Facing dementia as a *we*

Investigating couples' challenges and
communicative strategies for managing
dementia

Elin Nilsson

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Abstract

We live longer than ever before, which means that we also live longer with disorders such as those connected with dementia. Most people diagnosed with dementia live in ordinary housing for a long time, relying on their social network for support, mainly involving spouses or adult children. There is limited research on how families and couples manage daily life with dementia, and social workers may only have knowledge and skills at a general level about older people with the condition.

The aim of this thesis is to investigate how couples manage dementia-related challenges, as well as whether and how these challenges and ways of managing relate to aspects of couples' *we-ness*. This aim has been specified in terms of research questions which involve the couples' communicative management of dementia-related challenges, and how they approach and talk about sensitive topics connected with dementia. An additional question involves how the couples relate to and use their *we-ness* in managing dementia. Multimodal conversation analytic theory and methodology has been adopted to study sequences from 15 video-recorded joint interviews involving couples where one of the partners had a diagnosis of dementia.

The articles demonstrate how the spouses managed dementia jointly, and how they used their common ground as a couple as an important resource for telling stories and remembering. When the spouses without dementia approached sensitive topics related to dementia, they made use of strategies such as mitigating talk, or touching the partner with dementia as they spoke. The spouses without dementia approached the issue of the future carefully, whereas the spouses with dementia were more direct in the way they talked about the future. A final finding involves the spouses without dementia using strategies such as giving clues or prompting to help their partner with dementia remember. However, this was seldom successful, and

may even have had face-threatening effects. Taken together, the different aspects of this thesis emphasise the challenges faced by the couples and the communicative strategies they used, as well as the abilities and agency which surfaced during a micro-level analysis of their interaction. The results are further discussed in the light of implications for social work education, practice and theory, largely highlighting the importance of adopting a couple-sensitive approach in which relational and interactional aspects are emphasised.

Sammanfattning

Vi lever längre än vad vi tidigare gjort, med den effekten att vi också lever längre med sjukdomar som demens. De flesta av de som diagnostiserats med demens bor länge i ordinärt boende och är ofta beroende av sitt sociala nätverk av främst makar eller barn till stöd. Det finns begränsad forskning om hur familjer och par utan formellt stöd hanterar tillvaron, och socialarbetare har ofta generell snarare än specifik kunskap och färdigheter i bemötande av äldre som lever med demens.

Syftet med denna avhandling är att undersöka hur par hanterar demensrelaterade utmaningar, såväl som om och hur dessa relaterar till aspekter av deras *vi-skap*. För att uppnå detta mål har det specificerats i forskningsfrågor beträffande parens kommunikativa hantering av situationer med demensrelaterade utmaningar, såväl som strategier för att närma sig känsliga ämnen som är kopplade till demens. En ytterligare fråga gäller hur paren relaterar till och använder sig av sitt *vi-skap* när de hanterar demens. Genom att utgå ifrån multimodal samtalsanalytisk teori och metodik har sekvenser från 15 videoinspelade intervjuer med par där en av partnern har en demensdiagnos studerats.

I artiklarna demonstreras hur partners hanterade demens gemensamt, och hur deras gemensamma grund som ett par var en viktig resurs för att berätta och minnas. När partners utan demens närmade sig känsliga ämnen med anknytning till demens använde de sig av strategier som mildrande prat eller beröring av partnern med demens under berättandet. Partners utan demens närmade sig frågan om framtiden på ett sätt som indikerar känslighet, medan partners med demens var mer direkta i sitt tal om framtiden. En sista konklusion är att partners utan demens använde sig av strategier såsom ledtrådar för att möjliggöra berättande och att minnas för personen med demens, något som

sällan hade framgångsrika följder vad det gäller att minnas och kunde till och med få ansiktshotande effekter. Resultaten diskuteras vidare vad gäller implikationer för sociala arbetets utbildning, praktik och teori. Här argumenteras för betydelsen av ett nytt tillvägagångssätt som synliggör parperspektivet, inom vilket relationella och interaktionella aspekter betonas.

List of included articles

Article I

Hydén, L-C. & Nilsson, E. (2015). Couples with dementia: Positioning the “we”. *Dementia*, 14(6), 716-733.

Article II

Nilsson, E. (2017). Fishing for answers: Couples living with dementia managing trouble with recollection. *Educational Gerontology*, 43(2), 73-88.

Article III

Nilsson, E., Ekström, A. & Majlesi, A-R. (Forthcoming article in press). Speaking for and about a spouse with dementia: A matter of inclusion or exclusion? *Discourse Studies*, 20(6).

Article IV

Nilsson, E. & Olaison, A. (2017). What is yet to come? Couples living with dementia orienting themselves towards an uncertain future. *Qualitative Social Work*, (E-pub ahead of print).

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Elin Nilsson

Svärtinge, April 2018

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1. Introduction and aim

[T]he field of gerontological social work must prioritize research efforts to address the dangerously understudied topic of dementia...There is a clear need for immediate efforts to improve competences and increase the workforce of capable providers in dementia care.

(Kaplan & Berkman, 2011:366)

Introduction

Progress in medicine, and better health-care, food and work conditions throughout the Western world, along with the baby boom in the 1940s, all mean we tend to live longer than we used to. This also means that we live longer with afflictions such as dementia-related conditions. A considerable number of people live with dementia, and numbers are growing rapidly. This thesis adds to modest existing knowledge about living with dementia by focusing on dementia-related challenges displayed and managed through multimodal interaction in couples. It also addresses how these challenges relate to two people's relationship as a couple.

Globally, the number of people with dementia is estimated to be 46.8 million (around 0.5% of the total population), and the number is expected to reach approximately 131.5 million by the year 2050 (Alzheimer's Disease International, 2016; Ferri et al., 2005). In Sweden alone, between 113 000 and 169 000 individuals are estimated to have dementia, around 8% of all people over the age of 65 and almost half of everyone over 90. Approximately 25 000 people develop dementia every year in Sweden, and just as many die of it annually (National Board of Health and Welfare, 2014a, 2014b, 2017). Most people continue to live in ordinary housing for a long time, and manage daily life with informal support (Szebehely & Trydegård, 2012).

The Swedish system of care for the elderly is characterised by universalism and egalitarian values for all. It involves a publicly provided, comprehensive, high-quality service available

to all citizens, which aims to reduce gender and class inequalities (Szebehely & Meagher, 2017; Szebehely & Trydegård, 2012). Care for the elderly in Sweden has mainly been financed through tax revenue (Blomberg, 2008; Szebehely, 2005). Services are expected to be offered according to need, and are not dependent on the ability to pay (Olaison, 2017; Szebehely & Trydegård, 2012). The Swedish Social Services Act is framework legislation which states that support and services should be provided for a person in need unless the needs can be met in other ways (SFS, 2001:453, chapter 4, §1).

However, over the last few decades, care for the elderly in Sweden has undergone substantial changes (Meagher & Szebehely, 2013; Szebehely & Meagher, 2017). These have involved a transformation influenced by neoliberal politics, with an emphasis on economic efficiency and cost reduction through competition between private and municipality-based care providers (Andersson & Kvist, 2015). Consequently there is now a more diverse, multidimensional system, with an increase in both private and public actors in care for the elderly (Blomberg & Pettersson, 2011). This development has resulted, among other things, in a reduction of the proportion of older people who are granted welfare services in terms of care for the elderly in Sweden (Meagher & Szebehely 2013; Szebehely & Meagher, 2017). Therefore, more people purchase services when their needs are not covered by social services, and this has consequences for families and carers with lower levels of education, who purchase services less frequently than those with higher education. This development affects women to a great extent, as they are the main carers and are more likely to reduce their formal labour time due to care responsibilities (Jegermalm, 2005; Jegermalm & Sundström, 2017; Ullmanen, 2015; Ullmanen & Szebehely, 2015; Saraceno, 2010; Szebehely & Meagher, 2017).

Alongside this development, Sweden has moved towards an increase in dependency on support from informal caregivers, who

are often family members, mainly spouses and grown-up children (Jönson & Harnett, 2015). It has been argued that Sweden is tending towards refamilialising care for the elderly and reverting to informal care (Szebehely & Trydegård, 2012).¹ Support from families is particularly taken for granted in care for the elderly, and relatives receive minimal financial support from the local municipality (for a discussion on this development, see e.g. Jegermalm & Jeppson Grassman, 2009). In the year 2000, out of the number of older people living at home receiving help, almost 75% of those in need of home care received support from their family rather than formal home care (Sand, 2015). This pattern is likely to have an effect on families living with challenges such as dementia-related conditions.

Dementia and social work

Social workers are in the front line of meeting couples facing dementia in terms of making assessments for the provision of services and support for them. The Swedish Social Services Act takes an individualised approach which emphasises self-determination for individuals with dementia (National Board of Health and Welfare, 2017; SFS, 2001:453, Ch. 4, §1; SOU, 2017:21), but at the same time people with the condition often rely on social networks for coping with daily life. The individual approach may therefore lead to challenges for care managers. They may need to take into consideration relationships and networks as part of individual assessments for support for a person with dementia.² How this balance is managed in terms of interacting with families is likely to have an effect on the type of

¹ See Saraceno (2010) for a discussion about developments in other EU-countries.

² For a discussion on the concept of ‘dependent independence’ and ‘interdependent relationships’ within social work with people with dementia, see Christie (2016).

services provided, which in turn will affect the families' daily ability to cope with dementia.

In social work practice, interaction with clients and relatives is a cornerstone (Fredin, 1993; Kullberg, 1994; Kullberg & Cedersund, 2001; Sarangi & Slembrouck, 2014), as it takes place through conversations with clients (Juhila, Mäkitalo & Noordegraaf, 2014; Seltzer & Kullberg, 2001; Shotter, 2002). This is also the case in interacting with potential clients living with dementia which, as noted above, is a severely understudied topic (Kaplan & Berkman, 2011; Ray et al., 2014). Present-day social workers often only have knowledge and skills at a general level in terms of supporting older people. In particular, they may lack dementia-specific skills or training for meeting the complex and changing challenges and needs of families and couples living with dementia (see e.g. Cedersund, 2013; Kaplan & Berkman, 2011; McGovern, 2011; Melin Emilsson, 2013). In social work education, knowledge about an ageing population, including those living with dementia, is an under-prioritised topic. In turn, this has an effect on attitudes towards dementia itself, and on the competences relating to dementia in gerontological social work (Keating, 2017; Richards et al., 2014; Rosen & Zlotnik, 2001).

Outside the field of social work research, there is a growing body of research and knowledge about life for people living in dementia care facilities. This knowledge is based on ethnographies and interview studies, as well as natural interactions at dementia facilities, and assessment meetings which involve staff (e.g. Beach & Kramer, 1999; Gray, 2014; Strandroos & Antelius, 2017), relatives (e.g. Österholm & Samuelsson, 2015) and other residents in a self-help group (e.g. Örulv, 2012). However, in Western society, including Sweden, two-thirds of all people with a dementia diagnosis live in ordinary housing rather than in a dementia care facility, and continue to do so for a long time with little or no formal support from social services (National Board of Health and Welfare, 2007). This

pattern means that informal care for a family member with dementia is widespread, and spouses are the most common caregivers (Alzheimer's Association, 2017; Odzakovic, Hydén, Festin & Kullberg, 2018). Despite this, within the field of social work, knowledge is scarce in terms of the lives of families and couples living with dementia, and the challenges they face (for some recent exceptions, see e.g. Christie, 2016; McGovern, 2011; Tanner, 2013; Tolhurst, Weicht & Kingston, 2016). By investigating dementia-related challenges faced by couples, this thesis contributes knowledge on the topic of dementia which can be used by social services in the assessment process, and to provide appropriate support.

Dementia-related challenges

A bio-medical approach to dementia has dominated research and practical work in the field for a long time. Viewing dementia from this perspective, challenges are mainly related to the deterioration of brain functions and the decline of the person's previous abilities, which in turn are considered to lead to a loss of self (Parker, 2001; McGovern, 2011). Within this perspective, challenges have mainly been understood in terms of dementia symptoms and the care burden for the relatives. However, there has been a shift towards a model which emphasises psychosocial aspects of dementia (Hydén & Antelius, 2017), Tom Kitwood being one of the most important researchers to influence this change (Marshall & Tibbs, 2006; Parker, 2001). Kitwood and his colleagues place the person at the forefront, alongside relational and interactional aspects, and dementia and decline remain in the background. Kitwood (1997) exemplifies this view through his definition of personhood 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, 1997:8).

Adopting a view which emphasises personhood and the abilities of a person with dementia, rather than decline (Kitwood, 1997), enables an individual to be viewed in terms of potential relationships with others. This implies that two individuals are part of a couple, and are not only affected by dementia *individually*, but also have to manage it as *a couple*. Research has argued that when *couplehood* is shared with a spouse, it may also be shared during periods of dementia (Kaplan, 2001). Couples can then face dementia as a *we* rather than two individual *I*:s, and they can be creative in finding new solutions to their changing situation (McGovern, 2011; Hellström, 2007a). Despite this, we still know little about the challenges couples face jointly (Davies & Gregory, 2007), how they actually manage these challenges as a *we* in joint interactions, and by which communicative resources available to them.

Dementia affects abilities at a cognitive as well as linguistic level, which in turn may lead to challenges in interacting with others, such as a spouse (Alzheimer's Association, 2017).³ However, there may also be an emotional layer to these challenges, such as the fact that a couple may not be able to share memories or even have a dinner conversation in the same way as before. Hence, couples have to manage the emotional challenges involved in life with dementia carefully, and individually as well as jointly. Couples may even need formal support in how to approach this management.

Where relational and interactional aspects are emphasised rather than bio-medical ones, there is a need to investigate the challenges couples face and how they manage them. Therefore, by investigating the interaction in couples, this thesis contributes knowledge in terms of both the challenges they face in interaction and the different communicative strategies they use for managing

³ Under the heading "Terminological clarification" (pp.10-11), I provide a detailed description of the different dementia diagnoses relevant to this thesis.

them. The aim and research questions will be further specified below.

Aim and research questions

The general purpose of this thesis is to add to knowledge about how couples with little or no formal support from social services manage the challenges they face in terms of interaction. This is important because these couples will probably make contact with social work professionals at some point in order to apply for support from social services or simply to ask for emotional support. It is therefore important for social work practitioners to gain an insight into how couples manage challenges. This will enable them to design appropriate support and general approaches in terms of interaction.

The aim is to investigate how couples manage dementia-related challenges in interaction within an interview context, considering whether, and how, these challenges and ways of managing relate to aspects of couples' *we-ness*.⁴ The aim will be approached through an interactionist framework involving multimodal conversation analysis theory and methodology (Mondada, 2016; Sidnell, 2013). The aim is specified in the following three research questions:

1. How do spouses jointly manage dementia-related challenges in interaction, and what are the consequences?
2. How do spouses jointly manage the act of approaching and talking about sensitive topics relating to dementia?
3. How do spouses relate to and use their *we-ness* in managing dementia?

⁴ See my understanding and use of this concept on p.12.

The answers to the above research questions have consequences and implications for social work education, practice and theory. These implications are discussed in the articles for this thesis, but are considered in more detail under the last two headings “Conclusions and discussion” and “Implications”. The next section will clarify some terminology.

Terminological clarification

First of all, clarification is needed regarding the use of the term *dementia* to define the condition afflicting the participants in this study. From October 1 2015, DSM-5 (Diagnostic and Statistical Manual of Mental Disorders) redefined the diagnosis of dementia as *major neurocognitive disorder*. However, as this thesis was already in progress when this decision was taken I decided to retain the term *dementia* throughout, in order to maintain stringency and minimise confusion. Dementia, (or *major neurocognitive disorder*) refers to a variety of different conditions or a collection of symptoms. The most common ones are Alzheimer’s disease (AD), which represents 60-70% of all cases of dementia, and vascular dementia which represents 20-30% of all cases. Alzheimer’s disease is characterised by atrophy and degeneration of brain cells, and vascular dementia is characterised by impaired blood vessels which do not provide sufficient oxygen to the brain (Alzheimer’s Association, 2017).

AD has a major impact on cognitive abilities. Common challenges involve episodic, semantic and working memory. Other challenges involve spatiality, ability to comprehend information and to solve problems, and coping with daily chores around the house as well as with personal hygiene (Alzheimer’s Association, 2017). Another range of challenges involves linguistic abilities. These include anomia (problems finding words), naming difficulties, problems connecting words and meanings, and in later stages problems understanding abstract

language (Emery, 2000; Smith et al., 2011). These inevitably affect people's ability to talk, and lead to challenges in terms of interaction (Alzheimer's Association, 2017). I occasionally use the specific term for the condition in the articles (such as AD); otherwise the term *dementia* is used throughout. In references to other studies, the term *dementia* often indicates AD or forms of dementia with common symptoms. In referring to studies on more uncommon forms of dementia which involve other challenges, such as frontotemporal, these will specifically be explained.

Another clarification involves the choices made when describing or defining the participants in this study. Throughout this thesis, I alternate between describing the individuals diagnosed with dementia as the *person with dementia*, *spouse with dementia* or *wife/husband with dementia*, and their partner as the *healthy partner*, *spouse without dementia* or *wife/husband without dementia*. There is no easy way of describing the participants without potentially 'labelling' them or ascribing them 'excess disability' (see Sabat, 2005). In the above descriptions, the participants are described in terms of diagnosis or lack of diagnosis, and they are occasionally also described in terms of gender and marital status. This is somewhat problematic, but it was important in the analysis to identify the person with the diagnosis.

Another plausible categorisation, in line with the above, is one derived from care and caregiving. However, I have refrained from using concepts involving care to refer to the couples interviewed for this thesis, as my starting point is their relationship as a couple rather than caring itself. Traditionally, care often implies asymmetry in the sense that one spouse gives and the other receives care (for an exception, see e.g. Torgé,

2014).⁵ My starting point is the spousal relationship rather than a relationship defined by care, but this does not neglect aspects of asymmetry which are inevitable with conditions of dementia. This said, the concept of care is widely used in the research presented in this thesis, and I refer to it accordingly.

A number of terms can be used to describe the relationship between partners in a couple and the quality of the relationship. However, I alternate mainly between *couplehood* and *we-ness* in this thesis, depending on the level of analysis to which it is applied. I use *we-ness* with regard to empirical expressions of closeness/distance to each other, and how the spouses orient towards a *we* or an *I* within the interaction. An example involves their use of pronouns in referring to themselves and others, which indicates the type of relationship (Benwell & Stokoe, 2006). The use of *I*, for example, would indicate more distance from a partner, and *we* more closeness. Expressions of *we-ness* can also be found in the participants' multimodal interaction (i.e. touching, gaze, tone of voice or bodily orientation). *Couplehood*, on the other hand, is mainly used as a theoretical concept indicating the level of intimacy or separateness expressed by couples (Kaplan, 2001), rather than involving an analysis of ongoing interaction.

Finally, I use the terms communication and interaction interchangeably throughout the thesis, and these also include multimodal (verbal and non-verbal) interaction between the participants. I reject the view of communication as transferring information from a sender to a receiver (Fiske, 1997). Instead, I adopt an approach where the functions and meanings of communicative contributions are based on shared construction and understanding between the participants (Sidnell, 2013). The field of communication and interaction is extensive, and beyond

⁵ See Wallroth (2016) for a nuanced and updated discussion regarding the concept of care.

the scope of this thesis. However, I will discuss its use in this thesis in chapter 5, “Analysing interaction”.

Thesis disposition

This thesis begins at chapter 2, with a description and discussion of previous research on aspects of life for couples with dementia. Chapter 3 provides a theoretical framework for analysing interaction, and chapter 4 describes the method and study in terms of participants, design, procedures and analysis. The chapter is rounded off with considerations regarding method, validity and ethics. Chapter 5 presents the articles, and conclusions are drawn and discussed in chapter 6. In the final chapter, 7, I discuss implications for education, practice and theory, ending with suggestions for further research. References, appendices and the full version of the four articles appear after chapter 7.

Facing dementia as a we

2. Previous research on couples and dementia

Traditionally, much of the research on how people with dementia and their spouses adjust to their progressing condition has emphasised the increased care burden for the spouse. One problem with focusing on care and the burden on couples is that dementia primarily is conceived to have an impact on the couples' relationship, partially mediated by the quality of their previous relation. It has been suggested that when one person develops dementia and their spouse takes on the role of carer, the quality of their former relationship will determine "the form that their relationship takes in the context of the dementia" (Ablitt, Jones & Muers, 2009:506). During the last decade or so, more focus has been directed towards the couple, the dyad, consisting of the person with dementia and the spouse without dementia (Braun et al., 2009).⁶

This chapter will begin by summarising research on the relationship between partners in a couple, and how couplehood is manifest and used in daily life in terms of managing dementia. I shall then provide an overview of research on how couples collaborate in interaction, in terms of practical matters and remembering. It is worth mentioning here that different types of study are presented in this chapter. A substantial number of researchers use a thematic framework involving couples' strategies, experiences and feelings. One group focuses on quantitative aspects of *we-ness*, for example, where interactionist researchers like myself present detailed analyses of interaction and emphasise collaborative aspects.

⁶ Relationships other than couples have also been seen as important in terms of ageing with or without dementia, such as siblinghood (McGovern & Gardner, 2015), friendship and dementia (e.g. Perion, 2016) and the child/parent caring relationship in general ageing (e.g. Ullmanen, 2015). There has also been critical research discussing heteronormativity and ageing (e.g. Sandberg, 2015).

Couplehood and dementia

Research on how married couples manage various kinds of chronic illness argues that dyadic coping can often be beneficial and can even affect the relationship positively (Berg & Upchurch, 2007). Research on everyday problem-solving involving elderly couples in particular indicates that they are often good at collaborating (Carstensen, Gottman & Levenson, 1995). This calls for a different way of thinking about how couples deal with dementia. They not only experience the impact of the disorder on their relationship, but can also make use of their relationship in managing it. Collaborative strategies for managing the condition may, in turn, have a positive effect on their relationship. Norton et al. (2009) found that the caregivers in their study who considered themselves closest to their partner, or closest to the person receiving the care for dementia, also reported receiving the most formal support and help in terms of caring. This may indicate that the formal support helped bring them closer to their partner. Norton et al. (2009) also argue that a good relationship between a spousal caregiver and a person with dementia may lead to a slower decline of cognitive functions (Norton et al., 2009), which would emphasise the importance of this pattern. Nourishing the relationship between spouses seems to be an investment worth making on a personal level, but equally at a societal level, such as in guidelines for treatment and care for individuals with dementia.

The concept of *couplehood* in relation to dementia was first used by Lori Kaplan (2001), and it classifies the extent to which a person in a relationship with an institutionalised spouse diagnosed with AD perceives him or herself as belonging to a *we* or an *I*. Kaplan's classification ranges from strong to weak couplehood, from "Till death do us part", "We, but...", "Husbandless wives/wifeless husbands" and "Becoming an I" to "Unmarried marrieds". Kaplan proposes that the way the

relationship develops at the onset of dementia depends on the quality of the relationship prior to dementia (Kaplan, 2001). The concept of couplehood has since been further used and developed by researchers within the field of dementia research (e.g. Hellström, Nolan & Lundh, 2005, 2007a; Hernandez, Spencer, Ingersoll-Dayton, Faber & Ewert, 2017; Molyneaux, Butchard, Simpson & Murray, 2011).

The field of knowledge on couples and dementia has been summarised in a number of research reviews involving both qualitative and quantitative studies (e.g. Ablitt et al., 2009; Braun et al., 2009; Wadham, Simpson, Rust & Murray, 2016). It becomes evident from these reviews that there are few studies involving spouses' joint comments on their experiences of dementia and couplehood, and this also emerges from most of the research presented in this chapter. The fact that couples do not participate jointly in studies has led to a lack of knowledge about interactional aspects of how couples manage life with dementia.

Several studies focus on how couples living with dementia go about their lives together. For instance, Hellström et al. (2005) conducted a case study in Sweden where the main focus was on a woman with dementia and her husband, and more specifically on their couplehood. One of the main findings was that the spouses tended to do things together rather than separately. Their care for each other was mutual in many cases, and this was interpreted as a way of supporting the relationship. Both spouses had strategies for caring for one another, even if efforts varied greatly between the two in many aspects. The authors even argued that at times the couple considered their couplehood to be superior to their separate personhoods (Hellström et al., 2005). Hellström et al. (2007a) also studied the strategies used by a number of couples to sustain couplehood, and found that in the earlier stages of dementia the couples were more active in working towards this strategy, summarised in themes such as "Talking things through", "Being affectionate and appreciative" and "Making the best of

things”. Even in the later stages of dementia the couples were active in maintaining their involvement with each other (Hellström et al., 2007a).

There are indications of a continued sense of commitment to the relationship despite dementia. Spouses are often interviewed separately, but Hernandez et al. (2017) argued that despite challenges connected to memory, spouses in couples could independently match the degree of intimacy to their partner’s rating. This would indicate a continued shared sense of couplehood despite dementia. Merrick, Camic and O’Shaughnessy (2016) found patterns in joint interviews that indicate a strong foundation of togetherness and commitment in couples living with dementia. Some couples express that the dementia had brought them even more close together. However, some couples instead expressed feelings of loss and altered structures due to dementia, which were partly managed by ‘flexible scaffolding’ by care partners (Merrick et al., 2016). On the same note, Davies (2011) studied commitment and marriage satisfaction in couples where one had a diagnosis of dementia, and found that the couples expressed their commitment to each other in four themes: “Partnership for life”, “Reciprocity”, “Resilience” and “Forgiveness”. The couples emphasised the collaboration rather than the individuality in attempting to preserve their *us* identity through the difficult times (Davies, 2011). Davies and Gregory (2007) also focused on marriage commitment in time of dementia, and they advocate for relationship-centred care rather than individually oriented, with support based on marriage biography (Davies & Gregory, 2007).

Molyneaux et al. (2011) found that couples’ previous levels of affection and couplehood were sustained regardless of whether or not they had dementia. Even though one spouse acknowledged being ‘technically a carer’, the couples did not want to identify themselves with the labels ‘carer’ and ‘cared for’. Their joint home was considered a safe place, but at the same time it also

represented the new limits in their lives (Molyneaux et al., 2011). Studies indicate that couples confront the effects of dementia jointly as a unit, and it causes great pain when the spouse with dementia starts to exhibit problems with remembering shared experiences on which their couplehood rests (Daniels, Lamson & Hodgson, 2007; Molyneaux et al., 2011). In the light of all these findings, I would argue that there is still potential for experiencing and making use of couplehood despite dementia. This becomes particularly evident in the couples' distress about potential separateness, such as not being able to share memories.

A number of studies highlight strategies used by couples to maintain a sense of normality in their life with dementia. In research by Molyneaux et al. (2011), couples indicated that the changes in their previously shared identity were challenging, and that their new roles were confusing. However, the couples tried to diminish these challenges, to nourish and maintain their couplehood, and to mitigate the problems in their current situation by normalising the symptoms of dementia, such as referring to them as 'normal ageing'. Clare and Shakespeare (2004) also found this pattern of normalising symptoms, and argued that this sometimes led to disagreements between the spouses. In line with research on couples trying to maintain normality, Foster (2011) explored the impact of dementia on couples from an individual perspective as well as from the point of view of couples. Foster argued that couples facing dementia are in a unique position in the sense that the marital relationship and everyday life itself can be used for coping with dementia. A major strategy employed by couples living with dementia involves restoring normality through means such as meaningful involvement, staying active and reducing the load, as well as through direct discussion and support (Foster, 2011).

Another strand of research draws on aspects of couplehood such as pronoun use, and specifically the use of *we*. A number of studies show that older couples express more *we-ness* (frequently

speak of themselves and their partner in terms of *we*) and invest more in their relationship than younger couples do (Sillars, Burggraf, Yost & Zietlow, 1992; Seider, Hirschberger, Nelson & Levenson, 2009). Expressing a strong *we-ness* leads to positive effects, which may be physiological (Rohrbaugh, Mehl, Shoham, Reilly & Ewy, 2008; Badr, Acitelli & Carmack Taylor, 2007; Seider et al., 2009), expressed as satisfaction with marriage (Buehlman, Gottman & Katz, 1992; Simmons, Gordon & Chambless, 2005; Williams-Baucom, Atkins, Sevier, Eldridge & Christensen, 2010), emotional, such as the ability to forgive the partner (Karremans & Van Lange, 2008; Ysseldyk & Wohl, 2012) or linked to solving problems together in a way which satisfies both partners (Simmons et al., 2005).

However, Daley, O'Connor, Shirk and Beard (2017) argues in opposition as in that taking a *we-approach* in spousal dyads of care does not have effect the spouses with dementia's cognitive or functional ability, or on caregiver anxiety, burden, depression or even relationship satisfaction. The only difference was that in dyads taking the *we-approach*, the caregiving spouses expressed more positive aspects of caring than those with a *me-approach*, which may then be connected to commitment to partner and relationship (Daley et al., 2017). Taken together, the research presented here indicates that couples continue to invest in and commit to their joint couplehood despite dementia. It is clear that they can be creative and strategic in adapting to the new experiences, and that it is often done jointly, in collaboration.

Couplehood in practical matters

Dementia has effects on the cognitive and linguistic abilities required for everyday activities, bringing challenges to couples' daily life. By giving couples different tasks to perform jointly, researchers have gained knowledge on how everyday situations can be dealt with. The focus of several studies has been the support given when a spouse carries out a task in collaboration

with a person with dementia, often referred to as *scaffolding* (see e.g. Hydén, 2011; Wood, Bruner & Ross, 1976). People with dementia can participate in rather advanced joint activities by making use of the cognitive and linguistic resources of a co-participant, particularly in terms of planning and carrying out an activity such as cooking (Hydén, 2014; Majlesi & Ekström, 2016).

Mealtime or kitchen duties have been used in dementia research for studying different relational and interactional aspects, since this is an activity most couples share. Majlesi and Ekström (2016) conducted a case study on video-recorded collaboration in a couple living with dementia, exemplified in the joint activity of baking. Not only did the spouse without dementia enable participation for the spouse with dementia through verbal and non-verbal instructions and supervision, the spouse with dementia actively made use of his/her environment and collaborative partner to participate in the activity. For instance, the spouse with dementia recurrently asked questions about the instructions, showing skilful interactional competence and an ability to compensate for the challenges of dementia (Majlesi & Ekström, 2016).

Spouses without dementia have been shown to make an effort to create a supportive working environment for the spouse with dementia, by making afternoon tea for instance (Vikström, Borell, Stigsdotter-Neely & Josephsson, 2005). This entailed making their situation comfortable and taking the main responsibility for the task. The spouses without dementia also gave practical support in terms of adapting the physical surroundings, changing activities and showing support for the contribution made by the spouse with dementia. Sometimes however, the support had a negative effect on the performance of the spouse with dementia. The reasons for this were interpreted as the supporting spouse giving insufficient or inappropriate support, or failing to respond to the needs of the partner with dementia, leaving him/her confused (Vikström et al., 2005).

Vikström, Josephsson, Stigsdotter-Neely and Nygård (2008) argue that when couples are talking about their co-operation, they often use phrases which include a collective pronoun (we) rather than an individualised pronoun (I). Furthermore, Vikström et al. (2008) showed how spouses rarely separated their roles in a task, but when asked to specify it was evident that they did many things separately rather than jointly, and that the spouse without dementia was doing most of the work. The authors pointed out that this can be seen as an attempt to sustain their couplehood despite the changed situation (Vikström et al., 2008). This relates to a discussion in the footnote on pages 38-39 about the pronoun *we* as an element in *elderspeak*, but in this setting it is analysed as joint agency by the couple, rather than an attempt to avoid potential failure or loss of face for the spouse with dementia. The above-mentioned studies show that on a practical level couples engage in considerable sustained joint activity aimed at increasing wellbeing and reducing loss of face for the spouse with dementia.

In contrast to the above, there could also be couples and situations where spouses carry out their activities more independently of one another. Keady and Nolan (2003) argue that when couples adapt to dementia they go through processes involving different ways of working together to manage the situation, but occasionally work separately or even alone. According to their research, for instance, in the early stages of dementia spouses were sometimes alone in making sense of the symptoms they noticed and experienced in their partner with dementia. This phase was often followed by one in which there was some kind of mutual acceptance of the situation, and aspects of “sharing the load” were more dominant than working alone. The spouses could then begin to work together as a couple facing an uncertain future with dementia (Keady & Nolan, 2003). Keady and Nolan (2003) propose that a major goal should be to enable couples to “work together” at an early stage, including making

“specialist services ... available on a continual basis to help support ‘the partnership’ - and the family – through this transition” (Keady & Nolan, 2003:30).

It has been argued that the practical reorganisation of duties in coping with dementia affects gender identities, where men may experience challenges in terms of identifying themselves as men caring for a wife with dementia, or taking on traditionally ‘female housework’ such as cooking and cleaning.⁷ Boyle (2014) indicated gendered patterns in cases where men whose wives had dementia took over household chores, and noted that men exercised choice and control in this process, taking on only the chores they found pleasurable. Some men were unwilling to share the cooking, and even when they did so they tended to take over the activity altogether, rather than allowing their wife with dementia to participate (Boyle, 2014). However, Hellström, Håkansson, Eriksson and Sandberg (2017) argue that men’s adjustments over time may result in integration, where the ‘caregiving’ becomes part of their identity rather than something external. One argument supporting this was that men gradually went from taking an “I-perspective” to a “we-perspective” (Hellström et al., 2017), similar to findings by Vikström et al. (2008).

The studies presented in this section involve activities at a practical level, but the emotional content of working together or apart is no less valuable for the more communicative level on which this thesis rests. The following section approaches this level through the concept of joint remembering.

Couplehood in remembering

As described earlier, couples’ practical collaboration in preparing a meal, for instance, is a growing field of research, but less

⁷ This pattern of caregiving as a role for women is also represented in statistics, where men as spousal caregivers receive more support from social services than women as spousal caregivers (Andersson, 2007).

research has focused on couples' collaboration in terms of remembering. A small number of studies have involved various kinds of intervention focusing on collaboration in enhancing memory performance for individuals with dementia.

Stigsdotter-Neely, Vikström and Josephsson (2009) argue that collaborative training in memory tasks involving a spouse without dementia alongside one with the condition improved the latter's ability to recall items, compared to people with dementia who had received no training or people with dementia who had received individual training but with help from a research assistant (rather than a spouse). However, while memory performance improved for the spouse with dementia after collaborative training, it declined for the partner without dementia, so that the performance of each was equalised (Stigsdotter-Neely et al., 2009).

Quayhagen and Quayhagen (2001) produced similar results, supporting the case for couples undertaking collaborative training on remembering. Collaborative training with a spouse led to improvements in immediate memory and verbal fluency for the spouses with dementia. In a previous study, Quayhagen and Quayhagen (1996) had also found that participation in a longitudinal intervention task with a collaborative focus actually enhanced the couples' quality of life.

Schmitter-Edgecombe, Howard, Pavawalla, Howell and Rueda (2008) studied the effect of using a multi-dyad memory notebook (MMN) with a partner. MMN is a tool for managing daily life. It includes a daily log, a calendar, and other functions involving personal notes and goals in life. They found that participants with very mild dementia, who made use of an MMN with the help of a spouse, increased their usage of the memory notebook and other memory strategies, and remembered to refer back to the notes as a post-treatment measure. During post-treatment, the spouses with dementia also felt more confident of receiving support from others, and the coaching spouses

indicated fewer symptoms of depression, so the training had beneficial effects for both partners (Schmitter-Edgecombe et al., 2008). A review by Kindell, Burrow, Wilkinson and Keady (2014) advocates communication through life-story work for staff and couples/families living with dementia, not necessarily to enhance remembering, but for emotional, interactional and practical care purposes, or to help couples through a difficult time. Kindell et al. (2014) introduce the issue of bringing potentially upsetting memories to the surface, which they consider a problem more related to staff than spouses, who are more likely to be aware of these risks. They also problematise the challenges of eliciting specific memories, and indicate that naturalistic methods may be more beneficial (Kindell et al., 2014).

Taken together, these studies indicate that couples living with dementia may benefit from a joint intervention which aims to improve memory, not only in terms of enhancing memory itself, but also in terms of general wellbeing.

Couplehood in collaborative interaction

As indicated in the previous section, collaboration between spouses may be fruitful for remembering. This section explores studies which focus on collaboration in interaction.

Hydén (2011) argues that not being able to tell stories and cherish a shared history is a potential threat both to the experience of belonging together and to the participants' individual identities and past. Most spouses and family members try to address the communicative challenges caused by progressing AD by taking over some of the functions lost by the person with dementia. Sustaining joint storytelling involving a person with fairly advanced dementia involves extensive repair work (see Samuelsson & Hydén, 2017). Repair involves activities for managing challenges within the ongoing interaction, such as finding words or tasks of a more epistemic character (Hydén, 2011; Schegloff, Jefferson & Sacks, 1977). Hydén (2011) argued

that this repair work is a mutually interpretive activity, in which both parties attempt to make themselves understood to each other. Interaction in the storytelling activity was characterised by a reorganisation and renegotiation of the interactional roles, so that the spouse without AD scaffolded the interaction. One participant often used scaffolding as a way of supporting or enabling participation by another participant, or in order to encourage them to do something. Scaffolding in this sense was interpreted as a sign of commitment to couplehood by the spouse, and it highlighted ways of sustaining it (Hydén, 2011).

Another strand of research focuses on interventions which aim to increase and improve communication. These might include tools with pictures, songs and other ways of encouraging communication. Scherrer, Ingersoll-Dayton and Spencer (2014) took a narrative approach in their *Dyadic dementia intervention*, drawing on aspects of joint remembering as a basis for communication in couples. They specifically used significant mementos such as photos or cards, focusing on the social and psychological effects of memory loss in dementia. Ekström, Ferm and Samuelsson (2017) provided people with dementia with personalised communication applications on tablet computers, and in one study gave one specifically to a couple. The results indicated an increase in communication for the couple, as well as in communicative initiatives by the person with dementia. This should nevertheless be treated with some caution, since communicating through a tablet also brought to the surface dementia-related problems such as not recognising a specific picture or failing to making sense of a suggested topic (Ekström et al., 2017). Yet another tool for improving communication for people with neurological disorders such as dementia involves 'talking mats', which consist of picture frameworks used on a textured mat. These represent an evaluation scale, a conversational topic or open questions/issues (Ferm, Bloch & Saldert, 2016). Ferm et al. (2016) found that in a couple living

with Parkinson's disease, the wife without Parkinson's tended to speak in terms of an inclusive *we*, rather than *I* or *you*. This was interpreted as a way of making participation less threatening for the spouse with Parkinson's, as well as a way of creating symmetry and companionship (Ferm et al., 2016). Finally, Fortune and McKeown (2016) show how couples living with dementia's participation in a leisure activity with other couples in the same position report of feelings of inclusion to a social setting. They also report of a decrease in the feeling of marginalisation that is often connected to life with dementia. The couples also indicate that the social activity of interacting with other couples in a similar situation also increases the closeness with their partner. Fortune and McKeown (2016) advocate for more activities aimed at interaction and relationships rather than individually oriented.

It appears that tools for improving and increasing communication for couples living with dementia are working, and are appreciated by couples. However the risk of being put on the spot as someone not remembering or not being able to remember has to be managed with sensitivity.

Summary

The above studies indicate that both the person with dementia and the spouse without dementia make considerable joint effort to manage the consequences of the condition. They develop and adapt their collaborative strategies, and learn to use scaffolding, for example, to compensate for the cognitive and linguistic losses brought on by dementia. It also appears that interventions which aim to improve collaboration can be successful. However, more work is required on the micro-level processes of interaction in couples. This thesis adds to this corpus of knowledge through its focus on multimodal (verbal and non-verbal) interaction and collaboration at micro-level. This will be discussed further in the

following chapter, which describes the theoretical framework used in the thesis for analysing interaction.

3. Analysing interaction

I should thus like to propose that it is not primarily through language that social work takes place but rather ‘in the language’. This does not mean only that one talks in social work, which is after all a trivial matter ... A social reality is constructed - for good and ill - in the linguistic encounter between the social worker and client, which becomes “real” in the instant that the parties embrace one another’s symbolic world and act in accordance with it (Fredin, 1993:2, translated from the Swedish by Kullberg & Cedersund, 2001).

I have adopted an interactionist framework in this thesis in order to explore the challenges couples face and how they manage them, as understanding interactional processes is an important foundation for engaging in social work practice. This interactionist approach will first be explained in terms of meaning and origin. This will be followed by a description and discussion of the main theoretical and methodological approach chosen, namely conversation analysis. The section will close with a discussion of the relevance of this approach for analysing interaction between partners in couples living with dementia.

An interactionist approach

In order for participants to understand each other in interaction, intersubjectivity, or a mutual understanding of the situation, is crucial (Schegloff & Sacks, 1973; Schütz, 1970). The emphasis on intersubjectivity has its roots in phenomenology, “the study or description of phenomena” (Hammond, Howarth & Keat, 1991:1). The thinking of sociologist Alfred Schütz (1970) is of importance in this thesis, specifically his emphasis on social aspects of phenomenology. However, Schütz himself was influenced by Edmund Husserl and Max Weber in terms of ideas around shared understanding, meaning-making and social action. Schütz (1970) related representations to a socially constructed “life world”, which is dependent on shared understanding of what is going on

around us and what we are doing. Shared understanding and intersubjectivity are made possible by using and interpreting signs in communication (Schütz, 1970).⁸

Schütz (1970) describes the process of reaching shared understanding in the following terms: “the observer keeps pace, as it were, with each step of the observed person’s action, identifying himself with the latter’s experiences within a common ‘we-relationship’”(Schütz, 1970:115).⁹ To put it differently, situations are interpreted as the activity unfolds. The way they are interpreted is affected by the actions leading up to the present situation, and these involve communicative contributions as well as the available background information. This reasoning relates to what Schütz refers to below as motivational understanding.

[T]he other’s reaction is the in-order-to motive of my own act. The prototype of all social relationship is an intersubjective connection of motives. If I imagine projecting my act, that you will understand my act and that this understanding will induce you to react, on your part, in a certain way, I anticipate that the in-order-to motives of my own acting will become because motives of your reaction, and vice-versa.

(Schütz, 1970:182)

The central issue in this quote is that interaction is designed in relation to who the interactants are, and to the fact that they anticipate the reaction of others when they design their own contributions. This line of reasoning has had great influence on the interactionist research conducted today, not least the conversation analytic method and theory described below, in which the participants’ contributions to interaction are often analysed in terms of what they do, how they are understood and how others respond to them within the ongoing interaction.

⁸ For a discussion on Schütz’s thoughts, and comparisons with Mead and his system of symbolic interactionism, see Schütz (1970:20-21).

⁹ In a ‘we-perspective’, each person has subjective experiences of him/herself in a situation, but at the same time experiences the situation and his/her understanding of it from the perspective of others (Schütz, 1970).

Conversation analysis

CA's aim is to focus on the production and interpretation of talk-in-interaction as an orderly accomplishment that is oriented to by the participants themselves. CA seeks to uncover the organization of talk not from any extraneous viewpoint, but from the perspective of how the participants display for one another their understanding of 'what is going on'.

(Hutchby & Wooffitt, 2008:13)

Conversation analysis (hereafter CA) is a scientific method as well as a theoretical departure for analysing social interaction from the participants' perspectives, and it derives from sociology and specifically by Harvey Sacks, Emanuel Schegloff and Gail Jefferson (Sacks, 1992; Sacks, Schegloff & Jefferson, 1974). CA was influenced by the phenomenological perspective described above, as well as by Harold Garfinkel's ethnomethodology (Garfinkel, 1967) and Erving Goffman's (1959, 1967) approach to face-to-face interaction. CA is concerned with the study of how participants design their talk and take turns in interaction (Sacks, 1992; Sacks et al., 1974). Sacks et al. (1974) argue that when people talk, one speaker tends to talk at a time and turns are taken with as short a gap as possible. They also consider that turn-taking is "locally managed, party-administered, interactionally controlled and sensitive to recipient design" (Sacks et al., 1974:696). Hence, we design our talk according to interactional rules, but also in terms of the people with whom we are interacting.

Participants' understanding of the interaction can be studied through the so-called *next-turn proof procedure*, which explores how each and every turn is understood and responded to by other participants. The focus is on what the participants *do* and *how others understand and respond to it*, rather than what they *say they do* (Sidnell, 2013).

While understandings of other turns' talk are displayed to co-participants, they are available as well to professional analysts, who are thereby afforded a proof criterion ... for the analysis of what a turn's talk

is occupied with. Since it is the parties' understandings of prior turns' talk that is relevant to their construction of next turns, it is THEIR understandings that are wanted for analysis. The display of those understandings in the talk of subsequent turns affords both a resource for the analysis of prior turns and a proof procedure for professional analyses of prior turns-resources intrinsic to the data themselves.

(Sacks et al., 1974:729)

As stated in the above quote, the participants' understanding, expressed in their turns, becomes visible to the researchers, and provides proof criteria for interpretation (this will be discussed further in considering validity on pp.61-64). With a focus on participant orientation and recipient design, CA is concerned with the local context of the interaction rather than an external context of grand discourses. CA avoids top-down explanations of why people do certain things. If not *actively oriented to* and hence made relevant by the participants within the interaction, often-used categorisations such as gender or ethnicity are not seen as explanations for a phenomenon in CA studies. In a bottom-up approach, discursive practices have to be displayed in the data by the participants themselves if they are to be part of the analysis (Hutchby & Wooffitt, 2008; Maynard, 2013). This approach fits well with the essence of this thesis, where there is no grand discursive or theoretical explanation for the participants' interaction or strategies. When patterns of interest are found, they are nevertheless connected to an existing repertoire of theoretical concepts such as *epistemics* and *face-saving*, which are described in more detail later in this chapter, and CA principles such as turn-taking and next-turn proof procedure, as described here.¹⁰

By means of new technology such as video and a 'visual turn' in research (Mondada, 2016), CA has now expanded and enabled

¹⁰ In one article I have adopted influences from positioning theory (Davies & Harré, 1990; Harré & van Langenhove, 1999; Korobov, 2001). However, as it was used in line with CA principles rather than as strict positioning theory, I do not expand on it further here.

multimodal interaction to be analysed too, through which the concept of the ‘embodied turn’ has been developed (Mondada, 2016; Nevile, 2015). Within the field of CA, multimodality highlights “the various resources mobilized by participants for organizing their action, such as gesture, gaze, facial expressions, body postures, body movements, and also prosody, lexis and grammar” (Mondada, 2016:4). Furthermore, multimodal resources have been shown to be of significance in negotiating and displaying different relationships (Hargie, Sanders & Dickson, 1994). These include indicating “with-markers” by touching or orienting towards another person, in contrast to a display of being “single” (Goffman, 1971). Gaze is also an important communicative resource for managing participation frameworks, such as allocating turns in interaction or indicating the addressee of a contribution (Goodwin, 1981; Rossano, 2013).

An analysis of multimodal resources will contribute to an investigation of interaction in people living with dementia, which will be considered in the next section.

Analysing interaction and dementia

A major challenge for couples living with dementia involves linguistics and interaction (Alzheimer’s Association, 2017; Ekström, Lindholm, Samuelsson & Majlesi, 2017). This includes challenges connected to finding words, naming, and understanding or using abstract language (Emery, 2000; Smith et al., 2011), as well as an increase in amount of repairs in interaction, as well as having challenges with providing repairs (Samuelsson & Hydén, 2017). As noted above, collaboration with others has been shown to be an effective way of meeting these challenges and sustaining common ground (e.g. Hydén, 2011; Hydén, Plejert, Samuelsson & Örvulv, 2013).

Despite these linguistic difficulties, people with dementia are often able to make use of, and interpret non-verbal

interaction (Hubbard, Cook, Tester & Downs, 2002), which enables shared understanding with others (Kontos, 2011; Zeiler, 2014). Although it may be difficult for a person with dementia to provide an expected answer or even to work out what the participants are talking about, there are indications that people with dementia orient themselves appropriately to the same interactional principles as people who do not have dementia. By making use of ordinary strategies rooted in turn-taking principles, a person with dementia can even repair or conceal his/her challenges in terms of interaction (see e.g. Jones, 2015; Kitzing & Jones, 2007).

It has been argued that multimodal interaction helps people with dementia to communicate and remember. Examples of successful action include attracting the attention of the person with dementia through gaze, giving the person enough time in conversation, asking questions, suggesting interpretations of what he or she says, providing multiple-choice cues and acknowledging the person's non-verbal resources such as gaze and gestures (Gray, 2014; Naleppa & Reid, 2003; Smith et al., 2011). Naleppa and Reid (2003) suggest the use of gentle touch to enable and increase non-verbal interaction in later stages of dementia.

In a research review, Kindell, Keady, Sage and Wilkinson (2017) suggest that this knowledge of strategies originates in micro-level analysis (such as CA and positioning theory), in which remaining competencies can be acknowledged as well as competencies rooted in relationships. It has also been argued that CA is beneficial in analysing interaction involving older people (Olaison & Cedersund, 2009) and people with dementia (Webb, 2017). Webb (2017) specifically highlights collaborative aspects which could challenge the previous concept of a person-centred perspective involving people with dementia, and how this perspective is used. Kindell et al. (2017) also emphasise the importance of other aspects of interaction involving people with

dementia, such as just *being together*. In regard to this study and couples living with dementia, multimodal resources can be useful in terms of experiencing and expressing closeness or *we-ness* in interaction.

The next section will further discuss how dementia-related challenges may be related to “knowledge in interaction”, such as issues involving remembering and the use of strategies to manage them. Interaction involving people with dementia may also prove a challenge not because of the symptoms themselves but as a result of other people’s behaviour and their preconceptions of what dementia is. This will be addressed as “unfavourable interaction”, which potentially affects the people with dementia in an unhelpful or even harmful way.

Knowledge in interaction

Shared knowledge of the world, sufficient for the practical purposes of the situation at hand, is a cornerstone of understanding in interaction (Schütz, 1970). Of specific interest for this thesis is Schütz’s reasoning on individuals’ and groups’ ‘store of experience’ and ‘stock of knowledge at hand’. These concepts are subjective but at the same time socially constructed through communication, and are crucial for social interaction (Schütz, 1970). In communicative situations, participants may have different expectations of what is or ought to be shared knowledge, or *common ground* (Clark, 2009; Enfield, 2006), and this may have to be managed carefully in interaction in order to save face. Common ground exists in all relationships in the sense that people who have met have shared something, and are mostly aware that this something has been shared. Hence, people who have shared an experience can assume in subsequent interaction that the other person remembers what was experienced jointly, and it can therefore be used as common ground for the interaction. Common ground is created and maintained piece by piece through communicative contributions (Clark, 2009).

Therefore, a crucial prerequisite for smooth interaction is that all participants keep track of shared aspects in their specific common ground, or as Enfield (2006:401) puts it: “At a personal level, the shared experiences of interactants are in common ground as long as the interactants know (and remember!) they were shared”.

Common ground is inevitably affected in couples where one has dementia and struggles with remembering, as are the assumptions of both spouses’ about *which knowledge* is or ought to be common ground. In interactionist studies, this can be explored in terms of epistemics, which has been defined as “the knowledge claims that interactants assert, contest, and defend in and through turns-at-talk and sequences of interaction” (Heritage, 2013:370). In this sense, epistemics, in terms of having or lacking access to knowledge and memories, is fundamental in establishing common ground and intersubjectivity. It is a major source of challenges and may be connected to asymmetry and/or lack of common ground in interaction involving individuals and families living with different types of dementia (Hydén & Samuelsson, 2018; Muntigl, Hödl & Ransmayr, 2014).

Related to the topic of knowledge and dementia, Goffman later contributed to the interactionist approach through his further elaborations on *participation frameworks*. These basically involve the knowledge interacting participants have at their disposal for understanding how different contributions to the interaction should be understood. Of specific interest here are the different stances (or footing) from which participants orient themselves, such as being the present speaker, an allocated recipient, a bystander or someone overhearing the interaction (Goffman, 1981). This perspective on interaction calls for great sensitivity from the participants in terms of keeping track of the distribution of talk and who is speaking at any one time, as well as the knowledge which is assumed. This may be challenging for

individuals with symptoms which affect cognitive abilities, such as people with dementia.

The way couples manage the challenging situation described above is investigated in this thesis. In these instances there is often an emotional level involving *not losing face*, or *not allowing others to lose face*, which is also one of Goffman's important contributions to self-presentation and face-to-face interaction (Goffman, 1959, 1967). Goffman (1967) and others argue that participants in interaction are morally responsible not only for saving face for themselves but also for their partners in interaction. This could involve mitigating actions, for example, in potentially face-threatening situations, such as using imprecise words rather than direct ones, or one of the participants laughing (Brown & Levinson, 1987; Goffman, 1967). This is particularly likely in situations involving participants with dementia (Lindholm, 2008). In interaction involving people with dementia, it is important to balance the need for patience and "waiting out" a response (Lindholm, 2010) with possible face-threatening action such as "putting someone on the spot", or risking failure in the project of providing a response (see e.g. Watson, Chenery & Carter, 1999). Hamilton (1994) also reports a particular effort to sustain conversation on the part of partners, perhaps because they are trying to save face. Face-saving strategies can be found in both verbal and non-verbal interaction, and there is an increase in - and emphasis on - research in the social sciences which involves non-verbal communication (Hargie et al., 1994), particularly in relation to dementia (Hubbard et al., 2002). Face-saving strategies are also a rational way of avoiding harm for people with dementia, and the next section will discuss situations where the interaction is unfavourable for the person with dementia.

Unfavourable interaction

Interaction and relations at micro-level are not always as satisfactory as described in the previous section. Occasionally people's behaviour and interaction with others may have negative consequences for people with dementia (Jones, 2015; Kindell et al., 2017). In some cases, challenges in interaction are more a result of not acknowledging or tuning in to the same life world as the person with dementia (Hydén & Samuelsson, 2018), or as proposed by Jones (2015:557) when expressing that “[t]he misalignment of intersubjectivity, or shared understandings between interlocutors, has profound implications for interaction and lies at the heart of the communicative challenges faced by people with Alzheimer's disease and their family”.

People with dementia commonly report experiences of social exclusion, and other people are chosen or choose themselves as spokesperson for the person with dementia, even in personal matters (Katsuno, 2005; Read, Toye & Wynaden, 2017; Snyder, 2002; Steeman, De Casterlé, Godderis & Grypdonck, 2006; Young, 2002; Österholm & Samuelsson, 2015). Österholm and Samuelsson (2015) show how, in assessment meetings for social services, people with dementia are positioned as less competent in a number of ways, including the use of something they refer to as *dementiaspeak*. Some of this behaviour involves talking over the head of the person with dementia, not responding to their initiatives, feelings, capacity or opinions, or using the diagnosis to imply a lack of competence. Samuelsson, Österholm and Olaison (2015) have compared this result to a study of equivalent settings with older people without a dementia diagnosis. For the group with dementia, they found that the care-manager or relatives in both groups used *elderspeak*, involving great variation in pitch and a slower rate of speech. Moreover, talking over the head of a person and ignoring their attempts to initiate conversation was observed mainly or

predominately in the group involving people with dementia (Samuelsson et al., 2015). Within the discussion on *elderspeak*, the use of the collective pronoun *we* rather than *you* for an older person is commonly referred to as a way of diminishing the person in the interaction (Samuelsson et al., 2015).¹¹

The behaviour and interaction described above can be understood in terms of *malignant social psychology* (a term coined by Kitwood, 1997), which refers to behaviour that may have negative effects for individuals with dementia. This includes behaviour such as *ignorance*, or speaking as if the person was not present, *infantilisation*, or speaking to the person as if s/he was a child, and *labelling*, where an angry reaction, for example, is seen as irrational hostility due to dementia instead of rational anger. In order to be a rational person with rights to decide, a person must be recognised as such, which is not possible if he or she is treated in a depersonalised way that diminishes self-worth (Kitwood, 1997).

People with dementia can also be exposed to *malignant positioning* (Sabat, Napolitano & Fath, 2004), where a person is placed in a position which must be declined or accepted, one which can define a person as well as limit his or her opportunity to act freely. This can be difficult for people with dementia, for example, as rejecting an unwanted position which has been

¹¹ For the analysis in this thesis, the pronoun *we* has been given a different meaning in that it is understood to indicate closeness, identity or agency in couples' stances. The context for this could be to refer to an action which is normally individual, i.e. *getting out of bed*, as something that *we* are about to do, suggested by care staff for instance: *Shall we get out of bed?* The consequence of this form of asking can be considered diminishing for the older person. However, I suggest another interpretation as described above, influenced by aspects of joint activity and collaboration (Hydén, 2011). If you are frail, the act of getting out of bed may not necessarily be an individual action but rather a joint one. Even if the person manages to get out of bed by him/herself, arriving at the point of initiating the action could be a joint project at both a communicative and practical level.

imposed on them often requires the ability to verbalise rejection (Sabat et al., 2004). Research by Lindholm (2010) and others (Sabat, 2008) argues that people with dementia can often be embarrassed by their own behaviour in a situation, such as failure to understand information or a question. This is often managed by responding with laughter instead of making it clear to the others that they have not understood the information, and this often ends the threatening situation (Lindholm, 2010; Sabat, 2008). This behaviour could make them more inclined to think that accepting the unfavourable position would be better than admitting incompetence. However, Christie (2016) argues that people with dementia can successfully demonstrate resilience and actively counterbalance this type of negative positioning in social work practice.

Sabat (2005) argues that psychosocial circumstances, such as being treated as incapable, can lower a person's ability in a certain situation, and may cause *excess disability* due to interaction rather than the effects of the dementia per se (Sabat, 2005). This concept should be taken into consideration in working with or living with a person with dementia, and also in conducting cognitive tests to assess the capability of a person with dementia. For instance, the process of assessing capability or competence is often carried out individually in a health-care clinic or a social services office, where the person might not feel at home, and the reason he or she is there involves a possible decrease in ability. Therefore, if a person performs poorly on the test, it does not necessarily mean that she or he would have performed as badly if the test had been taken at home or in a similar safe place (Sabat, 2005). In other words, tests like this, or being evaluated and assessed by social services in terms of "what the person can/cannot do", could lead to excess disability and psychological stress. I return to this matter in considering dementia and ethics on pages 67-68.

Summary

This thesis analyses couples' challenges and management of these in interaction at a general level, and involves positioning, epistemics, participation frameworks and strategies for managing sensitivity at a specific level. A major thread throughout is the couples' multimodal interaction. I argue that this deepened understanding of interaction between partners in couples will be of value for social work encounters with individuals and families living with dementia, and micro-level analysis of interaction is important for developing gerontological social work involving people living with dementia.

Dementia involves cognitive, linguistic and interactional challenges for couples. In interaction, spouses in couples may not "be on the same page" in terms of which knowledge they each have access to, or how it should be managed in terms of interaction. They have shared a life together which one partner occasionally does not appear to remember, and this inevitably involves an emotional layer. Face-saving strategies are one way of managing this sensitivity in interaction, but couples may need support with these issues, which is why they should be addressed professionally as well. The following chapter will describe the study in detail, and the procedure used for analysis in the thesis.

Facing dementia as a we

4. Method - The study, analysis and considerations

The following section will describe the study in detail in terms of participants and the procedure for conducting the interviews. This is followed by a description of the conversation analytic methodology and procedures adopted in the thesis. The final section involves a discussion of validity, and methodological and ethical considerations of the study.

The study

This study is based on joint video-recorded interviews with couples where one of the partners has a diagnosis of dementia. The interviews are analysed at micro-level by means of conversation analytic theory and methodology. The study has links to CEDER (Centre for Dementia Research), a longitudinal, interdisciplinary project on dementia at Linköping University in Sweden, which ran between 2011 and 2016 and was funded by the National Bank of Sweden Tercentenary Foundation (Grant no. M10-0187:1).

Participants

A total of 15 couples were included in this study, consisting of men and women who were all born in Sweden and were living there together. One of the spouses in each couple had a dementia diagnosis; one participant had vascular dementia and the remaining 14 had Alzheimer's disease at the time of the interview.¹² In half of the couples the woman had a dementia

¹² In the articles, I have stated that one participant had Lewy Body dementia, but this was because his/her diagnosis was changed after the interview. Since the analysis in this thesis is based on the first-round interviews, the diagnosis on this occasion is given as the definitive one. In one article, I also state that one participant had mixed dementia. However, this participant was never interviewed, so this constitutes an error in the article.

diagnosis and in the other half the man. All participants with dementia had received their diagnosis quite recently, on average 3 years before the interview (the earliest was diagnosed approximately 6 years before the interview and the latest the same year as the interview took place). All the participants with dementia had a mild form of the condition according to the Mini-Mental State Exam (Folstein, Folstein & McHugh, 1975). However, because there was no clarity on how long prior to the interview the exam was taken, this measure is not particularly informative in terms of the aim of this thesis. It seems likely that some of the participants had developed moderate dementia at the time of the interview.

All participants were between 61 and 82 years old at the time of the interview ($Md=69$ years).¹³ The couples were in relationships which had lasted between 12 and 60 years, ($Md=44$ years) (see Table 1). All of them had married at some point during this time, most of them quite early in their relationship. They had at least one child together, or children from a previous marriage ($M=2.3$ children). All couples were living on their own with little or no formal care or social-service provision. Most of the couples had recently moved from a house to an apartment.

In providing information about the couples' professional experience, while also preserving a level of anonymity I have adopted the English division of blue and white collar workers. However, I am aware of the difficulty of using this categorisation and that salaries and status may differ. The following description is therefore rough but hopefully adequate for providing some information about the couples' professional background. As used here, *blue collar* refers to manual labour which requires a

¹³ The age of the participants at the time of the interview is correct here. The ages are slightly different in the articles since I did not use the age of the participants at the time of the interview in a consistent way, and sometimes I used their year of birth.

uniform (e.g. nurse, construction worker or fire-fighter), and *white collar* refers to work in an office environment (e.g. official, teacher or self-employed). Seventeen of the total participants had mainly been employed in white collar jobs and 13 in blue collar jobs. In all but three couples, both spouses had been employed in the same category.

Table 1 presents the couples in terms of which partner had dementia, gender, age and duration of their relationship. All names are figurative, and other information which had the potential to disclose anonymity has been changed appropriately.

Table 1.

Participants- Gender and diagnosis	Age at time of interview	Duration of relationship in years
Nora W, AD	63	44
Vilgot M, S	66	
Nils M, AD	66	41
Minna W, S	61	
Tore M, AD	76	57
Ellen W, S	76	
Elvira W, AD	79	60
Lennie M, S	82	
Tomas M, AD	67	39
Nanna W, S	69	
Olivia W, AD	71	49
Werner M, S	74	
Ove M, AD	68	46
Ing-Britt W, S	64	
Edit W, AD	72	47
Allan M, S	73	
Egon M, AD	71	12
Agneta W, S	69	
Elsie W, AD	71	41
Örjan M, S	72	
Johan M, VD	65	42
Natalia W, S	61	
Erland M, AD	74	52
Inger W, S	72	
Annie W, AD	67	49
Leif M, S	68	
Ulla W, AD	73	37
Stefan M, S	70	
Olga W, AD	63	43
Sölve M, S	62	
	<i>Md</i> =69 years	<i>Md</i> =44 years

* W=Woman, M=Man, AD=Alzheimer's disease, VD=Vascular dementia, S=Spouse without dementia.

Procedure

The interviews were carried out during the years 2011-2014, twelve of them between 2011 and 2012 and the remaining three in 2014. Nurses at two geriatric clinics made first contact with the potential participants, and those who expressed interest were sent written information about the study (Appendix A). The nurses and doctors at the geriatric clinics also decided on appropriate couples to contact. For this reason, and for reasons of confidentiality, I do not know how many couples they excluded in the selection or which couples these were. However, I was informed of one couple who withdrew their participation after they had been given information about the study. The couples were contacted by phone by the author or an affiliated colleague after they had given their approval for us to do so.

All interviews took place at the participants' local geriatric clinic, but they were given the choice of having the interviews in their home or somewhere else if they were not comfortable with coming there. The participants were given this choice to ensure they were comfortable (Murray, 2003). The approach to choosing the location of the interviews is further discussed in the section on methodological considerations below (see pp.60-61). The room in the first clinic was larger than in the second, and it had an examination bed in the background. There was also a tablecloth, and a little ornament of two birds was placed on the table. Both rooms had a window, a table and four chairs. The room in the second clinic had a computer in the background. In all interviews the participants were provided with a glass of water.

The spouses were interviewed jointly as a couple by two researchers (Prof. Lars-Christer Hydén and the author or Associate Prof. Ingrid Hellström). All participants were videotaped in order to capture non-verbal as well as verbal communication (i.e. the multimodal interaction). An audio

recorder was also used in all interviews in case the camera failed to work, as well as in order to obtain good sound; this is a common way of collecting data for conversational and interactional multimodal analysis (Drew, 2003).

The seating was arranged in an F-formation, which “arises whenever two or more people sustain a spatial and orientational relationship in which the space between them is one to which they have equal, direct, and exclusive access” (Kendon, 1990:209). In this case, the couples were seated opposite the two interviewers, divided by a small table. In this way, the couples could be recorded by one video camera, and the interviewers who were sitting across the table could be recorded by another camera. The second camera recording the researchers was used for six of the interviews. In the remaining interviews, only the couples were videotaped, for logistical reasons such as managing transcriptions and files. We decided that although it would be beneficial, there was little advantage in capturing the interaction on two cameras compared to the efforts. The cameras were set up beforehand, but switched on only after the participants had given their approval for us to do so. The same procedure was used for the audio recorder which was placed in the middle of the table. For this thesis I have mainly analysed interactions from the camera capturing the couples, but occasionally I checked where the interviewers’ gazes were oriented at a specific time if I thought it would be relevant to the analysis.

At the time of the interview the participants were once again given the same information about the study verbally and in writing (Appendix A), in terms of giving their written consent to participate in the study (Appendix B). The participants were informed about their rights to end the interview at any time, or withdraw their participation from the study without giving a reason, and with no effect on their further treatment at the clinic. This was important to emphasise in order to minimise the risks of pressurising participants, and is discussed in more detail under

ethical considerations below (HSFR, 2018). The participants were given the information that the interviews do not normally take more than an hour.

The interviews had a task-oriented structure with a main focus on interactive and communicative aspects rather than on content-related ones. The interviews were task-oriented in the sense that the couples were given three different tasks one after the other, and the interviewers allowed participants plenty of time to elaborate on these tasks, as well as time to collaborate on their answer. The tasks were chosen in order to challenge the couples in terms of jointly remembering the distant past, the recent past and the present past such as yesterday. The couples were asked questions about their shared life which were mainly episodic and autobiographical, such as memories of specific experiences or events, and these were potentially emotionally charged. The act of telling a story also had the potential to activate their memory in terms of procedure, in other words *how* to tell a story.

The common aspect of the three tasks was that they enabled an investigation of how the participants collaborated and co-constructed their answers jointly, and the tasks were successfully tested in a pilot study within CEDER. Despite the potential challenges involving memory for individuals with dementia, studying how people with the condition remember things along with a spouse highlights aspects of joint or collaborative remembering (Hydén & Forsblad, 2017). In this sense, I was interested in how the couples managed this together, rather than necessarily pinpointing which type of memory caused challenges. This frame draws on the idea that cognition can actually be distributed across several people, although this can be asymmetric when it involves a neurocognitive disorder such as dementia.

The formulations of the tasks given in the interviews were very similar across the interviews. I provide the phrase in both

Swedish and English, and indicate the main task in bold in order to disentangle it from subsequent follow-up questions which could be used if the participants struggled with the task.

1. Kan ni berätta lite om när ni träffades första gången?

Ni får börja precis var ni vill, bestämma hur ni vill berätta och vad ni vill berätta. Ni bestämmer.

Could you (plural) to tell us a little about when you met for the first time?

You may start wherever you wish and you may decide how and what you wish to tell us. You decide.

2. Kan ni berätta om när ni började upptäcka att X hade problem med att minnas (eller det ord de använt tidigare för besvären, eller diagnosen)?

Är det något område i ert liv som inte påverkas alls av det här.

Can you tell us about when you started noticing that X had problems regarding memory (or the word they used to describe their difficulty, or their diagnosis)?

Is there any area of your life that is not affected at all by this?

3. Kan ni berätta om en helt vanlig dag, till exempel igår?

Vad gjorde ni? Vem gjorde vad?

Would you like to tell us about an ordinary day, for example yesterday?

What did you do? Who did what?

The first task, or question, was introduced and discussed until the participants signalled that they had finished, and only then was the second question asked. This kind of interview is suitable for interviewing people with dementia, since they often need considerable time to understand and answer questions (Lindholm, 2010). To round off the interviews, I asked the participants several background questions, such as when they got

married, their work history and their need for support in daily life (see Appendix C for interview guide). At times it was difficult for the couples to give a simple answer to these questions, but this led to many rich answers and also provided background information.

The interviews lasted between 27 and 61 minutes ($M=44$ minutes). At the end of the interviews the participants were asked if they would consider participating in a second interview in one year's time. All responded positively to this, and subsequent interviews were conducted yearly for five years within CEDER. However, these subsequent interviews were not included in the analysis for this thesis.

Analytical procedure

Transcribing

In interactionist studies, and particularly in CA, the act of careful listening and manual transcribing is the first and a crucial step of the analysis (Bolden, 2015; Hepburn & Bolden, 2013). Transcriptions are representations of the recorded interaction, and are used for the analysis in combination with the recorded material.

With regard to the material for this thesis, I have personally transcribed only five of the interviews in full for a number of different reasons. The first reason was that in the first years of working on the thesis my focus was specifically on pronoun use and identity, and less on participant orientation and interactional details. I therefore began by transcribing the interviews with fewer interactional details, highlighting pronoun use instead. Secondly, CEDER is a research group where a number of different disciplines are represented, and since other researchers also use these data for research, linguists employed by CEDER transcribed a large proportion of the interviews in accordance

with CA. However, when I became familiar with CA myself, I began to use the Jeffersonian transcription style (Jefferson, 1984), combined with Mondada's conventions (Mondada, 2016), for non-verbal contributions (see Appendix D), and amended and revised the transcriptions used for the articles. Peräkylä (2006) describes this as follows: "the significance of detail can only be judged on the basis of what the details contribute to the understanding of the phenomenon that is investigated, in the context of the questions asked and arguments put forward in the paper" (Peräkylä, 2006:96). In line with this, the level of detail in the transcripts is different in all articles, depending on the focus of the article and on the preferences of journals. For instance, sometimes more multimodal resources were included and sometimes fewer, and in one article I included only the English version of excerpts, leaving out the Swedish original. The reason was mainly to cut down on the number of words to release more space for analysis. This choice was made after consideration. We, the authors, decided that excluding the Swedish did not affect the analysis significantly, and since this journal was not specialised in interaction per se this would hopefully not upset the readership too much. Throughout the thesis, the couples' non-verbal activity generated almost as much interest as their verbal activity, since it correlates neatly with, and sometimes even enables verbal activity, such as talking about sensitive matters.

The major disadvantage of not transcribing all the interviews myself was that I did not feel as in tune with the material I had not transcribed. An attempt was made to compensate for this by going through the transcripts many times, as well as viewing the videos and listening to the recordings of the interviews. On the other hand, I had participated in all but three of the interviews, so I felt relatively close to the material despite not having transcribed it all. The fact that different people had transcribed them also generated extra work, such as coding for pronouns. Here, I had to adapt the detailed CA transcripts to a

more general level to make them comparable. In contrast, for subsequent detailed analysis of interaction, I had to adapt the less detailed transcriptions to include, for example, non-verbal aspects, as well as other details such as intonation, speech delivery, pauses, volume and pitch, overlapping talk and voice quality (such as low or smiley voices). This was the first step in working with transcriptions. The next involved scrutinising them for uses of pronouns and categorising them to correspond to the aims of the thesis. This step will be described below.

Coding and analysing pronouns

A thread in this thesis is the study of how the spouses used pronouns to refer to themselves and their partners, or their *positioning* (Korobov, 2001; Korobov & Bamberg, 2007). For one article, I focused specifically on the first-person individual *I* and the plural *we*, and for another I focused on third-person positioning of *she* and *he*. To be able to make sense of pronoun use by all participants in the interviews (including pronouns used by the interviewers), I coded all pronouns in the transcriptions in terms of who said them and the person to whom they referred. The pronouns were summarised in an Excel file. For example, I was only interested in the *we*:s referring to the couples, and all the *we*:s referring to someone else were therefore excluded from the analysis. Similarly, I was only interested in the third-person pronouns referring to a spouse, so I extracted those and left all other third-person pronouns aside if they referred to someone else.

This quantitative approach to pronoun use proved very useful in gaining an understanding of the extent of one pattern compared to another. For example, I found that it was common for spouses without dementia to refer to their spouse with dementia using a third-person pronoun, such as *he* or *she*, whereas the opposite pattern, where a spouse with dementia positioned their partner this way, was less frequent. There may be

a number of reasons for this. One probably derives from the fact that the design involves an interview about life with dementia, making the person with dementia the focus of the positions. However, it is plausible that since one partner has dementia and the other does not, this situation, where one speaks for the other in the third person, is common outside the interview context as well, such as in health-care interactions or encounters with social services personnel.

Finding and analysing conversational phenomena

As described, the first step in the analysis for this thesis was to transcribe, and also, as noted above, to calculate and summarise pronoun use. The next step was to find a potentially interesting phenomenon, guided by the principle that “[i]t is not the phenomenon as a linguistic object which is the focus of interest for CA, but the interactional work being accomplished via turns at talk” (Hutchby & Wooffitt, 2008:105). Hence, I was interested in how the participants managed specific instances in interaction, and whether there was a pattern or feature connecting their ways of managing them, which could be referred to as a phenomenon. This search for interesting phenomena was conducted by studying the detailed transcriptions and videos of interview interactions with couples.

CA does not reject the idea that an external context influences the participants within the local context. However, if it is not visible in the specific case for analysis, the influence of the external context cannot be assumed or taken for granted. Hence, in approaching a new set of data the study should be as ‘unmotivated’ or objective as possible, attempting to leave preconceptions and theories aside (Hutchby & Wooffitt, 2008; Sidnell, 2013). A major part of the process of finding a phenomenon and building a collection is to present anonymised recordings of interactions to fellow researchers. This is often done without instructions about what to look for in the data, and

everyone can share their views and interpretations of the interactions. In order to study the articles in this thesis, several data sessions, workshops and conferences were held nationally and internationally with senior researchers from different disciplines (see discussion on validity, pp.61-62).

According to CA, a phenomenon can consist of an action, such as telling, inviting or asking, which is accomplished through the use of different communicative practices (Sidnell, 2013). In my studies, I have encountered actions such as prompting, complaining, inquiring, and inviting a spouse with dementia to an on going telling. How the participants make use of *fishing* (Pomerantz, 1980) as a strategy to enable remembering will serve as an example of the analytical process in this thesis. This phenomenon was discovered by trawling through the data with the specific aim of my thesis in mind. A recurrent pattern was found where the spouse without dementia provided clues to enable the spouse with dementia to tell them something specifically, or prompted him/her to tell it. This phenomenon was mainly found in cases where the information was something the person 'should know', such as work history or children's names. As with all the phenomena analysed in the articles, I coded and grouped them together manually in different files, labelling them so that the video excerpts matched the label on the corresponding transcription excerpts. When I had grouped all the similar cases into one collection, a thorough process of comparison of each case was possible.

As soon as a conversational phenomenon has been discovered, the next step is to describe its sequential context, in other words which types of turn precede and follow it, and how the phenomenon unfolds within the interaction. This is a basis for a robust description of the phenomenon, which can include information such as *who* the current speaker is, and *how* something is negotiated within the interaction, etc. Having given a detailed description of one particular case of the phenomenon,

the researcher then returns to the collection of cases to see if the other cases can be described in terms of this account. This is a constant process of going back and forth between the details in particular cases and the synoptic view of collections of cases (Hutchby & Wooffitt, 2008; Sidnell, 2013). To return to the example of fishing, I identified several examples of *fishing sequences* which appeared to have a similar sequential organisation. This phenomenon was found within nearly all interactions in couples, and the *fishing* was made almost exclusively by the spouse without dementia and not by the one with dementia.

The final step is to give a formal account of the phenomenon, a generalised account for all cases in the collection (Hutchby & Wooffitt, 2008; Sidnell, 2013). At this stage, if the work has been done thoroughly, the phenomenon has been described and generalised to the extent that it can be considered context-free, so that it has similar sequential organisation across contexts. This in turn makes the interpretations valid (Heritage, 2011), which is further discussed in the section on validity (pp.61-64). The *fishing sequences* played out in the following way. Within a response to an interviewer's question the person without dementia demonstrated that he/she was unable to remember or retrieve requested information, and the spouse without dementia provided clues (sometimes invited by the spouse with dementia and sometimes not) to help him/her remember. This was followed by non-remembering, which was sometimes accompanied by signs of embarrassment displayed by the spouse with dementia. I chose to compare examples which were similar also in terms of when they took place in the interview. For sequential visibility, Hoey and Kendrick (2018) propose the use of examples in relation to questions or the beginning of a specific topic, which is also what I did in this process.

Within interactionist studies like these, it is also important at this point to search for and describe cases (Hutchby & Wooffitt,

2008; Sidnell, 2013). In terms of challenges with remembering and fishing for information, the deviant case is presented in the article as the first example in which there is no trouble displayed due to the challenge of remembering, but rather a successful sequence of enabled remembering by the couple. Description of deviant cases is further discussed in regard to validity (p.64). The following section will discuss some of the considerations and consequences involved in making choices regarding methodology, validity and ethics.

Considerations in terms of method

My methodological considerations mainly involved the design of the interview, including features such as audio and video recording, joint interviewing and the location as a medical setting. However, there were issues in terms of selecting participants for the study, which will be discussed at the end of this section.

Interview questions

The design of the interview questions inevitably has an effect on the answers. By referring to the spouses as *you* (plural, *ni* in Swedish) instead of *you* (singular, *du* in Swedish), the participants are positioned as a couple. It is plausible that this had effects on how they positioned themselves throughout the interview. Perhaps the pronoun *we* became more salient and accessible for the couples than the pronoun *I*. Being aware of this issue was important in analysing the data on pronouns, in the sense that less emphasis was placed on *how many we:s* or *s/he:s* the spouses used, and more on qualitative aspects of *how* they were using them in the context.

Another consideration involves the design of the tasks given in the interviews. An important aspect of the study was to see how the spouses collaborated and solved problems as a couple

and as individuals, which is why they were given three questions to consider and discuss jointly as tasks. In advising care-givers, Lindholm (2010) argues against asking people with dementia open-ended questions, and suggests instead closed questions which can be answered with a *yes* or *no*. In contrast, Ramanathan-Abbott (1994) argues that open-ended questions enable people with dementia to take an active part in the conversation. For this study, I was interested in how the spouses engaged in this task of joint telling, and how they might collaborate in solving it. In other words, task-oriented open-ended questions were well suited to the purpose of this study.

Lindholm (2010) also points to the difference between questions in terms of memory, reporting more successful communication in questions which require the use of semantic memory rather than those which require episodic memory of recent events (Lindholm, 2010; Small & Perry, 2005). Lindholm's (2010) arguments are of importance with regard to the wellbeing of the people with dementia, in the sense of putting them on the spot and exposing them to potential failure. However, this has to be balanced with the role of research, since there is much knowledge to be gained in how the couples manage the task of talking about their life and challenges jointly, a topic which is further discussed in considerations regarding ethics (p.65). Another point on the subject of remembering is the question of *what it actually is*; is it the act of bringing the exact memory of an experience to the surface? This is a cognitively framed understanding of remembering as an "inner process". An understanding more in agreement with the CA tradition is that remembering can take place in social interaction with others (Potter & Edwards, 2013; Shotter, 1990), through scaffolding sequences for instance (see e.g. Hydén, 2011; Wood et al., 1976). This understanding is also more in line with how it is employed in the context for this thesis.

Audio and video recording

There is also a need for reflection on the potential effects of audio and video recording during the interview. It has been argued that participants enjoy telling their story and do it with considerable reflection, even when there is a camera directed at them (Murray, 2003), which we also found to be true for most of our interviewees. All participants were given the chance to decline to be video-recorded, although no one did so. Despite this, it cannot be ruled out that the participants were affected in some way by talking in front of a camera. Nevertheless, several of the participants reported after the interviews that it was strange how quickly they had forgotten they were being recorded, and how they had enjoyed the interview. A number of contextual factors besides the camera may or may not have influenced the interaction, such as profession, gender, age or class. However, it is important not to import categorisation like this into the analysis if it is not clearly manifest by the participants.

There is also a risk that the camera made participants regulate themselves more than usual, encouraging them to present themselves in a more favourable way because they were being observed and recorded. This may have included presenting themselves in a way which was commensurate with socially accepted norms, the so-called *social desirability effect* (Passer & Smith, 2003). This study did not attempt to obtain the “most truthful picture” of the participants, nor did it suggest that this was possible. Instead, my emphasis was on negotiation and the ways in which participants gave joint or individual accounts in interaction. It has been argued that micro-analysis of video data is an important tool in displaying new layers of interaction and relations (see e.g. Majlesi, Nilsson & Ekström, 2017), and may even be crucial for accessing behavioural details in professional practice (Peräkylä, 2006).

Interviews and CA

A primary principle in traditional CA is the use of recordings of social activities as they *occur naturally*, activities which would have occurred regardless of the researcher's intention or influence, and without *researcher provocation* (Speer, 2007; Stivers & Sidnell, 2013). However, despite some resistance CA has lately begun to find its way into recorded-interview studies, (Mondada, 2013; Wooffitt & Widdicombe, 2006), which is how it is used in this thesis. In making use of CA in analysing interviews, I take as my starting point the notion that interviews are relevant instances of social interaction in conducting social research, as proposed by Wooffitt & Widdicombe (2006). On the other hand, Mondada (2013) argues that interviews constrain social activities, which is partly why they ought to be studied *as an interview* rather than as a method of gathering data on *naturally occurring social activities* (Mondada, 2013). Speer (2007) addresses this by arguing that all participants in an interview should be studied on equal terms. In the case of the current study, this involved both the couples and the interviewers, and the latter were seen as members of the current *interview context* rather than as potential contaminators of the situation. This was partly possible in the design of this thesis, and in cases where it became relevant to include a study of the interviewers' multimodal contributions to the interaction, I have done so when possible. All verbal contributions are of course an integral part of the analysis. As indicated by Wooffitt and Widdicombe (2006), I argue that by adopting core principles of CA as next-turn proof procedure, social interaction within the context of an interview setting can be analysed in a similar manner to *naturally occurring interaction*.

The main reason for designing the study in this way was that there was little chance of capturing joint storytelling by couples living with dementia outside an interview context. Since my research questions involve how the couples manage challenges

and talk about sensitive topics *in interaction*, the design had to enable the interaction, as it may not have been captured otherwise (see Speer (2007) for a similar discussion regarding feminist studies).

Interview context

According to CA, interactions become institutional when the participants orient themselves towards them as institutions. For instance, when a patient refers to a doctor's expertise (Heritage, 2005), or an interviewee refers to the interviewer's expertise as medical rather than that of a social-science researcher, the patient is orienting him or herself towards a medical institution. This happened occasionally during the interviews in this thesis, where some of the participants with dementia seemed uncertain about our affiliations as researchers, and occasionally referred to us as medical experts, which indicates orientation towards a medical institution (Heritage, 2005). Whether their orientation towards us is as interviewers or medical experts, this orientation must be included as part of the analysis of these sequences. This was the case in one of the articles in this thesis, where it was discussed.

Another related limitation of this study also involves the potential influence of the medical context on the interviews. The participants were given the choice of having the interviews at the geriatric clinic or at another place of their choice, such as their home. All participants agreed to come to the geriatric clinic, though at least one participant expressed some discomfort about it during the interview. In hindsight, presenting their home environment as the main choice rather than the clinic could possibly have reduced this kind of distress. It is important not to draw unfounded conclusions. The fact that an interaction takes place in a hospital does not necessarily constitute evidence of orientation towards an institutional context.

A final remark involving the medical setting concerns the process of recruiting to this study and the criteria for inclusion. As noted above, the participants were recruited via geriatric clinics, and nurses and doctors selected eligible participants. There is potential bias in this selection in that they may have given information about the study to couples who were “keen on talking”, “having a good relationship” and/or “able to have a joint conversation”. I have no information about this process, as my only stipulation was to recruit participants in couples who had recently been diagnosed. The couples in this study were also quite homogenous in the sense that they were Caucasian, had Swedish as their first language and were in a man-woman relationship. However, they were slightly more heterogeneous in terms of age, ranging from 61 to 82 years. All this may or may not have influenced the results, but this cannot be verified within the design of the thesis.

Considerations on validity

This thesis adopts an interactionist approach throughout. The discussion on validity in the thesis will therefore focus on interactionist studies with an emphasis on a CA approach. Validity can be understood as the trustworthiness of inferences and how they are supported by the data within the local context, rather than based on objective standardised measurement (Mishler, 1990; Peräkylä, 2011). Mishler (1990) outlines this understanding of validity, which is based on the understanding and agreement of a community of scholars.

In sketching out a new perspective, I will begin by reformulating validation as the social construction of knowledge. With this reformulation, the key issue becomes whether the relevant community of scientists evaluates reported findings as sufficiently trustworthy to rely on them for their own work.

(Mishler, 1990:417)

Furthermore, Mishler emphasises that scholarly expertise, creativity and pragmatism are required for conducting research and drawing conclusions about a study's validity, as well as for attempting to replicate a study (Mishler, 1990). In CA, the use of data sessions is an important aspect of acquiring skills as an interactionist researcher, and also in discussing validation and interpretations with scholars in the same field. As noted above, this approach was adopted in this thesis as part of the analysis.

The analysis has also made use of the next-turn proof procedure. This is a core principle for interpretation within the CA tradition, as it provides indications of how a contribution is understood in the local context by the participants themselves. In the formal sense, this thesis focuses on the behaviour displayed by the participants in the interaction, so it is not concerned with the inner cognitive processes of the participants' minds. For an interpretation to be relevant, its meaning has to be evident, based on the preceding and following turns. A contribution can never be isolated from the local context. This form of validity is significant in conversation analytic work due to its strict organization of turns at talk (Peräkylä, 2011; Sidnell, 2013). This reasoning is also applicable to this study. By taking the participants' understanding of the ongoing interaction as the starting point, interpretations of the activities are made from this perspective too. This makes the interpretations credible.

It has been argued that the interpretations made by a CA researcher tend to have apparent validity by being common sense. In other words, the idea should become apparent as soon as it has been described (Peräkylä, 2011). This thesis has therefore taken the approach that the inferences or conclusions drawn should be easy to identify in the excerpts and analytical discussions in the articles. An example is the concept of *fishing*, which creates an image of a person providing certain bait, clues in this case, to enable another person to give specific information (Pomerantz, 1980). If this is done properly, the concept is

transparent for the reader when it is described, and therefore has apparent validity (Peräkylä, 2011). It is the researcher's task to raise awareness of this phenomenon and make this knowledge useful, to enable contrast with other studies.

It has also been argued that CA has strong ecological validity in the sense that the material is collected from natural, everyday interactions (Hoey & Kendrick, 2018), so that the phenomena studied are close to *how things happen in real life*. Ecological validity is worth addressing here in terms of the data used in this thesis, which are collected from interviews. The issue is linked to the discussion on methodological considerations (pp.59-60), in which I argue that CA methodology enables the detailed study of these interview interactions in terms of multimodal interaction. By doing so, I express my awareness of how these interviews are not equivalent to how situations would take place *in real life*, even if assessment meetings or similar encounters resemble them in terms of structure. However, I argue that the topics in the interviews are similar to the everyday topics which may have been discussed jointly by couples living with dementia on several occasions in their private life, or in encounters in institutional practices. My argument is that the gain exceeds the loss in terms of accessing knowledge which would otherwise have been missed. This format of similar interviews enables a rich corpus of interactions which can be contrasted with each other, and this would not have been possible otherwise.

Interviewing 15 couples living with dementia provides an opportunity to generalise the findings to interaction in a population outside the field of dementia studies. It relates to what Peräkylä describes as “[f]inding the generic from the particular” (Peräkylä, 2011:421). A number of patterns of human interaction emerge from the interviews which could apply not only to several occasions within an interview but also across interviews and couples. This gives the interpretations a level of credibility, and indicates that the patterns may also be found in other couples in

general, or couples experiencing dementia or other chronic illness, depending on the pattern. In the concluding discussion and implications (Chapters 6 and 7), I discuss the findings from the articles as if they were drawn from what CA terms “naturally occurring interaction”. However, by expressing my awareness of the potential limitations of this design, I once again emphasise the points made in this paragraph, and argue that my results are valuable for research and practice outside the interview context in terms of couples living with dementia.

Although most studies are concerned with finding collections of cases which could apply to a larger population, it is equally relevant to search for deviant cases which do not follow the pattern (Peräkylä, 2011; Sidnell, 2013). Describing and analysing deviant cases lends credibility to interpretations of the pattern and makes the data more transparent. My aim was to describe one case in each article which deviated from the general pattern, however this has not been explicated as deviant in all articles. The cases found and described in the articles for this thesis were similar to the cases belonging to the patterns described, but they played out differently in terms of sequential organisation, and were apparent without specifically searching for them.

Ethical considerations

The study was approved by the Regional Board for Ethical Vetting at Linköping University (2011/143-31). All data were stored in a safety box as well as by CEDER on a safe online server which was only available to the researchers involved in the project. In considering methodology, I have drawn on ethical aspects in terms of the interview process, such as putting participants on the spot by giving them a task. I will not repeat or discuss them here but will focus instead on ethical codes for research, and will discuss the matter of informed consent at the end of this section.

Ethical codes for research

Doing research with human beings calls for sensitivity in terms of the process, and even more so when half of the participants have a dementia diagnosis. The Swedish Council for Research in the Humanities and Social Sciences (HSFR, 2018) provides guidelines to support research with human beings. An important consideration is to decide whether the research is of benefit to anyone, the so-called *research requirement*, and to ensure that researchers aim to develop existing knowledge as well as improve methods. In relation to the study for this thesis, the potential harm the research might cause must be weighed against the gains, and then a decision must be taken about whether the good exceeds the bad. There was no apparent harm to the participants in this study, and I argue that the benefits exceed the drawbacks in the sense that all families living with dementia could benefit from the results. I therefore proceeded with the study on this basis.

HSFR argues that it is a person's right not to be exposed to psychological or physical harm, humiliation or indignity. This is referred to as the *individual protection requirement* (HSFR, 2018). It entails four sets of demands for research, which are the *information requirements*, *consent requirements*, *confidentiality requirements* and *use requirements*, (HSFR, 2018). As this thesis is based on research with participants who may be cognitively affected by dementia, the discussion will mainly involve consent requirements but will also touch on information requirements.

Information requirements basically mean that the participants should be informed about their part in the project and what the conditions are, and that their participation is voluntary and can be withdrawn at any time without their having to explain why. All information that could affect the participants' willingness to participate should be included (HSFR, 2018). The participants in my study were given written and verbal

information about the research (Appendix A) before the interview, to enable them to give informed consent. The participants had recently been diagnosed, and this was taken into consideration in designing the information for the study. We did not wish to cause excess disability (Sabat, 2005) by oversimplifying the information. However, in hindsight we could possibly have made more effort to adapt the information sheet to their challenges, such as simplifying the description and purpose of the study.

The potential cognitive challenges meant that the interviewers paid special attention to participants' non-verbal communication in this process, for signs of understanding or discomfort. By discussing the guidelines for research and assuring the participants that we knew nothing about their previous history other than that they had been to the clinic before with symptoms of dementia, we also stressed that we were researchers and not members of the medical team.

The other challenge was to address *consent requirements*. These involve obtaining the consent of the participants and/or their next of kin if the person is under the age of 15 and/or if the research is ethically sensitive. An important aspect of this is to make sure that each participant has understood correctly what the consent entails, that s/he has knowledge of the research and that s/he has the option to withdraw consent. There should be no pressure to participate (HSFR, 2018). For this study, the concerns mostly involved ensuring that the participants had understood the information about consent and that there was no pressure for participation expressed by anyone, researcher or spouse without dementia.

Another issue related to minimising pressure on participation was that the participants were contacted by their local geriatric clinic and not directly by the researchers. This choice was made in order to protect the potential participants' confidentiality and right to remain anonymous before giving their

consent to participate. However, a negative consequence of this precaution could be that some may have felt pressurised to participate, as they may have seen the clinic as a form of authority. We addressed this matter by including information about how the research was completely separate from their care, and ensured them that if they chose not to participate, this would have no effect at all on their treatment at the clinic. However, we still cannot be sure of the processes or reasoning which ultimately persuaded the couples to participate.

Dementia and ethics

It is surprising that there is nothing in the requirement for informed consent (HSFR, 2018) about how to proceed if there is any doubt about a person's ability to give consent. In research with people who have dementia, a clear-cut line cannot be drawn in terms of *whether* or *when* the person is "incompetent" or "incapable" of giving consent. The participants in this study had recently received their dementia diagnosis. However, many of them had been experiencing dementia for a long time before this. It is possible that decisions and opinions change from day to day for a person with dementia, and it was therefore also important to pay attention to embodied, non-verbal displays of discomfort as well as to ask for consent at the time of the interview.

In research, capacity is considered to reflect whether a person has understood the content and information about the research and its consequences (Cubit, 2010). Further on, according to Appelbaum and Grisso (1988), the capacity to make decisions requires an ability to understand information, an ability to appreciate the nature of a situation and its likely consequences, an ability to reason with the information and weigh options logically, and an ability to communicate the choice. This is a lot to ask of any person, and perhaps too much to ask of a person with dementia. One way to approach potential incapacity is to ask the participants to take a cognitive test to measure their capacity.

However, research (e.g. Hellström, Nolan, Nordenfelt & Lundh 2007b) has shown that tests like these can make the participants feel inadequate and incompetent. Furthermore, Sabat (2002) exemplifies the weaknesses of standardised tests for cognition by highlighting a person who had been intellectual and had had a rich vocabulary before she contracted AD. Measurements showed that she had a higher cognitive ability than she actually experienced, because she had had greater capacity in the first place (Sabat, 2002). This points to a subjective dimension of competence and capacity, which cannot easily be captured with standardised tests.

In this study, no standardised tests were used to measure capacity. Instead, informed consent was approached as a process where it was discussed at the time of contact and again at the time of the interview, rather than signing a single consent document. Nor did I consider it relevant to consult a proxy in order to obtain consent for the individuals with dementia, since the spouses made a joint decision about whether or not to participate. Research (Dewing, 2002; Hellström et al., 2007b) has indicated that many participants with dementia enjoy taking part in research when the circumstances are adapted to their dementia. Should people therefore be excluded from research when researchers are unsure about whether they can understand the information they are given, but give their consent in a traditional sense? Hellström et al., (2007b) oppose to the excluding of people with dementia from research, and they argue that it is not a question of *should we* include them in research, but that it is rather a question of *how should it be done?*

5. Presentation of articles

This section will provide a summary of the articles, beginning with a discussion about the process of writing them. Articles I, III and IV were written in collaboration with supervisors and colleagues at CEDER, and Article II was written by myself. Co-writing as a process has taught me a great deal about different ways of framing an article, but most of all it has taught me how to recognise my own skills and challenges. Writing with senior colleagues has also made me push myself further and sharpen my arguments.

If it were possible to disentangle “who did what”, this would be the place to do it. However, I argue that this is not possible. In the first article, my co-author and main supervisor, Lars-Christer Hydén, is a professor of social psychology as well as a dementia researcher. Nevertheless, the project of writing was very much a collaboration, in which I coded the pronouns and made some of the transcriptions, and Lars-Christer was in charge of framing the article. In other words, the analysis was truly a joint project in which we both contributed on equal terms. My co-authors for Article III, Ali Reza Majlesi and Anna Ekström, held postdoctoral positions at CEDER at the time of writing, focusing on interaction by means of conversation analytic framework. We spent many hours going through videos and transcriptions, and made joint presentations at conferences. Their expertise influenced me in many ways, and the article changed many times along the way before it ultimately became one I could take responsibility for and stand behind as a main author. Anna Olaison, my co-author for Article IV, is also my assistant supervisor. Her expertise is in interaction and gerontological social work, which was very valuable in terms of framing the article. Although I wrote the articles in collaboration with senior researchers, I had the main responsibility for the analysis and taking forward the writing

process. Taken together, these different collaborations have taught me a great deal about becoming a researcher and writing articles.

Article I

Couples with dementia: Positioning the ‘we’

(Hydén, L-C. & Nilsson, E. (2015). *Dementia*, 14(6), 716-733.)

The aim of this first article was to investigate how spouses in couples living with dementia position themselves in relation to each other by analysing their use of pronouns, especially the *we*. This focus was motivated by previous research that demonstrates how spouses in couples take on the challenge of facing dementia as individuals but also to a great extent as a couple (Davies, 2011; Hellström et al., 2005; Molyneaux et al., 2011).

In this article, we analysed 11 video recorded interviews with Swedish couples in which one of the spouses has a dementia diagnosis. First we conducted a quantitative step in which all pronouns used in the interviews were counted and categorised in terms of who used them and whom they indicated. We found that the spouses in couples often take the position as a *we* in the interaction, however the spouses with dementia less so compared to the spouses without dementia. In the next step we studied the qualitative functions of their positions based on pronoun use, mainly *we* and *I*, in which we adopted an interactionist framework when combining a conversation analytical approach (Sidnell, 2013) with positioning theory (Harré & van Langenhove, 1999). In line with previous research, the analysis indicated that the use of the pronoun *we* can function as way of positioning, experience and consider oneself as part of a couple in time of dementia. Further, we argue that the spouses’ use of *I* has the function of positioning and experiencing oneself as an individual

in relation to the couple. We also add to previous research (e.g. Hydén, 2011) by arguing that the spouses successfully make use of *scaffolding* when managing joint storytelling. One of the major challenges for couples living with dementia is to be able to retain a *we* in face of the progression of the dementia disease. Through their flexible positioning, we argue that the spouses can establish and negotiate quite a complex and emotionally charged web of relationships.

Article II

Fishing for answers: Couples living with dementia managing trouble with recollection

(Nilsson, E. (2017). *Educational Gerontology*, 43(2), 73-88.)

The second article focuses on managing challenges linked to dementia, specifically problems remembering a shared life. Dementia affects cognitive abilities in a number of ways. Challenges involving memory are some of the most common, and inevitably affect both spouses in couples. Partners in couples have extensive common ground based on shared memories and experiences, and this also constitutes the basis for their interaction.

In this study, 12 video-recorded interviews with Swedish couples where one of the spouses had a dementia diagnosis were analysed. It focused on instances in which the spouse with dementia was unable to remember information it was assumed s/he would know, so-called *type-1 knowable* (Pomerantz, 1980) information. This was further discussed in terms of expectations regarding *epistemic access* (Stivers, Mondada & Steensig, 2011). The analysis benefited from multimodal conversation analytic theory and method (Mondada, 2016; Sidnell, 2013), through which three different patterns emerged.

In the first pattern, the management was not considered

problematic. The spouse with dementia indicated that repair was required, and his/her partner with no further comment instantly provided repair. More communicative turns were involved in the other two patterns, where the spouses without dementia prompted their partner to remember through *fishing techniques* (Pomerantz, 1980). These patterns led to two conclusions: (1) different expectations of *what is* or *should be* common ground may cause communicative problems and distress for the spouses, and (2) spouses without dementia may use fishing techniques as a way of managing the challenges of remembering. I further suggest that these techniques do not necessarily enable the person with dementia to remember the required information. On the contrary, they may cause embarrassment and potentially face-threat for the person with dementia.

Article III

Speaking for and about a spouse with dementia: A matter of inclusion or exclusion?

(Nilsson, E., Ekström, A. & Majlesi, A-R. (Forthcoming article in press). *Discourse Studies*, 20(6).)

Previous research on dementia and communication highlights the fact that people living with dementia are excluded from, or even ignored in interaction (Kitwood, 1997), and that others speak for them or over their heads in matters concerning them, for instance in assessment meetings with social services (Österholm & Samuelsson, 2015). This third article focuses on instances where spouses without dementia position their partner with dementia as a third party in ongoing interaction about dementia-related trouble.

The article benefited from multimodal conversation analytic theory and method (Mondada, 2016; Sidnell, 2013) in analysing 15 video-recorded interviews with Swedish couples, where one of

the spouses had a dementia diagnosis. In a similar way to Article I, the interviews were trawled for pronoun use, and spouses without dementia were often found to speak about their partner with dementia in the third person, as a *he*, *she* or using their full name. The opposite pattern, where spouses with dementia used pronouns in this way, was rare.

A qualitative step followed, based on the pattern of pronoun use, which investigated the concept of speaking *for* or *about* someone in his/her presence. The sequences studied involve how couples managed the joint act of talking about negative experiences related to the dementia of one of the spouses, who in turn was referred to in the interaction by using a third-person pronoun. Based on our findings, we argue that speaking *for* and *about* someone can be balanced with attempts to include the person in the conversation in different ways. This article involves a more detailed analysis than the previous two, and there is a specific emphasis on the use of multimodal resources to engage in, or to engage a partner in, the conversation. We argue that spouses with dementia can indicate their consent to other people in terms of talking about their dementia trouble. They can actively include themselves in a story told about themselves, as well as being actively included by their spouse as a co-speaker. Embodied resources such as touching and gaze have been shown to be of particular importance in approaching sensitive experiences involved in dementia, as well as including a spouse with dementia in the conversation in different ways. The results are discussed in relation to aspects of *we-ness* and *co-constructions* used in storytelling activity by couples living with dementia.

Article IV

What is yet to come? Couples living with dementia orienting themselves towards an uncertain future

(Nilsson, E. & Olaison, A. (2017). *Qualitative Social Work*, E-pub ahead of print.)

This fourth article focuses how couples in which one of the spouses has a diagnosis of dementia jointly orient themselves to an uncertain future with dementia. Research on support for couples facing dementia indicates that the process of requesting and obtaining information about the illness is crucial but often insufficient (Johnston & Terp, 2015; Meyer, 2017; Tolhurst et al., 2016). There are few current studies on how couples *collaborate* to talk about their future with dementia and what it may entail, or studies on how they adapt to it as a couple and as individuals (see e.g. Hellström and Torres, 2016).

This analysis benefits from multimodal conversation analytic theory and method (Mondada, 2016; Sidnell, 2013) in studying video-recorded interactions in interviews with 15 couples living with dementia. In the examples, one, several or all of the participants alternate between taking epistemic stances as *knowing* and *unknowing*, as well as ascribing stances to others (Goodwin, 1981; Heritage, 2013). Based on our findings, we argue that either or both spouses can actively inquire about the progression of one partner's dementia, and that they can do this individually, on behalf of the other partner or on behalf of the couple. However, in doing so, spouses without dementia indicate their awareness of the uncertainty involved in a future with dementia, whereas spouses with dementia are more direct in their inquiry and do not necessarily indicate uncertainty. Moreover, we argue that either or both spouses can also indicate that they are happy not to know about the progression of the condition, and to manage the uncertainty by taking it day by day.

Furthermore, we argue that both the act of inquiring about the future, and couples display of oppositional stances regarding the inquiry can be sensitive matters which call for additional interactional work. We demonstrate how this is managed through multimodal resources such as hesitations, gesturing and mitigating the topic. The findings suggest a need to develop communicative practice to enable couples to collaborate in talking about dementia, as well as a need for social workers to find ways of providing emotional support to both individuals and couples.

Facing dementia as a we

6. Conclusions and discussion

The intention of this section is to answer the research questions, and to summarise and synthesise the main findings from the four articles. The starting point for this thesis was the fact that couples living with dementia manage life for a long time with no, little or unsatisfactory support from social services (Johnston and Terp, 2015; Meyer, 2017; Tolhurst et al., 2016), and that more knowledge is needed in order to support gerontological social work with people with dementia (Kaplan & Berkman, 2011).

The aim of the thesis was to investigate how couples manage dementia-related challenges in interaction, and to consider whether, and how, these challenges and ways of managing relate to aspects of couples' *we-ness*. To fulfil this aim, I studied interactions in interviews with couples living with dementia, benefiting from multimodal conversation analytic theory and method (Mondada, 2016; Sidnell, 2013). This approach has been shown to be of great value, since it enables detailed analysis of contributions from all participants, shedding light on relational and collaborative aspects of the interaction as well as the multimodal resources employed by the couples. The aim was specified in three research questions, which will be responded to briefly here. However, it is more thoroughly synthesised under the headings: "Starting from the *we*", "Inclusion and collaboration" and "Approaching sensitive topics".

The answer to the research question: "How do spouses jointly manage dementia-related challenges in interaction, and what are the consequences?" can be found in all the articles. I have identified several instances which couples indicated they considered challenging. These were mainly communicative but were also emotional. They include *not being able to remember* (Articles I, II and III) and the situation where spouses without dementia *had to talk for or about their spouses with dementia* (Article III) for different reasons. These challenges involved

greater efforts in terms of interaction for the spouses without dementia. They had to take more responsibility for getting information across, and at the same time had to negotiate emotional challenges such as *saving face* (Article II) for all participants. I have shown that the communicative strategies employed by spouses in couples to manage dementia-related challenges can be successful and beneficial for interaction and wellbeing. These include *scaffolding* (Articles I and II), *giving* the person with dementia *time* or *clues* to retrieve the information (Article II) or *including* themselves or their spouse in the conversation in different ways (Article III). However, the same strategies may also be less beneficial in terms of consequences for interaction and wellbeing, in the sense that they may not successfully save face or bring memories to the surface, and may in fact have the opposite effect (Article II).

Another emotional and communicative challenge for these couples involved *relating to their uncertain future with dementia* (Article IV). The strategies employed by the couples or individual spouses include *actively seeking information about the progression of the condition*, or taking a “*day-by-day*” approach. The consequences of this approach are less well-defined, since the other participants did not contribute any further information about it, except by highlighting the fact that the future was uncertain. In this sense, the consequence was simply that, despite requests for information, they reached a consensus on the uncertainty and on the impossibility of obtaining information on how the dementia was progressing.

Many of these challenges relate to the second research question: “How do spouses jointly manage the act of approaching and talking about sensitive topics relating to dementia? The couples employed different strategies to approach sensitive topics, including *mitigating* or *normalising the topic* (Articles III and IV), making use of different *multimodal resources*, particularly *embodied* ones (Article III), or simply making use of

more interactional resources to approach the topic (Articles III and IV).

All the above-mentioned challenges and strategies have a potential effect on the couples' wellbeing and sense of sustained *we-ness*. However, there are also indications that this *we-ness* is actually necessary for employing the strategies, and this appears throughout the articles in one way or another. It is part of the response to the third research question: "How do spouses relate to and use their *we-ness* in managing dementia?" which will be further discussed below under the heading "Starting from the *we*". The next section will synthesise the findings to help understand them in more detail.

Starting from the *we*

And it is thus that the hand or foot in touch with a person can function as a "relationship marker," that is, a sign that stakes out a relationship claim. (Important among these are "with markers" which establish who is in a with with whom.)

(Goffman, 1971, 2010:43)

The concept of *we* in couples has been an important feature in writing this thesis. It considers how the couples make use of their joint life and their common ground as a couple in facing and managing dementia, as well as their sensitivity towards each other within the interaction. For instance, when spouses with dementia indicate challenges in terms of memory, spouses without dementia can make use of "with-markers", as proposed by Goffman (1971), in order to mark their togetherness despite the sensitive situation of talking about a "lost memory" (Article III). Couples living with dementia might maintain a stable and solid *we* in managing dementia, but also have the option to depart from this *we* and take positions as individuals (Article I). Dementia is a chronic illness to which there is no known cure, so there is inevitably an emotional level to the spouses' *we*, not only in their current situation but also in relation to an uncertain

future. The couples are probably experiencing a gradual loss of some cognitive and communicative abilities, but also a potential or experienced loss of themselves as a *we*. This is addressed in all the articles.

The common ground shared by spouses in couples is often extensive (Clark, 2009; Enfield, 2006). The concept of common ground has been shown to be useful in understanding this process of loss, in the sense that dementia not only involves a loss of cognitive abilities, but also an emotional loss of shared life and memories. In terms of the interview situation, the couples can make use of their common ground when the person with dementia indicates that they are challenged by not being able to remember. In this sense, common ground is beneficial in terms of managing dementia-related challenges such as remembering. Common ground could also be beneficial in understanding why spouses without dementia tend to use a strategy of *fishing for answers*, since the “lost” memory may be emotionally charged. If the spouse with dementia is unable to remember shared experiences from their joint life, there is no one to validate it for the spouse without dementia and no one to reminisce with (Article II). All the studies in this thesis can be related in one way or another to the common ground spouses share, and this may be threatened. This pattern, I argue, represents great sensitivity for everyone in interactions, and includes considerations involving potential failure or loss of face for either or both of the partners.

Adding to previous research (i.e. Hydén, 2011; Wood et al., 1976), I have also found many examples of successful *scaffolding* in couples, and have presented a selection of them (Articles I, II and III) in which the spouse who does not have dementia supports the partner with dementia in terms of remembering and finding words. This thesis contributes to this corpus of research by illustrating in detail how the spouses remain attentive to each other in the interaction, and how support is often provided in a timely way following a verbal or non-verbal invitation by the

spouse with dementia (Articles II and III). Hence, the *we* in couples is an important basis for the person with dementia's ability to contribute to communication. The *we* is also the starting point for inclusion and collaboration in interaction, which forms the subject of the next section, alongside a discussion on how sensitive topics are approached.

Inclusion and collaboration

Look me in the eyes. Make sure I am attending to what you are about to say. Don't make me a speech; just tell me what you want me to know. If you have questions about if I "got" it or not, engage me in conversation and check to see if I understand. If I am having trouble understanding, use examples and comparisons with which I should be familiar. Get more of my senses involved than just words.

(Taylor, 2008:153)

Despite this insightful description by a person with Alzheimer's disease, there is a long tradition of viewing people with dementia as "empty shells", which has had a profoundly negative impact on the treatment of people with a dementia diagnosis (Behuniak, 2011). However, in line with a developing perspective of viewing individuals with dementia as people with agency and personhood (Kitwood, 1997), this thesis has indicated that storytelling and interaction involving couples living with dementia are often active, collaborative and inclusive activities in which they make use of shared and embodied multimodal resources in interaction (in line with e.g. Hydén, 2013).

An important effect of the detailed analysis used here is that it can highlight competences and timely contributions, or agency, which would have been neglected had another method been used. Studying minimal contributions, such as nodding and interjections like *hmm*, highlight active participation by the spouse with dementia, rather than ignorance or exclusion by others. Examples include minimal contributions by people with dementia (*hmm*, *mmm*, etc.), tone/strength of voice (e.g.

adopting a questioning or smiling tone), and non-verbal contributions (nodding, gaze, shaking head, etc.), all of which become visible through the detailed style of transcription. This involves non-verbal activity which is enabled through video recordings. By studying multimodal activity in couples, it can be argued that the spouse with dementia often actively invites scaffolding by their partner through verbal requests for repair, through gaze or through hesitation. In contrast to previous research on people with dementia and exclusion from interaction (e.g. Österholm & Samuelsson, 2015), I have argued that by studying non-verbal contributions, the activity of being *spoken for* can be, and often is, prefaced by an invitation by the spouse with dementia, either verbally or via gaze or a nod to their spouse (Article III; Majlesi et al., 2017).

As in verbal talk, non-verbal contributions have effects on ongoing interaction. If a spouse was telling a sensitive story in the presence of his/her partner with dementia, a gaze from the latter recurrently produced a shift in which the spouse without dementia changed from a third-person pronoun *s/he* to either *you* or *we* (Articles III and IV). Hence, the spouses with dementia actively engaged in the interaction and affected how it unfolded by using tools available to them. This presents a more multifaceted picture of agency and dementia than the previous image of exclusion and passivity. This type of approach also contributes to the visibility of communicative collaboration and joint strengths in interaction. Hamilton (2008) describes this collaborative process in living with dementia as a dance, “which highlights the interactions as process rather than as product, researchers examine moment-to-moment turns or moves that display interlocutors’ meaning-making and relationship building as these emerge across the interaction ... In the dance, interdependence between or among partners is accentuated” (Hamilton, 2008:99).

As mentioned above, spouses who do not have dementia often make good collaborative partners in terms of interaction. However, I have argued that attempts at collaboration or inclusion, such as *fishing for answers*, can sometimes be less beneficial for remembering, and even for wellbeing in general. For instance, despite requests for time, partners did not give their spouses with dementia enough time to remember (Article II).

This thesis has also shown how the communicative strategies employed by couples to include a spouse with dementia in telling stories can be less successful for interaction, or even contribute to what is referred to as communicative breakdown (Powell, Hale & Bayer, 1995). This can be seen in the performance of spouses with dementia when they have trouble keeping the conversation going, and struggle to find names or memories. This pattern could potentially indicate separateness rather than closeness in couples, since it is based on different epistemic expectations about the cognitive ability of the person with dementia (Article II). Hence, the act of *fishing* could have an excluding effect in the sense that it emphasises difference and asymmetry as a result of dementia, and could therefore have a face-threatening effect (Goffman, 1967). In a review, Hamilton (2008) further discusses aspects of prompting to remember what “ought to be remembered”, and sees this as potentially negative for the person with dementia, suggesting that open-ended questions could introduce opportunities for creativity instead. She also suggests that support groups, with peers who also have dementia, can act as a zone free from prompts or negative judgements by others (Hamilton, 2008). This is also indicated by Örülv (2012).

As proposed by Kitwood (1997), ignorance and exclusion are commonly experienced and displayed in interaction with people with dementia. However, by adopting a micro perspective of the interaction, a pattern becomes visible which highlights the agency of both parties in counteracting ignorance. I have also argued that

active participation by people with dementia is at risk of being neglected by less detailed analysis, and that their contributions support their inclusion in the interaction (Article III). This is further developed in a chapter on the methodological advantages of video data as opposed to audio alone (Majlesi et al., 2017).

Approaching sensitive topics

Given that you have something that you want to utter to a particular other, how do you go about getting into the circumstances that will allow you appropriately to do so? (The opposite question is of interest too, namely, How do you go about avoiding the circumstances in which you would be obliged to disclose something you would rather not?)

(Goffman, 1983:32)

Life with dementia inevitably comes with challenges in terms of approaching certain topics in interaction in couples, as well as in interaction involving others. Talking about life with dementia could occasionally come across as a complaint (Lindström & Sorjonen, 2013), as may have been the case in accounts by the spouses without dementia which were directly related to his/her partner's dementia (Article III). Such instances have to be managed carefully when the person with dementia is also present in the interaction (Lindström & Sorjonen, 2013). In line with how Goffman (1983) puts it above, approaching a topic you would rather not approach calls for additional interactional work and resources. Memories of the past are not the only area which brought challenges for the couples (Articles I, II and III), and this thesis has also explored aspects of couples' joint talk about the present and the future with dementia (Articles III and IV).

In Article III, the topic of dementia-related challenges involves past but also present challenges of daily life with dementia. I have argued that this kind of telling calls for increased interactional work by the spouse without dementia, and that embodied resources are effective as a strategy for managing talk about sensitive topics related to dementia in a spouse's co-presence. Furthermore, I have argued that the potential

sensitivity involved in talking about dementia-related challenges can be managed and counteracted by making use of non-verbal resources such as touching, for instance by placing a hand on their spouse with dementia during the aspects of telling which appear to be sensitive. The use of multimodal resources by the spouse without dementia can help include the spouse with dementia in the interaction despite its sensitive character (Articles III and IV).

Being part of a couple comes with certain expectations of what the relationship is, and what it should be now and in the future. Talking about challenges related to couplehood as the “erosion of the *we*” (Article I), or a future with progressing dementia for one of the spouses (Article IV), can be emotionally charged, and approaching this topic may call for additional interactional work. I argue that the spouses without dementia approach the topic of the future in a cautious way, potentially because of the co-presence of their spouse with dementia, whereas the spouse with dementia can be more direct in his/her talk about the future. Both spouses in couples can ask for more information about the future with dementia, but the spouses without dementia are keener to indicate their awareness of the uncertainty that characterises the future. Occasionally the spouses approach the future by positioning themselves as a *we* in the talk. By doing so, spouses erase asymmetry in terms of one spouse having dementia, and indicate that this is a shared experience rather than individual (Article IV).

Approaching the future carefully, expressing awareness of the uncertainty connected to it and taking the position as a *we* is behaviour that is likely to be related to theories on strategies for face-saving and politeness commonly applied by all interactants. Not only are we keen on saving face on behalf of interactional partners, we also have to design our talk so that there is no potential loss of face for ourselves (Brown & Levinson, 1987; Goffman, 1967). These findings are of relevance for educational

and practical purposes in professional encounters with people with dementia and their acquaintances, but also in terms of making a theoretical contribution to the field of dementia and social work research. This topic will be discussed in the following section.

7. Implications

This chapter will discuss the conclusions, this time exploring them in terms of their implications for social work education, practice and theory. The final section of this thesis considers possible links to further research on the lives of couples living with dementia.

Educational and practical implications

As indicated throughout this thesis, in social work education and practice across the Western world there is a lack of knowledge about, and support for, individuals and couples living with dementia (Kaplan & Berkman, 2011; McGovern, 2011; Melin Emilsson, 2013). Sweden itself lacks gerontological courses within a generalist social work education. My conclusions suggest to address this knowledge gap from a relational and interactional perspective, which I argue would be useful in designing, providing and implementing appropriate education for social workers and support for couples facing dementia.

Relationships

A person-centred approach is well established in many Western countries, and has been evaluated and elaborated to include relational aspects. In health-care settings, the term relationship-centred care (hereafter RCC) is applied to many different models and approaches today. The common element in all RCC approaches is the inclusion of as many individuals as possible in the network surrounding a person with dementia, in terms of experiences and feelings, as well as reciprocal and interconnected relationships in care (Beach, Inui & the Relationship-centred Care Research Network, 2006; Nolan, Davies, Brown, Keady & Nolan, 2003; Smith et al., 2010). These approaches, in which the emotions and experiences of several parties are highlighted, have

shown benefits. However, they do not problematise the RCC approach in terms of its potentially practical consequences for practice and policy.

Olaison and Cedersund (2008) exemplify negative positioning in social work practice with older people (not specifically afflicted with dementia) and their relatives. They illustrate how a wife who cared for her ill husband positioned him as weaker than he positioned himself, in order to receive home help from social services (Olaison & Cedersund, 2008). This possibly also caused him excess disability which was not caused by the dementia *per se* (Sabat, 2005). This instance is problematic, as it raises questions of autonomy and wellbeing in terms of the circumstances in which these values accrue, and for whom. The wife in the example cited by Olaison and Cedersund (2008) possibly needed support, and positioned her husband as weak in order to obtain it, whereas the husband denied this position, possibly to project himself as stronger. Of importance here is how the concept of need is understood, and for whom the services are designed and addressed, for an individual or for people within a relationship.¹⁴ This ties in to the discussions on a relational approach (Nolan et al., 2003; Smith et al., 2010), in which all parties in a relationship are evaluated and participate on equal terms, not necessarily highlighting a person with dementia. This is not the case in care for the elderly or the welfare system in Sweden, which is heavily individualised (National Board of Health and Welfare, 2017). The support available for families living with dementia is no less individually directed. People either receive support as a caregiver or as a receiver of care/client (Sand, 2015).

¹⁴ For a discussion on need in the context of social work, see Larsson (2009) and Olaison (2009), and for a characterisation of need in the context of health-care priority setting, see Gustavsson (2017).

From what has been presented so far, knowledge of dementia and relationships still has to be incorporated into social work. I argue that a relational approach to dementia care, partly suggested by Kitwood but largely developed by subsequent thinkers (Beach et al., 2006; Nolan et al., 2003; Smith et al., 2010), could have more influence in social work practice. Relationships are beginning to be taken into consideration in gerontological social work, but less so with regard to dementia (see Naleppa & Reid, 2003). In Sweden today, the most acute medical and care-related needs are prioritised at the expense of more social and existential needs (Olaison, 2009), so that priority is given to the oldest and frailest (Meagher & Szebehely 2013; Szebehely & Trydegård, 2012). A family-centred approach, in which the social worker engages with the client's network, and which aims to strengthen families rather than just individuals (Adams & Nelson, 1995), is often used in social work aimed at improving situations for children. However, this is rarely used today in gerontological social work involving people with dementia (Washburn & Grossman, 2017). I argue that there is a possible bridge of interdisciplinary connections that can be explored further. It would be fruitful to make use of knowledge from neighbouring disciplines such as health-care and/or linguistics in order to develop an approach in gerontological social work which involves people with dementia.

In *relational social work*, the “central idea is that change emerges from a reciprocal aid, both between people in difficult circumstances, family members, friends and neighbours, and between the network and the social worker” (Raineri & Cabiati, 2016:1005). Raineri and Cabiati (2016:1011) propose that social workers should use a relational approach as a basis for meeting clients, guided by the stance: “We can help each other to understand what makes you feel well (and makes me feel better as well), and together we can set about achieving it.” This approach emphasises open dialogue, reciprocity and a focus on

recognising strengths for all involved (Calcaterra, 2017). Raineri and Cabiati (2016) discuss Kitwood's idea of personhood for people with dementia (Kitwood, 1997), and emphasise this as a potential contribution and link to relational social work.

This reciprocal and strengths-based approach is apparently different from the dominant work for most social workers as helpers and experts (Washburn & Grossman, 2017), in which the experience of dementia by the families can be neglected in decisions about services (Calcaterra, 2017; Folghereiter, 2004; McGovern, 2011; Raineri & Cabiati, 2016; Tanner, 2013). Sandberg (2001) also highlights the need for competence and sensitivity in preparing for the experience of placing a family member in a care home. This process requires skilled professionals in order to meet the changing needs of these families and to support people through the emotional experiences involved in separation and changing roles (Sandberg, 2001). I consider this thesis to contribute to addressing this knowledge gap in gerontological social work and in relational social work involving couples living with dementia.

Interaction

Social work practice also rests on interaction with clients in terms of evaluating, assessing and providing appropriate services to individuals and families. However, interaction has often been taken for granted rather than examined in detail. By talking to clients, the social worker can obtain a picture of their problems, as well as what is required to solve them. Despite this, there is much less representation of interactionist studies at micro-level than organisational or systemic studies at macro-level (Antaki & Widdicombe, 1998; Juhila et al., 2014; Kullberg, 1994; Sarangi & Slembrouck, 2014; Seltzer & Kullberg, 2001). Fredin (1993) argues that “[b]y viewing the language not only as a tool but as a necessary condition for achieving the goal of the organisation, valuable and necessary information is gained about the encounter

between social workers and clients” (Fredin, 1993:1, my translation).

Social work interaction takes place within institutional practice characterised by aspects of asymmetry and goal-orientation (Fredin, 1993; Heritage, 2005; Kullberg, 1994). This becomes evident in the fact that social workers dominate and define the interaction, both quantitatively in terms of time on an interactional “floor”, and qualitatively in terms of “interactive, semantic, strategic and perspective dominance” (Fredin, 1993:189). This division of interactional work poses challenges for social workers in terms of knowledge and skills, not least in terms of allowing the perspectives of people living with dementia to be included. Nordh (2016) as well as Nordh and Nedlund (2017) argue that in assessment meetings in caring for the elderly, care managers are not sufficiently guided by policy, and have to develop their own strategies for managing assessments of clients with dementia, at the same time balancing the perspectives of relatives. Asymmetry and clients’ different expectations have been noted in social-service encounters which focus on meetings with people with dementia and their relatives, where the social worker has to balance the voice of the relative with the voice of the person with dementia (e.g. Nordh & Nedlund, 2017; Österholm & Hydén, 2018; Österholm & Samuelsson, 2015). Research in social sciences (e.g. Fredin, 1993; Juhila et al., 2014; Shotter, 2002) attempts to take a client’s view of communicative practice in studying social work interaction, however it is indicated that the perspectives of relatives, or the couple, who are not clients per definition also poses challenges for social workers.

Couples have strategies for managing challenges, such as those involved in remembering, daily activities and communication. Layers of emotion are inherent in these challenges. Not being able to perform an activity or contribute to a conversation affects both spouses emotionally, for example. Hence, there is a need to focus on all layers in terms of support,

including the practical, the communicative and the emotional. The contribution of this thesis lies in its emphasis on relational aspects of interaction, raising awareness about the potentially important approach of interacting with *a couple* or *a family*, rather than necessarily highlighting individuality in social work encounters. Attending to the clients' own positioning, whether it being an *I* or a *we* should be taken seriously, and I argue that there is much information to be gained in those stances. The spouses' contributions, expectations and perspectives may be intertwined and similar, but they may also diverge (see Articles II and IV). As this thesis has shown, this approach may be difficult in the sense that interaction within couples can be complex, however it ought to be acknowledged in practice.

In order to raise awareness of instances such as those described above, researchers have to find ways of conveying this knowledge to practitioners and social work students. To spread the results of this thesis more broadly, I suggest an interactionist design in which practitioners and social work students follow a communicative process from the perspectives of couples, as if they were in their shoes (see Stokoe, 2014, for a methodological approach). Understanding the couples' situation from *their own perspective* enables the acquisition of knowledge about the challenges, strategies and strengths in their relationship as a couple, and this could be of use in social work encounters and assessments.

Finally, as discussed in the conclusions earlier, for couples facing a present and future life with dementia it can be a struggle to manage potential and actual losses, such as the loss of *we-ness*, loss of closeness, physical and cognitive deterioration for the spouse with dementia, changes in personality and even the future death of either of the spouses. These kinds of loss and emotional stress are approached to different extents in the support provided for couples living with dementia. Spouses in couples are often offered support separately, with different support for relatives

and the ones diagnosed (Daley et al., 2017; Sand, 2015). This individual support should by no means be diminished. However, spouses in couples may not be given access to the tools for managing their potentially sensitive situation jointly, which is a problem that should be addressed at education and practice level.

As noted, throughout the Western world the knowledge of gerontological social work, specifically knowledge of dementia, is on a generalist rather than specific level in social work educational programmes (Kaplan & Berkman, 2011; Keating, 2017; Richards et al., 2014; Rosen & Zlotnik, 2001). In encounters involving people living with dementia, the latter are often asked about their life and their situation, which can potentially place them in a delicate position in terms of what they are asked to talk about. There is a need for knowledge which could support training for social workers in terms of dealing with sensitive topics in interaction with families living with dementia and with professional carers. These topics could include sexual orientation, spirituality, social class and even forms of death and dying, as well as daily challenges connected to symptoms of ageing and dementia. The ability to contribute to good dementia care requires a dialectical approach, in which the behaviour and emotions of professionals and family members need to be addressed as part of the problem and the solution (Kitwood & Bredin, 1992; Marshall & Tibbs, 2006). Having the tools for talking about sensitive topics benefits the people with dementia in terms of well being, but also relatives, social workers and care workers in dementia facilities.

In summary, this relational and interactional approach fits well with practices proposed in RCC and relational social work, a framework in which the experiences and challenges for all involved are acknowledged and respected (Beach et al., 2006; Nolan et al., 2003; Raineri & Cabiati, 2016; Smith et al., 2010). In terms of managing dementia, combining knowledge on the challenges and communicative strategies employed by couples

with a theoretical extension of the relational approach, which sees them as a potential *we* rather than exclusively two *I*s, could contribute to improved social work practice and dementia care. This approach involving a supporting partnership has been suggested by scholars from different disciplines such as nursing (e.g. Daley et al., 2017; Keady & Nolan, 2003) and social work (e.g. McGovern, 2011), and would be strengthened by the relational social work described earlier by Raineri and Cabiati (2016).

The bio-medical approach to dementia has dominated policy and practice throughout the Western world. It involves measuring individuals, and experiences of family members are approached individually. However, the individual approach is now being challenged by researchers like myself and others, in that: “Thinking of dementia as a family problem rather than a problem for the person, or the person and the carer, can be very constructive” (Marshall & Tibbs, 2006:194). This relational methodology in dementia care is discussed here in terms of relevant approaches to social work, such as relational social work. This model would focus on the experiences and challenges in couples and others affected by dementia, and the basis for change would involve the strengths and challenges displayed and shared by these individuals and their relationships. In line with relational social work, open dialogue should support this change, which calls for experienced social workers with sufficient training and knowledge to take on the task. The strengths of an interactionist perspective also contribute to addressing the complexity of the issue. Rather than a formalised description of “how to communicate with couples living with dementia”, taking the perspective of the participants and combining knowledge about their interaction and relationships will be the “take home message” from this thesis to social work education and practice. The following section explores implications regarding theory further.

Theoretical implications

Understand life with dementia through the lens of a phenomenological approach, means addressing the perspective of the people, focusing not least on those who face challenges in expressing themselves verbally or even with embodied expression. Scholars within the phenomenological tradition (e.g. Kontos & Martin, 2013; Käll, 2015, 2016; Zeiler, 2014) have emphasised the person underneath what was previously considered “the empty shell” of an individual with dementia, but at the same time have attempted to erase the line between consciousness and the body by referring to the “lived body”. The lived body is constantly developing through its relations with the world and other beings, even if a person has dementia. Kontos and Martin (2013) acknowledge the potential risk of reducing a person to body, but researchers in this tradition turn against a dualist approach in which mind and body are separated (Kontos & Martin, 2013; Käll, 2015, 2016; Zeiler, 2014).

In this thesis, I have analysed sequences from the participants’ perspective in an attempt to “put myself in their shoes”. This has helped gained some level of access to their understanding of the ongoing interaction. By doing this, new layers of ability and refined interaction have emerged, such as collaboration, and active, multimodal inclusion and participation. This aligns neatly with the phenomenological idea that people with dementia are not helpless victims but active participants, very much like people without dementia, who experience and develop in interaction with others, particularly in terms of embodied interaction (Kontos & Martin, 2013; Käll, 2015, 2016; Zeiler, 2014).

The empirical results and conclusions from this thesis also add to this framework through their descriptions of active contributions and alignment within interactions. These include seeking the gaze of others, and minimal contributions or

continuers such as “hmm” or nodding. How the spouses organise this shows constant awareness of their own part in the interaction, as well as the contributions and actions of partners and others. Even when one spouse is the main speaker, the presence of his/her spouses has effect on how the talk unfolds and by which means. By arguing that minds and bodies are not easily separated in interaction involving couples living with dementia, I consider that this conclusion aligns neatly with the phenomenological tradition of dementia research suggested by Kontos and Martin (2013), Käll, (2015, 2016) and Zeiler (2014). This view stands in contrast to the commonly mentioned duality of neurocognitive disorders such as dementia (Käll, 2015).

A further theoretical implication for this thesis involves a different understanding of epistemics with reference to interaction in couples living with dementia. A person who has experienced something is often understood to have primacy over this knowledge, which is known as *epistemic primacy* (Stivers et al., 2011). However, this thesis has contributed to the debate by challenging the individual division used here, suggesting instead that knowledge (such as remembering) does not necessarily exist within individuals, but can be acquired through interaction.

The situation for the couples in this thesis raises questions about who has primacy over, or responsibility for, remembering and making assessments about certain knowledge (Stivers et al., 2011). Being part of a couple often entails a great deal of shared experiences, but some memories are experienced separately. Hence, a person who has experienced something has primacy over this knowledge, but sometimes, as when a person has dementia, s/he has to be reminded about this experience by a spouse. The management of these instances may pose a communicative and emotional challenge for the couples. Even though the preferred order is that the person who has had the experience should remember it (Pomerantz, 1980; Stivers et al., 2011), the couples in the study for this thesis have found ways of

adapting their interaction in accordance with new circumstances. Hence, if a person with dementia does not appear to remember a specific topic, it is not necessarily considered a problem but treated as “normal” for their situation, which helps save face and contributes to the wellbeing of the person with dementia (Articles II and III). This thesis has also shown how people with dementia rely on their partner’s epistemic access to their subjective experiences and memories (Articles I, II and III). This distribution of memory enables continued personhood for people with dementia, and a continued ability to tell stories and interact. This has previously been described as distributed cognition, or “a theoretical framework with less focus on the individual’s abilities and losses, but rather on trying to understand the individual’s actions as part of a communicative and cognitive ecosystem” (Hydén, 2014). In regard to this thesis, how the couples often talk as a *we* indicates that they dilute the importance of individualising experiences, knowledge and memories, and by doing so also manages the potential face-threats connected to being the one who has dementia.

In short, by adopting a ‘couplehood-lens’ in terms of interaction with couples living with dementia, we can see things which would otherwise have been invisible. These include aspects of collaboration and strategies, and of *we-ness* as a resource but also as a challenge in managing dementia. In line with McGovern (2011, 2015) and others, I support a new model for social work and dementia practice, policy and research, where the focus would lie not in the decline of abilities but rather in the strengths and challenges involving individuals, relationships and interaction. By taking a relational, interactional and embodied approach towards understanding life with dementia, this model poses challenges to existing legislation for dementia care.

In the Swedish guidelines for dementia care (National Board of Health and Welfare, 2017), people with dementia should always retain self-determination (in cases where no proxy is

assigned), but are nevertheless often neglected or ignored when cognitive abilities deteriorate, and the partner or family member acts as a vicarious voice (Hydén, 2008; Österholm & Samuelsson, 2015). Perhaps this exclusion of a person with dementia becomes inevitable as dementia progresses. It is also possible that guidelines are rather deficient, in that they are individualistically constructed and neglect the family as a unit, unless (put rather harshly) partners or family members are there as carers. In other words, is it feasible to rely on a theoretical framework which suggests that dementia afflicts only the individual, or is it possible to suggest that it is actually a couple or a family who receive the diagnosis, as they often all live with it to some extent? And is it reasonable to continue to emphasise the role of cognition for people with dementia, or is there a shift towards including also embodied aspects of communication? Research presented earlier by Norton et al. (2009) shows that when spouses care for their partner with no formal support, this is often at the expense of their relationship. In terms of exploring and drawing the lines for future social work policy and practice involving couples living with dementia, a suggestion from this thesis is therefore to extend Kitwood's person-centred care (1997). This would involve enhancing a *we*-perspective and shifting from seeing a "person-with-DEMENTIA", to a "PERSON-with-dementia" (as suggested by Kitwood, 1997), and eventually to including the "COUPLE-with-dementia" (or "RELATIONS-with-dementia").

Further research

As mentioned previously, there is an urgent need for research on dementia and relationships in social work and dementia studies. In the light of this, there are a number of possible starting points, and I shall describe the ones I consider to be most relevant. I have mainly looked at the material for this thesis without gender-glasses, searching largely for instances of couples' communicative

strategies in managing challenges connected to dementia. Nor have I studied practical challenges and strategies for managing their daily life. However, some interesting questions have been raised by other researchers' studies on gendered patterns of household chores where one spouse has dementia. I can see many similarities in terms of the spouse without dementia taking over the previous chores of the spouse with dementia, and how this has to be dealt with from a gender perspective in terms of habits and identity (Boyle, 2014; Hellström et al., 2017). One way forward from my thesis would be to add to previous findings by acknowledging these similarities, but also by expanding the knowledge through detailed description of the processes of communicating and negotiating. Different ways of communicating about a situation can emerge from an interactionist perspective, such as the effect produced when the abilities of a wife with dementia are described in her co-presence, such as her ability to cook (Boyle, 2014).

Another option would be to collect data on same-sex couples, in order to study the reorganisation of chores and compare this to different-sex couples. The criteria for inclusion in this study included no specific request for same-sex couples, and we were not given access to same-sex couples in this thesis. Since dementia mainly affects people later in life, there could be a stigma attached to living in same-sex relationships, given the lack of formally acknowledged same-sex relationships in the geriatric clinics we recruited from. This could change if younger same-sex couples with dementia were to attend memory clinics at an early stage. In this way, they would become visible and could be recruited for research.

This thesis has only focused on first-round interviews with couples. However, as researchers at CEDER have continued to follow these couples over a further four years, there are opportunities for longitudinal studies of all the phenomena and processes discussed in this thesis. This contribution to knowledge

of processes over time will be unique in the fields of gerontological social work and dementia research, adding to the modest longitudinal interactionist work done by Hamilton (1994), for example.

A final suggestion for further research is to make longitudinal comparisons between people living with different types of dementia, in terms of their collaborative management of problems with memory for instance. The symptoms experienced, and the stage a person has reached in the progression of the illness, probably affect how they and their interactional partners react to the challenges connected to remembering or understanding information. For instance, if the person with dementia does not consider him/herself to have problems, the interactional sequence would most probably play out differently to one where the person is clearly aware of the problems. I argue that all the above proposals for further research would make important and novel contributions to social work research and practice in terms of the lives of people and families living with dementia.

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Appendices

Appendix A - Information about study

Att tappa minnet: kommunikativ kompensation och hantering av symtom

Bakgrund och syfte: Syftet med forskningsprojektet är att undersöka och försöka förstå hur personer som exempelvis har genomgått en utredning för minnessvårigheter och deras anhöriga hjälps åt i vardagliga samtal och hur de uppfattar och beskriver sina svårigheter och dess inverkan på deras liv. Även om minnesproblem är vanligt förekommande, vet vi inte så mycket om hur personer med minnesproblem och deras anhöriga hanterar sin situation.

Förfrågan om deltagande: Med denna information tillfrågar vi dig om att delta i en vetenskaplig studie som vill belysa hur man tillsammans samtalar, exempelvis minns det gemensamma livet, och hur man uppfattar eventuella sjukdomar. En ökad förståelse av era upplevelser och kunskaper är viktig för att vården och omhändertagandet av människor med exempelvis minnessvårigheter skall kunna vidareutvecklas.

Hur går studien till? Studien bygger på intervjuer som spelas in. Intervjun genomförs av två forskare. All insamlad information kommer att behandlas konfidentiellt. Du kan få ta del av studieresultat muntligt eller skriftligt, i grupp eller enskilt.

Frivillighet: Deltagandet är frivilligt och innebär ingen risk för dig. Om du önskar kan du avsluta ditt deltagande när som helst under studieperioden utan särskild förklaring. Om du inte vill delta i projektet eller vill avbryta ditt pågående deltagande så kommer det inte på något sätt att påverka sedvanlig behandling eller omhändertagande.

Ansvariga för forskningen är:

Forskningshuvudman: Linköpings Universitet

Huvudansvarig forskare: **Lars-Christer Hydén**, professor, LiU.

Elin Nilsson kommer att medverka vid intervjuerna.

Har Du ytterligare frågor och funderingar kring forskningen är Du välkommen att kontakta oss: Lars-Christer Hydén (tel: XXXX) eller Elin Nilsson (tel: XXXX)

Appendix B - Sheet for informed consent

Att tappa minnet: kommunikativ kompensation och hantering av symptom

Syftet med forskningsprojektet är att undersöka och försöka förstå hur personer som exempelvis har genomgått en utredning för minnessvårigheter och deras anhöriga hjälps åt i vardagliga samtal och hur de uppfattar och beskriver sina svårigheter och dess inverkan på deras liv. Även om minnesproblem är vanligt förekommande, vet vi inte så mycket om hur personer med minnesproblem och deras anhöriga hanterar sin situation.

Studien bygger på intervjuer som spelas in. Intervjun genomförs av två forskare. All insamlad information kommer att behandlas konfidentiellt. Du kan få ta del av studieresultat muntligt eller skriftligt.

Deltagandet är frivilligt och innebär ingen risk för Dig. Om Du önskar kan Du avsluta Ditt deltagande när som helst under studieperioden utan särskild förklaring. Om Du inte vill delta i projektet eller vill avbryta Ditt pågående deltagande så kommer det inte på något sätt att påverka sedvanlig behandling eller omhändertagande.

Ansvariga för forskningen är professor Lars-Christer Hydén och Elin Nilsson, Linköpings universitet.

Har Du ytterligare frågor och funderingar kring forskningen är Du välkommen att kontakta någon av oss: Lars-Christer Hydén (tel: XXXX) eller Elin Nilsson (tel: XXXX)

Jag har läst igenom informationen om projektet och ger mitt medgivande att ingå i studien.

Stad Datum

Appendix C - Interview guide

Uppgifter och Bakgrundsuppgifter

I. Uppgifter

Dessa uppgifter syftar inte till att fungera som intervjufrågor! Det är uppgifter som vi är intresserade av att se hur personerna tillsammans löser.

1. Gemensam historia – att minnas tillsammans

Vi skulle vilja att ni berättar lite om er själva och er historia, när och var ni träffades och vad som hände sedan.

Ni får börja var ni vill och själv bestämma hur och vad ni vill berätta.

2. Diagnos, sjukdom

Vad vi har förstått så har du P (personen med demensdiagnos) vissa svårigheter/problem med att X:a (använd det ord som personen med demens själv använder för att beskriva sig själv eller sina problem).

Alternativt, om så är möjligt: Vad vi har förstått så har du P fått diagnosen X (det ord som personen med diagnos använder plus eventuellt ord som anhörig använder).

- Skulle ni kunna berätta om svårigheterna/problemen med att X:a.

- Finns något område som inte alls har påverkats av X?

- Finns det något positivt som X har medfört?

3. En vanlig dag

Vi är nyfikna på hur en vanlig dag ser ut för er.

Skulle ni kunna berätta om vad ni gjorde igår?

Det ni gjorde tillsammans och det ni gjorde var och en för sig.

II. Bakgrundsuppgifter

Samlas genom frågor mot slutet av intervjun

	Man	Kvinna
Ålder:		
Gifta sedan:		
Tidigare äktenskap:		
Sammanboende sedan:		
Gemensamma barn – ålder:		
Barn 1		
Barn 2		
Barn 3		

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Barn 4		
Särkullsbarn - ålder:		
Barn 1		
Barn 2		
Barn 3		
Barn 4		
Födelseland (om annat än Sverige)		
Språk: talar annat språk än svenska flytande		
Utbildning:		
Grundskola/folkskola		
Fackskola		
Gymnasie		
Postgymnasial utbildning		
Yrke (huvudsakligt):		
Pensionär sedan:		
Socialt stöd		
Har ni haft någon som har hjälpt er med vardagliga uppgifter senaste veckan?		
Har ni haft någon som har hjälpt er med vardagliga uppgifter senaste månaden?		
Har ni kontakt med någon daglig verksamhet?		
Har ni kontakt med demensförening/anhörigförening		

Appendix D - Transcription conventions

.hh	In-breath.
oo	Quieter than surrounding speech.
Capital letters	Louder than surrounding speech.
< >	Slower than surrounding speech.
> <	Faster than surrounding speech.
()	Unheard or unclear utterance.
[]	Overlapping speech.
(.)	Pause in seconds.
\$	Smiley voice.
=	No discernible silence between utterances.
:	Prolonged speech.
↑ / ↓	Rising/falling intonation.
<i>Grey italic</i>	Non-verbal action.
* *	Delimit descriptions of one speaker's actions.
^ ^	Delimit descriptions of another speaker's actions.
Etc.	For each participant, a specific symbol is used.
*--->	Action described continues across subsequent lines.
---->*	Action described continues until the same symbol is reached.
>>--	Action described begins before the beginning of the excerpt.
.....	Action's preparation.
>>>>	Action's retraction.

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Articles I-IV

Article I

Hydén, L-C. & Nilsson, E. (2015). Couples with dementia: Positioning the “we”. *Dementia*, 14(6), 716-733.

Article II

Nilsson, E. (2017). Fishing for answers: Couples living with dementia managing trouble with recollection. *Educational Gerontology*, 43(2), 73-88.

Article III

Nilsson, E., Ekström, A. & Majlesi, A-R. (Forthcoming article in press). Speaking for and about a spouse with dementia: A matter of inclusion or exclusion? *Discourse Studies*, 20(6).

Article IV

Nilsson, E. & Olaison, A. (2017). What is yet to come? Couples living with dementia orienting themselves towards an uncertain future. *Qualitative Social Work*, (E-pub ahead of print).

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Papers

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