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Linn Hege Førsund

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Dementia in spousal relationships

- Exploring the views of spouses of partners living in long-term care

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Demens i parrelasjoner – Ektefellers perspektiver når partner bor i bo- og omsorgstilbud.

Denne avhandlingen peker på den sentrale betydningen som parrelasjonen fortsatt kan å ha for ektefeller etter at partneren deres med demens har flyttet til et bo- og omsorgstilbud, og fremhever betydningen av å tilrettelegge for dette. Fra tidligere forskning om demens i parrelasjoner vet vi at til tross for de mange tapene som ektefeller opplever, og de betydelige følgene som et demensforløp ofte har, kan det å opprettholde nær kontakt og gjensidighet i relasjonen være viktig. Imidlertid er hovedtyngden av forskningen om demens i parrelasjoner utført med fokus på ektefeller til personer med demens som fortsatt bor i hjemmet. Hensikten med denne avhandlingen var derfor å utforske parrelasjonens betydning sett fra ektefellens perspektiv når partner bor i bo- og omsorgstilbud, utforske hvordan parrelasjonen kan opprettholdes og hvilken betydning de fysiske og psykososiale omgivelsene kan ha for opprettholdelse av parrelasjonen.

Avhandlingen viser hvordan ektefellenes erfaringer etter flytting var dominert av opplevelsen av å miste fellesskapet i relasjonen med sin partner. Disse erfaringene var både relatert til den fysiske og mentale adskillelsen fra partneren, og følelsen av å være alene. Flyttingen betydde at ektefellene måtte finne nye måter å fortsette livet alene i hjemmet på, noe som kunne oppleves vanskelig på grunn av minnene om partneren som hjemmet representerte. Besøkene i bo- og omsorgstilbudet ble derfor viktig for å opprettholde rollen som ektefelle og styrke samhørigheten med partneren. Funnene viste hvordan ektefellene arbeidet for å opprettholde kontinuitet i relasjonen gjennom hele sykdomsforløpet ettersom sykdommen endret forutsetningene for kommunikasjon og samhandling. Imidlertid strevet ektefellene med å finne sin plass i bo- og omsorgstilbudet, og det ble tydelig at de fysiske og psykososiale omgivelsene ga ulike muligheter for samhandling. Særlig partnerens rom og tilgang på støtte fra helsepersonell var forhold som så ut til å ha betydning for ektefellenes mulighet til å opprettholde parrelasjonen med partneren i bo- og omsorgstilbudet.

Avhandlingen ble designet som en konstruktivistisk grounded theory studie. Kvalitative intervjuer, deltagende observasjoner med ektefeller og observasjoner av det fysiske miljøet i bo- og omsorgstilbudene dannet datagrunnlaget for studien. Syv menn og åtte kvinner i alderen 64 til 90 år deltok. Alle hadde langvarige relasjoner bak seg med en partner som nå led av moderat-alvorlig til alvorlig demens og bodde i et bo- og omsorgstilbud.

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Veiledere: Siri Ytrehus, Riina Kiik og Kirsti Skovdahl
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English abstract

Dementia in spousal relationships - Exploring the views of spouses of partners living in long-term care

Background
Facing dementia in spousal relationships may affect caregiving spouses' familiar means of communicating and interacting with their partners, impact their ability to maintain mutual support and connection, and cause them to live through several losses. Despite such grave consequences, some studies have found that maintaining close contact and feelings of reciprocity within their relationships is still crucial to many spouses. Given that dementia is inevitably progressive in its nature, relocation to a long-term care facility is often unescapable. Such a significant change in living conditions will influence spouses' life situation and their ability to maintain continuity in their relationship. However, studies specifically focusing on spouses' experiences in this life situation and their ability to maintain relationships after placing a partner with dementia in long-term care are scarce. What spousal relationships might mean for spouses following their partners' relocation to long-term care and how the long-term care setting may influence spouses' opportunities to maintain contact with their partners are areas that remain relatively unexplored.

Aim
The main aim of this thesis was to explore the meaning of spousal relationships for spouses of partners with dementia living in long-term care. In addition, this thesis also aimed to explore and describe how spouses maintain relationships with their partners with dementia living in long-term care, and how physical and social environments influence spouses' opportunities to maintain relationships when visiting a partner with dementia living in long-term care.

Design and methods
This qualitative study was designed using constructivist grounded theory. This approach was chosen because it enable the exploration of ongoing social and interactional processes and how participants construct meanings and actions in specific situations. Fifteen spouses were recruited from long-term care facilities in five different municipalities in Norway: they were seven men and eight women from 64 to 90 years of age. All the spouses had long-term relationships with a partner who suffered from moderate/severe to severe dementia and lived in long-term care. Interviews, participant observations with partners and observations of the physical environment in the long-term care facilities composed the data for the study. Applying a constructivist grounded theory design enabled concurrent engagement in the data collection and analysis. An emphasis on comparative methods and the development of increasingly focused memos guided the analysis.

Findings
The findings demonstrated that the spouses' experiences were dominated by the dynamic experience of losing couplehood following the relocation of their partner. These experiences were connected to the physical separation from their partner and the sense of being alone as well as to the loss of a shared past and the inability to share a mutual future. Despite these experiences, being involved and experiencing continuity in the relationship still seemed important. To maintain continuity in their spousal relationship, the spouses constructed togetherness by facilitating situations in which they could connect with their partners. To facilitate these situations, visit routines were altered and adapted to the progression of their partners' dementia. Opportunities for private interactions in individual rooms and proximity

to support from health personnel were highlighted as important environmental factors for the maintenance of relationships in long-term care.

Conclusion

This thesis highlight the central meaning the spousal relationship seem to have for spouses following their partners' relocation to long-term care. Relocating their partner and continuing life alone at home requires spouses to reconstruct their ways of living; however, their agency is challenged because of the memories of their partner their home represents. To counteract this experience of discontinuousness, spouses adjust their visiting routines and use everyday activities as continuity-preserving practices to maintain continuity in their relationship. This appears to be important for the maintenance of continuity in their relationships and as a means of reconstructing their known role and identity as a spouse. However, spouses also struggle to find their place in the long-term care facility, which may influence their opportunity to maintain continuity in their relationship. While the common areas seem to pose difficulties for reconnecting, the continuity-preserving practices that occur in individual rooms appear to be particularly important in terms of spouses' opportunities to maintain continuity in their relationships. In addition, health personnel may play a significant role in supporting spouses' use of continuity-reserving practices to maintain continuity in their spousal relationships.

Implications for practice and research

The findings of this study demonstrate the importance of acknowledging and supporting spouses' continuity-preserving practices in their efforts to maintain continuity in their spousal relationships both by providing spouses with support and by ensuring there are spaces in which these continuity-preserving practices can occur. This study recommends that further research be undertaken to investigate this important yet relatively unexplored subject area. A focus on expanding the sample to involve spouses with a wider range of characteristics, particularly in regard to gender, age and relational background is recommended. In addition, including long-term care facilities with different characteristics related to factors such as spatial organization, organizational setting, staff policy and different sizes and features is also likely to be important.

Forord og takksigelser

Når jeg nå sitter og skriver dette, markerer det slutten på en lang, lang reise. En reise som har tatt meg med til de høyeste topper av mestring og fornøyelse og de dypeste daler av usikkerhet og fortvilelse. For det er slik jeg har opplevd PhD-livet, litt som en berg-og-dal bane. Parallelt med denne reisen har også det vanlige livet gått sin gang. Det å leve livet er en fulltidsbeskjeftigelse, og er på ingen måte en reise rett frem det heller. Under PhD -perioden har livets ulike utfordringer og finurligheter til tider tatt så mye plass, at det å gjennomføre en doktorgrad mest har fremstått som et adspredelsesprosjekt. Men fokuset på fremdrift og troen på gjennomføringsevne har hele tiden vært der, selv om rammene ikke alltid har gjort det mulig å gå like fort frem som jeg hadde håpet. Derfor er jeg desto mer stolt nå, at jeg innenfor den tilmålte stipendiat tiden, har klart dette likevel. Imidlertid er ikke det å gjennomføre et PhD -arbeid et sololøp, selv om det til tider kan føles ensomt. Det er mange som skal takkes for å ha gjort det mulig å fullføre.

Først av alt må jeg takke Tom Olav. Kjære, snille mannen min som har vært klippen i livet mitt uansett oppturer og nedturer. Du har hatt troen på meg når det har buttet, og heiet meg frem når jeg har trengt det aller mest. Takk. Stor inspirasjon har jeg også hentet fra barna mine, Thea og Marius. De som aldri dømmer meg etter andre kriterier enn mine evner som mamma, og som hverken bryr seg om kompliserte analyser eller halvferdige manuskript. Dere har minnet meg om at dette tross alt bare handler om en doktorgrad. Da de spurte for en måned siden; hva skjer når du er ferdig med den avhandlingen mamma? Blir du pensjonist da? Så fikk det meg til å tenke på hvilken betydning denne avslutningen har for meg. Jeg blir heldigvis ikke pensjonist enda, men det føles litt som at det er nå livet begynner, i alle fall det profesjonelle livet, der alle muligheter nå ligger åpent for meg.

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Sist, men absolutt ikke minst, må jeg takke deltagerne i denne studien. De eldre ektefellene som tok meg imot, og delte sine personlige erfaringer om en ganske så personlig del av sine liv. Det betyr alt for meg at dere ville stille opp, og jeg har forsøkt alt som står i min makt å vise dere den respekten og verdigheten som dere fortjener gjennom dette arbeidet. Stor takk skal også rettes til kontaktpersonene ute i kommunene som gjorde rekrutteringen mulig. Uten dere hadde ikke dette arbeidet kommet til.

Linn Hege Førsund
Holmestrand, oktober 2016

List of papers included in this thesis

Paper I

Førsund, L. H., Skovdahl, K., Kiik, R., & Ytrehus, S. (2015). The loss of a shared lifetime: a qualitative study exploring spouses' experiences of losing couplehood with their partner with dementia living in institutional care. *Journal of Clinical Nursing, 24*(1/2), 121-130. doi:10.1111/jocn.12648

Paper II

Førsund, L. H., Kiik, R., Skovdahl, K., & Ytrehus, S. (2016). Constructing togetherness throughout the phases of dementia: A qualitative study exploring how spouses maintain relationships with partners with dementia who live in institutional care. *Journal of Clinical Nursing*, *25*(19/20), 3010-3025. doi: 10.1111/jocn.13320

Paper III

Førsund, L. H., & Ytrehus, S. (2016). Finding a place to connect: A qualitative study exploring the influences of the physical and social environments on spouses' opportunities to maintain relationships when visiting a partner with dementia living in long-term care. *Dementia*, Published ahead of print on June 17, 2016. doi:10.1177/1471301216656087

TABLE OF CONTENTS

1 INTRODUCTION

Facing dementia in spousal relationships may affect caregiving spouses' familiar means of communicating and interacting with their partners, impact their ability to maintain mutual support and connection, and cause them to live through several losses (Ablitt, Jones, & Muers, 2009; Evans & Lee, 2014; Pozzebon, Douglas, & Ames, 2016). Despite such grave consequences, some studies have found that maintaining close contact and feelings of reciprocity within their relationships is still crucial to many spouses when they still have their partner living at home (Davies, 2011; Graham & Bassett, 2006; Hellstrom & Lund, 2007; McGovern, 2011; Molyneaux, 2012). Given that dementia is inevitably progressive in its nature, successively increasing the depending of the person with dementia on others, relocation to a long-term care facility is often necessary during the course of this syndrome (Kenigsberg et al., 2016; Ray, Ingram, & Cohen-Mansfield, 2015). Such a significant change in living conditions will influence spouses' life situation and their ability to maintain their relationship with their partner. However, most of the research exploring the influences of dementia on spousal relationships has focused on the experiences of spousal caregivers of persons with dementia living at home (Daniels, Lamson, & Hodgson, 2007; Davies, 2011; Graham & Bassett, 2006; Harris, Adams, Zubatsky, & White, 2011; Hellstrom & Lund, 2007; Molyneaux, 2012; O`Shaughnessy, Lee, & Lintern, 2010). Some have concentrated on placement decisions (Graneheim, Johansson, & Lindgren, 2014; Johansson, Ruzin, Graneheim, & Lindgren, 2014; Kraijo, Leeuw, & Schrijvers, 2015), and others have explored the experience of spouses of older people in long-term care not specific to dementia (Braithwaite, 2002; Sandberg, Lundh, & Nolan, 2001). Furthermore, when experiences related to having a relative with dementia in long-term care have been explored, the specific experiences of spouses have received inadequate attention because their experiences are often aggregated with those of other family members or relevant other people (Bramble, Moyle, & McAllister, 2009; Crawford, Digby, Bloomer, Tan, & Williams, 2015; Gillies, 2011; Hemingway, MacCourt, Pierce, & Strudsholm, 2016; Rognstad, Sagbakken, & Nåden, 2015). Studies specifically focusing on spouses' experiences after placing a partner with dementia in long-term care have received scant attention. The few studies that have been published (Cahill, Doran, & Watson, 2012; Hennings, Froggatt, & Payne, 2013; Høgsnes, Melin-Johansson, Norbergh, & Danielson, 2014; Kaplan, 2001; Mullin, Simpson, & Froggatt, 2013) show that spouses experience several changes in their life situation after placing a partner in long-term care. These changes are related to both the alterations in their own role as a visiting spouse and to their sense of belonging to the relationship (Hennings et al., 2013; Høgsnes et al., 2014; Mullin et al., 2013). What spousal relationships might mean for spouses following their partners' relocation to long-term care and how the long-term care setting may influence spouses' opportunities to maintain contact with their partners are areas that remain relatively unexplored. This study was therefore designed to contribute to filling this gap in the research literature.

1.1 AIM OF THE THESIS

The main aim of this thesis is to explore the meaning of spousal relationships for spouses of partners with dementia living in long-term care. In addition, this thesis also aims to explore and describe how spouses maintain relationships with their partner with dementia living in long-term care, and how physical and social environments influence spouses' opportunities to maintain relationships when visiting a partner with dementia living in long-term care.

1.2 CLARIFICATION OF CENTRAL CONCEPTS APPLIED IN THE THESIS

A central concept in this thesis relates to the terms “spouse”, “spouses” and “spousal relationships”. Throughout this thesis, the term “spouse” will be used to refer to the caregiving partner, whereas the term “partner” will be used to refer to the person with dementia. Conceptually, a spouse is not considered equivalent only to a married partner; instead, “spouse” is used to describe a marital partner or common-law spouse who cohabited and was in a relationship with the person with dementia before and during relocation to long-term care. From this perspective, a spousal relationship is not judged or analysed according to the partners` formal relationship but rather understood as describing an ongoing relationship between two individuals, regardless of whether they are formally related as spouses. It is important to note for the forthcoming sections that this study emphasizes the views of spouses who are older people.

Another central concept in this thesis is long-term care. As myriad institutions and living arrangements exist within the health care system, defining institutional care for persons with dementia is conceptually challenging. Long-term care was chosen and is used throughout the thesis to describe a facility providing segregated care units for persons with dementia. Further explanation and discussion of how such facilities are built and organized are provided in forthcoming sections.

1.3 DISPOSITION OF THE THESIS

The ambition of this thesis is to provide insight into the meaning of spousal relationships for spouses with partners with dementia living in long-term care. This requires highlighting spouses' voices throughout the thesis. The forthcoming chapters are divided into seven parts. The next chapter, chapter two, provides insight into the theoretical perspectives framing this thesis and situates the thesis within the existing body of research. Chapter three provides comprehensive insight into the rationale for choosing constructivist grounded theory. Chapter four presents the methodological approaches that were used throughout the study and discusses the methodological choices and assumptions as well as the ethical considerations that were employed during the study. The fifth chapter summarizes the main findings in the three papers published from the study and provides a foundation for the sixth chapter, which discusses these findings and provides theoretical abstractions regarding how these results can be understood. The final chapter (chapter seven) concludes and discusses implications for practice and research.

2 BACKGROUND

2.1 CONSTRUCTING SELF, PLACE AND IDENTITY

Consistent with the emphasis on the more subjective and holistic way of recognizing and understanding dementia that has been highlighted in the field of dementia research over the past years, the importance of studying the social environment surrounding a person with dementia have been highlighted (Woods, 2005). In an article reviewing research developments related to family carers and persons with dementia, Nolan, Ryan, Enderby, and Reid (2002), note the importance of capturing the intersubjective dimensions of dementia by reflecting on the relational aspects of care. This study will explore one such dimension of the relational aspects by studying the meaning of spousal relationships in long-term care and how spouses maintain relationships with a partner with dementia in such a setting. To place the empirical contribution of this thesis into a theoretical framework, perspectives from symbolic interactionism were selected. Symbolic interactionism[1] focuses on the way in which people produce, maintain and alter meaning through interaction with each other, and through sharing symbols, such as vocal sounds (language), facial expressions, skin touch or hand movements (gestures) (LaRossa & Reitzes, 2009). A main premise of this perspective is that it is through adjusting to others in social relationships that we construct and reconstruct our sense of self (Charmaz, 1995, 2014).

The view of the self as primarily socially constructed in symbolic interactionism is based on Mead`s (1934) assumption of human beings' fundamental ability to mirror the self. Mead (1934) contended that through the conduct of social life and the sharing of language and gestures, individuals become self-conscious. He was a compelling advocate of the duality of the construction of self because he distinguished between the "I" and the "me". The self as "I" reflected the processual development of self, containing a person's response to others attitudes, being the self, or repertoire of selves as Sabat (2005) called it, with which the person act in social settings. Whereas the mirrored self, the self as a more stable object, was conceptualized by (Mead, 1934) as "me" and was asserted to contain relatively established

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[1] Symbolic interactionism is a perspective with a long history and several academic antecedents have contributed to its development (LaRossa & Reitzes, 2009). Most scholars agree that it was founded on the philosophical concepts established by George H. Mead (1934) and was later developed into a more methodological approach by Herbert Blumer (1969). Symbolic interactionism has also influenced the development of knowledge within the field of environmental gerontology (Chaudbury & Rowles, 2005).

and structured personal characteristics, values, belief and judgements through which individuals could define themselves. Based on influences from Mead (1934), among others, Thorsen (1998) describes the reconstruction of multiple selves as an ongoing task throughout the entire life course, and adds an important perspective to the understanding of symbolic interactionism regarding how we can understand the development and construction of self and identity in old age, which is relevant to this thesis. She contends that because of the frequent changes that occur and influence a person's life from a lifespan perspective, older people might become trained experts in mastering transitions and in preserving continuity despite the changing demands of their environment. The self, she clarifies, will be developed and reconstructed throughout the entire life, not in phases but as a result of being confronted with transitions and incidents that demand reorientation (Thorsen, 1998, p. 96). To achieve a sense of continuity despite experiencing such changes and discontinuity, continuity-preserving practices must be used. For older people, this might include reconstructing their life history in light of their new experiences, using reminiscence to reconstruct past memories and using everyday tasks to maintain continuity (Thorsen, 1998). We know that experiencing dementia in spousal relationships may cause significant changes in a couple's life situation and that these situational changes might influence the nature of the relationship between the partners (Evans & Lee, 2014). How spouses make sense of these changes may influence their response to- and interaction with their partner (de Vugt & Verhey, 2013; Gaugler & Teaster, 2006; Quinn, Jones, & Clare, 2016; Wong et al., 2012). The theoretical perspectives presented in this chapter may contribute to gaining a better understanding of the processes defining spouses' responses, efforts and strategies in such a situation and aid us in understanding how they maintain their relationships.

As I now turn to elucidating the concept of identity, it is important to note that certain tensions and differences appear within and between theories of identity regarding how this term is defined and conceptualized (Dittmann-Kohli, 2005; Kellner, 1992). Explicating the many theories of self and identity will be too extensive; however, I will nevertheless draw some specific lines here in order to clarify some distinctions of relevance for this thesis. On the one hand, there are the theories that define identity in terms of a substantial self as a discoverable and essential part of the self, thus determining who a person is (Kellner, 1992). On the other hand, other theories view identity as continually constructed and reconstructed through social interactions and adaption to different roles, tasks and contexts throughout the life course (Dittmann-Kohli, 2005). Taking the latter perspective, which will serve as the basis for the understanding of identity in this thesis, means assuming that a person may hold various identities that contribute to constructing his or her self (Dittmann-Kohli, 2005; Rubinstein & de Medeiros, 2005; Sabat & Harré, 1992) and that identity construction may be understood as an enduring and life-long task (Dittmann-Kohli, 2005; Thorsen, 1998). Identity, especially in the sense of personal identity and understood as “who I am”, is a term that is perhaps foremost associated with the tradition of psychology (Dittmann-Kohli, 2005). The self as an object, “me”, might in some cases be easily confused with personal identity, which is often described as the identity that reflects a person’s way of mirroring herself and defining, locating and differentiating from others (Charmaz, 1995; Sabat & Harré, 1992). Self, self-concept and identity are terms that are therefore sometimes used interchangeably (Dittmann-Kohli, 2005). Role identity, on the other hand, may be more associated with sociology, describing the specific characteristics of the roles that define activities and obligations within social structures (Dittmann-Kohli, 2005). Among gerontologists and within the lifespan research, age identity is often an essential topic, particularly in relation to the question of whether one feels younger than, the same age as or older than one’s true age (Dittmann-Kohli, 2005). Age identity is also related to role identity or perhaps most commonly to the loss of roles and role identity, which is often described as characterizing old age (Thorsen, 1998). In this relation, there are also gendered identities that, consistent with Mead`s (1934) conceptualization of the self as a process, might be considered as unfixed, complex and constructed (Dittmann-Kohli, 2005). In addition, gendered identities might be historically and culturally bound and must also be linked with different traditions and assumptions prevailing in different generations regarding gendered roles (Thorsen, 1998).

Depending on a person’s affiliation with the social collectives, identities may be negotiated and valued against the collectives in which the person takes part, and new identities may be constructed and shaped trough interaction with others (Mead, 1934). Simultaneously, social identities may also be bestowed on individuals by other people, and individuals may adopt collective identities (Charmaz, 2014). Individuals may also choose to play out different identities depending on the social and situational context, as described in Goffman`s dramaturgical view on people’s presentation of self (1959). These social collectives could be larger, demographic groups such as gender, ethnicity or age; for example, identification with a certain cohort or generation may reflect a person’s age identity. Identities might also be played and constructed in smaller social collectives, such as family units or in spousal relationships (Dittmann-Kohli, 2005). The latter constitute an important collective in connection to the focus of this thesis. Relational identity is described in the literature (Gergen, 2009, 2015; Rogers-de Jong & Strong, 2014) as a type of identity that defines how individuals in spousal relationships may share a mutual identity as an expression of their experience of togetherness. When viewing identity in this manner, the couple's relational identity belongs to neither of the individuals in the relationship; rather, it is co-constructed between them (Gergen, 2009). This means that even if the members of a couple hold a shared identity that is not theirs but belongs within the relationship, the partners may identify with it and use it as a reflection to construct and reconstruct their own self and identity. Rogers-de Jong and Strong (2014) described how couples who shared a strong relational identity expressed a sense of "we-ness" as a manifestation of their mutual understanding of the value of their existing relationship.

To accentuate the shared experiences of living with dementia in spousal relationships, couplehood has emerged in the dementia literature as an important concept (Evans & Lee, 2014). Couplehood can be described as partners' experiences of friendship, intimacy, trust and support within the relationship (Evans & Lee, 2014; Hellstrom & Lund, 2005; Hellstrom & Lund, 2007; Kaplan, 2001; McGovern, 2011; Molyneaux, 2012; Wadham, Simpson, Rust, & Murray, 2015). Both Baikie (2002) and Mullin, Simpson, and Froggatt (2011) showed that despite the many changes caused by dementia – i.e., loss of physical intimacy, lack of reciprocal communication, inability to share mutual activities or memories and loss of emotional and practical support – spouses still expressed a strong sense of commitment to their relationship. Similar findings were identified in a meta-synthesis exploring the impact of dementia on relationships and couplehood conducted by Wadham et al. (2015), who stated that: "Couples' strong sense of commitment to each other and their struggle to hold on their shared identity as a couple was highlighted in all reviewed papers" (p. 467). Thus, couplehood can be understood as the relationship between committed individuals that is characterized by an "us" identity or a sense of "we-ness" (Davies, 2011; Kaplan, 2001; Kaplan, Ade-Ridder, Hennon, Brubaker, & Brubaker, 1995). However, even though several studies have noted the strong relational identity that may characterize some couples when they live at home, some studies have also asserted that experiencing couplehood in dementia must be considered an iterative process that evolves over the course of dementia progression. Moreover, those experiences may change from day to day and from person to person (Graham & Bassett, 2006; Hellstrom & Lund, 2005; Hellstrom & Lund, 2007; Merrick, Camic, & O'Shaughnessy, 2016; O`Shaughnessy et al., 2010). Merrick et al. (2016) suggested that couples` process of adjusting to the situation of living with dementia could be recognized as an ongoing fluctuation between loss-oriented and reconstruction-oriented positions, which reminds us of the importance of recognizing the interchangeability that characterizes the situation of living with dementia in close relationships.

Understanding spousal relationships from this perspective requires accepting that the maintenance of relationships is a continuous process, through which partners continually construct and maintain (or undermine) their own selves and each other's selves'. Along with progression of dementia, it is likely that the reciprocal maintenance of selves will be challenged, rendering the person with dementia dependent on the surrounding social environment to preserve his or her sense of self (Sabat, 2005). Gubrium (2005) states that adopting a medical perspective of people severely affected by dementia would imply considering only the cognitive deficits when determining the presence or absence of selfhood of a person with dementia. Taking an interactionist perspective, he argues, may offer more possibilities because an "unseen" self may be preservable despite a person's deficits and may become visible through interactions with the social environment and the interpretive efforts of people close to the person. Maintenance of self, both individual selves and relational identities, will thus be dependent on the relationship because the self is not only something we carry with us but also something we construct and maintain through social relationships. However, as Gubrium (2005) contends, whether spouses choose to despair or to sustain their partners' self and their relational identity despite severe dementia may also depend on the specific social world in which they are oriented. There may be several factors influencing spouses' opportunities to maintain their relationship with a partner with dementia living in long-term care; for example, their relational history with their partner, personal characteristics and resources, experiences of symptoms and challenges following the progression of dementia and the context in which these factors are relevant.

The construction and reconstruction of self and identity always occurs in a context that represents opportunities and boundaries for people's self-maintenance practices (Dittmann-Kohli, 2005). The feature of the long-term care context under study is that it is built and organized as a public institution with certain environmental features and involves several stakeholder groups that adopt different roles and identities (Garsjø, 2008). In addition, the long-term care setting also represents the home of the person with dementia and constitutes the place where social relationships are maintained (Falk, Wijk, Persson, & Falk, 2013). To understand how such a complex environment might influence spouses' interactions with their partners, we must study both the environment as a physical structure providing spaces for interactions and how spouses might use these spaces. Place, as a concept, refers to the sense of being in place, including how one may feel connected with one`s self, and one`s physical and social environments (Chaudbury & Rowles, 2005). This is consistent with the assumptions of symbolic interactionism, which emphasize the continuous reciprocal processes occurring between the individual, collectivity and environment (Charmaz, 2014). Chaudbury and Rowles (2005) argue that "the life experience of the self is strongly influenced by interaction with an "other", whether that other is one`s fellow human beings or the residential environment" (p. 13). This is consistent with the symbolic interactionist premise stating that people form meanings from what they do; thus meanings are tied to practice (Charmaz, 2014). The establishment of physical, social and personal bonds to an environment may transform "spaces" into "places" and thus create a sense of being in place as an expression of place attachment and continuity (Rowles & Bernard, 2013). Attachment to place is a set of feelings that emotionally bond a person to a place because of that place's role as a setting for experience (Rubinstein & Parmelee, 1992). Thus, place attachment is acknowledged as an important aspect of old age, because it may represent a process of maintaining continuity, self and identity (Wahl & Oswald, 2010). Studying these processes as spouses' experience them is therefore important. The experiences of living through dementia in spousal relationships and the relocation of a partner to long-term care may influence spouses' experiences of maintaining a continuing self.

2.1 LIVING WITH DEMENTIA IN SPOUSAL RELATIONSHIPS

Family caregivers play a fundamental role in caring for persons with dementia (Brodaty & Donkin, 2009; Wimo, Jönsson, Bond, Prince, & Winblad, 2013), and WHO considers these caregivers one of the cornerstones in dementia care worldwide (World Health Organization, 2012). In Norway, family caregivers contribute extensively to the care of elderly people with dementia (Vossius et al., 2015). Even though no legal obligation to care for a family member exists in Norway, the normative obligation still seems to be strong in families (Ulstein, 2007). Another incentive for providing care is a commitment to continue relationships, which is considered a strong motivation, especially among spouses (Quinn, Clare, & Woods, 2015). Commitment may be influenced by love and affection for another person, and it can be morally driven, either because a person lacks alternatives or due to a sense of duty stemming from external pressures or to feelings of obligations to the person afflicted with dementia (Quinn et al., 2015). The largest proportion of family caregivers are spouses, followed by adult children and children-in-law, and women still outnumber men (Brodaty & Donkin, 2009; Wimo et al., 2013; World Health Organization, 2012). Spouses are in some circumstances considered a vulnerable group of caregivers because they are often older and may suffer from multiple chronic health conditions (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). Spouses caring for a partner with dementia may have a fourfold risk of developing symptoms of depression compared with non-dementia caregiving spouses (Joling et al., 2010). Studies also indicate that spouses are generally more at risk of experiencing caregiving burden than other family members, which may contribute to mental health problems and reduced well-being (Ask et al., 2014; Pinquart & Sörensen, 2003b, 2011; Schultz & Martire, 2004). In general, spouses often provide more care and are more reluctant to seek help than other family members (Friedemann & Buckwalter, 2014; Pinquart & Sörensen, 2011). Focusing on spouses as caregivers is therefore highly relevant.

The chronic and progressive development of dementia, which inevitably results in the loss of a person`s physical abilities and cognitive function, might have various interacting causes (Kenigsberg et al., 2016). Alzheimer`s disease occurs most frequently, followed by vascular dementia, Lewy Body dementia and the frontotemporal types of dementia (Grossman, Bergmann, & Parker, 2006; Mitchell et al., 2012; Pountney, 2008). Some scholars have stated that the diagnosis of dementia alone conveys little about the most suitable approach for meeting the needs of the person with dementia and their family (Nolan et al., 2002; Woods, 2005). By taking a symbolic interactionist stance in this thesis, the challenges and difficulties influencing the interactions between spouses and their partners with dementia are weighted more heavily than the biomedical effects resulting from the different diagnoses of dementia. From the view of spouses, dementia will likely influence their daily lives as well as the dynamics of their spousal relationship and everyday interactions (Ablitt et al., 2009; Baikie, 2002; Evans & Lee, 2014; Quinn, Clare, & Woods, 2009). Their experiences are therefore the focus of the forthcoming sections.

Providing care for a partner with dementia is often a long-term, evolving process that involves several key phases due to the progressive development of symptoms (Kenigsberg et al., 2016). These phases can be linked to the challenges of living with dementia and are often divided into three stages, which are typically classified as mild, moderate and severe (World

Health Organization, 2012). The first stage, often called mild dementia, is described as the time when forgetfulness, word-finding problems, difficulties in keeping track of time and places, and decision-making challenges may manifest. Mood and behaviour may also change (Grossman et al., 2006). The initial indications that something is wrong may materialize slowly for spouses, and because of the slow and gradual decline that characterizes the progression of dementia, these symptoms may be overlooked and attributed to "normal aging" in the beginning (Clare, 2002; Prakke, 2012; Quinn, Clare, Pearce, & van Dijkhuizen, 2008). Particularly in long-lasting spousal relationships, gradual changes requiring adjustments in daily life may be easily overlooked if the partners are so interconnected that gradual role shifts are not acknowledged initially (Evans & Lee, 2014). Compensating strategies may also occur unintentionally among the partners (Clare, 2002), including minimizing the problems of the partner with dementia (Quinn et al., 2008). When cognitive difficulties and/or changes in behaviour become more noticeable, normalizing what is occurring is no longer possible. This may encourage spouses to reach out for help (Robinson, Clare, & Evans, 2005). Even if the disclosure of a dementia diagnosis is a severe shock (Bamford et al., 2004; Derksen, Vernooij-Dassen, Gillissen, Olde Rikkert, & Scheltens, 2006), spouses may also experience relief because they have confirmation of their suspicions and can gain a better understanding of their partners' difficulties (de Vugt & Verhey, 2013; Derksen et al., 2006; Prakke, 2012). The time from the initial acknowledgement of change to receiving a diagnosis of dementia has often been described as a period dominated by worry, frustration and suspicion (Clare, 2002; Prakke, 2012). A diagnosis may help spouses make sense of what is happening and aid them in attributing some of the difficulties within the relationship to dementia, rather than ascribing everything to reduced interpersonal dynamics (Baikie, 2002).

As dementia progresses into the moderate stage, the functional capability of the person living with dementia is more restricted, and this will subsequently require spouses' continuous engagement in care (de Vugt & Verhey, 2013; Gaugler & Teaster, 2006), affecting them as individuals as well as influencing their relationship with their partner. Providing care for a partner with dementia is documented to have several negative consequences, often described as caregiver burden in the literature. Caregiver burden is multidimensional and covers responses to the physical, psychological, emotional, social and financial stressors associated with the caregiving experience (Etters, Goodall, & Harrison, 2008). Many of the difficulties associated with the progression of dementia may potentially influence spouses' experiences at this stage. For example, communication problems, related to both speech and comprehension, become more severely affected in this stage and may influence spouses' interactions with their partner (Large & Slinger, 2015). The increasing impairment of cognitive function is often followed by more severe mood and behavioural changes (World Health Organization, 2012). Although evidence is inconclusive (Ornstein & Gaugler, 2012), behavioural disturbances such as aggression, agitation and nighttime wandering seem to be associated with caregiver burden. Moreover, spouses experience losses such as the loss of personal freedom to engage in cherished hobbies, the loss of social interactions with others outside their home, the loss of the companionship of their partner and the loss of control over their situation (Chan, Livingston, Jones, & Sampson, 2013; Large & Slinger, 2015).

Despite the grave effects described above, we now know that some caregivers also have positive experiences related to their involvement in caregiving, although this is less emphasized in the literature (Lloyd, Patterson, & Muers, 2014). Some of the favourable aspects of caregiving for spouses described in the literature include feelings of gratitude and emotional rewards gained through feeling appreciated, increased role satisfaction and experiences of personal growth when mastering the caregiving process (Lloyd et al., 2014; Netto, Jenny, & Philip, 2009; Peacock et al., 2010; Sanders, 2005). These positive caregiving experiences are associated with greater well-being and decreased levels of burden and depression in a meta-analysis by (Pinquart & Sörensen, 2003a). To understand these positive experiences, it is important to identify the aspects that influence their occurrence. Some aspects that have been emphasized include the occurrence of enriching events in daily life (Carbonneau, Caron, & Desrosiers, 2010; Pinquart & Sörensen, 2004) and feelings of competence in performing the caregiving role (Pinquart & Sörensen, 2004; Quinn, Clare, & Woods, 2012). Experiencing low role captivity and being motivated to assume the caregiving role have also been mentioned as factors associated with experiences of finding meaning in caregiving (Quinn et al., 2012). However, the most important influencing factor described in the literature seems to be the quality of the relationship between spouses' and their partners. Several studies have indicated that the quality of both the previous and the existing relationship influence spouses' caregiving experience (Harris et al., 2011; Hellstrom & Lund, 2005; Hellstrom & Lund, 2007; Prakke, 2012; Quinn et al., 2009; Quinn et al., 2012; Shim, Barroso, & Davis, 2012; Shim, Barroso, Gilliss, & Davis, 2013). In the literature, better quality in the previous and daily relationship are related to increased well-being, reduced burden and stronger involvement in the care of their partner among spouses (Carbonneau et al., 2010; Lloyd et al., 2014). Studies have also indicated that positive reciprocity can contribute to increased well-being and that increased well-being is associated with less depression and distress for the caregiving spouse (Braun, Mura, Peter-Wight, Hornung, & Scholz, 2010; Monin, Schulz, & Feeney, 2015).

As people with dementia reach the last and most severe stage of dementia, difficulties such as severe memory disturbances; unawareness of time and place; problems recognizing family, friends and familiar objects; mobility difficulties; and increased need for assisted self-care may make them entirely dependent on assistance (World Health Organization, 2012). Additional challenges may involve, for example, aggression or nonverbal agitation, and the person's ability to participate in verbal communication may be severely reduced. This is the stage during which long-term care is required in most cases (Ray et al., 2015). While placement in care may previously have been considered the endpoint of family caregiving, it is now understood that many caregivers remain involved, albeit with different levels of intensity and contribution (Gaugler, 2005). Some studies have described placing a partner in long-term care as a relieving factor for caregiver burden among spousal caregivers (Gaugler, Mittelman, Hepburn, & Newcomer, 2009; Gaugler, Roth, Haley, & Mittelman, 2008). However, the majority of studies indicates that this is not the case, suggesting that many spouses still experience the same level of burden (Almberg, Grafstrom, & Winblad, 1997; Gaugler, Pot, & Zarit, 2007; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Schultz & Martire, 2004) or even increased distress (Ask et al., 2014) following placement. Several factors may influence the experience of burden after placing a partner in long-term care. For some spouses, relocating their partner may imply greater freedom in deciding what to do in their everyday life; however, relocation might also provoke feelings of guilt and remorse about "giving up" caring for their partner at home (Høgsnes et al., 2014). Some studies have also found spouses' fading ability to communicate with their partner and the lack of reciprocity in conversations to be important factors that negatively influence spouses during this stage of progression (Hennings et al., 2013; Mullin et al., 2013).

In addition to feelings of guilt and lack of feeling close to their partner, spouses' grief reactions can also provoke negative responses to a partner's relocation. Fiske and Jones (2005) described bereavement, especially the loss of a spouse, as one of the most stressful events that can be expected to occur in later life. Even though these spouses` partners are still living, grief is a normal reaction because it is a response to the significant loss associated with being physically separated from their partners on daily basis (Crawford et al., 2015). Two concepts of grief related to dementia in particular have been reflected in the caregiving literature: anticipatory grief and ambiguous loss (Chan et al., 2013; Dupuis, 2002; Frank, 2008; Large & Slinger, 2015). Anticipatory grief was conceptualized by Rando (2000) as grief that is experienced when anticipating losses in the future. However, it can also encompass losses that are presently occurring and those already experienced (Frank, 2008). Ambiguous loss is defined as a situation in which a loved one is perceived as physically present while psychologically absent or physically absent but psychologically present (Boss & Couden, 2002). Grieving the loss of a partner who is still physically present but simultaneously mentally unreachable was noted as a feature of experiencing dementia in the spousal relationship in the interview studies performed by Hennings et al. (2013) and Mullin et al. (2013). The spouses interviewed by Hennings et al. (2013) described this type of grieving as a grief without beginning or end that could not be halted as long as their partner was still alive. Spousal caregivers' anticipatory grief may occur during all stages of dementia; however, the most severe grief reactions occur in the moderate and late stages when ambiguous losses are increasingly apparent, especially relationship-related losses, causing stress reactions and higher risk for the development of depression and burden (Chan et al., 2013; Large & Slinger, 2015; Noyes et al., 2010). Placing a partner in care may exacerbate feelings of guilt and failure among spouses, which are core features related to anticipatory grief and may worsen an already difficult situation (Chan et al., 2013).

Research has also indicated that spouses may struggle to adjust to their new role following placement of their partner in long-term care (Crawford et al., 2015). On the one hand, the adjustment processes seem to be related to finding their role as a visiting spouse in terms of both determining how often they should visit (Hennings et al., 2013) and engaging in the surveillance opportunity that visiting represents for some spouses (Mullin et al., 2013). Crawford et al. (2015) showed that some spouses also found it difficult to relinquish their caregiving role because they still wanted to be involved. Cahill et al. (2012) disclosed that the gradual evolution of a relationship with staff involving trust was important for spouses' own role adjustment as caregivers in the long-term care setting. The struggle to adjust to a new role after the placement of their partner also seemed to be connected to spouses' difficulties in finding their own role as a solitary partner in their relationship (Crawford et al., 2015). Kaplan (2001) described this as adjusting to the role of an "unmarried married". Some spouses interviewed in the studies by Hennings et al. (2013) and Mullin et al. (2013) actually expressed that their role would be clearer if their partner had actually died because then they could have moved on with their own lives. Despite these challenges and the fact that most spouses continued in their role as a helping caregiver after the relocation of their partner, Mullin et al. (2013) found that the majority of the spouses they interviewed seemed to identify more with the role of husband or wife than with the role of "carer" following the placement of their partner with dementia in care.

As this comprehensive review has demonstrated, several factors seem to influence spouses' situation after relocating a partner with dementia to long-term care; however, few studies have investigated the meaning of the spousal relationship from the perspective of spouses. This underlines the importance of concentrating on the meaning of spousal relationships for spouses after moving their partner to long-term care in addition to more explicitly exploring how spouses maintain relationships with their partner with dementia.

2.2 UNDERSTANDING SPOUSAL RELATIONSHIPS IN LONG-TERM CARE

Of the nearly 47 million people estimated to be living with dementia worldwide (Prince et al., 2015), at least 77 000 are estimated to live in Norway (Alzheimer Europe, 2013)[2]. Norway has a well-developed welfare system established to care for persons with dementia and other groups of patients. The healthcare system is mainly divided into community care and hospital-based care and is based on the notion of offering equal access to health care for all citizens irrespective of social status, income or place of residency (Stamsø, 2012). Long-term care for persons with dementia is provided within the primary health care services (community care) and is owned and operated by local governments (Ytrehus, 2002). It is estimated that approximately 40% of persons with dementia are living in long-term care (Høyland, Kirkevold, Woods, & Haugan, 2015). Persons with dementia requiring long-term care are assigned to ordinary nursing home wards, specialized care units for persons with dementia or sheltered housing for persons with dementia (Kirkevold, Eek, & Engedal, 2012). The different conceptualizations of long-term care are mainly rooted in the major development of institutional care that has occurred over the past few decades, as well as the decentralization of community care (Stamsø, 2012). In addition, even if this is not a unique Norwegian

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[2] Unfortunately, studies providing precise estimates of the prevalence of dementia in Norway are lacking (Norwegian Ministry of Health and Care Services, 2015a). However, Alzheimer Europe estimated that at least 77 000 people were living with dementia in Norway in 2012, representing 1,56% of the total population of 4 960 482 (Alzheimer Europe, 2013). Because this estimate is based on people who have been diagnosed with dementia, the actual prevalence is likely underestimated (Norwegian Ministry of Health and Care Services, 2015a).

phenomenon (see, for example, Marquardt, Bueter, and Motzek (2014)), the construction of new long-term care facilities and the renewal of older buildings containing nursing homes have resulted in a variety of housing and living arrangements for the frail elderly and persons with dementia (Ytrehus, 2002). Some facilities are in close proximity to regular nursing homes, whereas others are built and operated as sheltered homes with 24-hour nursing and care services (Bank, 2009). Differences also exist in their physical design, size, and location (Høyland et al., 2015). However, despite these variations in housing arrangements, the care services provided within the different facilities are presumed to be very similar; differences among them mainly relate to payment policies and their legal frameworks (Ytrehus, 2002). Ideally, these facilities should be built and organized to sustain a sense of community among patients, they should be characterized by domestic qualities and good living environments, and they should be organized to provide person-centred care that is integrated into daily routines and everyday life (Bank, 2009; Daatland, Høyland, & Otnes, 2015; Gjøra, Eek, & Kirkevold, 2015; Høyland et al., 2015). In general, most Norwegian long-term care facilities are designed with homelike features and offer individual rooms for residents (Høyland et al., 2015; Kirkevold et al., 2012). This is in accordance with international standards and the research literature regarding the optimal environmental design for persons with dementia living in long-term care (Calkins, 2009; Davis, Byers, Nay, & Koch, 2009; Day, Carreon, & Stump, 2000; Marquardt et al., 2014). A spatial organization that provides understandable environments and supports wayfinding is a characteristic emphasized in the literature that facilitates independence and autonomy as well as community among patients (Marquardt, 2011; Marquardt & Schmieg, 2009). The literature also emphasizes access to individual rooms to provide opportunities for patients to have a private life (Davis et al., 2009; Day et al., 2000; Verbeek, van Rossum, Zwakhalen, Kempen, & Hamers, 2009).

Although the research base on housing design for persons with dementia is comprehensive, a modest number of studies (Chapman & Carder, 2003; Innes, Kelly, & Dincarslan, 2011; Verbeek, van Rossum, Zwakhalen, Ambergen, et al., 2009) have considered how the environment can be designed, organized and used to promote the maintenance of spousal relationships. This is also a subject that is overlooked in Norwegian guidelines about housing design in dementia care, such as those provided from The Norwegian State Housing Bank (2009), and in the most recently published national policy plans and strategies concerning dementia care (Norwegian Ministry of Health and Care Services, 2007a, 2013, 2015a, 2015b). In their review of Norwegian housing – and living arrangements for persons with dementia, (Høyland et al., 2015) found that even though the research base is explicit about the importance of designing and organizing a physical environment that may support and encourage ongoing social relations, there is a lack of studies providing evidence and descriptions of practical implementation.

Studying the reciprocal interaction between person and environment has been an important focus in environmental gerontology for years (Wahl & Oswald, 2010; Wahl & Weisman, 2003). An important insight from this research is that the environment cannot be solely defined by its physical characteristics, it must also be understood and positioned in the context of ongoing social interactions and cultural practices (Chaudbury & Rowles, 2005; Wahl & Oswald, 2010). Several studies (Bramble et al., 2009; Cohen et al., 2014; Gaugler, 2005; Norheim & Sommerseth, 2014; Rognstad et al., 2015) have noted that family caregivers still consider participation and involvement as important after placing their relative in care, even though the involvement of family caregivers in long-term care has been traditionally limited (Gaugler, 2005). Being involved can be especially important for spousal caregivers, who may have lived with their partner most of their lives and therefore may benefit considerably from maintaining their relationship with their partner following placement (Crawford et al., 2015). Maintaining relationships is important not only for spouses. In a recent meta-synthesis emphasizing the experience of relations among persons with dementia, researchers also identified the importance of continued relations with family and friends for persons with dementia after relocation to long-term care (Eriksen et al., Manuscript accepted for publication). As relocation to a long-term care facility separates spouses from their partners on a daily basis, visiting is emphasized as an important means of maintaining relationships and remaining involved in long-term care (Bramble et al., 2009; Gladstone, 1995; Nolan & Dellasega, 1999; Sandberg et al., 2001). However, there are few studies exemplifying how the physical environments in long-term care for persons with dementia should be organized and adapted to allow visiting and aid spouses in maintaining contact with their partner with dementia (Innes et al., 2011). This underscores the importance of exploring how physical and social environments influence spouses' opportunities to maintain relationships when visiting a partner with dementia living in long-term care, which is the focus of this thesis.

3 RESEARCH DESIGN

3.1 CHOOSING GROUNDED THEORY

Determining which research design provides the best opportunities to appropriately respond to the research questions proposed in a study is a primary concern in all research activities (Jeon, 2004). It was also a quest in this project. A qualitative design was preferred because of the general suitability for answering research questions focusing on exploring people`s experiences and everyday manner of acting (Silverman, 2005, 2006). However, qualitative research involves myriad different approaches connected to different paradigms, traditions and historical contexts (Creswell, 2007; Denzin & Lincoln, 2011; Savin-Baden & Howell Major, 2013; Silverman, 2005). Constructivist grounded theory was chosen as the approach that best fit the aim of this study. First, because it uses systematic yet flexible guidelines to construct theory from inductive data (Charmaz, 2014). The inductive approach that guides the method was judged appropriate because the focus of this study was to investigate a phenomenon that has been relatively unexplored. For the same reason, the theory’s systematic approach, which allows for ongoing data collection and analysis throughout a study, was also considered relevant because of the benefit gained by concentrating on subjects that participants emphasize (Charmaz, 2014). In addition, the use of iterative strategy to move back and forth between data and analysis and the use of comparative strategies to explore expressions of meanings, actions and processes were also considered relevant (Corbin & Strauss, 2008). Last but not least, the study of action is a central element in grounded theory, and instead of viewing action as stemming from within individuals, constructivist grounded theory emphasizes that action arises from social relationships (Bryant & Charmaz, 2007). As the aim of this study was to investigate the maintenance of spousal relationships and the meanings and processes connected to the practices spouses use to maintain these relationships, the appropriateness of selecting constructivist grounded theory was also confirmed.

Choosing a research design is not entirely related to selecting a methodological approach. It is equally important to be attentive to one’s worldview as a researcher. This worldview, or paradigm (Guba & Lincoln, 2008), will act as a guiding principle and encompass the ontological, epistemological and methodological assumptions that shape both the construction of knowledge and the possible interpretations of the findings developed from it (Denzin & Lincoln, 2011; Savin-Baden & Howell Major, 2013). Grounded theory cannot be articulated as a simple method or approach; rather, it must rather be understood as a collection of approaches, methodologies and even ontological and epistemological considerations regarding how to construct new knowledge through research (Bryant & Charmaz, 2007). Being explicit about the ontological and epistemological underpinnings guiding this study and the interpretation of the different versions of grounded theory is therefore important. This is the subject of the next section, which also addresses the practical implications of selecting constructivist grounded theory.

3.2 ONTOLOGICAL AND EPISTEMOLOGICAL ASSUMPTIONS OF GROUNDED THEORY

Several different forms of grounded theory have emerged since the two sociologists Barney Glaser and Anselm Strauss initially presented grounded theory in the middle of the 1960`s (Savin-Baden & Howell Major, 2013). At the time, the positivistic tradition had a strong foothold within the sociological research communities in the United States, and quantitative methods held an ever more dominant position at the expense of qualitative-oriented research approaches (Alvesson & Sköldberg, 2009; Strauss & Corbin, 1997). When Glaser and Strauss published their book, *The Discovery of Grounded Theory: Strategies for Qualitative Research* (1967), their work was considered a counterpoint to the increasingly disciplinary trends within the research communities at that time (Strauss & Corbin, 1994). They sought to demonstrate that results from qualitative studies conducted using systematic methods could have as much significance as studies using statistical analysis (Bryant & Charmaz, 2007). Through their successful collaboration in the studies of dying patients in US hospitals (Glaser & Strauss, 1965, 1968), these authors developed a systematic methodological strategy to generate theory by analysing data, which was intended to serve as a clear foundation for systematic qualitative research[3] (Allen, 2010).

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[3] It is important to note that even though grounded theory typically has been associated with qualitative methods, the original intention of *The Discovery of Grounded Theory* was to inform readers how to generate theory from both qualitative and quantitative data. Scholars worldwide still perform and publish mixed methods grounded theory studies (Walsh et al., 2015).

Even though classic grounded theory[4] is currently claimed to be ontologically and epistemologically flexible (Walsh et al., 2015), the initial grounded theory methodology was situated in a positivistic paradigm (Guba & Lincoln, 2008). The original grounded theory had a clear epistemological orientation that assumed that the world and its reality can be discovered, explored and understood (Allen, 2010). The word “emerge” is, for example, a widely used term in the initial description of the methodology (Glaser & Strauss, 1967). The researcher was regarded as a “tool” who could objectively observe the "real" world that was waiting to be discovered (Bryant & Charmaz, 2007). These epistemological assumptions and the logical and systematic approach of grounded theory methods reflected Glaser`s rigorous quantitative training (Charmaz, 2014; Jeon, 2004). Since the mid-1960s, Glaser has made significant contributions to the improvement of classic grounded theory through his academic work and troubleshooting seminars (Walsh et al., 2015).

Strauss came from a somewhat different research community. Through his doctoral studies at the University of Chicago, he was introduced to the sociologists Herbert Blumer and George Mead, who belonged to what became known as the so-called “Chicago school” – a community of pragmatism-oriented researchers at the University of Chicago (Bryant & Charmaz, 2007). Pragmatists considered people to be self-aware beings with the ability to reflect on themselves and their actions (Benton & Craib, 2011). They held that the source of knowledge was to be found in socially shared problems and that knowledge in itself was regarded as a social phenomenon. With roots in pragmatism, symbolic interactionism was launched as a theoretical perspective of the study of social life (Blumer, 1969), a perspective by which Strauss was greatly inspired (Allen, 2010; Covan, 2007). Strauss unfortunately died in 1996, but his legacy still has considerable influence on grounded theory, particularly through the ongoing work of his collaborative partner, Juliet Corbin (2008, 2014).

When considering the foundations from which constructivist grounded theory developed, we must examine social constructionism (Bryant & Charmaz, 2007). Even though it was relatively evident in the first edition of *Constructing Grounded Theory* (Charmaz, 2006), Charmaz is more direct in placing constructivist grounded theory in a social constructionist

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[4] C*lassic grounded theory* refers to the methodology and subsequent paradigm originally presented in *The Discovery of Grounded Theory*, which have been extensively elaborated by Glaser in several subsequent publications.

paradigm in her newest edition of the book (Charmaz, 2014). She embraces the ontological assumption of a social reality that is multiple, processual and constructed and assumes that knowledge is constructed through interactions between those studying and those being studied (Charmaz, 2014). Social constructionism was introduced as a concept in the mid-1960s by the German sociologists Berger and Luckmann in their book, *The Social Construction of Reality* (Berger & Luckmann, 1966). Currently, social constructionism embraces a wide variety of perspectives, theories and practices, and several scholars have provided significant contributions over the years in developing the wide-ranging viewpoints of this paradigm (Lock & Strong, 2010). One of the recent and foremost contributors to the social constructionist perspective is Kenneth Gergen (2015). He explains that whatever we presume to be the truth about the world, how we view ourselves and how we comprehend the choices we make about our actions are actually a result of how interactional experiences from the past are interpreted. According to social constructionism, meaning is constructed and reconstructed through social interactions, and language therefore plays a significant role (Lock & Strong, 2010). According Gergen (2015), the truth about the world we are living in is constructed as we communicate and converse with others.

The book, *Social Construction of what?* (Hacking, 1999), raised the relevant question of "what is it that is really constructed?" Constructionism in its most extreme version could according to Hacking (1999), be understood as emphasizing that everything that exists is a construction; thus, reality is a construction. A more moderate understanding of constructionism accepts that reality exists, while acknowledging that the social reality in which people live and create their everyday life is constructed through social relations (Hacking, 1999). Charmaz's ontological perspective is that reality does exist; however, it is shaped and constructed through relations and interactions between people. The reality that each individual understands is thus a representation of an interpreted reality, not an exact picture of it (Charmaz, 2008, 2014). Consequently, there may be not one but several possible realities that can be experienced as "true". Additionally, she also claims that a person who is studying a reality must also be considered being a part of that reality (Charmaz, 2011; Charmaz & Mitchell, 2001).

Charmaz's epistemological position is that the development of knowledge occurs through dialogue and interaction between a researcher and a participant, who together construct the data emerging from the empirical field (Charmaz, 2004, 2006, 2008, 2011, 2014). However, according to Charmaz`s ontological viewpoint, as reality depends on personal beliefs and values being constructed through – and influenced by – contextual factors, the data that surface must be considered subjective (Charmaz, 2011; Charmaz & Mitchell, 2001). Consequently, the possibility of generalization on the basis of this type of research is, of course, limited (Charmaz, 2011). However, this is not the goal of constructivist grounded theory. Instead, using an inductive starting point, the goal is to follow the leads in the empirical data to provide a meaningful image of reality and construct a theory that can potentially explain the processes that are occurring (Bryant & Charmaz, 2007; Charmaz, 2006, 2014).

3.3 IMPLICATIONS FOR RESEARCH DESIGN AND METHODS

This study is positioned within the same ontological and epistemological perspectives as (Charmaz, 2014), which presume a social reality that is multiple, processual and constructed and consider knowledge to be constructed through interactions. One of the key principles of constructivist grounded theory adapted in this study is that data and analysis are co-constructed during the interaction between the researcher and participant (Charmaz, 2014). From a constructivist perspective, meaning is not latent within individuals and waiting to be discovered; rather, it is created as individuals interact with and interpret each other. This approach presumes that data collection, data analysis and methodological strategies are constructed (Bryant & Charmaz, 2007). Based on this assumption, the research context and the researchers` positions, perspectives, priorities and interests must be accounted for (Bryant & Charmaz, 2007; Creswell, 2007). Researchers are responsible for not only interpreting how participants in a study find meaning in their actions but also reflecting on how, as researchers, they have interpreted the results (Bryant & Charmaz, 2007). This places considerable demands on a researcher's ability to self-reflect, which must be integrated as an ongoing practice throughout the research process (Charmaz, 2014).

Kvale and Brinkmann (2010) use the metaphor of the traveller when explaining how data are constructed in a constructionist paradigm. The traveller leaves for a foreign country, meets and converses with different people, and has many stories to tell when returning home. The story that is passed on by the traveller to the audience upon return must be considered a knowledge construction resulting from a process that involves both data gathering and analysis during the travel period and not as an accurate presentation of objective data discovered along the way (Kvale & Brinkmann, 2010). Rapley (2001) argues that at a general level, a researcher must choose to consider the data as either a resource or a topic. Viewing data as a resource implies reflecting interview data as a transparent window to participants' reality beyond the interview, whereas considering the data a topic implies reflecting a reality jointly constructed by the interviewer and interviewee. This way of defining knowledge construction is likely most consistent with the constructivist version of grounded theory, and it corresponds to the underpinnings of this study. Selecting constructivist grounded theory for this study required adopting a researcher role that was influenced by the traveller described by Kvale and Brinkmann (2010) and viewing the research material as a topic as explained by Rapley (2001). Charmaz (2014) views the creation of knowledge as not only constructed but also co-constructed, indicating that one cannot account for the construction of knowledge from the side of the researcher only, as participants will also contribute to constructing the final product. Just as Rapley (2001) and Silverman (2006) emphasized, the need to see participants' contributions as one version among others is important when considering the ways in which the research topic can be reflected.

Charmaz (2014) advocates that in order to place participants' stories in their situational and social context and to sustain researchers' reflexivity in this process, writing memos is a crucial tool. Thus, this practice was adopted from the beginning of the current research project. In one of my methodological memos, which I wrote during the first phase of sampling, I concretised how I was positioning myself in terms of constructing data at that time:

> *They (the spouses) have a story to tell, regardless of my meeting with them. It may be too extreme of a relativistic approach to assert that the knowledge will be constructed in the meeting with me, because they have their story anyway. Nevertheless, it is clear that my presence, my preconceptions and attitude most certainly will affect which version of their story they choose to tell.*
>
> *My methodological note, 28.02.2013*

This exemplifies the stance on relativism taken in this study, which underlines the ontological and epistemological assumption of a multiple world that is co-constructed through social interactions. I contend that taking this stance from the initiation of the process of constructing the data was an appropriate choice. Glaser (2002) criticized constructivist grounded theory for placing the researcher’s impact on the data in the foreground instead of privileging participants’ concerns, whereas Rapley (2001) argued that the notion of co-constructing accounts has garnered too little attention. The way in which I position this study on the continuum from the realist to the relativist approach does not take the extreme relativistic approach of as attributing “everything” to constructions. However, I identify more with Bryant and Charmaz (2007), who claim that the reality that is being studied, and later presented through the results, is shaped and constructed through relations and interactions between people. Thus, the presented reality might be one possibility, among others.

4 METHODS

The journey through the research process begins by defining an area of interest, positioning the study, finding and recruiting participants, and then constructing data corresponding to the research questions (Savin-Baden & Howell Major, 2013). Charmaz (2014) describes methods as a tool for discovering interesting leads in the data. However, she states that methods alone cannot provide a researcher with insight. It is how methods are used that matters, and the preconceptions introduced into the research will certainly influence what can be perceived. Rather than pursuing a linear methodology in which data collection is followed by analysis, grounded theory emphasizes a "back and forth" approach to research in order to focus data collection, strengthen theoretical understanding and explore "gaps" in the developing theory (Charmaz, 2004; Corbin & Strauss, 2008; Glaser, 1978). The adoption of grounded theory does not lead to a linear research process; instead, it involves a circular process through which the meaning of the subjects being explored is constructed during the interactions between the researcher and the participant (Charmaz, 2014). Data collection and data analysis are simultaneous, implying that new pieces of the puzzle can be added at any time in the course of analysis. This approach is most commonly described as theoretical sampling and is one of the main strengths of using this methodology (Charmaz, 2004, 2014; Corbin & Strauss, 2008; Covan, 2007; Glaser & Strauss, 1967). However, even though the circularity of the research process is an advantage when employing grounded theory, it creates complications in terms of how to report the data. It is difficult to fully grasp the circularity of the process and how the different stages of the research process lead to new discoveries, decisions and implications. Nevertheless, transparency regarding these concepts is crucial to evaluating the research (Charmaz, 2014). The next sections will therefore provide detailed descriptions of the dynamic research process that characterized the utilization of this study.

4.1 BEGINNING THE RESEARCH PROCESS

Savin-Baden and Howell Major (2013) raise the following relevant question: "How much of the research is related to researchers' interests, experiences, beliefs and personal positions? (p. 69)" This is a key question to ask – and to answer – particularly when applying constructivist grounded theory, as Charmaz underlines when asserting that researchers must be aware of what is brought into a research project. She suggests that it is difficult, if not impossible, to put aside everything that defines you as a person – both personally and professionally (Charmaz, 2014). Taking a constructivist stance to the research process therefore means that a researcher can never be regarded as separate from the research phenomenon or considered an outside observer of the world being studied (Bryant & Charmaz, 2007). Instead, the researcher is perceived more as a part of the world being studied, bringing personal and professional values, beliefs and experiences to the research site (Charmaz, 2014). Being reflexive to what is introduced to the field regarding these perspectives is therefore essential (Charmaz, 2008, 2014).

My initial preconceptions became visible when deciding on the research phenomenon for this study. Through my professional background as a nurse, I had encountered many people with dementia. Numerous meetings with next-of-kin caregivers for these individuals supplemented these experiences. Along with my growing experience as a nurse, I developed a special interest in these caregivers as a group. While I was impressed by their perseveration as caring caregivers, I was often simultaneously struck by their overwhelming burden. As I prepared to begin work on my master's thesis, my interest in exploring spouses' experiences of relocating a partner to a special care unit for persons with dementia seemed relevant. I finished my master's degree by conducting a qualitative study of this topic, only to discover that while some answers had been discovered, several more had appeared. This realization was the starting point for the current research project.

I was determined to adopt an open-minded approach when I entered the "research arena", even though I also acknowledged the unmanageability of a completely open-ended approach, which Bryant and Charmaz (2007) and Creswell (2007) highlighted as nearly impossible to achieve. To try to articulate my preconceptions about the research topic, I had to adopt a strategy of identifying them, and I therefore considered sensitizing concepts as a useful tool. The notion of the sensitizing concepts was originally described by (Blumer, 1969) and simply represents broad concepts that may serve as a loose frame to begin examining an area of interest. The concepts provide a researcher with tentative ideas to pursue and can serve as a starting point for inquiry (Charmaz, 2014). I used sensitizing concepts in this study by using them as a way of expressing the vantage points for the study while developing the research protocol and an initial interview guide. The concepts were developed by reviewing the literature relating to the research topic and involved themes such as experiences of caregiving strain/gain, caregiving role, everyday life at home and in the long-term care, relational experiences of spouses in the long-term care environment and issues concerning relocation of a partner. As this study adapted the iterative practice of concurrent data construction through sampling and analysis, the literature review was not completed by developing sensitizing concepts; it was utilized as an ongoing practice from the moment the protocol was composed and throughout the entire research process. This was an important means of approaching the field, both to adjust the literature review to the emerging concepts discovered in the data and to identify areas for further inquiry.

4.2 DETERMINING THE INCLUSION CRITERIA

The selection of the research site(s) is a critical element of the research process (Savin-Baden & Howell Major, 2013) To maintain the focus on spouses with partners with dementia, it was necessary to recruit participants with partners with an established diagnosis of dementia. I therefore sought to recruit from long-term care facilities that provided segregated dementia care. To gain insight into and to facilitate a comparison of data derived from the different types of long-term care settings for persons with dementia, both special care units (SCUs) and sheltered homes were the preferred research sites. Given the variety of housing solutions available in Norway (Ytrehus, 2002), the long-term care settings had to adhere to the following inclusion criteria: provide segregated care for persons with dementia, designed as small and homelike units with ten or fewer residents each, and provide 24-hour care services with permanent staff. The number of required settings was not determined in advance because of the uncertainty regarding how many participants would be available from the different long-term care settings.

The inclusion criteria for participation in this study were very broad: older spouses or partners/common law partners of patients relocated to a long-term care facility for persons with dementia that adhered to the described inclusion criteria for the settings. The participants also had to be able to provide voluntary informed consent.

Spouses, partners and common law partners were chosen to maintain a focus on this specific role. Spouses who have lived together with their partner for many years will in most cases have a completely different role in relation to the person with dementia than, for example, a son, daughter, grandchild, or sibling or other relatives or friends (Ulstein, 2007). Moreover, in addition to experiencing the severe consequences of dementia, spouses must also address the changing relational roles and increasing difficulties involved in preserving mutual support and connection in their relationships (Evans & Lee, 2014; Wadham et al., 2015). Both female spouses and male spouses were eligible for inclusion.

This study emphasized older spouses’ experiences. However, precisely how old is an elderly person? A common definition in the western world has been the chronological age of 65 years (World Health Organization, 2016a). However, the World report on ageing and health underlines the diversity of older people, stating that the health condition of a 60-year-old might be worse than that of an 80-year-old depending on physical and mental health status (World Health Organization, 2015). Consequently, the use of a precise age limit did not seem appropriate for this study, although 65 years was used as a guideline for the approximate threshold.

4.3 THE PROCESS OF RECRUITING PARTICIPANTS

Telephone contact was made with nursing managers working in long-term care facilities adhering to the inclusion criteria. The facilities were selected from five municipalities in the southern parts of Norway where contact was established with directors of health care services. These directors served as gatekeepers and conveyed information to the nursing managers. Twenty-seven facilities housing 863 residents in total were contacted. The long-term care facilities were approached individually during the period from February 2013 to May 2014. In advance of the telephone contact, written information about the study, the inclusion criteria used to select participants and the recruitment procedure were mailed to the managers (see Appendix V). All twenty-seven settings except one were willing to assist with the recruitment. The manager who refused reported a lack of capacity to help because the facility was in the middle of an internal reorganization process.

The managers who helped recruit participants were all nurses with good knowledge about the facility, the patients and the patients’ next-of kin. They asked individuals who fulfilled the criteria of an elderly spouse or partner of a person with dementia whether they were interested in participating in the study. Of the 863 residents, only 31 had spouses or partners still living and able to participate, according to the managers. The managers asked all of these 31 individuals if they were willing to participate in the study. Sixteen refused to participate because of emotional distress, frailty or heavy burden. This left a sample of fifteen people for inclusion in the study. The sample size was partially determined by challenges and time constraints with regard to recruitment and by practical considerations such as the management of the data. At the end of the sampling period, the categories were considered to be sufficiently saturated according to Charmaz (2014) p. 213: "the point when gathering fresh data do not give new theoretical insights nor reveal new properties of the theoretical categories". However, determining that saturation is fulfilled by a sample consisting of 15 participants may be overly ambitious. Other perspectives could have emerged from the inclusion of additional participants; for example, by including spouses with characteristics that were different from those of the spouses recruited for this sample. Nevertheless, to fulfil the aim of research that guided this study, the homogeneous sample of 15 spouses was determined to be sufficient.

Eight women and seven men constituted the final sample. Their ages ranged between 64 and 90 years, and the average age was 78.8. Eight of the fifteen participants were above the age of 80. All the participants had long-lasting relationships with their partners: a minimum of 20 years. Eleven of the fifteen spouses were married to their partners and one was a common-law spouse. The sample also included two widowed spouses and one divorced spouse. These individuals did not meet the initial inclusion criteria, but because their experiences were considered relevant for informing the research questions, they were included. The participants reported their partners' stage of dementia to be moderate/severe to severe. Four of the spouses reported that their partners' dementia was caused by Alzheimer's disease, four indicated that the cause was vascular dementia or a combination of vascular dementia and Alzheimer's disease, and two reported that their partners suffered from Lewy Body dementia. One of the spouses supposed that her partner's dementia was related to high alcohol consumption, whereas the rest reported unknown causes. The length of stay in long-term care varied from six months to seven years. All the participants were retired and lived alone. All the participants except two had adult children. The common-law spouse did not have children together with his partner, although they had children separately. The proportion of the help the spouses received from their grown up children varied: some reported receiving a great deal of help, whereas others reported others minimal help or none at all.

The participants were recruited from five municipalities of different sizes located in southern Norway. With the exception of one – an urban district with more than 50 000 inhabitants – the municipalities were characterized as rural districts with less than 20 000 inhabitants each. All the municipalities offered segregated services for persons with dementia in long-term care. The urban district had several nursing homes with specialized care units for persons with dementia, but it did not offer sheltered homes. The rural districts offered both types of long-term care, although on a smaller-scale (a small number of patients per facility).

The participants were recruited from five specialized care units in four nursing homes and four sheltered homes from the five municipalities. The nursing homes were relatively large, with several units each (from 6 to 12). The sheltered homes were generally smaller in terms of both size and number of residents and typically contained only one, two or three units each. Both the nursing homes and sheltered homes were designed with homelike features and organized into smaller units. All the homes offered individual rooms for their residents. Some of the buildings were newly renovated, whereas others were older. The presentation of the results will not distinguish between nursing homes and sheltered homes, as they were interpreted as being very similar in terms of organization of care. The term “facility” or “long-term care facility” are used in this study.

4.4 MOVING FORWARD WITH THEORETICAL SAMPLING

One of the cornerstones in applying grounded theory is the use of theoretical sampling as the sampling strategy. Glaser and Strauss underscored the importance of using theoretical sampling:

> *Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges.*
>
> (Glaser & Strauss, 1967, p. 45)

Charmaz (2014) argues that using theoretical sampling is beneficial because 1) it provides a systematic method for using inductive data to construct abstract analytical categories about actions and processes and 2) fulfilment of the method involves an ongoing process of simultaneous data collection and analysis, constant comparison and memo writing, which facilitate a profound understanding of the interactions and processes emerging from the material. Finding and constructing data was a continuous process throughout this study. The inclusion of additional materials changed in relation to the development of new insights derived from theoretical sampling and the need to elaborate different perspectives of the research phenomenon. Thus, interviews, personal written accounts, participant observations and observations of the physical environments were ultimately added to the methods as sources of data. The forthcoming sections will describe how this process occurred.

4.5 CONSTRUCTING DATA THROUGH INTERVIEWS

Charmaz (2014) emphasizes the importance of gathering rich data. Interviews have often been used as the primary tool for obtaining rich data in grounded theory (Charmaz, 2014; Corbin & Strauss, 2008) and are one of the most frequently used qualitative methods (Silverman, 2006). Gaining insight into how individuals make sense of events and experiences is considered a main reason for conducting interviews in qualitative research (Silverman, 2005). A common rationale for interviews is that they may reveal phenomena that might not emerge through the use of quantitative methods, for example, as different methods will illuminate different aspects of the studied world (Denzin & Lincoln, 2011). However, we must also recall that criticisms have been raised regarding what Seale, Gobo, Gubrium, and Silverman (2004) call researchers' overreliance on qualitative research to bring researchers closer to the authentic experiences of participants' lives. Interviews as such, they assert (Seale et al., 2004), should not be misunderstood as a means of discerning how participants actually think and feel; rather, they are a means of exploring how participants *practise* their everyday life in the light of the research topic and what they choose to reveal about this practice. Thus, these authors offer an important reminder about what qualitative research can and cannot achieve when asserting a constructionist position. Acceptance of this assumption aligns well with the adoption of the constructivist version of grounded theory, in which co-construction, interaction and interpretive understandings are highlighted (Bryant & Charmaz, 2007; Charmaz, 2004, 2008, 2014). Moreover, interviewing is flexible in its approach and allows for the exploration and discussion of important issues relating to the participants' situation, experiences and actions (Silverman, 2005). Additionally, because interviews can be open-ended, they provide the interviewer with some level of control in guiding the focus of the interview (Rapley, 2001; Silverman, 2006). Conducting interviews were therefore determined to fit this aims of this project well, as interviews offer a meaningful way of exploring spouses' situation, actions and interactions.

Intensive interviewing is described by Charmaz (2014) as a method of conducting interviews in grounded theory research. The key characteristics of this interview method involve in-depth explorations of how participants' describe their experiences and situations using open-ended questions and emphasizing an understanding of participants' perspective and meanings. Intensive interviewing seeks to understand the research participants' language, meanings, actions, emotions and body language (Charmaz, 2014, p. 58). Moreover, in addition to serving as a means of initiating inquiry, intensive interviewing also provides tools for advancing the theoretical analysis through mutual conversations (Charmaz, 2014). The main principles of intensive interviewing were adopted for this study; however, a more conversational interviewing style was employed during interviews. The main reason for this was the arguments raised by Silverman (2006) and Rapley (2001), who contested the actual likelihood of performing mutual conversations in research, which is one of the characteristics of intensive interviews. Because of the influence of the researcher as a person with a special interest and agenda, they (Rapley, 2001; Silverman, 2006) contend that qualitative interviews might be "conversational" but that they can never be a "mutual conversation". In this study, this meant that in accordance with the emphasis on adopting an open-ended approach that emphasized the participants' perspectives and the adoption of a conversational interviewing style, there was a clear research agenda prevailing during the interviews. This is further clarified in the following section.

When I started this project, my experience as an interviewer was relatively limited. This led me to reflect extensively on the interview situation and to prepare thoroughly before engaging in the interviews. Constructing the interview guide was one method of preparing for the interviews. The interview guide (see Appendix X) was based on sensitizing concepts, and its intended use was as a tool for ensuring the exploration of essential themes during the interviews, as recommended by Charmaz (2014). Although the interview guide was fairly detailed, my intention was not to follow the interview guide literally from start to finish. Rather, the general purpose of interviewing was to encourage the participants to speak personally and at length about their experiences. Nevertheless, constructing the interview guide helped me prepare for the initial interviews in such a way that I had a good grasp of the questions I sought to highlight. This offered a measure of comfort as I initiated the interviews.

Thorough preparation in advance of the interviews also increased my reflexivity about how to ask questions and which questions to ask to facilitate the collection of rich data. In addition to active listening, asking open-ended questions that begin with *what* and *how* and using follow-up questions that begin with *why* are strategies recommended by Silverman (2006). Ogden and Cornwell (2010) conducted a study aiming to assess which components of an interview best predicted richness. They found that in addition to asking open-ended questions, framing questions in both the past and the present could enhance the generation of rich data. All of these perspectives appeared to be relevant to this study. Then, I read Rapley (2001). He argues that no one interview style will create "better data" because of the interactional nature of interviews. He also notes that even if interviews are open-ended, they will never be free from topical control by the researcher: the researcher decides the topic and guides and promotes the conversation using questions, silence and responses. The interview will be collaboratively constructed, but the interviewer is still the one in control (Rapley, 2001). This criticism was regarded as relevant, and served as an important reminder, especially in relation to the interpretation of the data constructed through the interviews.

The sampling process began by interviewing a convenience sample consisting of five spouses recruited by health personnel based on the inclusion criteria for the study. The interviews evolved via a conversational interviewing style (Silverman, 2005). Balancing the significance of allowing the participants to share their stories as freely as possible with my need as a researcher to maintain a focus on the research topic was a considerable challenge, especially in the beginning. To ensure an open-ended approach that emphasized the participants' words and meanings, I began the interviews by asking an open-ended question, "Can you tell me how it all started?" In addition to encouraging the participants to elaborate their story, this question elicited experiences from their pasts, as recommended by (Ogden & Cornwell, 2010). Several of the participants responded with a sentence similar to the following: "It did not start with the diagnosis of dementia; it started many years ago, when I met my partner". This raised my awareness regarding the context in which their stories evolved and guided my focus away from the spouses' experiences with the disease and symptoms to how dementia influenced their relationships. The spouses were therefore asked to elaborate on their stories about experiencing dementia in spousal relationships, to explain how they acted in their current, daily lives when their partner was living in long-term care, and to share their thoughts about the future.

After interviewing the first five participants, I realized that the experiences expressed by these spouses were essentially inseparable from their situation as a partner in a relationship that was changing because of the progression of dementia. The coding process began immediately and provided insights into how these spouses actively took part in their relationships on new premises and how they strategically reacted to the alterations. The stated goal of using grounded theory strategies is to focus data collection on the construction of theory that is grounded in the data (Glaser & Strauss, 1967). Therefore, the sampling process transitioned to theoretical sampling beginning with participant six and was guided by the concepts emerging from the spouses' relational concerns about "How can we be together in this setting?".

From this point forward, the recruitment, interviewing and analysis were undertaken in a stepwise manner to ensure that opportunities were available to elaborate and saturate the emerging categories. Twenty-one interviews were conducted that lasted from 50 minutes to 2.5 hours and performed in a conversational manner. With the exception of three interviews, which occurred in a room in a long-term care facility, all the interviews occurred in the spouses' private homes in accordance with their preference. During the interviews, the participants served coffee and chocolate and/or cookies. This resulted in an informal atmosphere in which the participants seemed comfortable. The spouses who were interviewed in a long-term care facility also seemed comfortable during interviews. No significant differences between those who participated in the interviews in a long-term care facility and those who participated in their own homes were observed. However, the participants who were interviewed in a facility were well-adjusted to being there, which may have caused them to feel more as if they were on familiar ground. Even though facilitating an atmosphere in which participants' feel comfortable is an essential element of conducting interviews, Silverman (2005) warns against making the interview context too pleasant. He asserts that an interview characterized primarily as a pleasant meeting can result in unfocused data and thus urges researchers to find a balance. The interviews conducted during this study were audiotaped using a Philips Pocket Memo dictation recorder and transcribed verbatim using Philips SpeechExec software. I found that mentioning the pocket recorder reminded the participants that this was indeed an interview, not a conversation over coffee.

Charmaz (2014) explains how the focused nature of theoretical sampling can sometimes lead to the need to ask more direct questions than were asked earlier in the research process. That was the situation in this project. To elaborate on the emerging categories, the participants were repeatedly asked to elaborate on what maintaining relationships with partners in long-term care meant to them, what they did to support the maintenance of their relationships, how the long-term care environment influenced their interactions and how their experiences and actions had changed since their partners` relocations. With the aim of clarifying statements and discussing evolving categories with the participants, six of the spouses participated in a follow-up interview within 6 weeks of the initial interview. To avoid placing additional strain on those spouses who expressed the strongest feelings of burden, only some of the participants were asked to engage in the follow-up interviews. These participants were selected on the basis of the impression they gave during first interview. Most of the interviews were conducted in face-to-face meetings; however, in accordance with some of the participants' requests, three of the interviews were accomplished via telephone. During this process, I was offered the personal written accounts of two participants. These personal accounts were judged as informative and useful and were therefore included in the material.

Transcripts of the interviews were used as the main material for coding. Some differences exist between classic and constructivist grounded theory in regard to deciding whether to record and transcribe interviews. Glaser (1978) advocates that taking notes during interviews is sufficient because a researcher will naturally remember what is important to building the theory. The advantage of such an approach is to minimize the risk of becoming lost in the details. Charmaz (2014) emphasizes the interactional construction of the interviews and argues that notes do not sufficiently preserve a conversation's tone and tempo and do not capture silences or statements. Silverman (2005) stated that recording interviews should be an obvious decision for researchers performing qualitative interviews. First, because recordings not only document what people say but also how they say it. Additionally, recordings can be listened to repeatedly, which can be an advantage when performing the analysis (Silverman, 2005). The choice to record and transcribe the interviews in this study was easy; the recordings helped me focus on both preserving the rich details from each interview and attending to the construction of the interview itself, as Rapley (2001) emphasizes. Each of the recordings were listened to several times, and memos were developed concurrently. This provided the basis for profound analysis. To contextualize the interviews, ensure the documentation of reflexions about conducting interviews, and to begin the initial analysis, field notes were written after each interview describing the setting, place, and participants and personal and methodological experiences and observations.

The evolving analysis called for other methods in addition to focused interviews. Through the process of interviewing and analysing the data, an awareness evolved regarding how terms and conditions in the physical and social environments appeared to influence the spouses' opportunities to maintain their relationships. Following this insight, a realization arose about the importance of capturing how environmental features might influence the spouses' opportunities to maintain their relationships and how they used the environment when visiting their partners. This was not possible to achieve solely by interviewing the participants. Consequently, I decided to include observations of the physical environments and participant observations in order to generate more data.

4.6 CONSTRUCTING DATA THROUGH OBSERVATIONS

Observations are a key method in ethnographic methodology, and the general purpose of observations in ethnographic studies is to observe actions as they are performed in specific settings (Gobo, 2008). Silverman (2006) highlights the value of using observations to study contexts and processes in order to understand how people act in certain situations in their natural settings. As such, he argues, observations can provide valuable insight into the research phenomenon and supply other methods in qualitative studies, even if conducting a full ethnographic study is not the main objective. The intention of supplementing this study's methodology with observations was not to perform a rigorous ethnographic study but to increase my understanding of the spouses' actions and practices. Mead (1934) underscored the difficulty of understanding people's conduct without first observing it within the context of the social community in which it unfolds. Additionally, Charmaz (2014) and Corbin and Strauss (2008) underlined the value of combining observations with interviews to enable the study of actions in the setting under research and to develop conceptual renderings of these actions.

The purpose of observing the physical environments was to gain greater insight into the contexts surrounding the experiences that the spouses' shared during the interviews. Charmaz (2014) emphasizes that the purpose of observation in grounded theory is not primarily to observe and describe the setting itself; rather, the processes and actions that occur in these settings are central. Moreover, observation is regarded as a useful method through which to understand the context that frames actions and processes (Charmaz, 2014; Corbin & Strauss, 2008) or, as Savin-Baden and Howell Major (2013) assert, aid the researcher in developing an understanding of the context surrounding the phenomenon under study (p. 392). Observing the settings therefore seemed relevant in this study. Initially, the research plan involved visiting all the facilities to gain insight into their environmental design and organization. However, difficulties arose in gaining access. The decision to include these observations in the research design was made relatively late in the research process, and I had to re-contact the facilities to request permission to perform observations. All the facilities were contacted by mail and telephone; however, two facilities declined: one was in the middle of a reorganization, and the other had experienced a change in management. Therefore, observations of the physical environments were conducted in six of the eight facilities.

The purpose of the participant observations was to develop further insight into how the spouses used the physical environment and how they interacted with their partners within that environment. Observations of basic social processes can support the achievement of a more complete understanding of an entire setting (Charmaz, 2014). Recruiting participants for the observational portion of this study had to be undertaken among the last five spouses who were recruited for the study because of required ethical approval (see chapter 4.10 for ethical procedures and considerations). Of these five spouses, one was widowed and one refused to participate because of feeling strained. The remaining three spouses agreed to participate in a follow-up study for one year. However, prior to the second observation, two of the spouses` partners died. Thus, only one couple was visited repeatedly (four times over a period of 9 months until the partner died).

To avoid being overwhelmed by data, Silverman (2006), Savin-Baden and Howell Major (2013) and Gobo (2008) highlight the importance of attempting to narrow the focus of the research before entering the field. A disposition regarding the areas of focus for the observations was therefore developed based on the results discovered during the interviews (see Appendix XI). The disposition was intended to serve as a starting point for sorting and refining the observations and to aid me in remaining focused on the gaps in the evolving conceptualization of the spouses’ maintenance of their relationships.

Researchers can adopt different roles during observation. The two main varieties noted by Gobo (2008) are non-participant and participant observations; within these extremes, he underscores, several degrees of participation and involvement exist, and he urges researchers to adopt a balance between participation and observation. According to Savin-Baden and Howell Major (2013), viewing observations as non-participatory raises an important question about whether it is even possible for a researcher to be a non-participant. Rather than positioning the role of the researcher within a range in which non-participation and participation constitute the extremes, they view the role as a continuum of roles, varying from peripheral participation to complete participation. In the middle of the authors' continuum there are three roles: passive, balanced and active participation. According to Savin-Baden and Howell Major (2013), when engaged in passive participation, a researcher is on the scene but has minimal involvement in it, whereas active participant observations involve a researcher who is functioning within the situations being observed. This type of observation requires longer engagement and is dependent upon the acceptance of the participants. Balanced participant observations, however, require researchers to join the participants' activities while simultaneously maintaining distance. In this study, two types of observations were generally accomplished: observations of the physical environment and participant observations with the spouses` and their partners. The role that I adopted changed depending on the nature of the observations and required me to be involved in various ways. Next, I describe the two observational approaches and the roles adopted for each of them.

The observations of the physical environments were conducted as scheduled visits to the facilities. These observations involved brief tours guided by one of the spouses whose partner lived in the facility. Assuming the role of a visitor was therefore deemed the most natural manner of fitting into the setting. Based on my experience as a nurse working in similar facilities, I felt as if I was on familiar ground to some extent, although I simultaneously experienced strong feelings that I did not fit into the setting. This may have been caused by my decision to adopt a more distant role: I identified myself as a passive observer – an observer who functions as a spectator or bystander and has limited interaction with others (Savin-Baden & Howell Major, 2013). However, adopting this role was in accordance with my expectations and plans. The visits were brief and only provided snapshots of ongoing daily life. They still provided valuable insight into the layout of the facilities and their environmental features. According to Savin-Baden and Howell Major (2013), this is valuable contextual information that is often overlooked in research. The visits also supplemented my understanding regarding how the spouses situated themselves in these environments and thereby enhanced my awareness of the spouses' roles in the facility and their perceptions of the environment.

The participant observations were conducted as visits and were scheduled with the participants to align with the period of time they were visiting. Several ethical considerations were taken into account regarding these visits, and they are described separately in chapter 4.10. The observations began with the spouses introducing me to their partners and explaining the purpose of the visit. Then, the three of us sat together conversing to the extent that this was possible. I was aware that the participants' partners were severely affected by their dementia; therefore, establishing a context that could provide a sense of assurance was vital. Initially, my plan involved actively participating in the couples' conversations, thereby adopting the role of an active observer as described by Savin-Baden and Howell Major (2013), as this role seemed most natural and appropriate for my presence there as a visitor. However, conditions influenced the situation in such a way that maintaining this role was not always possible. The most important influence was the area in which the observations were conducted: observations with two couples were conducted in common areas, and observations with the last couple occurred in the partner with dementia`s individual room. I found that the conversations unfolded differently depending on the surroundings, and I will now explain how my role as an observer differed between the two settings.

When visiting two of the spouses and their partners, the observations occurred in the common area because this was their preferred location. These sessions were somewhat influenced by the activities occurring around us, such as interactions with residents, personnel and others, and it was difficult to sustain a conversation. Therefore, the observer's role became more passive than I had initially planned. The role varied somewhat, however: from being actively involved to maintaining distance and passively observing the couples' interactions and conversations. My role during these observations was therefore equivalent to the balanced observer role described by Savin-Baden and Howell Major (2013). A balanced observer is described as a researcher who strives to balance the roles of the insider and the outsider (Savin-Baden & Howell Major, 2013), which generally reflects the challenges I experienced during these sessions. Nevertheless, these observations provided insight into the terms and conditions influencing the spouses' interactions with their partners in the common areas and was, in this sense, extremely valuable to the advancement of the analysis and the theoretical development of the grounded theory.

The observations with the last participant and his wife occurred in her individual room. The observer's role was slightly different in this setting. The visits were calmer and were characterized by my presence as a visitor in their private space. We sat together on the partner's sofa, drinking coffee and actively conversing about different matters that interested them. The repeated observations with this couple enabled our confidence in one another to grow because we became more familiar with each other during each session. This created opportunities to ask about different topics related to my research questions. Even so, because of the participant’s wife`s condition, the couple sometimes conversed together; for example, when she became anxious and he had to reassure her about the situation. Therefore, the observer role was still balanced in this setting, and occasionally even reflected that of an active observer who claims a central position in the setting (Savin-Baden & Howell Major, 2013). These observations increased my understanding of the significance of an individual room and enhanced my awareness of the value of the individual room to spouses’ interactions in the later phases of dementia and how spousal relationships can unfold within these rooms.

Recording and documenting observations is a crucial element of conducting fieldwork (Gobo, 2008; Silverman, 2006). The role I adopted as a visitor to the facilities had two consequences in this sense: first, audiotaping conversations was not considered appropriate because I did not want to influence the informal nature of these conversations. Second, withdrawing to write field notes was not natural in the intimate surroundings in which these observations occurred. For this reason, neither audiotaping nor writing field notes occurred during these visits. However, time was allotted following the observations to write comprehensive field notes.

The field notes varied slightly according to the different approaches used during the observations. The visits that involved observing the physical environment resulted in detailed descriptions of the characteristics and arrangement of the physical environments, the environmental features, the size and design of the common areas and individual rooms, and access to outdoor areas. In addition, outlines of the spatial organization of the units were also constructed.

The field notes from the participant observations were organized differently. Corbin and Strauss (2008) argue that collecting data in the field will stimulate theoretical ideas and that purely descriptive writing is therefore challenging because of the natural urge to analyse and categorize what we see. Additionally, separating field notes from memos can be a challenging practice when performing field work as part of a grounded theory study (Charmaz, 2014; Corbin & Strauss, 2008). Therefore, to keep analytical memos and descriptive field notes separate, Corbin and Strauss (2008) suggest using a scheme developed by Schatzman and Strauss (1973). This scheme involves dividing the field notes into three categories. The first category, observational notes (ONs), describes what occurred and what the researcher saw as purely as possible (Corbin & Strauss, 2008). Summaries from the informal conversations that occurred during the observations are integrated into these observational notes. The second category, theoretical notes (TNs), represents the researcher's reflections on and analytical ideas about the observed events. Such theoretical notes can also be regarded as memos (Corbin & Strauss, 2008). This category was used to elaborate my conceptual understanding of what I observed, to compare notes about environmental features with observations of how the spouses used them, and to explore emerging ideas related to the theoretical understanding of these findings. These efforts were essentially part of the analysis. Finally, the third category, methodological notes (MNs), represents methodological reflections or reminders regarding the procedural aspect of the observations (Corbin & Strauss, 2008). These were used to elaborate on my role as researcher during the observations and how this role altered depending on the situation. Organizing the field notes in this way provided valuable help during the analysis and supported reflexivity.

4.7 CONSTRUCTING THE DATA ANALYSIS

Beginning the analysis process is similar to entering an interactive analytic space, according to Charmaz (2014). This implies that a researcher not only interacts with participants to elaborate and compare codes and categories but also that the analysis prompts the researcher to interact with the empirical data while endeavouring to understand the implicit meanings and actions that are emerging. Thus, the data analysis, including the coding procedure, must be regarded as a construction (Charmaz, 2014).

The analysis was a long-lasting process that began with my involvement in the coding process from time of the first interview. The process evolved as I ensured that the codes were compared with the data and discussed during subsequent interactions with the participants, and it was further advanced through my engagement in the participants' sphere during the observations. The interpretation of the data and the development of an understanding of the meaning of the data were shaped and structured through meetings with the participants and scrutiny of the literature, by writing analytical memos and through numerous discussions with peers, colleagues, students and others. The analysis for this study was therefore characterized by a dynamic and ongoing process that developed throughout the entire project. New insights, developments, knowledge and conceptualizations continually advanced the analysis.

Capturing this process as a linear description in this chapter is therefore challenging. However, I will attempt to provide a picture of this iterative process. Most of the analytic work described here was performed in accordance with Charmaz (2014); however, important inspiration was also derived from Corbin and Strauss (2008). Moreover, memo writing constituted a central method supporting the process of generating and analysing the data and will be explained thoroughly in the next chapter.

The constant comparative method is a method of analysis that generates successively more abstract concepts and theories through inductive processes of comparing data with data, data with code, code with code, code with category, category with category and category with concept (Charmaz, 2014, p. 342). The analytical practice begins with coding, which serves as a link between the raw data and the conceptualizations explaining the data (Charmaz, 2014; Glaser & Strauss, 1967). Coding in grounded theory encourages studying actions and processes and consists of different phases: first, initial coding involving naming each word, line, or segment of data; next, more focused, selective phases that use the most meaningful or frequent initial codes to sort, synthesize, integrate, and organize larger amounts of data; and finally, the use of theoretical sampling to develop the properties, boundaries and relevance of a category or a set of categories in order to develop a theoretical understanding of the empirical data (Charmaz, 2014).

The initial coding in this project involved coding the material line-by-line, meaning that each line of written data was coded by asking, “What is going on?” Each page of the transcripts was divided into three columns with the transcribed text in the middle. Then, codes were labelled on the right side. I endeavoured to use codes that were as close as possible to the participants’ statements during this process and coded using gerunds whenever possible. Coding with gerunds is a method of coding that is recommended by Charmaz (2014) and Glaser and Strauss (1967) because it helps maintain a focus on the participants’ voices and supports the detection of processes and actions in the material. I found that viewing the data in this manner required training and experience; therefore, coding with gerunds also represented a learning process during my analysis.

At an early point, the interviews exposed the participants' perceptions of how their partner's dementia influenced their relationships[5]. The initial coding uncovered a sense of being alone while still married, and codes such as "separation", "experiences of being alone", and "losing couplehood" illuminated a preliminary direction towards what was later identified as the process of losing couplehood. Simultaneously, the initial coding revealed another aspect emerging in the data: the codes also indicated that the spouses were endeavouring to maintain involvement in their relationships in response to the experience of losing couplehood. This was represented by codes such as "being together," "making contact" and "facilitating togetherness". The initial codes reflecting the different aspects of "losing" and "maintaining" were then grouped into overarching categories in the left column of the table, and these codes shaped the subsequent analysis. Then, the text was marked with different colours depending on the categories to which the content belonged. Codes that dealt with the category of losing couplehood, for example, were noted by the colour green. Codes related to the category of how spouses maintained their relationship was marked by yellow. Thus, it was easy to orient in the text and to prepare for the next step of the analysis.

The initial phase was followed by a more focused coding phase. In grounded theory, this phase is characterized by the use of the most frequent initial codes to sort a larger amount of data, eventually resulting in core categories (Charmaz, 2014). The discovery of the different aspects of couplehood covered in the initial codes directed this more focused phase of the coding process. The initial codes were used to review all the data, searching for verification of when, why and under what circumstances these initial codes became visible. Lines of text that illustrated each code relating to the identified categories (marked by different colours in the transcripts) were transferred from the transcripts into a table with different columns that displayed the categories vertically and the interviews horizontally. Subsequently, the analysis addressed both of the processes discovered in the data and distinguished between "losing" and "maintaining". One table was therefore developed for the category of losing couplehood, whereas another was developed for the category describing how spouses maintained their relationships. Ordering the codes and categories in this manner facilitated the comparison of

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[5] From the very beginning of the analysis process, I was aware of how spouses weighted their alternating experiences of being connected with versus being disconnected from their partner, both because of their partner's dementia and as a consequence of their physical separation. It was therefore clear to me that the first paper had to reflect this aspect of the spouses' situation. As I was working with the material, I gradually realized how wide-ranging the spouses' senses of connectedness/disconnectedness were. Therefore, in parallel with my analysis efforts, I began exploring definitions and concepts that were broad enough to cover the overall relational experience of separation caused by dementia that was expressed by the spouses during the interviews. Of several words that potentially described this concept, couplehood was determined to be the most suitable for sharing the spouses' experiences.

the data, both within each interview and between interviews, and assisted in connecting the codes to the categories and in elaborating the relationship between the categories. At this point in the analysis, I realized that describing both the process of losing couplehood and the strategies the spouses used to combat this experience was too extensive an endeavour to capture in one manuscript. Therefore, I decided to move forward by analysing these two categories separately.

The preliminary category of losing couplehood was analysed for context and process according to the instructions provided by Corbin and Strauss (2008).[6] Coding in this manner increased my understanding of the sets of conditions, interactions and responses identified in the material. It was clear that the losses experienced by the spouses were related not only to losing a shared everyday life but also to the loss of shared memories and the inability to experience a shared future. The core category "*loss of a shared lifetime"* was constructed based on this realization and is described in the first paper. To sort and elaborate on the categories belonging to this core category (*loss of a shared everyday life*, *loss of a shared past* and *loss of a joint future)*, I decided to develop a conditional matrix in which the properties and dimensions of each category were conceptualized and the relationships between them were integrated. The analysis showed how each category encompassed the conditions *separation*, *being alone* and *loss of couplehood* that form the context of the losses experienced by spouses and built a structure for the subcategories. Additionally, these losses were reflected in the phases of the spouses' lives: *present, past and future.* A figure (published in paper I) was ultimately developed to describe the subcategories, main categories and the core category that constitute the process of losing couplehood.

Establishing the process of losing couplehood led to the need for further exploration of the way in which the spouses were able to construct togetherness in order to experience a sense of couplehood with their partner. The coding process for the preliminary category describing the spouses` strategies for maintaining their relationship proceeded by focusing on asking questions of the material regarding the spouses' use of visiting routines to maintain

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[6] I was at that time enrolled in a PhD course in qualitative analysis. Writing a draft of a paper was part of the examination, and since the supervisor of this course focused on how to conduct analysis as described by Corbin and Strauss (2008), it was natural for me to proceed with this approach for the first paper. Later, when I was engaged in focused coding for the second paper, I chose to use full descriptions as proposed by Charmaz (2014). However, I found that the procedures were very similar, with Corbin and Strauss (2008) providing somewhat more detailed guidelines for "how to do it", which offered me valuable experience to use in the subsequent analysis.

involvement: What are the spouses' visiting routines? When and where are they used? How do the visiting routines resemble each other, and why do the spouses use them? With what consequences are they understood? The core category describing how spouses constructed togetherness to preserve continuity in their relationship using visiting routines gradually emerged. Moreover, the core category identified under what circumstances the spouses' visiting routines became visible, how the different visiting routines related to each other, and what factors influenced these relationships. To facilitate the sorting of the categories and aid in perceiving the full range of relationships between the codes and categories, a table (published in paper II) was developed. Then, an analysis of the material relating to process, as described by (Charmaz, 2014), identified how the spouses adapted their visiting routines to their partner's presentation of symptoms and declines and how their usage of routines altered according to the progression of dementia. Three phases defined the spouses' experiences of the dementia progression following the relocation of their partner. The identified phases were then compared with the spouses' visiting routines to construct three categories: "*maintaining involvement and intimacy to preserve continuity in their relationship*," "*structuring visits to facilitate interaction and communication*" and "*pursuing moments of mutuality to preserve continuity in a deteriorating relationship*." These categories illustrate how the spouses used visiting routines to "construct togetherness" and how the visiting routines changed throughout the phases of dementia, in the process of "*constructing togetherness throughout the phases of dementia"*.

The detailed analysis had thus far resulted in an understanding of how the spouses experienced losing couplehood with their partners following relocation (paper I) and how they responded to this loss by using visiting routines to maintain togetherness in their relationships in the institutional setting (paper II). Even though the analytical path may appear to be very evident in this description, it was not a clear, linear procedure. Coding and analysing is a process, not a linear endeavour, and it is also flexible: turning back to perform fresh analysis is a possibility, as is moving forward to write about the codes and categories in analytical terms (Charmaz, 2014). This was a helpful approach, as the analysis demonstrated that in order to understand how the spouses maintained relationships in the long-term care setting, an exploration of the physical and social environments that influenced their efforts was needed. This recognition led to systematic observations of what was occurring in the long-term care settings.

Field notes from the observations were written, read and analysed concurrently in order to clarify how the codes and categories identified through the earlier coding process were expressed through the observations. The literature on environmental gerontology was assessed simultaneously to increase theoretical sensitivity. An analysis of the observations revealed that two specific arenas were significant for spousal interactions: the common areas inside the facilities and the individual rooms. Therefore, returning to the interviews to examine the spouses' expressions regarding using these arenas became important. I began re-analysing all the transcripts and used "common areas" and "individual rooms" as codes to search for data about when, why and under what circumstances the different arenas were used. An understanding began to emerge regarding the various implications of the spaces as places to connect and how these spaces were used differently in this context. To elaborate on this emerging concept, data from the interviews and observations were now compared both internally and between data. The alternation between studying the field notes and examining the categorization of the interviews aided in advancing the analysis towards a focus on the properties and dimensions characterizing the spouses` interactions with their partners in the designated areas of the facilities. The significance of making spaces into places to "find a place to connect" became apparent and was elaborated in paper III.

4.8 USING MEMO WRITING AS AN ANALYTICAL AND REFLECTIVE TOOL

Charmaz (2014) notes that in addition to a clear point of departure, being reflexive also involves constant evaluation of initial ideas and comparisons with emerging data. Memo writing was an essential activity in this process. It helped me transition from the sensitizing concepts to scrutinizing what was important for the participants; and, thus paving the way to focus on what was important in the next step of the research process.

Charmaz highlights the value to grounded theorists in taking the opportunity "stop and write whenever ideas occur to them" (Charmaz, 2014, p. 18). Ideas can be fragile, Glaser says (Glaser, 1978; Glaser & Holton, 2004), and instead of talking to others about their ideas, researchers should write them down to avoid having them disappear. This act is conceptualized as memo writing, which is regarded as a crucial method in grounded theory of prompting early engagement in analysis (Charmaz, 2014; Corbin & Strauss, 2008; Glaser & Strauss, 1967). Thus, writing memos is a method that is widely used in all versions of grounded theory, and it supports analysis by linking data to codes and codes to categories

(Charmaz, 2014; Corbin & Strauss, 2008). Additionally, writing memos is a means of concentrating on the reflective process that should characterize the research process (Alvesson & Sköldberg, 2009). It is therefore considered particularly important when applying constructivist grounded theory because of the need to reflect on and record the path of theory construction (Mills, Bonner, & Francis, 2006). Memo writing can serve as an important tool in this endeavour and can aid researchers in questioning, analysing and obtaining a better understanding of encounters with participants (Charmaz, 2014). Practicing memo writing throughout the research process thus facilitates placing the data collection and the individual meetings with participants in a contextual setting and linking them together (Mills et al., 2006).

Memos were written continually throughout the entire research process in this study and supported the successive analysis of the material and the gradual achievement of the abstraction level. The memos varied in form, length, subject and quality. Some of the memos were written only as short post-it notes and some were notes on my phone, whereas others were more comprehensive computer-based documents. Whereas some were written immediately following the interviews, others were created during the transcription, analysis or writing process. Some of the memos concerned reflections on the content of the interviews, some concerned methodological aspects – for example, how to proceed methodologically in the next step of the process of theoretical sampling – and some considered my own role as a researcher and my experiences conducting the interviews and observations. Throughout the research process, memo writing became an increasingly important tool to facilitate creativity and the elaboration of thoughts and ideas that required further inquiry.

My intentions relating to the quality of the memos were intentionally maintained at a subtle level from the beginning of the project: the most important aspect was maintaining a focus on continuous writing, and the memos were only for my own usage. Memos were written as soon as I had an idea; therefore, the memos were rather unfocused in the beginning. However, as the project developed, the memos became increasingly focused. This resulted in an extensive collection of memos reflecting different aspects of the research project, providing invaluable support when transitioning into the late stages of the analysis and the conceptualization of the findings. Moreover, the memos also served as documentation of the choices and abstractions that were made during the research process and that led to the construction of the findings that were eventually presented in the papers. The ability to return to and consult these memos whenever I was uncertain about the focus and direction of the analysis offered reassurance throughout the entire project.

The written memos also documented my own development as a researcher. Conducting this study can be regarded similarly to making a journey in terms of not only to exploring the substantial area of the spouses' experiences but also to navigating the grounded theory landscape as a novice researcher. The use of memo writing documented this journey and illustrated my growth from a novice researcher to a more insightful researcher. Additionally, writing memos proved valuable in sustaining awareness of my role as a researcher when co-constructing the data from the interviews and observations, conducting the data analysis, and constructing the presentation of findings.

4.9 DISCUSSION OF THE METHODS

Advantages and shortcomings exist for any methodological approach chosen for a study. One of the main advantages of applying grounded theory in this study was the use of theoretical sampling. Maintaining an explicit emphasis on advancing the analysis through this iterative and focused sampling method and using different types of data to enlighten the research questions facilitated the accumulation of increasingly focused data and enhanced the conceptual understanding of the dynamic processes inherent in the spouses' situation and the conditions influencing those processes. An additional advantage was the inductive approach, which ensured an explicit focus on the participants' weighting of perspectives. The simultaneous inductive discovery and abductive reasoning of the data supported the construction of analytic categories that were grounded in the data.

Nonetheless, some shortcomings also emerged from the use of this methodological approach. One shortcoming was the lack of an overview from the beginning of the project regarding which sources of data would be required during the project. This caused some practical challenges during recruitment, as there were situations when obtaining access to the field to gather more data was difficult and time consuming. Although there was no doubt that theoretical sampling contributed positively to the endeavour to saturate the categories because of its focused and iterative approach to data collection and analysis, there may have been one additional risk involved. The use of theoretical sampling may have guided me as a researcher towards a one-sided focus, thereby excluding subjects or phenomena that may have had the potential to enlighten the categories further or spur the analysis in different, undiscovered directions. However, using comparative methods, which allowed the emerging categories to be continually compared and successively tested against new interviews and observations, may have counterbalanced this effect. Codes are constructions defining how we observe, understand and interpret data. Even though the codes are concrete and similar to the empirical data, they are constructions arising from language, meanings and perspectives (Charmaz, 2014). My words, my views and my definitions came into play when deciding on a code for a fragment of the empirical data. It may have appeared to be a perfect fit; however, it may still have been interpreted differently in other contexts and situations.

One issue that must be considered in relation to the methods is the process of recruiting the participants. Health personnel in 27 facilities recruited the participants. These facilities housed 863 residents, and of these residents, only 31 were assessed as having spouses eligible for participation in this study. Because of the procedure used to recruit the participants, there was no opportunity to determine whether this situation actually mirrored reality. Nevertheless, the identification of only 31 potential participants was somewhat surprising, and this sample was smaller than expected. Some possible explanations should therefore be considered. One may be that this number reflects the actual demography of the facilities' residents, which could suggest that most of the residents in these facilities did not have a living spouse or partner. Unfortunately, this is an unknown factor in the current study. However, some reflections can be accomplished. A recent report (Vossius et al., 2015) indicated that residents cohabiting with a spouse or partner before relocation had a higher level of care needs after relocation than residents who had been living alone. This indicates that those who live alone – for example, because of being widowed – might relocate to long-term care earlier than those who cohabit with a partner. This may explain why few of the residents seemed to have a living partner: as long as they still cohabit with a partner, they remain living in their homes.

Another reason may be that the personnel who recruited the participants were cautious about who they asked and thereby filtered the selection of the participants. The sample appeared to be remarkably homogeneous, especially regarding the spouses' history of having long-lasting relationships with their partner and their expressed commitment to maintain relationships in long-term care. The recruiting procedure might have influenced these results, and given a group of spouses that was particularly dedicated. This study focused on older individuals.

Being old and perhaps frail may create challenge for some spouses in terms of involving themselves after the relocation of their partner. The fact that over 50% (16 of 31) of the spouses asked to participate in this study refused because of feeling strained, burdened or frail indicate that this might be the case for some spouses. The likelihood of recruiting those who were more physically fit and able to remain involved might therefore have been higher, both because they may have been easier to access as more frequent visitors to the facility and because the health personnel may have developed a closer relationship with them. Those who actually accepted the invitation to participate in this study may reflect this group of people. However, this remains uncertain, as there was no information available about those who refused to participate.

This study used a combination of methods to construct the data. Charmaz (2014) claims that in order to obtain rich data, collecting other sources of data may be relevant. Using more than one method may support the development of a broader perspective of the phenomenon being studied (Savin-Baden & Howell Major, 2013; Silverman, 2005). Charmaz (2014) also specifies that data may vary in quality and that the relevance of the data to the studied phenomenon may differ. Therefore, a researcher must continually judge what data are needed to advance emerging ideas and theoretical developments and eventually decide which methods that are best suited to constructing these data. The inclusion of observations as a method for collecting data in this study was made some time after the study commenced. This caused some practical difficulties in relation to access to research sites as well as to the inclusion of the participants in the observational portion of the study. The observations provided valuable insights into the analytical rendering of the categories, even so, the study may have benefited from greater depth in the observational portion of the study. This may therefore be considered a limitation of the study, although the observations might also serve as an example of how forthcoming studies might be designed to further develop the findings presented here.

Finally, when discussing methods, the credibility and originality of this study must be addressed. Charmaz (2014) criteria for evaluating grounded theory studies include credibility, originality, resonance and usefulness. A strong combination of credibility and originality, she asserts, will increase a study`s resonance and usefulness as well as the value of the study (Charmaz, 2014, p. 338). According to (Charmaz, 2014), the credibility of this study should be judged by the richness of the constructed data as well as by the logical links established between the empirical data, analytical categories and theoretical argumentation. The study's credibility was strengthened by the depth of the interviews that were performed, which facilitated the richness of the data. The study's credibility was reinforced by the use of theoretical sampling, which ensured that a wide range of empirical observations were ultimately included in the data. Combining the interviews and observations, in addition to performing systematic comparisons between the empirical observations and developed categories, increased the understanding of the material and supported the construction of the evidence required to develop credible theoretical renderings.

Originality should be judged according to the conceptual rendering of the data and the theoretical significance a study Charmaz (2014). This study provides in-depth insights into a subject that has previously been under-investigated, which in itself contributes to extending the current knowledge in the field. The study's originality was established by adopting an inductive approach, which allowed the participants' expressions to surface from the beginning of the project. An evolving understanding of the participants' views and actions and what these contributions might mean was facilitated through the use of theoretical sampling, which contributed to the originality of the findings. Constructivist grounded theories are positioned in specific situations, times and places (Bryant & Charmaz, 2007). Theoretical renderings constructed using this method must therefore be considered as providing an understanding of complex processes, views and actions situated in the specific situations in which they were constructed (Charmaz, 2014). The results from this study must therefore be considered to be created from the shared experiences and relationships with the participants, and the results provide a constructed interpretation of reality for these spouses who have a partner with dementia living in long-term care. However, the methodological rigour applied to this study, the systematic and logical links made to the existing research, and the conceptualization of specific theoretical perspectives are all factors that increase the resonance of the study and consequently its value (Charmaz, 2014). Performing this study may therefore have uncovered results that are relevant to individuals other than the spouses who were directly involved. Usefulness is judged based on the ability of the research to contribute to the interpretation of generic processes and implications that people might use in their everyday life (Charmaz, 2014). For spouses with long-lasting relationships whose partners with dementia live in long-term care, these results may be recognizable and valuable. However, it is also important to emphasize that the results constructed in this study do not in any way provide a formula for scrutinizing the correctness of spouses' situations, experiences, and actions in general, as concepts such as a correct manner of acting likely do not exist. Applying such a formula may only place unreasonable pressure on spouses in similar situations in terms of how they should feel or act. The findings may nevertheless prove valuable in their consistency in describing the processes involved in defining spouses' situations following the relocation of a partner and in explaining spouses' actions. These descriptions and explanations can be used as a base of knowledge for the development of support services intended for spousal caregivers in long-term care; hence, the results may also be valuable for health personnel, policy makers and education providers.

4.10 ETHICAL CONSIDERATIONS

Current Norwegian laws, regulations and guidelines (Norwegian Ministry of Health and Care Services, 2008; Norwegian Ministry of Justice and Public Security, 2001) and ethical principles for medical research as declared in the Declaration of Helsinki (World Medical Association, 2013) were followed throughout the study. A project application was submitted at the beginning of the project period to the Regional Committees for Medical and Health Research Ethics. The committee determined that the research fell outside the Health Research Act (Norwegian Ministry of Health and Care Services, 2008) (REK Southeast 2011/2401, see Appendix I). A notification form to the Norwegian Data Protection Official (NSD) was therefore completed, and approval (NSD No 29923, see Appendix II) was obtained prior to processing the personal data. Later, when observations were added to the research methods, causing the spouses` partners to be included as part of the study, a new project application was submitted to the Regional Committees for Medical and Health Research Ethics as a precaution. However, the committee still judged the project to fall outside the Health Research Act (REK Southeast 2011/2401, see Appendix III). Approval from the Norwegian Data Protection Official was therefore obtained to conform with the notification obligation (NSD No 29932, see Appendix IV).

The main rule when processing personal data in research is to obtain informed consent from the participants (Norwegian Ministry of Justice and Public Security, 2001; World Medical Association, 2013). Consent from the participants in this study was obtained both orally (through the managers who assisted with the recruitment) and in writing when meeting the participants at the time of the first interview. Information was provided to the participants prior to obtaining their written consent, which described the voluntariness of participation, the anticipated benefits and potential risks of participation, and the participants' right to withdraw their consent without any consequences (see Appendix VI). To protect the privacy of the participants and the anonymity of their personal information, confidentiality was maintained during the course of the study as recommended by the World Medical Association (2013). Data containing identifiable personal information were treated in accordance with the law regulating personal data (Norwegian Ministry of Justice and Public Security, 2001). This involved the nursing managers' distributing the participants' names and contact information only to me after obtaining permission from the participants. The participants names were replaced with a reference number (1,2,3,…) prior to the transcription of the interviews and field notes, and a list of the participants' names and telephone numbers was maintained separately in a safe secured with a digital code, together with the written consent forms. The transcripts and field notes were anonymized and stored on an encrypted computer, and the audiotapes were stored on a secure research database at the University College of Southeast Norway.

Consistent with the Declaration of Helsinki (World Medical Association, 2013), assessing the possible risks and burdens related to participation in the study was important. Participation was determined to not represent any considerable risks. My professional competence as a nurse with a master's degree in geriatric health care was also judged to contribute to ensuring that the study was carried out in a safe manner and that the strain on the participants was minimized to the extent possible. However, participating in interviews and observations may still generate feelings of strain or emotional distress; in addition, using a qualitative approach leads to close contact between the researcher and participant, which may increase strain or distress. Therefore, addressing ongoing issues related to ensuring the participants' comfort was necessary.

During the interviews with the participants, the spouses was informed about their right to end the interview at any time. They were also asked to speak up if they wanted to take a break or if they were feeling uncomfortable. None of the spouses did so during interviews; however, I was careful with follow-up questions when I noticed an area that a spouse had difficulty discussing. Providing the spouses with space and time when they cried was also emphasized. Additionally, even though most of the participants seemed confident in sharing their stories, some of them seemed more strained than others. This was the reason that only some of the participants were invited to participate in the follow-up interviews.

Precautions were also taken in relation to recruiting the participants for the observations. Approval for the observational portion of the study from the Norwegian Data Protection Official allowed the recruitment of participants from among the existing sample. Of the fifteen spouses first recruited for this study, five were eligible to be recruited for the participant observations based on this approval. Of these five participants, one was widowed, and one declined to participate. Three spouses were therefore asked to participate in the participant observations; all of them received a separate consent form created for this portion of the study and were informed about their right to resign (see Appendix VII).

Although the spouses` experiences were the focus of this part of the study, the participant observations of the spouses visiting their partners could not be considered fruitful unless the partners were included. Particular care was required when approaching the partners to obtain consent because of their dementia. Current approaches to obtaining consent have been criticized for over-emphasizing participants' cognitive abilities (McKeown, Clarke, Ingleton, & Repper, 2010). Obtaining consent in its traditional form means that potential participants should be fully informed, and able to understand the implications and potential risks of participating in research (World Medical Association, 2013). Obtaining such consent from persons with dementia may not be possible because of the progressive nature of their symptoms. However, despite the decline in their cognitive function, they may still have the ability to express emotions and share their experiences (Dewing, 2002). Therefore, identifying practical solutions that enable their voices to be heard has been emphasized (Hellstrom, Nolan, Nordenfelt, & Lundh, 2007; McKeown et al., 2010). In this study, consent was considered unconditionally situational, as, e.g., Dewing (2002) recommended. He advocates a model for obtaining consent that considers the capacity of persons with dementia in situation-specific contexts and builds on the individuals' remaining strengths rather than highlighting their weaknesses (Dewing, 2002, 2007). In this study, this meant that each observational session was considered unique in terms of obtaining consent and determining which approach would best allow the partners to participate in meaningful interactions during the observations. One of the participating spouses' wife provided consent after receiving customized verbal and written information (see Appendix VIII), a procedure that was repeated for each observational session. The other two partners were included after substitutional consent was provided by their spouses, as the partners had difficulty communicating verbally. Irrespective of how the partners’ consent was given, it was considered to be unconditionally situational; therefore, the expressed well-being of the spouses` partners was continuously assessed during the observations. The spouses were also asked to assess their own and their partners’ well-being during these sessions. A relationship with the spouses had already been established through the interviews, which facilitated the establishment of interactions that were characterized by assurance and confidence among the spouses and the persons with dementia. Nevertheless, it was important to bear in mind that the person with dementia could be negatively affected by a stranger’s presence, no matter how the context and relationship were adjusted. Moreover, the partners’ ability to verbally express their meanings could also be diminished because of their declining functional capability. I was therefore prepared to terminate the observations and leave the scene if I witnessed any signs of discomfort or anxiety. However, the observations did not appear to negatively affect any of the participants, neither the spouses nor their partners. None of the observations was therefore terminated because of the participants’ discomfort.

5 FINDINGS

This following section will present the main findings reported in the three papers published as part of the study presented in this thesis. Full-text articles are attached at the back.

5.1 PAPER I

Førsund, L.H., Skovdahl, K., Kiik, R. og Ytrehus, S. (2015). The loss of a shared lifetime: a qualitative study exploring spouses' experiences of losing couplehood with their partner with dementia living in institutional care. *Journal of clinical nursing*, *24*(1-2): 121-130. doi:10.1111/jocn.12648

Aim

To explore and describe spouses' experiences of losing couplehood with their dementia-afflicted partner living in institutional care.

Main findings

One of the main finding in this study was the strong feeling of being alone that was experienced by all the spouses, caused by physical separation from and the absence of the partner. The first category, *Loss of a shared everyday life*, described how the spouses' feelings of losing couplehood were strongly connected to these feelings of being alone and that they were associated with various aspects of being separated from their partner in everyday life. Even though this varied day-by-day for the spouses, they often experienced feelings dominated by emptiness, the absence of their partner and aloneness that resulted from their separation from their partner. The sense of aloneness seemed stronger in situations in which the spouses were by themselves, typically in their homes. In addition to physical separation, their feelings of losing couplehood were also connected to a sense of separation resulting from the difficulties they experienced in connecting with their partner. The progression of dementia interfered with the spouses' ability to connect with their partner and participate in their partner's everyday life. Specifically, the loss of speech and the ability to communicate seemed to contribute to a sense of separateness because the partner was inaccessible in daily life. The inability to preserve mutual support amplified the experience of being alone; even though they had families and friends supporting them, some of the spouses indicated that this support did not compensate for the absence of and support from their partner. The feeling of being alone also contributed to dilemmas in various social settings related both to their new social role of being alone while still married and to how others related to them as caregivers. Although they all expressed that they felt married, there was variation in how the spouses experienced being their partners' lovers. Some did not view their partner as their lover, whereas other spouses expressed feelings that were still affectionate. Despite the experience of losing their partner, they still felt as if they were in love and had emotional feelings for their partner. One spouse even expressed that his feelings as stronger because they were blended together (love, care, sympathy and affection). To counteract the feeling of losing couplehood, many of the spouses visited their partner frequently. Several of the participants said that their visits were an effort to re-establish a sense of mutuality and that this somehow compensated for their separation. Glimpses of reciprocity, connectedness and interdependence were occasionally experienced during these visits, provided the partners were still able to respond in some way to their spouses.

One of the other main findings of this study was that the spouses` experience of losing couplehood was not only related to their everyday life as described in the first category but also connected to different phases of their lives, contributing to an overall sensation of a lost lifetime. The second category, *Loss of a shared past*, described how the spouses experiences related to their partners' reduced ability to remember their mutual history contributed to the feeling of losing couplehood: the spouses were left alone with the memories of a lifetime together. The feeling of being alone was often intensified when the spouses were home because their homes contained many memories of a life together with their partner. This experience was reported particularly by the spouses who were still living in the home they shared for years with their partner. The spouses also found it challenging when their partner did not recognize their mutual home, their children or places that had specific meaning for them as a couple. Moreover, the spouses realized that their lifetime together with their partner would end in separation: the opportunity to share a mutual future was gone. The third category, *Loss of a joint future*, described how the spouses' opportunity to share a mutual future with their partner was lost because of the progressing disease. The spouses experienced that their plans and ideas for their future had to change, and some expressed that they did not feel as if they had a future together at all. This was partially related to the spouses own ageing process as well as to their uncertainty about their future after realizing they must face the future alone. This created anxieties for some of the spouses, particularly in terms of what would happen if they died before their partner; the spouses did not want to leave their partner alone.

As demonstrated, the findings in this study showed that the spouses’ experience of losing couplehood was connected to an overall sensation of a lost lifetime: they could neither reconnect through mutual memories nor enjoy a shared future. Nevertheless, one main finding is that these experiences did not appear to be constant; rather, the spouses wavered between different feelings depending on the situation.

Conclusion

The spouses’ experiences of losing couplehood were dynamic and related to each couple`s entire life. The spouses wavered between the senses of loss and belonging to the couplehood, depending on the situation.

5.2 PAPER II

Førsund, L.H., Kiik, R., Skovdahl, K. og Ytrehus, S. (2016). Constructing togetherness throughout the phases of dementia: A qualitative study exploring how spouses maintain relationships with partners with dementia who live in institutional care. *Journal of Clinical Nursing*, *25*(19-20), 3010-3025. doi: 10.1111/jocn.13320

Aim

To explore and describe how spouses maintain relationships with partners with dementia who live in institutional care.

Main Findings

The main finding of this study was how the spouses endeavoured to preserve continuity in their relationship through the three phases of dementia progression following the placement of their partner in institutional care. To address the various challenges associated with the different phases of dementia, the spouses continually searched for new ways to connect with their partners. By adjusting their visiting routines, they facilitated situations in which they constructed togetherness. The first category, “*maintaining involvement and intimacy to preserve continuity in their relationship*”, illustrated how visiting routines helped the spouses preserve continuity in their relationships during the first phase after placement when communication and interaction with their partners was relatively unchanged. To preserve continuity and lessen their longing for their partner, the spouses visited regularly. Regular visits also seemed to help them satisfy their desire to remain involved and fulfil their own obligations to continue caring for their partners. Despite experiencing strains such as sorrow, grief and despair in relation to the visits, visiting was still important. To preserve continuity in their relationships, the spouses initiated different activities. The partners' individual rooms were frequently used because the rooms offered space to sit and talk without interference and recreate routines, habits and activities from their mutual pasts. Most of the spouses experienced that their partners' dementia had already greatly interfered with their abilities to be intimate; thus, intimacy was not a crucial part of their activities during visits. Some of the spouses reported that taking their partners for car rides offered the best conditions for privacy and opportunities to preserve continuity in their relationship.

The second category, "*structuring visits to facilitate interaction and communication*", explained how the timing of the visits was increasingly important in facilitating interaction and communication and in preserving continuity during the second phase as the dementia progressed and the partners' deteriorating function challenged the spouses' ways of interacting and communicating with them. In addition to the progression of symptoms, the partners' capacity to participate in mutual interactions and engage in conversations was increasingly challenged, and it fluctuated throughout the day. The spouses therefore scheduled visits for periods when their partners were more awake and capable of interacting. Structuring visits also involved determining how to end the visits. Saying goodbye was a challenging part of the visits, and feelings of sadness and despair were associated with these farewells. The opportunity to leave without objections from their partners increased their feelings of continuity because they could leave without feeling as if they had let their partner down. The spouses therefore scheduled their visits to fit the routines of the units, enabling them to leave when new events began and facility personnel could divert their partners' attention.

Finally, the third category, "*pursuing moments of mutuality to preserve continuity in a deteriorating relationship*", demonstrated how preserving continuity in the relationship appeared to be challenging when the partners' dementia progressed into the last phase and communicating and interacting became difficult. Other types of interaction were therefore needed. To construct togetherness, the spouses' activities generally involved physical embraces and closeness, such as holding hands, stroking their partner's hair or sitting entwined. Emotional togetherness was constructed by sharing moments together. Irrespective of how they connected, most of the spouses expressed that they only experienced moments of mutuality in this phase because their partner's lucidity fluctuated. To protect themselves from exhaustion and sustain their ability to preserve some sense of continuity in their relationship, most of the spouses decreased the frequency of their visits during this phase, even though visiting was still considered important. In contrast, some of the spouses maintained regular visits, visiting several times per week during the last phase. They expressed a desire to maintain involvement or to monitor the care being provided. As their partners' dementia worsened, support from others during visits seemed important for the spouses. Some brought family members to keep them company, whereas others preferred that professionals be present and tended to use common areas more than individual rooms during their visits.

Conclusion

Being involved and experiencing continuity in the relationship were still important to the spouses after their partners were placed in institutional care. The spouses constructed togetherness by facilitating situations in which they could connect with their partners. To facilitate these situations, the spouses' visit routines were altered and adapted to the progression of their partners' dementia.

5.3 PAPER III

Førsund, L.H. og Ytrehus, S. (2016). Finding a place to connect: A qualitative study exploring the influences of the physical and social environments on spouses' opportunities to maintain relationships when visiting a partner with dementia living in long-term care. *Dementia*. Published ahead of print on June 17, 2016. doi:10.1177/1471301216656087

Aim

To explore how physical and social environments influence spouses' opportunities to maintain relationships when visiting a partner with dementia living in long-term care.

Main findings

The findings showed that identifying a place in the long-term care facility where the spouses could connect with their partners was important in maintaining relationships. Two sections describe the role of physical and social environments in the *individual rooms* compared with the *common areas* in the spouses’ place-making processes.

The individual room

One of the main findings of this study was that for the spouses, opportunities to interact privately with their partners were important in facilitating the maintenance of relationships. Therefore, the individual room, which was at their partners’ disposal, had a central meaning for the spouses in maintaining their relationship with their partner. The use of an individual room was important because it not only allowed the spouses to continue their private life with their partners but also represented something familiar, and the spouses appeared to be motivated by a sense of belonging to the room itself. The spouses reported that decorating these rooms in a homelike style was important for both increasing their partners’ feelings of being at home and supporting their own feelings of belonging. Familiar objects rendered these spaces more familiar, provided topics of conversation and prompted recollections of common memories. Familiar spaces also supported the spouses’ opportunities to maintain familiar roles, routines and habits and continue interacting with their partners in ways that were familiar from their mutual pasts.

The frequent use of the individual room during visits may explain why the spouses specifically noted that the dimension and size of the room were important when considering environmental features. Spacious rooms were appreciated the most because they provided ample seating capacity for visitors. Even though most of the spouses noted the importance of familiarising the individual rooms to render the space more homelike, some also mentioned that the room was nevertheless a public place. The spouses` impressions were confirmed during the observations: some of the rooms were, despite their homelike decorations, characterized by the institutional setting: they were designed with sterile surfaces, neutral colours, intense lightning and limited space. The spouses mentioned experiencing difficulties in using an individual room for private interactions when the room became increasingly unfamiliar and they no longer had places to sit because remedies and equipment replaced the furniture.

The common areas.

The size and design of the common areas appeared to be essential features according to the spouses, and the spouses particularly emphasized the importance of spaces to sit for private interactions. However, according to the spouses, the availability of seating in the common areas varied. This seemed to influence the spouses' choice of use: the limited seating capacity resulted in the visiting spouses interacting with other residents, which inhibited private interactions with their partners. One main finding was therefore that the common areas appeared to be less important in maintaining relationships. However, it appeared that in addition to the size of the common areas, the homelike style of these spaces was also important to the spouses. Additionally, some expressed that a pleasant atmosphere and good relations with the health personnel could render common areas the preferred place to be during visits, despite the lack of privacy. One main finding was that the health personnel were a significant component of the social environment in the common areas. Proximity to the health personnel appeared to be particularly important to the spouses whose partners had severe dementia. In the later phases of dementia, the spouses mentioned feeling safer when they were able to call for help if necessary. Close proximity to health personnel was also considered important in the first period after relocation, when the spouses were becoming familiar with the health personnel and adjusting to their roles as visiting caregivers. Being involved and taken care of by the personnel seemed important during this phase when everything was new.

Conclusion

Opportunities for private interactions were important to the spouses in maintaining relationships with their partners with dementia living in long-term care. The individual room is therefore an important feature for spouses. Individual rooms provide spouses with opportunities for privacy with their partner and support their ability to maintain familiar and valuable roles, routines and interactions from their past. Spacious rooms appear to be important as they provide sufficient room for both necessary equipment and seating for visitors.

Common areas seemed to pose challenges for the spouses because smaller spaces require individuals to be closer to one another, and the opportunity for privacy is therefore nearly non-existent. Nevertheless, some of the spouses preferred to use the common areas as a place to connect, most likely because these spaces offered proximity to health personnel. Gradually establishing relationships with health personnel appeared to be crucial in the spouses' process of developing a sense of place. Therefore, an awareness of the importance of health personnel in supporting spouses' abilities to maintain their relationships is essential.

6 DISCUSSION

The main aim of this thesis was to explore the meaning of spousal relationships for spouses of partners with dementia living in long-term care. In addition, this thesis also aimed to explore and describe how spouses maintain relationships with their partner with dementia living in long-term care, and how physical and social environments influence spouses' opportunities to maintain relationships when visiting a partner with dementia living in long-term care. The main finding of this study was that the spousal relationship appeared to have a central meaning for the spouses when their partner with dementia lived in long-term care. The findings indicate that even though the spouses' experiences were dominated by the dynamic experience of losing couplehood (paper I), being involved and experiencing continuity in the relationship was still important (paper II). To maintain continuity in their spousal relationship, the spouses constructed togetherness by facilitating situations in which they could connect with their partners. To facilitate these situations, the spouses' visit routines were altered and adapted to the progression of their partners' dementia (paper II). Opportunities for private interactions in individual rooms and proximity to support from health personnel were highlighted as important environmental factors for the maintenance of relationships (paper III).

6.1 TOWARDS THEORY CONSTRUCTION ABOUT SPOUSES' USE OF CONTINUITY-PRESERVING PRACTICES TO MAINTAIN SPOUSAL RELATIONSHIPS IN LONG-TERM CARE

The act of constructing theories in constructivist grounded theory must be considered an interpretative endeavour that aims to understand how people act and construct meaning from their actions. Theorizing from this perspective thus assumes the potential for multiple realities and prioritizes understanding over explanations (Charmaz, 2014). This is consistent with Mead`s (1934) symbolic interactionism, which underscores the emergent and processual move towards theoretical abstraction and conceptualization of a studied phenomenon and presumes that knowledge is situated and located in particular positions, perspectives and experiences (Charmaz, 2014). With this as a background, the final portion of this thesis will provide theoretical abstractions about how spouses use continuity-preserving practices to maintain spousal relationships in long-term care. To seek theoretical insights about a studied phenomenon and establish proposals for theoretical abstractions, Charmaz (2014) suggests establishing relationships among the circumstances, situations, events, actions and experiences in the material. This will therefore be undertaken before moving forward with the theory construction.

The circumstances in this study are that the progression of dementia created difficulties for the spouses in terms of caring for their partner at home, and they consequently had to relocate their partner to long-term care. Both the progression of symptoms and the placement itself, which must be regarded as a significant event, created a set of experiences. As shown in the findings section, different ongoing processes become relevant after the spouses' relocation of their partner into long-term care. The spouses' profound experiences of loss, separation and aloneness, which were explained in paper I, significantly influenced the spouses' daily lives and their life situations. The spouses expressed a temporal feeling of disconnectedness from their partner, which was related to the loss of a shared everyday life, the loss of shared memories from the past and the anticipated loss of a shared future. Altogether, these events and experiences constituted the situation, which in paper I was described as the process of losing couplehood. To counteract the experience of losing couplehood and to achieve a sense of togetherness, the spouses used a set of strategies to maintain continuity in their relationship through the different phases of dementia (paper II). To identify a way to connect with their partners, they established visiting routines that were revised and adapted to their partners' condition. When their efforts to construct togetherness were successful, they experienced a momentary feeling of couplehood and a sense of "we-ness". By contrast, when their efforts failed, the spouses experienced the loss of couplehood, a feeling that was strongly connected with the sense of being "I". These processes of losing couplehood and constructing togetherness occurred not in a vacuum but within the context of specific physical and social environments. Paper III showed how different environmental features could promote or hinder the spouses' opportunities to maintain their relationship and how they endeavoured to identify a place in the long-term care environment to connect with their partner and maintain their relationship.

Theory construction is a process (Mead, 1934). Having established the relationship between the findings of the three papers and the relationship among the circumstances, situations, events, actions and experiences in this study, theorizing may progress by conducting comparisons and theoretical conceptualizations with support from the literature (Charmaz, 2014). The abstractions and conceptualizations that are provided here must be considered both interpretative and suggestive and cannot be treated as an indisputable explanation. Although it is suggestive, this effort to develop a theoretical abstraction regarding how we can understand the importance of maintaining continuity in spousal relationships for spouses with partners living in long-term care is nevertheless important. It offers an opportunity to both understand how spouses may construct meaning from their efforts to maintain continuity in their relationships and provide support for spouses' maintenance practices. The next sections will therefore focus on presenting a suggestive theory of spouses' use of continuity-preserving practices to maintain spousal relationships with partners in long-term care. Three different sections focus on different aspects of the theory: the first section focuses on understanding the importance of maintaining continuity in spousal relationships, the next section focuses on how continuity-preserving practices can be used to maintain continuity in relationships, and the last section focuses on how physical and social environments may influence spouses' use of continuity-preserving practices.

6.2 MAINTAINING CONTINUITY IN SPOUSAL RELATIONSHIPS WHEN A PARTNER WITH DEMENTIA IS LIVING IN LONG-TERM CARE

The importance of maintaining continuity in their relationship with a partner living in long-term care was expressed in some way by all of the spouses' who participated in this study, regardless of whether their relationship involved formal marriage (papers I, II, III). It seemed as if the spouses' previous relationships with their partners were characterized by a strong sense of mutuality, and even though the spouses experienced losing couplehood, they still reported experiencing some sense of "we-ness" as part of their relational identity, at least occasionally (paper I). We know from previous studies that the quality of the past relationship may be important in terms of spouses' involvement in their present relationship (Quinn et al., 2009). The quality of their previous relationship might therefore have been essential in determining the importance the spouses placed on their spousal relationship in this study, particularly since the study sample must be considered relatively consistent in terms of spousal commitment and the longevity of the spousal relationship. However, understanding the spouses' commitment to their relationship only from this perspective may not fully identify and explain the variety of influences and causes that might be involved in the difficult situation experienced by the spouses in this study. Other possible accounts must therefore be explored.

The spouses’ emphasis on maintaining their relationships following the relocation of their partner could be perceived as an effort to preserve continuity in a life situation that is highly influenced by discontinuousness. The crucial day when the spouses relocated their partner with dementia from their home to a long-term care facility seemed to constitute a symbolic marker that divided the spouses’ lives from their partners. Mead (1934) underscored the temporal meaning of time for human beings: he asserted that as long as nothing extraordinary happens, time simply flows away without reflection. However, as soon as something unexpected occurs – for example, an unforeseen situation or a difficult experience – this event will prevent people from moving on seamlessly and will give rise to a partition that divides the past from the present and sparks the need to take action in order to maintain continuity. The relocation of a partner into long-term care might symbolize such an event. In the gerontological literature, especially within the ageing theories describing the life course perspective, this concept is often understood as transition (Bengtson, Elder, & Putney, 2005). One way of perceiving transitions is that they involve crossing into a new phase of life, implying the incorporation of new norms, roles and responsibilities (Thorsen, 1998). Unexpected, rarely occurring and unpredictable transitions, such as relocating a partner to long-term care, may provoke experiences of discontinuation, (Thorsen, 1998) explains. The relocation of their partner might therefore be an example of a transition that might challenge spouses’ established daily lives and lead to experience of discontinuousness. Paper I demonstrated that the relocation event denoted an obligatory shift of direction in the spouses’ habitual way of living and required them reconstruct their plans for the future (paper I). Simultaneously, the spouses were also forced to develop new strategies for continuing their relationship with their partner in the long-term facility (paper II).

The findings of this study show that the relocation of their partner represented not only a physical separation for the spouses but also an experiential separation from a relationship filled with memories of a life with their partner (paper I). A common approach in environmental gerontology is to define the meaning of home for older people in relation to their physical, social and personal bonding to a place (Oswald & Wahl, 2005; Sixsmith, 1986). Because older people often live and age in the same place long term, they commonly construct strong ties to their home (Wahl & Oswald, 2010). Familiarity with the home and the important events that may have unfolded there constitute a basis for connection between a person and the environment (Wahl & Oswald, 2010). Consequently, the home can be conceptualized within the personal significance and symbolic meaning it holds as a meaningful “place” (Rubinstein & de Medeiros, 2005) and perceived as an integral part of a person’s history and sense of identity and continuity (Oswald & Wahl, 2005). Following their partners’ relocation, the spouses appeared to experience difficulty placing themselves in their homes because of the absence of their partner and their feelings of emptiness and aloneness (paper I). The home seemed to represent a place where their partner was physically absent but kept psychologically present, which can be interpreted as a feeling of ambiguous loss (Chan et al., 2013; Large & Slinger, 2015; Noyes et al., 2010).

The situation of having their partner living in long-term care represented discontinuity in relation to both to their past lives and expected future (paper I), which prompted the spouses to take actions in response. It is a common presumption in the life course literature that people strive for predictability and continuity (Bengtson et al., 2005; Thorsen, 1998). One of the important principles within this perspective is viewing individuals as agentic actors in constructing meaning in their lives (Thorsen, 1998). People construct meaning based on relationships, events, actions and experiences from earlier life stages and use these experiences to reconstruct meaning through action within current structural and conditional opportunities and constraints, Bengtson et al. (2005) asserts. Given this perspective, it is understandable why being left alone in the home they have shared with their partner and in which they have created a lifetime of memories together may be experienced as difficult by spouses (paper I). This perspective may also explain why maintaining continuity in relationships was found to have such a significance in this study: in the context of an everyday life defined by discontinuity, reconstructing continuity may be an important way of coping with the situation.

One essential motive for maintaining continuity in relationships may be that spouses feel that they are rewarded by receiving something in return for their efforts (Lloyd et al., 2014). Whether this “something” is experiencing short glimpses of couplehood, as explained in paper I, or experiences of togetherness, as explained in paper II, these are outcomes that most certainly contribute to supporting spouses’ experiences of maintaining continuity. According to the symbolic interactionist perspective, people use social relationships to construct selves and mirror oneself and identity (Mead, 1934). The ability to perform known roles is also an important aspect of constructing self and identity (Dittmann-Kohli, 2005). The spouses in this study, who had lived most of their adult lives in a long-lasting relationship, had developed a strong relational identity as conceptualized by (Gergen, 2009), which was explicated as couplehood in paper I. When the spouses' relational identity was threatened because of the progression of dementia and separation, preserving continuity in their relationship may have become particularly important because their spousal relationship served as an important mirror in constructing their own self and identity (Mead, 1934). Papers I, II and III showed that the identity of being a spouse seemed to be particularly important to several of the participants. In addition, it is also reasonable to believe that their role as a spouse was well incorporated in their way of mirroring their own self (Dittmann-Kohli, 2005). One possible explanation of the importance of continuing their spousal relationship may therefore be that the maintenance of relationships can be interpreted as a means of preserving continuity by reconstructing known identities and carrying out established roles.

Constructing identities must also be considered historically and culturally bound and linked with traditions (Dittmann-Kohli, 2005). The participants in this study belong to an age cohort that traditionally has exhibited a strong moral commitment to the maintenance of relationships (Oswald & Wahl, 2005). This may influence how they maintain their identity as a spouse independent of the challenges they face. Being morally committed to remaining involved might also be a strong motivation for continuing relationships (Quinn et al., 2015). Even if the findings in this study did not clarify the existence of moral commitment among the spouses, we might interpret the findings provided in papers I and II that this was an implicit aspect – among several aspects – in some of the spouses' perceptions of the situation. However, moral commitment might be a motivational factor that it is more difficult to discuss with others, especially for older individuals (Thorsen, 1998). This may explain why such views were not clearly articulated in the current study.

As previous studies have indicated (Braun et al., 2010; Monin et al., 2015), love and devotion also stood out as a strong motivational element for the spouses in this study in terms of continuing their relationships with their partner. Although this did not appear to be relevant for all the participants, many of the spouses expressed that they still had strong feelings for their partner (paper I). It is therefore important to avoid undervaluing this finding when considering other aspects. Continuing the role of a loving wife or husband may represent the continuity of these spouses' long-term relationships and may be important in how they reconstruct their identity after the relocation of their partner. Conversely, spouses may also choose to adopt the role of a loving spouse as interpreted via Goffman`s (1959) theory about the presentation of self. The spouses may adopt this role either because they feel that it is the most accepted role in the social collective or because they feel obligated due to the conventions of their age cohort (Thorsen, 1998). According to Charmaz (1995), the concept of identity indirectly takes into account people's wish to define themselves. Thus, when faced with a challenge, people may implicitly construct preferred identities based on their desires, hopes or plans. For the spouses who participated in this study, whose lives were influenced by interactions with a partner who was increasingly separated from them both mentally and physically (paper I), constructing an identity based more on their idealized picture of reality may have been a means of surviving and protecting themselves. Moreover, being a spouse is a known role with which they can identify, and it symbolizes continuity with a lived life. In a situation over which spouses have little control, adopting a familiar, albeit idealized, role, may be a way of compensating for the uncontrollable influences of their situation and taking control to preserve continuity. O'Rourke, Claxton, Kupferschmidt, Smith, and Beattie (2011) explained the concept of "marital idealization" as a strategy in which spouses tend to idealize their marriage and the premorbid personality of their partner. This strategy may serve as a buffer against the distress that may appear in the aftermath of a dementia diagnosis. Within the perspective of symbolic interactionism, spouses' tendency to discount negative experiences from the past or set aside negative memories of their shared life may contribute to an exceedingly positive portrayal of their partner and their marital relationship, and it is from this portrayal that they construct their current relational identities. However, even though marital idealization may represent a self-deceptive strategy, the study by O'Rourke et al. (2011) showed that using this strategy may be advantageous for spouses. The authors found that caregiving appeared to be less stressful when interpreted against the backdrop of a married life recalled as close to perfect. Given this perspective, marital idealization cannot be rejected as a useless strategy, although we cannot determine whether it is relevant for the spouses in this study.

Previous research has indicated that differences may exist between men and women in terms of how they perceive the effects of spousal involvement in caregiving. The most prominent difference noted in the literature is that husbands seem to feel rewarded by repaying their wives for care provided during their lives together, whereas wives tend to view caring more as a continuation of their relationship with their partner (Peacock et al., 2010; Ribeiro & Paul, 2008). These results coincide to some extent with the interpretation of gender identity as a learned manner of acting in which women are perceived as more relational-oriented and men are perceived as more self-directed beings (Thorsen, 1998). The literature furthermore indicates that husbands tend to report more personal growth because of their increasing confidence in mastering new skills such as cooking or doing household tasks (Netto et al., 2009; Ribeiro & Paul, 2008; Sanders, 2005), whereas wives seem to express the benefits of involvement in more spiritual and emotion-based terms (Sanders, 2005). Gender differences, such as those presented in the literature, were surprisingly absent from the findings of this study. The possibility that this is a result of a methodological weakness – for example, a lack of focus on identifying such differences in the interviews and analysis – or that the participants somehow under-communicated such differences cannot be ruled out. However, it is possible that in regard to maintaining continuity in long-term relationships such as those studied here, gender differences might be less important. For example, it is possible that the challenges the spouses experienced in maintaining continuity in their relationship, such as the progression of dementia and the relocation of their partner into long-term care, overshadowed possible gender differences or ways of acting related to their gender roles. Viewing gendered identities as constructed and reconstructed throughout the life course in this thesis is consistent with (Thorsen, 1998). Thorsen (1998) conceptualizes the meaning of gender as essential to older people's construction of self. In their search for continuity in their own life following the relocation of their partner, spouses may need to prioritize among the different possible roles they might assume and select the role that will best support their experience of continuity. Although this prioritization is not a conscious act, a well-known adaption strategy among older people involves enhancing the meaning of the remaining areas of their life when one area is threatened by discontinuity (Thorsen, 1998). Overemphasizing the spousal role in relation to other roles might therefore be interpreted as a means of adapting to the situation and may contribute to undermining their gendered identity.

Another possible explanation for the similarities between the men and women in this study may be that gender differences in the maintenance of relationships in long-term care are more associated with how spouses perceive their situation than how they act. As this study concentrated on processes and actions rather than exploring the effects of the caregiving situation on the spouses, such differences did not surface. Nevertheless, there are indications in the literature that women seem to perceive more stress and burden than men and that this may be related to self-efficacy and coping strategies (Etters et al., 2008; Friedemann & Buckwalter, 2014). The literature indicates that men generally accept their role as a caregiver more as a challenge than an obligation and that they are more task-oriented, which may help them repress their emotional responses (Mc Donnell & Ryan, 2013; Robinson, Bottorff, Pesut, Oliffe, & Tomlinson, 2014). Almberg, Grafström, and Winblad (1997) suggested that whereas men tend to use problem-focused coping strategies, women might be more prone to employing emotion-focused coping strategies, which are related to experiences of burnout and the development of depression. However, Adelman et al. (2014) argue that caregiving is multidimensional and a highly subjective experience. In addition, Friedemann and Buckwalter (2014) remind us that some studies have also indicated that men and women may experience the same level of burden, although men may be more reluctant to disclose it. Given the gender differences described in the caregiving literature, it is somewhat surprising that these differences did not clearly surface in the data from this study. Although some potential explanations for this have been presented, it is clear that this subject warrants further research in the future.

Finally, one additional explanation for the importance of spousal relationship must also be considered: the possibility of a methodological bias in the results. Rogers-de Jong and Strong (2014) describe the possible effect of co-constructing identities with interviewees while interviewing, and this aligns with Rapley`s (2001) assertion that interviews are collaboratively constructed. This notion may be particularly relevant when discussing experiences of mutuality with marital partners, as this may increase their sense of the relational closeness being discussed (Rogers-de Jong & Strong, 2014). The possibility that this type of bias occurred here, as the focus of the study evolved into a relational focus on how spouses maintained relationships in long-term care, cannot be ruled out. However, it is also important to consider that this study provides a strong indication that the spousal relationship actually is important for spouses following the relocation of their partner to long-term care. The discussion of possible explanations presented here is important in order to fully explore the influences that may be involved in difficult conditions such as experiencing dementia in spousal relationships. However, it is important to avoid using these explanations to undermine the actual result of this study, which indicates that maintaining relationships with a partner with dementia living in long-term care has a central meaning in some spouses’ lives. The phenomenon of continuing commitment to the relationship and desire to remain involved in care after placement is a result that is not unique to this study, as other studies have highlighted the same finding (Hennings et al., 2013; Kaplan, 2001; Mullin et al., 2013). This adds more strength to the current study’s result. Refusing to take this finding into account might hinder the ability to provide spouses with the support they need to maintain their relationships.

6.3 USING CONTINUITY-PRESERVING PRACTICES TO MAINTAIN CONTINUITY IN RELATIONSHIPS WITH PARTNERS IN LONG-TERM CARE

Visiting appeared to be an important action that the spouses took to reconstruct continuity following the relocation of their partners into care. By developing new ways of acting, people may reconstruct self and identity after loss or change, Charmaz (2014) claims. She further explains that a person’s habitual ways of acting and doing may be considered the link between the self as a process and the self as an object. Following relocation, the spouses’ relationship with their partner moved into a new phase. The worsening of their partners’ mental and physical state had already been occurring for quite some time. Nevertheless, following their partners’ relocation, the spouses seemed to construct their partners’ dementia progression into phases of deterioration defined by their partners’ ability to interact and respond to the spouses’ signals (paper II). Losing couplehood was a process resulting from the deterioration of their partners’ capabilities, and it influenced their ability to co-construct a relational identity (paper I). By developing interpretations of the consequences of their partners’ dementia progression, not as an understanding of the biomedical brain processes but in relation to their ability to make contact and continue their relationship, the spouses acted proactively to counteract the consequences of dementia and maintain continuity. This result therefore underscores the importance of emphasizing the intersubjective dimensions of dementia in addition to focusing on the medical aspects of deterioration and treatment, as others have also urged (McGovern, 2011; Nolan et al., 2002; Woods, 2005).

Mead (1934) contended that depending on the emerging situation, a person might use different strategies to retain a sense of continuity by reconstructing past and present experiences, habits and social roles. Papers II and III showed that spouses used different strategies to maintain continuity in relationships according to the phases of their partners’ dementia progression following relocation to long-term care, which may serve as an example of how continuity might be actively constructed in such situations. Thorsen (1998) explained how older people might become experienced in reconstructing their present life situation in the light of present events and past experiences. The marital history of the spouses who participated in this study seemed to serve as an important backdrop to their efforts to reconstruct continuity, such as reconstructing well-known habits and routines during visits (paper I), reconstructing memories by viewing old photographs (papers II and III) or visiting places with a special meaning (paper II). Thorsen (1998) called such activities continuity-preserving practices and explained how such practices can be interpreted as a way that older people reconstruct continuity during discontinuousness. Older people may be reluctant to use active coping strategies, she clarified; therefore, using everyday activities intentionally, even if they are scarcely noticeable to others, might serve as an important strategy for maintaining continuity (Thorsen, 1998).

The continuity-preserving practices employed by the spouses in this study seemed to take the form of trivial daily activities. Examples of the activities that the spouses initiated included sharing a cup of coffee, taking their partner for a stroll in a wheelchair, looking at photographs or reading family histories, playing cards, reading the paper and making small talk, taking their partner for car rides, solving a crossword or just spending time together with their partner (papers I, II and III). Although such activities may appear insignificant to outsiders, they may hold a special meaning for the spouses in terms of maintaining some semblance of their relational identity, even if this becomes gradually more difficult (paper I). For the spouses, performing continuity-preserving practices may also represent a way of maintaining continuity in their own role as a spouse. Maintaining their role as a spouse may serve to counteract the uncertainty related to assuming a role that may appear unstable and unfamiliar because of the loss of their partner in their daily life (paper I). Since the role of being a spouse is a well-known role from the past, this may be important (Thorsen, 1998).

Reminiscence has been emphasized as an important means of performing continuity-preserving practices (Thorsen, 1998). This study showed that the spouses’ partners gradually lost the ability to share mutual memories from their past (papers I and II). Interpreting the reconstruction of mutual memories from the past as a continuity-preserving practice may explain why the inability to share mutual memories had such grave consequences for the spouses’ experiences of losing couplehood (paper I). The memories of their shared past with their partner was incorporated into their own self and identity in addition to being part of their relational identify (Mead, 1934; Thorsen, 1998). The inability to reconstruct past memories with their partner may therefore also inhibit the spouses’ experience of maintaining continuity of their own selves. Because increasing memory problems influence their partners’ ability to participate in reminiscence, engaging in other continuity-preserving practices such as daily activities may be the only way to maintain a connection with their past as husband and wife.

Supporting spouses' abilities to maintain such activities and acknowledging the significance of these activities as continuity-preserving practices therefore seems important.

6.4 THE INFLUENCE OF THE PHYSICAL AND SOCIAL ENVIRONMENT ON SPOUSES' OPPORTUNITIES TO MAINTAINING CONTINUITY IN RELATIONSHIPS

The relocation of a partner to a long-term care facility caused a sudden change in the living arrangements of the spouses and seemed to represent discontinuity in the spouses' lives. From the day of relocation, the spouses had to live separately from their partner – alienated in separate "homes" (papers I, II and III). Relocating their partner into long-term care not only led to a difficult home situation for the spouses (paper I) but also meant that the spouses had to become accustomed to the unfamiliar environments associated with their partner's new home (paper III). Relocation to a long-term care facility is associated with major change and transition for older people (O`Shea & Walsh, 2013) and for spouses with partners with dementia (Hennings et al., 2013). Long-term care environments represent unfamiliar settings, and the routines and practices in such settings are often unknown to outsiders (Cutchin, 2013).

Mead (1934) claimed that if an individual is confronted with sudden changes in life circumstances, such as being separated from a partner and having to relate to a new home, a discontinuation of the enduring self may arise. The real effect of this discontinuation is then dependent on the agency of the subjective self, "I". If the "I" succeeds in reconstructing continuity, the negative consequences of the change might be mediated (Mead, 1934). Finding a place to connect, as conceptualized in paper III, described the active undertakings, used by the spouses to reconstruct a sense of being in place in such unfamiliar settings as the long-term care facilities. Rowles and Bernard (2013) described how transforming anonymous spaces into meaningful places could represent one way of reconstructing meaning when confronted with discontinuity in regard to the physical environment and may serve as a means of understanding the processes that influence spouses' opportunities to reconstruct continuity after relocating their partner. Rubinstein and Parmelee (1992) called this process place attachment, which represents how people create new bonds with a place in the context of their ongoing lives to support their experience of a continued self. The experience of being in place may thus be understood as a way of maintaining continuity of a person's self and identity (Chaudbury & Rowles, 2005) and reflects the reciprocal interaction between the individual, social collectivity and environment in constructing self and identity (Charmaz, 2014). Adapting a sense of being in place appeared to be important for the spouses' in order to reconstruct continuity after their partners' relocation and for their ability to maintain continuity in their relationship (paper III).

Some environmental features seemed to be more beneficial than others in facilitating the spouses' continuity-preserving practices. A main finding in this study was the significance of the individual room for the spouses' opportunities to maintain continuity in their relationship (papers II and III). Individual rooms are features of long-term care environments that have been emphasized as important in relation to housing design for persons with dementia (Davis et al., 2009; Day et al., 2000) and for residents in terms of supporting their construction of attachment to place (Falk et al., 2013). This study offers insights into the role that individual rooms may play in facilitating continuing contact between residents and their close relatives and illustrates how spouses in particular perceive the importance and use of these rooms. These are interesting findings, which clearly deserve more attention from research in the future.

Spaciousness was one feature of individual rooms that seemed especially important to facilitating the spouses' opportunities to continue their relationships. Spacious rooms provided the opportunity to personalize a room and offered increased flexibility in relation to how the room could be decorated (paper III). Decorating a room with familiar objects may create opportunities for spouses to reconstruct continuity with their past lives as husband and wife, which may be one reason that spaciousness was emphasized. The literature gives examples of strategies such as using valued belongings to decorate a room to ease the place-making process (Rowles & Bernard, 2013; Rubinstein & Parmelee, 1992; Sherman & Dacher, 2005). Spacious rooms may also provide more seating capacity for visitors, which was highlighted in paper III as an important prerequisite for the use of the room. Rowles and Bernard (2013) argued that how people use these spaces also influences how they identify with the environments, and these uses are considered essential for developing an overall sense of familiarity with these spaces. Reconstructing familiar habits and routines and recalling memories were emphasized as important continuity-preserving practices by Thorsen (1998) and emphasized as important place-making strategies by Rowles and Bernard (2013), Sherman and Dacher (2005) and Rubinstein and Parmelee (1992). Providing spaces that can be personalized and that enable the continuation of familiar rituals and routines is therefore important in order to support spouses' efforts to find their place within the long-term care environments, enable them to continue their role and identity as a spouse if desired, and ultimately facilitate ongoing contact between spouses and their partners. This may also explain why some of the spouses appeared to find individual rooms more difficult to use in the later stages of their partner's dementia, when more remedies and equipment were required. When personal belongings and objects that provide a sense of belonging to the room disappear, maintaining continuity with a shared past may be more difficult. This may also explain why some of the spouses chose other locations for their interactions with their partners during visits.

The common areas seemed to be somewhat difficult to use during the spouses' visits because of the cramped spaces (paper III). Because long-term care facilities for persons with dementia in Norway are generally designed as small units with only few residents in each unit, the common spaces are often limited in terms of size (Bank, 2009). The units to which the spouses in this study had relocated their partners differed in terms of both design and size. However, all the units were built and designed in accordance with existing guidelines, and each housed a maximum of 10 residents, which meant that the common spaces offered inside each unit were relatively limited. The importance of promoting community among patients and designing a spatial arrangement that facilitates proximity to common spaces are well-known housing design concepts in the dementia literature (Marquardt et al., 2014). Until now, few studies have studied aspects of dementia care housing design from the perspective of spouses or explored the effects that different housing solutions may have on supporting ongoing spousal interactions. However, the findings of this study, which indicate that spouses are reluctant to use common spaces for private interactions (paper III), may serve as a reminder of the different perspectives that should be considered when designing dementia care facilities. Small units are still emphasized in the Norwegian guidelines (Norwegian Ministry of Health and Care Services, 2015a), although the international research literature is somewhat inconclusive concerning the best size and arrangement for dementia care units (Marquardt et al., 2014). The findings in this study cannot provide guidance for the dimensions of long-term care facilities; however, the study findings indicate that facilitating opportunities for private interactions in common spaces are important in terms of spouses' opportunities to maintain continuity in their relationship (papers II and III). Small units may be limited in the spaces available in common areas that can be used by spouses to interact privately with their partners.

For the spouses, close proximity to health personnel seemed to become increasingly important during visits as communication problems became increasingly apparent and their partners became more dependent on advanced care and support from health personnel (papers II and III). This appeared to be an important reason that some of the spouses preferred to use common areas as a place to connect (paper III). The relationships between health personnel, residents and their families have emerged in the literature as important components of the social environment in long-term care facilities (Brown Wilson, 2009; Woods, Keady, & Seddon, 2008). Prioritizing the relationship between the people involved in care – the resident, health personnel and the resident's family – is a cornerstone of person-centred care for people with dementia (Edvardsson, Winblad, & Sandman, 2008). Person-centred care has become an important care philosophy and a basic framework for health care practice that is now incorporated in Norwegian national health policy plans (Norwegian Ministry of Health and Care Services, 2015a, 2015b); a recently published report also emphasized people-centred services (World Health Organization, 2016b). One of the most cited and perhaps most important contributors to the emergence of person-centred philosophies in dementia care is Thomas Kitwood, who highlighted the potential for and importance of sustaining personhood among people with dementia (Kitwood, 1997). Although Kitwood focused primarily on the person with dementia, he also acknowledged the value of the social relationships in which that individual's personhood is constructed and reconstructed (Woods et al., 2008). Over the years, person-centred care as a practice and philosophy of care has been elaborated, developed, reviewed and conceptualized by countless contributors, see, for example, Brooker (2004); Edvardsson, Fetherstonhaugh, and Nay (2010); Edvardsson et al. (2008); McCormack (2003, 2004); McCormack and McCance (2006, 2016) or Morgan and Yoder (2012). Through the development of different frameworks informing person-centred care practices, the importance of incorporating family as partners in care has also been increasingly emphasized, and it has sometimes been conceptualized as relationship-centred care (Nolan, Davies, Brown, Keady, & Nolan, 2004; Woods et al., 2008). Involving family as partners in care is now highlighted as an essential part of the definition of good quality care, especially within person-centred dementia care services and in relation to gerontological nursing practice (Edvardsson et al., 2008; McCormack, 2004). The findings of this study revealed that the relationship between the spouses and health personnel was dynamic and evolved over time and that the spouses perceived it differently (paper III). Although some of the spouses emphasized the support they gained from health personnel, examples were also provided of the misunderstandings and mistrust that sometimes characterized their relationship with health personnel; some spouses also mentioned that becoming familiar with each other was an evolving and time-consuming process (paper III).

There may be many reasons that spouses and health personnel sometimes strive to establish a reciprocal and trusting relationship, as indicated in this study. Both Brown Wilson (2009) and Hemingway et al. (2016) argued that in facilities with high staff turnover or more part-time personnel or casual staff, establishing nurturing relationships may be difficult. Chaudbury and Rowles (2005) claimed that identity construction in relation to the experience of place attachment is dependent on a social process: people`s socialization of spaces takes time, and this includes the development of social relationships. Cahill et al. (2012) claimed that spouses’ regular visits to long-term care facilities can foster a relationship with staff that engenders trust; however, these authors also highlighted the gradual evolution that often characterizes such a relationship. The findings of this study suggested that spouses are particularly vulnerable during the first period following the relocation when everything is new and they are attempting to find their place in the environment (paper III). Given these findings, health personnel should likely endeavour to establish relationships with spouses that encourage reciprocal trust and confidence at the time a partner is relocated.

7 CONCLUSIONS AND IMPLICATIONS

7.1 CONCLUSION

The spousal relationship seemed to have a significant meaning for the spouses in this study when their partner with dementia was living in long-term care. Altogether, the processes of losing couplehood (paper I), constructing togetherness (paper II) and finding a place to connect (paper III) described the spouses' agency in maintaining continuity in their spousal relationship after the relocation of their partner with dementia to long-term care. These findings explicate the struggle that spouses experience on several levels to comprehend their situation, which seems to be connected to the experience of having to relate to and act within two separate arenas: one as a solitary spouse at home and one as a visiting spouse in the long-term care facility. Continuing life alone at home requires spouses to reconstruct their ways of living; however, their agency is challenged because of the ambiguous presence of their partner and because life at home takes place in an arena that strongly reminds them of their past life. To counteract this experience of discontinuousness, spouses adjust their visiting routines and use everyday activities as continuity-preserving practices to maintain continuity in their relationship. This seems to be important to the maintenance of continuity in their relationship and to their efforts to reconstruct their role and identity as a spouse. However, spouses also struggle to find their place in the long-term care facility. While common areas appear to pose difficulties as a place for reconnection, the continuity-preserving practices that occur in individual rooms seem to be particularly important to the spouses' opportunities to maintain continuity in their relationships. In addition, it seems that health personnel may play a significant role in supporting spouses' use of continuity-preserving practices to maintain continuity in their spousal relationships. The findings in this study therefore argue for the importance of acknowledging and supporting spouses' continuity-preserving practices in their efforts to maintain continuity in their spousal relationships by both providing spouses with support and ensuring there are spaces in which continuity-preserving practices can occur.

7.2 IMPLICATIONS FOR PRACTICE

Given the lack of drug treatments that are able to halt or reverse the progression of dementia, governments are urged to develop public policies and services that can enable people with dementia and their families to live well from diagnosis to end of life (Kenigsberg et al., 2016;

Pountney, 2008). In 2007, Norway was one of the first countries in Europe to launch a comprehensive policy plan for the development of dementia care services and caregiver support (Norwegian Ministry of Health and Care Services, 2007a). One of the main priorities of this plan was the development of conversation groups and educational schools for caregivers. Developing more respite care and day care services for persons with dementia, among other support services, was a priority in the plan (Norwegian Ministry of Health and Care Services, 2007a). The priorities for the future development of dementia care services and caregiver support were launched in a new policy plan in December 2015 (Norwegian Ministry of Health and Care Services, 2015a). The primary ambition of this plan is to develop a society that is more open-minded and inclusive of persons with dementia and their caregivers. One of the main priorities is to develop support services that are more individually tailored to meet the needs of persons with dementia and their caregivers. However, similar to the first plan from 2007 (Norwegian Ministry of Health and Care Services, 2007a), this new policy plan (Norwegian Ministry of Health and Care Services, 2015a) focuses mainly on support services aimed at supporting caregivers while keeping persons with dementia at home. The findings in this study, which portrayed spouses' situations after the relocation of a partner with dementia to long-term care, indicate the need to support spouses during the phase of dementia when the person with dementia lives in long-term care. This study described spouses' desire for extensive and ongoing involvement and outlined the challenging situation that spouses experience, especially when they are at home. Acknowledging and addressing these issues will likely be important for the development of future support services.

The findings in this study clearly support the importance of involving spouses as collaborators in the care of their partners. However, the findings also suggest that spouses must undergo a time-consuming process to become known to health care personnel and find their place in a long-term facility after the relocation of their partner. This suggests that despite being informed and directed by policy plans emphasizing the need to adopt a person-centred approach that includes strong collaboration with spouses, some long-term care facilities still seem to fall short in terms of involving spouses as partners in care. Considering the important role that health personnel appear to play in spouses' efforts to maintain continuity in their relationship with their partners, emphasizing the establishment of trusting relationships with spouses visiting their partners is clearly a subject that should be prioritized to a greater extent in the future. In the following sections, some suggestions are provided regarding how spouses might be involved and supported in their efforts to maintain continuity in their relationships.

The significance of being involved and continuing relationships is highlighted throughout this study. Encouraging family to participate and collaborate as partners in long-term care facilities will likely be a growing trend in the future. Family involvement is highlighted as an important resource within the health care system for future elderly and dementia care services (Norwegian Ministry of Health and Care Services, 2006, 2007a, 2013, 2015b). Support services that aim to support spouses' abilities to remain involved in their partners' care are therefore important. Greater involvement may enhance their sense of being in place, as they will know the personnel better and be better adjusted to the environment, which may increase their resilience and ability to continue being involved in their partners' care. Therefore, inviting spouses to participate in a dialogue about how they may contribute, if that is their desire, without placing any pressure on them is of great importance. However, health personnel must be sensitive to spouses` needs, as there are several factors influencing their situation, particularly their present and past relationship with their partner. The overall quality of the relationship will influence spouses' experiences of their partners' dementia and may range from dysfunctional and non-supportive to strong, supportive and functional relationships (Davies & Gregory, 2007). Taking into account such factors and knowing that spouses' own relational identity might determine the type of support they need is therefore important. In addition, knowing spouses' relational background may also serve as a reference in regard to understanding why spouses use different approaches to caregiving involvement and spousal commitment after placement in care. Additionally, acknowledging the close and intimate relationships that some spouses still have with their partner, even though their partner lives in long-term care and is affected by dementia, is equally important. To openly discuss the importance of nurturing intimate relationships in long-term care, if desired, requires serious consideration of spouses and their needs.

The findings of this study indicated that some of the spouses expressed a need for support in maintaining their relationships, especially in the later stages of their partners' dementia. As this study showed, the spouses used everyday activities as continuity-preserving practices in order to maintain continuity in their relationships with their partner. The primary focus of health personnel working within long-term care settings is often helping and caring for patients with different functional capacities (Kane & Kane, 2005). Identifying and appreciating the importance of ordinary activities, such as the continuity-preserving practices depicted in this study, may place additional demands on health personnel during an already busy day. Acknowledging such activities can be especially difficult to prioritize if the facility has a clinical focus (Kane & Kane, 2005). Nevertheless, when interpreted as continuity-preserving practices, such actions seemed to be important to the spouses' efforts to maintain continuity in their relationship with their partner and continue their role and identity as a spouse. Helping such activities to flourish may not be very resource demanding, however. First, providing outdoor and indoor environments where spouses can maintain their continuity-preserving practices is important and is outlined in the next paragraph. Health personnel might also support spouses' maintenance practices by facilitating situations in which spouses can experience moments of togetherness with their partner. Providing and organizing enrichment activities in which spouses and their partners can participate or excursions out of the facility, if the partner is capable, are examples of strategies that may offer important support for spouses' continuity-preserving practices.

Health personnel may also play a crucial role in organizing the physical environment to ensure there is space for spouses during visits. This is crucial for supporting spouses' continuity-preserving practices. How the environment in long-term care facilities is designed and organized to support the maintenance of spousal relationships is a subject that is highly overlooked in the Norwegian guidelines on housing design in dementia care, such as those provided by Bank (2009). There is also a lack of such considerations in the most recently published national policy plans and strategies concerning dementia care (Norwegian Ministry of Health and Care Services, 2007a, 2013, 2015a, 2015b). However, the findings of this study indicated that environmental features may play a significant role in supporting spouses' use of continuity-preserving practices to maintain continuity in their relationships. The individual room was highlighted as a particularly important place to connect. Given these findings, it is therefore recommended that spouses be given discretion regarding how individual rooms are furnished and used and that they be involved if their partners' room requires modifications in terms of adding or removing furniture. This study's findings also indicated that common areas may serve as an important place for interactions if the environment is properly adapted, especially because these areas offer proximity to health personnel if assistance is needed. Because common areas are somewhat limited in terms of space and there are many considerations to address in relation to the users of these areas, modifications to the environment may be necessary. However, such modifications do not have to be extensive: establishing semi-private zones where spouses and their partners can be private while remaining in close proximity to health personnel may serve as an example of a simple initiative to facilitate private interactions.

The findings of this study noted the insecurity that many of the spouses expressed regarding their future and what they might expect as their partner's symptoms progress. The situation of being a spousal caregiver and losing one's partner to dementia might also lead to substantial challenges related to of end-of life issues. Because of the communication problems that often accompany advanced dementia, spouses may not be able to discuss such issues with their partner, who would probably be the closest person under different circumstances. This might add to the loneliness that the findings indicated the spouses are already experiencing. Involving spouses in conversations about the future and what they can expect may help spouses to cope with their ambiguous role. Late-stage dementia requires advanced care, and the new guidelines assume that both patients with dementia and their family will benefit from a palliative care approach that is person-centred and family focused (The Norwegian Directorate of Health, 2015). Including family in end-of-life care decisions was emphasized in a white paper defining optimal palliative care in older people with dementia (van der Steen et al., 2014). Ongoing family involvement is one of the cornerstones of the palliative approach (The Norwegian Directorate of Health, 2015; van der Steen et al., 2014). Until now, speaking of palliation in dementia care has not been a common practice in Norway, even though dementia is clearly a syndrome that requires advanced end-of-life care. The findings of this study, which demonstrate the strong involvement that some spouses have during the course of their partner's dementia and the numerous anxieties they often experience, suggest that health personnel should pay more attention to involving spouses as full partners in care as soon as relocation occurs. This partnership might involve collaboration and exchange of information with spouses and providing support to spouses. Using a palliative care approach may serve as a useful frame for establishing such routines.

To address spouses' difficult situation and their worries about their situation and their futures, which were apparent in many of the interviews in this study, other support services might also be beneficial. Important support has been offered to many spouses and other family caregivers through conversational groups and educational schools (Gjøra, 2016). Such support interventions have been established and developed in 2/3 of the Norwegian municipalities over the course of the past 10 years; however, they have mainly been offered during the period when the person with dementia lives at home (Gjøra, 2016). This study provides insight into the very specific difficulties and challenges that spouses might experience in the aftermath of relocating their partner to long-term care. This suggests the need to develop a package of support programmes that are designated for caregivers in long-term care for both educational schools and conversation groups. Examples of subjects for an educational programme intended to support spouses during the phase of being caregiver for a partner in long-term care could involve, for example, sharing knowledge about late-stage dementia and palliative care, everyday institutional life and collaboration practices, ethos of care, spouses' adjustment needs and place-making processes in long-term care facilities and how daily activities can be used as continuity-preserving practices. The findings of this study also suggest that some conversational groups should likely be designated for spouses with partners with dementia living in long-term care. In particular, because spouses experience difficulties in relation to their ambiguous role as a visiting spouse to a partner who is physically present but mentally absent. In addition, to the challenges in communicating these experiences and receiving understanding from "outsiders" demonstrate the need to establish and facilitate forums in which spouses might meet other people with partners with dementia living in long-term care.

The findings of this thesis denote the challenging home situation that some spouses experienced after the relocation of their partner. This highlights the need for a more active approach in endeavouring to ease spouses' situation at home. Spouses with partners with dementia are often older people, and they may suffer from comorbid illness and frailty in addition to their difficult situation as a caregiving spouse. Additionally, spouses are likely to be living alone. Research has indicated that being an elderly caregiving spouse of a person with dementia may be associated with negative health effects (Pinquart & Sörensen, 2007). Assessing and charting spouses' health condition fell outside the scope of this study; however, the difficulties that arose in relation to recruiting participants suggest the need to consider spouses' general frailty, although this is only speculative. Regardless of their state of health, the difficulties that characterize spouses' situations highlight the need to provide outreach services to assess their health and well-being during this phase of their partner's illness.

New protocols were recently released by the Norwegian government to encourage the development of preventive home visits as a service to all people above 75 years of age. Such services are provided with the intention of supporting independent living among elderly people and preventing illness and functional impairment (Norwegian Ministry of Health and

Care Services, 2016). This type of service may serve as an important outreach service to provide needed support for spouses. The health personnel providing these services should be aware of the difficulties that spouses experience after relocating their partner and should pay greater attention to this specific group of elderly people. However, it may also be difficult for health personnel with little previous knowledge about the spouses and their history to provide the needed support. Notably, personnel working in long-term care facilities may be those having the most accurate insights into the situation of spouses. As this study indicates, spouses may be reluctant to share the difficulties they are experiencing in continuing their life at home after the relocation of their partner. This underscores the importance of health personnel engaging spouses in dialogues about their experiences and needs. In cases in which personnel are uncertain about the well-being of a spouse, they might offer support through follow-up phone calls after spouses have returned home following a visit or by involving other family members, for example. In cases in which spouses lack a social network, involving volunteer organizations or people to visit those spouses might be appropriate.

Specific suggestions for practice:

Supporting spouses' maintenance practices may include the following:

- Involving spouses as partners in care and inviting them to engage in dialogue about how they may want to contribute, their needs for support and their preferences for involvement without placing demands on them
- Talking about and nurturing intimate relationships in long-term care, if this is desired
- Identifying, acknowledging and facilitating the use of ordinary activities as continuity-preserving practices
- Arranging the physical environment to ensure there is space for spouses during visits
- Granting spouses discretion in terms of how their partners' individual rooms are furnished and used and involving spouses if their partners' room requires modifications to add or remove furniture
- Establishing semi-private zones in common areas where spouses and their partners can have private interactions while remaining in close proximity to health personnel if assistance is required
- Involving spouses in conversations about the future and what they can expect

- Involving spouses as full partners in care from the day of relocation using a palliative care approach that may involve collaboration and exchange of information with spouses and providing support to spouses
- Launching educational programmes intended to support spouses during the phase of being a caregiver to a partner in long-term care
- Establishing conversational groups designated for spouses with partners living in long-term care to facilitate forums where they can meet others who share their situation

7.3 IMPLICATIONS FOR RESEARCH

Acknowledging the importance of and supporting the ability of spouses to maintain continuity in their spousal relationships after the relocation of a partner with dementia to a long-term care facility is the main finding of this study. Nevertheless, more research is needed to further investigate this important and relatively unexplored subject area. The next paragraphs therefore note some recommended directions for future research, and a number of specific suggestions for research questions are proposed at the end.

This study combined data from interviews about spouses' descriptions of their situation with observations of the influences of the long-term care environment to explore spouses' opportunities to maintain continuity in their relationship. This constituted a new and original contribution to the caregiving literature and generated interesting findings. However, this study involved only a few long-term care facilities and a small and homogeneous sample. It is therefore recommended that further research focus on expanding the sample to include spouses with a wider range of characteristics, particularly in regard to gender, age and relational background. In addition, including long-term care facilities with different characteristics related to factors such as spatial organization, organizational setting, staff policy and different sizes and features is important. Such a study design would most likely benefit from the inclusion of more extensive and reoccurring observations of the physical environments and ongoing activities during visits in addition to adapting a longitudinal design that involves interviews with all the stakeholders in a facility. Such a study would have the opportunity to generate important knowledge about the influence of different housing solutions on spouses' opportunities to remain involved and maintain their relationships, to provide insight into how the use of environments may vary over time and to include the perspectives of various stakeholders.

Because the findings of this study indicated that spouses strive to comprehend the implications of continuing their life when alone at home following the relocation of their partner, future research should focus on gaining more in-depth insights into this phenomenon. With the aim of developing interventions to support spouses in this challenging situation, future studies should focus on how spouses describe their experience of relating to and acting within two different arenas and how their situation is influenced by, for example, economic issues, practical matters, social support, and health-related factors, among others. Interventions aiming to aid spouses in this situation should likely include programmes designed to support spouses while at home and when visiting their partner's facility. As existing support programmes mainly focus on caregivers of partners living at home, more research must be conducted to develop and tailor specific programmes for spouses with partners living in long-term care.

Specific suggestions for research questions:

- How do men and women differ in relation to the maintenance practices they use for their spousal relationship after the relocation of a partner with dementia to a long-term care facility?
- How do the characteristics of a long-term care facility influence spouses' maintenance practices when a partner with dementia lives there?
- How do health personnel perceive their influence on and efforts to support spouses' maintenance practices and to aid spouses in preserving continuity in their relationships?
- What is the meaning of maintaining spousal relationships as described by persons with dementia living in long-term care?
- How does the perceptions and use of the long-term care environments vary for spouses and their partners throughout the phases of dementia?
- What characterizes spouses' situation when at home after their partner has relocated to a long-term care facility, and how do spouses endeavour to comprehend this situation?
- What are spouses' needs in terms of individual support when their partner with dementia lives in long-term care, and what should a tailored support programme include?

8 REFERENCES

Ablitt, A., Jones, G., & Muers, J. (2009). Living with dementia: A systematic review of the influence of relationship factors. *Aging and Mental health, 13*(4), 497-511. doi:10.1080/13607860902774436

Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *JAMA, 311*(10), 1052-1060. doi:10.1001/jama.2014.304

Allen, L. M. (2010). A critique of four grounded theory texts. *The Qualitative Report, 15*(6), 1606-1620. Retrieved from http://nsuworks.nova.edu/tqr/vol15/iss6/16?utm_source=nsuworks.nova.edu%2Ftqr%2Fvol15%2Fiss6%2F16&utm_medium=PDF&utm_campaign=PDFCoverPages

Almberg, B., Grafstrom, M., & Winblad, B. (1997). Caring for a demented elderly person - burden and burnout among caregiving relatives. *Journal of Advanced Nursing, 25*(1), 109-116. doi:10.1046/j.1365-2648.1997.1997025109.x

Almberg, B., Grafström, M., & Winblad, B. (1997). Major strain and coping strategies as reported by family members who care for aged demented relatives. *Journal of Advanced Nursing, 26*(4), 683-691. doi:10.1046/j.1365-2648.1997.00392.x

Alvesson, M., & Sköldberg, K. (2009). *Reflexive Methodology. New Vistas for Qualitative Research* (2 ed.). London: SAGE.

Alzheimer Europe. (2013). *Dementia in Europe Yearbook 2013*. Retrieved from http://www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks

Ask, H., Langballe, E. M., Holmen, J., Selbæk, G., Saltvedt, I., & Tambs, K. (2014). Mental health and wellbeing in spouses of persons with dementia: the Nord-Trøndelag health study. *BMC Public Health, 14*(1), 1-12. doi:10.1186/1471-2458-14-413

Baikie, E. (2002). The impact of dementia on marital relationships. *Sexual and Relationship Therapy, 17*(3), 289-299. doi:10.1080/14681990220149095

Bamford, C., Lamont, S., Eccles, M., Robinson, L., May, C., & Bond, J. (2004). Disclosing a diagnosis of dementia: a systematic review. *International Journal of Geriatric Psychiatry, 19*(2), 151-169. doi:10.1002/gps.1050

Bengtson, V. L., Elder, G. H., & Putney, N. M. (2005). The Lifecourse Perspective on Aging: Linked Lives, Timing, and History. In M. Johnson (Ed.), *The Cambridge Handbook of Age and Ageing* (pp. 493-502). Cambridge: Cambridge University Press.

Benton, T., & Craib, I. (2011). *Philosophy of social science. The philosophical foundations of social thought* (2 ed.). Hampshire: Palgrave Macmillan.

Berger, P. L., & Luckmann, T. (1966). *The Social Construction of Reality. A Treatise in the Sociology of Knowledge*. Harmondsworth: Penguin Books.

Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Berkeley and Los Angeles: University of California Press.

Boss, P., & Couden, B. A. (2002). Ambiguous Loss from Chronic Physical Illness: Clinical Interventions with Individuals, Couples, and Families. *Journal of Clinical Psychology, 58*(11), 1351-1360. doi:10.1002/jclp.10083

Braithwaite, D. O. (2002). “Married widowhood”: Maintaining couplehood when one spouse is living in a nursing home. *Southern Communication Journal, 67*(2), 160-179. doi:10.1080/10417940209373227

Bramble, M., Moyle, W., & McAllister, M. (2009). Seeking connection: family care experiences following long-term dementia care placement. *Journal of Clinical Nursing, 18*(22), 3118-3125. doi:10.1111/j.1365-2702.2009.02878.x

Braun, M., Mura, K., Peter-Wight, M., Hornung, R., & Scholz, U. (2010). Toward a better understanding of psychological well-being in dementia caregivers: the link between marital communication and depression. *Family Process*, *49*(2), 185-203 doi:10.1111/j.1545-5300.2010.01317.x

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience, 11*(2), 217-228. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181916/

Brooker, D. (2004). What is person-centred care in dementia? *Reviews in Clinical Gerontology*, *13*(3), 215-222. doi:http://dx.doi.org/10.1017/S095925980400108X

Brown Wilson, C. (2009). Developing community in care homes through a relationship-centred approach. *Health & Social Care in the Community*, *17*(2), 177-186. doi:10.1111/j.1365-2524.2008.00815.x

Bryant, A., & Charmaz, K. (2007). Grounded Theory in Historlical Picture: An Epistemological account. In A. Bryant & K. Charmaz (Eds.), *The SAGE Handbook of Grounded Theory* (pp. 31-58). London: SAGE.

Cahill, S., Doran, D., & Watson, M. (2012). Guidelines for nursing homes delivering end-of-life care to residents with dementia across the island of Ireland. *Quality in Ageing & Older Adults, 13*(1), 60-70. doi:10.1108/14717791211213625

Calkins, M. P. (2009). Evidence-based long term care design. *Neurorehabilitation*, *25*(3), 145-154. doi:10.3233/NRE-2009-0512

Carbonneau, H., Caron, C., & Desrosiers, J. (2010). Development of a conceptual framework of positive aspects of caregiving in dementia. *Dementia*, *9*(3), 327-353. doi:10.1177/1471301210375316

Chan, D., Livingston, G., Jones, L., & Sampson, E. L. (2013). Grief reactions in dementia carers: a systematic review. *International Journal of Geriatric Psychiatry, 28*(1), 1-17. doi:10.1002/gps.3795

Chapman, N. J., & Carder, P. C. (2003). Privacy Needs When Visiting a Person With Alzheimer's Disease: Family and Staff Expectations. *Journal of Applied Gerontology, 22*(4), 506-522. doi:10.1177/0733464803254339

Charmaz, K. (1995). The Body, Identity, and Self: Adapting to Impairment. *The Sociological Quarterly, 36*(4), 657-680. Retrieved from http://www.jstor.org/stable/4121346

Charmaz, K. (2004). Keynote Address: Fifth International Advances in Qualitative Methods Conference. Premises, Principles and Practices in Qualitative Research: Revisiting the Foundations. *Qualitative Health Research*, *14*(7), 976-993.

Charmaz, K. (2006). *Constructing Grounded Theory. A practical Guide through qualitative analysis*. London: Sage.

Charmaz, K. (2008). Constructionism and the Grounded Theory Method. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of constructionist research* (pp. 397-413). New York: The Guilford Press.

Charmaz, K. (2011). Grounded Theory Methods in social justice research In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE Handbook of Qualitative Research* (pp. 359-381). Thousand Oaks: SAGE.

Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). Thousand Oakes, LA/London, UK: SAGE.

Charmaz, K., & Mitchell, R. G. (2001). Grounded Theory in Ethnography. In P. Atkinson, A. Coffey, S. Dalamont, J. Lofland, & L. Lofland (Eds.), *Handbook of Ethnography* (pp. 160-175). London: Sage.

Chaudbury, H., & Rowles, G. D. (2005). Between the Shores of Recollection and Imagination: Self, Aging, and Home. In G. D. Rowles & H. Chaudbury (Eds.), *Home* *and Identity in Late Life. International Perspectives* (pp. 3-21). New York: Springer Publishing Company.

Clare, L. (2002). We'll fight it as long as we can: Coping with the onset of Alzheimer's disease. *Aging & Mental Health, 6*(2), 139-148. doi:10.1080/13607860220126826

Cohen, L. W., Zimmerman, S., Reed, D., Sloane, P. D., Beeber, A. S., Washington, T., . . . Gwyther, L. P. (2014). Dementia in Relation to Family Caregiver Involvement and Burden in Long-Term Care. *Journal of Applied Gerontology, 33*(5), 522-540. doi:10.1177/0733464813505701

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: techniques and procedures for developing grounded theory* (3 ed.). Thousand Oaks, Calif.: Sage.

Corbin, J., & Strauss, A. (2014). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (4th ed.). Thousand Oakes: Sage publications.

Covan, E. K. (2007). The Discovery of Grounded Theory in Practice: The Legacy of Multiple Mentors. In A. Bryant & K. Charmaz (Eds.), *The SAGE Handbook of Grounded Theory* (pp. 58-75). London / Thousand Oakes: SAGE publications Ltd.

Crawford, K., Digby, R., Bloomer, M., Tan, H., & Williams, A. (2015). Transitioning from caregiver to visitor in a long-term care facility: the experience of caregivers of people with dementia. *Aging & Mental Health, 19*(8), 739-746. doi:10.1080/13607863.2014.962008

Creswell, J. W. (2007). *Qualitative inquiry & research design. Choosing among five approaches*. Thousand Oaks: SAGE.

Cutchin, M. P. (2013). The Complex Process of Becoming At-Home in Assisted Living. In G. D. Rowles & M. Bernard (Eds.), *Environmental Gerontology* (pp. 105-123). New York, NY: Springer Publishing Company.

Daatland, S. O., Høyland, K., & Otnes, B. (2015). Scandinavian Contrasts and Norwegian Variations in Special Housing for Older People. *Journal of Housing For the Elderly, 29*(1-2), 180-196. doi:10.1080/02763893.2015.989778

Daniels, K. J., Lamson, A. L., & Hodgson, J. (2007). An exploration of the marital relationship and Alzheimer's disease: One couple's story. *Families, Systems, & Health, 25*(2), 162-177. doi:10.1037/1091-7527.25.2.162

Davies, J., & Gregory, D. (2007). Entering the dialogue: Marriage biographies and dementia care. *Dementia, 6*(4), 481-488. doi:10.1177/1471301207084366

Davies, J. C. (2011). Preserving the ‘‘us identity’’ through marriage commitment while living with early-stage dementia. *Dementia, 10*(2), 217-234. doi:10.1177/1471301211398991

Davis, S., Byers, S., Nay, R., & Koch, S. (2009). Guiding design of dementia friendly environments in residential care settings: Considering the living experiences. *Dementia, 8*(2), 185-203. doi:10.1177/1471301209103250

Day, K., Carreon, D., & Stump, C. (2000). The therapeutic design of environments for people with dementia a review of the empirical research. *The Gerontologist, 40*(4), 397-416. doi:10.1093/geront/40.4.397

de Vugt, M. E., & Verhey, F. R. J. (2013). The impact of early dementia diagnosis and intervention on informal caregivers. *Progress in Neurobiology, 110*, 54-62. doi:http://dx.doi.org/10.1016/j.pneurobio.2013.04.005

Denzin, N. K., & Lincoln, Y. S. (2011). Introduction. The Discipline and Practice of Qualitative Research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE Handbook of Qualitative Research* (4th ed., pp. 1-21). Thousand Oaks, CA / London, UK: SAGE.

Derksen, E., Vernooij-Dassen, M., Gillissen, F., Olde Rikkert, M., & Scheltens, P. (2006). Impact of diagnostic disclosure in dementia on patients and carers: Qualitative case series analysis. *Aging & Mental Health, 10*(5), 525-531. doi:10.1080/13607860600638024

Dewing, J. (2002). From Ritual to Relationship: A person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia, 1*(2), 157-171. doi:10.1177/147130120200100204

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia, 6*(1), 11-25. doi:10.1177/1471301207075625

Dittmann-Kohli, F. (2005). Self and Identity. In M. L. Johnson, V. L. Bengtson, P. G. Coleman, & T. B. L. Kirkwood (Eds.), *The Cambridge Handbook of Age and Ageing* (pp. 275-292). Cambridge: Cambridge University Press.

Dupuis, S. L. (2002). Understanding Ambiguous Loss in the Context of Dementia Care. *Journal of Gerontological Social Work, 37*(2), 93-115. doi:10.1300/J083v37n02_08

Edvardsson, D., Fetherstonhaugh, D., & Nay, R. (2010). Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. *Journal of Clinical Nursing, 19*(17-18), 2611-2618. doi:10.1111/j.1365-2702.2009.03143.x

Edvardsson, D., Winblad, B., & Sandman, P. O. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology, 7*(4), 362-367. doi:http://dx.doi.org/10.1016/S1474-4422(08)70063-2

Eriksen, S., Helvik, A.-S., Juvet, L., Skovdahl, K., Førsund, L. H., & Grov, E. K. (Manuscript accepted for publication). The experience of relations in persons with dementia: A systematic meta-synthesis *Journal of Dementia and Geriatric Cognitive Disorders*.

Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners, 20*, 423-428. doi:doi:10.1111/j.1745-7599.2008.00342.x

Evans, D., & Lee, E. (2014). Impact of dementia on marriage: A qualitative systematic review. *Dementia, 13*(3), 330-349. doi:10.1177/1471301212473882

Falk, H., Wijk, H., Persson, L. O., & Falk, K. (2013). A sense of home in residential care. *Scandinavian Journal of Caring Sciences, 27*(4), 999-1009. doi:10.1111/scs.12011

Fiske, A., & Jones, R. S. (2005). Depression. In M. e. Johnson, V. L. Bengtson, P. G. Coleman, & T. B. L. Kirwood (Eds.), *The Cambridge Handbook of Age and Aging* (pp. 245-251). New York: Cambridge University Press.

Frank, J. B. (2008). Evidence for Grief as the Major Barrier Faced by Alzheimer Caregivers: A Qualitative Analysis. *American Journal of Alzheimer's Disease and Other Dementias, 22*(6), 516-527. doi:10.1177/1533317507307787

Friedemann, M.-L., & Buckwalter, K. C. (2014). Family Caregiver Role and Burden Related to Gender and Family Relationships. *Journal of Family Nursing, 20*(3), 313-336. doi:10.1177/1074840714532715

Garsjø, O. (2008). *Institusjonssosiologi. Perspektiver på helse- og omsorgsinstitusjoner. [In Norwegian] [The Sociology of Institutions. Perspectives on Institutional Care]* Oslo: Gyldendal Akademisk.

Gaugler, J. E. (2005). Family involvement in residential long-term care: A synthesis and critical review. *Aging & Mental Health, 9*(2), 105-118. doi:10.1080/13607860412331310245

Gaugler, J. E., Mittelman, M. S., Hepburn, K., & Newcomer, R. (2009). Predictors of change in caregiver burden and depressive symptoms following nursing home admission. *Psychology and Aging, 24*(2), 385-396. doi:10.1037/a0016052

Gaugler, J. E., Pot, A. M., & Zarit, S. (2007). Long-term adaption to institutionalization in dementia caregivers. *The Gerontologist, 47*(6), 730-740. doi:10.1093/geront/47.6.730

Gaugler, J. E., Roth, D. L., Haley, W. E., & Mittelman, M. S. (2008). Can counseling and support reduce burden and depressive symptoms in caregivers of people with Alzheimer's disease during the transition to institutionalization? Results from the New

York University caregiver intervention study. *Journal of the American Geriatrics Society, 56*(3), 421-428. doi:10.1111/j.1532-5415.2007.01593.x

Gaugler, J. E., & Teaster, P. (2006). The Family Caregiving Career. *Journal of Aging & Social Policy, 18*(3-4), 141-154. doi:10.1300/J031v18n03_10

Gergen, K. J. (2009). *Relational Being. Beyond Self and Community*. Oxford: Oxford University Press.

Gergen, K. J. (2015). *An Invitation to Social Construction* (Third ed.). London: SAGE Publications Ltd.

Gillies, B. (2011). Continuity and loss: The carer`s journey through dementia. *Dementia, 11*(5), 657-676. doi:10.1177/1471301211421262

Gjøra, L. (2016). *Å favne bredt og treffe rett. En sammenfatning av satsningen under Demensplan 2015. [In Norwegian] [A summary of the priorities stemming from the Dementia Plan 2015]* Tønsberg: Forlaget Aldring og helse.

Gjøra, L., Eek, A., & Kirkevold, Ø. (2015). *Nasjonal kartlegging av kommunenes tilrettelagte tjenestetilbud for personer med demens. [In Norwegian] [National mapping of services for persons with dementia]* Sem/Oslo: Nasjonal kompetansetjeneste for Aldring og helse.

Gladstone, J. W. (1995). The marital perceptions of elderly persons living or having a spouse living in a long-term care institution in Canada. *The Gerontologist, 35*(1), 52-60. doi:10.1093/geront/35.1.52

Glaser, B. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.

Glaser, B. (2002). Constructivist grounded theory? *Forum qualitative Sozialforschung/Forum: Qualitative Social Research, 3*. Retrieved from http://www.qualitative-research.net/index.php/fqs/article/viewArticle/825/1792

Glaser, B., & Holton, J. (2004). Remodeling Grounded Theory. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 5*(2). Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/607/1316

Glaser, B., & Strauss, A. (1965). *Awarness of dying*. Chicago: Aldine.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: strategies for qualitative research*. Chicago: Aldine.

Glaser, B., & Strauss, A. (1968). *Time for Dying*. Chicago: Aldine.

Gobo, G. (2008). *Doing ethnography*. London: Sage.

Goffman, E. (1959). *The Presentation of Self in Everyday Life*. New York: Doubleday.

Graham, J. E., & Bassett, R. (2006). Reciprocal relations: The recognition and co-construction of caring with Alzheimer's disease. *Journal of Aging Studies, 20*(4), 335-349. doi:http://dx.doi.org/10.1016/j.jaging.2005.12.003

Graneheim, U. H., Johansson, A., & Lindgren, B.-M. (2014). Family caregivers' experiences of relinquishing the care of a person with dementia to a nursing home: insights from a meta-ethnographic study. *Scandinavian Journal of Caring Sciences, 28*(2), 215-224. doi:10.1111/scs.12046

Grossman, H., Bergmann, C., & Parker, S. (2006). Dementia: a brief review. *The Mount Sinai journal of medicine, New York, 73*(7), 985-992. Retrieved from http://web.a.ebscohost.com/ehost/pdfviewer/pdfviewer?sid=44d6c895-c1a5-40ac-92d1-62afcaf8ef7e%40sessionmgr4010&vid=2&hid=4106

Guba, E. G., & Lincoln, Y. S. (2008). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Landscape of Qualitative Research* (pp. 255-287). Thousand Oakes: Sage.

Gubrium, J. F. (2005). The social worlds of old age. In M. Johnson, V. L. Bengtson, P. G. Coleman, & T. B. L. Kirkwood (Eds.), *The Cambridge Handbook of Age and Aging* (pp. 310-316). New York: Cambridge University Press.

Hacking, I. (1999). *The social construction of what?* Cambridge: Harvard university press.

Harris, S., Adams, M., Zubatsky, M., & White, M. (2011). A caregiver perspective of how Alzheimer's disease and related disorders affect couple intimacy. *Aging and Mental health, 15*(8), 950-960. doi:http://dx.doi.org/10.1080/13607863.2011.583629

Hellstrom, I., & Lund, U. (2005). "We do things together": a case study of "couplehood" in dementia. *Dementia, 4*(1), 7-22. doi:10.1177/1471301205049188

Hellstrom, I., & Lund, U. (2007). Sustaining "couplehood": Spouses` strategies for living positively with dementia. *Dementia, 6*(3), 383-409. doi:10.1177/1471301207081571

Hellstrom, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics, 14*(5), 608-619. doi:10.1177/0969733007080206

Hemingway, D., MacCourt, P., Pierce, J., & Strudsholm, T. (2016). Together but apart: Caring for a spouse with dementia resident in a care facility. *Dementia, 15*(4), 872-890. doi:10.1177/1471301214542837

Hennings, J., Froggatt, K., & Payne, S. (2013). Spouse caregivers of people with advanced dementia in nursing homes: A longitudinal narrative study. *Palliative Medicine, 27*(7), 683-691. doi:10.1177/0269216313479685

Høgsnes, L., Melin-Johansson, C., Norbergh, K. G., & Danielson, E. (2014). The existential life situations of spouses of persons with dementia before and after relocating to a nursing home. *Aging & Mental Health, 18*(2), 152-160. doi:10.1080/13607863.2013.818100

Høyland, K., Kirkevold, Ø., Woods, R., & Haugan, G. (2015). Er smått alltid godt i demensomsorgen? Om bo- og tjenestetilbud for personer med demens. [In Norwegian] [Is small always the best in dementiacare? About public housing solutions for persons with dementia] *SINTEF FAG*. Retrieved from http://www.ks.no/contentassets/1392e8fff1a847eb8b632ac582afa98a/rapport.pdf

Innes, A., Kelly, F., & Dincarslan, O. (2011). Care home design for people with dementia: What do people with dementia and their family carers value? *Aging & Mental Health, 15*(5), 548-556. doi:10.1080/13607863.2011.556601

Jeon, Y.-H. (2004). The application of grounded theory and symbolic interactionism. *Scandinavian Journal of Caring Sciences, 18*(3), 249-256. doi:10.1111/j.1471-6712.2004.00287.x

Johansson, A., Ruzin, H. O., Graneheim, U. H., & Lindgren, B.-M. (2014). Remaining connected despite separation – former family caregivers' experiences of aspects that facilitate and hinder the process of relinquishing the care of a person with dementia to a nursing home. *Aging & Mental Health, 18*(8), 1029-1036 doi:10.1080/13607863.2014.908456

Joling, K. J., van Hout, H. P. J., Schellevis, F. G., van der Horst, H. E., Scheltens, P., Knol, D. L., & van Marwijk, H. W. J. (2010). Incidence of Depression and Anxiety in the Spouses of Patients With Dementia: A Naturalistic Cohort Study of Recorded Morbidity With a 6-Year Follow-Up. *The American Journal of Geriatric Psychiatry, 18*(2), 146-153. doi:http://dx.doi.org/10.1097/JGP.0b013e3181bf9f0f

Kane, R. L., & Kane, R. A. (2005). Long Term Care. In M. Johnson (Ed.), *The Cambridge Handbook of Age and Aging* (pp. 638-646). Cambridge: Cambridge University Press.

Kaplan, L. (2001). A Couplehood Typology for Spouses of Institutionalized Persons With Alzheimer's Disease: Perceptions of "We"–"I"*. *Family Relations, 50*(1), 87-98. doi:10.1111/j.1741-3729.2001.00087.x

Kaplan, L., Ade-Ridder, L., Hennon, C. B., Brubaker, E., & Brubaker, T. (1995). Preliminary Typology of Couplehood for Community-Dwelling Wives:" I" Versus" We". *The International Journal of Aging and Human Development, 40*(4), 317-337. doi:10.2190/1Q99-EG0B-3VW2-EBKB

Kellner, D. (1992). Constructing postmodern identities. In S. Lash & J. Friedman (Eds.), *Modernity and Identity*. Oxford UK and Cambridge USA: Blackwell.

Kenigsberg, P.-A., Aquino, J.-P., Bérard, A., Gzil, F., Andrieu, S., Banerjee, S., . . . Robert, P. (2016). Dementia beyond 2025: Knowledge and uncertainties. *Dementia, 15*(1), 6-21. doi:10.1177/1471301215574785

Kirkevold, Ø., Eek, A., & Engedal, K. (2012). Development of residential care services facilitated for persons with dementia in Norway. *Aging clinical and experimental research, 24*(1), 1-5. doi:10.1007/BF03325351

Kitwood, T. (1997). *Dementia reconsidered. The person comes first*. Berkshire: Open University Press.

Kraijo, H., Leeuw, R., & Schrijvers, G. (2015). How spouses evaluate Nursing Home Placement of their demented partner: a study about the end of perseverance time. *Scandinavian Journal of Caring Sciences, 29*(1), 101-109 109p. doi:10.1111/scs.12137

Kvale, S., & Brinkmann, S. (2010). *Det kvalitative forskningsintervjuet [In Norwegian] [Interviews]* (2. utgave ed.). Oslo: Gyldendal Akademisk.

Large, S., & Slinger, R. (2015). Grief in caregivers of persons with Alzheimer’s disease and related dementia: A qualitative synthesis. *Dementia, 14*(2), 164-183. doi:10.1177/1471301213494511

LaRossa, R., & Reitzes, D. C. (2009). Symbolic interactionism and family studies. In P. G. Boss, W. J. Doherty, R. LaRossa, & W. R. Schumm (Eds.), *Sourcebook of Family Theories and Methods: A Contextual Approach* (pp. 135-166). New York: Plenum Press.

Lloyd, J., Patterson, T., & Muers, J. (2014). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia*. doi:10.1177/1471301214564792

Lock, A., & Strong, T. (2010). *Social constructionism: Sources and stirrings in theory and practice*. New York: Cambridge University Press.

Marquardt, G. (2011). Wayfinding for People with Dementia: A Review of the Role of Architectural Design. *HERD: Health Environments Research & Design Journal, 4*(2), 75-90. doi:10.1177/193758671100400207

Marquardt, G., & Schmieg, P. (2009). Dementia-Friendly Architecture: Environments That Facilitate Wayfinding in Nursing Homes. *American Journal of Alzheimer's Disease and Other Dementias, 24*(4), 333-340. doi:10.1177/1533317509334959

Marquardt, G. P., Bueter, K. M. A., & Motzek, T. M. (2014). Impact of the Design of the Built Environment on People with Dementia: An Evidence-Based Review. *HERD : Health Environments Research & Design Journal, 8*(1), 127-157. doi:10.1080/13607860902845574

Mc Donnell, E., & Ryan, A. (2013). Male caregiving in dementia: A review and commentary. *Dementia, 12*(2), 238-250. doi:10.1177/1471301211421235

McCormack, B. (2003). A conceptual framework for person-centred practice with older people. *International Journal of Nursing Practice, 9*(3), 202-209. doi:10.1046/j.1440-172X.2003.00423.x

McCormack, B. (2004). Person-centredness in gerontological nursing: an overview of the literature. *Journal of Clinical Nursing, 13*, 31-38. doi:10.1111/j.1365-2702.2004.00924.x

McCormack, B., & McCance, T. V. (2006). Development of a framework for person-centred nursing. *Journal of Advanced Nursing, 56*(5), 472-479. doi:10.1111/j.1365-2648.2006.04042.x

McCormack, B., & McCance, T. V. (2016). Underpinning principles of person-centred practice. In B. McCormack & T. V. McCance (Eds.), *Person-Centred Practice in Nursing and Health Care: Theory and Practice* (2 ed., pp. 13-36). Oxford: Wiley Blackwell.

McGovern, J. (2011). Couple meaning-making and dementia: challenges to the deficit model. *Journal of Gerontological Social Work, 54*(7), 678-690. doi:http://dx.doi.org/10.1080/01634372.2011.593021

McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing, 19*(13-14), 1935-1943. doi:10.1111/j.1365-2702.2009.03136.x

Mead, G. H. (1934). *Mind, Self and Society. From the standpoint of a social behaviorist*. Chicago and London: The University of Chicago Press.

Merrick, K., Camic, P. M., & O'Shaughnessy, M. (2016). Couples constructing their experiences of dementia: A relational perspective. *Dementia*, *15*(1), 34-50. doi:10.1177/1471301213513029

Mills, J., Bonner, A., & Francis, K. (2006). Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice, 12*(1), 8-13. doi:10.1111/j.1440-172X.2006.00543.x

Mitchell, S. L., Black, B. S., Ersek, M., Hanson, L. C., Miller, S. C., Sachs, G. A., . . . Morrison, R. S. (2012). Advanced dementia: state of the art and priorities for the next decade. *Annals Of Internal Medicine, 156*(1), 45-51. doi:10.7326/0003-4819-156-1-201201030-00008

Molyneaux, V. (2012). The co-construction of couplehood in Dementia. *Dementia, 11*(4), 483-502. doi:10.1177/1471301211421070

Monin, J. K., Schulz, R., & Feeney, B. C. (2015). Compassionate Love in Individuals With Alzheimer's Disease and Their Spousal Caregivers: Associations With Caregivers' Psychological Health. *The Gerontologist, 55*(6), 981-989. doi:10.1093/geront/gnu001

Morgan, S., & Yoder, L. H. (2012). A Concept Analysis of Person-Centered Care. *Journal of Holistic Nursing, 30*(1), 6-15. doi:10.1177/0898010111412189

Mullin, J., Simpson, J., & Froggatt, K. (2011). Experiences of spouses of people with dementia in long-term care. *Dementia, 12*(2), 177-191. doi:10.1177/1471301211418096

Mullin, J., Simpson, J., & Froggatt, K. (2013). Experiences of spouses of people with dementia in long-term care. *Dementia: The International Journal of Social Research and Practice*, *12*(2), 177-191. doi:10.1177/1471301211418096

Netto, N. R., Jenny, G. Y. N., & Philip, Y. L. K. (2009). Growing and gaining through caring for a loved one with dementia. *Dementia, 8*(2), 245-261. doi:10.1177/1471301209103269

Nolan, & Dellasega, C. (1999). 'It's not the same as him being at home': creating caring partnerships following nursing home placement. *Journal of Clinical Nursing, 8*(6), 723-730. doi:10.1046/j.1365-2702.1999.00325.x

Nolan, M., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond person-centred care: a new vision for gerontological nursing. *International Journal of Aging and Human Development in association with Journal of Clinical Nursing, 13*(3a), 45-53. doi:http://dx.doi.org/10.1111/j.1365-2702.2004.00926.x

Nolan, M., Ryan, T., Enderby, P., & Reid, D. (2002). Towards a more inclusive vision of dementia care practice and research. *Dementia, 1*(2), 193.

Norheim, A., & Sommerseth, R. (2014). Forutsetninger for pårørendeinvolvering i sykehjemstjenesten: Informal carer involvement in nursing homes - Necessary conditions. *Nordic Journal of Nursing Research*, *34*(3), 9-13. doi:10.1177/010740831403400303

Norwegian Ministry of Health and Care Services. (2006). Stortingsmelding 25 (2005-2006). Mestring, muligheter og mening. Fremtidens omsorgsutfordringer. [In Norwegian] [Report No 25 (2005-2006) to the Storting: Coping, possibilities and meaning. Long Term Care, Future Challenges]. Retrieved from https://www.regjeringen.no/contentassets/16e39820de5c485da382fd99165afaf7/no/pdfs/stm200520060025000dddpdfs.pdf

Norwegian Ministry of Health and Care Services. (2007a). "Den gode dagen". Demensplan 2015. [In Norwegian] ["Making most of the good days". Dementia Plan 2015] Retrieved from https://www.regjeringen.no/globalassets/upload/HOD/Vedlegg/Omsorgsplan_2015/Demensplan2015.pdf

Norwegian Ministry of Health and Care Services. (2008). Lov om medisinsk og helsefaglig forskning (helseforskningsloven). [In Norwegian] [Medical and Health Research Act] Retrieved from https://lovdata.no/dokument/NL/lov/2008-06-20-44

Norwegian Ministry of Health and Care Services. (2013). Stortingsmelding 29 (2012-2013). Morgendagens omsorg. [In Norwegian] [Report No 29 (2012-2013) to the Storting: Healthcare of tomorrow] Retrieved from https://www.regjeringen.no/contentassets/34c8183cc5cd43e2bd341e34e326dbd8/no/pdfs/stm201220130029000dddpdfs.pdf

Norwegian Ministry of Health and Care Services. (2015a). Demensplan 2020. Et mer demensvennlig samfunn. [In Norwegian] [Dementia Plan 2020. A more dementiafriendly community] Retrieved from http://www.aldringoghelse.no/ViewFile.aspx?ItemID=7975

Norwegian Ministry of Health and Care Services. (2015b). Meld. St. 26 (2014-2015). Fremtidens primærhelsetjeneste - nærhet og helhet. [In Norwegian] [Report No 26 (2014-2015) to the Storting: Community care of tomorrow] Retrieved from https://www.regjeringen.no/contentassets/d30685b2829b41bf99edf3e3a7e95d97/no/pdfs/stm201420150026000dddpdfs.pdf

Norwegian Ministry of Health and Care Services. (2016). Rundskriv om forebyggende hjemmebesøk i kommunene. [In Norwegian] [Directive about outreaching services in community care] Retrieved from https://www.regjeringen.no/contentassets/92fac736a57b48b0a60f9bf04acdad5b/rundskriv-i-2-2016-om-forebyggende-hjemmebesok-i-kommunene.pdf

Norwegian Ministry of Justice and Public Security. (2001). Lov om behandling av personopplysninger (personopplysningsloven). [In Norwegian] [The Act of Handling and Processing Personal Data] Retrieved from https://lovdata.no/dokument/NL/lov/2000-04-14-31

Noyes, B. B., Hill, R. D., Hicken, B. L., Luptak, M., Rupper, R., Dailey, N. K., & Bair, B. D. (2010). Review: The Role of Grief in Dementia Caregiving. *American Journal of Alzheimer's Disease and Other Dementias, 25*(1), 9-17. doi:10.1177/1533317509333902

O'Rourke, N., Claxton, A., Kupferschmidt, A. L., Smith, J. Z., & Beattie, B. L. (2011). Marital idealization as an enduring buffer to distress among spouses of persons with Alzheimer disease. *Journal of Social and Personal Relationships, 28*(1), 117-133. doi:10.1177/0265407510386135

O`Shaughnessy, M., Lee, K., & Lintern, T. (2010). Changes in the couple relationship in dementia care: Spouse carers` experiences. *Dementia, 9*(2), 237-258. doi:10.1177/1471301209354021

O`Shea, E., & Walsh, K. (2013). Transforming Long-Stay Care in Ireland. In G. D. Rowles & M. Bernard (Eds.), *Environmental Gerontology. Making Meaningful Places in Old Age* (pp. 125-153). New York: Springer Publishing Company.

Ogden, J., & Cornwell, D. (2010). The role of topic, interviewee and question in predicting rich interview data in the field of health research. *Sociology of Health & Illness, 32*(7), 1059-1071. doi:10.1111/j.1467-9566.2010.01272.x

Ornstein, K., & Gaugler, J. E. (2012). The problem with “problem behaviors”: a systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient–caregiver dyad. *International Psychogeriatrics, 24*(10), 1536-1552. doi:http://dx.doi.org/10.1017/S1041610212000737

Oswald, F., & Wahl, H.-W. (2005). Dimensions of the meaning of Home in Later Life. In G. D. Rowles & H. Chaudhury (Eds.), *Home and Identity in Late Life. International perspectives* (pp. 21-47). New York, NY: Springer Publishing Company.

Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H., & Sourtzi, P. (2007). Caring for a relative with dementia: family caregiver burden. *Journal of Advanced Nursing, 58*(5), 446-457. doi:10.1111/j.1365-2648.2007.04250.x

Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., . . . Henderson, S. R. (2010). The Positive Aspects of the Caregiving Journey With Dementia: Using a Strengths-Based Perspective to Reveal Opportunities. *Journal of Applied Gerontology, 29*(5), 640-659. doi:10.1177/0733464809341471

Pinquart, M., & Sörensen, S. (2003a). Associations of Stressors and Uplifts of Caregiving With Caregiver Burden and Depressive Mood: A Meta-Analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 58*(2), 112-128. doi:10.1093/geronb/58.2.P112

Pinquart, M., & Sörensen, S. (2003b). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 250-267. doi:10.1037/0882-7974.18.2.250

Pinquart, M., & Sörensen, S. (2004). Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: a meta-analytic comparison. *Aging & Mental Health, 8*(5), 438-449 doi:10.1080/13607860410001725036

Pinquart, M., & Sörensen, S. (2007). Correlates of Physical Health of Informal Caregivers: A Meta-Analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 62*(2), P126-P137. Retrieved from http://psychsocgerontology.oxfordjournals.org/content/62/2/P126.abstract

Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging, 26*(1), 1-14. doi:10.1037/a0021863

Pountney, D. (2008). The many faces of dementia. *Nursing older people, 20*(9), 18-21. Retrieved from http://web.b.ebscohost.com/ehost/pdfviewer/pdfviewer?sid=02e853ea-9a23-4efc-8bdf-5003ecbae4db%40sessionmgr103&vid=1&hid=115

Pozzebon, M., Douglas, J., & Ames, D. (2016). Spouses’ experience of living with a partner diagnosed with a dementia: a synthesis of the qualitative research. *International Psychogeriatrics, 28*(4), 537-556. doi:10.1017/S1041610215002239

Prakke, H. M. (2012). Spousal relationships in which one partner has early cognitive problems. *Dementia, 11*(2), 199-215. doi:10.1177/1471301211421363

Prince, M., Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T., & Prina, M. (2015). *World Alzheimer Report 2015. An analysis of prevalence, incidence, cost and trends*. London: Alzheimer`s Disease International.

Quinn, C., Clare, L., Pearce, A., & van Dijkhuizen, M. (2008). The experience of providing care in the early stages of dementia: An interpretative phenomenological analysis. *Aging & Mental Health, 12*(6), 769-778. doi:10.1080/13607860802380623

Quinn, C., Clare, L., & Woods, B. (2009). The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging and Mental health, 13*(2), 143-154. doi:10.1080/13607860802459799

Quinn, C., Clare, L., & Woods, R. T. (2012). What predicts whether caregivers of people with dementia find meaning in their role? *International Journal of Geriatric Psychiatry, 27*(11), 1195-1202. doi:10.1002/gps.3773

Quinn, C., Clare, L., & Woods, R. T. (2015). Balancing needs: The role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia, 14*(2), 220-237. doi:10.1177/1471301213495863

Quinn, C., Jones, I. R., & Clare, L. (2016). Illness representations in caregivers of people with dementia. *Aging & Mental Health*. doi:10.1080/13607863.2015.1128882

Rando, T. A. (2000). *Clinical dimensions of anticipatory mourning: Theory and practice in working with the dying, their loved ones, and their caregivers*. Champaign, IL, US: Research Press.

Rapley, T. J. (2001). The art(fulness) of open-ended interviewing: some considerations on analysing interviews. *Qualitative Research, 1*(3), 303-323. doi:10.1177/146879410100100303

Ray, C. A., Ingram, V., & Cohen-Mansfield, J. (2015). Systematic review of planned care transitions for persons with dementia. *Neurodegenerative disease management, 5*(4), 317-331. doi:10.2217/nmt.15.23

Ribeiro, O., & Paul, C. (2008). Older male carers and the positive aspects of care. *Ageing and society, 28*(02), 165-183. doi:10.1017/S0144686X07006460

Robinson, C. A., Bottorff, J. L., Pesut, B., Oliffe, J. L., & Tomlinson, J. (2014). The Male Face of Caregiving: A Scoping Review of Men Caring for a Person With Dementia. *American Journal of Men's Health, 8*(5), 409-426. doi:10.1177/1557988313519671

Robinson, L., Clare, L., & Evans, K. (2005). Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging & Mental Health, 9*(4), 337-347. doi:10.1080/13607860500114555

Rogers-de Jong, M., & Strong, T. (2014). Co-constructing "We" and "Us". Joint talk and storytelling with cohabitating couples. *Narrative Inquiry, 24*(2), 368-385. doi:10.1075/ni.24.2.10jon

Rognstad, M.-K., Sagbakken, M., & Nåden, D. (2015). Pårørendes rolle som ressurs og samarbeidspartner: En studie med fokus på pårørende til pasienter med demenssykdom i sykehjem: Family members’ role as resources and collaborating partners: A study focusing on dementia and long-term stay in a nursing home. *Nordic Journal of Nursing Research, 35*(1), 57-64. doi:10.1177/0107408314560478

Rowles, G. D., & Bernard, M. (2013). The meaning and significance of place in old age. In G. D. Rowles & M. Bernard (Eds.), *Environmental gerontology: Making meaningful places in old age* (pp. 3-24). New York, NY: Springer Publishing Company

Rubinstein, R., & Parmelee, P. (1992). Attachment to Place and the Representation of the Life Course by the Elderly. In I. Altman & S. Low (Eds.), *Place Attachment* (Vol. 12, pp. 139-163). New York, NY: Springer US.

Rubinstein, R. L., & de Medeiros, K. (2005). Home. self and identity. In G. D. Rowles & H. Chaudbury (Eds.), *Home and Identity in Late Life. International Perspectives*. New York: Springer Publishing Company.

Sabat, S. R. (2005). The self in Dementia. In M. Johnson, V. L. Bengtson, P. G. Coleman, & T. B. L. Kirkwood (Eds.), *The Cambridge Handbook of Age and Aging* (pp. 332-338). New York: Cambridge University Press.

Sabat, S. R., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and society, 12*(04), 443-461. doi:http://dx.doi.org/10.1017/S0144686X00005262

Sandberg, Lundh, & Nolan. (2001). Placing a spouse in a care home: the importance of keeping. *Journal of Clinical Nursing, 10*(3), 406-416. doi:10.1046/j.1365-2702.2001.00497.x

Sanders, S. (2005). Is the Glass Half Empty or Half Full? *Social Work in Health Care, 40*(3), 57-73. doi:10.1300/J010v40n03_04

Savin-Baden, M., & Howell Major, C. (2013). *Qualitative research. The essential guide to theory and practice*. London and New York: Routhledge.

Schatzman, L., & Strauss, A. (1973). *Field research*. Englewood Cliffs: NJ: Prentice Hall.

Schultz, R., & Martire, L. M. (2004). Family Caregiving of Persons With Dementia. Prevalence, Health Effects, and Support Strategies. *The American Journal of Geriatric Psychiatry, 12*(3), 240-249. doi:http://dx.doi.org/10.1097/00019442-200405000-00002

Seale, C., Gobo, G., Gubrium, J. F., & Silverman, D. (2004). Introduction: Inside qualitative research. In C. Seale, G. Gobo, J. F. Gubrium, & D. Silverman (Eds.), *Qualitative Research Practice* (pp. 1-11). London: Sage.

Sherman, E., & Dacher, J. (2005). Cherished Objects and the Home: Their Meaning and Roles in Later Life. In G. D. Rowles & H. Chaudbury (Eds.), *Home and Identity in Late Life. International persepectives* (pp. 63-79). New York, NY: Springer Publishing Company.

Shim, B., Barroso, J., & Davis, L. L. (2012). A comparative analysis of stories of spousal categivers of people with dementia: Negative, ambivalent, and positive experiences. *International journal of nursing studies, 49*, 220-229. doi:10.1016/j.ijnurstu.2011.09.003

Shim, B., Barroso, J., Gilliss, C. L., & Davis, L. L. (2013). Finding meaning in caring for a spouse with dementia. *Applied Nursing Research, 26*, 121-126. doi:http://dx.doi.org/10.1016/j.apnr.2013.05.001

Silverman, D. (2005). *Doing qualitative research* (2 ed.). London: Sage.

Silverman, D. (2006). *Interpreting qualitative data* (3 ed.). London: Sage.

Sixsmith, J. (1986). The meaning of home: An exploratory study of environmental experience. *Journal of Environmental Psychology, 6*(4), 281-298. doi:http://dx.doi.org/10.1016/S0272-4944(86)80002-0

Stamsø, M. A. (2012). *Velferdsstaten i endring. [In Norwegian] [The Welfare State in Change]* Oslo: Gyldendal Akademisk

Strauss, A., & Corbin, J. (1994). Grounded theory methodology. An overview. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 273-286). Thousand Oaks, CA: Sage Publications.

Strauss, A., & Corbin, J. (1997). *Grounded theory in practice*. Thousand Oaks, California: Sage Publications.

The Norwegian Directorate of Health. (2015). Rapport om tilbudet til personer med behov for lindrende behandling og omsorg mot livet slutt – å skape liv til dagene, IS-2278. [In Norwegian] [Report about the services for people with palliative Care needs - to create life to the days, IS-2278] Retrieved from https://www.regjeringen.no/contentassets/a4b45c8f57e741bdbb3bfb32c6b9ef43/rapport_hdir_palliasjonsrapport_160315.pdf

The Norwegian State Housing Bank. (2009). Rom for trygghet og omsorg - Veileder for utforming av omsorgsboliger og sykehjem. [In Norwegian] [Spaces for security and care - A guide for designing sheltered homes and nursing homes] Oslo. Retrieved from http://biblioteket.husbanken.no/arkiv/dok/3488/nylink_rips.pdf

Thorsen, K. (1998). *Kjønn, livsløp og alderdom. En studie av livshistorier, selvbilder og modernitet. [In Norwegian] [Gender, Life Course and Ageing. A study of lifestories, self images and modernity]* Bergen- Sandviken: Fagbokforlaget.

Ulstein, I. (2007). *Dementia in the family*. Oslo: Faculty of Medicine, University of Oslo.

van der Steen, J. T., Radbruch, L., Hertogh, C. M., de Boer, M. E., Hughes, J. C., Larkin, P., . . . Volicer, L. (2014). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine, 28*(3), 197-209. doi:10.1177/0269216313493685

Verbeek, van Rossum, E., Zwakhalen, S. M., Kempen, G. I., & Hamers, J. P. (2009). Small, homelike care environments for older people with dementia: a literature review. *International Psychogeriatrics, 21*(02), 252-264. doi:http://dx.doi.org/10.1017/S104161020800820X

Verbeek, H., van Rossum, E., Zwakhalen, S. M., Ambergen, T., Kempen, G. I., & Hamers, J. P. (2009). The effects of small-scale, homelike facilities for older people with dementia on residents, family caregivers and staff: design of a longitudinal, quasi-experimental study. *BMC Geriatrics, 9*(1), 3. doi:10.1186/1471-2318-9-3

Vossius, C., Selbæk, G., Ydstebø, A. E., Benth, J. S., Godager, G., Lurås, H., & Bergh, S. (2015). Ressursbruk og sykdomsforløp ved demens (REDIC). Retrieved from http://www.aldringoghelse.no/ViewFile.aspx?ItemID=7959

Wadham, O., Simpson, J., Rust, J., & Murray, C. (2015). Couples' shared experiences of dementia: a meta-synthesis of the impact upon relationships and couplehood. *Aging & Mental Health, 20*(5), 463-473. doi:10.1080/13607863.2015.1023769

Wahl, H.-W., & Oswald, F. (2010). Environmental Perspectives on Aging. In D. Dannefer & C. Phillipson (Eds.), *The SAGE Handbook of Social Gerontology* (pp. 111-124). Thousand Oaks, LA/London, UK: SAGE.

Wahl, H.-W., & Weisman, G. D. (2003). Environmental Gerontology at the Beginning of the New Millennium: Reflections on Its Historical, Empirical, and Theoretical Development. *The Gerontologist, 43*(5), 616-627. doi:10.1093/geront/43.5.616

Walsh, I., Holton, J. A., Bailyn, L., Fernandez, W., Levina, N., & Glaser, B. (2015). What Grounded Theory Is…A Critically Reflective Conversation Among Scholars. *Organizational Research Methods, 18*(4), 581-599. doi:10.1177/1094428114565028

Wimo, A., Jönsson, L., Bond, J., Prince, M., & Winblad, B. (2013). The worldwide economic impact of dementia 2010. *Alzheimer's & Dementia, 9*(1), 1-11. doi:http://dx.doi.org/10.1016/j.jalz.2012.11.006

Wong, C., Merrilees, J., Ketelle, R., Barton, C., Wallhagen, M., & Miller, B. (2012). The experience of caregiving: differences between behavioral variant of frontotemporal dementia and Alzheimer disease. *American Journal of Geriatric Psychiatry, 20*(8), 724-728. doi:10.1097/JGP.0b013e318233154d

Woods, B. (2005). Dementia. In M. e. Johnson, V. L. Bengtson, P. G. Coleman, & T. B. L. Kirkwood (Eds.), *The Cambride Handbook of Age and Aging* (pp. 252-260). New York: Cambridge University Press.

Woods, B., Keady, J., & Seddon, D. (2008). *Involving Families in Care Homes. A Relationship-Centred Approach to Dementia Care*. London: Jessica Kingsley Publishers.

World Health Organization. (2012). *Dementia: a public health priority*. Retrieved from Geneva, Switzerland: http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1

World Health Organization. (2015). World report on ageing and health. Retrieved from http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf?ua=1

World Health Organization. (2016a). Definition of an older or elderly person. Retrieved from http://www.who.int/healthinfo/survey/ageingdefnolder/en/

World Health Organization. (2016b). Working for health and growth: investing in the health workforce. Report of the High-Level Commission on Health Employment and Economic Growth. Retrieved from http://apps.who.int/iris/bitstream/10665/250047/1/9789241511308-eng.pdf?ua=1

World Medical Association. (2013). World Medical Association Declaration of Helsinki. Ethical Principles for Medical Research. Involving Human Subjects. *JAMA, 310*(20). Retrieved from http://www.wma.net/en/30publications/10policies/b3/17c.pdf doi:doi:10.1001/jama.2013.281053

Ytrehus, S. (2002). Housing Policy for Frail Elders in Norway: A Study of the Implementation of Housing Reforms in Norwegian Municipalities. *Journal of Housing For the Elderly, 16*(1-2), 107-123. doi:10.1300/J081v16n01_08

Paper I

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ORIGINAL ARTICLE

The loss of a shared lifetime: a qualitative study exploring spouses' experiences of losing couplehood with their partner with dementia living in institutional care

Linn Hege Førsund, Kirsti Skovdahl, Riina Kiik and Siri Ytrehus

Aims and objectives. To explore and describe spouses' experiences of losing couplehood with their dementia-afflicted partner living in institutional care.

Background. Despite the losses and experiences of discontinuity due to the cognitive decline caused by dementia, the feelings of belonging and reciprocity in close relationships are still crucial to many couples. However, these experiences of spouses with partners living in institutional care are not well documented and are thus the focus of this study.

Design. A constructivist grounded theory approach was used to capture the relational processes described by the spouses.

Methods. Conversational interviews were conducted with $n = 10$ spouses of dementia-afflicted persons living in institutional care. Data were analysed using the constant comparative method.

Results. The spouses' experiences of losing couplehood were primarily connected to separation from the partner and the sense of being alone. They were also related to the loss of the shared past and future. However, these experiences did not seem to be constant; short glimpses of connectedness, reciprocity and interdependence contributed to a feeling of couplehood, although these were only momentary.

Conclusions. The spouses' experiences of losing couplehood were dynamic and were related to the couple's entire life. The spouses wavered between senses of loss and belonging to couplehood, depending on the conditions characterising the moment.

Relevance to clinical practice. Healthcare personnel must recognise the severity of some spouses' experiences of losing couplehood and be aware of how these experiences can fluctuate and be situation dependent.

What does this paper contribute to the wider global clinical community?

- The spouses' experiences of losing couplehood were dynamic and related to the couple's entire life.
- The spouses facilitated couplehood through diverse strategies to counteract the feeling of loss; this contributed to short glimpses of couplehood if they succeeded.
- Supporting spouses highlights the importance of identifying, understanding and validating their shared, unique experiences.

Key words: couplehood, dementia, grounded theory, interviewing, nursing home, spouses

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Introduction

As the ageing population grows, more people are being afflicted with dementia (Prince *et al.* 2013). In addition to influencing the lives of the sufferers themselves, the progressive nature of dementia is likely to cause changes in the relationship between partners in affected couples (Schultz & Martire 2004, Andrèn & Elmståhl 2008, Ablitt *et al.* 2009, Mullin *et al.* 2011). Dementia caregiving has traditionally been associated with stress and burden (Etters *et al.* 2008), contributing to negative health effects, such as depression and anxiety for the caregiver (Schultz & Martire 2004, Schoenmakers *et al.* 2010, Wolfs *et al.* 2012). Dementia research and practice must have a more inclusive vision (Nolan *et al.* 2002). Caregiving is not a uniformly negative experience; many caregivers are rewarded and satisfied (Netto *et al.* 2009, Shim *et al.* 2013). Several studies (Hellstrom & Lund 2005, 2007, McGovern 2011, 2012, Molyneaux 2012) have highlighted the importance of a relational understanding of the lived experience of dementia.

Background

In a systematic review, Evans and Lee (2013) explored the impact of dementia on marriage. They reported that the couple's relationships changed, particularly in terms of their companionship, reciprocity in their partnership and the nature of their relationship. They found that the sense of companionship diminished as the dementia advanced and that dementia challenged the communication, reciprocity and intimacy within the couple (Evans & Lee 2013).

Despite the losses and changes described by Evans and Lee (2013), the importance of feelings of belonging, reciprocity and continuity within close relationships has been highlighted by others (Graham & Bassett 2006, Hellstrom & Lund 2007, Walters *et al.* 2010). Walters *et al.* (2010) explored the spouses' experiences of continuity and discontinuity in their relationship with a dementia-afflicted partner. They suggested that experiencing continuity was significant for the overall experiences of caregiving and that the participants' sense of continuity with the past was an influencing factor. The maintenance of meaning-making processes, through which spouses construct new ways of relating with their partner in the context of dementia, may also influence the caregiving experience (McGovern 2012). Furthermore, the quality of the past relationship is also significant, as it might influence the caregiving role (Walters *et al.* 2010), well-being of the spouse (Quinn *et al.* 2009), experiences of the present relationship (Prakke 2012, Shim *et al.* 2012, 2013) and the commitment towards sustaining couplehood (Hellstrom & Lund 2007).

Couplehood has emerged as an important concept for describing how dementia impacts the relationship as a whole, including the partners' experiences of friendship, intimacy, trust and support within the relationship (Evans & Lee 2013). Kaplan (2001) developed a typology of couplehood and identified five typological clusters describing the different degrees of separation caused by dementia. She asked spouses to range their perceptions of couplehood by marking on a continuum, ranging from 'I' (no couplehood) to 'we' (strong couplehood). She suggested that couplehood is best understood as the extent to which individuals have feelings of 'we'-ness, rather than being an 'I'. Others have also explored the concept of couplehood. Hellstrom and Lund (2007) described the active processes in which couples take part to sustain their couplehood through maintaining affection and reciprocity. Molyneaux (2012) found that spouses enhance couplehood through mutual reminiscence and purposeful recollection of their shared history. McGovern (2012) showed how emotional growth, deepened intimacy and enhanced creativity seemed to contribute to couplehood and a sense of 'we'-ness, improving well-being of both partners.

The multitude of terms used in previous research to describe the relational processes affected by dementia makes the selection of vocabulary for this study difficult. Evans and Lee (2013) used different terms describing various aspects of these processes, namely 'couplehood', 'companionship' and 'partnership', for different perspectives of the caregiving experience. Other examples of terms that have been used in literature are 'connectedness/separateness' (O'Shaughnessy *et al.* 2010), 'togetherness/detachment' (Graham & Bassett 2006), 'continuity/loss' (Gillies 2011) and 'continuity/discontinuity' (Walters *et al.* 2010). These terms were all considered. However, 'couplehood' is a concept broad enough to cover the overall relational experience of separation caused by dementia (Evans & Lee 2013) and was therefore considered most applicable for this study.

The short literature review documented in this section reveals the relatively large number of studies that consider the impact of dementia on close relationships. However, most research in this area has explored how the early stages to mid-stages of dementia impact the relationship of couples living at home. Given that dementia is a progressive disease, the effects of these processes of decline on relationships in the later stages of the disease must be studied. Eventually, institutional care is needed for persons affected by dementia, and only a few studies (Kaplan *et al.* 1995, Kaplan 2001) have addressed couplehood between committed

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individuals in institutional settings. Therefore, the focus of this study was to explore how spouses experience loss of couplehood. A deeper understanding of spouses' experiences in the context of institutional care is crucial to understand their needs, provide individualised support and facilitate services for their well-being (McGovern 2012, Molyneaux 2012, Palmer 2013).

Methods

Aim

The aim of this study was to explore and describe spouses' experiences of losing couplehood with their dementia-afflicted partner living in institutional care.

Design

The constructivist grounded theory is informed by symbolic interactionism, underlying an interpretative approach assuming that there is a reality existing. However, this reality is shaped and constructed through relations and interactions between people (Bryant & Charmaz 2007). In using this approximation, we assume that knowledge is developed through interactions with the participants and that the meanings of the themes being explored are created in the discourse between the researcher and the participant. Additionally, the methodology enables the exploration of social and interactional processes (Charmaz 2006, Bryant & Charmaz 2007). The aim of this study was to explore spouses' subjective experiences and construct concepts concerning important issues in their lives. The application of the constructivist version of grounded theory was therefore considered to be particularly relevant for this study. Our findings are presented here by integrating the hallmarks of grounded theory (i.e. the principles of: sensitising concepts, theoretical sampling, memo-writing and constant comparative analyses) (Charmaz 2006, Corbin & Strauss 2008).

Participants

The participants ($n = 10$) were recruited by healthcare personnel in four different nursing homes in a Norwegian municipality. They were strategically selected from amongst older spouses of persons diagnosed with dementia who lived in institutional care; their ages ranged between 64–90 years. Seven of the participants were older than 80. All spouses (five men, five women) had marriages lasting longer than 40 years; they were retired, and all, except one childless person, had grown children. Their partners had been living in institutional care for 8–48 months, and their degree of dementia ranged from moderate to severe.

Ethical considerations

All participants gave their voluntary informed consent. The study was approved by the Norwegian Social Science Data Services (NSD).

Data collection

Theoretical sampling

In the beginning, a convenience sampling approach was applied. During sampling, data were constantly compared and memos were written continuously to develop ideas to pursue in the later stages of the sampling procedure (Charmaz 2006, Corbin & Strauss 2008). Based on the findings from axial coding and the development of increasingly focused memos, the sampling procedures advanced to theoretical sampling. The main focus in theoretical sampling is to elaborate and refine the evolving categories (Charmaz 2006). We therefore followed the participants' weighting of relational concerns and how this influenced their everyday life. Consequently, sampling was focused on illuminating these identified – but still suggestive – categories.

Interviewing

Conversational interviewing was used to capture the spouses' experiences (Charmaz 2006, Corbin & Strauss 2008). The interviews, lasting between 50 minutes to two and a half hours, were audiotaped and conducted at a place of the participant's choice. Two of the participants shared unprompted, written reflections; these were included in the material. To contextualise the interviews (Charmaz 2006), field notes were made during the interviews concerning the setting, place, participant and other observations of interest. The interviews were transcribed continuously.

A brief thematic interview guide was developed for the first interviews using sensitising concepts (Charmaz 2006). Sensitising concepts were used as vantage points elaborated and chosen based on literature concerning themes, such as caregiving strain/gain, caregiving role, everyday life, relational experiences and issues concerning relocation of a partner. However, the participants were encouraged to tell their stories from the beginning when their partner succumbed to the disease. They were initially given an open-ended question: 'Can you tell me how it all started?' The interview then proceeded in a conversational manner, aiming to explore the issues the participants considered

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important and supplemented with probes aiming to fill the gaps in the evolving categories.

Data analysis

Data were analysed using the constant comparative method (Corbin & Strauss 2008), utilising three phases: initial coding, axial coding and selective coding.

Initial coding involved labelling segments of the data with codes describing what was occurring. This process contributed to a clear vision of what the interviews were really about, identifying different aspects of loss as a theme covered in all of the interviews.

The coding process proceeded with axial coding. The initial codes (i.e. 'separation', 'experiences of being alone', 'losing couplehood') were applied to all of the interviews, searching for verification of when, why and under what circumstances these initial codes became visible. The constant comparison of data both internally and between interviews developed our understanding of the constructed categories, linking the codes to them as well as elaborating the relationship between the categories. Memos were constantly written, and to increase the theoretical sensitivity (Charmaz 2006), the literature was processed simultaneously.

Selective coding was used according to the instructions described by Corbin and Strauss (2008), in which the data were analysed for context (p. 88) and process (p. 100). This coding increased our understanding of the sets of conditions, interactions and responses identified in the material. The core category: *loss of a shared lifetime* appeared at this point. The categories were then sorted and elaborated through using a conditional matrix (Corbin & Strauss 2008), in which the properties and dimensions of each category were conceptualised and the relationships between them were integrated. The categories were well developed (i.e. theoretically saturated; Charmaz 2006, Corbin & Strauss 2008). Three main categories (see Fig. 1; *loss of a shared everyday life, loss of a shared past* and *loss of a*

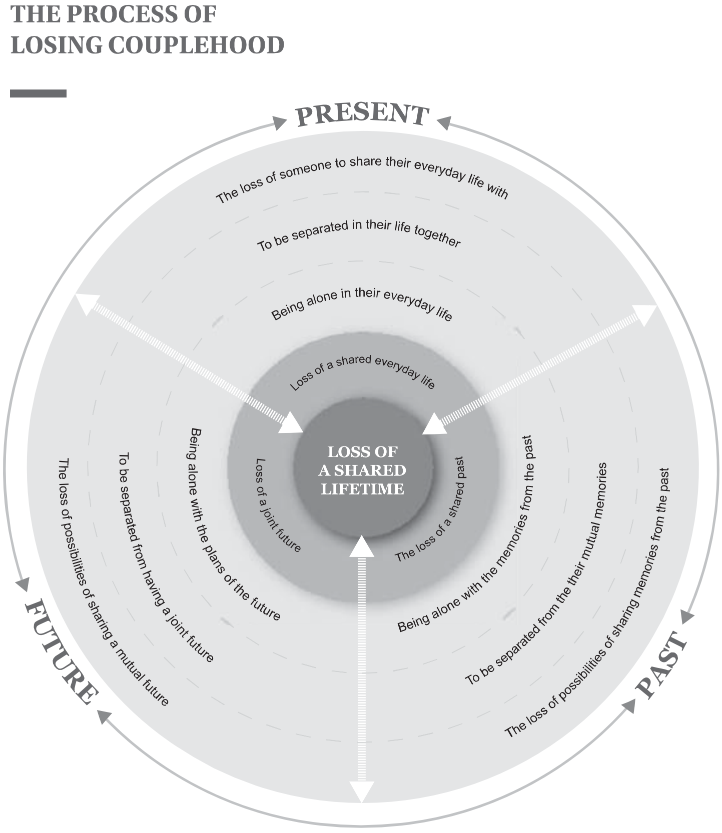

Figure 1 Illustration of the subcategories, main categories and the core category that constitute the process of losing couplehood.

joint future) constructed the core category and reflected the losses experienced by the spouses. Each category encompassed the conditions *separation, being alone* and *loss of couplehood* that form the context of the losses and build structure for the subcategories. Additionally, these losses reflected the phases of the spouses' lives: *present, past and future* (Corbin & Strauss 2008).

Results

The interviews showed that even though the days varied for the spouses, they often had feelings dominated by emptiness, lack of the other and aloneness that resulted from the separation from their partner. The sense of aloneness seemed stronger in situations in which the spouses were by themselves, typically in their homes.

To counteract the feeling of being alone, many of the spouses frequently visited their partner. The possibility of experiencing couplehood seemed more likely in the institutional setting. During visits, strategies were used, such as recollection of mutual memories, viewing photos from the past or just being together, attempting to connect with their partner. When these strategies succeeded, the pleasure of experiencing short glimpses of connectedness, reciprocity and interdependence contributed to a momentary feeling of couplehood. Conversely, when the strategies failed, the feeling of being alone was intensified.

The findings reveal that the spouses experienced an overall sensation of a lost lifetime; they could neither reconnect through mutual memories nor enjoy a shared future. Nevertheless, these experiences did not seem constant; rather, the spouses wavered between diverse feelings, depending on the situation.

In the following sections, the three identified main categories, *loss of a shared everyday life, loss of a shared past* and *loss of a joint future*, will be presented.

Loss of a shared everyday life

The physical separation and the absence of the other created a strong feeling of being alone. This was typical for all participants. One spouse (Participant 3) described this feeling as a sense of emptiness: *empty chair, empty bed*, explaining how he experienced the absence of his wife as a *physical nonpresence. The feeling of her not being here is almost palpable*, he said and clarified:

> I want, after all, to be a whole person, and I am not. I can admit that. You live of course. ... There is a wall lacking. It is a half, you are a half. Even though you function and still carry on, you are alone

The progression of dementia interfered with the spouses' ability to be connected to their partner and hindered them from participating in their partner's everyday life. Some spouses expressed a sense of frustration because they had trouble interpreting their partner's signals and were not able to help. Specifically, the loss of speech and the ability to communicate seemed to contribute to a sense of separateness because the partner was inaccessible in daily life:

> The worst part is that I don't know how he is doing 'inside'. If he is in his own ... Sometimes I kind of feel he is in another world. But I don't know. (Participant 8)

The inability to preserve mutual support added to the experience of being alone on a daily basis. Many of the participants did have family and friends supporting them, which seemed important. However, some spouses indicated that this support did not compensate for the absence of support from, and of the presence of, their partner.

The feeling of being alone also contributed to dilemmas in various social settings. First, the spouses' found that their new solitary role affected their interaction with others. They had to play a social role they had never before performed, especially when invited to settings in which they had previously been together, such as dinner parties, or other events with mainly couples present. Second, the sensation of participating alone but still married was explained as problematic. Some spouses felt this new role was difficult because they still felt a strong commitment to their role as part of a couple. Some participants said that the role of being widowed would have been easier because their own emotional expectations of the role would be clearer. Third, they felt that others primarily saw them as caregivers and that this role limited them. However, two of the spouses said they were so absorbed by their commitment to their partner's situation that they felt they had nothing to contribute to social settings. They feared that others would be overwhelmed by their concerns, so they avoided situations in which they had to share their experiences with others. One of them summed up some of these dilemmas:

> Then we will be three ... You see? Almost as 'the odd man out'. And what should they talk to me about? Am I supposed to sit there, constantly talking about my husband and his illness, or ... Then, I think it is better when they call and ask me to join them at the theatre. Then you don't have to have that conversation. (Participant 5)

The experience of being their partners' lovers varied amongst the spouses, although they all expressed that they were married. Some spouses felt they did not view their

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partner as their lover; Participant 6 said: *It's like visiting an older person you care for. You distance yourself*. The feeling of being lovers was gone. In contrast, other spouses expressed their feelings as still affectionate. Despite the experience of losing their partner, they still felt like they were in love and had emotional feelings for their partner. One spouse even expressed his feelings as stronger because they were blended together (love, care, sympathy and affection):

> I have always loved her. It hasn't decreased following her disease. It is somehow mixed with sympathy, I guess. I feel sorry for her sitting like that. But I still love her, I do. (Participant 10)

Some spouses discovered a new dilemma concerning how to relate to possible new intimate friendships without violating the marriage promise. Whereas some of them expressed they would never think of getting involved with another as long as they were married, others admitted they were longing for someone to share their everyday life with. However, the fact that they were still married, even though they were alone, rendered this an insoluble problem:

> I once said yes and made a promise. We are married. I haven't had any strong desires to initiate any intimate relationships with other women. I'm kind of old-fashioned, I guess. (Participant 7)

To counteract the feeling of lost couplehood, many of the spouses visited their partner frequently. Several participants said that their visits were an effort to re-establish a sense of mutuality and that this somehow compensated for their separation. Glimpses of reciprocity, connectedness and interdependence were sometimes experienced during these visits, provided the partners were still able to give some sort of a response to the spouses. As one of the participants said:

> When she sits up there, in the atmosphere … Then, there are glimpses and moments that are really encouraging. Otherwise, it is the same; she mostly talks about her mother and all of that. But there are glimpses every now and then … (Participant 3)

Loss of a shared past

Many memories of their mutual life together were connected to the spouses' homes. However, their homes constantly reminded them that they were alone. Particularly, spouses still living where they had lived during the years together with their partner described: *He used to sit over there, this is his chair* (Participant 8), or *She used to lie on that sofa* (Participant 4) pointing at the furniture during the interview:

> You think you have been together for so long, done things together, built a home together. And suddenly there you are. You are alone … (pause) Am I going to live in this big house where we somehow did … ? (Participant 5)

The spouses said that their partners' reduced capability to remember their mutual history contributed to a loss of couplehood; they were alone with memories from their lifetime together. The spouses found it challenging when their partner did not recognise their mutual home, their children or places that had a certain meaning for them as a couple:

> I remember one time, when we were in the cabin. Like; what are we doing here? What is the point of being here? And so on. Then, I remember, I was merely a little angry. Because, I felt I was hurt. That this place, in which we have had so much pleasure together, and suddenly it was like it meant nothing. That was strange. (Participant 9)

The spouses attempted to stimulate their partners' memories. When they were visiting, different strategies were used; they showed pictures of their family, photographs from their past, or important objects from their history. However, the strategies often failed because of the decline caused by the disease, which confirmed the gap that existed between them:

> I learned the long-term memory wasn't the first to disappear. So I thought: OK, we have had a long lifetime together from which we can share our memories. I made several attempts in this direction. I reminded her of our youth, our childhood, my student days, the first job I had and things like that. No response, not at all. That was hard. (Participant 4)

Loss of a joint future

The spouses lost the possibility of having a future together with their partner. They could not fulfil the plans and ideas they had for their mutual future. Suddenly, they did not have a future together, or the future they had planned was changed. One of the spouses expressed this dilemma:

> Why him? The year before, we bought ourselves a camper. We were supposed to have our aging future together in the camper, travelling around and … So, now, I drive the camper by myself. (Participant 5)

They realised that travelling or visiting familiar places together would be impossible in the future. This realisation caused an internal struggle. As Participant 4 explained:

The pleasure of the good memories is balanced by the pain caused by the realisation of never being able to experience the same again with the person you love.

The spouses questioned what their future would be like; they realised they would be alone. *I take one day at a time* was a statement expressed by several participants (1, 2, 3, 4), describing their approach to their future plans. They felt that making such plans was difficult because they did not know how long they would have their partner. One spouse said she had *frozen* her life, waiting for the future to begin when *it was all over*; she wanted her future to be a *new start* (Participant 5). Others expressed their sense of lacking a future; they stated they did not feel they had a future at all, partly related to their ageing process but also to the uncertainty of their future being alone. *I realise I will reach a point when health problems might appear. How could I manage that all alone?* (Participant 4). Insecurity was also connected to the thought of what would happen if they died before their partner because they did not want to leave their partner alone:

I have thought of that many times, that I wish my husband dies first. So he doesn't need to be left alone like that ... (Participant 1)

Discussion

The aim of this study was to explore and describe spouses' experiences of losing couplehood with their dementia-afflicted partner living in institutional care. The findings reveal how the spouses lost their feelings of couplehood with their partner. These experiences were primarily connected to feelings of being alone and were associated with various aspects of being apart in everyday life. However, they were also connected to other aspects of their lives. Separation from their partner, resulting from the functional decline, left them alone with the recollections of their lifetime together. Moreover, the spouses realised that their lifetime together with their partner was going to end in separation; the opportunity of sharing a future was gone. Their experience of loss was connected to different phases of their lives, demonstrating an overall sensation of a lost lifetime.

The experience of loss – 'I' vs. 'we'

Couplehood, as defined by Kaplan (2001), refers to the extent to which individuals perceive themselves as being an 'I' or having feelings of belonging to a 'we'. In contrast to the spouses interviewed by Kaplan (2001), categorising the spouses in our study within a typology of 'I' – 'we' was challenging. The spouses in our study rather seemed to incorporate a sense of movement between these positions. They expressed a strong feeling of being alone and separated from their partner. This feeling could be seen as consistent with the feeling of being an 'I' (Gladstone 1995, Kaplan 2001) or 'working alone' (Hellstrom & Lund 2005, 2007) and corresponds to an experience of discontinuity (Walters *et al.* 2010). Although this experience varied, some spouses also emphasised that they were still married although they were alone. Their feelings of belonging to a 'we' seemed strong. Evans and Lee (2013) reported that the last stages of dementia were a time of confusion for the spouses; they were unsure whether their marriage still existed. Our participants, however, did not appear confused; they seemed quite confident of their positions. However, their experiences of being an 'I', as opposed to 'we', were not static; they wavered between the sense of feeling alone and belonging to the couplehood.

As other studies have suggested (Gladstone 1995, Walters *et al.* 2010, Koren 2011), maintaining continuity from the past relationship to sustain the experience of being 'we' was important to the spouses in our study. Perhaps their long-lasting relationships influenced this commitment; the result might have been different if the participants had been more unequal in the quality and duration of their relationships. Nevertheless, as Hellstrom and Lund (2005, 2007) identified in their studies, the spouses in this study used strategies to preserve some semblance of a couplehood with their partners. Tactics to enable togetherness (Graham & Bassett 2006) and recollection of memories from the past (Molyneaux 2012) were used during visits, to facilitate couplehood. When these strategies succeeded, a sense of 'we' -ness was recaptured, which contributed to a momentary experience of continuity. However, if the progression of dementia hindered the recreation of the 'we', the spouses felt alone. The spouses' experiences of couplehood therefore alternated between the experiences of being part of a 'we' and feeling like an 'I', depending on the situation. Our findings therefore suggest that the experiences related to the loss of couplehood, for committed spouses at least, could be situational.

As Hellstrom *et al.* (2005) also suggested, the progressiveness of dementia was a conditional factor in our study. Cognitive decline resulting from dementia clearly influenced the ability to share everyday experiences and to reconnect through shared memories. Recollection of past memories has been previously recognised as crucial to sustain

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continuity (Walters *et al.* 2010) and better understand current experiences (Molyneaux 2012). In this study, the ability to connect through memories was only partially present; sometimes it was even absent, influencing the ability to seek continuity in past experiences. Experiences of discontinuity were increasingly apparent for the spouses of partners who were in the later stages of the disease. Additionally, short glimpses of couplehood were invaluable for these spouses because of their infrequent appearance. Perhaps this experience contributed to the wavering between being an 'I' vs. a 'we' and explains why the experiences of couplehood were only momentary.

Most research in this field has explored the experiences of spouses caring for partners living at home (Hellstrom & Lund 2005, 2007, O'Shaughnessy *et al.* 2010, Walters *et al.* 2010, Molyneaux 2012). This study therefore contributes to an evolving understanding of couplehood experienced by spouses who have partners living in institutional care. Our findings indicate that the spouses' experiences may represent an ongoing process of re-evaluating their own role as a 'separated' spouse and repositioning themselves in their belonging to their partner. Using the concept of couplehood proved valuable in this connection, as it contributed to highlighting the spouses' overall experiences of losses related to their relationship.

The process of losing couplehood in this study occurred in an institutional setting, which is often experienced as an unfamiliar setting (Hennings *et al.* 2013) in which others control events. Our findings highlight the importance of acknowledging the vulnerability and uniqueness of these spouses' situations and underscore the importance of including specific groups of caregivers in future studies. Furthermore, exploring the conditions influencing the senses of couplehood for spousal caregivers in institutional settings could provide a direction for future research. Additionally, research needs to further explore the strategies used by spouses to facilitate couplehood in institutional settings, the support required for these strategies and the ability to achieve couplehood under these circumstances. Ultimately, exploring these factors from both perspectives of the dyads could provide crucial insight into how relationships evolve in institutional settings and advance the understanding of couplehood as a concept of understanding couples' experiences in institutional care.

Limitations

Caution is needed in generalising our data, as they only relate to the experiences of 10 spouses, who had long-lasting relationships with their partner. The relatively uniform sample in this study must be considered in interpreting the results. Additionally, spouses were recruited through the institutions where their partners lived. This factor might have influenced the results. Spouses who visited the institutions most frequently could possibly represent spouses who were more committed to their relationships. Additionally, interviewing spouses about these experiences could be challenging, as participants might wish to idealise the importance of their long-lasting relationship. However, the interviews in this study did not give such an impression.

Conclusion

The spouses' experiences of losing couplehood were dynamic and related to the couple's entire life. The spouses wavered between the senses of loss and belonging to the couplehood, depending on the situation.

Relevance to clinical practice

Recognising the severity of some spouses' experiences of losing couplehood is crucial for healthcare personnel. Awareness of how these experiences could fluctuate and be situational is also important. Individualised approaches that emphasise identification, understanding and validation of the unique experiences of spouses are needed to support the spouses. This study also identified the importance of having a sense of belonging to the couplehood, although this was only experienced briefly in advanced stages of dementia. Support services and organisational arrangements should recognise this experience and consider the importance of sustaining and facilitating couplehood in the institutional environment.

Furthermore, recognising the various roles spouses hold is also important. Whereas some spouses have an active role as the caregiver, others may wish to maintain their role as a spouse, even in the institutional setting. In the later stages of dementia, spouses may only have the role of visitor; posing unrealistic demands to participate in care for these spouses should be avoided. Initiating support groups could provide needed support for spouses. Interaction with others who have partners in institutional care might be helpful for some spouses. Support of the spouses should additionally recognise their concerns related to a future alone.

Disclosure

The authors have confirmed that all authors meet the ICMJE criteria for authorship credit (www.icmje.org/ethical_1author.html), as follows: (1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content and (3) final approval of the version to be published.

References

Ablitt A, Jones G & Muers J (2009) Living with dementia: a systematic review of the influence of relationship factors. *Aging and Mental health* **13**, 497–511.

Andrèn S & Elmståhl S (2008) The relationship between caregiver burden, caregivers‘ perceived health and their sense of coherence in caring for elders with dementia. *Journal of Clinical Nursing* **17**, 790–799.

Bryant A & Charmaz K (2007) *The Sage Handbook on Grounded Theory*. Sage, London.

Charmaz K (2006) *Constructing Grounded Theory. A Practical Guide through Qualitative Analysis*. Sage, London.

Corbin JM & Strauss AL (2008) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, 3rd edn. Sage, Thousand Oaks, CA.

Etters L, Goodall D & Harrison BE (2008) Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of the American Academy of Nurse Practitioners* **20**, 423–428.

Evans D & Lee E (2014) Impact of dementia on marriage: a qualitative systematic review. *Dementia* **13**, 330–349.

Gillies B (2011) Continuity and loss: the carer's journey through dementia. *Dementia* **11**, 657–676.

Gladstone JW (1995) The marital perceptions of elderly persons living or having a spouse living in a long-term care institution in Canada. *The Gerontologist* **35**, 52–60.

Graham JE & Bassett R (2006) Reciprocal relations: the recognition and co-construction of caring with Alzheimer's disease. *Journal of Aging Studies* **20**, 335–349.

Hellstrom I & Lund U (2005) "We do things together": a case study of "couplehood" in dementia. *Dementia* **4**, 7–22.

Hellstrom I & Lund U (2007) Sustaining "couplehood": spouses‘ strategies for living positively with dementia. *Dementia* **6**, 383–409.

Hellstrom I, Nolan MR & Lund U (2005) Awareness context theory and the dynamics of dementia: improving understanding using emergent fit. *Dementia* **4**, 269–295.

Hennings J, Froggatt K & Payne S (2013) Spouse caregivers of people with advanced dementia in nursing homes: a longitudinal narrative study. *Palliative Medicine* **27**, 683–691.

Kaplan L (2001) A couplehood typology for spouses of institutionalized persons with Alzheimer's disease: perceptions of "we"–"I"*. *Family Relations* **50**, 87–98.

Kaplan L, Ade-Ridder L, Hennon CB, Brubaker E & Brubaker T (1995) Preliminary typology of couplehood for community-dwelling wives: "I" versus "we". *International Journal of Aging and Human Development* **40**, 317–337.

Koren C (2011) Continuity and discontinuity: the case of second couplehood in old age. *The Gerontologist* **51**, 687–698.

McGovern J (2011) Couple meaning-making and dementia: challenges to the deficit model. *Journal of Gerontological Social Work* **54**, 678–690.

McGovern J (2012) Couplehood and the phenomenology of meaning for older couples living with dementia. *New York University Silver School of Social Work* Doctoral thesis New York University, New York, NY, p. 166.

Molyneaux V (2012) The co-construction of couplehood in dementia. *Dementia* **11**, 483–502.

Mullin J, Simpson J & Froggatt K (2011) Experiences of spouses of people with dementia in long-term care. *Dementia* **12**, 177–191.

Netto NR, Jenny GYN & Philip YLK (2009) Growing and gaining through caring for a loved one with dementia. *Dementia* **8**, 245–261.

Nolan M, Ryan T, Enderby P & Reid D (2002) Towards a more inclusive vision of dementia care practice and research. *Dementia* **1**, 193–211.

O‘Shaughnessy M, Lee K & Lintern T (2010) Changes in the couple relationship in dementia care: spouse carers‘ experiences. *Dementia* **9**, 237–258.

Palmer JL (2013) Preserving personhood of individuals with advanced dementia: lessons from family caregivers. *Geriatric Nursing* **34**, 224–229.

Prakke HM (2012) Spousal relationships in which one partner has early cognitive problems. *Dementia* **11**, 199–215.

Prince M, Bryce R, Albanese E, Wimo A, Ribeiro W & Ferri CP (2013) The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimer‘s & Dementia* **9**, 63–75.

Quinn C, Clare L & Woods B (2009) The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: a systematic review. *Aging and Mental health* **13**, 143–154.

Schoenmakers B, Buntinx F & Delepeleire J (2010) Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic review. *Maturitas* **66**, 191–200.

Schultz R & Martire LM (2004) Family caregiving of persons with dementia. Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry* **12**, 240–249.

Shim B, Barroso J & Davis LL (2012) A comparative analysis of stories of spousal caregivers of people with dementia: negative, ambivalent, and positive experiences. *International Journal of Nursing Studies* **49**, 220–229.

Shim B, Barroso J, Gilliss CL & Davis LL (2013) Finding meaning in caring for a spouse with dementia. *Applied Nursing Research* **26**, 121–126.

Walters AH, Oyebode JR & Riley GA (2010) The dynamics of continuity and discontinuity for women caring for a spouse with dementia. *Dementia* **9**, 169–189.

Wolfs CAG, Kessels A, Severens JL, Brouwer W, de Vugt ME, Verhey FRJ & Dirksen CD (2012) Predictive factors for the objective burden of informal care in people with dementia: a systematic review. *Alzheimer Disease and Associated Disorders* **26**, 197–204.

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Paper II

JCN Journal of Clinical Nursing

Journal of Clinical Nursing

ORIGINAL ARTICLE

Constructing togetherness throughout the phases of dementia: a qualitative study exploring how spouses maintain relationships with partners with dementia who live in institutional care

Linn Hege Førsund, Riina Kiik, Kirsti Skovdahl and Siri Ytrehus

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Aims and objectives. To explore and describe how spouses involve themselves in the relationship with their partners with dementia who live in institutional care.

Background. Positive reciprocity between partners has been proven to be significant for spouses with partners living with dementia at home. However, little is known about spousal involvement after placement of a partner in an institutional setting. This subject was therefore the focus of this study.

Design. Constructivist grounded theory was used to develop meaningful concepts considering the relational processes experienced and described by the spouses.

Methods. Interviews were conducted with 15 spouses (eight women and seven men ranging in age from 64–90 years) of dementia-afflicted persons living in institutional care. Theoretical sampling, constant comparison and memo-writing guided the data collection and analysis.

Results. The analysis showed how the spouses adopted different visiting routines to preserve continuity in their relationship throughout the phases of dementia. Three categories described how these visiting routines were used and adapted along with their partners' dementia progressions in the process of constructing togetherness: 'maintaining involvement and intimacy to preserve continuity in their relationship,' 'structuring visits to facilitate interaction and communication' and 'pursuing moments of mutuality to preserve continuity in a deteriorating relationship.'

Conclusions. Being involved and experiencing continuity in the relationship seemed important to the spouses after their partners' placement in institutional care. In the process of constructing togetherness, visiting routines were used to facilitate situations in which they could connect with their partners. These routines were continuously adjusted throughout the phases of dementia.

Relevance to clinical practice. There is a need for a systematic approach to provide sufficient support to spouses throughout their partners' dementia progressions to assist their ongoing involvement.

What does this paper contribute to the wider global clinical community?

- Some spouses are extensively involved in the relationships with their partners after the partners are relocated to institutional care.
- Healthcare personnel need to consider the ways in which spouses might use visiting routines to construct togetherness and mutual interactions in institutional care and recognise how these routines can change throughout the dementia course.
- Spouses need to be supported systematically throughout their partners' dementia progressions to assist their ongoing involvement in institutional care.

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Introduction

Dementia is a progressive condition that affects people worldwide. Being a spousal caregiver for a person with dementia can cause mental health problems and reduced well-being (Ask *et al.* 2014). Although studies have indicated that placing a partner with dementia in a nursing home relieves the spousal caregiver's burdens (Gaugler *et al.* 2008, 2009), the majority of studies have suggested that even after placement, many spouses still experience burdens (Papastavrou *et al.* 2007) and depressive symptoms (Schultz & Martire 2004, Gaugler *et al.* 2007). Recently, there have been indications that some spouses actually experience increased distress after placing their partners (Ask *et al.* 2014) in institutional care. Given the severe consequences of dementia, nursing home admission is often unavoidable in the later stages. The last stages of dementia are often associated with severe incapacities, such as impaired memory, inability to recognise familiar faces, severe verbal incapacity and total functional dependence (Mitchell *et al.* 2012). Experiencing these changes will, in addition to being burdensome for the spouses (Adelman *et al.* 2014), influence their relationship with their partner by separating them both physically, as a result of nursing home placement, and mentally, due to the increasing difficulties in preserving mutual support and connection (Førsund *et al.* 2015).

Background

There is growing interest in the role of the relationships between spouses and partners with dementia in the spouses' caregiving experiences (Evans & Lee 2014). Several studies have indicated that many spouses still express a strong sense of commitment to their relationships (Baikie 2002, Hellstrom & Lund 2005, 2007, Hennings *et al.* 2013) and that positive reciprocity between partners can contribute to increased well-being for the caregiving spouse (Braun *et al.* 2010, Mullin *et al.* 2013). Monin *et al.* (2014) showed how spouses who felt more compassionate love for their partners reported a decreased caregiver burden and more positive experiences related to their caregiving role compared with those who felt little compassionate love.

Related to the progressive nature of dementia, spouses who care for partners with dementia also experience ongoing multiple losses and must continuously adapt to new demands (O'Shaughnessy *et al.* 2010). Changing relational roles and the inability to maintain mutual support and togetherness in the relationship add to this experience and challenge the companionship, reciprocity and intimacy within the partner relationships (Evans & Lee 2014). Loss of companionship because of communication problems was found to be the most difficult consequence of dementia for the coresident spouses who were interviewed by Murray *et al.* (1999).

Having an affirmative relationship with the person with dementia appears to be a positive aspect of caregiving that actually mediates the challenges associated with the caregiving role (Carbonneau *et al.* 2010). A number of studies have indicated that the quality of both the previous and existing relationships influences the spouses' caregiving experiences (Hellstrom & Lund 2005, 2007, Quinn *et al.* 2009). Kramer (1993) and Shim *et al.* (2012) found that a good quality relationship before diagnosis was one of the most important influences on positive outcomes for the caregiving spouses.

Research has indicated that relocating a partner to institutional care may negatively influence spouses (Ask *et al.* 2014). Gaugler (2005) reviewed the literature on family involvement in institutional care and found that family members visited frequently and were extensively involved. These results were confirmed by Cohen *et al.* (2014). Ross *et al.* (1997) asked 46 wives of nursing home patients about their visiting routines and found that 20% of the wives visited daily and 80% visited multiple times per week. A longitudinal analysis showed that visit frequency did not change significantly after the 9-month follow-up. Tornatore and Grant (2002) found similar results among caregivers of persons with Alzheimer's disease and suggested that their enduring involvement might have influenced the burdens they still reported after placing their relatives in institutional care.

As we understand, the literature on families' experiences following institutionalising relatives is expanding. However, how spouses maintain their relationships after a partner is placed in institutional care is relatively unexplored. How

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spouses remain involved in their partners' lives after the partners are relocated must be addressed in the research. Most of the existing studies either lack an explicit focus on dementia (Ross *et al.* 2001, Eika *et al.* 2014), do not specifically include spouses (Tornatore & Grant 2002, Cohen *et al.* 2014) or fail on both counts (Gaugler 2005). Specifically highlighting the spouses' experiences is important given the influences of the relationship changes on their caregiving experiences. In addition, addressing the caregivers' needs in depth is increasingly important considering the indications of ongoing distress after their partners are relocated.

Methods

Aim

This study aimed to explore and describe how spouses involve themselves in the relationship with their partners with dementia who live in institutional care.

Design

This study aimed to explore and construct meaning from spouses' experiences and was designed using constructivist grounded theory (Charmaz 2014). Applying this approach implied focussing explicitly on theoretical sampling, providing concurrent engagement in the data collection and analysis and enabling the emerging categories to be constantly compared and successively tried against new interviews. This approach was chosen because it allowed for exploring the ongoing social and interactional processes and for studying how the participants construct meanings and actions in specific situations.

Context

Norway has a well-developed universal welfare model for the care of the older, and service provision is organised by self-governing municipalities. The key types of services available are nursing homes, sheltered housing and home nursing (Ytrehus 2011). Institutional care is owned and operated by local governments, and persons with dementia requiring institutional care are allocated to either ordinary nursing home wards, specialised care units (SCUs) for persons with dementia or sheltered housing for persons with dementia (Kirkevold *et al.* 2012). Despite the variations in housing arrangements, the care services provided within them are similar; the differences are mainly relevant with regard to payment policies and the legal framework (Ytrehus 2011).

Recruitment

For this study, the participants were recruited from SCUs in four nursing homes (A–D) and four sheltered housing units (E–H) in five (I–IV) different municipalities in Norway (Table 1). To ask for collaboration, telephone contact was made with department managers in 27 institutional settings that housed 863 residents. Institutions were approached one by one during sampling in the period from February 2013–May 2014. Written information about the study, inclusion criteria and recruitment procedure were mailed to the managers who were willing to help (only one refused to collaborate). The department managers, who were all nurses, asked persons who fulfilled the criteria for being the older spouse or partner of a person with dementia living in institutional care whether they were interested in participating in the study. Of the 863 residents, only 31 had spouses or partners still living and were able to participate, as assessed by the managers. All were asked if they were willing to participate. A total of 16 refused to participate due to emotional distress, frailty or heavy burden, leaving a sample of 15 persons for inclusion in the study (Table 2). This sample included two widowed spouses and one divorced spouse, who did not meet the initial inclusion criteria. However, because their experiences were considered to be relevant to the study, they were included.

Ethical considerations

Because the sample in this study appeared to be vulnerable, it was emphasised not to exert any pressure towards potential participants during recruitment. Before volunteering, the participants were given verbal and written information about the study and their right to withdraw. Written consent was obtained before the initial contact with interviewer. Information about voluntariness was repeated at the first meeting. The study was approved by the Norwegian Social Science Data Services (NSD).

Participants

The sample consisted of seven men and eight women aged from 64–90 years with an average age of 78·8 years. The participants reported that their partners' stage of dementia was moderate/severe to severe and that they had been living in institutional care for eight months to seven years before the interviews, five in sheltered housing units and ten in SCUs. The majority of the participants were married; the participants were, therefore, termed 'spouses.' See Table 1 for additional contextual details.

Table 1 Characteristics of participants

Pseudonyms	Amelia	Sophia	Carl	Herman	Brith	William	Peter	Lisa	Ingrid	Lucas	Louisa	Jonas	Otto	Hannah	Maria
Age	80–89	80–89	90–99	80–89	60–69	70–79	70–79	80–89	80–89	80–89	70–79	70–79	80–89	70–79	60–69
Gender	Female	Female	Male	Male	Female	Male	Male	Female	Female	Male	Female	Male	Male	Female	Female
Civil status	Married	Married	Married	Widowed	Married	Married	Married	Married	Married	Married	Married	Common-law spouse	Married	Widowed	Divorced
Having grown-up children together?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	No	Yes	No
Proportion of family support as reported by participants	Quite much	A lot	A lot	Quite much	Not at all	A lot	A lot	Not at all	A lot	Quite much	Not much	A lot	Not at all	A lot	Not at all
Participation in support groups	No	Yes	No	Yes	No	Yes	Yes	Yes	Yes	No	Yes	No	No	No	No
Type of dementia as reported by participants	Alzheimer	Alzheimer	Vascular/ Alzheimer	Lewy Body	Alzheimer	Unknown	Vascular	Unknown	Vascular	Alzheimer	Unknown	Unknown	Lewy Body	Vascular	Alcohol related dementia
Stage of condition as reported by participants	Severe	Moderate/ severe	Severe	Deceased	Severe	Severe	Moderate/ severe	Severe	Severe	Moderate/ severe	Severe	Severe	Severe	Deceased	Severe
Number of years together as a couple:	>55	>55	>65	>60	>40	>50	>60	>60	>50	>60	>45	>20	>50	>55	>20
Number of years having partner in institutional care:	1·5–2	2–2·5	2·5–3	2–2·5	3–3·5	4–4·5	4–4·5	1–1·5	0·5–1	3·5–4	6·5–7	1·5–2	3–3·5	2·5–3	6–6·5
Visit frequency	Two times a week	Four times a week	Three to four times a week	Six to seven times a week	Six to seven times a week	One time per week	One to two times a week	Six to seven times a week	Two times a week	Three times a week	Two times a week	Four times a week	Two times a week	Two times a week	One time per week
Type of institution	NH	NH	NH	NH	NH	NH	NH	NH	NH	NH	SH	SH	SH	SH	SH
Institution ID	B	B	B	B	A	B	C	D	D	C	E	F	G	G	H
Municipality ID	I	I	I	I	II	I	I	I	I	I	III	III	IIII	IIII	IV

NH, Nursing Home; SH, Sheltered Housing.

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Table 2 Recruitment procedure

Type of Institutional Care	Number of institutions contacted	Total amount of residences housed in the institutions	Number of participants asked about participation	Number of participants willing to participate
Nursing Home	5	433	15	10
Sheltered Housing	22	430	16	5
Total	27	863	31	15

Theoretical sampling

Five spouses were first recruited and interviewed. The sampling commenced and progressed to theoretical sampling from participant six onwards, guided by the emerging concepts about spouses' weighting of their relational concerns regarding 'How can we be together in this setting?' First, suggestive categories, such as 'being together' and 'facilitating togetherness,' were illuminated through ongoing analyses and the development of increasingly focussed memos. Recruitment and interviewing were undertaken stepwise to ensure that we had opportunities to elaborate and saturate the categories throughout the ongoing data collection and analysis (see Table 3 for timeline). The sample size of 15 participants was, in part, determined by challenges related to recruitment. At the same time, we considered the categories to be sufficiently saturated pertaining to 'the point when gathering fresh data do not give new theoretical insights nor reveal new properties of the theoretical categories' (Charmaz 2014, p. 213).

Interviewing

Constructivists see both data and analysis as created from shared experiences and relationships with participants (Charmaz 2014). The interviews, lasting from 50 minutes to 2·5 hours, were therefore performed in a conversational manner, aiming to explore the participants' perspective regarding their personal experiences. The interviews were audio-taped, transcribed verbatim and conducted at a place of the participant's choice. To contextualise the interviews, field notes were made during the interviews concerning the setting, place, participants and other observations of interest.

The participants were encouraged to tell their stories from the beginning when their partners succumbed to the disease. The interviews started with an open-ended question: 'Can you tell me how it all started?' Suggestive categories started to emerge in the analysis during the first interviews (see examples above). Theoretical sampling, aiming to elaborate on the categories and specify the relationships between them, subsequently indicated areas that required probing for additional data. The participants were, therefore, requested to elaborate on what the visits meant to them and how they maintained their relationships during visiting. They were also asked about their visiting routines, what they did while visiting, and how these routines had changed after their partners' relocations.

Table 3 Sampling overview

Pseudonyms	Timeline	Follow-up interview	
Amelia	February–March 2013	Yes	Two weeks after first interview
Sophia	February–March 2013	Yes	Two weeks after first interview
Carl	February–March 2013	No	Written reflections were provided retrospectively
Herman	February–March 2013	Yes	Two weeks after first interview, written reflections were also provided retrospectively
Brith	February–March 2013	No	
William	May–June 2013	No	
Peter	May–June 2013	No	
Lisa	May–June 2013	No	
Ingrid	May–June 2013	No	
Lucas	July–August 2013	No	
Louisa	February–March 2014	Yes	Two weeks after first interview
Jonas	February–March 2014	Yes	Six weeks after first interview
Otto	February–March 2014	Yes	Six weeks after first interview
Hannah	April–May 2014	No	
Maria	April–May 2014	No	

With the aim of clarifying statements and discussing the evolving categories with the participants, some spouses, Amelia, Sophia, Carl, Louisa, Jonas and Otto (pseudonyms), participated in one follow-up interview within six weeks after first interview. To avoid straining those spouses who expressed feeling the most burdened, only some participants were asked to participate. These participants were selected on the basis of what impression they gave during the first interview. Most interviews were performed in face-to-face meetings; however, to concur with some participants' requests, three interviews were accomplished by phone. In addition, Carl and Herman shared unprompted, written reflections regarding their experiences as spousal caregivers; these reflections were included in the material.

Data analysis

The transcripts from the 21 interviews, written reflections, field notes and memos were analysed according to the principles described by Charmaz (2014). The analysis was performed by the first author; however, the entire group of authors participated in the process of developing categories.

Initial coding involved line-by-line coding with gerunds. Each line of written data was coded by asking 'what is going on?' The gerunds were used as codes to help us concentrate on actions and maintain consistency within the data. Initial codes, such as 'being together,' 'making contact' and 'facilitating togetherness,' identified how the spouses were working to maintain involvement in their relationships.

The coding process proceeded with focussed coding. The initial codes were used to go through all the data searching for verification of when, why and under what circumstances the initial codes became visible. The spouses' usage of visiting routines to maintain involvement emerged. Asking questions about these routines aided the elaboration of categories: What are the spouses' visiting routines? When and where are they used? How do the visiting routines resemble each other, and why do the spouses use them? With what consequences are they understood?

In addition to ongoing theoretical sampling, comparing data both internally and between data broadened our understanding of the developing categories. To increase theoretical sensitivity, the literature was assessed simultaneously. The writing of analytical memos aided the development of a theoretical understanding of the material. The core category describing how spouses constructed togetherness to preserve continuity in their relationship by using visiting routines gradually emerged. It was identified under what circumstances the spouses' visiting routines became visible, how the different visiting routines were related to each other and what factors influenced these relationships. To aid the sorting of categories and help us see the full range of relationships between the codes and categories, a table was developed (Table 4).

Finally, a processual analysis (Charmaz 2014) was performed to define and conceptualise the relationship between the spouses' experiences and actions, and the events attributed to their partners' dementia progression. The following three phases defining the spouses' experiences of the dementia progression after relocation of their partners were identified: (1) *the first phase* after placement when communicating and interacting with their partners were still relatively unchanged; (2) *the second phase* when dementia was progressing and deteriorating functions challenged the spouses' ways of interacting and communicating with their partners and (3) *the third phase* when communicating and interacting with their partners became challenging. The identified phases were compared with the spouses' visiting routines, and the following three categories were constructed: 'maintaining involvement and intimacy to preserve continuity in their relationship,' 'structuring visits to facilitate interaction and communication' and 'pursuing moments of mutuality to preserve continuity in a deteriorating relationship.' These categories illustrate how the spouses used visiting routines to 'construct togetherness' and how the visiting routines changed throughout the phases of dementia, in the process of 'constructing togetherness throughout the phases of dementia.'

Findings

The spouses used visiting routines to preserve continuity in their relationship in the process of 'constructing togetherness throughout the phases of dementia.' The process consists of three categories. The first category illustrates how visiting routines helped the spouses preserve continuity in their relationships during the first phase. The second category describes how the timing of the visits was increasingly important in facilitating interaction and communication during the second phase. Finally, the third category shows how preserving continuity in the relationship appeared to be challenging when the spouses' partners' dementia progressed in the last phase. Visiting frequency, activities and ways of interacting, therefore, changed.

Maintaining involvement and intimacy to preserve continuity in their relationship

To preserve continuity in their relationship, the spouses visited regularly in the first phase after placement in institutional care. Maintaining regular visits seemed to lessen their longing for their partner, sustained their sense of still playing significant roles in their partners' lives and helped them to fulfil their marriage promises. Some spouses even explained that regular visits satisfied their desire to stay involved and fulfil their own obligations to continue caring,

Table 4 Focused coding ‘constructing togetherness’

Transcript	What is the category?	When does the category occur?	Where does the category occur	Why does the category occur?	How does the category occur?	Consequences
	Maintaining involvement and intimacy to preserve continuity in their relationship	When does ‘maintaining involvement and intimacy to preserve continuity in their relationship’ occur?	Where does ‘maintaining involvement and intimacy to preserve continuity in their relationship’ occur?	Why do spouses ‘maintain involvement and intimacy to preserve continuity in their relationship’ during visiting?	How do spouses ‘maintain involvement and intimacy to preserve continuity in their relationship’?	With what consequences do we understand ‘maintaining involvement and intimacy to preserve continuity in their relationship’?
We are sitting in the room, just the two of us. Then I find the album and her diary and read a little bit. So we sit in the car; we take both shorter and longer trips. We always stop by a restaurant or café; she very much appreciates that	Maintaining involvement and intimacy to preserve continuity in their relationship	During visiting in the first phase	In the areas where the spouses can be in private with their partners	Because being involved is important Because they want to preserve continuity in their relationship Because visiting fulfils their spousal obligations Because they want to share intimate moments Because they want to make contact Because the experience conforms with their previous ways of interacting	By visiting frequently By being together the way they used to be By doing things as they did before By establishing safe environments to facilitate interactions By being together to recreate memories from the past	Spouses maintain involvement and intimacy to preserve continuity in their relationship in the process of ‘constructing togetherness’
	Structuring visits to facilitate interaction and communication	When does ‘structuring visits to facilitate interaction and communication’ occur?	Where does ‘structuring visits to facilitate interaction and communication’ occur?	Why does spouses ‘structure visits to facilitate interaction and communication’ during visiting?	How does spouses ‘structure visits to facilitate interaction and communication’?	With what consequences do we understand ‘structuring visits to facilitate interaction and communication’?

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Table 4 (continued)

Transcript	What is the category?	When does the category occur?	Where does the category occur	Why does the category occur?	How does the category occur?	Consequences
I developed this routine so that I arrived at a time when she had been sleeping after dinner. Then she could be a little more awake and lucid. My reasoning was that it would be easier for me, or it would be easier for her, if I leave her when something is going to happen in the unit. If, immediately after I have left, she is occupied with something else, then she will feel the less…If she can feel loss and sorrow, she will feel it less	Structuring visits to facilitate interaction and communication	During visiting in the second phase when dementia worsens and communication is challenged	In areas where the spouses can be in private with their partners	Because it's easier to make contact when their partners are more awake and lucid Because it is easier to communicate when their partners are more awake and lucid Because interactions are improved when their partners are more awake and lucid	By establishing regular visit routines By making sure to visit at the times when visits will be most productive By scheduling visits to fit the unit's routines By facilitating affirmative farewells	Spouses facilitate interactions and communication to preserve continuity in their relationship in the process of 'constructing togetherness'
	Pursuing moments of mutuality to preserve continuity in a deteriorating relationship	When does 'pursuing moments of mutuality to preserve continuity in a deteriorating relationship' occur?	Where does 'pursuing moments of mutuality to preserve continuity in a deteriorating relationship' occur?	Why does spouses 'pursue moments of mutuality to preserve continuity in a deteriorating relationship' during visiting?	How does spouses 'pursue moments of mutuality to preserve continuity in a deteriorating relationship'?	With what consequences do we understand 'pursuing moments of mutuality to preserve continuity in a deteriorating relationship'?

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Table 4 (continued)

Transcript	What is the category?	When does the category occur?	Where does the category occur	Why does the category occur?	How does the category occur?	Consequences
If the weather is nice, we go out for a little walk, viewing the garden and stuff like that. Gathering flowers. Sitting down on a bench down there listening to the birds. Stuff like that. I do not like to sit in the room because I think it is easier when there are others around us. Then all of a sudden, she has these moments when she remembers both names and other things. However, it is only a little glimpse. A couple of minutes, and then it is gone	Pursuing moments of mutuality to preserve continuity in a deteriorating relationship	During visits in the last phases of dementia	Usually in the public areas where spouses can be in private with their partner but still have access to support from others Sometimes in the private rooms with family members to keep them company	Because experiencing mutuality is important even if communication and interactions are challenged by dementia Because moments when they feel connected with their partners maintain a sense of being together Because continuity in the relationship is important even when dementia is progressing into the last phases	By decreasing the frequency of visits to protect themselves against exhaustion By being together in places where others are present By seeking support and advice from others By sharing mutual moments By interacting in other ways than using verbal communication	Spouses preserve moments of mutuality to preserve continuity in their relationship in the process of 'constructing togetherness'

as this routine decreased the negative impact on their consciences. An example of that situation, Maria, was still involved in the care of her partner even after divorce. She expressed that her visits were, for the most part, motivated by her feelings of obligation. Nevertheless, she explained that despite their divorce, she was still his nearest relative and, therefore, wanted to preserve their relationship even if they were no longer married.

The spouses expressed that they often experienced sorrow, grief and despair after their visits because they were confronted with their partners' decline and the hopelessness of their own situations. Despite these strains, visiting was still important to preserve continuity in their relationship with their partners, especially in the first phase. Ingrid explained:

> Ingrid: If a visit has been particularly difficult, when I come home, I think: 'No. Now I wait a few days before I visit.' But then again, I do want to see him, you see? So, you can't, you can't keep away. So, at the same time as you do it for your own conscience, you do it because you would like to see him.
>
> I: Do you miss him?
>
> Ingrid: Yes, I do.

Being private seemed important in the first phase after the partners' placement in institutional care. Different activities were initiated to preserve continuity in their relationships. The partners' private rooms were frequently used because the rooms offered space to sit and talk without interference. The rooms also provided opportunities for the spouses to recreate previous routines, habits and activities known from their mutual pasts. They initiated activities, such as looking at photographs, reading family histories, playing cards, relaxing, drinking coffee together, reading the paper and making small talk.

> We are sitting in the room, just the two of us. Then I find the album and his diary and read a little bit. Hannah

Even in the first phase, most of the spouses had experienced that their partners' dementia had already greatly interfered with their abilities to be intimate; as such, intimacy was not a crucial part of their activities during visits. However, a few of the spouses reported using the private room to share intimate moments during which they could give their partners hugs and kisses. For them, this moment was important to preserve continuity in their relationship. Herman clarified:

> I always started the visits in her room. I showed up a little earlier when she'd had her afternoon nap, so that I got a few minutes with her in privacy. I wanted to give her a little kiss, hug her and say intimate things to her. Say how much I loved her and stuff like that. I only did that when we were alone.

A few of the spouses reported that taking their partners for car rides offered the best conditions for privacy and opportunities to preserve continuity in their relationship. Carl explained:

> So we sit in the car; we take both shorter and longer trips. We always stop by a restaurant or café; she very much appreciates that.

The spouses were undisturbed in the car, and they could share intimate moments and create new, mutual memories in a safe environment. The car also enabled them to seek familiar places where they could recall memories from their mutual pasts and preserve some sense of continuity in their relationship.

Structuring visits that facilitate interaction and communication

To preserve continuity in their relationships in the second phase when dementia was progressing, the spouses expressed that structuring when to visit was increasingly important. In addition to the symptom progressions, the partners' capacities to participate in mutual interactions and engage in conversations were increasingly challenged and the partners' capacities fluctuated throughout the day. The spouses, therefore, scheduled visits for periods when their partners were more awake and capable of interacting. 'Usually, I arrive in the unit around half past ten to eleven. He is more lucid then,' Amelia said. Louisa elaborated:

> I have to be there in the morning. Because he is very tired in the afternoon and then he gets so angry. I found out it is better when I visit in the morning.

Saying goodbye was a challenging part of the visits; the spouses associated feelings of sadness and despair with these farewells. The opportunity to leave the facility without experiencing objections from their partners increased their feelings of continuing their relationships because they could leave without the strong feeling of letting their partner down. Otto explained:

> Otto: It is difficult every time. Therefore, I have to monitor and wait for mealtime. Then I have to persuade her to sit down at the table, before the personnel take over; they help her with dinner.
>
> I: So, you basically have to sneak away?
>
> Otto: Yes, when she sits down and starts to think about the food, then I can sneak out. If I say, 'I'll come back on Sunday,' then usually it turns out OK. (Sobbing).

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Structuring visits, therefore, involved also how to end the visits; the spouses scheduled their visits to fit the routines of the units. This situation enabled them to leave their partners at the moment when new events were initiated and the personnel in the units could divert their partners' attention.

Pursuing moments of mutuality to preserve continuity in a deteriorating relationship

Preserving continuity in the relationship was challenging for the spouses when their partners' dementia developed into the last phase when communicating and interacting with their partners became challenging. To protect themselves from exhaustion and sustain their abilities and strengths to preserve some sense of continuity in their relationship, most spouses decreased visiting frequency in this phase.

Louisa, for example, stated that she visited her partner more rarely compared with the first years after his placement:

> I visit him two times a week. I think that is sufficient. He doesn't know who I am, or if I come there or not. It is a familiar face, a familiar voice. There is nothing more.

Nevertheless, preserving some sense of continuity in the relationship was important for Louisa. She felt affection and love for her husband even though he was nearly unresponsive to her presence.

> So, I keep holding on to that relationship. I still call him things like 'my boyfriend' or 'my sweetheart' because he somehow … I have a very good relationship with him even though he doesn't have a relationship with me.

Some spouses maintained regular visits, still visiting several times per week during the last phase. They expressed a desire to maintain involvement; the visits were, therefore, equally important as before, although the severity of their partners' dementia complicated their abilities to have conversations and interact with them. Lisa specified that the reason why she maintained her visit frequency was because she wanted to monitor the care being provided to her husband.

As dementia worsened, the support from others helps them preserve continuity in their relationships and seems important for spouses during visits. Some spouses brought family members to keep them company during visits; bringing grown-up children were especially considered to be very supportive. Others wanted professionals to be present more frequently and tended to use the common areas more than private rooms during their visits. Having healthcare personnel nearby seemed to be sufficient as a precaution for spouses because they knew that help was not far away if it was needed. Several spouses also stated that they wanted healthcare personnel to advise them regarding how they might interact with their partners when verbal communication became challenging; however, the extent of desired interaction with healthcare personnel varied.

Preserving continuity in their relationship was increasingly challenging as verbal communication was made more difficult. Other types of interaction were, therefore, needed. To construct togetherness, activities generally entailed physical embraces and closeness, such as holding hands, stroking the partner's hair or sitting entwined. Emotional togetherness was constructed through sharing mutual moments, such as looking at beautiful flowers, listening to birds singing, feeling the sun's warmth or listening to music. Irrespective of how they connected, most spouses expressed that they only experienced moments of mutuality in this phase, as their partner's lucidity fluctuated. Lucas described:

> Then all of a sudden, she has these moments when she remembers both names and other things. However, it is only a little glimpse. A couple of minutes, and then she is gone.

Discussion

The aim of this study was to explore and describe how spouses involve themselves in the relationship with their partners with dementia who live in institutional care. The findings demonstrated how the spouses worked to preserve continuity in their relationship throughout the three phases describing the experiences of their partners' dementia progressions after placement in institutional care. To meet the various challenges associated with the different phases of dementia, the spouses continuously searched for new ways to connect with their partners. By adjusting their visiting routines, they facilitated situations in which they constructed togetherness. Simultaneously, a gradual withdrawal from desiring privacy to seeking company with others in the care environment underscored the increasing difficulties in interacting with their partners.

Among the wealth of studies on the experiences of caregivers for persons with dementia, this study provides important insight into the situations of older spouses with partners who live in institutional care. The study's findings contribute valuable knowledge to the research field, first by highlighting dementia's impact on spousal relationships in its later phases, when the disease causes major intrapersonal and interpersonal distress, and additionally by underscoring the importance of maintaining spousal relationships in old age. Furthermore, this study demonstrates the relevance of

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recognising dementia as manifesting itself in the context of social interactions, as previously highlighted (Baikie 2002).

Maintaining continuity with the past can be important for finding meaning in current experiences (Hellstrom & Lund 2005, 2007, Shim *et al.* 2012). Especially for older people, preserving continuity with the past is highly important (Troll & Skaff 1997). The activities that took place in the private rooms appeared to be targeted at preserving continuity. Privacy appeared to be important, especially during the first phase when certain interactional exchanges were still taking place. Molyneaux (2012) described how couples who still lived together at home coconstructed their relationships by maintaining mutual affection in accordance with their relationship histories. Not even in the first phase did the spouses in this study seem to coconstruct their relationships; dementia had already considerably influenced their likelihood of having balanced reciprocal interactions. Instead, the spouses used visiting routines to facilitate situations in which they could connect with their partners; they constructed togetherness to maintain continuity in their relationships.

This study corresponds with earlier studies of Baikie (2002) and Hennings *et al.* (2013), for example, regarding the spouses' strong commitment to their relationships. Even the divorced participant was still extensively involved, although she was not legally married to the patient. Corresponding to the findings by Ross *et al.* (2001), who found that 'love and devotion' was the predominant reason for spouses to visit, spousal involvement appeared to be the primary motive for the spouses in this study. The participants' relatively old ages could be a reason as they were part of a cohort that was perhaps more committed to relationships compared with younger caregivers (Levenson *et al.* 1993, Pierce *et al.* 2001). However, the spouses could be motivated to maintain involvement for other reasons. Pierce *et al.* (2001) stated that different types of commitment might be assessed when spouses are considering engaging in the caregiving role (p. 31). The authors divided commitment into enthusiastic vs. moral. Being enthusiastically committed involved the desire to stay involved, in contrast to moral commitment, which stems from an obligation towards the other person. Most spouses in this study gave the impression of being enthusiastically committed. However, it is likely that moral commitment also motivated the spouses. Expressing involvement in such terms as obligation and duty could be difficult, however, given that those terms could contradict the anticipated ideals and values related to family caregiving and could provoke social pressure to maintain relationships. Considering the participants' old ages, this factor could also have been a cohort effect (Pierce *et al.* 2001).

Regarding maintaining visit frequency, our results contradict earlier findings. Cohen *et al.* (2014) and Ross *et al.* (1997) indicated that family caregivers sustained their visit frequencies irrespective of their relatives' cognitive statuses. The majority of spouses in this study, however, appeared to address the challenges related to changing interactions by reducing visiting frequency, which seemed particularly apparent in the last phase when the spouses reported increasing challenges in communicating with their partners and only minimal reciprocity. de Vugt *et al.* (2003) investigated the relationship between behavioural and psychological symptoms (BPSD) in patients with dementia, such as irritability, agitation, delusions or apathy, and changes in the marital relationship. They found that apathy was a significant predictor for relationship change and proposed that apathy diminished the couple's abilities to participate in mutual activities and share common experiences. We do not have accurate data in this study regarding the existence of BPSD among the partners with dementia because the existence of BPSD was never mentioned as an isolated challenge by the spouses. Spouses might not be aware of whether their partners' challenges are caused by cognitive decline or behavioural disturbances, as they will likely only relate to the difficulties they experience in having reciprocal interactions. Whereas for healthcare personnel, this situation provides an important area for refinement of interventions. Being aware of the interactional difficulties behavioural disturbances can cause is important, especially if the patient suffers from apathy (de Vugt *et al.* 2003). Valuable interventions to support spouses could provide specific counselling aimed at increasing their abilities to have meaningful interactions with their partners and encourage involvement of other family members to support them. The facilitation of meaningful activities in which the couple can participate can provide valuable moments of reciprocal interactions and at the same time function as purposeful involvement of the patient.

The participants' relatively old ages (eight participants were over the age of 80 years) must also be accounted for when considering the reasons for reduced frequency of visiting. Despite the spouses' attempts to facilitate togetherness, preserving continuity in their relationship was challenging in the last phase. Some spouses, therefore, experienced the visits as exhausting, and reduced visiting to save their energy. Visiting a partner with severe dementia could be especially burdensome if the spouse is old and frail. Reducing visit frequency could therefore be an unavoidable consequence of the spouse's own failing health. Healthcare personnel should be aware that variations in functional status could play a role, especially because older spouses

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might want to continue involvement, but lack the opportunities to continue visiting. Support from professionals might, therefore, be required.

Decreasing visit frequency could also be interpreted as a type of problem-focussed coping strategy used by the spouses (Li *et al.* 2012). Avoiding situations as their partners' conditions severely declined could have been a way to control their feelings of strain. Multiple studies have indicated that spouses are burdened and vulnerable to depression and mental health problems after their partners are relocated to institutional care (Papastavrou *et al.* 2007, Ask *et al.* 2014). This study's findings might complement the outcomes from other studies; the spouses' ongoing involvement, despite the serious impact of dementia on their relationships, could clarify why the spouses are still distressed.

The spouses' excessive sense of distress in this study could also be related to their long-lasting relationships. Spouses with longer relationships could be more affected by their partners' progressive dementia because their long-established forms of interactions with their partners are now challenged (Hellstrom & Lund 2005, 2007). Shim *et al.* (2012) indicated that the quality of both the present and the previous relationships can influence the caregiving experience. Most spouses in this study expressed that their previous relationships had been good. However, it was obvious that the relationships were suffering from major changes and that the challenges related to communication and interaction between the individuals were similar, independently related to the participants' formal relationships. This situation might explain the consistency of this study's results; as long as they are involved, the spouses encounter the same interactional challenges.

Some spouses sustained their visit frequencies even during the later phases of their partners' dementia. Even if togetherness could not be coconstructed, these spouses were likely able to achieve some type of reciprocity with their partners. Previous studies have found that higher levels of compassionate love corresponded to lower levels of caregiver burden (Monin *et al.* 2014). In addition, positive reciprocity has been highlighted as crucial to increasing positive caregiving experiences (Braun *et al.* 2010, Mullin *et al.* 2013, Monin *et al.* 2014). If the spouses' sense of continuity in their relationships was persistent, their urge to decrease visit frequency was likely diminished.

Limitations

Several aspects must be considered when interpreting the results. First, it appeared difficult to find spouses/partners in the institutional settings we contacted. Of 863 residents, a total of 31 potential participants is slight. This number could reflect the actual demography of spouses/partners in institutional care. It could also likely result from recruiting participants through healthcare personnel. Even if department managers did not give the impression of filtering the selection of participants, we do not know if this situation mirrors reality because they were instructed to not exert pressure when recruiting participants due to ethical considerations. Even if the sample of 15 participants was considered to be sufficient in terms of saturating categories as explained by Charmaz (2014), there are different ways of accounting for sufficiency. It is reasonable to expect that other variations related to spouses' experiences could have appeared if the sample was differently judged for sufficiency and consequently expanded.

Second, the conventional sample consisting of 15 older spouses/partners with long-lasting relationships must also be considered. It might have been easier to recruit spouses/partners who were committed and involved rather than those who tended to resign. Furthermore, this study targeted older participants. Older caregivers could suffer from frailty or in other ways be hindered from involvement in care. The minor share of invited participants who actually participated in the study illustrates this point. Therefore, it is reasonable to think that those who volunteered to participate might be the more active and involved individuals. Finally, previous studies have demonstrated that happily married people are more likely to volunteer for research studies on relationship matters compared with unhappily married people (Levenson *et al.* 1993).

Third, the retrospective approach that the spouses were encouraged to take might have influenced the findings with regard to the spouses' descriptions of their involvement and visiting routines. Although previous research has revealed that the overall memories of their relationship trajectories are generally accurate (Karney & Frye 2002), others have suggested that some aspects of spouses' memories about their experiences can be lost, whereas others can be more polarised when asked to recall, especially after their relatives' death (McCarthy *et al.* 1997). The validity of the retrospective data provided in this study, especially those provided by the widowed spouses, can therefore be questioned. McCarthy *et al.* (1997) underscored that carers' experiences will have their own validity, irrespective of when they are reported. However, this perspective will, of course, call for awareness about the reality in which the results are constructed (Charmaz 2014). To arrange for transparency about what was characterising the unique situation of each participant, background characteristics were provided.

Fourth, the three categories that were presented separately in this article were not easily separated in reality. The categories must be accounted as abstractions of spouses' experiences through the phases of dementia, not exact accounts of them. Even if most participants expressed having partners in the last phases of dementia, only those who were widowed had experiences associated with all aspects from their partners' diagnosis to their death. Including widowed spouses in the study, therefore, strengthened our interpretations about the spouses' experiences of the full trajectory of dementia and enabled our presentation of the different phases reflected in the categories.

Conclusion

Being involved and experiencing continuity in the relationship were still important to the spouses after their partners were placed in institutional care. Spouses constructed togetherness by facilitating situations in which they could connect with their partners. To facilitate these situations, visit routines were altered and adapted to the progression of their partners' dementia.

Relevance to clinical practice

This study emphasised the significance of enabling spouses to maintain relationships in institutional care. It also underscored the importance of healthcare personnel's awareness of how spouses use visit routines to construct togetherness and mutual interactions and how these routines can change. In the future, the necessity for a more systematic approach towards supporting spouses' involvement will be important.

Of particular importance is the necessity of training healthcare personnel regarding the significance for spouses to maintain continuity in their relationship with their partners in institutional care. After placing the spouses' partners in institutional care, healthcare personnel should engage in an ongoing dialogue with the spouses to clarify their requirements for support. Such an active approach must consider that the spouses' need for support can change along with the progression of their partners' symptoms of dementia and that their requirements may vary among individuals depending on their own state of health, family relations and access to support from family or support groups. The healthcare personnel should also be aware that for those spouses who lack family support, additional support from professionals during visiting might be needed.

Support groups and educational programmes intended for informal caregivers should be offered to spouses who place their partners in institutional care to increase their understanding concerning the symptoms and progressions of dementia because these resources could support their process of constructing togetherness. In addition, support groups and educational programmes might offer them more insight into the routines and practices in the institutional settings, so that their own visiting routines could be better adjusted.

Implications for future research

Future research should involve larger samples to enable exploring how spouses can be supported systematically in institutional care. Longitudinal studies involving both halves of the dyads should be designed to explore how spousal relationships change throughout the different phases of dementia. This research could provide important knowledge regarding couples' experiences. Furthermore, studying how visit routines can be used as coping strategies for caregiving spouses in institutional care settings is necessary, and studies that explore specific groups of caregivers, including different genders, ages and relationships, will provide valuable insight into this growing knowledge base. Finally, future studies should also address the association between relational interactions and the requirements for facilitating institutional care environments.

Contributions

LHF, RK, KS and SY contributed in developing the study design, LHF performed the data collection, LHF, RK, KS and SY contributed in performing data analysis, LHF, RK, KS and SY contributed in the manuscript preparation.

Conflict of interest

The authors have no conflicts of interest to declare.

References

Adelman RD, Tmanova LL, Delgado D, Dion S & Lachs MS (2014) Caregiver burden: a clinical review. *Journal of the American Medical Association* **311**, 1052–1060.

Ask H, Langballe EM, Holmen J, Selbæk G, Saltvedt I & Tambs K (2014) Mental health and wellbeing in spouses of persons with dementia: the Nord-Trøndelag health study. *BioMed Central Public Health* **14**, 413–425.

Baikie E (2002) The impact of dementia on marital relationships. *Sexual and Relationship Therapy* **17**, 289–299.

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Braun M, Mura K, Peter-Wight M, Hornung R & Scholz U (2010) Toward a better understanding of psychological well-being in dementia caregivers: the link between marital communication and depression. *Family Process* **49**, 185–203.

Carbonneau H, Caron C & Desrosiers J (2010) Development of a conceptual framework of positive aspects of caregiving in dementia. *Dementia* **9**, 327–353.

Charmaz K (2014) *Constructing Grounded Theory*, 2nd edn. Sage, Thousand Oakes, CA.

Cohen LW, Zimmerman S, Reed D, Sloane PD, Beeber AS, Washington T, Cagle JG & Gwyther LP (2014) Dementia in relation to family caregiver involvement and burden in long-term care. *Journal of Applied Gerontology* **33**, 522–540.

Eika M, Espnes GA, Söderhamn O & Hvalvik S (2014) Experiences faced by next of kin during their older family members' transition into long-term care in a Norwegian nursing home. *Journal of Clinical Nursing* **23**, 2186–2195.

Evans D & Lee E (2014) Impact of dementia on marriage: a qualitative systematic review. *Dementia* **13**, 330–349.

Førsund LH, Skovdahl K, Kiik R & Ytrehus S (2015) The loss of a shared lifetime: a qualitative study exploring spouses' experiences of losing couplehood with their partner with dementia living in institutional care. *Journal of Clinical Nursing* **24**, 121–130.

Gaugler JE (2005) Family involvement in residential long-term care: a synthesis and critical review. *Aging & Mental Health* **9**, 105–118.

Gaugler JE, Pot AM & Zarit SH (2007) Long-term adaptation to institutionalization in dementia caregivers. *The Gerontologist* **47**, 730–740.

Gaugler JE, Roth DL, Haley WE & Mittelman MS (2008) Can counseling and support reduce burden and depressive symptoms in caregivers of people with Alzheimer's disease during the transition to institutionalization? Results from the New York University caregiver intervention study. *Journal of the American Geriatrics Society* **56**, 421–428.

Gaugler JE, Mittelman MS, Hepburn K & Newcomer R (2009) Predictors of change in caregiver burden and depressive symptoms following nursing home admission. *Psychology and Aging* **24**, 385–396.

Hellstrom I & Lund U (2005) "We do things together": a case study of "couplehood" in dementia. *Dementia* **4**, 7–22.

Hellstrom I & Lund U (2007) Sustaining "couplehood": spouses' strategies for living positively with dementia. *Dementia* **6**, 383–409.

Hennings J, Froggatt K & Payne S (2013) Spouse caregivers of people with advanced dementia in nursing homes: a longitudinal narrative study. *Palliative Medicine* **27**, 683–691.

Karney BR & Frye NE (2002) "But we've been getting better lately": comparing prospective and retrospective views of relationship development. *Journal of Personality and Social Psychology* **82**, 222–238.

Kirkevold Ø, Eek A & Engedal K (2012) Development of residential care services facilitated for persons with dementia in Norway. *Aging Clinical and Experimental Research* **24**, 1–5.

Kramer BJ (1993) Marital history and the prior relationship as predictors of positive and negative outcomes among wife caregivers. *Family Relations* **42**, 367–375.

Levenson RW, Carstensen LL & Gottman JM (1993) Long-term marriage: age, gender, and satisfaction. *Psychology and Aging* **8**, 301–313.

Li R, Cooper C, Bradley J, Shulman A & Livingston G (2012) Coping strategies and psychological morbidity in family carers of people with dementia: a systematic review and meta-analysis. *Journal of Affective Disorders* **139**, 1–11.

McCarthy M, Addington-Hall J & Altmann D (1997) The experience of dying with dementia: a retrospective study. *International Journal of Geriatric Psychiatry* **12**, 404–409.

Mitchell SL, Black BS, Ersek M, Hanson LC, Miller SC, Sachs GA, Teno JM & Morrison RS (2012) Advanced dementia: state of the art and priorities for the next decade. *Annals of Internal Medicine* **156**, 45–51.

Molyneaux V (2012) The co-construction of couplehood in Dementia. *Dementia* **11**, 483–502.

Monin JK, Schulz R & Feeney BC (2014) Compassionate love in individuals with Alzheimer's disease and their spousal caregivers: associations with caregivers' psychological health. *The Gerontologist* **55**, 981–989.

Mullin J, Simpson J & Froggatt K (2013) Experiences of spouses of people with dementia in long-term care. *Dementia* **12**, 177–191.

Murray J, Schneider J, Banerjee S & Mann A (1999) EUROCARE: a cross-national study of co-resident spouse carers for people with Alzheimer's disease: II—a qualitative analysis of the experience of caregiving. *International Journal of Geriatric Psychiatry* **14**, 662–667.

O'Shaughnessy M, Lee K & Lintern T (2010) Changes in the couple relationship in dementia care: spouse carers' experiences. *Dementia* **9**, 237–258.

Papastavrou E, Kalokerinou A, Papacostas SS, Tsangari H & Sourtzi P (2007) Caring for a relative with dementia: family caregiver burden. *Journal of Advanced Nursing* **58**, 446–457.

Pierce T, Lydon JE & Yang S (2001) Enthusiasm and moral commitment: what sustains family caregivers of those with dementia. *Basic and Applied Social Psychology* **23**, 29–41.

Quinn C, Clare L & Woods B (2009) The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: a systematic review. *Aging and Mental Health* **13**, 143–154.

Ross MM, Rosenthal CJ & Dawson P (1997) Spousal caregiving in the institutional setting: visiting. *Journal of Clinical Nursing* **6**, 473–483.

Ross MM, Carswell A & Dalziel WB (2001) Family caregiving in long-term care facilities. *Clinical Nursing Research* **10**, 347–363.

Schultz R & Martire LM (2004) Family caregiving of persons with dementia. Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry* **12**, 240–249.

Shim B, Barroso J & Davis LL (2012) A comparative analysis of stories of spousal caregivers of people with dementia: negative, ambivalent, and positive experiences. *International Journal of Nursing Studies* **49**, 220–229.

Tornatore JB & Grant LA (2002) Burden among family caregivers of persons with Alzheimer's disease in nursing homes. *The Gerontologist* **42**, 497–506.

Troll LE & Skaff MM (1997) Perceived continuity of self in very old age. *Psychology and Aging* **12**, 162–169.

de Vugt ME, Stevens F, Aalten P, Lousberg R, Jaspers N, Winkens I, Jolles J & Verhey FRJ (2003) Behavioural disturbances in dementia patients and quality of the marital relationship. *International Journal of Geriatric Psychiatry* **18**, 149–154.

Ytrehus S (2011) Housing procurement for the frail elderly: public or private responsibility? The view of the elderly in Norway. *Journal of Housing for the Elderly* **25**, 89–106.

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Finding a place to connect: A qualitative study exploring the influences of the physical and social environments on spouses' opportunities to maintain relationships when visiting a partner with dementia living in long-term care

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Abstract

The purpose of this qualitative study was to explore how physical and social environments influence spouses' opportunities to maintain relationships when visiting a partner with dementia living in long-term care. Interviews with 15 spouses whose partners lived in long-term care facilities for persons with dementia, observations of physical environments and participant observations were conducted. The results showed how finding a place for spouses to connect in the long-term care facility was important in maintaining relationships. Access to individual rooms was an important feature that enabled connections throughout the phases of dementia, whereas common areas appeared more difficult to use because small spaces limited private interactions. Health personnel were important in sustaining spouses' abilities to maintain their relationships in long-term care facilities for persons with dementia.

Keywords
qualitative research, spouses, dementia, relationship, long-term care

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Introduction

Experiencing dementia in close relationships can be challenging; in addition to experiencing the severe consequences of dementia, spouses must address relational changes because of increasing difficulties in preserving mutual support and connection in their relationships (Evans & Lee, 2014; Graham & Bassett, 2006; Hellstrom & Lund, 2005, 2007; Wadham, Simpson, Rust, & Murray, 2015). Because dementia is a progressive syndrome, relocation to a long-term care facility is nearly inevitable when dementia progresses into the later stages (Kenigsberg et al., 2016; Ray, Ingram, & Cohen-Mansfield, 2015). Research has indicated that despite the feelings of despair and hopelessness that often follow placing a partner in care, many spouses nevertheless wish to continue their relationships and maintain togetherness with their partners after relocation (Førsund, Kiik, Skovdahl, & Ytrehus, Manuscript in press; Førsund, Skovdahl, Kiik, & Ytrehus, 2015; Kaplan, 2001; Kaplan, Ade-Ridder, Hennon, Brubaker, & Brubaker, 1995). Sustained connection and involvement have not only been recognised as meaningful for the spouses, but continuous contact with close relatives has also been documented to be crucial for persons with dementia (Goodman, Amador, Elmore, Machen, & Mathie, 2013; Harmer & Orrell, 2008).

Visiting in long-term care has been emphasised as important as a manner of continuing the relationship between partners (Bramble, Moyle, & McAllister, 2009; Gaugler, 2005; Gladstone, Dupuis, & Wexler, 2006; Nolan & Dellasega, 1999; Sandberg, Lundh, & Nolan, 2001). Both the design and structure of the institutional environment affect visiting spouses' opportunities to interact with their partners when visiting. Nevertheless, although some examples exist in the literature (Chapman & Carder, 2003; Cruz, 2006; Fleming, Kelly, & Stillfried, 2015; Innes, Kelly, & Dincarslan, 2011), few researchers have studied how institutional settings are adapted to allow persons with dementia and their partners to maintain contact. In this study, we therefore explore how the physical and social environments in institutional care settings for persons with dementia influence elderly spouses' opportunities to maintain contact and continue their relationships with their partners when visiting.

Background and perspectives

As a classical field of research, environmental gerontology has highlighted the importance of housing design in long-term care for the elderly (e.g. Lawton, 1983, 1985; Wahl, 2001; Wahl & Oswald, 2010; Wahl & Weisman, 2003). Explicit attention has focused on the interactions between ageing persons and their physical and social environments (Wahl & Weisman, 2003). An important insight is that the environment cannot solely be defined by its physical characteristics; an environment must also be understood and placed in the context of on-going social interactions and cultural practices (Chaudhury & Rowles, 2005; Wahl & Oswald, 2010). To understand the environmental conditions influencing spouses' interactions with their partners in long-term care, we must therefore account for both the physical and social environments surrounding them.

Making spaces into places

One manner of looking at the influences of the physical and social environments on spouses' ability to maintain relationships is to explore the manner in which spouses can create their

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own place and integrate themselves into the environment. Rowles and Bernard (2013) described the process of transforming anonymous spaces into meaningful places; developing emotional attachment and maintaining familiar routines can transform even unfamiliar spaces into places with personal meaning and the potential to provide opportunities for meaningful interactions. Place making is a description of this process used by Aminzadeh, Molnar, Dalziel, and Garcia (2013) to describe the adjustment needs and efforts related to housing transitions for persons with dementia. When relocating into a care home, persons must reconstruct their sense of being *in place*; patients must convert something that is neutral into a place that has meaning in the context of their continuing lives. Consequently, the experience of being 'in place' is closely related to self-identity (Aminzadeh et al., 2013; Rowles & Bernard, 2013). Rubinstein and Parmelee (1992) called this process place attachment. Place attachment, they say, can be viewed as a set of feelings that emotionally binds the person to the place because of certain experiences. Furthermore, attachment to place is also related to the person's need to maintain a continued sense of being the self. The self can be understood within Sabat and Harré's (1992) conceptualisation of the *self* as a construction of the personal identity and personal agency that persists as a continuum behind the socially and publicly presented repertoire of *selves*. Related to Rubinstein and Parmelee (1992) notions, continuing the sense of being self must be understood within the context of the person's life course and place attachment can thus be experienced both through current experiences and as part of memories. Rowles and Bernard (2013) add to this understanding that the reconstruction of space into place must involve the use of the environment. Finally, Örulv (2010) emphasised the importance of social interactions within environments to sustain the place-making process.

Place-making processes for visiting spouses

For spouses, the relocation of a partner indicates not only a physical separation; relocation must be considered an experiential separation from a relationship filled with memories of a life course with their partners (Førsund et al., 2015). How spouses create their places within the spaces of the institutional environments will most certainly influence their adaption to this separation and affect their opportunities to maintain continuous contact with their partners. Many factors can influence spouses' abilities to make sense of the space as a place to connect. Constructing a sense of being *in place* can be particularly demanding for spouses visiting the care facilities because both the setting and the situation are unfamiliar. The dwelling can be perceived as a place offering visitors little sense of control over the circumstances (Rowles & Bernard, 2013) and a setting often lacking clear boundaries between public and private spaces (Cutchin, 2013). How these factors may be connected to the spouses' place-making processes and what spousal caregivers view as important in institutional environments to provide the best opportunities for them to remain involved are not well known.

With regard to housing design for persons with dementia, the literature is relatively coherent regarding the optimal environmental design for persons living in long-term care; see, for example, Calkins (2009); Davis, Byers, Nay, and Koch (2009); Day, Carreon, and Stump (2000); G. P. Marquardt, Bueter, and Motzek (2014); Schwartz (1999). However, a recent critique emphasised that guidelines of environmental design should address spatial disorientation and wayfinding difficulties more specifically (O'Malley, Innes, & Wiener, 2015). Spatial proximity to common spaces is a characteristic emphasised in the literature

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to facilitate community among patients (Ablitt, Jones, & Muers, 2009; G. Marquardt, 2011; G. Marquardt & Schmieg, 2009; G. P. Marquardt et al., 2014). The literature also emphasises access to individual rooms to provide opportunities for patients to have a private life (Davis et al., 2009; Day et al., 2000; Verbeek, van Rossum, Zwakhalen, Kempen, & Hamers, 2009). However, how spouses identify their place in these spaces is not clarified in the research. For example, we do not know how spouses experience the private spaces as a place to connect or how the private and common spaces are used during visits. Such questions are therefore the focus of this study. Specifically, the purpose of this study is to explore how physical and social environments influence spouses' opportunities to maintain relationships when visiting a partner with dementia living in long-term care.

Design and methods

This study is part of a PhD project exploring how spouses' maintain relationships with partners living with dementia in long-term care in Norway. A qualitative research design involving methods as interviews, participant observations with spouses and observations of physical environments in long-term care facilities compose the data for the study. Qualitative research may include various strategies for systematic collection, organisation and interpretation of data (Silverman, 2006). Among the different approaches defining qualitative research, grounded theory is widely used (Savin-Baden & Howell Major, 2013). The main PhD project, in which this study is a part of, is designed using constructivist grounded theory (Charmaz, 2014). Emphasising theoretical sampling, constant comparison and memo writing as a methodological approach throughout the research process was therefore considered relevant. However, it is important to have in mind that grounded theory can be defined and used in many different ways; both as a methodology, as a method of analysis or as a qualitative research approach (Savin-Baden & Howell Major, 2013). The way in which we chose to use grounded theory in this paper is in line with the descriptions of grounded theory as a qualitative research approach.

Settings, participants and recruitment

Major development of new long-term care facilities as well as the renewal of older buildings containing nursing homes has occurred in Norway over the last two decades, resulting in a great variation in how long-term care facilities intended for persons with dementia are organised and designed (Ytrehus, 2002). Persons with dementia needing institutional care are allocated to ordinary nursing home wards, specialised care units for persons with dementia (SCU) or sheltered housing for persons with dementia (Kirkevold, Eek, & Engedal, 2012). Despite the variations in housing arrangements, the care services provided within the facilities are relatively similar (Ytrehus, 2002). Generally, Norwegian long-term care facilities are designed in small units with homelike features offering individual rooms for residents and are organised to provide personal care integrated into daily routines and everyday life (Kirkevold et al., 2012). Although local variations do exist, differences between the facilities are primarily concerned with payment policies and the legal framework (Ytrehus, 2011).

Participants were recruited from SCUs in four nursing homes (A–D) and four sheltered housing units (E–H) in five (I–IV) different municipalities in Norway (see Table 1).

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Table 1. Characteristics of the long-term care facilities.

Institution ID	B	B	B	B	A	B	C	D	D	C	E	F	G	G	H
Type of institution	NH	NH	NH	NH	NH	NH	NH	NH	NH	NH	SH	SH	SH	SH	SH
Number of residents in unit	10	10	10	7	8	7	8	7	7	8	8	8	8	8	6
Municipality ID	I	I	I	I	II	I	I	I	I	I	III	III	IIII	IIII	IV

NH: Nursing home; SH: Sheltered home.

To facilitate comparison of data derived from different varieties of housing solutions, only units adhering to the inclusion criteria of providing segregated care for persons with dementia, being designed as small and homelike units with 10 or fewer residents each, and having 24-hour care services with permanent staff were included.

Fifteen spouses participated in the study, seven men and eight women aged from 64 to 90 years with an average age of 79 years (see Table 2). Most participants were married to their partners with dementia; participants were therefore termed 'spouses'. However, two widowed spouses, one divorced spouse and one common law spouse also participated because their experiences were considered relevant to the study. Participants reported their partners' stage of dementia to be moderate/severe to severe, having lived in institutional care for eight months to seven years prior to the interviews: 5 in sheltered housing units and 10 in SCUs. The sample size of 15 participants was partially determined by challenges with regard to recruitment and by practical considerations such as management of data and time consumption. Simultaneously, at the end of sampling, the categories were considered to be sufficiently saturated according to Charmaz (2014): 'the point when gathering fresh data do not give new theoretical insights nor reveal new properties of the theoretical categories' (p. 213).

Ethical considerations

The study was approved by the Norwegian Social Science Data Services (NSD).

Before volunteering, participants were given verbal and written information regarding the study and their right to withdraw. Written consent was obtained before the first contact with the interviewer. Information regarding participation being voluntary was repeated at the first meeting. Because the sample in this study appeared vulnerable, interviewers emphasised not to place any pressure on potential participants during recruitment. Therefore, only some spouses participated in follow-up interviews and/or observations.

Of the 15 spouses first recruited to this study, only 5 could be recruited for participation in participant observations based on the existing ethical approval. Among these five participants, one was widowed and one refused participation. Three spouses therefore constituted the sample for participant observations. Although spouses' experiences were the focus of this study, participant observations of spouses visiting their partners were not considered useful unless the partners were included. Particular care was taken in approaching these partners to obtain consent. Current approaches to obtaining consent have been criticised for over-emphasising participants' cognitive abilities (McKeown, Clarke, Ingleton, & Repper, 2010). Therefore, identifying practical solutions to enable their voices to be heard has been emphasised (Hellstrom, Nolan, Nordenfelt, & Lundh,

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Table 2. Characteristics of participants.

Pseudo-nyms	Agnes	Elise	Ted	Jim	Emily	David	Scott	Helen	Mariel	Michael	Olivia	Leo	Charlie	Andrea	Carolina
Age	80–89	80–89	90–99	80–89	60–69	70–79	70–79	80–89	80–89	80–89	70–79	70–79	80–89	70–79	60–69
Gender	Female	Female	Male	Male	Female	Male	Male	Female	Female	Male	Female	Male	Male	Female	Female
Civil status	Married	Married	Married	Widowed	Married	Married	Married	Married	Married	Married	Married	Common-law spouse	Married	Widowed	Divorced
Type of dementia as reported by participants	Alzheimer	Alzheimer	Vascular/ Alzheimer	Lewy Body	Alzheimer	Unknown	Vascular	Unknown	Vascular	Alzheimer	Unknown	Unknown	Lewy Body	Vascular	Alcohol-related dementia
Stage of condition as reported by participants	Severe	Moderate/ severe	Severe	Deceased	Severe	Severe	Moderate/ severe	Severe	Severe	Moderate/ severe	Severe	Severe	Severe	Deceased	Severe
Number of years together as a couple:	>55	>55	>65	>60	>40	>50	>60	>60	>50	>60	>45	>20	>50	>55	>20
Number of years having partner in institutional care:	1.5–2	2–2.5	2.5–3	2–2.5	3–3.5	4–4.5	4–4.5	1–1.5	0.5–1	3.5–4	6.5–7	1.5–2	3–3.5	2.5–3	6–6.5
Visit frequency	2 times a week	4 times a week	3–4 times a week	6–7 times a week	6–7 times a week	1 time per week	1–2 times a week	6–7 times a week	2 times a week	3 times a week	2 times a week	4 times a week	2 times a week	2 times a week	1 time per week

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2007; McKeown et al., 2010). In this study, consent was considered unconditionally situational, as for example, Dewing (2002) recommended. In practice, this practice indicated that each observational session was considered unique in terms of obtaining consent and determining which approach would allow the partners to participate in meaningful interactions during observations. Charlie's wife gave consent after being given customised verbal and written information, and this procedure was repeated for each session. The other partners were included after substitutional consents given by their spouses. The expressed well-being of the partners was the focus and continuously assessed with the spouses during observations. However, the observations did not appear to negatively affect the partners; therefore, none of the observations was terminated because of partners' discomfort.

Data collection

Using grounded theory means emphasising a 'back and forth' approach to the field in order to focus the data collection, strengthen the theoretical understanding and explore 'gaps' in a developing theory. This approach is most commonly described as theoretical sampling and is considered as one of the main strengths when using this methodology (Charmaz, 2014). Even if developing theory was not the aim of this study, applying grounded theory as a methodological approach implied focusing on an iterative process of data collection and analysis. This meant applying theoretical sampling as a sampling strategy, supporting the development and refinement of categories by on-going processes including data gathering, analysis and memo writing. Table 3 provides a sampling overview.

Interviews were conducted in a conversational manner and lasted from 50 minutes to 2.5 hours. Interviews were audiotaped, transcribed verbatim and conducted at a place of the participant's choice; three interviews were conducted in a room in the long-term care facility and the rest in spouses' respective homes. To contextualise the interviews, field notes were taken afterwards describing the setting, place, participants and other observations of interest. The participants were encouraged to tell their stories openly; interviews therefore began with an open-ended question: 'Can you tell me how it all started?' As suggestive categories began to emerge, theoretical sampling, focused on elaborating on the categories and specifying the relations between them, subsequently indicated areas to examine in more depth.

To clarify statements and discuss evolving categories with participants, six of the spouses participated in one follow-up interview within six weeks of the first interview. To avoid strain on those spouses who expressed feeling the most burdened, only a few participants were requested to participate. These conversations occurred either over the phone or in face-to-face meetings according to the participants' preferences. In addition, Ted and Jim shared unprompted, written reflections regarding their experiences as spousal caregivers; these reflections were also included in the material.

The purpose of observing the physical environments was to develop insight into the contexts surrounding spouses' experiences as shared in interviews. Observation is regarded as a useful method with which to understand context (Charmaz, 2014) and was therefore considered appropriate. The plan was to visit all facilities; however, difficulties arose in obtaining access to two of the facilities; only six of the eight facilities were therefore observed. Focus areas during observations were prepared as a starting point for the sorting and refinement of observations (see Table 4).

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Table 3. Sampling overview.

Pseudonyms	Institution ID	Timeline	Follow-up interview		Observations
Agnes	B	February–March 2013	Yes	2 weeks after first interview	Observations of the physical environment
Elise	B	February–March 2013	Yes	2 weeks after first interview	Observations of the physical environment
Ted	B	February–March 2013	No	Written reflections were provided retrospectively	Observations of the physical environment
Jim	B	February–March 2013	Yes	2 weeks after first interview, written reflections were also provided retrospectively	Observations of the physical environment
Emily	A	February–March 2013	No		Observations of the physical environment
David	B	May–June 2013	No		Observations of the physical environment
Scott	C	May–June 2013	No		Observations of the physical environment
Helen	D	May–June 2013	No		No
Mariel	D	May–June 2013	No		No
Michael	C	July–August 2013	No		Observations of the physical environment
Olivia	E	February–March 2014	Yes	2 weeks after first interview	One participant observation
Leo	F	February–March 2014	Yes	6 weeks after first interview	Four participant observation sessions over a period of nine months
Charlie	G	February–March 2014	Yes	6 weeks after first interview	One participant observation
Andrea	G	April–May 2014	No		Observations of the physical environment
Carolina	H	April–May 2014	No		No

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Table 4. Focus for observations.

Spouses	Physical environments
Duties and tasks	Spatial layout and organization
Usage of environments	Physical structures and features of a) common areas b) individual rooms
Roles, relations and interactions	Opportunities to give a personal touch to the surroundings Options for privacy

Participant observations were ultimately added to the sampling methods to develop further insight into how spouses used the physical environment and interacted with their partners within that environment. Charmaz (2014) emphasised how observations of basic social processes can help the researcher obtain a more complete understanding of the entire setting. Thus, we wanted in-depth knowledge of a limited number of cases rather than general insight into many cases. The plan was to recruit some of the spouses from the interviews to participate in repeated observations over a period of one year. Three spouses agreed to participate. However, before the second observation, two of the spouses' partners died. Thus, only one couple were visited repeatedly (four times in the course of nine months until the partner died).

Observations were conducted as settled visits in the long-term care units. Assuming the role of a visitor was deemed the most natural manner of fitting into the setting. Thus, neither audiotapes of conversations nor field notes occurred during visits. However, thorough field notes were written in the aftermath with self-made outlines of the spatial organisation of the units (see examples in Figures 1, 2 and 3). One of the spouses whose partner lived there showed the first author around the facilities to observe the physical environment. Although these visits were short and only provided snapshots of on-going daily life, these visits enhanced our understanding of spouses' roles in the facility and their views of the environment. Participant observations began with spouses introducing the researcher to their partners, explaining the purpose of the visit. Then, we all sat together. The plan was to actively participate in the couples' conversations; however, because of the areas in which the different observations were conducted, the conversations unfolded differently. Participant observations with Leo and Olivia and their partners occurred in the common areas. These sessions were somewhat influenced by all that occurred around us, such as interactions with patients, personnel and others. The observer's role therefore became more passive than we had initially planned and was characterised more by passive observation of the couples' interactions and conversations than by actively participating although the roles varied somewhat. Nevertheless, these observations provided insight into the terms and conditions of spouses' interactions with their partners in these areas. The observations with Charlie and his wife occurred in her private room. Here, the observer's role was characterised by being their visitor in their private space and actively conversing with them regarding different matters the couple was interested in. The repeated observations with Charlie and his wife led to our having more confidence in one another because we were getting to know one another better in each session. These observations therefore increased our understanding of the significance of the individual room for spouses' interactions and how spousal relationships could unfold within these rooms.

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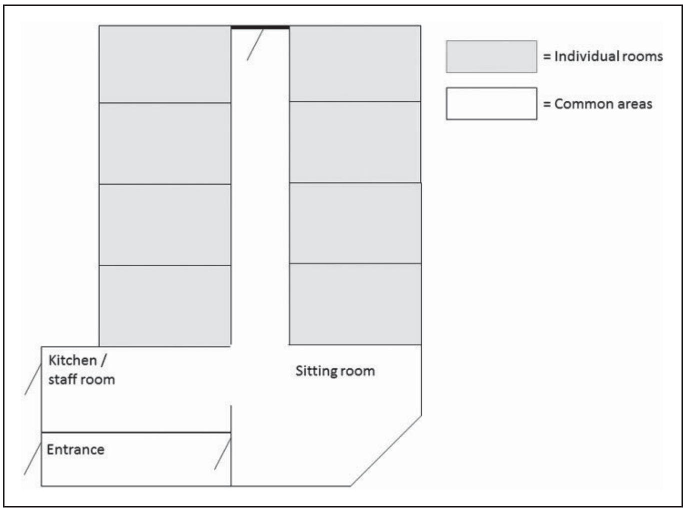

Figure 1. Outline of faculty E.

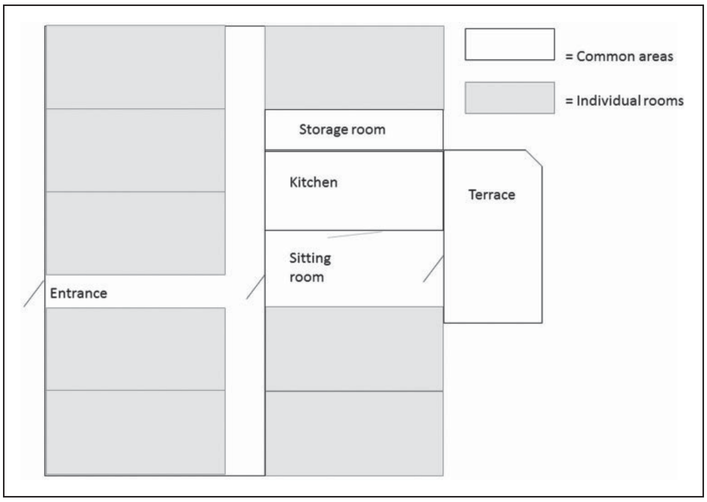

Figure 2. Outline of faculty G.

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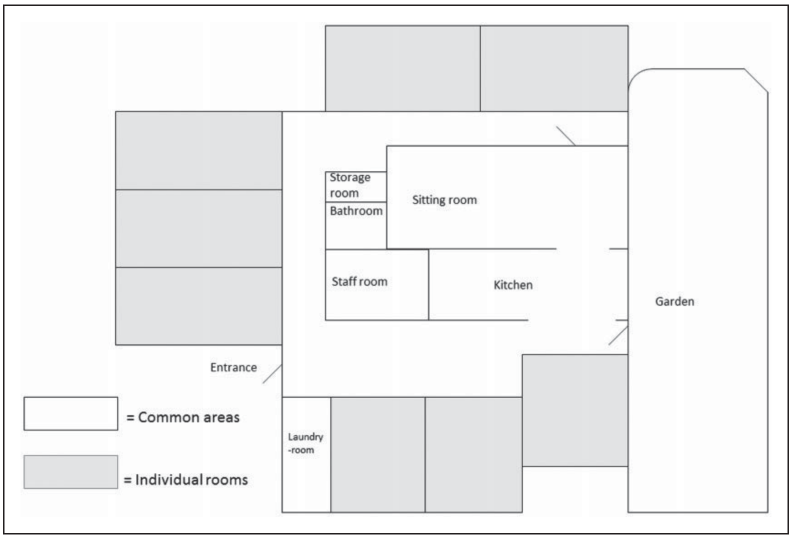

Figure 3. Outline of faculty F.

Data analysis

Emphasis on comparative methods as described by Charmaz (2014) and the development of increasingly focused memos guided the analysis.

Interviews were first analysed, and the results (see references for detailed descriptions of the analysis) provided a comprehensive understanding of how spouses experienced losing couplehood with their partners after relocation (Førsund et al., 2015) and how they maintained their relationships in the institutional setting (Førsund et al., Manuscript in press). Analysing interviews raised awareness of how terms and conditions relating to the physical and social environments appeared to influence spouses' opportunities to maintain their relationships. This analysis led to systematic observations of what was unfolding in the institutional settings.

It became clearer by observations that two particular arenas were significant for spousal interactions: the common areas inside the facilities and the individual rooms. Therefore, going back to the interviews to examine the spouses' expressions regarding using these arenas became important. 'Common areas' and 'individual rooms' were used as codes when we re-analysed all of the data, searching for verification of when, why and under what circumstances the different arenas were used. An understanding of the various implications of the spaces as places to connect and how spaces were used differently in this context began to emerge. To elaborate on this emerging concept, data from interviews and observations were now compared both internally and between data, and literature concerning environmental gerontology was assessed simultaneously to increase our theoretical sensitivity. The meaning of making spaces into places to 'find a place to connect' emerged as a core category in this process.

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Results

The findings presented in this section represent a synthesis of our analysis from both interviews and observations. Two sections describe the role of physical and social environments in the individual rooms compared with the common areas in spouses' place-making processes describing the core category 'finding a place to connect'.

The individual room

The spouses indicated that access to an individual room was important to allow for private interactions and connections. It appeared that the individual room was considered particularly important as a place to connect in the first period after relocation. One motivation for using the individual room was that the room provided space to sit and talk uninterrupted. The spouses appreciated the moments of privacy that the room offered. Andrea said,

> We went to his room so that we could talk. It was quieter there, because in the common areas, the others wanted to talk, you know! But, he rather wanted to talk with me, so in the room, we got to talk more then.

The frequent use of the individual room during visits may explain why spouses specifically noted the dimension and size of the room to be important when considering environmental features. Spacious rooms were most appreciated because the space provided opportunities for ample seating capacity for visitors. All spouses had the opportunity to furnish and decorate their partners' rooms according to their own and their partners' requirements. However, small rooms did not allow the same freedom of choice or ample seating capacity that larger rooms did. Several spouses emphasised this finding.

The use of the individual room was not only important because it allowed spouses to continue a private life with their partners. The room also appeared important because it represented something familiar, and spouses appeared motivated by a sense of belonging to the room itself. Spouses reported the importance of decorating the room in a homelike style. Spouses often placed family pictures on the walls and brought well-known objects that meant something special to both partners such as a bookshelf to hold the most appreciated books, a doll with sentimental value, plants or a basket for knitting. Decorating was not only important to increase their partners' feelings of being at home in the room but was also essential to support their feelings of belonging; familiar objects rendered the spaces more familiar. The pictures and objects also provided things to talk about and prompted recollections of common memories of family and friends. In addition, spouses expressed that familiar spaces supported their opportunities to maintain familiar roles, routines and habits and continue interacting in a manner familiar from their mutual pasts with their partners. One example is the case of Charlie; observations indicated that his partner had a large room containing a seating area and homelike design (see Figure 3: Outline of facility 'F'). Charlie explained that the room was quite important and described his everyday interactions with his wife in the room:

> We just sit and talk. Eh... talk, there is not so much talking anymore.... I oftentimes solve a crossword puzzle or something. If it's a Sunday, she will take a nap on the bed after dinner. Then, those who work here serve us a cup of coffee and maybe some cakes. That is what we do.

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Even if most spouses consider the importance of familiarising the individual rooms to render the space more homelike, some spouses also problematised the fact that the room was nevertheless a public place. Ted clarified, ‘I have tried to make it more homelike. Nevertheless, it is a sickroom. It is and will always be a sickroom’. He chose to take his wife for a car ride when visiting instead of using areas in the facility. It was clear that Ted, and others, associated the room with the illness shaping their situation. Spouses’ impressions of the rooms were confirmed during observations; some rooms were, despite homelike decorations, nevertheless characterised by the institutional setting, designed with sterile surfaces, neutral colours, intense lightning and sparse spaces. Several factors appeared to affect this impression by the spouses; first, a hospital bed was part of the equipment in each room; spouses associated the bed with sickness and hospitals although they understood why the bed was necessary. Second, although health personnel encouraged spouses to decorate the rooms with private objects and pictures, the degree to which rooms could be independently decorated remained quite limited. For example, Agnes reported how the restrictions on hanging pictures on the wall were frustrating:

> I just have to avoid looking at the pictures; we had to use a small rail from which the pictures were supposed to hang. Then they are not hanging at the same height of each other… It really irritates me.

Third, although the individual room was supposed to be private, some spouses experienced the room as only semi-private because it lacked a door lock on the inside. Spouses reported that even if they were seeking privacy in the room, the door remained unlocked. Consequently, other residents or health personnel were free to interrupt their interactions at any time. Finally, some spouses reported that it was particularly disruptive when the progression of dementia caused health personnel to replace furniture with remedies and equipment. Such changes not only made the room feel more featureless but also rendered it difficult to find places to sit in the room. Olivia clarified this:

> His room was actually nice before. However, when he started to use the wheelchair, they told us they had to remove his armchair to make room for the remedies. Therefore, now I think it is empty and dreary there. Practically it’s just the sickbed and a night table there.

Many of the spouses expressed how difficult it was to continue using the room for private interactions when the room became more unfamiliar and couples no longer had places to sit in the room.

The common areas

How spouses used the common areas differed. Similar to the individual rooms, the size and design of the common areas appeared to be essential features. Spouses particularly emphasised the importance of spaces to sit for private interactions. However, according to the spouses, the availability of seating in the common areas varied. Observations confirmed this diversity; although all of the observed units had living rooms, the size and seating capacity varied (see Figure 1, 2 and 3 for examples of outlines). These differences may have affected their use; some spouses having partners in facilities with the most cramped common areas expressed frustration over a lack of seating areas. Leo explained; ‘The only place to sit during visits is together with the patients. Then, there is no privacy’.

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It appeared that not only the size of the common areas was important for the spouses, the decorations and the atmosphere in the common areas engaged the spouses and appeared to affect the choice of where to sit during visits. Most spouses stressed the importance of a homelike style. One example was Mariel, whose partner was living in what she described as a newly renovated care home with design features characterised by bright and spacious rooms (this facility was not observed). She explained how she, despite the modern design, nevertheless found the premises featureless:

> It's very nice and spacious, it is not that.... It has this kind of an institutional character; it‘s not homelike. They [the residents] are like sitting in the corridors. It has no warmth.... There is lots of furniture, but the spaces lack that sense of being intimate and cosy.

One of the other facilities included in the study was considerably older, and observations revealed that both the private rooms and common areas were small. Elise's partner lived there, and she emphasised that although there were few private areas, there was a great deal of atmosphere in the common areas. She described paintings and pictures on the walls and homelike decorations. This atmosphere and the good relations with the health personnel working there made her feel welcome and comfortable and rendered the common areas the preferred places to be during visits, despite the lack of privacy.

Using the common areas encouraged spouses to interact with residents and the health personnel. Spouses related to the residents in various manners; however, contact was generally unavoidable because of the relatively small spaces that characterised the facilities. A few of the spouses who had frequented the facilities the longest felt a sense of community with the residents, and observations indicated how the spouses actively related to the residents. However, most spouses explained that interacting with the residents was challenging because of their restricted abilities to participate in social interactions. Consequently, spouses did not feel they had anything in common. Charlie reported often avoiding the common areas, noting the seriousness of the residents' conditions and the difficulty of taking an active role in relating to the residents. Jim reported using the common areas but nevertheless felt no sense of community with the patients:

> It was not much interaction with the other residents. The majority of them were withdrawn. It's because of their illness, I think. One of them was very chatty, but that was an exception. We sat in the same room, were drinking the same coffee and eating the same cookies, but nothing more.

The health personnel were also a significant component of the social environment in the common areas. Having proximity to the health personnel appeared particularly important to spouses whose partners had severe dementia. In the later phases of dementia, spouses expressed feeling safer being able to call for help if necessary. In addition, partners' ability to communicate verbally was generally restricted in the later stages of dementia. Using the common areas during visiting therefore seemed to be comforting when conversation was difficult. Mariel explained, 'I do not like to use the [private] room because I think it is easier when there are others around. So, we sit there in the living room and... talk. However, there is no conversation; he is too sick'.

Making contact with health personnel was not only considered important to the spouses in the later phases of their partners' dementia but also in the first period after relocation. When everything was new, being involved and taken care of by health personnel were important. Spouses reported that during the first period after relocation, health personnel were getting to know the spouses and the spouses were adjusting to their roles as visiting

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caregivers. Spouses experienced frustration because health personnel were not always updated on their desires and requests; consequently, misunderstandings occasionally occurred. This situation was expressed in Olivia's story of her first meeting with the facility's personnel after she relocated her husband. Olivia wanted to take an active role and be involved in his care; however, the healthcare personnel restricted her actions:

> I was not allowed to visit him. Because once he ran from there, and that was right after I had visited. Therefore, they figured they wanted to keep me away. One month passed by. I was there, but they refused to let me inside. I was just crying. It was so hard.

Despite such situations, spouses generally described the health personnel in a positive manner. They were referred to as '*caring*', '*nice*' and '*gentle*'. The spouses reported often being provided with coffee when they visited, a simple but important gesture making them feel welcomed and sustaining their feelings of belonging.

Discussion

The purpose of this qualitative study was to explore how physical and social environments influence spouses' opportunities to maintain relationships when visiting a partner with dementia living in long-term care. The findings indicate that for many spouses, opportunities for private interactions were key to facilitating the maintenance of relationships. The individual room was particularly appreciated as a place to connect because a private room provided space for private interactions. In addition, spouses valued the opportunity to create a homey atmosphere there. The room therefore appeared to have a central meaning, providing opportunities for spouses to maintain relationships with their partners. Both the dimensions and size of the room influenced how the space was used; use also appeared to change as the dementia progressed. Use of the common areas was influenced by the relatively restricted spaces characterising the sitting rooms. The limited seating capacity resulted in visiting spouses interacting with the other residents, which inhibited private interactions with their partners. The common areas therefore appeared to be less important in maintaining relationships. However, being in the common areas provided safety because of the proximity of health personnel. This appeared important, particularly in the later phases of dementia.

Finding a place to connect

Relocating a partner to institutional care causes a major upheaval in spouses' lives. Spouses are not only separated from their partners on a daily basis but must also adjust their roles as visiting spouses and adapt to new surroundings, both of which influence their options to act and interact with their partners. Finding a place to connect is a manner of explaining this adaption process, implying both adaption and emotional attachment to the physical and social environments characterising the long-term care facility (Wahl & Oswald, 2010). Feelings of attachment are particularly important when spouses are seeking a place to connect. Adapting to a new place can provide a sense of belonging in unfamiliar surroundings and enable meaningful interactions to occur within that space (Rowles & Bernard, 2013). Reconstruction of familiar routines, recollection of memories and utilising familiar objects are examples of approximations that can sustain the adaption process (Oswald & Rowles, 2006; Rowles & Bernard, 2013; Sherman & Dacher, 2005). Thus,

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finding a place to connect is a process that can occur regardless of physical structures and surroundings. However, as this study shows, some environmental features in long-term care facilities can influence how spouses are able to find their places and increase their opportunities to maintain their relationships with their partners.

The individual room is clearly a significant place in which to connect. Although all facilities included in this study provided individual rooms, sizes and dimensions varied. Facilitating private interactions appears important, particularly when spouses can recreate familiar roles and routines after their partners' relocation. In addition, private rooms are important because a private room can house well-known objects, photographs or other valued things. These are important aspects of the place-making process as described by Sherman and Dacher (2005). Rowles and Bernard (2013), Rubinstein and Parmelee (1992) and Wahl and Oswald (2010) also discussed manners in which to create a sense of home and belonging to the space to sustain feelings of attachment. This study emphasises these important prerequisites to helping spouses find their place to enable a continuation of their identity as a spouse and aid in the creation of meaningful interactions in unfamiliar spaces.

In this study, we have provided several examples of how individual rooms are furnished and decorated to promote good seating accommodations and a pleasant atmosphere for private interactions. Spacious rooms are important. Particularly in the later phases of dementia when partners required remedies and equipment, some spouses experienced that there was no room for them. This lack of space hindered them from creating a homey atmosphere in the room and restricted their use of the area because of lack of seating. Spouses' considering individual rooms to be important during this phase may be slightly surprising because severe symptoms and impaired ability to participate in social interactions often characterise this stage of dementia (Mitchell et al., 2012). However, for some spouses, maintaining a relationship is not always about the ability to converse. Continuing contact and connection may simply be a matter of having opportunities to spend time together. Such a practical and simple thing as a place to sit would then be essential to assist spouses in finding a place in which to connect. This finding is consistent with Chapman and Carder (2003), who interviewed visiting caregivers regarding the significance of having good seating accommodations in the patients' rooms. These caregivers said that when the bed was the only available seating in the room, spouses preferred using other areas of the facility during visits although those other areas may have been unsatisfactory.

The common areas in most facilities were small, with few places offering privacy. Being in these areas therefore meant close contact with others, both residents and health personnel. Findings indicate how some of the spouses therefore avoided using the common areas and preferred the individual room. In addition to most spouses' desire for privacy, their choosing of which spaces to use was influenced by the role the spouses adopted when visiting the facility. This role was influenced by the role of being a spouse and characterised by their emotional connection with their partners. In particular, some of the husbands reported avoiding the common areas because they did not desire interacting with other patients. We cannot disregard the possible implications of gender here; being an active participant in the environment may be more closely related to the female role than the male role. Oswald and Wahl (2005) observed differences with regard to how older women and men bonded to a place and suggested that women more often bonded by everyday behaviour, whereas men tended to emphasise privacy and retreat. Conversely, the female role may include a stronger feeling of obligation to relate to and help other residents. The wives interviewed here were

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part of a cohort that Oswald and Wahl (2005) suggested as perhaps more committed to historically based gender roles related to commitment to care. Simultaneously, men may feel more comfortable with a more private role in the private areas; the role of a spouse is a well-known identity, and continuing the partner role after relocation can promote confidence and support the place-making process (Wahl & Oswald, 2010). Several other factors may also affect the partner's role in the environment. Some spouses emphasised that communicating with residents was challenging because of the severity of their dementia. Being present in common areas in long-term facilities for persons with dementia generally requires relating to different persons with different degrees of functional and cognitive impairment (Kuhn, Kasayka, & Lechner, 2002). Relating to the different stages of dementia can be a painful reminder of what is ahead for their own partners and thus constitutes an additional burden. Moreover, perhaps what is most important for these spouses is the opportunity to use their time and resources on interactions with their partners when visiting. Interacting with other residents in the facility may not therefore be a priority.

Conversely, some spouses chose the common areas when visiting. Being present in the common spaces generally indicated a closer proximity to health personnel. When dementia has progressed into the last stages, spouses may feel insecure regarding how to relate to the partner, which may affect interactions. The presence of health personnel may therefore provide spouses with the assurance necessary to create a connection.

Even if many spouses valued proximity to health personnel, relationships did not appear static, but developed over time, as Olivia's story particularly illustrated. The example from her experiences indicated that her needs as a caregiver were not entirely affirmed in the first period after her partner's relocation. However, as time passed, Olivia's relationship with the health personnel improved. Adjustment to health personnel is most likely a continuous process, similar to adjustment to the physical environment. Chaudhury and Rowles (2005) argued that the physical environment is given meaning by personal engagement and that the transformation of spaces into personally meaningful places occurs by 'socialisation of the spaces over time' (s. 13). Thus, some spouses' relations with personnel and residents and the necessity of using the common areas as their place to connect may result from their long period as visiting caregivers. Rowles and Bernard (2013) underscored the importance of a connection with the social relations *at* the place as an important requirement in the place-making process.

Discussion of method

Using several sources of data is a strength of this study. Including observations in addition to interviews provided invaluable insight into how the terms and conditions of the physical and social environments influence spouses' opportunities to maintain relationships in institutional settings. Participant observations with couples in which one of the partners suffered from dementia proved fruitful. Our findings demonstrated the importance of including persons with dementia in research. This study may therefore be an example of how similar studies can be designed in the future and may highlight the need not only to report the voices of the caregivers, as we have done in this study, but also examine the experiences of persons with dementia concerning space and place in long-term care.

The primary advantage of applying grounded theory in this study was using theoretical sampling as a strategy for data collection and analysis. Keeping explicit focus on advancing analysis through a more focused sampling method, and using different types of data helped

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us to accumulate a higher level of conceptual understanding of conditions influencing spousal interactions in institutional settings. One disadvantage of theoretical sampling, as experienced here, is the lack of overview in the beginning of the project regarding which sources of data would require thorough development. Consequently, there were situations in which obtaining access to the field to gather the needed data was difficult. This experience indicates the need to plan for a comprehensive approach to the research field from the beginning when applying this sampling strategy, to ensure that access to return for more data is available.

Conclusions

Finding a place to connect in a long-term care facility is important for spouses' ability to continue their relationships with their partners after relocation. This study has shown that the individual room is an important feature in maintaining spousal contact throughout all phases of dementia, including the final phase. A room provides opportunities to continue valuable roles, routines and interactions from the past. Making anonymous rooms into meaningful places by decoration with furniture, photographs and familiar objects is important. Additionally, if spouses are to be provided the opportunity to continue their relationships, the physical environment must be accommodating. Providing places to sit in the individual room in long-term care facilities may appear insignificant; however, providing places for spouses to sit privately with their partners can enable the continuation of everyday interactions and support spouses seeking to maintain their relationships with their partners. Spacious rooms can ensure sufficient room for both needed equipment and good seating accommodations.

For most spouses, common areas are somewhat challenging to use because small spaces require individuals to be closer to one another. Consequently, privacy is nearly non-existent. Opportunities for private interactions are important in the maintenance of relationships in long-term care. Nevertheless, some spouses prefer common areas as a place to connect, most likely because of a need for proximity to health personnel. Gradually establishing relationships with health personnel appears crucial in the process of spouses' developing a sense of place. An awareness of the importance of health personnel in sustaining spouses' abilities to maintain their relationships is important.

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References

Ablitt, A., Jones, G., & Muers, J. (2009). Living with dementia: A systematic review of the influence of relationship factors. *Aging and Mental health*, *13*(4), 497–511. doi:10.1080/13607860902774436

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Aminzadeh, F., Molnar, F. J., Dalziel, W. B., & Garcia, L. J. (2013). An exploration of adjustment needs and efforts of persons with dementia after relocation to a residential care facility. *Journal of Housing For the Elderly*, *27*(1–2), 221–240. doi:10.1080/02763893.2012.754824

Bramble, M., Moyle, W., & McAllister, M. (2009). Seeking connection: Family care experiences following long-term dementia care placement. *Journal of Clinical Nursing*, *18*(22), 3118–3125. doi:10.1111/j.1365-2702.2009.02878.x

Calkins, M. P. (2009). Evidence-based long term care design. *Neurorehabilitation*, *25*(3), 145–154. doi:10.3233/NRE-2009-0512

Chapman, N. J., & Carder, P. C. (2003). Privacy needs when visiting a person with alzheimer's disease: Family and staff expectations. *Journal of Applied Gerontology*, *22*(4), 506–522. doi:10.1177/0733464803254339

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Thousand Oakes, LA/London, England: SAGE

Chaudhury, H., & Rowles, G. D. (2005). Between the shores of recollection and imagination: Self, aging and home. In G. D. Rowles, & H. Chaudhury (Eds.), *Home and identity in late life. International perspectives* (pp. 3–18). New York, NY: Springer Publishing Company

Cruz, E. D. (2006). Elders' and family caregivers' experience of place at an assisted living center. *OTJR: Occupation, Participation and Health*, *26*(3), 97–107. doi:10.1177/153944920602600303

Cutchin, M. P. (2013). The complex process of becoming at-home in assisted living. In G. D. Rowles, & M. Bernard (Eds.), *Environmental gerontology* (pp. 105–123). New York, NY: Springer Publishing Company

Davis, S., Byers, S., Nay, R., & Koch, S. (2009). Guiding design of dementia friendly environments in residential care settings: Considering the living experiences. *Dementia*, *8*(2), 185–203. doi:10.1177/1471301209103250

Day, K., Carreon, D., & Stump, C. (2000). The therapeutic design of environments for people with dementia: A review of the empirical research. *The Gerontologist*, *40*(4), 397–416. doi:10.1093/geront/40.4.397

Dewing, J. (2002). From ritual to relationship: A person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia*, *1*(2), 157–171. doi:10.1177/147130120200100204

Evans, D., & Lee, E. (2014). Impact of dementia on marriage: A qualitative systematic review. *Dementia*, *13*(3), 330–349. doi:10.1177/1471301212473882

Fleming, R., Kelly, F., & Stillfried, G. (2015). 'I want to feel at home': Establishing what aspects of environmental design are important to people with dementia nearing the end of life. *BMC Palliative Care*, *14*(26). doi:10.1186/s12904-015-0026-y

Førsund, L. H., Kiik. R., Skovdahl, K., & Ytrehus, S. (Manuscript in press). Constructing togetherness throughout the phases of dementia: A qualitative study exploring how spouses maintain relationships with partners with dementia who live in institutional care. *Journal of Clinical Nursing*. Accepted 26.03.16

Førsund, L. H., Skovdahl, K., Kiik, R., & Ytrehus, S. (2015). The loss of a shared lifetime: A qualitative study exploring spouses' experiences of losing couplehood with their partner with dementia living in institutional care. *Journal of Clinical Nursing*, *24*(1–2), 121–130. doi:10.1111/jocn.12648

Gaugler, J. E. (2005). Family involvement in residential long-term care: A synthesis and critical review. *Aging & Mental Health*, *9*(2), 105–118. doi:10.1080/13607860412331310245

Gladstone, J. W., Dupuis, S. L., & Wexler, E. (2006). Changes in family involvement following a relative's move to a long-term care facility. *Canadian Journal on Aging*, *25*(1), 93–106. doi:http://dx.doi.org/10.1353/cja.2006.0022

Goodman, C., Amador, S., Elmore, N., Machen, I., & Mathie, E. (2013). Preferences and priorities for ongoing and end-of-life care: A qualitative study of older people with dementia resident in care

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homes. *International journal of nursing studies*, *50*(12), 1639–1647. doi:http://dx.doi.org/10.1016/j.ijnurstu.2013.06.008

Graham, J. E., & Bassett, R. (2006). Reciprocal relations: The recognition and co-construction of caring with Alzheimer's disease. *Journal of Aging Studies*, *20*(4), 335–349. doi:http://dx.doi.org/10.1016/j.jaging.2005.12.003

Harmer, B. J., & Orrell, M. (2008). What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. *Aging and Mental Health*, *12*(5), 548–558. doi:10.1080/13607860802343019

Hellstrom, I., & Lund, U. (2005). "We do things together": A case study of "couplehood" in dementia. *Dementia*, *4*(1), 7–22. doi:10.1177/1471301205049188

Hellstrom, I., & Lund, U. (2007). Sustaining "couplehood": Spouses' strategies for living positively with dementia. *Dementia*, *6*(3), 383–409. doi:10.1177/1471301207081571

Hellstrom, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, *14*(5), 608–619. doi:10.1177/0969733007080206

Innes, A., Kelly, F., & Dincarslan, O. (2011). Care home design for people with dementia: What do people with dementia and their family carers value? *Aging & Mental Health*, *15*(5), 548–556. doi:10.1080/13607863.2011.556601

Kaplan, L. (2001). A couplehood typology for spouses of institutionalized persons with alzheimer's disease: Perceptions of "We"–"I"*. *Family Relations*, *50*(1), 87–98. doi:10.1111/j.1741-3729.2001.00087.x

Kaplan, L., Ade-Ridder, L., Hennon, C. B., Brubaker, E., & Brubaker, T. (1995). Preliminary typology of couplehood for community-dwelling wives: "I" Versus "We". *The International Journal of Aging and Human Development*, *40*(4), 317–337. doi:10.2190/1Q99-EG0B-3VW2-EBKB

Kenigsberg, P.-A., Aquino, J.-P., Bérard, A., Gzil, F., Andrieu, S., Banerjee, S., ... Robert, P. (2016). Dementia beyond 2025: Knowledge and uncertainties. *Dementia*, *15*(1), 6–21. doi:10.1177/1471301215574785

Kirkevold, Ø., Eek, A., & Engedal, K. (2012). Development of residential care services facilitated for persons with dementia in Norway. *Aging Clinical and Experimental Research*, *24*(1), 1–5. doi:10.1007/BF03325351

Kuhn, D., Kasayka, R. E., & Lechner, C. (2002). Behavioral observations and quality of life among persons with dementia in 10 assisted living facilities. *American Journal of Alzheimer's Disease and Other Dementias*, *17*(5), 291–298. doi:10.1177/153331750201700508

Lawton, M. P. (1983). Time, space, and activity. In G. D. Rowles, & R. J. Ohta (Eds.), *Aging and milieu: Environmental perspectives on growing old* (pp. 41–61). New York, NY: Academic Press

Lawton, M. P. (1985). Housing and living environments of older people. In R. H. Binstock, & L. K. George (Eds.), *Handbook of aging and the social sciences* (Vol. 2, pp. 450–478). Burlington, MA: Academic Press

Marquardt, G. (2011). Wayfinding for people with dementia: A review of the role of architectural design. *HERD: Health Environments Research & Design Journal*, *4*(2), 75–90. doi:10.1177/193758671100400207

Marquardt, G., & Schmieg, P. (2009). Dementia-friendly architecture: Environments that facilitate wayfinding in nursing homes. *American Journal of Alzheimer's Disease and Other Dementias*, *24*(4), 333–340. doi:10.1177/1533317509334959

Marquardt, G. P., Bueter, K. M. A., & Motzek, T. M. (2014). Impact of the design of the built environment on people with dementia: An evidence-based review. *HERD: Health Environments Research & Design Journal*, *8*(1), 127–157. doi:10.1080/13607860902845574

McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, *19*(13–14), 1935–1943. doi:10.1111/j.1365-2702.2009.03136.x

Downloaded from dem.sagepub.com at University College of Southeast Norway on October 31, 2016

Mitchell, S. L., Black, B. S., Ersek, M., Hanson, L. C., Miller, S. C., Sachs, G. A., . . . Morrison, R. S. (2012). Advanced dementia: State of the art and priorities for the next decade. *Annals of Internal Medicine*, *156*(1 Pt 1), 45–51. doi:10.7326/0003-4819-156-1-201201030-00008

Nolan, M., & Dellasega, C. (1999). 'It's not the same as him being at home': Creating caring partnerships following nursing home placement. *Journal of Clinical Nursing*, *8*(6), 723–730. doi:10.1046/j.1365-2702.1999.00325.x

O'Malley, M., Innes, A., & Wiener, J. M. (2015). Decreasing spatial disorientation in care-home settings: How psychology can guide the development of dementia friendly design guidelines. *Dementia*, Published online before print June 24, 2015. doi:10.1177/1471301215591334

Oswald, F., & Rowles, G. D. (2006). Beyond the relocation trauma in old age: New trends in elders' residential decisions. In H.-W. Wahl, C. Tesch-Römer, & A. Hoff (Eds.), *New dynamics in old age: Environmental and societal perspectives* (pp. 127–152). Amityville, NY: Baywood

Oswald, F., & Wahl, H.-W. (2005). Dimensions of the meaning of home in later life. In G. D. Rowles, & H. Chaudhury (Eds.), *Home and identity in late life*. *International perspectives* (pp. 21–45). New York, NY: Springer Publishing Company

Ray, C. A., Ingram, V., & Cohen-Mansfield, J. (2015). Systematic review of planned care transitions for persons with dementia. *Neurodegenerative disease management*, *5*(4), 317–331. doi:10.2217/nmt.15.23

Rowles, G. D., & Bernard, M. (2013). The meaning and significance of place in old age. In G. D. Rowles, & M. Bernard (Eds.), *Environmental gerontology: Making meaningful places in old age* (pp. 3–24). New York, NY: Springer Publishing Company

Rubinstein, R., & Parmelee, P. (1992). Attachment to place and the representation of the life course by the elderly. In I. Altman, & S. Low (Eds.), *Place attachment* (Vol. 12, pp. 139–163). New York, NY: Springer

Sabat, S. R., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society*, *12*(04), 443–461. doi:http://dx.doi.org/10.1017/S0144686X00005262

Sandberg, J., Lundh, U., & Nolan, M. R. (2001). Placing a spouse in a care home: The importance of keeping. *Journal of Clinical Nursing*, *10*(3), 406–416. doi:10.1046/j.1365-2702.2001.00497.x

Savin-Baden, M., & Howell Major, C. (2013). *Qualitative research. The essential guide to theory and practice*. London and New York: Routhledge

Schwartz, B. (1999). Assisted living: An evolving place type. In B. Schwartz (Ed.), *Aging, autonomy, and architecture: Advances in assisted living*. Baltimore, MD: The Johns Hopkins University Press

Sherman, E., & Dacher, J. (2005). Cherished objects and the home: Their meaning and roles in later life. In G. D. Rowles, & H. Chaudbury (Eds.), *Home and identity in late life*. *International persepectives* (pp. 63–79). New York, NY: Springer Publishing Company

Silverman, D. (2006). *Interpreting qualitative data* (3rd ed.). London, UK: Sage

Verbeek, H., van Rossum, E., Zwakhalen, S. M., Kempen, G. I., & Hamers, J. P. (2009). Small, homelike care environments for older people with dementia: A literature review. *International Psychogeriatrics*, *21*(02), 252–264. doi:http://dx.doi.org/10.1017/S104161020800820X

Wadham, O., Simpson, J., Rust, J., & Murray, C. (2015). Couples' shared experiences of dementia: A meta-synthesis of the impact upon relationships and couplehood. *Aging & Mental Health*, *20*(5), 463–473. doi:10.1080/13607863.2015.1023769

Wahl, H.-W. (2001). Environmental influences on aging and behaviour. In J. E. Birren, & K. W. Schaie (Eds.), *Handbook of the psychology of aging* (5th ed. pp. 215–237). California, LA/London, UK: Elsevier

Wahl, H.-W., & Oswald, F. (2010). Environmental perspectives on aging. In D. Dannefer, & C. Phillipson (Eds.), *The SAGE handbook of social gerontology* (pp. 111–124). Thousand Oaks, LA/London, UK: SAGE

Wahl, H.-W., & Weisman, G. D. (2003). Environmental gerontology at the beginning of the new millennium: Reflections on its historical, empirical, and theoretical development. *The Gerontologist*, *43*(5), 616–627. doi:10.1093/geront/43.5.616

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Ytrehus, S. (2002). Housing policy for frail elders in Norway: A study of the implementation of housing reforms in Norwegian municipalities. *Journal of Housing For the Elderly*, *16*(1–2), 107–123. doi:10.1300/J081v16n01_08

Ytrehus, S. (2011). Housing procurement for the frail elderly: Public or private responsibility? The view of the elderly in Norway. *Journal of Housing For the Elderly*, *25*(1), 89–106. doi:10.1080/02763893.2011.545749

Örulv, L. (2010). Placing the place, and placing oneself within it: (Dis)orientation and (dis)continuity in dementia. *Dementia*, *9*(1), 21–44. doi:10.1177/1471301210364449.

Author Biographies

Linn Hege Førsund is about to finish her doctoral studies in health sciences at the Norwegian University of Science and Technology in 2016. She has been studying elderly spouses' with partners living with dementia in long-term care in Norway, and explored how spouses' maintain relationships in these settings. She is registered nurse with a master's degree in clinical geriatric health care. She works as assistant professor at the Department of Nursing Science, Drammen at the University College of Southeast Norway. Her primary field of lecturing and supervising students is within the field of elderly- and dementia care.

Siri Ytrehus is working at the Institute for health studies at Sogn og Fjordane University College in Norway. She has undertaken a broad range of research projects over many years. Her research activities include studies of marginalized groups, housing for the elderly, family and dementia care.

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Appendix I

Appendix

I. REK sør-øst 2011/2401 Svar på fremleggingsvurdering [In Norwegian]
[REK Southeast 2011/2401 Response to project application]
II. NSD Prosjektnummer 29923 Tilbakemelding på melding om behandling av personopplysninger [In Norwegian]
[Response to notification form]
III. REK sør-øst 2011/2401 Svar på fremleggingsvurdering vedrørende utvidelse av datainnsamlingsgrunnlaget [In Norwegian]
[REK Southeast 2011/2401 Response to application about inclusion of observations]
IV. NSD Prosjektnummer 29923 Bekreftelse på endringer [In Norwegian]
[Confirmation of amendment]
V. Informasjonsskriv til ansatte om forskningsprosjekt [In Norwegian]
[Written information about the study]
VI. Forespørsel og samtykkeerklæring til ektefeller om deltagelse i studie [In Norwegian]
[Written information to participants about the study and consent form]
VII. Forespørsel og samtykkeerklæring til ektefeller om deltagelse i observasjoner [In Norwegian] [Written information to participants about observations and consent form]
VIII. Forespørsel og samtykkeerklæring til personer med demens om deltagelse i observasjoner [In Norwegian] [Written information to persons with dementia about observations and consent form]
IX. Takkeskriv med kontaktinformasjon [In Norwegian]
[Letter of gratitude with contactinformation]
X. Intervjuguide [In Norwegian]
[Interviewguide]
XI. Fokus for observasjoner [In Norwegian]
[Focus for observations]

Linn Hege Førsund

From:	post@helseforskning.etikkom.no
Sent:	16. desember 2011 09:20
To:	Linn Hege Førsund
Subject:	REK sør-øst 2011/2401 Flytting til offentlige bo og omsorgsløsninger for personer med demens sett i et ektefelleperspektiv
Importance:	High

Hei,

Viser til innsendt framleggingsvurdering, mottatt 06.12.2011, i forbindelse med ovennevnte prosjekt.

Formålet med prosjektet er få frem kunnskap om ektefellers opplevelser og erfaringer knyttet til flytting av en partner til ulike former for bo- og omsorgstilbud beregnet for personer med demens.

Komiteen mener at prosjektet ikke faller inn under helseforskningsloven som forutsetter at formålet med prosjektet er å skaffe ny kunnskap om helse og sykdom. Prosjektet trenger ikke forhåndsgodkjenning fra REK.

REK antar for øvrig at prosjektet kommer inn under de interne regler som gjelder ved forskningsansvarlig virksomhet. Søker bør derfor ta kontakt med enten forskerstøtteavdeling eller personvernombud for å avklare hvilke retningslinjer som er gjeldende.

Med vennlig hilsen

Gjøril Bergva
Rådgiver

REK sør-øst

Tlf: 22 84 55 29

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

NSD

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel +47-55 58 21 17
Fax +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Linn Hege Førsund
Avdeling for helsefag
Høgskolen i Buskerud
Postboks 235
3603 KONGSBERG

Vår dato: 23.03.2012 Vår ref:29932 / 3 / HIT Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 21.02.12. Meldingen gjelder prosjektet:

29932	*Flytting til ulike former for bo- og omsorgstilbud for personer med demens – et ektefelleperspektiv*
Behandlingsansvarlig	*Høgskolen i Buskerud, ved institusjonens øverste leder*
Daglig ansvarlig	*Linn Hege Førsund*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/forsk_stud/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://www.nsd.uib.no/personvern/prosjektoversikt.jsp.

Personvernombudet vil ved prosjektets avslutning, 01.07.16, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Vigdis Namtvedt Kvalheim

Hildur Thorarensen

Kontaktperson: Hildur Thorarensen tlf: 55 58 26 54
Vedlegg: Prosjektvurdering

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 29932

Prosjektets formål er å belyse ektefellers situasjon og behov i forbindelse med flytting av partner, forbedre kunnskap om samhandling med familien, og aktualisere omgivelsenes betydning for familieomsorg i bo- og omsorgstilbud for personer med demens.

Utvalget består av ca. 20 eldre ektefeller/samboere til personer med demens som har flyttet til offentlige bo- og omsorgsløsninger, i fire-fem store/mellomstore kommuner på Østlandet. Rekruttering skjer via kommunen, og videre via kontaktpersoner i aktuelle enheter, som formidler forespørsel til aktuelle deltakere. Det legges vekt på at utvalget er over 65 år, at vedkommende er fysisk og psykisk i stand til å delta og har ektefelle/partner som har bodd minst 3 måneder på institusjon. Personvernombudet forstår det slik at prosjektleder ikke vil kjenne identiteten til deltakerne før de evt. samtykker til deltakelse.

Det innhentes skriftlig samtykke basert på skriftlig informasjon. Personvernombudet finner informasjonsskrivene tilfredsstillende.

Data innhentes ved personlig intervju. Det vil bli benyttet lydopptak som behandles elektronisk. Datamaterialet vil være knyttet til direkte personidentifiserende opplysninger via kode som viser til adskilt koblingsnøkkel. Datamaterialet registreres på pc i nettverkssystem tilknyttet virksomheten, samt på krypterte minnepinner.

I denne studien er det informantenes opplevelser som er i fokus, men man vil likevel sannsynligvis ikke komme utenom opplysninger om dement ektefelle/partner. Personvernombudet anbefaler at man oppmuntrer informantene til å forsøksvis gi relevant informasjon om prosjektet til ektefellene, og at dersom det er mulig, innhentes et aktivt samtykke fra disse (gjerne muntlig overfor egen partner).

Behandlingen av personopplysninger vedrørende informantene vil være basert på samtykke, jf. personopplysningsloven § 8 første ledd § 9 a). I den grad det vil bli registrert personopplysninger om dement ektefelle/partner (og det ikke kan innhentes et gyldig samtykke fra vedkommende), finner ombudet at behandlingen kan hjemles i personopplysningsloven §8 d, § 9 h og § 20 b).

Datamaterialet anonymiseres når prosjektet er avsluttet, senest innen 01.07.2016. For at datamaterialet skal være anonymt må navn (på samtykkeerklæringer og koblingsnøkkel) slettes. I tillegg må indirekte personidentifiserende opplysninger slettes eller grovkategoriseres/omskrives, slik at ingen enkeltpersoner kan gjenkjennes. Lydopptak slettes.

Linn Hege Førsund

From:	post@helseforskning.etikkom.no
Sent:	13. september 2013 12:33
To:	Linn Hege Førsund
Subject:	Sv: REK sør-øst 2011/2401 Flytting til offentlige bo og omsorgsløsninger for personer med demens sett i et ektefelleperspektiv

Hei,
Viser til din henvendelse av 12.08.13 og beklager lang svartid.

Det fremgår at det er aktuelt å utvide datainnsamlingsgrunnlaget til å inkludere deltagende observasjon i tillegg til samtaleintervjuer.

Prosjektet er tidligere vurdert å falle utenfor helseforskningsloven. Prosjektet har derfor ikke hatt behov for forhåndsgodkjenning fra REK. En utvidelse av datainnsamlingsgrunnlaget som ovenfor nevnt endrer ikke på dette, slik at prosjektet kan fortsette uten godkjenning fra REK.

REK har tidligere uttalt at prosjektet antas å komme inn under de interne regler som gjelder ved forskningsansvarlig virksomhet. Det anbefales derfor at du tar kontakt med enten forskerstøtteavdeling eller personvernombud for å avklare hvilke retningslinjer som er gjeldende.

Med vennlig hilsen

Claus H.Thorsen
rådgiver
sekretariatet REK sør-øst

Linn Hege Førsund

From:	Hildur Thorarensen <hildur.thorarensen@nsd.uib.no>
Sent:	3. januar 2014 11:24
To:	linnhf@hibu.no
Subject:	Prosjektnr: 29932. Flytting til ulike former for bo- og omsorgstilbud for personer med demens – et ektefelleperspektiv

BEKREFTELSE PÅ ENDRINGER

Vi viser til endringsmelding mottatt 22.11.2013 samt telefonsamtale 03.02.2014, og har registrert følgende endringer:

- PROSJEKTSLUTT
Prosjektslutt endres fra 01.07.2016 til 01.07.2017. Utvalget får muntlig informasjon om utsettelsen.

- METODE
Observasjon legges til som metode.

- UTVALG
Utvalget utvides til å inkludere ektefeller med demens fra det opprinnelige utvalget. Der det er mulig innhentes det samtykke fra vedkommende selv. Dersom enkelte ikke har full samtykkekompetanse, vurderer personvernombudet det slik at opplysningene behandles med hjemmel i personopplysningsloven § 8 d) og § 9 h).

Det anses ikke som potensielt belastende for vedkommende å delta i prosjektet. Det opplyses at vedkommende vil bli gitt tilpasset informasjon, samt at nærmeste pårørende (ektefelle) også deltar, og eventuelt gir en uttalelse om hvorvidt opplysninger om vedkommende kan anvendes i studien.

Det vurderes at den valgte fremgangsmåten for inklusjon av personer uten full samtykkekompetanse, bidrar i betydelig grad til å redusere personvernulempen ved deltakelse. Det vurderes videre at opplysningene vil kunne komme gruppen som helhet til gode. På bakgrunn av dette finner personvernombudet at samfunnsinteressen i at behandlingen finner sted, overstiger ulempen den medfører for den enkelte registrerte.

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Personvernombudet forutsetter at prosjektopplegget for øvrig gjennomføres i tråd med det som tidligere er innmeldt, og personvernombudets tilbakemeldinger. Vi vil ta ny kontakt ved prosjektslutt.

--
Vennlig hilsen/best regards

Hildur Thorarensen
Rådgiver/Adviser

Norsk samfunnsvitenskapelig datatjeneste AS
(Norwegian Social Science Data Services)
Personvernombud for forskning
(Data Protection Official for Research)
Harald Hårfagres gate 29, 5007 BERGEN

Tlf. direkte: (+47) 55 58 26 54
Tlf. sentral: (+47) 55 58 81 80
Faks: (+47) 55 58 96 50
Email: hildur.thorarensen@nsd.uib.no
Internettadresse: www.nsd.uib.no/personvern

Informasjonsskriv til ansatte om forskningsprosjektet

”Flytting til offentlige bo- og omsorgstilbud for personer med demens – et ektefelleperspektiv”

I forbindelse med min doktorgrad arbeider jeg med et forskningsprosjekt som handler om ektefeller/partnere til personer med demens, og hvordan de opplever det å flytte sin partner til et bo- og tjenestetilbud for personer med demens. Studien vil belyse ektefellers situasjon og behov i forbindelse med flytting av partner. Målet er å bidra til økt forståelse for ektefellers situasjon, slik at helsetjenesten i større grad kan møte deres behov, både med tanke på samarbeid og oppfølging, men også i forhold til tilrettelegging av bo- og tjenestetilbud for personer med demens. Prosjektet vil bli utført av undertegnede i samarbeid med professor Siri Ytrehus ved Diakonhjemmet høgskole, professor Kirsti Skovdahl ved Høgskolen i Buskerud og Vestfold og professor Riina Kiik ved NTNU. Prosjektet er lagt frem for REK sørøst og Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste (NSD).

I forbindelse med prosessen med å rekruttere informanter til studien har jeg behov for din hjelp. I dette skrivet finner du aktuell informasjon om hvilke informanter som ønskes til studien, og hvordan studien skal gjennomføres.

Informasjon om hvordan undersøkelsen vil bli gjennomført

Dette er en kvalitativ studie, og datainnsamlingsmetoden vil være samtaleintervju. Intervjuet vil foregå som en samtale. Jeg ønsker at ektefellen forteller om hvordan han/hun har opplevd det at partneren har flyttet til et bo- og tjenestetilbud, og hvordan hverdagslivet ser ut for ektefellene nå. Intervjuet vil ta 1-2 timer og kan enten foregå her i enheten, eller hjemme hos ektefellen. Intervjuet vil bli tatt opp på lydbånd og deretter skrevet ned på papir. Lydbåndet vil bli slettet når prosjektet avsluttes, senest sommeren 2017. Alle opplysninger som samles inn og som publiseres vil være anonymiserte slik at det ikke vil være mulig å kjenne igjen hvem som har gitt opplysningene. Resultater fra studien vil publiseres i vitenskapelige publikasjoner.

Linn Hege Førsund
Stipendiat
Institutt for sykepleievitenskap
Høgskolen i Buskerud og Vestfold
Tlf: 992 76 335

Praktisk informasjon

Det jeg konkret ønsker hjelp til fra deg er følgende:

Under er det beskrevet noen utvalgskriterier for deltagelse i studien. Dersom du har ektefeller/partnere som fyller disse utvalgskriteriene, ønsker jeg at du tar kontakt med dem, informerer dem om studien (se eget punkt) og gir dem et informasjonsskriv.

Utvalgskriterier

Informantene skal velges ut på bakgrunn av følgende kriterier:

- Ektefeller eller samboer/partner til personer med demens som er tildelt langtidsplass/bolig i bofellesskap
- Ektefeller eller samboer/partner som selv kan gi et frivillig informert samtykke

Viktig informasjon som må gis til ektefellen

Det er viktig at du informerer ektefellen om at det er frivillig og delta i studien og at han/hun kan trekke seg som deltager når som helst, selv om han/hun tidligere har sagt ja til deltagelse. Dersom ektefellen ønsker å trekke seg trenger ikke vedkommende oppgi noen grunn, det vil heller ikke få noen konsekvenser.

Formidling av kontaktinformasjon

Dersom ektefellen ønsker å delta i studien må han/hun skrive under med navn og telefonnummer på samtykkeerklæringen som ligger vedlagt med informasjonsskrivet som du gir til ektefellen. Svarslippen sendes/formidles til meg.

Dersom ektefellen samtykker i dette, kan også navn/telefonnummer formidles direkte til meg fra deg. Samtykkeerklæringen kan da undertegnes når jeg treffer ektefellen.

Linn Hege Førsund
Stipendiat
Institutt for sykepleievitenskap
Høgskolen i Buskerud og Vestfold
Tlf: 992 76 335

Dersom ektefellen ønsker mer informasjon om studien før vedkommende bestemmer seg, kan kontaktinformasjonen formidles til meg etter hans/hennes samtykke, jeg vil deretter ta kontakt for en utfyllende orientering.

Dersom du har spørsmål relatert til studien er det bare å kontakte meg, Linn Hege Førsund, på telefonnummer: 992 76 335, eller mail: linn.hege.forsund@hbv.no

Jeg ser frem til å samarbeide med deg og sier på forhånd takk for hjelpen!

Med vennlig hilsen
Linn Hege Førsund

Linn Hege Førsund
Stipendiat
Institutt for sykepleievitenskap
Høgskolen i Buskerud og Vestfold
Tlf: 992 76 335

NTNU
Det skapende universitet

HBV
Høgskolen i Buskerud og Vestfold · Profesjonshøgskolen ·

Forespørsel om deltakelse i forskningsprosjektet
”Flytting til offentlige bo- og omsorgstilbud for personer med demens – et ektefelleperspektiv”

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie om hvordan ektefeller/samboere opplever det å flytte sin partner til en demensbolig. Hensikten med prosjektet er å belyse ektefellers situasjon og behov i forbindelse med flytting av partner til et bo- og omsorgstilbud for personer med demens. Det søkes også kunnskap om hvordan ektefeller opplever at parrelasjonen endrer og utformer seg når partneren bor i et offentlig omsorgstilbud. Målet er å bidra til økt forståelse for ektefellers situasjon, slik at helsetjenesten i større grad kan møte deres behov, både i forhold til samhandling med personalet og organisering av tilbud, men også i forhold til tilrettelegging av det fysiske miljøet.

Sammen med ca. 20 andre ektefeller som har flyttet sin partner til en demensbolig, får du denne forespørselen om deltagelse i forskningsprosjektet. Deltakerne er valgt fra noen kommuner på Østlandet på bakgrunn av hvilken type bo- og omsorgstilbud som disse kommunene tilbyr til personer med demens. Denne forespørselen blir formidlet via den enheten hvor din partner bor. Din identitet er ukjent for meg inntil du eventuelt samtykker i å delta i denne studien.

Presentasjon

Mitt navn er Linn Hege Førsund. Jeg er stipendiat ved Høgskolen i Buskerud og Vestfold og dette prosjektet vil bli en del av min doktorgrad. Prosjektet vil bli utført av undertegnede i samarbeid med professor Siri Ytrehus ved Diakonhjemmet høgskole, professor Kirsti Skovdahl ved Høgskolen i Buskerud og Vestfold og professor Riina Kiik ved NTNU.

Hva innebærer studien?

Deltagelse i studien innebærer at jeg ønsker å gjennomføre et intervju med deg. Intervjuet vil foregå som en samtale mellom oss to, og vil ta om lag en til to timer. Intervjuet vil tas opp på lydbånd og deretter skrives ned på papir. I intervjuet vil jeg spørre om hvordan du har opplevd din situasjon etter at din partner ble syk og senere flyttet, om hvordan du vurderer din partners nye bosted og hvordan hverdagslivet i den nye boligen er for dere som ektepar. Intervjuet kan finne sted i enheten hvor din partner bor, eller jeg kan komme hjem til deg. Det kan bli aktuelt å gjennomføre oppfølgende intervju. Jeg vil da ta kontakt med deg på nytt om dette.

Mulige fordeler og ulemper ved å delta

Deltagelse i et intervju slik som dette innebærer en tett kontakt mellom deg som deltager og meg som intervjuer. For noen kan dette oppleves nærgående. På den andre siden kan det også oppleves positivt å få dele erfaringer og opplevelser med en som er interessert. Jeg vil presisere at du velger selv hva du ønsker å dele med meg i intervjuet, og at du når som helst kan avbryte dersom du ønsker dette.

Hva skjer med informasjonen om deg?
Intervju vil bli oppbevart på et datasikret område på Høgskolen i Buskerud og Vestfold. Systemet ivaretar gjeldende lovverk. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun undertegnede som har adgang til navnelisten og som kan finne tilbake til deg.

Det vil ikke være mulig å gjenkjenne deg eller din partner i resultatene av studien når disse publiseres samlet for alle deltagerne.

Alle lydopptak og personopplysninger om deg vil bli slettet etter prosjektets avslutning, senest innen sommeren 2017. Anonymiserte utskrifter av intervjuene vil bli lagret på forskningsserveren til Høgskolen i Buskerud for fremtidig bruk i forbindelse med publisering. Disse utskriftene vil ikke på noen måte kunne kobles til deg.

Resultatene fra denne studien vil publiseres i vitenskapelige publikasjoner. Dersom du ønsker det har du rett til innsyn i disse.

Frivillig deltakelse
Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for deg eller din partner.

Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din eller din partners situasjon.

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Studien er fremlagt for Regional Etisk Komité, REK-Sørøst og Personvernombudet ved Norsk Samfunnsvitenskapelig Datatjeneste (NSD).

Kontaktinformasjon
Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte meg:
Linn Hege Førsund
Spesialsykepleier i aldring og eldreomsorg, MNsc, stipendiat
Fakultet for helsevitenskap, Høgskolen i Buskerud og Vestfold
Tlf: 99 27 63 35
E-mail: linn.hege.forsund@hbv.no

NTNU
Det skapende universitet

HBV
HØGSKOLEN I BUSKERUD OG VESTFOLD - PROFESJONSHØGSKOLEN

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert av ansatt i enheten hvor det er rekruttert fra, dato)

Forespørsel om deltakelse i forskningsprosjektet

”Flytting til offentlige bo- og omsorgstilbud for personer med demens – et ektefelleperspektiv»

Delstudie 2

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en utvidet del av forskningsstudien om hvordan ektefeller/samboere opplever det å flytte sin partner til en demensbolig. I denne delen av studien er hensikten å få en dypere innsikt i på hvilken måte parrelasjonen fortsetter å eksistere når en av partene bor i et offentlig omsorgstilbud for personer med demens, og utforske omgivelsenes betydning for ektepars mulighet til å fortsette parrelasjonen. Det er behov for kunnskap om hvordan parrelasjonen utvikles etter at en av partene flytter til et omsorgstilbud, målet er derfor å bidra til økt forståelse for dette slik at helsetjenesten i større grad kan møte ektefellers behov, både i forhold til samhandling med personalet, men også i forhold til tilrettelegging av det fysiske miljøet.

Sammen med andre ektefeller som har deltatt i den første delen av denne forskningsstudien får du denne forespørselen om deltagelse i denne utvidede delen. Dine opplevelser ga grunnlag for et ønske om og utforske mer i dypet, for å se hvordan du og din partner har det i demensboligen når dere er sammen.

Presentasjon

Denne utvidede delen vil også ivaretas av undertegnede, som er Linn Hege Førsund. Delstudien inngår i mitt doktorgradsprosjekt som utføres i samarbeid med professor Siri Ytrehus ved Diakonhjemmet høgskole, professor Kirsti Skovdahl ved Høgskolen i Buskerud og professor Riina Kiik ved NTNU.

Hva innebærer studien?

I denne delen av studien vil det gjennomføres deltagende observasjoner med ektepar. Dette innebærer at jeg ønsker å ta følge med deg på besøk til partneren din i demensboligen der din partner bor. Jeg ønsker å være sammen med deg og din partner i de aktivitetene som dere gjør til vanlig når dere er sammen. Min rolle som deltagende observatør er å være sammen med dere, og jeg vil delta i samtaler og aktiviteter slik det faller seg naturlig. Som observatør vil jeg først og fremst fokusere på hva dere to gjør når dere er sammen, hvor dere er når dere er sammen og hvordan dere snakker eller forholder dere til hverandre. Jeg vil ikke være tilstede i mer intime situasjoner for eksempel i forbindelse med stell, toalettbesøk eller lignende.

Innimellom vil jeg kunne trekke meg tilbake for å skrive ned notater fra det jeg observerer. Jeg vil også ha med meg en lydopptaker. Dersom det ligger til rette for dette, og du og din partner samtykker, vil jeg kunne ta opp enkelte samtaler som vi har på lydbånd. Jeg vil imidlertid spørre dere i hvert enkelt tilfelle dersom dette skulle bli aktuelt.

Mulige fordeler og ulemper

Deltagelse i en observasjons studie som denne kan oppleves som nærgående. Deltagelse innebærer at jeg som forsker deltar i deres aktiviteter og er til stede som en tredje part. Jeg vil imidlertid legge til rette for at det skal oppleves så lite invaderende som mulig, og du og din partner kan når som helst be meg avbryte dersom dere ønsker.

Deltagelse i denne typen studie kan også oppleves positivt da du og din partner har muligheten til å dele deres opplevelser med en som er interessert. Jeg vil også i etterkant av besøket legge til rette for en samtale mellom oss to der vi kan diskutere hvordan det å delta i denne studien opplevdes.

Hva skjer med informasjonen om deg?

Notater fra besøkene der jeg var sammen med dere og eventuelle lydopptak og utskrifter fra intervju vil bli oppbevart på et datasikret område på Høgskolen i Buskerud og Vestfold. Systemet ivaretar gjeldende lovverk. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun undertegnede som har adgang til navnelisten og som kan finne tilbake til deg.

Det vil ikke være mulig å gjenkjenne deg eller din partner i resultatene av studien når disse publiseres samlet for alle deltagerne. Resultatene fra studien vil publiseres i vitenskapelige publikasjoner. Dersom du ønsker det har du rett til innsyn i disse.

Alle personopplysninger og eventuelle lydopptak vil bli slettet etter prosjektets avslutning, senest innen juli 2017. Anonymiserte notater fra besøkene og utskrifter av eventuelle intervjuer vil bli lagret på forskningsserveren til Høgskolen i Buskerud og Vestfold for fremtidig bruk i forbindelse med publisering. Disse utskriftene vil ikke på noen måte kunne kobles til deg.

Frivillig deltakelse
Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for deg eller din partner.

Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din eller din partners situasjon.

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Studien er fremlagt for Regional Etisk Komité, REK-Sørøst og Personvernombudet ved Norsk Samfunnsvitenskapelig Datatjeneste (NSD).

Kontaktinformasjon
Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte meg:
Linn Hege Førsund
Sykepleier, MSc i aldring og eldreomsorg, stipendiat
Fakultet for helsevitenskap, Høgskolen i Buskerud og Vestfold
Tlf: 99 27 63 35
E-mail: linn.hege.forsund@hbv.no

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert av Linn Hege Førsund, dato)

Forespørsel til personer med demens om deltakelse i forskningsprosjektet

”Flytting til offentlige bo- og omsorgstilbud for personer med demens – et ektefelleperspektiv»

Delstudie 2

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie om hvordan ektefeller til personer med demens opplever det når partneren har flyttet til en demensbolig. I denne delen av studien er hensikten å få en dypere innsikt i på hvilken måte parrelasjonen fortsetter å eksistere når en av partene bor i et offentlig omsorgstilbud for personer med demens, og utforske omgivelsenes betydning for ektepars mulighet til å fortsette parrelasjonen. Denne typen kunnskap er viktig for å utvikle omsorgstilbud som ivaretar begge ektefellene.

Sammen med andre personer som bor i en demensbolig får du denne forespørselen. Din ektefelle har allerede deltatt i den første delen av denne forskningsstudien, du får derfor denne henvendelsen gjennom din ektefelle. Selv om det er ektefellen din sine opplevelser som er særlig fokusert i denne studien, ansees det som svært viktig at du også bidrar til å belyse dette temaet. Dette er bakgrunnen for at du blir spurt om å delta.

Presentasjon

Denne studien vil ivaretas av undertegnede, som er Linn Hege Førsund. Delstudien inngår i mitt doktorgradsprosjekt som utføres i samarbeid med professor Siri Ytrehus ved Diakonhjemmet høgskole, professor Kirsti Skovdahl ved Høgskolen i Buskerud og Vestfold og professor Riina Kiik ved NTNU.

Hva innebærer studien?

Deltagelse i denne studien innebærer at jeg ønsker å ta følge med din ektefelle på besøk til deg i demensboligen der du bor. Jeg ønsker ved besøket å være sammen med deg og din ektefelle i de aktivitetene som dere gjør. Når jeg er sammen med dere vil jeg delta i samtaler og aktiviteter slik det faller seg naturlig. Jeg vil først og fremst fokusere på hva dere to gjør når dere er sammen, hvor dere er når dere er sammen og hvordan dere snakker eller forholder dere til hverandre. Jeg vil ikke være tilstede i mer intime situasjoner som for eksempel i forbindelse med stell, toalettbesøk eller lignende.

Innimellom vil jeg kunne trekke meg tilbake for å skrive ned notater fra det jeg ser. Jeg vil også ha med meg en lydopptaker. Dersom det ligger til rette for dette, og du og din ektefelle samtykker, vil jeg kunne ta opp enkelte samtaler som vi har på lydbånd. Jeg vil imidlertid spørre dere i hvert enkelt tilfelle dersom dette skulle bli aktuelt.

Mulige fordeler og ulemper

Deltagelse i denne studien kan oppleves som nærgående. Deltagelse innebærer at jeg som forsker er sammen med deg og din ektefelle som en tredjepart og deltar i deres aktiviteter. Jeg vil hele tiden ta hensyn til dine behov og legge til rette for at denne opplevelsen blir så god som mulig. Jeg vil være forberedt på å avbryte besøket når som helst dersom du blir sliten eller av andre grunner ønsker at jeg skal gå.

Deltagelse i denne typen studie kan også oppleves positivt da du har muligheten til å dele dine opplevelser med en som er interessert. Ditt bidrag kan dessuten komme andre i samme situasjon til nytte. Jeg vil under besøket legge til rette for at du kan dele dine erfaringer om hvordan det er å delta i denne studien.

Hva skjer med informasjonen om deg?

Notater fra besøkene der jeg var sammen med deg og din ektefelle, og eventuelle lydopptak og utskrifter fra intervju vil bli oppbevart på et datasikret område på Høgskolen i Buskerud. Systemet ivaretar gjeldende lovverk. Alle opplysningene vil bli behandlet uten navn og fødselsnummer. Det vil ikke være mulig å gjenkjenne deg eller din ektefelle i resultatene av studien når disse publiseres samlet for alle deltagerne.

Alle personopplysninger og eventuelle lydopptak vil bli slettet etter prosjektets avslutning, senest innen sommeren 2017.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for deg eller din partner.

Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Samtykket kan også gis muntlig til din ektefelle. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din eller din ektefelles situasjon. Dersom du trekker deg fra studien, kan du kreve å få slettet opplysninger.

Studien er fremlagt for Regional Etisk Komité, REK-Sørøst og Personvernombudet ved Norsk Samfunnsvitenskapelig Datatjeneste (NSD).

Kontaktinformasjon

Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte meg:
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E-mail: linnhf@hibu.no

NTNU
Det skapende universitet

HBV

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Stedfortredende samtykke når berettiget, enten i tillegg til personen selv eller istedenfor

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(Signert av nærstående, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert av Linn Hege Førsund, dato)

NTNU
Det skapende universitet

HØGSKOLEN I BUSKERUD OG VESTFOLD
HBV
PROFESJONSHØGSKOLEN

Takk for din deltagelse!

Jeg vil med dette takke for din deltagelse i forskningsprosjektet ”Flytting til offentlige bo- og omsorgstilbud for personer med demens – et ektefelleperspektiv”.

Resultatene fra denne studien vil bli publisert i internasjonale vitenskapelige artikler. Dersom dette er ønskelig kan du få tilgang til disse artiklene når de blir publisert.
Forventet avslutningsdato er juli 2017.

Alt som er blitt sagt i dette intervjuet vil bli anonymisert og behandlet konfidensielt.
Det er helt frivillig å delta. Så fremt resultatene fra intervjuet ikke har inngått i analyser eller er publisert kan du på et hvilket som helst tidspunkt trekke deg uten å måtte begrunne dette nærmere. Dersom du trekker deg vil ikke dette få noen konsekvenser, verken for deg eller din partner.

Har du spørsmål i forbindelse med deltagelsen kan du gjerne ta kontakt med meg på telefonnummer: 992 76 335, eller mail: linn.hege.forsund@hbv.no

Med vennlig hilsen

Linn Hege Førsund

Linn Hege Førsund
Stipendiat
Fakultet for helsevitenskap,
Høgskolen i Buskerud og Vestfold
Tlf: 992 76 335

Intervjuguide

- Kan du fortelle om hvordan det hele begynte da din partner ble syk?
- Hvordan opplevde du det da din partner flyttet?
- Hvordan ser hverdagen din ut etter at partneren din flyttet?
- Hvordan vil du beskrive demensboligen der partneren din bor?
- Hvordan vil du beskrive din partners rom i demensboligen?
- Hvor i boligen er dere når du besøker partneren din og hva gjør dere?
- Hva tenker du om fremtiden?

Avslutningsvis, er det noe vi ikke har snakket om som du ønsker å ta opp?

Fokus for observasjoner

Ektefelleperspektivet

- Hva de gjør – plikter og oppgaver
- Hvordan de bruker bomiljøet
- Hvilken rolle de tar, relasjoner og samhandling med andre

Boligstruktur

- Hvordan enhetene ser ut – romlig struktur, utforming og organisering av bomiljøet, fellesarealer, private rom
- Hvilke muligheter det er for å gi omgivelsene et personlig preg
- Hvilke muligheter det er for privatliv