia

Dementia is an umbrella term for conditions of progressive cognitive impairment, including Alzheimer's disease, Vascular dementia, Lewy body dementia and frontotemporal dementia (World Health Organization, 2020). I am using the term *dementia* regardless of the specific diagnosis. The DSM-5 criteria (Diagnostic and Statistical Manual of Mental Disorders) for dementia states that dementia includes conditions of neurocognitive disorders in a range from minor to major dementia. However, in the updated version of DSM-5 from 2015, the concept of dementia has been removed and replaced by neurocognitive disorder and includes conditions characterized by cognitive impairment. Dementia is also categorized by the level of support needed because of the progressive nature of the condition, i.e. the three stages of mild, moderate and severe dementia, regardless of the particular type of dementia (American Psychiatric Association, 2013).

Dementia is not a natural part of the ageing process with age identified as the main risk factor in its development (Ferri et al., 2005; Prince et al., 2015). Dementia most often results in a progressive dependency, both from cognitive decline and the subsequent functional limitations, meaning that a person with dementia becomes dependent on support from the people around them and from the healthcare services and social care services (Ferri, Sousa, Albanese, Ribeiro & Honyashiki, 2009; Prince, Prina & Guerchet, 2013). The cognitive symptoms of dementia include impaired orientation and learning, problems with memory function and attention and challenges with interpretation and communication skills. Consequently, the symptoms of dementia impact upon interaction and relationships on several dimensions and can affect the everyday lives of the persons (and their partners) (Alzheimer's Association, 2016; World Health Organization, 2020). Communication and interaction have been highlighted as the main challenge for couples living with dementia as it significantly, and detrimentally, impacts the couple's relationship (Boots, de Vugt, Withagen, Kempen, & Verhey, 2016; Evans & Lee, 2014; Marmstål Hammar, Williams, Merranius, & McKee 2019; Werthon & Monk, 2008).

In line with the increasing number of older people globally, the number of people with dementia is also increasing. In 2017, it was estimated that 50 million people worldwide were living with dementia, and that this figure will further increase to 150 million people by year 2050 (Alzheimer's Disease International, 2018). In the United Kingdom (UK) it was estimated that 850,000 people were living with dementia in year 2016, and this number is predicted to rise to one million people by 2025 (Alzheimer's Society, 2016). In Sweden, the prevalence of dementia was estimated to be about 158,000 people in 2012 and the incidence was approximately 25,000 people each year (National Board of Health and Welfare, 2014). Nearly two-thirds of people with dementia live in their own homes. This applies to high-income countries worldwide (Odzakovic, Hydén Festin & Kullberg, 2019; Prince et al., 2014). Nearly 50% of the care and social costs of dementia in UK (GBP 26.3billion) comprises unpaid care cost (Lewis et al., 2014; Prince

et al., 2014) and the corresponding figures of the cost in Sweden is GBP 8 billion, in which nearly 20% is estimated to be unpaid care costs (Wimo, Jönsson, Bond, Prince & Winblad, 2013). This means that a significant amount of home-based care and support for people with dementia is provided by informal caregivers, such as partners.

Despite the fact that most people with dementia live in their own homes, knowledge about such circumstances is sparse, compared to people with dementia who live in nursing homes. In Sweden there has been, and still is, a tradition of mainly associating people with dementia with nursing home care, which is also evident in Sweden's national guidelines for the care of people with dementia. The guidelines largely focus on the three phases of dementia (mild, moderate and severe) (National Board of Health and Welfare, 2017) and this could contribute towards the priority of the phase of severe dementia in which people with dementia generally live in nursing homes.

Most people with dementia want to live at home for as long as possible (Tarricone & Tsouros, 2008). However, it is not only these preferences that impact the number of people with dementia who live at home. For instance, apart from the fact that care and support at home is regarded as the best prerequisite for providing person-centred care for people with dementia (Prince, Prina & Guerchet, 2013), there has been a significant reduction in nursing home placements in Sweden (National Board of Health and Welfare, 2014). This has led to a reduced likelihood of being granted a nursing home placement. However, research shows that "ageing in place" is beneficial for the cognitive function of people with dementia (Lee & Waite, 2018) who often benefit from living in environments in which they recognize themselves in relation to their surroundings and in their own homes. Thus, living in a familiar environment is considered to lead to a higher degree of independence and satisfaction (Gould & Basta, 2013; Lee & Waite, 2018; Nygård, 2004; Tarricone & Tsouros, 2008). Having the opportunity to live in one's own home generates a sense of belonging (Bigonnesse, Beaulieu & Garon, 2014; De Witt, Ploeg & Black, 2009; Gillsjö, Schwartz-Barcott, & von Post, 2011) and a familiar neighbourhood fosters a sense of attachment and inclusion which contributes towards sustaining relationships (Keady et al., 2012; Keady, 2014; Odzakovic, 2020; Ward et al., 2018; Wiles, Leibing, Guberman, Reeve & Allen, 2012).

2.2. Couples living with dementia

Many people with dementia live at home together with their partners, who will often become informal caregivers for care and support (Lipszyc, Sail & Xavier, 2012; Merrick, Camic, & O'Shaughnessy, 2016). However, couples living with dementia at home often need support from health care services and social services in order to continue living together. It is estimated that nearly 85% of all couples require some form of support in their daily lives (Alzheimer's Disease International, 2009). The type of support provided for people with dementia living at home often involves day-care centres and other arenas for meeting other people with dementia and engaging in activities (Alzheimer's Disease International, 2016; Gilhooly et al., 2016). The most common support for the partners of people with dementia is support groups and education regarding dementia and informal caregiving (Chien et al., 2011; Frias et al., 2020). Thus, support provided for people with dementia and their partners is often fragmented, divided into different types of support (Clare et al., 2012; Gilhooly et al., 2016; Hellström, Nolan & Lundh, 2007a; Merrick et al., 2016) and does not include relationship-based support in the context of the couple's everyday life (Brodaty & Donkin, 2009). The Swedish guidelines on the care of people with dementia (National Board of Health and Welfare, 2017) state that relationship-based support programmes *can* be offered to people with dementia and informal caregivers. This proposal received a six on a scale of 1-10, where 1-3 comprise measures that *should* be offered, 4-6 are measures that *can* be offered and 8-10 are measures that *can be offered in exceptional cases*. Thus, relationship-based support programmes became priorities that *can* be offered and thereby also forming part of the new Swedish national strategy for the care of people with dementia (National Board of Health and Welfare, 2019).

Whilst these are encouraging signs, research indicates that couples often are left on their own to deal with the relational and emotional challenges of dementia (Campbell et al., 2016; Samsi et al., 2014). Moreover, the evidence suggests that psycho-social support at both parties in the care relationship can improve the quality of life for both partners (Moon & Adams, 2012; Sprange et al., 2015). Furthermore, the support provided to couples living with dementia is often unresponsive to their needs (Alzheimer's Disease International, 2016). This may be because people with dementia and their partners are considered to be a homogeneous group (Purkis & Ceci, 2015) based on the dementia diagnosis and the expected symptom-related problems. Whilst the existing support for people with dementia and their partners is important, failure to address issues of personalisation makes it difficult to understand the couple's relationship dynamics and how they can be best supported in the context of their relationship.

Several studies have described and discussed the problem of overlooking and “lifting” people with dementia or their partners out of their everyday context by neglecting interpersonal issues (Martire et al., 2010; Phinney, 2002; Robinson et al., 2005; Van’t Leven et al., 2014; Whitlatch, 2001). That said, the relatively small number of joint dyadic interventions that include both the caregiver and the care-receiver have shown promising results for both the wellbeing, relationship quality and quality of life for both parties, although there is a tendency to mix people with dementia and subgroups of caregivers (spouse, adult child, friend) thus blurring up the nature of the relationship and a genuine couplehood approach (the concept of couplehood is described in the next section) (Braun et al., 2009; Moon & Adams, 2012; Smits et al., 2007; Van’t Leven et al., 2014). This also results in that the target of support, type of intervention and how support is delivered are being matched with an overall group of dyads, regardless of the specific nature of their relationship (Merrick et al., 2016; Moon & Adams, 2012).

2.3. Personhood and Couplehood

2.3.1. Personhood

The importance of viewing health and illness from a bio-psycho-social perspective was first introduced by the American psychiatrist Georg Engel (1977). Engel (1977) criticized the dominant biomedical perspective, which he considered to be restricted and disease-oriented, and argued instead that health and illness should be viewed from a wider perspective than the presence or absence of a disease. In his revised approach, the wider perspective placed a greater emphasis on the person’s experiences of health and illness and added a psychosocial dimension. In the 1970s and 1980s, the disease-oriented perspective of health and illness had a major impact on the negative positioning of people with dementia. People with dementia were considered to “be” their illness and were mainly understood based on the brain injury. Working in the UK at the Bradford Dementia Group, Kitwood (1987, 1989, 1997) was a pioneer in his efforts to implement a broader view of people with dementia, in which the person comes first, not the disease. Kitwood (1997, p. 8) coined the term personhood which he defined as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust”. Kitwood therefore argued that the major threats to a person’s sense of personhood arises out from malignant social psychology, which involves the negative approaches and treatment of a person with dementia. The malignant social psychology aimed to explain the threats to a person’s sense of personhood when s/he is treated by others in a patronising and excluding manner based on dementia. Examples of these negative approaches towards people with dementia are when the person with dementia is ignored, not included in conversations/the community, and is treated like a child.

Kitwood (1997) further suggested that holistic and person-centred care could contribute towards preserving personhood for people living with dementia. From the late 1980s and throughout the 1990s, Kitwood's work, and the work of the Bradford Dementia Group in the UK, had a major impact on research, care, policy, education and the views of people with dementia (see for example: Kitwood, 1988; Kitwood, 1990a; Kitwood, 1990b; Kitwood, 1997; Kitwood & Bredin, 1992a; Kitwood & Bredin, 1992b), a legacy that continues to this day (Kitwood & Brooker, 2019). A number of social researchers both contemporaneously and subsequently, have followed in Kitwood's footsteps by questioning the positioning of a loss of self in dementia. For example, Sabat & Harré (1992) argued that the self remained intact throughout the lived experience of dementia, a position that Sabat (2002) later defined as existing as self 1, self 2 and self 3. In this approach, self 1 refers to the expressions of experience located in space, time and values embodied in our life world. In other words, self 1 relates to our personal identity and how lived experiences have shaped and impacted upon our lives. Self 2 relates to how we perceive our manifold selves with regard to our attributions, both physical and psychosocial, and how we have contributed to our surroundings by our attributions of appearance, knowledge, values and roles. Self 3, in contrast, includes both how we see ourselves (subjectively) and how other people view us (objectively). As such, self 3 consists of higher order constructs that are compromised when living with a dementia, for example when a person becomes lost in a (seemingly) familiar location and asks for help. In such circumstances, self 3 could be considered as the most vulnerable self as it is affected by other people's views of us and our reactions and response as to how we are viewed. Currently, the bio-psycho-social and person-centred approach towards people with dementia has come a long way. However, the biomedical approach is still deeply rooted in the care of people with (Sabat, 2011; Sabat, 2014) and it is not uncommon for this approach to still be adopted.

When looking more closely at Kitwood's definition of personhood at page 18, and for the context of this thesis, it is interesting to note that his definition largely comprises an interpersonal understanding of personhood. Through Kitwood's definition, a person must also be understood in the context of relationships and interaction. By this, the definition of personhood could be interpreted to mean that a major part of personhood involves the recognition and validation of self through relationships and social contexts and that relationships also have the potential to contribute to a sustained sense of personhood. Thus, this interpersonal understanding of personhood recognizes the importance of couple relationships (Hellström, Nolan & Lundh 2005; 2007a; Phinney, 2002; Whitlatch, 2001). Developing the couple approach further, Kitwood (1997) also argued having an identity is to knowing who we are, both in mind and in feeling, and to have a sense of continuity with the past – thereby having a story to tell others. Living in a couple relationship should have the potential of strengthening and confirming a person's narrative of the past, thus strengthening their sense of personhood (Hellström et al 2005; 2007a).

2.3.2. Couplehood

The concept of couplehood was first created by Kaplan (2001) and was described as sense of belonging to a “we” or an “I” in a spouse relationship with a person with

dementia living in institutional care. The aim of Kaplan's research was to understand how nursing home placement impacts couple relationships. Kaplan suggests that sense of couplehood depended upon how a relationship was experienced in the past and the degree of change that the couple experienced with the nursing home placement. The concept of couplehood has been further developed and investigated by several researchers (e.g. Keady, 1999; Hellström, Nolan, & Lundh, 2005, 2007a; Molyneaux, Butchard, Simpson, & Murray, 2011) and is often described as the interpersonal, mutual relationship of couples. For example, Keady (1999) highlights the need to help couples "working together" in order to manage their situation and to sustain sense of mutuality and couplehood. He found that the efforts on the part of the partner without dementia to maintain the involvement of the partner with dementia were central. Hellström et al. (2005), further explored the ways in which couples with dementia are "working together" by "doing things together" in order to create and maintain a sense of couplehood. In a study from the mid 2000's, Hellström et al. (2007a) described the dynamics of couplehood using three broad phases: 'sustaining couplehood'; 'maintaining involvement' and 'moving on'. My understanding and definition of the sense of couplehood is: the subjective feeling of mutuality, a confidence in the notion that both partners contribute to the relationship, and a mutual understanding (and interest) of the notion that the wellbeing of "us" is dependent on the wellbeing of both partners. I also suggest that other people's objective view of the couple as two people belonging together contributes to the subjective understanding of a sense of couplehood. This definition of couplehood is applied to the thesis.

2.4. Potential challenges to couples' sense of couplehood

It has been argued that the major threat to relationship quality and couples' sense of couplehood occurs when the relationship develops into a caregiver-care-receiver relationship (Hedman, 2014; Hellström et al., 2007a; Ingersoll-Dayton, Spencer, Kwak, Scherrer, Allen, & Campbell, 2013). This development can take place when quality time together as a couple becomes increasingly less frequent and the roles of caregiver and care-receiver take precedence. Research shows that couples living with dementia work hard to maintain a sense of couplehood and nurture their relationships (Boylstein & Hayes, 2012; Hellström et al., 2007a; Wadham et al., 2016) and that it can be a demanding task. Accordingly, the progressive nature and the symptoms of dementia, such as the impact on memory, communication and everyday living, entail challenges and demands about adapting to such changes (Berg & Upchurch, 2007; O'Shaughnessy et al., 2010). In the literature, these challenges and changes are often described in terms of loss, most commonly described as loss for the partner without dementia (Merrick et al., 2016). Examples of the described losses are: loss of roles in the relationship, loss of couple identity, loss of shared decision-making, and loss of dealing with life's challenges together (Davies, Gilliss, Deshefy-Longhi, Chestnutt & Molloy, 2011).

A low sense of relationship quality and low sense of couplehood can have many negative consequences for both partners, including depressive symptoms, increased strain on the partner without dementia (Ablitt, Jones, & Muers, 2009; Allen et al., 2017) and it can accelerate the progression of dementia both cognitively and functionally (Norton et al., 2009). Moreover, strain experienced by caregivers (Gaugler, Yu, Krichbaum & Wyman, 2009; Stefhan et al. 2014) and low relationship quality has been shown to increase the need for nursing home placement (Brodaty & Donkin, 2009; Joseph, Fang, Kathleen, & Jean, 2009; Spruytte, Van Audenhove, & Lammertyn, 2001). Thus, it has been suggested that support targeted at the quality of a couple's relationship is a protective factor for the couples' wellbeing and has the potential to reduce the negative impact on the relationship (Ablitt et al., 2009; Hellström et al., 2005, 2007a; Keady, 1999; McGovern, 2011) and increase the possibility of the couple living together at home for a longer period of time (Gould & Basta, 2013).

2.5. Experiences of couples living with dementia

Research about the relationship experiences of couples living with dementia, in which the views of both the person with dementia and the partner without dementia are included, remains sparse (Ablitt et al., 2009; Braun et al., 2009; Clare et al., 2012; Forbat, 2003; Hellström et al., 2007a; Wadham et al., 2016). The focus is most often on the experiences of the partner without dementia including the person's experiences of the couple relationship (Merrick, Camic & O'Shaughnessy, 2016). This not only results in the experiences of the person with dementia being overlooked, but it also overlooks the contribution of people with dementia to research within this field. However, there are exceptions in the research in which the focus is directed towards couplehood and couple identity. In addition to the work of Keady (1999) and Hellström et al. (2007a), described in the section of couplehood on page 19-20, Davies (2011) found that couples worked together to maintain their "us identity" (p. 227) by valuing their commitments to each other through reciprocity, resilience, and forgiveness. Molyneaux et al. (2011) explored the experiences of dementia on couple relationships and identified five themes of strategies as being representative of the couples' co-construction of couplehood: 'shifting identities within couplehood', 'maintaining the relationship despite dementia', 'the good old days', 'technically being a carer' and 'sharing experiences of dementia'. Thus, the couples' strategies for sustaining couplehood spanned over their whole lives together, from deriving satisfaction from reminiscing about earlier times to making the most of their current situation. In a study by Merrick et al. (2016), findings revealed that the couples "worked together" to make sense of their situation and to adjust to dementia in order to maintain their identity as a couple and to normalize their situation.

In a recent study by Hernandez, Spencer, Ingersoll-Dayton, Faber & Ewert (2019) couples assessed their couple identity and couplehood by using an adapted version of the Inclusion of Other in the Self (IOS) scale (Aron, Aron, & Smollan, 1992). The scale comprised three pictures: the first picture had two circles labelled "Me" and "My Partner" separated from each other; the second picture had the same two circles overlapping at the

middle; and the last picture had the two circles overlapping in a singular circle. In one half of the 18 couples, the partners chose congruent pictures. The nine remaining couples chose incongruent pictures, i.e. the partners did not experience their relationship in the same way. In four of the couples who chose incongruent pictures, the partner with dementia chose the singular circle while the partner without dementia chose the overlapping circles. The authors suggested that an explanation of the different depictions of the relationship and the ratings of partners without dementia of a lower sense of couple identity could derive from the fact that the partner without dementia had started to operate independently, (also in line with Kaplan's (2001) towards becoming an "I") usually as a result of taking over the couples' everyday responsibilities. This pattern, i.e. that the partner without dementia feels more separated over time from their partner, was originally described by Hellström et al. (2007a) and Keady and Nolan (2003). Moreover, this finding may also be seen as an additional incentive for including both partners in the assessment of the relationship. A reoccurring phenomenon in almost all of the studies described above was that couples appear to nurture their sense of couplehood by "doing things together" (Davies, 2011; Hellström et al., 2005, 2007a; Hernandez et al., 2019), and that the sense of couplehood appeared to increase when partners deal with dementia as a team.

2.6. Salutogenesis in dementia

The term salutogenesis relates to the focus of wellbeing and health and derives from positive psychology (Pretorius, Walker, & Heyns, 2009). Salutogenesis was first applied to a health-oriented model by Antonovsky (1979, 1987). The model focuses on coping, i.e. how people handle stressors, but also on the positive development that occurs when people manage stressors in a constructively successful way. Antonovsky (1996) recognized that the "generalized resistance resources" that a person possesses facilitates the coping process. The generalized resistance resources are comprised both by the resources of the individual and by people around the individual. Key to Antonovsky's model is the concept of Sense Of Coherence (SOC) which in turn, involves the dimensions of comprehensibility, manageability and meaningfulness. The first component "comprehensibility" relates to the experience of predictability and sense-making of a stimuli or stressor. The second component "manageability" implies the extent to which people perceive that they have the necessary resources required to handle the demands that comes with the stressors. The third component "meaningfulness", which is also classified as the most important component, implies the person's sense of meaning, purpose and the motivation to deal with the demands that emerge through the particular stressor (Antonovsky, 1979, 1987; Lillekroken, Slettebø, & Hauge, 2015).

Sense of Coherence is originally applied to the stressors that arise from human life, such as divorce, illness, death of a loved one, as well as to objectively less significant stressors, such as minor individual changes. Sense of coherence has recently been applied in terms of meaningfulness for the caregivers of people with dementia, i.e. from a salutogenic, health-promoting perspective to caregiving in dementia (see for example, Moore et al., 2013; Oliveira, Zarit, & Orell, 2019; Pretorius et al., 2009; Wennerberg, Eriksson, Lundgren, & Danielsson, 2018). It has been shown that a strong sense of coherence helps caregivers meet the challenges as their role of caregiver to a loved one. However, few studies have focused on the positive aspects of the caregiving situation, such as meaningfulness (Wennerberg et al., 2018), and is therefore also an example of the predominant focus on the negative aspects of couple relationships in dementia, in which support is directed towards one person of the dyad.

In research in which the concept of salutogenesis or health promotion is applied to a person with dementia, it is usually in regards to preventing the development of dementia (see, for example, Lautenschlager, Almeida & Flicker, 2003; Schiepers, Köhler, Deckers, Irving, O'Donnell & Akker, 2018; Travers et al., 2009). However, I argue that salutogenesis and sense of coherence can also be applied to interdependent relationships, such as couple relationships where perceived dyadic comprehensibility, manageability, and meaningfulness could nurture a health-oriented approach to dementia and the related challenges. A health-oriented and resource-oriented approach could help to focus couples on maintaining the healthy aspects of relationships, such as the sense of couplehood and the wellbeing of couple's everyday life. Furthermore, sense of couplehood and the support from a partner could also be viewed as a powerful resistant resource.

Self-management interventions can be seen as a salutogenic element of chronic conditions. Self-management is a form of support that is guided by encouraging individuals with chronic conditions to manage their daily lives with or despite of their condition and to live as well as they can with the condition (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Martin et al., 2015; Mountain & Craig 2012). There is sparse evidence to suggest the availability of self-management for couples living with dementia at home (Mountain, 2006; Martin et al., 2015; Laakkonen et al., 2016). However, self-management in chronic conditions is often about the management of symptoms of an illness, but when it comes to self-management in dementia it should instead be targeting the stressors and challenges in everyday life (Martin et al., 2015). In line with this, Hickman, Wiersma and Harvey (2015) found that the three core skills for self-management in dementia should focus on “adaptation to change”, “finding meaning and purpose” and “communication”.

2.7. Research context of this thesis

The Neighbourhoods and Dementia study started on the 1st May 2014 and ran until the 31st October 2019. The Neighbourhoods and Dementia study was funded under key commitment 12 of the first UK Prime Minister's Challenge on Dementia (Department

of Health, 2012) with a focus on the everyday connection of people with dementia to everyday spaces, places and people. The Neighbourhoods and Dementia study was conducted through eight work programmes and people living with dementia (and relatives) were placed at the heart of each work programme positioned, wherever possible, as co-researchers (see for example: Keady and the neighbourhoods and dementia study team, 2014, Swarbrick & Open Doors, 2018; Swarbrick et al., 2019; Calvert, Keady, Khetani, Riley, Open Doors Research Group & Swarbrick, 2020). This thesis describes the research in work programme 6 called “Living Life and Doing Things Together” (Dr Ingrid Hellström lead and Principal Investigator) which is an international work programme with the overall aim of developing and testing an empirically based self-management (couple-management) guide for couples living at home and in which one partner has dementia. The research was conducted in both Sweden and in the UK. The primary research question of work program 6 was to explore how, following a diagnosis of dementia, a couple-oriented self-management course provided in primary care can sustain and enrich everyday life and maintain neighbourhood integration.

2.7.1 Collaborative research

The most commonly used term when describing research that involves the target group in the research process, or parts of the research process, is Patient and Public Involvement (PPI). There is, as yet, no conventional definition of PPI. In a recent published scoping review by Miah et al. (2019), PPI is defined as “involvement in research being carried out ‘with’ or ‘by’ members of the public rather than “to”, “about” or “for” them (p.2). The benefits of PPI for researchers have been suggested to include for example a better understanding of the community, challenging beliefs and attitudes, and to enhance quality of data. Benefits for the patients and public involved have been suggested to include for example new skills, support and friendship, and satisfaction. PPI is also considered to increase the relevance and utility of the research (Staley, 2009) and may also facilitate the dissemination and implementation of the research.

According to the results of the scoping review by Miah et al. (2019), only 20 studies (19 from UK, 1 from the Netherlands) conducted in the European Union between the years 2000 to 2018 met the inclusion criteria for PPI in dementia research. However, there has been a significant increase of research carried out together with people with dementia (Morbey et al., 2019), which is an important development as people with dementia have often been excluded from research (Hellström, Nolan, Nordenfelt, & Lundh, 2007b; Swarbrick et al., 2019). In a recent publication of research ethics (Alzheimer Europe, 2019), Helen Rochford-Brennan, within the European Working Group of People with Dementia, states that:

“Research is about more than the topic being researched; it is about placing a value on our voice, realizing that people with dementia have insights and worthwhile contributions. Research ethics are important but we must not get so concerned about ethics that we take an overly paternalistic view and exclude people living with dementia” (p.3)

This quote might represent the exclusion of people with dementia due to the nature of the diagnosis, and also the strict rules and ethical concerns that precede research with people with dementia, such as the issue of informed consent. It has been, and is, common to turn to proxies to ask people with dementia to take part in research. Sometimes this is a stipulation of ethics committees, but it is also as a consequence of the views of people with dementia as not being able to speak and advocate for themselves (Clarke & Keady, 2002). The significance of involving people with dementia as the experts of lived experience has been highlighted in order to enhance trustworthiness and transparency of the research process (Swarbrick et al., 2019). It is also a matter of research priorities as researchers themselves need to turn to people with dementia and their relatives to find out what they want and need (Scottish Dementia Working Group, 2014). In summary therefore, ethical committees should take into account the person with dementia's rights to participate in studies and not only their rights to protection.

The Neighbourhoods and Dementia study was guided by a co-researcher strategy where the co-researcher discourses reflected “a desire to move away from references to ‘user’ and ‘patient and public involvement’, towards a more collaborative partnership between groups of people living with dementia, academic researchers and service providers” (Swarbrick et al., 2019 p. 3167). This is in line with the report by Alzheimer Europe (2019) where the term patient is questioned. And I agree, regardless of whether you are sometimes a patient, you are still a member of the public. Led by Dr Caroline Swarbrick, work program 1 of the Neighbourhoods and Dementia study had the aim to facilitate involvement of people with dementia in all of the eight work programs and mobilised a number of advocacy and activist groups of people with dementia to make this happen. Study II within this thesis was carried out in accordance with the collaborative design with people with dementia and their partners, from identifying priority areas of research to confirming the validity of the findings. This thesis was also guided by the core principles for involving people with dementia in research, developed by Scottish Dementia Working Group (2014), a research group of people with dementia. To the best of my knowledge, Sweden is far behind these initiatives as compared to the UK, especially in the use of a collaborative research approach in dementia studies. In conclusion, involving people with dementia in research has many benefits for researchers, and for people with dementia and partners, as it often contributes towards a sense of inclusion and empowerment (Di Lorito et al., 2017).

3. RATIONALE

It is estimated that over 50 million people worldwide are living with dementia and that this figure will further increase to 150 million people by year 2050. By including all people affected by dementia, such as their partners, intergenerational family members and the local neighbourhood network, the population would be significantly multiplied. The majority of people with dementia live in their own homes and are often supported by their partner. Most people with dementia wish to live at home with their family for as long as possible, which has also been highlighted to be the best prerequisites for wellbeing, preserved identity, independence and relationships. The symptoms of dementia, such as challenges in communication and interaction, entail a threat to a couple's relationship quality. Low relationship quality can, in turn, lead to many negative consequences for the couple's wellbeing and they may therefore need support to sustain relationship quality and sense of couplehood. However, support provided for couples is often divided, targeting one partner in the relationship and therefore has less potential to support the couple as a unit, their relationship and everyday life. In addition, the long history of disease-orientation in dementia has impacted on the type of support provided for couples living with dementia.

These circumstances have resulted in a focus of illness specific issues and caregiver burden. The views of couple relationships in dementia and what type of support they require needs to be investigated, broadened and supplemented with relationship-based support that support positive aspects and utilize their resources. In fact, the limited amount of research that is focused on couples' relationships and resources has shown to have the potential to increase wellbeing of both partners and to alleviate negative consequences, such as depression, nursing home placement (not always negative) and the decrease of relationship quality. Based upon the importance of supporting couples with dementia in sustaining relationship quality and a sense of couplehood, my starting point in this thesis was to conduct couple-based, inclusive and health promoting research where the wellbeing and the resources of couples living with dementia is at the centre. Given that the number of couples living with dementia will increase in the coming years, there is also need for support that is not solely dependent on resources in health care. Accessible support, such as self-management tools could have the potential to positively impact the everyday lives of couples with dementia and could also contribute to less strain on community resources.

4. AIMS

The overall aim of this thesis is to explore couple-centred interventions in dementia and to develop and test a salutogenic, resource-oriented and couple-based intervention in which one partner has dementia living at home.

Specific aims:

Exploring

Study I – Part A: To gain knowledge of the ‘what and why’ (types, objectives and outcomes) of couple-centred interventions.

Study I – Part B: To explore the ‘what’ and ‘why’ (types, objectives and outcomes) of joint dyadic interventions in which the majority of participants are couples/spouses.

Developing

Study II: To identify the relevant content for a self-management guide by using the outcomes of previous research in combination with knowledge and experiences of couples in which one partner has a diagnosis of dementia.

The developing part includes a description of the development of the DemPower application in which the self-management guide (couple-management guide) was delivered.

Testing and Evaluating

Study III: To investigate the feasibility and acceptability of the DemPower application in couples living together at home, in which one partner has dementia.

Study IV: To explore the experiences of using the DemPower application in couples living together at home, in which one partner has dementia.

5. THEORETICAL FRAMEWORK

In this chapter I will describe the framework and concepts that have guided the thesis. The theoretical framework of everyday life has permeated the research from planning to analysing. Although this thesis is in the field of nursing, I have initially used sociology to understand the phenomenon of everyday life. In order to support and care for a person, we should try to understand a person with dementia in the context of relationships and everyday life. I believe that the understanding of a person's lifeworld provides at least an opportunity to provide person-centred and couple-centred care tailored for both the person with dementia and their partner. Following an attempt to describe and define everyday life, I will elaborate on sociology in terms of the importance of understanding the couple's lifeworld (Schütz, 1972). This was an important standpoint in the developing part of the thesis.

5.1. The theory of everyday life

Throughout this thesis, the concept of everyday life arises. I started thinking about what everyday life means to couples living with dementia, reflected in my intention to genuinely reproduce the experiences and knowledge of these experts. However, I first had to examine what "everyday life" actually meant.

Two of the first and most commonly cited social constructivist theorists who discussed the everyday life were Henri Lefebvre (1984) and Michel de Certeau (1984). Lefebvre (1991) described everyday life as "related to all activities, and encompasses them with all their differences and their conflicts; it is their meeting place, their bond and their common ground..." (p. 97). He suggests that everyday life refers to the mundane routines that are often taken for granted and provide comfort, but sometimes also boredom (Lefebvre, 1971). This "taken-for-granted" description of everyday life is also in accordance with the understandings of the activities of everyday life suggested by both Schütz & Luckman (1973) and Scott (2009). Michel de Certeau (1984) highlighted that people create and practice their everyday lives, thus assuming that everyday life is something that people "do". Again, everyday life appears to be related to activities.

In the literature, everyday life can also be considered to be a daily rhythm, something that happens every 24 hours (Bovone, 1989) and is characterized by repetitive cycles of "doing". Thus, we often engage in similar mundane activities, in the same order and at the same time, day after day. The routine and repetitive nature of our everyday world is thereby safe and predictable (Scott, 2009). A more recent social theorist who has discussed and researched the phenomenon of everyday life is Susan Scott. She defines everyday life in three dimensions: social order, rituals and routines, as well as challenges to the taken for granted. She suggests that the most ordinary everyday life components are emotions, home, time, eating, health, shopping and leisure, i.e. everyday activities. In

conclusion, everyday life appears to refer to these unremarkable things that are mundane and familiar, but also often private and personal (Scott, 2009).

5.2. First- and second-order constructs of everyday life

Drawing on the social constructivism approach to the theory of everyday life, the developing part of this thesis aimed to understand and reproduce how couples living with dementia view their everyday lives and what is important for them. Alfred Schütz is best known for his book “The Phenomenology of the Social World” (1972) in which he makes a distinction between the person’s perception of the world and how science communicates people’s perceptions of the world. He used Husserl’s (then) recently coined concept of the “life world” and argued that sociological research is a social reality understood through “common sense” and through an intersubjective reality. As a consequence, in attempting to understand or examine a person’s experience of their life world, the researcher had to turn to the primary source, thereby obtaining the person’s life world through a first-order construct, i.e. from the person experiencing the life world under study. The researcher then reproduced the first-order constructs through second-order constructs and, for the narrative to be credible, the first-order constructs and second-order constructs had to be in congruence, that is, as the persons see their life world, the researcher should also have interpreted it and reproduced it.

5.3. Significant concepts of this thesis

5.3.1. Salutogenesis

Individual resources and dyadic resources are of great significance for how couples living with dementia manage the challenges they face as individuals, as a couple, and in meetings with others. The concept and meaning of salutogenesis had its natural place in this thesis when the problem-orientated and disease-focused approach to dementia became evident. I have briefly described the concept of “sense of coherence” in the background section to the thesis and will now add to this section by describing the fundamentals of Antonovsky’s theory. Aron Antonovsky was a professor of medical sociology. He researched the factors that comprised and sustained health, despite the presence of illness. He stated that people revolved around the opposite poles of health and illness. In order to better understand perceived health despite an illness, Antonovsky focused on the resources people have to deal with the stressors that an illness brings to their life and it is therefore about how we manage physical, mental and emotional stressors. In Antonovsky’s book “The Mystery of Health” (1987), he coined the term Sense of Coherence, which includes the three components of comprehensibility, manageability and meaningfulness (outlined in the background section) that are regarded as the components necessary to

achieving a sense of coherence and, despite an illness, moving towards the health pole (Antonovsky, 1987).

5.3.2. Transition

Transition is a central concept of nursing and has been widely used in nursing research and practice, most commonly in studying the transition of health-illness. Transition is also a familiar concept in stress and adaptation theories (Chick & Meleis, 1986). Transition theory has been used to study several areas of nursing such as oncology, cardiovascular diseases, women's health and transitions related to nursing home placement (Im, 2011). In the nursing field, transition often refers to the nurse's identification and guidance of a person through the transition.

The term *transition* has its roots in the Latin word *transire*, which can be described as the passage from one life phase to another. The passage or process starts with a sense of disconnectedness caused by the disruption (i.e. a stressor such as an illness). This is followed by phases of coping and adjustment to change, called the patterns of response. At the end of the process, if the transition is successful, the person/persons experiencing the transition will achieve more stability relative to the situation during the process. Thus, transition involves an ongoing phenomenon within a time span, but also the perception and meaning of the person/persons experiencing it. (Chick & Meleis, 1986). It is interesting to note that salutogenesis also focuses on the perceived "meaning" of a stressor. Meaningfulness is one of the components of sense of coherence and is considered to be the most important component for the understanding and the "arrival" at a new situation. In this thesis, I have chosen to use the term *transition* to underpin the adaptations and changes in relationship to the everyday life of couples in which one partner has dementia.

6. METHODS & ANALYSIS

Both qualitative and quantitative methods were used to address the research questions and the aims of the three parts of this thesis: *Exploring*, *Developing*, and *Testing and Evaluating*. Qualitative methods were used in all three parts of the thesis by exploring couple-centred interventions (study I), developing and refining the couple-management intervention (study II) and evaluating the intervention (study III, IV). Quantitative methods were mainly used in the testing and evaluating part (study III). An overview of the designs and methodologies used are displayed below (Table 1).

Table 1. Overview of designs and methodologies

Part, study	Design	Research question	Inclusion criteria	Data collection	Substrates/participants	Data analysis
Exploring, I (A)	Narrative review	What are the types, objectives and outcomes of couple-centred interventions in dementia in which both partners jointly participate in the intervention?	PwD (or MCI) participating together with CP, living in ordinary housing, PwD and CP not separated during intervention	Academic Search Premier, CINAHL, PsycINFO, PubMed, Scopus and Web of Science from January 2000 to August 2017	6 studies	Guidelines for a narrative review by Green, Johnson and Adams (2006).
Exploring, I (B)	Exploratory scoping review	What types of interventions have been conducted for couples living with dementia in which the majority of the sample comprise couples, and what were the objectives and outcomes of the interventions?	PwD (or person with MCI) participating together with CG living in ordinary housing. PwD and CG not separated during the intervention	Academic Search Premier, CINAHL, PsycINFO, PubMed, Scopus, and Web of Science from January 2000 to August 2017	21 studies	Framework for scoping reviews by Arksey & O'Malley (2005)
Developing, II	Empirical collaborative approach	What are the relevant topics for a self-management guide (couple-management) for couples living with dementia at home?	Couples of any gender, living in their own home, and a diagnosis of dementia for one partner.	Semi-structured interviews and expert groups	n = 5 community-dwelling couples with dementia	Hybrid approach of a thematic analysis by Fereday and Muir-Cochrane (2006)
Testing and Evaluating, III	Prospective non-randomized feasibility study	Is the "DemPower" application feasible for and acceptable to couples living with dementia at home?	Couples in a long-term relationship in which one partner has dementia, living at home. Both partners understand and speak English/Swedish.	Questionnaires and data usage tracking	n = 21 community-dwelling couples living with dementia in Sweden and the UK.	Descriptive statistics

Testing and Evaluating, IV	Explorative interview study	What were the experiences of “DemPower” and engaging with “DemPower” as a couple living with dementia at home?	Semi-structured interviews	n = six couples who participated in the feasibility study	Thematic analysis by Braun & Clarke (2006)
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PwD = Person with Dementia, MCI = Mild Cognitive Impairment, CP = Care Partner (partner), CG = Care Giver (all kinds of informal caregivers, including partners)

6.1. Exploring

6.1.2. Methods

The exploratory part of the thesis involves the two linked reviews of study I, which were primarily planned, performed, analysed and reported by TB. Both of the reviews aimed to explore couple-centred interventions in dementia, but with different approaches. The first review was a narrative review (study I A) conducted according to the guidelines for a narrative review by Green, Johnson and Adams (2006). The intention of a narrative review is to describe, summarize and synthesize research in the subject field and provide a conclusion based on the evidence. The guidelines by Green et al. (2006) are not presented as a step-by-step process but focus on transparency by clearly describing how the study was performed. This includes *sources of information*, *search terms and delimiting*, and the *selection criteria* employed. The narrative review aimed to explore the “what and “why” (types, objectives and outcomes) of interventions aimed at couples in which one partner has dementia and in which the couple jointly participate. The second review (study I B) was performed as a response to the results of the first review, since the first review was too narrow in its inclusion criteria and did not target dyadic interventions in which the sample comprised a majority of couples. The aim of the second review was to explore the “what” (types of interventions) and the “why” (objectives and outcome measures) of dyadic interventions in which the samples comprised a majority of couples/spouses and in which people with dementia and caregivers jointly participated. In order to broaden the scope of the couple-centred interventions, a framework for scoping reviews by Arksey and O’Malley (2005) was used. The purpose of scoping reviews is to map existing research which, in turn, can identify knowledge gaps and thereby the direction of further research. The framework by Arksey and O’Malley (2005) includes five stages: identifying the research question, identifying relevant studies, selection of studies, charting the data and collating, summarising and reporting the results. For both reviews, data collection was conducted through searches in Academic Search Premier, Cinahl, PsycInfo, PubMed, Scopus and Web of Science from 2000 to August 2017 and was limited to English. The same search terms and limits were used for both reviews. A Boolean string was established using truncated search terms and adapted to the specific databases in which the searches were performed. The search terms used to identify the population and the intervention are shown at the next page.

Population

Dementia OR “Alzheimer’s disease” OR
“mild cognitive impairment”

Family OR caregiver* OR dyad* OR
marriage OR spouse* OR couple* OR
care partner” OR” informal caregivers”
OR “next of kin”

Limits: 2000/1-2017/08, English lan-
guage

Intervention

“Self-care” OR “self-management” OR
support OR education OR advice OR re-
habilitation

Intervention OR implementation

6.1.3. Analysis

The searches for the first review (study I A) generated a total of 5,711 references. After organizing references and after duplicates had been removed, 3,303 abstracts remained to be reviewed for relevance. 667 of these studies were scanned in full text. Only five of these met the inclusion criteria for the review. The main reason for exclusion was that many of the studies had samples of mixed relationships and separate sessions for people with dementia and partners. The reference lists of the five articles were read and this generated one additional article. The next step of analysis was to read the six articles multiple times and extract data from the articles into a pre-prepared evidence table of key categories of interest (Green et al., 2006). The categories of interest were: type of intervention, sample, diagnosis, implemented where and by whom, objective/goals, outcome measures and main findings. The searches for studies in the second review (study I B) generated the same number of references as the first review (5,711) and followed the same pattern until the selection of studies from the 667 that were scanned in full text. Of these, a significant number of articles were excluded (647) because many of the studies involved separate support for the person with dementia and the caregiver. Twenty articles met the inclusion criteria and, by reviewing the reference lists of these articles, one more article was included. The summary table (called *evidence table* in the first review) comprised the same key categories, except for the category of main findings. In both reviews, procedures and results were discussed in the research group in order to ensure consistency.

6.2. Developing

6.2.1. Methods

The two reviews of the exploring part, along with a review of the literature in the research field of couples living with dementia, identified the knowledge gap of couple-centred interventions in which both partners jointly participate, with the aim of supporting resources and couple relationships. This was the starting point for the development of the couple-management guide. The developing part includes the qualitative interview study (study II) in which the themes of the couple-management guide were identified, as well as a description of the DemPower application, in which the couple-management guide was further developed and delivered. The aim of study II was to identify relevant content for a couple-management guide aimed at couples in which one partner has dementia. A qualitative approach was adopted in order to gain in-depth knowledge of how couples experience their relationships and what they consider important for maintaining relationship quality and wellbeing in their everyday lives. An interview study was selected as it is well suited to a thorough study of a small number of individuals which, in turn, creates the conditions for understanding the phenomenon that it intends to study (Patton, 2002). Thus, an interview study is appropriate when seeking knowledge of people's lived experience (Patton, 2002; DiCicco-Bloom & Crabtree, 2006) and aims to capture the individuals' own perspectives of reality, including feelings, thoughts and experiences (Patton, 2002).

Study II was conducted in three phases, the first and second phase was conducted in Sweden by TB and the third phase by TB in Sweden and by Reena Lasrado (RL) in the UK. The first phase identified topic areas in couplehood and wellbeing in the everyday life of couples living with dementia through a comprehensive literature search of previous research. Fourteen themes were identified and served as a draft framework for potential themes for a couple-management guide. The second phase involved ten interviews with five Swedish couples living with dementia at home. The couples were recruited from a memory clinic in the county of Östergötland, Sweden. The primary objectives of the interviews were to confirm the relevance of themes in the draft framework, to represent the subjective meaning of the themes (Schütz, 1973) and to add new themes of relevance from the interview data. Between the interviews, couples could record their comments and their own experiences by adding comments to the framework or by using a disposable camera or a dictaphone (resources distributed during the first interview). When interviewing and co-researching with people with dementia, it is important to provide multiple ways for them to participate and for them to do this when it suits them the best (Bartlett, 2012). This often provides opportunities for increased participation which, in turn, leads to increased data quality (Swarbrick et al., 2019). The second interview was a follow-up interview that included data collection. All interviews were performed with the couple as a unit in their own home. Interviews were audio recorded and transcribed verbatim and all comments were gathered in documents. Co-researchers' characteristics are displayed at the next page in table 2.

Table 2. Co-researchers' characteristics (study II)

	Couple 1	Couple 2	Couple 3	Couple 4	Couple 5
Gender PwD/P	F/M	M/F	M/F	F/M	M/F
Age PwD/P	74/77	71/67	74/72	74/74	77/73
Diagnosis	Alzheimer	Alzheimer	Alzheimer	Alzheimer	Alzheimer
Length of time since diagnosis (years)	8	7	8	3	8

(PwD = Partner With Dementia, P = Partner without dementia).

The interviews with couples had provided first-order information (Schütz, 1973) from a small sample. The third phase of study was to use the themes as sensitizing concepts being tested for empirical validity in expert groups of people with dementia and their relatives in Sweden and in the UK (the findings were also translated into English). The third phase procedure can be seen as being similar to a member check process. However, the member check method originally means that the researcher takes back parts of the analysis to the participants in order to verify the accuracy of the findings (Creswell, 2014). In this case, member checking was conducted by experts from the target group.

6.2.2. Analysis

A hybrid approach to thematic analysis (Fereday & Muir-Cochrane, 2006) was adopted to analyse the developing part of the thesis (study II). The hybrid approach to thematic analyses involves both an inductive and a deductive phase. A deductive approach can generally be described as starting from an already existing specific hypothesis or theoretical framework initial to the data collection. The specific theoretical framework of this study was the draft framework compiled by the 14 themes. Meanwhile, an inductive approach responds to the detection of patterns and themes from the collected data, not controlled by a predetermined reference (Patton, 2002). The first step of the hybrid approach was to develop a template of themes. I used the themes from the draft framework for this purpose. See an example of themes from the constructed template below.

Theme 1

Name of theme: The meaning of home
 Definition: Physical and emotional space of home
 Description: Description of home or feelings of being at home and in familiar surroundings.

Theme 2

Name of theme: Comfort/safety inside home
 Definition: Physical safety, adaptations facilitating everyday life.
 Description: Descriptions of comfort, safety and function of home related to everyday living

The following deductive analysis process was performed by applying interview data to the draft framework. Themes from the template were matched with segments of data that were representative of the themes, see example below.

Theme from the template	The meaning of home
Segment from transcribed interviews	<i>“I feel peace and harmony in my home. We like to go out as well, but there’s nothing better than coming home when you’ve been out, closing the door behind us and just relax”</i>

The next step of the hybrid approach involved the inductive analysis of data, called *additional theming*. This was the phase in which the themes were data driven, i.e. that emerged through the interview data:

Data-driven theme:	State of mind/living as usual
Explanation of theme:	Coping strategies and description of how to adapt to changes
Data from interviews:	<i>“It’s a matter of living as usual. Doing as much as possible in the way we usually do”.</i>

The last step of the hybrid approach was to incorporate themes from the deductive and the inductive analysis (i.e. from the template and data-driven). Themes were then clustered and connected to form the main themes. The consultation meetings with the expert groups were conducted after the data analysis and after the themes had been confirmed, revised or added in accordance with the findings from the interviews.

6.3. Brief description of DemPower

The results of study II informed the themes of the trademarked DemPower app. The themes were refined and structured under four main themes with 18 corresponding sub-themes (table 3). DemPower is a multimedia application with text, audio and video sources. The app’s design focuses on making the interface simple and easy to access through user-centred and participatory approaches. The contents are storyboarded and converted into animated videos and films of couples sharing their approaches to everyday life and couple relationships. The app’s homepage lists the main themes, navigational buttons are available at the bottom of the screen and there is a help menu at the top of each screen throughout the app. A paper manual was also developed to supplement the help menu. Each main theme has an introduction with text, audio and animated video. When choosing a subtheme in the main theme, this begins with an introduction followed

by a film of couples talking about their life within the particular theme. The film is followed by suggestions for activities and, at the end, couples can choose to click on “further information” in order to read documents (or sometimes watch videos) with information and tips on the topic area (figure 1).

The introduction sections for the main themes and subthemes are based on previous research of why the relevant theme and subtheme were assessed as being important for couples living with dementia – and are presented as text and audio in the app. In order to develop the animation and videos for the app, a film company in the UK was consulted. The film company made the animations for both the Swedish and the UK version of the app, as well as the filming of video clips in the UK and the voiceover for all information in the UK version of the app. The UK film company used professional actors in the video clips. For the Swedish version of the video clips, a film company was consulted for the filming and voiceover. “Simulating patients” from Linköping University were used as the actors in the videos together with a coach and TB who arranged the filming and trained the actors. The script used in the film clips is based on the interviews of the couples in study II. The suggestions for activities in the app include discussions within the couple, checklists of actions that could facilitate everyday life and activities about doing things together as a couple and nurturing the couple relationship. Further information, tips and advices were collected from knowledge bases such as the Alzheimer Society and Alzheimer Australia. The same information appears in the Swedish and English version of the app, except in the section that provides the contact details for support resources. The content of DemPower was developed in Sweden by TB. After translation of the interviews and documents (where necessary) and when all applications had been granted permission from knowledge bases (by TB), RL, at The University of Manchester, recruited the couples, planned filming and collected data at the English site. Meanwhile, TB carried out the corresponding procedures in Sweden. The technology behind the app was developed by James Schumm (IT Research Software Engineer) from The University of Manchester in close collaboration with TB and RL.

Table 3. Content of DemPower (study III)

Themes	Subthemes	Activities	Further information
Home and neighbourhood	The meaning of home	Take pictures	
	Inside	Use checklist to identify required changes	PDF, further information about home adjustments
	Outside	Walk together, take pictures and discuss	PDF about technology, PDF about security
	Couplehood	Describe positive relationship experiences, listen to music and express emotions	

Meaningful activities and relationships

Physical exercise	Watch videos, exercise and keep a log	PDF about exercises for older people, PDF about guidelines for physical activity
Doing things together at home and outdoors	List tasks to do together and then choose one	4 PDF:s with tips for doing things together
Individual activities	List individual activities and schedule time	
Adapting activity to capability	Revisit the task list and discuss how to adapt	
Mental exercise	Games (apps downloaded to the tablet)	

Meeting, sharing and caring in your neighbourhood

3.1 Socializing with friends and family	Schedule meeting appointments, keep a visitor log and share the communication sheet with family and friends	PDF about tips for friends, PDF about tips for visitors, PDF containing general tips on how to engage with a person with dementia
3.2 Meeting others who live with dementia	Visiting social groups, dementia cafes...	
3.3 Informing each other and other people	Share your experiences with neighbours and discuss them	

Managing communication and emotions

4.1 Being a comfort and a friend	Discuss your ways of comforting each other	
4.2 Living as usual and keeping a routine	Plan a routine and display	
4.3 Stress	Watch stress management video/ audio and follow instructions	
4.4 Conflicts	List strategies helpful for conflict management	
4.5 Future and planning	Use the future planning checklist	
4.6 Communication	Examine the listed strategies and add to them	

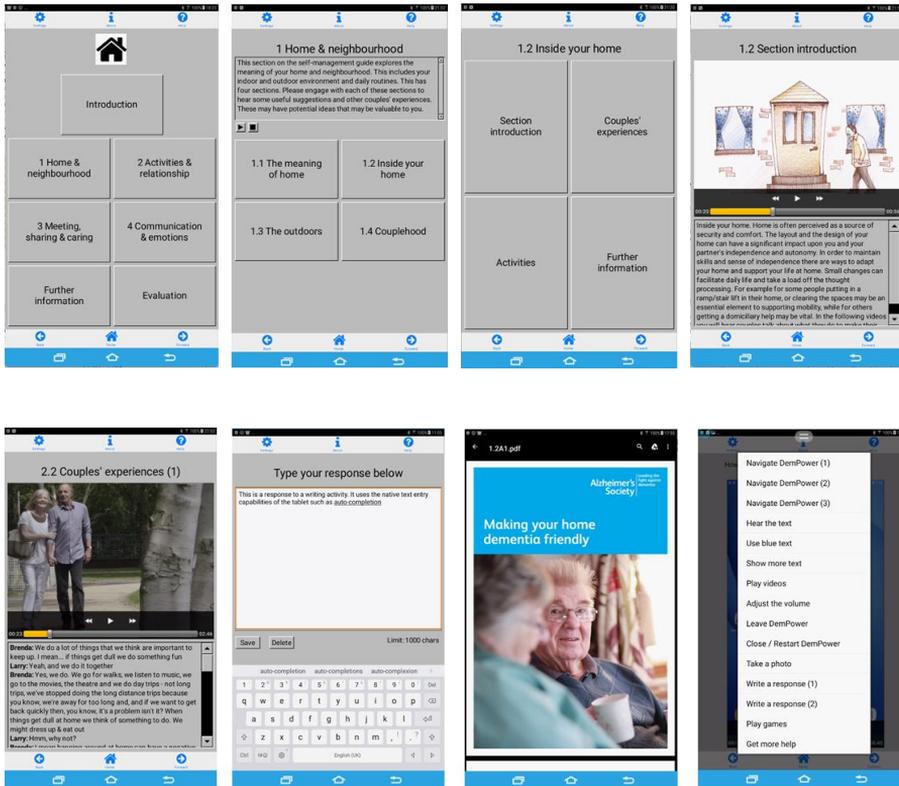


Figure 1. Screenshots of DemPower (study III)

6.4. Testing and Evaluating

6.4.1. Methods

The first phase of the testing and evaluation section describes the feasibility study (study III) in which the DemPower application was tested among couples living with dementia in Sweden and in the UK. Initial to the feasibility study, the DemPower application was tested within a couple from work programme 4 in the Neighbourhoods and Dementia study (Keady, 2014). This further confirmed the content as being relevant and relatable and that evaluation forms were clear, although some minor revisions of the app structure were desirable.

The primary outcome measures of the feasibility study were recruitment capability, sample size and completion rates to determine whether a randomized controlled trial could be conducted in the future, and to evaluate the usability and acceptability of DemPower. In order to assess the recruitment capability, the study was informed by Lancaster, Dodd, & Williamson (2014) recommendation for assessing critical parameters,

such as recruitment and retention rate. Researchers from both sites (TB, RL) held a detailed record of the total number of target population accessed, recruited and retained. Also, notes were kept regarding time taken for recruitment, number of contacts, visits, the challenges encountered, reasons for withdrawals and the factors that influenced the recruitment and completion rates. A framework for feasibility studies by Bowen et al., (2009) was used to assess feasibility and acceptability (appendix II). Usage data were gathered from the tablets (tablets were provided to couples at baseline) at the end of the study and couples received theme-specific evaluation questionnaires designed by the researchers to complete when they had finished a main theme of DemPower (see an example of theme-specific evaluation and the usability questionnaire in appendix I). The study also explored the acceptability and relevance of secondary outcomes used in the study, which involved measures of quality of life, self-efficacy, interconnectedness and mutuality assessed at baseline and follow up (appendix II). Secondary outcomes were measured for both partners at baseline and post intervention. Researchers also documented their experiences, challenges, follow-up and evaluation, relevance of outcome measures and intervention and procedures during the trial. Data collection was conducted by TB in Sweden and by RL in the UK. Couples had at least three months to complete the app. Both sites included at least two home visits, one initial to the intervention in order to obtain consent, to introduce the app and for baseline measures, and one home visit when the app was completed in order to collect usage data, feasibility and acceptability outcomes, as well as secondary outcomes. Follow-up phone calls were made by the researchers (TB and RL) after one and two months, and continuous contact with the couples was also maintained during the intervention through mail and text messages adapted to the wishes of the couples. The couples were also encouraged to contact the researchers to update their progress and ask for support, if required.

The second part of the testing and evaluation involved conducting a qualitative interview study (study IV, conducted by TB) to supplement the evaluation of the feasibility study in which most of the outcomes were quantitative. The research question of the study was: What was the experiences of “DemPower” and engaging with “DemPower” as a couple living with dementia? Semi-structured interviews were conducted with six of the Swedish couples who had completed the DemPower study. When the follow-up assessments and data collection of study III were conducted in Sweden, the couples were asked to participate in study IV. They were asked to participate in the order in which they had completed the feasibility study. The interview guide comprised five questions related to potential positive and/or negative experiences of engaging in DemPower as a couple, and if/how couples had used DemPower in their everyday lives – see questions below:

How did you experience testing DemPower together?

Did you find anything positive about DemPower?

Did you find anything negative about DemPower?

Has DemPower contributed (positively or negatively) to your relationship, as a couple?

Did you use any information from DemPower? If so, how did you use it?

The interviews lasted between 20–45 minutes and took place in the couple’s home. The interviews were audio recorded and transcribed verbatim.

6.4.2. Analysis

The analysis of the feasibility study involved descriptive statistics, such as measures of mean and median central tendency and spread (standard deviation, inter-quartile range, range) (Overholser & Sowinski, 2007). The outcome measures and evaluation questionnaire data were anonymized and entered on a spreadsheet that was transferred to IBM Statistical Package for the Social Sciences (SPSS) version 24. Statistical analysis was conducted by Mark Hann (Dr of Maths/Statistics). The data from the open-ended questions from the theme-specific questionnaires and process evaluation were processed using NVivo and analysed thematically. The usage data were analysed using Excel. The analysis in study IV were conducted using thematic analysis, which involves the following six steps: familiarization with the data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes, and producing the report (Braun & Clarke, 2006). See an example from the analysis of study IV in table 4 below:

Table 4. Thematic analysis (study IV)

Main theme	Subtheme	Code
Growth of the relationship	Transition	Mutual development
		Interdependent relationship
	Taking time to sit together	Talk things through
		Sharing emotions
	Closeness	Physical closeness
		Validation

7. ETHICAL CONSIDERATIONS

All studies in this thesis were performed in accordance with the Declaration of Helsinki (World Medical Association, 2013). Ethical approval was obtained for the studies from the Regional Ethical Review Board, Linköping, Sweden and by the National Health Service Research Ethics Committee in the UK. The studies were assigned the following codes: study I (not required), study II: 2014/419-31, study III: 2017/281-31 and 17/NW/0431, study IV: 2018/539-3. For studies II, III and IV, written and verbal consent was obtained and all data were kept confidential and stored in a secure place. The participating couples received oral and written information about the studies and that they could withdraw from the research without giving any reason. A process consent procedure was used during all the studies, meaning that the researchers enabled the couples to continuously make informed decisions from the point of initial contact to completion of the study (Cowdell, 2006; Dewing, 2002; Hellström et al., 2007b).

It is undisputed that it can be regarded as ethically sensitive to interview and involve people with dementia in research and that it entails tensions within the academy through multiple dilemmas regarding the responsiveness to the needs of people with dementia and the form of research being conducted (Aldridge, 2014). People with dementia are often referred to as a “vulnerable group”. Such vulnerability relates to the decision-making ability of people with dementia. Thus, safeguarding their rights is a key issue in dementia research (Cowdell, 2006). For all people, the basis for having the capacity to consent is understanding the nature of the research, being aware of the potential risks of participation, the ability to withdraw and to give informed consent (Cowdell, 2006). The researcher should also undertake validating actions for the preservation of ethics, meaningful engagement and personhood (Cowdell, 2006), such as conducting the interviews in familiar surroundings, using common terminology and plain language and giving time for the participants to respond (Beuscher & Grando, 2009; Scottish Dementia Working Group, 2014), but also showing interest in the participant as a person, ensuring their well-being, and that the research is conducted in the way the participant wants it to be conducted (Scottish Dementia Working Group, 2014).

The World Medical Association (2013, paragraph 20) states in particular that:

“Medical research with a vulnerable group is only justified if the research is responsive to the health needs or priorities of the group and the research cannot be carried out in a non-vulnerable group. In addition, this group should stand to benefit from the knowledge, practices or interventions that result from the research”.

This statement is significant for the research in this thesis in several ways: the research has been conducted in a so-called vulnerable group and the nature of the research could not have been conducted in a non-vulnerable group since it aimed to explore lived

experience. Furthermore, not only does the research intend to contribute to the research field, it also intends to be beneficial for couples living with dementia. I believe that the rationale for benefits and research priorities for people with dementia and their partners has been properly investigated and underpinned in order to meet this criterion. However, as stated in the section on collaborative research (p. 24-25), there is a tendency that research within people with dementia can be too paternalistic with its gatekeeping and safeguarding approaches, which could lead to exclusion, rather than inclusion (Witham, Beddow & Haigh, 2015). In fact, collaborative research can be a successful pathway to continually assess interest in order to ensure the willingness and consent to participate. However, researchers must always reflect on the issues that threaten the dignity and autonomy of people with dementia.

There could also be several benefits for people with dementia who participate in research, such as increased self-confidence, intellectual stimulation, a sense of being valued and useful, social benefits (Baldwin, Napier, & Wright-St Clair, 2018; Hellström et al., 2007b; Littlechild, Tanner & Hall, 2015), as well as through a collaborative approach, such as the approach adopted in this thesis. I have had the privilege of establishing relationships with the participating couples. We have met for lunch or “fika” together and, at the couple’s initiative, I have been invited to wonderful lunches at couple’s homes outside the research context. Thus, we have established a mutual trust. I believe that we have managed to create an optimal balance, with mutual respect, and have not let our relationships affect the research. Regardless of whether or not the couples decided to continue participating in the research, we have met or stayed in touch during the studies. There is no doubt that the participating couples in this research have been important to me in many ways, both as co-researchers and for the persons they are. I also believe that, as a researcher and a person, I have in some way been important to them. It has also been important for me, but particularly for the recognition of the couples’ contributions, to involve them and update them about the studies during the course of the thesis. At the end of the “Neighbourhoods and Dementia” study in April 2019, one of my supervisors and the chief investigator of the research programme John Keady, held an “end of study conference” for all the work programmes. The presentation of the research in this thesis (work programme 6) was planned and held (in English) by me and a co-researching couple from Sweden. After the presentation, I interviewed the couple about their experiences and about being “at the centre of attention”. The partner with dementia stated that “It didn’t feel like I was at the centre of attention because there were many more people with dementia there. In fact, I have never felt less like an outsider and at the centre”. This quote can be explained by the fact that, in the UK, people with dementia are involved in research and included in society in a more contemporary and validating way than in Sweden at present.

8.RESULTS AND FINDINGS

8.1. Exploring

Six studies were identified and described in the first review (study I A). The objectives of the studies most commonly related to improving the cognitive function of the person with dementia, while the objectives of improving wellbeing were most commonly applied to the partner without dementia. The outcome measures were mirrored in the objectives by focusing on the cognitive function of the person with dementia and depression and the relationship quality of the partner without dementia. The review concluded that interventions aimed at people with dementia and their partners without dementia overlook relationship dynamics by failing to target the relationship and by not including the person with dementia in the assessment of the relationship. Regardless of the couple-orientated and joint interventions, the relationship was not placed at the centre and the interventions adopted a problem-based approach. The results of the second review (study I B) included 21 studies of various types of interventions. The main outcome measures for people with dementia are in line with the results of the first review, i.e. focused on cognitive function. The outcome measures for caregivers (partners included) were caregiver burden and depression. This review is also in line with the first review regarding negative outcomes, lack of a genuine dyadic approach, lack of tailored support, neglect of interpersonal issues and overlooking the views of people with dementia. The review also recognizes that measures of caregiver burden and relationship quality should be considered in samples of mixed relationships because of the different significance of burden and relationship quality for a spouse as opposed to an adult child or friend.

8.2. Developing

The confirmed themes from the deductive approach and the added themes from the inductive approach were connected to the four main themes: “Home and Neighbourhood,” “Meaningful Activities and Relationships,” “Approach and Empowerment” and “Couplehood”, with corresponding subthemes. The consultation meetings with expert groups resulted in the themes being confirmed as being of relevance to couples living with dementia, and identified one additional theme, “intimacy”, which corresponded to one of the main themes. The draft framework of themes was revised and is shown in the figure on next page (figure 2).

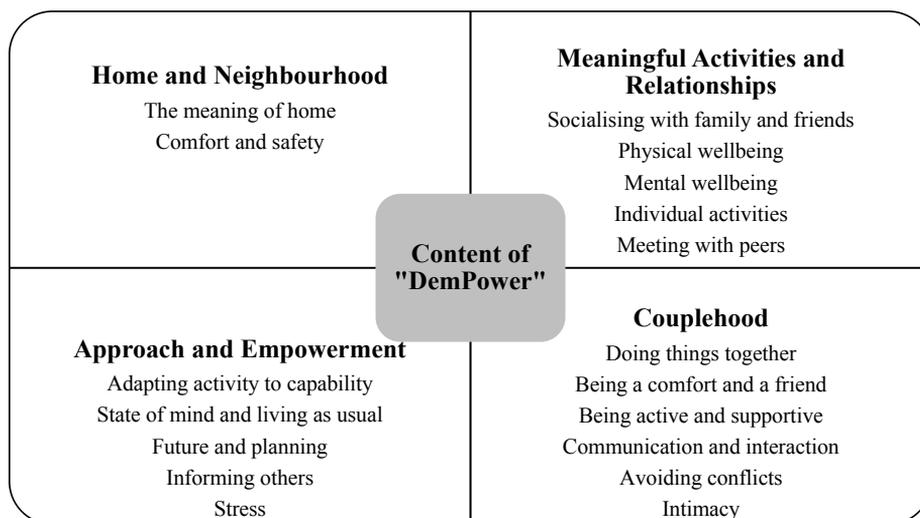


Figure 2. Confirmed themes and added theme

8.3. Testing and Evaluating

Between October 2017 and November 2018, a total of 25 couples from the UK and 19 couples from Sweden were recruited for the feasibility study (study III). The recruitment procedures in Sweden and the UK differed and there were pros and cons in the available methods. Access to couples with dementia was easier in the UK due to an online platform on which people with dementia and their relatives could declare an interest in participating in research. In Sweden, there were fewer potential couples to approach because of the dependency on memory clinics, although the interest and full participation was higher. Forty-three couples from both sites completed baseline measures, with 21 couples completing the majority of the follow-up measures. The overall study completion rate was 48% (UK=9/25, Sweden=12/19). See a shortened table of couples' characteristics in table 5 on the next page.

Table 5. Shortened table of couples' characteristics

	PARTNER WITH DE- MENTIA		PARTNER WITHOUT DEMENTIA		
	UK N=24	Sweden N=19	UK N=24	Sweden N=19	
AGE					
	51–60	3 (12.5%)	1 (5.3%)	2 (8.3%)	1 (5.3%)
	61–70	8 (33.3%)	5 (26.3%)	11 (45.8%)	7 (36.8%)
	71–80	11 (45.8%)	7 (36.8%)	10 (41.6%)	10 (52.6%)
	81–90	2 (8.3%)	6 (31.6%)	1 (4.1%)	1 (5.3%)
GENDER					
	M	13 (54.1%)	13 (68.4%)	11 (45.8%)	6 (31.6%)
	F	11 (45.8%)	6 (31.6%)	13 (54.1%)	13 (68.4%)
TYPE OF DIA- GNOSIS					
	Alzheimer's	9 (37.5%)	11 (57.9%)	N/A	N/A
	Frontal Temporal	0 (0.0%)	1 (5.3%)		
	Lewy Body	0 (0.0%)	2 (10.5%)		
	Mild Cognitive Im- pairment	2 (8.3%)	0 (0.0%)		
	Parkinson's	0 (0.0%)	1 (5.3%)		
	Vascular	3 (12.5%)	0 (0.0%)		
	Mixed	9 (37.5%)	0 (0.0%)		
	Unspecified	1 (4.1%)	4 (21.1%)		

Note:

Variable-specific column percentages do not always sum to 100 due to rounding.

1 UK Couple did not provide demographic information.

A total of 18 (86%) couples completed all parts of the DemPower and the first theme 'Home and Neighbourhood' received the most visits (average 250 visits), while 'Communication and Emotions', the last theme, received an average of 122 visits during the study period. Most couples across both sites stated that the app was simple, easy to use, comprehensive, visual and helpful. The utility scale data revealed that the UK couples liked using the app more frequently than the Swedish couples. However, the Swedish couples found the app easier to use and were more confident with the technology. The most significant results of the secondary outcomes were for people with dementia regarding the DEMQoL (Quality of life in Dementia) (Smith et al. 2007). There was a 5.2-point increase (score range 28 – 112) on average from baseline to follow up measures. The overall results of study III suggest that the intervention (DemPower) is both feasible and usable in home settings among couples in which one partner has dementia.

The findings of study IV resulted in three themes: *Growth of the relationship*, *We are not alone* and *Positive approach*. The themes are clearly linked to the couple's recognition of their transition as a couple living with dementia. The salutogenic approach of DemPower permeated the couple's discussions in several themes of the app. The couples liked the idea of focusing on the positive resources in their relationship and everyday lives, and also liked the easy access to information and support in the DemPower app.

9. OVERALL FINDINGS AND DISCUSSION BY MASTER THEMES

In this section I have condensed the themes and bullet points from the findings of *Exploring, Developing, Testing, and Evaluating* and linked them into master themes. The master themes represent the core findings and conclusions of the thesis and are presented and discussed below.

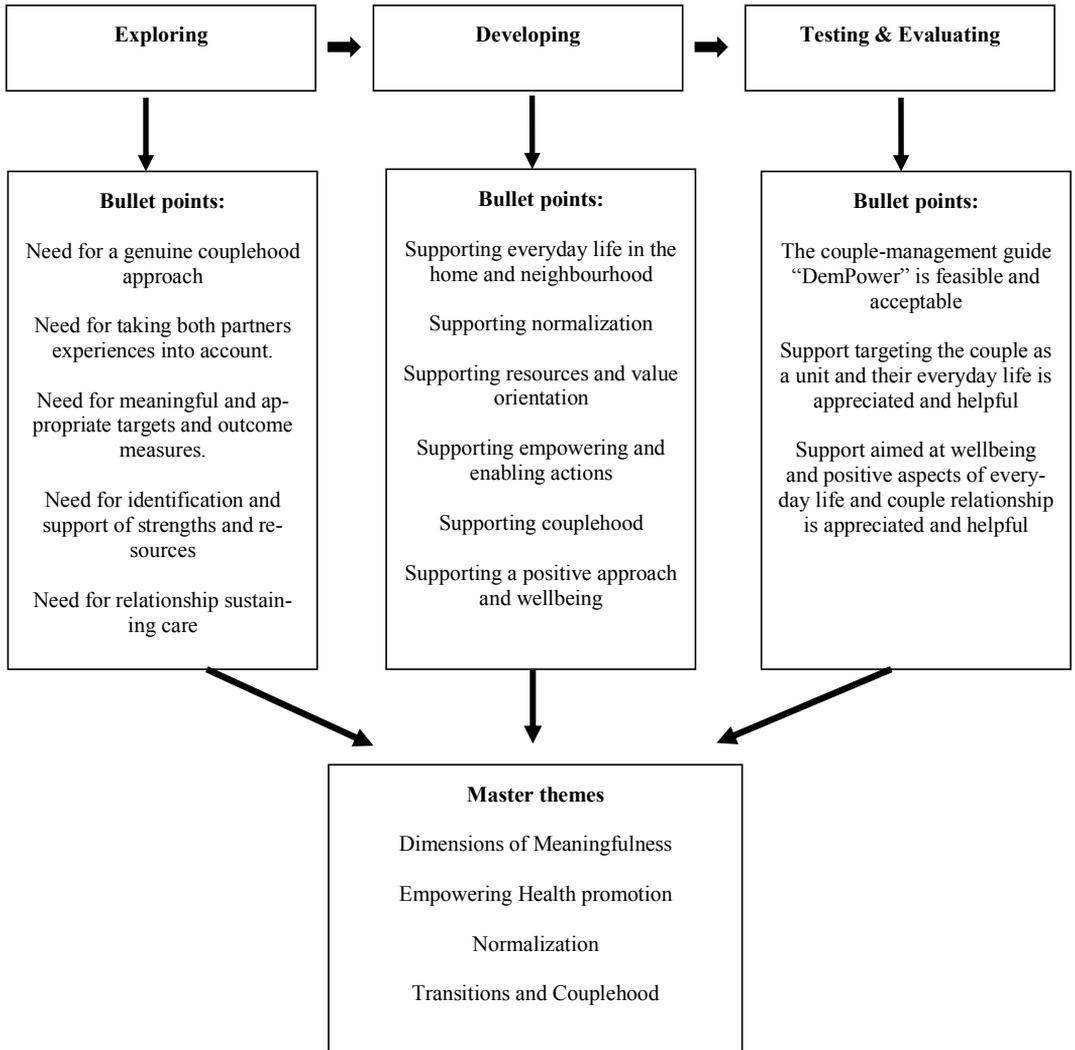


Figure 3. Concluding synthesis by master themes

The concluding synthesis of the findings resulted in the four master themes; *Dimensions of meaningfulness*, *Empowering health promotion*, *Normalization*, and *Transitions and Couplehood* (figure 3). Quotes outlined below ends with “research participant” when the quote was not included in the studies (participant took part in one of the studies) and with the studies Roman numeral when they were included in the studies.

9.1. Dimensions of meaningfulness

The master theme of *Meaningfulness* is multifaceted in this thesis. It represents the meaningfulness of couple-centred interventions, sense of meaningfulness in couples living with dementia and the meaningfulness for people with dementia participating in research.

9.1.1. Meaningfulness of couple-centred interventions

The linked reviews of study I revealed that couple-centred interventions need to be tailored to the specific couple to a higher extent in order to increase meaningfulness. Although research has shown that the negative impact of dementia is common, researchers must ensure whether such problem-oriented interventions and outcomes are relevant and meaningful to the specific couples before the intervention is carried out (Martire et al., 2010; Van't Leven et al., 2014). The most common targets of support for couples living with dementia were related to cognitive function, depression and caregiver burden (study I). In a review of outcome measures used in dementia trials and mild cognitive impairment, the authors found that of the 805 identified trials, cognitive outcomes were reported in 70 % while outcomes of quality of life were reported in 12 % (Harrison, Noel-Storr, Demeyere, Reynish & Quinn, 2016). Interestingly, cognitive outcomes have been identified as less important and outcomes of wellbeing as most important by people with dementia and partners (Reilly et al., 2020). Furthermore, the primary threatening aspects for couples living with dementia are described as “losses”, such as loss of roles in a relationship and loss of couple identity (Davies et al., 2011). The most frequently used outcomes identified in study I, i.e. caregiver burden and depression are perhaps more the consequence of the experience of loss and are not standalone events for the partners of people with dementia. Thus, it should be of importance to prevent these losses by focusing upon wellbeing and relationship quality in couple-centred interventions. Supportive actions towards couples' relationships should also be useful in terms of social costs, since the willingness of the partner without dementia to care is often reduced when they experience a high level of relationship loss (Davies et al., 2011). Whilst each intervention could be constructed as promoting health in one way or another, adopting a problem-oriented approach may affect the couples negatively by assuming that they are depressed and that the partner without dementia feels burdened.

Another aspect of the meaningfulness of outcomes and targets are the measures of relationship quality, when they are used. In line with others (see, for example, Clarke & Keady, 2002; Daniels, Lamson & Hodgson, 2007), I argue that the meaningfulness of dyadic interventions is reduced when relationship quality is only assessed in one person of the relationship (Study I). The same issue of reduced meaningfulness arises when the relationship quality and caregiver burden are measured in samples of mixed relationships and are therefore not interpreted in the right relationship context (Study I; Merrick et al., 2016). For example, the significance of relationship quality and burden ought not to be the same for a partner as it is for an adult child. Interventions in which the sample comprises couples only are sparse. It is much more common to mix subgroups of caregivers (study I). There are several reasons for mixing subgroups of caregivers, such as recruitment problems, a desire to apply the findings to a broader population, as well as financial issues (Martire et al., 2010). In order to increase the meaningfulness of interventions with mixed samples, it may be helpful to plan targets and outcome measures that apply to a more heterogeneous group. Health-promoting targets and outcomes, such as quality of life and resources, should have a wider breadth of meaningfulness in such interventions.

I explored factors of meaningfulness in terms of what couples with dementia felt were important to their relationships and everyday lives in order to increase the possibility of developing a form of support that met their needs (study II). According to the interviews conducted in study II (including expert group meetings) and study IV, it emerged that it was desirable to have aids that support positive resources which, in turn, encourage couples to think positively:

“I thought it was very nice that it (DemPower) was not problem-oriented... this was something where you highlight the positive and everything that you can do. You don’t have to be depressed in beforehand... (study IV)

A recent published study (Reilly et al., 2020) used a consensus method to develop a core outcome set with outcomes that communicated outcomes that mattered most to people with dementia living at home. Thirteen core outcome items, many of them related to social health, were identified by people with dementia and partners. The item that got the highest level of agreement (95%) was “the importance of relationships” which was described as “continuing good relationships with people who are important to you” (p.5), a theme that was also included in Dempower (study II, III). This finding further highlights the need for using and developing outcomes that support couples’ relationships and everyday wellbeing.

9.1.2. Meaningfulness in the everyday life

There is, of course, meaningfulness in the lives of couples living with dementia on many levels and it would be unethical to judge what is meaningful or not to other human beings. However, the research in this thesis has been able to identify a number of broad areas of meaningfulness for couples living with dementia (study II). I have chosen to discuss meaningfulness in terms of what *dementia* has brought to the dimension of meaningfulness in the couples' lives. Meaningfulness, according to Antonovsky (1979, 1987), refers to the ability to see all situations, even those you do not wish to arise, as challenges worthy of investment. Similarly, meaningfulness in the theory of transition refers to the ability to find meaning in a stressor/ illness (Kelley & Thibaut, 1978). The "ability" to find meaning implies a couples' approach to a challenging situation. The study participants in this thesis have indeed shown that they invested in their relationships after the onset of dementia and that, in many ways, they have adopted a positive approach. The positive approach often appeared to be a deliberate strategy of finding meaning and coping with an uncertain future:

...It's probably a conscious strategy to live from day to day. There's no point wallowing in misery... (*study II*)

We decided not to be those kinds of discontented people but instead would take responsibility for finding fun things to do. We believe it is possible for us to choose our mood to some extent. There's no point in getting angry over a bit of dust here and there. There are more important things. (*study II*)

The couples had found a "new" meaningfulness since the onset of dementia by spending more time together in their everyday life. They stated that they had somehow become even closer to each other and that their relationship and everyday life were more important than ever (study II). This, in turn, demonstrates that the meaningfulness had developed into a lower degree of individual meaningfulness and a higher degree of dyadic meaningfulness, and was also further evidence that support for couples living with dementia should be supplemented by support that targets them as a unit.

9.1.3. Meaningfulness in taking part in research

I started the interviews in study II by asking the couples what their expectations were of participating in the study as co-researchers and informants. In study IV I asked the couples how/whether DemPower had impacted them positively. The answers I received were mainly related to the meaningfulness of being able to contribute to research and, in turn, being able to do things for others. Regarding the importance of involving people with dementia in research, one of the study participants stated this clearly:

“It has felt good that we (*people with dementia and partners*) not only get to read about everything but that you (*researchers*) really make contact with those to whom the research applies” (*research participant*)

As stated above, the couples felt meaningfulness by doing something for other couples who will be in a similar situation in the future:

...It’s felt good that we have been valuable to research ... that we can perhaps do something... for others who receive a diagnosis” (*study IV*)

The couples also appreciated that they were thought of and that doing something for them was considered a priority and important. They said that they felt valued, meaningful and useful (Studies II, IV). A feeling of being useful and doing good was described as being important and empowering in general, as many of the couples were involved in voluntary organizations in order to make meaningful contributions to the community.

9.2. Empowering health promotion

There is still a tendency to highlight deficiencies rather than the strengths of people with dementia (Martin, Turner, Wallace, Choudhry, & Bradbury, 2013; Philipson et al., 2019; Rodgers, 2018). This unusual phenomenon, defining and referring to people based on limitations, seems to be much more common when it comes to people with dementia than people with other chronic conditions. A rather telling example of how couples attempted to focus on what they can do instead of what they can’t do was when I asked a couple with dementia if they used to reminisce (trigger memories, a method of interaction). The couple said: *we’re not going to spend our time trying to remember things because that’s the problem, remembering.*

I have noticed the deficit focus on people with dementia and couples with dementia through my background as a nurse, but also through the research in this thesis. I will problematize this issue below with regards to healthcare and the general public. However, I first want to convey how the people with dementia in this thesis viewed their own health:

If I’m to be honest, I don’t feel sick (*research participant*)

The most important thing is that we are healthy, have fun and enjoy each other’s company (*research participant*)

I don’t feel sick. Of course, there are some difficulties, but we live like we have always lived (*research participant*)

These quotes indicate that people with dementia, despite having a dementia diagnosis, did not consider themselves to be “ill”. However, they may change their view as/if their symptoms increase. The point is that this was their own view of their health, and where they were in the “spectrum of health and illness” (Antonovsky, 1987), which would be the most important thing to consider, regardless of context. This further implies that the experience of health and illness in people with dementia and couples with dementia must be valued to a greater extent and that the approach towards them should be in line with how they see themselves.

9.2.1. Health promotion in dementia care

I have discussed perspectives of health promotion in research above in relation to problem orientation and disease orientation of targets and outcomes, and how it may impact couples living with dementia. As within the research, there can be a risk that healthcare professionals unwittingly impose upon couples a disease orientation towards dementia, for example by the way in which they disclose a diagnosis of dementia. It was clear that the couples I met referred to their future by the stages of dementia, including the fear of the last phase. What they were less aware of, however, was that the progression of dementia is highly individual (Alzheimer’s Association, 2012). There are, of course, influential factors that may have affected the couple’s view of their future, such as online information, which some couples used, while others did not (study II) (also found in Hellström & Torres, 2013). What I want to highlight and suggest is that we should emphasize the positive aspects to a greater extent in all meetings with “patients”. We should emphasize that it is possible to live well with dementia for a long time and that how dementia develops is highly individual. We should also acknowledge the couple’s positive attitude to their future and allow them to live in the present which, in this thesis, was a commonly adopted strategy for couples to live well with dementia and was therefore also adopted in DemPower (study II, III):

... Living from day to day is probably a conscious strategy. There’s no point wallowing in misery because, if it comes, it will come on its own (*study II*)

However, DemPower included all sorts of approaches to life with dementia and did not specify a “correct” approach. In regard to the above, it should also be emphasized that information and education on dementia are not the opposite to incorporate hope. My point is to highlight the importance for healthcare to reflect on where the emphasis is placed – on health or illness.

Another aspect I want to highlight in this issue of the impact of healthcare is the suggestion and application of a palliative approach, as early as the diagnosis, towards people with dementia (see, for example, Sundelöf & Tegman, 2019; Svenskt Demenscentrum, 2020), while we do not suggest such an approach for other chronic conditions. Nor is there anything in the Sweden’s national guidelines for the care of people with dementia that supports such an approach (National Board of Health and Welfare, 2017). Furthermore, people with dementia can live up to 20 years with the condition (Alzheimer’s

Association, 2012). I do not question the palliative philosophy; it is inherently holistic and health-promoting. On the other hand, I think the term palliative is extremely loaded in both healthcare and also among the general public as it may be associated with a near-death and that there is no longer anything that can be done to improve the situation. From my perspective, it would be a pedagogical challenge to explain the “palliative approach” to people with dementia, or anyone with a chronic condition at the time of diagnosis. This is what one of the study participants said about being diagnosed with dementia:

Our tip is to live in the present and make the most of your time. Then, it’s (dementia) not something you die from in two days, so you don’t have to hurry and you don’t have to change everything (*study IV*)

The above quote reflects the couple’s efforts to *live* with dementia. However, I’m inclined to agree that the palliative philosophy, i.e. a holistic health-promoting approach should be the go-to approach for people with dementia. However, why not simply call it a holistic health-promoting approach? What I’m trying to shed light on here is how healthcare runs the risk of depriving people of hope, even though we strive to do good.

9.2.2. The influence of society on couples with dementia

The manner in which people view themselves is influenced positively and negatively by other people and the environment. In this thesis, some of the couples felt that they were sometimes treated patronizingly (study II), although not necessarily on purpose. As an example, couples felt that the “over helpful” approach was not in accordance with their needs and was also demoralising. Again, it is a balancing act between support and the assumption of the need for support. However, it is difficult to know how to approach and support people with dementia without knowledge (note: the approach should also be individualized). In fact, public knowledge of dementia remains low (Phillipson et al., 2019) and the stigmatisation of people with dementia still exists (Phillipson et al., 2019; Rodgers, 2018; study II). Thus, receiving a dementia diagnosis is not only associated with negative feelings of being diagnosed with an illness and how to manage it. Many people are also worried about how others will treat them (Batsch & Mittelman, 2012).

People with dementia often have a sense of shame, low self-esteem and perceive that their social status as citizens has been reduced due to the dementia diagnosis (Rodgers, 2018). The stigma itself may also affect people with dementia negatively, leading to decreased psychological and physical wellbeing and the risk of social isolation (Phillipson et al., 2019). As a result of the stigma, people with dementia may also view themselves as being less competent. This “self-stigmatisation” is also an issue that is related to the application of empowering actions such as self-management because barriers are also found in people with dementia (study I B). Martin et al. (2013) found that barriers to self-management are present on several levels, among healthcare professionals, the general public and among people with dementia. The authors suggest that the main barriers in

healthcare and the general public appeared to be a deficit focus, lack of services with a positive and enabling approach, and the view of people with dementia as being passive recipients of care. People with dementia themselves had worries, fears and a lack of confidence towards self-management, which may reflect the overall view of self-management for people with dementia. According to studies III and IV, couples with dementia embraced the self-management approach and also the technology. As stated in the background (p. 23), self-management in dementia should focus on the core skills of “adaption to change”, “finding meaning and purpose” and “communication” (Hickman, Wiersma & Harvey, 2015) and it is in these areas that DemPower has demonstrated a measure of efficacy and ease of use (study II, III, IV). As such, in order to be transferable, self-management in couples with dementia may need to be delivered in the same way as DemPower and with a couple-management approach (study III). Moreover, a person with dementia may also need the regular support of their partner to successfully manage their self-management behaviours and actions.

I will now discuss aspects of the general public that can be seen as disabling people with dementia and cultivating a deficit focus. We have all read headlines about how we can prevent the development and the “suffering” of dementia. One of the couples from study II was very upset about how it could be considered “okay” to write about dementia and talk about dementia without substantiating the argument with actual knowledge. They said that a well-known TV personality in Sweden had negatively affected their positive outlook of their future and other people’s view of them by her statement on national TV:

... The future ... it was she ... (*mentions the name of the TV personality*). She had read something about Alzheimer's, that from the time you receive a diagnosis, you only live four more years... She said it on TV! She should be fired for that (*study participant*)

This is an example of how the general public’s unreflective negative approach may impact a couple’s prospects of living well with dementia. Another example from Sweden of how public assumptions may impact couples with dementia is the widespread statement about dementia being an “illness of the relatives”. This statement generates an expected burden on relatives as early as at the onset of dementia. It also downgrades and overlooks the person with dementia’s feelings and experiences of living with dementia. Several people with dementia in this thesis put themselves aside and stated that their dementia is and will be much more difficult for their partner, as they referred to dementia as a relative’s illness. Public awareness of dementia and the inclusion of people with dementia in society and normalization could contribute to a more nuanced picture of dementia which, in turn, enables people with dementia. We must learn from the experts, and they are trying to fight stigma by informing others about dementia:

We have always been very open about it. It’s nothing to be ashamed of. I can’t help it... (*Study II*)

9.3. Normalization

It has been argued that researching everyday life is trivial. However, on the other hand, nothing of the larger scale life events would happen without people doing small scale events of everyday life (Scott, 2009). The couples in this thesis considered normalization and living as usual as being the keys to living as well as possible with dementia (study II, III). These findings are in line with previous research (see, for example, Genoe & Dupuis, 2014; van Nes, Jonsson, Abma & Deeg, 2013). In turn, these findings highlight all the “unremarkable” things of everyday life (Scott, 2009) as being of great importance to couples living with dementia. I assume that everyday life is important to all people but may become more remarkable when it is not taken for granted. Thus, having a chronic condition may initiate a value orientation towards everyday life.

Compared to other chronic conditions such as Parkinson’s, in which the condition itself often creates limitations for the person participating in everyday life (Susin, 2012), dementia creates limitations both through the condition but also through the community’s limitations in including people with dementia. People in the couple’s immediate surroundings, neighbourhood and community may need to support the couple to live a normal life by facilitating inclusion and participation in everyday life. Normal things such as shopping, going for a walk and meeting other people (Scott, 2009) can be facilitated through community measures. Such measures are necessary in order to make society more “dementia-friendly”. Dementia-friendly relates to “a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognize their full potential” (Alzheimer’s Disease International, 2016, p. 10). Several countries around the world such as Japan, the UK and Australia, are investing in dementia-friendly communities (Herbert & Scales, 2019; World Health Organization, 2012). These initiatives are seen as actions of inclusion. Meanwhile, the “dementia villages”, which can be found, for example, in The Netherlands and Denmark, have been criticized for excluding people with dementia from normal communities by having them live in parallel communities (see, for example, Haeusermann, 2018). Indeed, it cannot be considered to be normalizing a life with dementia when people with dementia are considered to not fit into a normal community.

The couples with dementia in this thesis did not want more than a normal life and did not have extraordinary needs. Their needs were the same as the universal needs of any other couple, i.e. the unremarkable activities of everyday life in the context of a couple relationship. Normalizing the needs of couples with dementia and their partners may be of particular importance for spreading a greater understanding in the general population and for communities to heed to and treat the needs of people with dementia and their partners as just normal needs that may have to be supported in order to be viable:

I feel it’s important to try and behave normally and not be thinking, “I can’t do this and I can’t do that. . .” (study II)

You shouldn't make too much of a fuss about it. Just keep living as normally as possible ...(*research participant*)

9.4. Transitions and Couplehood

A sense of couplehood on the basis of mutuality and interdependence has been important for the interpretation of potential transitions that occur within couples living with dementia (study II, IV). I will return to this later. Hellström et al. (2005), highlighted that the most positive relationships are reciprocal relationships with a balance of “independence, dependence and interdependence” (p 18), with a focus on the interdependence component. When looking at the theory of interdependence (Kelley & Thibaut, 1978), interdependence is described as the exchange of personal relationships. The theory states that the success of a relationship lies within the balance of positive outcomes (rewards) and negative outcomes (costs) that are gained through the relationship. If the positive outcomes overshadow the negative, it is more likely that the relationship will last and that the people involved will be satisfied. The theory of interdependence, through its description of equal personal investment, is worth being questioned in the event of illness and disability, perhaps even in old age. In the case of an older couple, perhaps with dementia, or where one of the partners has disabilities, it is more difficult to apply the theory, i.e. when the couple has lived together for a long time and shared important life events, the importance of interdependence is probably not that both partners invest equally; it is more important that the investment contributes to the wellbeing of the unit. Thus, the significance of interdependence for couples living with dementia may undergo a transition towards involving a higher degree of interconnectedness. In an example of driving, one of the couples emphasized that it doesn't matter who “does it” as long as they do it together “It's true, no matter what we do, we do it together, we are attached to each other and then it doesn't matter who is driving”.

Although it is usually a natural development that the partner without dementia needs to take greater responsibility for the couple's wellbeing (Hellström et al. 2005; 2007a), and therefore can be seen to invest more, it does not necessarily mean that the rewards are not as high for the partner without dementia as for the partner with dementia. As I have described in the background section of the thesis, my interpretation of couplehood significantly involves the aspect of dyadic wellbeing. In accordance with Swall, Williams and Marmstål Hammar (2019), the rewards appear to lie in mutual love, care and togetherness. Nevertheless, transitions can be beautiful but also hurtful. One husband described the transition in interaction and communication regarding a wife with dementia as follows: “It's not about what we say, it's how we say it”. It was probably painful to not be able to communicate and interact as they used to, but they had made sure that the atmosphere between them was friendly and loving. During the interviews and chats with this couple (study II), it was amazing to see how the husband guided his wife in the most wonderful way so that she could express herself. It was also noted that she had no problem showing that she could not remember, and it was quite natural for her to ask him for help.

I think it reflected the “dependence on couplehood”. Identifying effective communication and interaction strategies has been found to be significant for maintaining value in couple relationships (study II; Berry, 2014; Bigonnesse et al., 2014; Boots et al., 2016; McGovern, 2011; Tanner, Tilse, & de Jonge, 2008; Wherton & Monk, 2008). Suggestions for how to learn communication strategies was implemented in this thesis through DemPower’s section on communication (study III).

The couples within this thesis viewed dementia as a dyadic condition. This meant that they also managed dementia together as a couple. One way to manage dementia, which they also considered as the most important aspect for their wellbeing, was to spend quality time together. As found in previous research outlined in the section of potential challenges to couplehood, “doing things together” added significantly to a sustained sense of couplehood. DemPower itself contributed to an activity that couples do together and further encouraged couples to do things together with its suggestions of activities for couples (study III).

In study II, I asked the couples which of the suggested themes in the draft framework they considered to be most important – and it was the theme “doing things together”. This indicates that sustaining a sense of couplehood and strengthening a sense of “us” is achieved by the togetherness of everyday life (Swall et al., 2019). This is in line with the suggestion by Hellström et al. (2005) that, when it comes to couples with dementia, the focus of support should be on couplehood rather than personhood, and that personhood and wellbeing can be sustained through couplehood. This, in turn, further highlights that supporting couples’ relationships and their strategy to sustain couplehood and wellbeing by “doing things together” could be one of the most important aspects of the salutogenic approach to couples living with dementia.

10.METHODOLOGICAL CONSIDERATIONS

10.1. Validity and reliability

Validity and reliability considerations are associated with quantitative studies. Validity relates to what extent a study target what it is intended to target, i.e. to what extent the findings correspond to the aim of the study. Reliability relates to the methods and procedures, if they are well described and structured in order to be reproduced (Polit & Beck, 2012). The design of reviews may be considered to be quite unclear when determining whether or not they are quantitative or qualitative. At first, I considered the narrative review as being primarily qualitative in its design due to my narratives on the interventions and my interpretations of the findings. However, I considered the scoping review to be primarily quantitative, partly because of my compilation of “how often” the same type of outcomes appeared in the articles. On the other hand, a qualitative study often has quantitative elements and a quantitative study probably always has qualitative elements related to the fact that different people conduct studies, measurements and interpret results. According to Polit and Beck (2016), reviews are a genre of their own.

The most important aspect for achieving validity and reliability in the reviews of study I relate to whether or not the approach has succeeded in answering the research questions and has been sufficiently described for the study to be repeated. Both reviews describe the search strategy, report on the search terms used and how the articles were selected. A recently developed quality assessment of narrative reviews highlights the components that should be considered to ensure the validity and reliability of a narrative review (Baethge, Goldbeck-Wood & Mertens, 2019). These components are in accordance with the procedures of the narrative review conducted by following the guidelines of Green, Johnson and Adams (2006). The scoping review followed a framework by Arksey and O’Malley (2005) in which they highlight that the key strength of a scoping review is that it can provide a rigorous and transparent method for mapping research areas. To strengthen the validity and reliability of both studies, I have used the PRISMA flowchart as a tool for transparency and for the studies to be reproducible (Moher, Liberati, Tetzlaff & Altman, 2009). The limitations that are most important to elucidate regarding study I is that it was difficult to find the predetermined categories in the articles (such as where the intervention was provided, by whom and whether the couple participated together), which meant that many articles needed to be read in full and many articles were excluded when this information was not disclosed, either in the abstract or in the article as a whole. It should also be emphasized that studies containing care programmes

or care management were excluded due to their multi-component nature, which was not described in detail. This led to difficulties in determining the content and whether the couples had jointly participated. This means that either the narrative review with its inclusion criteria or the scoping review with its inclusion criteria can be considered comprehensive in the field of joint interventions for couples in which one partner has dementia living at home.

With regard to the validity and reliability of study III, it concerns both the aforementioned well-described method and process and the instruments and methods used to determine the feasibility and acceptability of DemPower, as well as secondary outcomes. We used a feasibility framework to determine the feasibility and study application by Bowen et al. (2009), which has been widely used, cited and recommended for determining feasibility (Orsmond & Cohn, 2015). To ensure that we had covered the feasibility of specific themes of DemPower, we developed questionnaires to supplement the feasibility framework (appendix II, study III). All secondary outcomes used in the study have been tested for validity (appendix II). The most important limitation of this study was the issue of recruitment. The recruitment procedure was not the same in Sweden as in the UK, and the contact between participating couples in Sweden and the UK with the researcher was different in frequency, primarily because the contact was adapted to the wishes of the couples. It was difficult to perform the recruitment and procedures in the same way across both sites, which may have impacted the recruitment and dropout rates.

10.2. Trustworthiness

According to Patton (2002) “an interesting and readable report provides sufficient description to allow the reader to understand the basis for interpretation, and sufficient interpretation to allow the reader to appreciate the description” (p. 503–504). Trustworthiness is the equivalent of validity and reliability in qualitative studies. As stated by Lincoln and Guba, the trustworthiness of research makes the findings “worth paying attention to” (Lincoln & Guba, 1985, p. 290). For the research to be worth paying attention to, it has to meet the criteria of credibility, which relate to the truth of the findings, transferability which relate to the research being applicable and transferable in other contexts, dependability, which relate to the validity of the findings, that they are consistent and can be repeated, and confirmability, which relate to the extent to which the findings are based on the study respondents (Lincoln & Guba, 1985). Trustworthiness will be discussed below in regard to studies II and IV.

Studies II and IV are based on a constructivism philosophy with a view of knowledge as being valid in a certain context and that reality is co-constructed (Patton, 2002). Knowledge differs from individual to individual, not just what they know, but also how they have come to know it. People with dementia and partners without dementia have expert knowledge in terms of “knowledge of” (Schütz, 1973). Study II uses the framework of first- and second-order constructs to outline the trustworthiness of the findings. Schütz (1973) argues that second-order constructs (the researcher’s constructs) gain trustworthiness through three postulates: *logical consistency* (i.e. typical constructs fully

compatible with formal logic and associated with universal meaning, objectivity and rationality), *subjective interpretation* (i.e. the research must grasp the subjective meaning of the actor), and *adequacy* (the researcher's constructs must be consistent with common sense experience and be understandable for actors in everyday life). To gain logical consistency, the draft framework, rooted in previous literature, together with an emphasis on normality, can be seen to reflect the *logical consistency* of the findings. The interviews with the couples enabled me to gain knowledge of people with lived experience, i.e. people with *subjective interpretation*. The third postulate, *adequacy*, was achieved by arriving at a consensus in the consultation groups, in which the subjective meaning of the theme was verified as being successfully maintained and thereby strengthened.

The above description of first- and second-order constructs also applies to study IV, in which the aim was to gain first-order information about the experiences of DemPower and to communicate them through my second-order constructs. The processes of studies II and IV were continuously discussed in the research group and clearly outlined in the studies in order to increase credibility and transparency. In both studies, the couples were interviewed together as a unit, which may have helped "the researcher" (me) get closer to reality since the presence of another person living in the situation serves as a back-up or reliability check for the researcher (Sohier, 1995) and contributes to the meaning of co-construction of a couple relationship. However, there are also limitations in dyadic interviewing, such as if one partner, for some reason, is not able to speak freely in front of the other partner (Sohier, 1995). Confirmability can be considered as being achieved in both studies with regard to the citations that support the raw data. The member check process, in which I returned to the target group for consensus on the findings, can be viewed as a form of triangulation (Lincoln & Guba, 1985; Patton, 2002) to strengthen the credibility of the findings. The most significant limitation of studies II and IV is the sample sizes. In study II, I consulted 40 people with dementia and the relatives of people with dementia in different contexts to confirm the findings. This procedure was also conducted in the UK in order to confirm the findings and the transferability to a UK context. With regard to study IV, only six couples out of the 12 Swedish couples who completed the DemPower feasibility study participated. This was not because they did not want to participate, it was because they were busy travelling and "doing things together" at the time of the interviews.

11.CONCLUSION AND IMPLICATIONS

11.1. Conclusion

It is time to listen to people with dementia and their partners in order to support the areas that matter the most to them. This thesis has contributed with knowledge by identifying areas of great importance to couples living with dementia, which were found to be their couple relationship in the context of a normal everyday life. This thesis has implications for research, healthcare and the public by highlighting the need for a salutogenic and health promoting approach toward people with dementia and their partners. Couples living with dementia nurture their sense of couplehood, relationship quality and wellbeing by focusing on their strengths and resources and by doing things together. The findings of this thesis suggest that a self-management tool is well-suited to adopt a salutogenic approach that support couples to live a normal life with their wellbeing as a couple in the centre.

11.2. Implications

11.2.1. Implications for research

Research within the dementia field can benefit from adopting an overall salutogenic and resource-oriented approach. Researchers should develop interventions that is meaningful to people with dementia and partners. This could be achieved by including people with dementia and partners in the research process. Interventions aimed at couples living with dementia should target their couple relationship in the context of everyday life. The targets and outcome measures within couple-centred interventions should focus on positive aspects of relationships rather than on problems and illness-specific issues. Self-management (couple-management) approaches could guide researchers when planning and conducting couple-based interventions.

11.2.2. Implications for healthcare

Healthcare within dementia should meet couples living with dementia in line with how they view their own health and empathize the healthy aspects of living with dementia. Healthcare professionals need to support couples' efforts to sustain relationship quality and sense of couplehood in order to help couples to live well with dementia. Healthcare professionals also need to reflect on how they impact on people with dementia and partners in order to help them to maintain hope and a positive approach.

11.2.3. Implications for the public

We need to start listen to people with dementia and learn from them. They are ready to tell us and help us to raise awareness of dementia and how we can support them. People with dementia and their partners are normal people with normal needs who wish to live a normal life. Sometimes they may need support from us to do so. People with dementia want to be included in the community, contribute to the community and deserve to be valued for the people they are and not based on their condition.

12. ACKNOWLEDGEMENTS

I would like to express my sincerest gratitude **to the experts in this thesis**. This is our research and you are the ones who could make it happen. I have truly enjoyed spending time with you and I am so grateful that you shared your lives and your expertise with me.

Ingrid Hellström, my main supervisor. I would like to thank you for your support and your individualized supervision. You have allowed me to grow with the trust you placed in me. I really appreciate your company - as a supervisor and as a person.

Agneta Kullberg, my supervisor, who has been there for me and helped me develop along the complicated academic track. Thank you for all our conversations. You always have such interesting things to say and your general knowledge is outstanding.

John Keady, my supervisor at The University of Manchester. Thank you for letting me be part of the Neighbourhoods and Dementia study. Having you as a supervisor, with your deep knowledge of dementia research, has been incredibly valuable.

Elzana Odzakovic, my friend and colleague who has shared this time with me. I appreciate our meetings, your support, and that we complement each other. I look forward to continuing to work with you in the near future.

All my colleagues in the Neighbourhoods and Dementia study, you will not be forgotten. You have been a great support during my doctoral studies and it has been a real privilege to be part of such a respected group of researchers in the field of dementia.

To the reviewers Elisabeth Hanson, Tiny Jaarsma, Ragnhild Hedman and Johan Lundgren of my “halvtidsseminarium” and “kappaseminarium”. Thank you for your guidance, time and expertise.

Reena Lasrado, with whom I have been closely working with during these years. You are positive in heart and soul.

Thanks to all colleagues at the Department of Social and Welfare Studies for your valuable guidance in seminars and discussions.

Tony Husband, thank you for providing the cover picture and for your outstanding service.

Lars-Christer Hydén, thank you for your initial guidance.

My family Roger, Ines and Gustav, thank you for supporting me through these years. I love you.

This thesis was supported by the Economic and Social Research Council (ESRC), National Institute for Health Research (NIHR) and the County Council of Östergötland, Linköping University from its strategic research fund for Health and Welfare.

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EXPLORING

Papers

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FACULTY OF MEDICINE AND HEALTH SCIENCES

Linköping University Medical Dissertation No. 1729, 2020
Division of Nursing Sciences and Reproductive Health
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