Foodwork and meals in everyday life among persons with dementia and their partners

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Abstract

The aim of this thesis was to explore and describe foodwork and meals for older persons with dementia and their partners in ordinary homes.

Descriptive and explorative designs were used in the four papers this thesis is based on. Longitudinal data, including older home-living unlike-sex twins, were analysed using descriptive and analytical statistics. An ethnographic approach was used to describe everyday life for persons with dementia. Interviews with partners and staff were analysed using thematic analysis and qualitative content analysis, respectively.

The results revealed that, among home-living older persons, there is an association between a person’s cognitive ability and nutritional status; i.e. low cognitive ability leads to increased risk of malnutrition. For home-living persons with dementia and their partners, foodwork and meals sometimes changed, meaning that shopping, preparing food and eating as well as social interaction become complicated, which seemed to lead to transitions in roles, routines and relations. There was foodwork that the persons with dementia could perform, and participants expressed a desire that abilities and independence be preserved. However, support was sometimes needed, and it was emphasized that this was based on the person’s needs, wishes and problems.

In conclusion, there is an association between decreased cognitive ability and increased risk of malnutrition. Furthermore, foodwork and meals affected both persons with dementia and their partners. Therefore, early intervention whereby both partners in a couple get individually adjusted support is of importance. Consequently, a person-centred care approach can be useful in arranging the support.
Original papers

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

Paper I

Paper II

Paper III

Paper IV

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Linda Johansson
Introduction

Traditionally, the provision of food and fluids to patients has been considered to be in the area of nursing, and already in the 1850s Nightingale wrote “Every careful observer of the sick will agree in this that thousands of patients are annually starved in the midst of plenty” (p. 37). Further, she described how nurses could help the patient eat and what kind of food was preferable (Nightingale, 1992). About 100 years later Henderson (2004) described that, in nursing, it is important to have knowledge about not only nutrition but also families’ social and cultural standards regarding food. However, even though it is quite common to assess nutritional status among older persons today, the phenomenon of meals is often overlooked; i.e. how older persons choose, prepare, serve and eat food (Amella & Aselage, 2011). Further, the Swedish Society of Nursing points out that intervention studies are needed, with persons’ problems and wishes serving as the basis in planning for care and meals (Swedish Society of Nursing, 2013).

It is reasonable to believe that Nightingale and Henderson were thinking about persons receiving hospital care when writing their theories. In our time, however, it is a different scenario: the number of beds in hospitals has decreased (McKee, 2004), and policies favour caring for older persons at home (Genet et al., 2011). This is also true for persons with dementia, and as the disease is increasing in the world (Alzheimer’s Association, 2013) it is important to further develop the care for these persons. Regarding meals in the home context among persons with dementia, little is known and further research is needed and called for (Aselage & Amella, 2010). Paying attention to, and increasing, the knowledge about meals is of great importance as it contributes to health and quality of life (Amella & Aselage, 2011). Therefore, the aim of this thesis is to explore and describe foodwork and meals for home-living older persons with dementia and their partners.
Background

The home as the arena for care

In Sweden, the national policy is that older persons should stay in their ordinary homes as long as possible (Ministry of Health and Social Affairs, 2003:91). Living in one’s own home is also what older people themselves have expressed as important (Tanner, Tilse, & De Jonge, 2008). In Sweden, many older people live in their own household, and this is also common among people with dementia (National Board of Health and Welfare, 2006b). However, when suffering from a dementia disease the ability to stay in one’s ordinary home is affected (Luppa et al., 2010), and persons with dementia tend to move to special housing earlier compared to others (National Board of Health and Welfare, 2005). To be able to stay in their ordinary home many older persons rely on support; approximately 250,000 older persons (>65 years) in Sweden use some kind of assistance (National Board of Health and Welfare, 2012). For persons with dementia, help and support from others becomes successively necessary, and cognitive impairment is associated with an increased use of home-help service (Meinow, Kåreholt, & Lagergren, 2005). In Sweden, formal dementia care involves staff from both the municipality and the county council, depending on what kind of care a person needs (National Board of Health and Welfare, 2010).

The Ädelreform took effect in 1992, changing the organization of care for older persons by giving municipalities the main responsibility for the care (Thorslund, Bergmark, & Parker, 1997). This is stressed in the Health and Medical Services Act and the Social Services Act, in which it can be read that the municipalities should provide for people to live independently in their own household, and are responsible for delivering good quality care to those in need (Ministry of Health and Social Affairs, 1982:763; 2001:453). These acts do not further describe the care to be delivered, or what is to be offered to those in need of support. In a European study, differences in home care have been found to be related to its organization and finances (Genet et al., 2011). In Sweden, it is common that municipalities have local guidelines...
regarding available assistance (Blomberg, 2004; Trydegård, 2000). Care managers in Sweden have expressed that they try to meet the older person’s needs but that this is not always possible because of limitations in the service (Dunér & Nordström, 2010), and they tend to make decisions – i.e. suggest assistance – that agree with local guidelines (Dunér & Nordström, 2006). This might be one explanation for why food distribution has increased in municipalities whilst support regarding food preparation in the home has decreased (County Administration Boards of Sweden, 2009). According to Larsson (2006), the total use of formal services decreased in the older population in Sweden between the 1980s and the 2000s. Instead, it is most common that those in need of help in the home receive informal care (Nordberg, Von Strauss, Kåreholt, Johansson, & Wimo, 2005; Sundström & Johansson, 2005) – despite the fact that the family’s efforts in caregiving are supposed to be a supplement to public care (Lagergren, 2002). However, this depends on the person’s social network, and those living alone receive less informal care compared to those living with someone, and single-living persons seem to receive a higher level of formal care (Larsson & Thorslund, 2002).

**Everyday life when living with dementia**

Approximately 36 million people worldwide have dementia (World Health Organization [WHO] and Alzheimer’s Disease International, 2012) and it is estimated that this number will double every 20 years, with the highest increase occurring in the developing countries (Ferri et al., 2006). Dementia mainly affects older people (WHO, 2012), and as the number of older people is rising around the world, more will develop a dementia disease (Alzheimer’s Association, 2013). For instance, approximately 1% of people have dementia at the age of 65 compared to over 50% of those in their 90s (Swedish Council on Technology Assessment in Health Care, 2008).

Dementia is a syndrome that includes several diseases, the most common are Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia. However, it is common for individuals to have mixed types. A dementia leads to a deterioration in cognitive function and affects, for instance, memory, orientation, learning ability, language and judgment. It is not only the individual who has dementia who is affected;
families, caregivers and society are all influenced physically, psychologically, socially and economically by the disease (WHO, 2012).

**Everyday life for persons with dementia**

Persons with dementia have described that they associate the disease with feelings of loss (Ostwald, Duggleby, & Hepburn, 2002), which can be related to the assertion that having a dementia can lead to difficulties performing daily activities (Agüero-Torres, Thomas, Winblad, & Fratiglioni, 2002; WHO and Alzheimer’s Disease International, 2012). Further, one’s ability to live independently can be affected (Luppa et al., 2010). Additionally, difficulties in managing the home situation increase gradually (von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012), with practical skills diminishing and problems performing ordinary activities arising along with problems dealing with new situations and activities (Steeman, de Casterlé, Godderis, & Grypdonck, 2006). In order to accomplish everyday activities, persons with dementia have described that they sometimes avoid certain situations (Gillies, 2000) and that their own expectations of what they are able to do decrease (De Boer et al., 2007). Further, relying on others (Steeman, Godderis, Grypdonck, De Bal, & De Casterlé, 2007), minimizing or denying what is happening, and comparing oneself with others who have more severe problems have also been described (De Boer et al., 2007). However, this does not mean persons with dementia per se become passive when experiencing problems; instead, it has been described how people actively try to find strategies for managing the situation (Nygård, 2004; von Kutzleben et al., 2012; Öhman, Josephsson, & Nygård, 2008). Keeping notes and writing in diaries are examples of such strategies (De Boer et al., 2007). Consequently, suffering from the same disease does not mean that the experiences are the same for all individuals with dementia. In an interview study, it was found that experiences ranged from those who did not feel it was “such a big deal” to those who described life as hell (Hulko, 2009).

Even though dementia is a progressive disease, positive aspects have been expressed. People with dementia usually try to uphold their life as much as possible by maintaining daily routines and activities (De Boer et al., 2007), by trying to live in the present (von Kutzleben et al., 2012) and by focusing
on their remaining abilities instead of the severities (Steeman et al., 2007). Feelings like optimism, satisfaction and appreciation have been expressed in descriptions of what it means to live with the disease (Ostwald et al., 2002). Further, relationships with others have been described in terms of love, affection and closeness (Steeman et al., 2007).

**Being the partner of a person with dementia and sharing everyday life**

Being the partner of a person with dementia has been experienced as a changed situation in which several aspects of daily life are affected. Even so, positive experiences appeared, and doing things together, for instance, could result in closeness and meaningfulness (Persson & Zingmark, 2006); it has also been described that there is still affection, love and closeness within the relationship (Hellström, Nolan, & Lundh, 2007). In a review examining relationships between family caregivers and persons with dementia, even increased closeness, warmth and mutual affection were found (Ablitt, Jones, & Muers, 2009). The importance of doing things without the person with dementia has also been expressed, as this offers time to rest, even though it was difficult to get this time alone. Conflicts arose when choosing between the needs of the person with dementia and one’s own needs (Persson & Zingmark, 2006).

A transition in the relationship is commonly described, whereby a couple moves from being equal partners towards a situation in which the healthy spouse becomes more of a caregiver than a partner (Walters, Oyebode, & Riley, 2010). Still, involving the person with dementia in activities has been described as important (Butcher, Holkup, & Buckwater, 2001). For example, in studies of wives caring for their husbands with dementia it has been found that they took over their husband’s old responsibilities but at the same time tried to include them in activities with fewer risks, like domestic work, to make them feel like they were contributing something (Hellström, Nolan, & Lundh, 2007). The transition resulted in partners giving up most of their own life to be able to take care of the person with dementia (Jansson, Nordberg, & Grafström, 2001). Making all the decisions for the couple can lead to feelings of loneliness and abandonment (Persson & Zingmark, 2006). This might result in feelings of stress and burden, as well as declined health.
(Brodaty & Donkin, 2009; Etters, Goodall, & Harrison, 2008), which have been found to be reasons for the person with dementia moving to special housing (O’Malley & Croucher, 2005). However, pride at achieving activities while caring for the partner with dementia has been described among husbands (Sanders & Power, 2009). Furthermore, appreciating the small pleasures in life and trying to find the positive things in life as well as living in the present can be ways to preserve the relationship (Hellström, Nolan, & Lundh, 2007).

Formal caregiving using a person-centred perspective

To be able to treat and care for persons with dementia within their life situation, a bio-psycho-social perspective is needed in health care. One way to achieve this would be through person-centred care. Kitwood (1997) was the first to articulate the importance of using a person-centred care as a response to the biomedical view that had previously been central in dementia care. There is no consensus regarding person-centred care but several researchers, like Brooker (2004), Edvardsson, Winblad, & Sandman (2008) and Slater (2006), have tried to describe the meaning of the concept. At least there seems to be an agreement that the concept includes several dimensions, and that the focus is on the person behind the disease instead of on the disease itself, whereby the person’s subjective experiences are of great importance (Brooker, 2004, 2007; Edvardsson et al., 2008; Slater, 2006). According to a review by Edvardsson et al. (2008), person-centred care includes: considering the personhood concealed but not lost; acknowledging the personhood in all aspects of care; creating a personalized care and environment; sharing decision-making; understanding behaviours from the subjective world of the person; and prioritizing relation and care tasks equally (Edvardsson et al., 2008). A recent study, in which persons with dementia, family and staff were interviewed, highlights the importance of including the family in the care (Edvardsson, Fetherstonhaugh, & Nay, 2010), the previous neglect of which has been pointed out in criticism of the concept. Nolan, Davies, Brown, Keady and Nolan (2004) highlight that this probably has to do with the individualistic focus of person-centred care.

In Sweden, person-centred care has not had as much clinical impact as in other countries (Edvardsson, 2011). However, Ekman et al. (2011) assert...
that formal caregivers today broadly acknowledge the meaning and importance of this concept for care. Recently, national guidelines were developed for health care professionals working with persons with dementia, whereby person-centred care is also advocated (National Board of Health and Welfare, 2010). One might argue that person-centred care is also important when caring for person with poor nutritional status, as research shows that an individualized nutritional programme based on a person’s problems, desires and resources can improve nutritional status (Lorefält & Wilhelmsson, 2012) health and cognitive ability (Wikby, Ek, & Christensson, 2009).

**Foodwork and meals at home**

There is no overall definition of nutrition, but it has usually been described from a biological perspective (Beauman et al., 2005), which can be distinguished, for instance, in the WHO’s (2013) definition: “Nutrition is the intake of food, considered in relation to the body’s dietary needs”. However, this perspective has been questioned (Beauman et al., 2005), which might be related to the fact that using a biomedical perspective in health care has been found to be insufficient. Instead, it is important to understand an individual within his/her surrounding context, i.e. have a bio-psycho-social perspective on the person (Engel, 1977). In studying meals the social and cultural aspects are included, i.e. how older persons choose, prepare, serve and eat food (Amella & Aselage, 2011). The definition of meal is complex, and in English it means both what is eaten and the event of eating (Meiselman, 2008). Oltersdorf, Schlettwein-Gsell and Winkler (1999), based on other researchers’ definitions, have described criteria for what comprises a meal, stating that meals can be defined based on the time of the day of the intake, the amount and combination of food, and whether or not there is social interaction between people. Sobal (2000) stresses that the meal is as much a social activity as it is a situation for easing hunger and thirst. Further, Fjellström (2004) and Mäkälä (2000) write that meals are social acts and something we share together with others and, depending on habits and values in a certain society or group, that people have notions of what constitutes a proper meal. The food included in the meal has been found to describe a person’s class, ethnic group or lifestyle affiliation, as well as other
social positions she/he holds, and is associated with one’s family and home (Anderson, 2005). Meals are preceded by planning and shopping as well as the preparation of food, which can be performed by the eater him/herself or by others; such activities have been described as foodwork (Bove & Sobal, 2006), and this term will be used in this thesis to describe such activities.

**Traditions, routines and roles**

Foodwork has traditionally been associated with a female role (DeVault, 1991), and women usually have the main responsibility for preparing food; this is especially true for older women (Gustafsson, Andersson, Andersson, Fjellström, & Sidenvall, 2003). According to a British study (Caraher, Dixon, Lang, & Carr-Hill, 1999), men tend to learn how to cook later in life and learn this from their partner more often compared to females, whilst women usually learn it at younger ages from their mothers. Similar results have been found in some Swedish studies, in which it has been found that women felt comfortable in these activities and that foodwork was not something they had to think about, but rather something they had always done and, therefore, were able to perform (Gustafsson et al., 2003; Sidenvall, Nydahl, & Fjellström, 2001). However, older women have described that they are anxious about becoming ill and losing their ability to carry out foodwork (Gustafsson et al., 2003). Further, divorced women and widows have expressed that their role and identity as a food provider ceased and resulted in feelings of loss (Sydner, Sidenvall, Fjellström, Raats, & Lumbers, 2007). In interviews with older men who had previously lived in a partnership, the opposite was revealed: this was often a new responsibility (Kullberg, Björklund, Sidenvall, & Åberg, 2010), and was difficult to perform due to lack of knowledge. Changes in roles in a couple could arise as the older woman became ill or frail, and when the change was slow the wife helped and taught the husband as he successively took on these responsibilities. However, these could be changes of a more natural character, like a result of retirement, which meant that foodwork was carried out as teamwork, with the woman still having the main responsibility and the husband being a helper (Sydner et al., 2007).
**Dependence and independence applied to the activities of foodwork and meals**

A disease like dementia might lead to severities in performing activities and make help from others necessary, for example during foodwork and meals. Using the concepts of dependence and independence regarding meals has recently been described by Fjellström and Mattsson Sydner (2013). The authors problematized the degree to which autonomy and independence should be promoted, since for persons who to some extent lack insight concerning their need of support it is a dilemma to preserve their independence and simultaneously make sure they attain a healthy food intake (Fjellström & Mattsson Sydner, 2013).

Both dependence and independence have previously been used and discussed together with ageing, which might be a result of ageing itself involving various kinds of dependence, like becoming financially dependent after retirement and the increased risk of becoming dependent on others as a result of disability and morbidity (Gibson, 1998). Dependence is usually described as negative and as something to be prevented, as well as a shameless and stigmatic concept, whilst both independence and autonomy are described as the opposite (Fine & Glendinning, 2005; Munnichs, 1976).

Dependence has been defined from a biomedical view, meaning that it has to do with the person’s ability to perform daily activities (Wilkin, 1987). However, it has also been emphasized that the concept includes a social dimension, meaning that relationships between people are important (van den Heuvel, 1976). Further, dependence can be understood as something that brings people together as humans (Sennett, 2004), which offers a more positive view of the concept. Still, dependence has previously been described as being related to ageism. This might be related to dependence usually being described together with not only old age but also childhood, which might be understood as an assertion that older persons should be treated the same way as children, since within both age groups people are recognized as being dependent on others. Further, the population of old persons, as well as their dependence, is rising and will likely continue increasing in the future, which also reinforces ageism (Bond & Cabrero, 2007).
Independence, on the other hand, means that one does not depend on anyone else; i.e., the concept actually excludes social relationships. One might argue that it is not possible to be totally independent of others. There is a third concept – interdependence – which emphasizes that there is a social world in which people meet and relationships are created, and that in some ways we are all dependent on each other (Munnichs, 1976). However, in a health care context independence is commonly used and described in a way that includes social relations in the concept (Bonikowski, Musto, Suteu, MacKenzie, & Dennis, 2012; Tamaru, McColl, & Yamasaki, 2007), which is in accordance with how the concept of independence is understood in this thesis.

In interview studies with older persons regarding foodwork and meals, independence and dependence seemed to be related to the ability to perform such activities. Moreover, independence seems to be highly valued and older women have expressed the importance of being independent from others and preserving meals and foodwork (Andersson & Sidenvall, 2001; Gustafsson et al., 2003; Kullberg et al., 2010; Sidenvall et al., 2001). The ability to cook has been described as being associated with the ability to live on one’s own (Porter, 2007). As independence is of great importance, if function decreases and cooking becomes difficult it can result in deficient meals (Gustafsson, 2002).

**Nutritional problems among home-living older persons**

Malnutrition occurs when food and nutrient intake do not meet an individual’s nutrient requirements (Skipper, 2012). With such a definition, a person might have an intake that is either lower or higher than the requirements. However, when it comes to older people the concepts of malnutrition and undernutrition are usually used interchangeably (Hickson, 2006). In a concept analysis among older people, malnutrition was found to mean “faulty or inadequate nutritional status; undernourishment characterized by insufficient dietary intake, poor appetite, muscle wasting and weigh loss” (Chen, Schilling, & Lyder, 2001, p. 139). In the clinical setting, a person with at least two of the following characteristics is considered to be undernourished: insufficient food intake; loss of weight, muscle or fat mass; fluid accumulation; or decreased hand grip strength.
Approximately 2% of older persons living at home are malnourished, and 24% are at risk of malnutrition (Guigoz, 2006). The consequences of malnutrition are poorer physical capacity (Ödlund Olin, Koochek, Ljungqvist, & Cederholm, 2005), decreased subjective health (Keller, Østbye, & Goy, 2004), increased risk of illness, and mortality (Akner & Cederholm, 2001).

Several factors, which can be of a physical, social or psychological nature, have an impact on older persons’ nutritional status. Older persons tend to contract illnesses more often than others do, and disabilities and decreased physical activity can lead to reduced food intake (Hickson, 2006) as it can affect the ability to cook and eat food (Pirlich & Lochs, 2001). As a consequence of illness, prescribed drugs are used, and these drugs often have side effects such as dry mouth and loss of appetite (Alibhai, Greenwood, & Payette, 2005). Further, older people often do not meet fluid intake requirements, even though fluid is one of the most important components in maintaining good nutritional status (Elsner, 2002). All these factors can be considered to be of a physical nature. Factors of a social nature can be related to, for instance, living arrangements. Living alone and receiving help seems to affect nutritional status negatively (Söderhamn, Christensson, Idvall, Johansson, & Bachrach-Lindström, 2012), which can be a result of decreased enjoyment in arranging the meal (Gustafsson & Sidenvall, 2002). Factors of a psychological nature include depression (Söderhamn et al., 2012) loneliness and stress which can lead to malnutrition (Hickson, 2006). Further, decreased cognitive ability is associated with malnutrition (Fagerström, Palmquist, Carlsson, & Hellström, 2011; HaeKwan, Kim, ByoungHoon, & ChanHyong, 2009).

**Foodwork and meals when living with dementia**

*Being a person with dementia and its effect on foodwork and meals*

Eating difficulties are common among persons with dementia (Manthorpe & Watson, 2003). Even persons in a mild stage of dementia seem to lose weight, which appears to be related to poor food intake (Holm &
Söderhamn, 2003). In a study including home-living persons with dementia it was found that almost 50% of the participants were malnourished or at risk of malnutrition (Roqué, Salva, & Vellas, 2013).

There are several factors that contribute to malnutrition in people with dementia. Most research aiming to describe problems regarding meals have been carried out in hospitals and special housing, and research among home-living persons with dementia is called for. Lack of appetite, a lost ability to recognize food, and eating things that are not appropriate or in small sizes are some of the problems that can occur when one suffers from dementia, which might lead to malnutrition (Aselage & Amella, 2010). Keller et al. (2008) have found that some of the problems described concerning eating in special housing or hospitals are also experienced by people living in ordinary homes. But, there are also other problems that might arise when a person lives in his/her own household, including challenges in buying and cooking food (Keller, Edward, & Cook, 2007; Keller et al., 2008). A recent study revealed that critical incidents regarding grocery shopping took place in the home of the person with Alzheimer’s disease, on the way to and from the grocery shop, as well as in the grocery shop. To manage the situation, participants used several strategies like double-checking, planning ahead or avoiding certain situations (Brorsson, Öhman, Cutchin, & Nygård, 2013).

**Changes in foodwork and meals experienced by partners**

Sharing meals has been referred to as a social activity, something enjoyable and a highlight of the day in interviews with family members of persons with dementia. However, changes and difficulties can arise, and it has previously been described that family members experience frustration, stress and conflict as a result of these changes (Keller et al., 2007). A few studies have focused on how foodwork and meals change, and as a result of this it has also been revealed that roles and routines in the families are affected. One study showed that female caregivers experienced a transition from working as a team to instead having the main responsibility and doing things alone; i.e., they had extended their current role as food provider. Male caregivers, however, described that as a result of their partner’s disease they had been forced to take over the responsibility and that it had become a challenge to perform these activities (Fjellström et al., 2010). Another study described
that when adjusting to living with a person with dementia men shifted from a passive role to an active one as food provider, whilst their female partners with dementia instead became increasingly passive as a result of a decreased capacity to manage activities. At the beginning of the process, the wife with dementia was the expert and the husband needed her knowledge to carry out foodwork and meals, but this shifted over time (Atta-Konadu, Keller, & Daly, 2011). Male caregivers have also stressed that when taking over this responsibility they learned that preparing meals is much more than just cooking, and that it was harder than their female partner had made it seem (Russell, 2001). Even though it might be a struggle to manage these new responsibilities, male spouses have expressed pride in achieving foodwork while caring for their partner (Sanders & Power, 2009).

**The Life Nourishment Theory**

Recently, the Life Nourishment Theory (LNT) was developed based on longitudinal studies including interviews with families in Canada living with dementia. According to this theory, meals are mirrors that reflect who we are, and studying meal situations may be one way to capture families’ experiences of overall daily life when a family member is suffering from dementia. There are three interrelated concepts that further explain the theory: being connected, honouring identity, and adapting to an evolving life (Genoe et al., 2012; Genoe et al., 2010; Keller et al., 2010). Being connected includes how relationships can be preserved, and help families stay united and interact both within the family as well as with others. Different parts promote the connection: being face to face, which means that people physically create meals together; participating psychologically, i.e. cognitive and emotional engagement; and getting and giving support, which could be of both a physical nature (for example helping with foodwork) and a psychological nature (like discussing problems and finding solutions) (Keller et al., 2010). Honouring identity means that both the individual and family identities are honoured by preserving dignity and autonomy, and by helping persons feel they are important. This process includes protecting dignity while struggling for autonomy, which has to do with having respect for oneself and for others, as well as being accepted for who you are. Having meaningful roles of importance for the person contributes to maintaining his/her identity. Reaffirming a sense of self in the world can be about, for
instance, preserving routines and traditions (Genoe et al., 2010). Adapting to an evolving life refers to the process of being aware of changes during meals and foodwork, and adjusting and adapting to these changes as the dementia continues to progress (Genoe et al., 2012).

**Support in foodwork and meals**

Aselage and Amella (2010) argue that there is a lack of research when it comes to supporting home-living persons with dementia regarding meals and preserving or improving nutritional status in the home environment. This can be one explanation for why nutritional guidelines are seldom used (Persenius, Hall-Lord, Bååth, & Larsson, 2008), as well as why nutritional interventions were only used in about 20% of the cases in a Dutch study among malnourished older persons receiving home-help (Meijers, Halfens, van Bokhorst-de van der Schueren, Dassen, & Schols, 2009). In a review of interventions to prevent malnutrition in people with dementia, those living in their ordinary homes were excluded, which was motivated with the explanation that these people have different problems that require other interventions compared to those in special housing or hospitals (Jackson, Currie, Graham, & Robb, 2011). However, one might argue that some of the interventions emphasized in the review can also be applicable to home-living persons, like educating caregivers, adjusting the environment and giving individual support. In the national guidelines for care in cases of dementia, which target persons in both ordinary and special housing, individualized care using several interventions is highlighted (National Board of Health and Welfare, 2010).

A study including both a literature review and focus groups interviews revealed that environmental modifications might be needed for home-living persons with dementia. Such interventions, which could help them participate in foodwork as much as possible with minimum risk, include installing timers, providing a place in the kitchen where they can sit and carry out foodwork, and making things visible so it is clear what and where they are (van Hoof, Kort, van Waarde, & Blom, 2010). For persons who are not able to prepare meals independently, food distribution (e.g. meals-on-wheels) can be used. However, a recent Swedish qualitative study among professionals involved in such a service revealed that it was found to be a
deficient intervention as the staff did not know what actually happened after they delivered the food; it would have been preferable to stay while the person ate (Pajalic, Persson, Westergren, & Skovdahl, 2012).
Rationale for the thesis

Previous research has shown that older persons highly value independence and living in their own household, which is in agreement with national policies. This can be jeopardized, however, if a person has insufficient nutritional intake. Nutrition should be understood from more than just a biomedical perspective; meals can be studied with a focus on social and cultural aspects of the phenomenon. However, there is a lack of knowledge regarding meals for home-living persons, not least among those with dementia. To be able to identify problems and develop evidence-based interventions for this group, whereby the person’s own problems and wishes serve as the basis when planning for care and meals, it is essential to explore the experiences of both the person with dementia and his/her partner as well as staff.
The aim of this thesis was to explore and describe foodwork and meals for older persons with dementia and their partners in ordinary homes. The research questions were:

How is nutritional status affected by cognitive impairment among home-living older men and women? (Paper I)

Which changes occur in couples regarding foodwork and meals? (Papers II and III)

Which functions are important to uphold regarding foodwork and meals? (Papers II, III and IV)

How can foodwork and meals be adjusted to the cognitive changes? (Papers II, III and IV)
Method

Design

Several designs were used when performing the four studies on which the thesis is based. An overview of the studies is found in Table 1. The results from the longitudinal descriptive study among home-living unlike-sex twins (Paper I) showed the need for further research on foodwork and meals for persons with dementia living at home. Since little is known (Aselage & Amella, 2010), qualitative methods were chosen to highlight this phenomenon (Polit & Beck, 2012). Thereafter, two studies focusing on the experiences of living with dementia were conducted (Papers II and III). In the study including persons with dementia (Paper II) an ethnographic approach was used which, according to Wolcott (2008), entails studying customary social behaviours to learn about the culture in a specific group of people. Further, this method can be used to describe people’s actions in everyday life (Hammersley & Atkinson, 1995). Therefore, in ethnographic studies data need to be collected in the natural setting, which makes it possible to study certain aspects of people’s daily life. Fieldwork is highly valued, and preferred data collection includes observations and interviews (Wolcott, 2008). In Paper II the results are based mainly on interviews but also include observations. The explorative and descriptive studies including persons with dementia (Paper II) and their partners (Paper III) revealed several challenges as well as a need for support to manage the complex situations they were facing. Since little is known about this, another qualitative study (focus group interviews) was conducted with staff (Paper IV) to describe and explore their views on how meals can be improved. Data collected in the interviews (Papers II and III), together with observations from the home visits, were used to create vignettes. These vignettes were further used as a basis for the discussions during the focus group interviews with staff (Paper IV).
Table 1. Overview of the included papers

<table>
<thead>
<tr>
<th>Study</th>
<th>Aim</th>
<th>Design</th>
<th>Method of data collection</th>
<th>Participants</th>
<th>Time of data collection</th>
<th>Method of data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>The aim of the study was to describe nutritional status in older persons living at home and to investigate factors of importance for nutritional status. Another aim was to describe possible relationships between nutritional status and health-related quality of life (HRQoL).</td>
<td>Longitudinal and descriptive</td>
<td>Individual structured interviews with fixed answers</td>
<td>n=258 elderly unlike-sex twins</td>
<td>1995-1997 1999-2001 2003-2005</td>
<td>Descriptive and analytical statistics</td>
</tr>
<tr>
<td>II</td>
<td>The aim of the study was to capture the self-descriptions of managing mealtime tasks by persons with dementia.</td>
<td>Exploratory and descriptive</td>
<td>Individual interview study with an ethnographic approach</td>
<td>n=15 persons with dementia</td>
<td>2008-2009</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>III</td>
<td>The aim of the study was to explore and describe spouses’ experiences of food activities and meals in couples in which one partner had dementia.</td>
<td>Exploratory and descriptive</td>
<td>Semi-structured interviews</td>
<td>n=10 partners living with a person with dementia</td>
<td>2008-2009</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>IV</td>
<td>The aim of the study was to explore and describe staff views on improving foodwork and meals for home-living persons with dementia.</td>
<td>Exploratory and descriptive</td>
<td>Focus-group interviews</td>
<td>n=22 staff (in 4 groups) working with home-living persons with dementia</td>
<td>2011-2012</td>
<td>Qualitative content analysis</td>
</tr>
</tbody>
</table>
Participants and setting

In Paper I the sample consisted of unlike-sex twins from the Swedish Twin Register, and more specifically from the national project “Aging in women and men: a longitudinal study of gender differences in health behaviour and health among elderly”. Inclusion criteria have previously been described in detail (Gold, Malmberg, McClearn, Pedersen, & Berg, 2002). A total of 249 twin pairs, or 498 persons, were interviewed at home by experienced research nurses during the period 1995-1997, i.e. Occasion 1 (OC1). This was a structured interview including sociodemographic background data, cognitive testing, health examination, drug registration and blood sampling. Two repeated interviews were carried out during 1999-2001 (Occasion 2 [OC2]) and 2003-2005 (Occasion 3 [OC3]). At OC3, an assessment of nutritional status (Mini Nutritional Assessment [MNA]) was conducted on 258 persons, and the sample in this study consists of these persons, who all still lived in their ordinary homes. Of these 258 persons, 128 were men and 130 women, and ultimately a total of 65 twin pairs had stayed intact (Figure 1).

A comparison of those at OC3 who participated (n=258) in Paper I and those who did not (n=48) showed that those who were excluded had significantly lower Mini-Mental State Examination (MMSE) scores (p<0.001) and Activity of Daily Living (ADL) functioning (p<0.001). No significant differences were found regarding sex or age.
Figure 1. Flowchart of participants in Paper I.

**OC1 (Occasion 1)**
1995-1997
n=498 persons (249 twin pairs)
Aged: 71-80

58 persons died. 60 dropped out: illness, frailty, unwillingness to participate.

**OC2**
1999-2001
n=380 persons

62 persons died. 12 dropped out: illness, frailty, unwillingness to participate.

**OC3**
2003-2005
n=306 persons

47 persons did not complete MNA. One person lived in special housing.

**Participants in Paper I**
n=258
Aged: 79-88
All data for Papers II, III and IV were collected in the same municipality in southern Sweden, with approximately 130,000 residents. All individuals received written and oral information about the interview study they were asked to participate in (Papers II, III and IV).

Participants in Papers II and III participated in a project called Food, Exercise and Memory Loss. The main aim of the project was to examine whether or not individual exercise and food interventions could improve health-related quality of life. Both qualitative and quantitative data were collected during the years 2008–2009 among home-living persons with dementia and their partners. Persons diagnosed with dementia by a physician 6–12 months prior to the time of data collection were asked to participate in the project by a public health nurse or similar, specialized in persons with dementia. If the person wanted to participate the primary nurse passed on contact information to the researcher, who contacted the person and gave him/her further information about the study. At least eight visits were conducted in each home, where the researcher and the person discussed food and meals. However, this depended on the person’s nutritional status, and in some cases 15 home visits were performed (Table 2). Notes were made after each visit, based on what was discussed and observed. A total of 35 persons with dementia were included in the project.

Fifteen persons with dementia were asked to participate in an interview study with an ethnographic approach (Paper II), since they were considered to be able to communicate verbally to an adequate extent. They all agreed to participate. All partners (11 persons) participating in the project were asked to participate in a separate interview study, and all but one gave consent (Paper III). Participants’ characteristics are presented in Tables 3 and 4, and the relationship between participants in Papers II and III are presented in Table 5.
Table 2: Collected data during each home visit with participants in Papers II and III.

<table>
<thead>
<tr>
<th>Week</th>
<th>Persons at risk of malnutrition</th>
<th>Well-nourished persons</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Weight</td>
<td>Assessment of eating function</td>
</tr>
<tr>
<td>0*</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>1</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>4</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>6</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>10</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>14</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>18</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>22</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>24*</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>52*</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

*If there was a partner living with the person with dementia, his/her health and burden of being a caregiver were assessed as well.
<table>
<thead>
<tr>
<th>Age</th>
<th>Gender</th>
<th>Living status</th>
<th>MNA</th>
<th>MMSE</th>
<th>Foodwork</th>
</tr>
</thead>
<tbody>
<tr>
<td>82</td>
<td>Female</td>
<td>Lives alone in flat.</td>
<td>24.5</td>
<td>25</td>
<td>Buys groceries herself. Receives meals-on-wheels from the home-help service.</td>
</tr>
<tr>
<td>84</td>
<td>Female</td>
<td>Lives with partner in co-operative flat.</td>
<td>25.5</td>
<td>22</td>
<td>Buys groceries and cooks home-made food together with her partner.</td>
</tr>
<tr>
<td>77</td>
<td>Male</td>
<td>Lives alone in house.</td>
<td>24.0</td>
<td>26</td>
<td>Buys groceries and warms up partly or ready-cooked meals himself.</td>
</tr>
<tr>
<td>71</td>
<td>Male</td>
<td>Lives with partner in flat.</td>
<td>22.0</td>
<td>30</td>
<td>Buys groceries together with partner. Partner cooks home-made food.</td>
</tr>
<tr>
<td>69</td>
<td>Male</td>
<td>Lives with partner in house.</td>
<td>24.0</td>
<td>16</td>
<td>Partner buys groceries and cooks home-made food.</td>
</tr>
<tr>
<td>78</td>
<td>Female</td>
<td>Lives alone in co-operative flat.</td>
<td>21.0</td>
<td>29</td>
<td>Buys groceries herself. Receives meals-on-wheels from the home-help service.</td>
</tr>
<tr>
<td>86</td>
<td>Female</td>
<td>Lives alone in co-operative flat.</td>
<td>23.0</td>
<td>21</td>
<td>Buys groceries and cooks home-made food herself.</td>
</tr>
<tr>
<td>77</td>
<td>Male</td>
<td>Lives with partner in house.</td>
<td>19.0</td>
<td>21</td>
<td>Partner buys groceries and cooks home-made food.</td>
</tr>
<tr>
<td>80</td>
<td>Female</td>
<td>Lives alone in co-operative flat.</td>
<td>24.5</td>
<td>21</td>
<td>Buys groceries herself. Receives meals-on-wheels from the home-help service.</td>
</tr>
<tr>
<td>79</td>
<td>Female</td>
<td>Lives with partner in co-operative flat.</td>
<td>25.0</td>
<td>27</td>
<td>Buys groceries and cooks home-made food herself.</td>
</tr>
<tr>
<td>85</td>
<td>Female</td>
<td>Lives alone in flat.</td>
<td>24.0</td>
<td>22</td>
<td>Buys groceries and cooks home-made food herself.</td>
</tr>
<tr>
<td>80</td>
<td>Female</td>
<td>Lives alone in flat.</td>
<td>24.0</td>
<td>23</td>
<td>Buys groceries and cooks home-made food herself.</td>
</tr>
<tr>
<td>77</td>
<td>Male</td>
<td>Lives alone in house.</td>
<td>26.0</td>
<td>28</td>
<td>Receives groceries and meals-on-wheels from the home-help service.</td>
</tr>
<tr>
<td>85</td>
<td>Female</td>
<td>Lives alone in house.</td>
<td>24.0</td>
<td>29</td>
<td>Buys groceries together with son. Receives meals-on-wheels from the home-help service.</td>
</tr>
<tr>
<td>79</td>
<td>Female</td>
<td>Lives with partner in flat.</td>
<td>26.0</td>
<td>25</td>
<td>Buys groceries together with partner, cooks home-made food herself.</td>
</tr>
<tr>
<td>Age</td>
<td>Gender</td>
<td>Living status</td>
<td>Foodwork</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----</td>
<td>--------</td>
<td>---------------</td>
<td>----------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>70</td>
<td>Female</td>
<td>Married and lives with husband in house.</td>
<td>Responsible for cooking even before partner was diagnosed with dementia. Now cooks home-made food and buys groceries herself.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>80</td>
<td>Female</td>
<td>Married and lives with husband in flat.</td>
<td>Responsible for cooking even before partner was diagnosed with dementia. Now cooks home-made food alone, and buys groceries together with her partner.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>83</td>
<td>Female</td>
<td>Married and lives with husband in flat.</td>
<td>Responsible for cooking even before partner was diagnosed with dementia. Now cooks home-made food and buys groceries herself.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>79</td>
<td>Female</td>
<td>Married and lives with husband in flat.</td>
<td>Responsible for cooking even before partner was diagnosed with dementia. Now cooks home-made food alone, and buys groceries together with her partner.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>73</td>
<td>Female</td>
<td>Married and lives with husband in house.</td>
<td>Responsible for cooking even before partner was diagnosed with dementia. Now cooks home-made food and buys groceries herself.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>76</td>
<td>Female</td>
<td>Married and lives with husband in house.</td>
<td>Responsible for cooking even before partner was diagnosed with dementia. Now cooks home-made food and buys groceries herself.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>78</td>
<td>Male</td>
<td>Married and lives with wife in house.</td>
<td>Responsible for cooking even before partner was diagnosed with dementia. Now cooks home-made food alone, and buys groceries together with his partner.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>86</td>
<td>Male</td>
<td>Married and lives with wife in terrace house.</td>
<td>Partner used to be responsible for cooking before being diagnosed with dementia. Now cooks home-made food and buys groceries together with partner.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>86</td>
<td>Male</td>
<td>Married and lives with wife in terrace house.</td>
<td>Partner used to be responsible for cooking before diagnosed with dementia. Now receives meals-on-wheels from the home-help service and buys groceries himself.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>63</td>
<td>Male</td>
<td>Lives with partner in co-operative flat.</td>
<td>Responsible for cooking even before partner was diagnosed with dementia. Now cooks home-made food alone, and buys groceries together with his partner.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*1In these cases the participants had taken over the main responsibility later in life, e.g. after retirement.*
Table 5: Relationship between participants in Papers II and III

<table>
<thead>
<tr>
<th>Participants Paper II (sex and age)</th>
<th>Participants Paper III (sex and age)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female, 82</td>
<td>Male, 86*</td>
</tr>
<tr>
<td>Male, 77</td>
<td>Female, 79*</td>
</tr>
<tr>
<td>Female, 78</td>
<td>Male, 79*</td>
</tr>
<tr>
<td>Female, 86</td>
<td>Female, 73*</td>
</tr>
<tr>
<td>Female, 80</td>
<td>Female, 76*</td>
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<tr>
<td>Female, 79</td>
<td></td>
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<tr>
<td>Female, 85</td>
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<td>Female, 80</td>
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<td>Male, 77</td>
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<td>Female, 85</td>
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<td>Female, 79</td>
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<tr>
<td>Female, 84*</td>
<td>Male, 86*</td>
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<td>Male, 71*</td>
<td>Female, 79*</td>
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<tr>
<td>Male, 69*</td>
<td>Female, 73*</td>
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<tr>
<td>Male, 77*</td>
<td>Female, 76*</td>
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<td>Female, 70</td>
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<td>Male, 78</td>
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<td>Female, 83</td>
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<td></td>
<td>Male, 86</td>
</tr>
<tr>
<td></td>
<td>Male, 63</td>
</tr>
</tbody>
</table>

* Both spouses in the couple were interviewed.

In Paper IV staff working with persons with dementia living at home participated, and a total of four focus groups interviews were performed. Two groups consisted of staff with medium-length university education, specialized in dementia. Contact with these persons had already been established, as they had been involved in requesting participation in the Food, Exercise and Memory Loss project. For the other two groups, a head of unit was contacted and asked to suggest two home-help groups consisting of nursing assistants. The composition of the focus groups is presented in Table 6. As different professionals are included, they will be collectively referred to as staff. A staff meeting was organized with each group, at which the researcher informed them orally and in writing, and requested their participation in the study.
Data collection

Quantitative data

In Paper I instruments measuring nutritional status and cognitive function, as well as questions that may have an impact on nutritional status, were used.

Instruments

The full *Mini Nutritional Assessment* (MNA) (Guigoz, Vellas, & Garry, 1994/1995) is the most commonly used tool in screening for nutritional status among older persons, and is also considered to be the most appropriate (Secher, Soto, Villars, van Kan, & Vellas, 2007). The MNA was developed to assess the nutritional status of frail older persons and consists of 18 items (anthropometric measurements, general assessment, dietary assessment, subjective assessment), with a maximum total score of 30. A score of less than 17 indicates that a person is malnourished, between 17 and 23.5 that the person is at risk of malnutrition, and above 23.5 that the person is well-nourished (Vellas et al., 1999).
The *Mini-Mental State Examination* (MMSE) was used to screen for cognitive function (Folstein, Folstein, & McHugh, 1975). The MMSE is commonly used both clinically and in research studies during diagnosis and screening (Tombaugh & McIntyre, 1992). Scores range between 0 and 30 (Folstein et al., 1975); how they should be interpreted is not definite, but Jönsson and Wimo (2009) suggest that 20 points or more be considered mild dementia, 10-19 moderate, and less than 10 severe.

**Supplementary variables**

The longitudinal study (Paper I) included questions on aspects that might have an impact on the nutritional status (Appendix A). In the thesis, two questions about health were dichotomized and used during the statistical analysis. A question about cognitive function was used in a similar way, hereafter referred to as memoryDL.

**Qualitative data**

**Individual interviews**

In Papers II and III, individual semi-structure interviews (Polit & Beck, 2012) were performed at the participants’ homes during 2008-09. This meant that interview guides (Appendix B) covering different aspects of meals and foodwork were used, inspired by previous studies about meals (e.g. Andersson & Sidenvall, 2001; Sidenvall et al., 2001) and by one of the researchers’ (B. Sidenvall) knowledge in this research area. Although an interview guide was used when interviewing the persons with dementia (Paper II), these interviews can best be described as conversations in which the researcher adjusted to the person. The interviews were performed at the third home visit or later, when the researcher and participants had established a relationship. The author conducted all interviews in the participants’ homes. In Paper II, one person with dementia was interviewed at an occasion when the partner was not at home. In the interviews with partners (Paper III), two informants chose to be interviewed when their spouses were away from home. In all other cases, if there was a partner, he/she was at home but in a different room from where the interviews were performed. Field notes were made by the author after all interviews, including both observations and thoughts. Detailed observations were made
of the present setting and the participants’ behaviours during the interviews with the persons with dementia (Paper II). Each participant was interviewed once, and each interview lasted 15 to 60 minutes (Paper II) and 13 to 45 minutes (Paper III).

**Focus group interviews**

During 2011-2012 focus group interviews were performed with staff, during which the participants read and discussed two vignettes. These vignettes were based on data from Papers II and III (Appendix A, Paper IV). Before being used in the focus groups, these vignettes were discussed with a public health nurse and a nursing assistant to ensure that the situations felt authentic, and it was determined that they did. The focus groups interviews started with everyone introducing themselves, and then the first vignette was distributed to the participants. All interviews were led by a moderator (me) and an assistant, as described by Krueger and Casey (2009). The moderator was responsible for the interviews, ensuring that everyone was involved in the interviews, and asking follow-up questions like “What do you mean by…” or, “Can you please tell us more about…”. The assistant was responsible for practical tasks, taking notes during the interviews, and summarizing each vignette at the end of the discussion. Each focus group lasted about an hour. All interviews (Papers II, III and IV) were recorded and transcribed verbatim.

**Data analyses**

**Quantitate data**

In Paper I parametric tests (Student’s t-test) were used for Body Mass Index (BMI) and MMSE, and non-parametric tests (Chi-2 tests) were used for all other variables. In the thesis, MMSE was instead analysed using non-parametric tests. In the logistic regression analysis (uni- and multivariate), the nutritional status was used as the dependent variable. Persons at risk of malnutrition or who were malnourished (PAR) were combined during the analysis and compared with those who were well-nourished (WN). Variables consisting of more than two possible responses were dichotomized. In the
logistic regression analyses, MMSE was dichotomized using the commonly used cutoff point of 23/24 (Aevarsson & Skoog, 2000; Grut, Fratiglioni, Viitanen, & Winblad, 1993). Tests for dependent variables were used to analyse differences over time (ANOVA [Paper I], Friedman’s test, Cochran’s Q test). Data have been analysed as both independent and dependent groups as the participants are unlike-sex twins, but since the results are similar the independent variables are presented. SPSS 19.0 was used to perform the statistical analysis in the thesis. Significant levels were set at p<0.05.

**Qualitative data**

Qualitative data were analysed using thematic analysis (Papers II and III) and qualitative content analysis (Paper IV).

**Thematic analysis**

Thematic analysis seeks to find repeated patterns and meanings across a data set (Braun & Clarke, 2006). Spradley (1979) describes thematic analysis as a method in ethnography whereby the theme is associated with the culture, whilst Field and Morse (1995, p. 139) do not relate to the cultural aspect but instead describe it as a “search for and identification of common threads that extend throughout an entire interview or set of interviews”. This distinction is quite good for describing the two different thematic analyses performed here. In paper II, the analysis was performed in accordance with ethnographic thematic analysis described by Wolcott (1994). Meanwhile, the analysis in Paper III was based on Braun and Clarke’s (2006) step-by-step guide for inductive thematic analysis, which rather agrees with Field and Morse’s (1995) definition of thematic analysis.

Wolcott (1994) describes three categories for transforming collected data in an ethnographic study, which were used as a basis for the analysis of Paper II: description, analysis and interpretation. Description involves presenting what is going on in the setting and orienting the reader. In the analysis, data should be structured to allow for the identification of patterns and the presentation of facts. Interpretation is a way to understand and draw conclusions from the data. It is part of the analysis process, but it is important to discuss the extent to which interpretation has occurred.
(Wolcott, 1994). In Paper II this way of transforming data was used as guidance during the analysis, which meant that notes from the observations were first written as vignettes to describe and increase the understanding of the settings and informants. The analysis started with reading the interviews several times and marking all text concerning foodwork and meals, as well as writing short summaries of all interviews. The summaries and the marked text from the first five interviews were used to find patterns and meanings and to create preliminary themes that agreed with the content of the data. These preliminary themes were then discussed with a co-author, and when agreement had been reached an analysis including all 15 interviews were performed whereby the themes were tested if they fit the whole data set. This was done by checking both whether the marked text in the remaining ten interviews fit the themes and whether the meaning of the whole data set seemed to be described in the themes. This meant that two of the authors in the paper discussed the themes continuously. Finally, three main themes with associated subthemes were created. To make sense of the findings, they were interpreted by referring to theories and previous research. Further, findings were critically reviewed and discussed with other researchers.

In Paper III the analysis began with writing summaries based on the interviews and field notes for each participant, which were then discussed with each participant during a second home visit. These were also recorded and transcribed and used in the analysis. In one case the second home visit was not carried out because of illness in the family, but data from the interview were included in the analysis. Braun and Clarke (2006) have identified six phases for a thematic analysis, but these should not be understood as a linear process; instead, there is a constant moving between them. The phases include the researcher becoming familiar with the data set (1), creating initial codes (2), searching for themes (3), reviewing themes (4), defining and labelling the themes (5) and finally writing the results (6) (Braun & Clarke, 2006). After all data were transcribed, the text was first read several times to get an overview of the content of the interviews. Data including spouses’ experience of foodwork and meals were labelled with a code. The codes were then sorted into potential subthemes, which were tested and reworked when necessary, and there was a constant moving between the data as a whole and the codes to search for patterns and
meanings. Finally, the analysis resulted in three subthemes describing how things used to be, what kind of changes had occurred, and how these changes were managed. During the analysis a metaphor used by one of the informants, ‘dancing on a slack tightrope’, was observed to capture a central feature of all interviews, and suited the content of the three subthemes. The metaphor made it possible not only to see how informants’ experiences fit together but also to highlight the diversities, and was therefore used to label the theme. The metaphor was found to consist of three components that further explained it and that suited the content of the three subthemes. Hence, these components were used to label the subthemes: Being on the platform, Being on the tightrope, and Using a balance pole. This metaphor was used when writing the report. It has previously been described that metaphors can be used in qualitative studies to structure data and give them meaning (Bonner & Greenwood, 2005; Carpenter, 2008; Sandelowski, 1998).

Content analysis
Content analysis can be described as a systematic technique used to find patterns in a text (Krippendorff, 2012). The description by Elo and Kyngäs (2008) of inductive content analysis was used during the analysis, which entails the selection of the unit of analysis, a massive reading of the text to make sense of the data, the performance of an open coding, the creation of categories through interpretation and an abstraction of the categories to the degree possible (Elo & Kyngäs, 2008). In Paper IV the analysis started with reading the transcribed interviews several times to get an overview of the data. The notes from the focus group interviews made by the assistant were also read through. The software program Atlas TI 6.2 was used for the coding and categorization process. Since the aim was to describe and explore staff views on improving foodwork and meals for home-living persons with dementia, all text about foodwork and meals was marked with a code; i.e. the open coding process was performed. During this process some codes were named slightly differently even though their content was similar; therefore, they were merged during the process. The final codes were then sorted depending on their content, and subcategories were created. Then, through abstraction, five categories were developed from these subcategories, and one main category was identified.
Ethical considerations

Regional Ethical Review Boards approved Papers I, II and III (dnr 95:53, 98:381, 03:124 Paper I, dnr M15-08 Papers II-III). The Declaration of Helsinki (World Medical Association [WMA], 2008) and the Ethical guidelines for nursing research in the Nordic countries (Northern Nurses’ Federation, 2003) were used as an ethical standpoint regarding confidentiality, information letter, informed consent and storage of collected data. When it comes to ethical considerations regarding Paper III, one must consider that the partners might have found it difficult not participating in the interview study since their spouse, the person with dementia, was already participating in the Food, Exercise and Memory Loss project. However, participation in the interview was voluntary, and the partners were asked separately about participation. Focus group interviews were performed with staff, who were informed about the study during a staff meeting, and additionally the interview was performed at the workplace, which might have affected their consent and participation (Paper IV). No formal approval was needed for Paper IV, but the Research Ethics Committee of the School of Health Sciences, Jönköping University, reviewed the study and raised no objections from an ethical point of view (7/2-12).

Several ethical issues arise when research includes persons with dementia (Paper II), and according to the WMA (2008) research on vulnerable groups should be avoided. On the other hand, the constant exclusion of people with dementia might lead not only to stigmatization in society as it signals that they lack the capacity to share their experiences (Wilkinson, 2001) but also to a stagnation in the development regarding nursing care for them (Northern Nurses’ Federation, 2003). A fundamental aspect of referring to persons with dementia as vulnerable is related to informed consent, as the disease might affect one’s ability to receive information and therefore also one’s ability to give informed consent (Slaughter, Cole, Jennings, & Reimer, 2007). However, the within-group differences are great, and it is therefore likely that people’s abilities also vary (Hellström, Nolan, Nordenfelt, & Lundh, 2007). It was experienced that the cognitive capacity differed between the participants. Among other things, this seemed to be related to whether the person lived alone or with a partner. For those living with a partner, both were always informed about the study, but the person with dementia was the
one who chose whether or not to participate. Single-living persons who remembered that the researcher was going to contact them and were also able to express the aim of the study were considered to be able to decide themselves whether or not to participate in the study. In some cases the researcher or primary nurse informed adult children about the study, after receiving consent from the person with dementia. The persons were able to live in their ordinary homes, and it was considered important to preserve their autonomy and prevent them from feeling offended. One example of such a situation was a woman who was informed and asked to participate by the public health nurse, and wanted to participate. The nurse asked if she could contact the woman’s adult child about the study, but the woman answered that she was capable of deciding such a thing herself. During each home visit the persons were informed and asked to participate, which has been described as important since a dementia can fluctuate from one occasion to the next (Hellström, Nolan, Nordenfelt et al., 2007). It should be clarified that significant others, and sometimes home-care staff and/or the public health nurse, were informed when a person was assessed as being at risk of malnutrition, but only after the person him/herself was informed of this.

Repeated visits have been described as important for a trustful relationship to be built between the participant and the researcher. As mentioned before, repeated visits were made to the person’s home and the interviews were carried out during the third visit at the earliest. However, even though the importance of building a relationship has been pointed out, there is a lack of research regarding ending a research project (Cowdell, 2006), which was found to be difficult. The number of home visits varied, but usually between eight and 15 visits were performed. This resulted in the emergence of relationship, making it possible to collect data. This relationship can be regarded as unequal, since the researcher had an agenda for the relationship and decided when to end it, but this of course affected the researcher’s feelings. Even more, it seemed to affect the participants, and some expressed sadness during the last home visit since this meant that the data collection was finished and that the home visits and relationship would now end.
Findings

Cognitive ability as an associated factor for malnutrition among home-living older men and women (I)

According to the MNA, 42 persons were assessed as being at risk of malnutrition and one as being malnourished. The median MNA score for persons at risk (PAR) of malnutrition was 22 [Q₁ 20.0 Q₃ 23.5], and 26.5 [Q₁ 25.0 Q₃ 27.5] for the well-nourished (WN).

Comparisons (OC3) between the persons at risk and the well-nourished showed that cognitive ability was significantly lower for those at risk compared to the well-nourished (MMSE: PAR md 27.0 [Q₁ 24.0 Q₃ 29.0], WN md 29.0 [Q₁ 27.0 Q₃ 30.0], p=0.018; memoryDL: PAR 26%, WN 7%, p=0.001). Using a cutoff point of 23/24 for MMSE revealed that of those at risk, 19% had an MMSE score of 23 or lower compared to 6% among well-nourished (p=0.004). Statistically significant differences in cognitive ability were also found four years earlier (OC2) (MMSE: PAR md 28.0 [Q₁ 25.0 Q₃ 29.0], WN md 29.0 [Q₁ 27.0 Q₃ 29.0], p=0.021; memoryDL: PAR 16% versus WN 6%, p=0.023).

Univariate logistic regression at OC3 showed that decreased cognitive ability had a significant impact on the odds of being at risk of malnutrition (MMSE: OR 5.0, p<0.001; memoryDL: OR 4.3, p=0.001). A multivariate logistic regression analysis including the variables MMSE (dichotomized), memoryDL, health poorer compared to four years ago, and hospital stay during the past two months showed that MMSE had the greatest impact on the odds of being at risk of malnutrition (OR 5.3 p<0.001). Performing within-group tests over the three test occasions, cognitive ability decreased over time in those at risk (MMSE p=0.02; memoryDL p=0.04) but not in the well-nourished.

A comparison of men and women regarding nutritional status (MNA) at OC3 showed no significant differences. Men at risk of malnutrition had
lower cognitive ability compared with well-nourished men (MMSE: md 26.0 [Q1 22.5 Q3 29.0], md 29.0 [Q1 28.0 Q3 30.0], p=0.001); this was not found in women. A multivariate logistic regression on the same variables as for the whole group, i.e. MMSE (dichotomized), memoryDL, health poorer compared to four years ago, and hospital stay during the past two months was performed. The outcome showed that the odds of being at risk of malnutrition increased with cognitive impairment (MMSE: OR 13.8, p<0.001), as well as with perceiving poorer health compared to four years ago (OR 5.0, p=0.011) for men. For women, recent hospital care (OR 6.4, p=0.042) and decreased cognitive ability (memoryDL: OR 5.1, p=0.030) were predictors for being assessed as being at risk of malnutrition.

Changes that occur in the couples regarding foodwork and meals (II, III)

The persons with dementia usually described that memory loss was not something that affected them during foodwork, and usually no difficulties in preparing or eating were expressed (II); partners also described how foodwork and meals were the same as before the disease. The dementia disease could fluctuate, though, and what had worked one day for the person with dementia might be a problem the next (III).

Some persons with dementia experienced that they did have some problems with their memory and that this affected the foodwork (II), and this was also expressed by partners (III). Changes that occurred concerned the person with dementia having trouble managing the shopping (II, III), as well as setting the table and cooking the food. The persons with dementia were no longer able to take the initiative regarding what to eat, chose to stay out of the kitchen, and were referred to as someone who no longer had an interest in foodwork or meals. As a result of the dementia, they were no longer able to cook since they could not handle the complex situation and, for instance, the food would turn out too spicy or some ingredients would be forgotten. The partners were not sure if the person with dementia understood this themselves (III).
Persons with dementia described how they had changed their ways of living as a result of their inability to perform foodwork on their own, and how they missed performing these activities (II). Partners described an increased responsibility for foodwork and meals since their spouses’ ability to prepare food had been affected by the disease. Only male partners mentioned this as new activities. It could be a problem when the person with dementia, who used to be in charge of the foodwork, no longer had the ability to prepare food (III). Changes also had to do with a new routine for meals whereby the person with dementia left home for the day care centre and ate his/her meals there a couple of days a week (II, III). This created a feeling of loss for the partner, even though it was not described as a problem (III).

Changes in eating also arose for the person with dementia as a result of the disease, which included having trouble remembering what one had eaten the day before (II) or forgetting to eat. Decreased appetite and a lack of feeling hungry were also described, as was eating constantly. For the partner, this could result in blaming him/herself for the person’s decreased food intake. Changed eating behaviour in persons with dementia was also noted, like avoiding certain foods, enjoying desserts more or imitating what the partner ate (III).

Another change, only mentioned by female partners, was the lack of conversation during meals, for instance resulting in spouses no longer receiving appreciation for the food they had prepared. Overall they talked less with each other, and partners found it hard to sustain conversation around the kitchen table (III).

Activities of importance to uphold regarding foodwork and meals (II, III, IV)

There was foodwork that the persons were able to carry out and perform independently, such as shopping, baking, cooking food, setting the table, peeling vegetables and washing the dishes (II, III). It was described that the persons with dementia wanted to do these things and preserve their independence (II). Staff also felt it was important to preserve the person’s own abilities and independence, and therefore that meals should be prepared
at the person’s own home. This also entailed that the person’s ability to eat independently or shop on his/her own was preserved, as it could result in the person feeling that he/she was competent and needed, as well as participating and contributing (IV). Partners who had taken over the responsibility in order to maintain a stable situation and uphold the couple’s routines mentioned that the knowledge and experience of the person with dementia were needed, because of the partner’s insecurity about how things should be done to prepare food and create proper meals (III).

**Adjusting foodwork and meals to cognitive changes (II, III, IV)**

Foodwork and meals sometimes had to be adjusted as changes occurred, which meant that persons with dementia found their own strategies and routines in order to be able to continue with these activities (II). Further, both family members and formal caregivers could help and support the person when needed (III, IV), and it was recommended that support be structured based on the person’s needs, wishes and problems (IV).

To be able to continue shopping, persons with dementia used shopping lists. One woman explained that she was able to remember what she needed to buy as long as she did not talk to people while she walked around the supermarket (II). Getting help from others with buying and bringing the groceries home could be used as a means of getting food (II, III, IV).

If a person was considered unable to perform foodwork independently, meals could be created together with him/her, and this help could come from either family members (II, III, IV) or formal caregivers. This meant giving support and help during foodwork, including being there and supervising but not taking over (IV). Giving orders or delegating tasks can help people with dementia take part in foodwork. To make them involved and aware in foodwork and meals, they could be verbally reminded of what was going to happen (III), and a menu of the meals for the whole week could help them get an overview (II).
Supervising included making sure the person used the right amount of ingredients, such as spices, or that he/she did not burn anything (IV). When ingredients were set out, the person with dementia recognized and understood what they were supposed to do (III), and after ingredients were used they could be put away to minimize the risk of using them twice (II). Technical devices could be used as an aid in maintaining foodwork. This meant that a timer could be used for the stove (II, IV) and that watches could also be used – not only ordinary watches to keep track of the time and to know when it was time to eat (II), but also special watches designed to help persons with memory loss. It was expressed that during more advanced activities the responsibility should be given to someone else (IV).

Occasionally, persons with dementia had to simplify the cooking to be able to manage. This meant preparing uncomplicated food or buying partly or ready-cooked meals that only need to be heated (II), or decreasing the workload by only being responsible for breakfast or the evening meal instead of all meals. Maintaining meals in the home meant that someone else had to take over the main responsibility for foodwork to ensure that the person received proper meals (IV). It was sometimes also a necessary strategy, for the partner to be able to prepare food, to exclude the person with dementia from the kitchen (III). For partners to learn how to manage these new activities, food classes allowing them not only to learn to cook but also to meet others in the same situation could be a solution (IV).

New habits and solutions were other ways of managing meals, and helped not only the person with dementia but also the partner. Meals-on-wheels, as well as eating at day care centres or restaurants, was described (II, III, IV), and assistance could be given to ensure that the person had access to mobility service or that someone accompanied him/her to the restaurants. Replacing ordinary meals with meals-on-wheels or pre-packaged products was expressed by staff as something frequently used today, but it was asserted that the meals should be cooked in the person’s home (IV). However, moving meals outside the home helped decrease the partner’s workload (III, IV). Even if there had been changes, home-like and familiar meals should be made, which meant that the food served should be what the person was used to eating and should taste like a home-cooked meal (IV); people could also find ways to preserve old habits, like serving the food like
in the past (II). The surrounding environment, such as when to eat and other old routines, should also be considered to make the meal as familiar as possible. However, staff expressed that some people actually liked trying new tastes (IV).

Eating sometimes needed attention as a result of changes. To make sure the person obtained adequate food intake, the food prepared should be dishes the person liked (III, IV), and products containing more fat could be used (III). Pedagogical meals in appetizing atmospheres were suggested (IV). If the person with dementia imitated food behaviour, one could put more food on one’s plate to make the person also took a larger portion (III). Attending and supervising during the meal made it possible to ensure that the person started eating as well as finished the meal (IV).

Since changes in conversation sometimes occurred, certain tricks were used to make the person with dementia converse during meals. Choosing to discuss things that happened in the old days, or in this very second, could make it possible to have a conversation. Partners described having adjusted to the silence, which meant either accepting it or using the radio to break the silence (III).
Discussion

Reflection on the findings

The main results from the four papers revealed that cognitive ability affects nutritional status, i.e. low cognitive ability leads to increased risk of malnutrition. Persons with dementia and their partners experienced that foodwork and meals were affected, and expressed transitions in roles, routines and relations. It was described that there was foodwork that the persons with dementia could perform, and that abilities and independence should be preserved if possible. Support was sometimes needed, and it was emphasized that this was based on the person’s needs, wishes and problems. Meals-on-wheels was commonly described as a solution when foodwork and meals deteriorated.

Decreased cognitive ability increases risk of problems with nutritional status and foodwork

The results show that low cognitive ability is associated with malnutrition among home-living older persons. Looking at the respective MMSE scores for those at risk of malnutrition and the well-nourished, there is a slight difference in median MMSE score (I), which raises questions of whether these differences are actually of clinical relevance. However, using a cutoff point of 23/24 clarifies such a difference as it is 19% among those at risk compared with 6% of well-nourished people who had an MMSE score lower than 23 at OC3 (I). Using such a cutoff point is common (Aevarsson & Skoog, 2000; Grut et al., 1993), but lacks the sensitivity needed for use as a diagnostic tool for dementia; i.e. the instrument tends to result in false positives. However, it is suggested that it be used as a screening tool (Grut et al., 1993). Furthermore, the subjective question regarding whether their memory affects daily life also showed that those at risk of malnutrition experienced that it affected their daily life to a higher extent compared with the well-nourished (I). One might argue, though, that this is just a single
question about cognitive ability. However, such a subjective question should not be neglected as it has been found to be associated with cognitive decline as well as dementia, especially in predicting future decline (Jonker, Geerlings, & Schmand, 2000). As in these results (I), an association between nutritional status and cognitive status has also been found (Fagerström et al., 2011; HaeKwan et al., 2009). Consequently, paying attention to persons with decreased cognitive ability is important in order to prevent nutritional problems: when assessing home-living persons with dementia, as many as 43% were assessed to be at risk of malnutrition and another 2% as malnourished (Roque et al., 2013). This suggests that insufficient attention is paid to improving nutritional status in home care or outpatient care, but might also be a result of the fact that when nutritional problems occur it is hard to improve the status among home-living persons. In a recent literature review including intervention studies between 2004 and 2012 on mealtime difficulties among persons with dementia, only two studies had been carried out in an outpatient care setting. In these studies, in which nutritional supplements and training/education programmes for physicians, caregivers and patients were given, some improvement was noted; however, there is insufficient evidence and research on this matter, not least in a Swedish context (Liu, Cheon, & Thomas, 2013).

The longitudinal study (I) showed that cognitive ability was lower even four years earlier for those at risk of malnutrition compared to the well-nourished, which indicates that as soon as a person experiences or is observed to have decreased cognitive ability, nutritional status should be assessed. Perhaps it should be standard that nutritional status is measured for all persons during the dementia assessment. Assessing nutritional status in all persons receiving in-hospital care, primary care or care provided by the municipality have been highlighted in the national quality register Senior Alert. Yet, the degree to which municipalities and county councils assess and register nutritional status varies (Senior Alert, 2013). This has been confirmed in interviews with nurses and nursing managers in Sweden, who described that nutritional assessment tools were seldom used (Persenius et al., 2008). Besides, as Watson (2011) states, assessing nutritional status does not mean it will improve. Instead, it should be understood as a first step towards being able to improve nutritional status when necessary.
Transition in roles, routines and relationships

Changes in foodwork and meals were described, and seemed to be related to which member of the couple used to be in charge of these activities (II, III). In the Life Nourishment Theory (LNT), adjusting to an evolving life is described as experiencing changes in a family in which a person has dementia, explained as a process by which the family becomes aware of, gives meaning to, and finally responds to the changes (Genoe et al., 2012). Evans and Lee (2013) used the transition concept to explain such changes in everyday life, in a review study including couples in which one partner had dementia. When it comes to roles in couples, this transition means that the person with dementia steps back from his/her ordinary duties and responsibilities whilst the partner takes on new ones (Evans & Lee, 2013). Using gender roles to explain the transitions in roles that occur in couples as a result of the dementia might be troublesome, as the results indicate that this probably has more to do with who used to be in charge of these activities rather than gender. However, these things seem to be intertwined when it comes to foodwork and meals. In Paper III it was male partners who described that having the main responsibility was something new, something they had learned later in life. Similar results were found in the study by Fjellström et al. (2010), in which particularly men described an unfamiliar situation regarding foodwork and meals even though they had sometimes played a peripheral role in the past. Persons previously not in charge of foodwork can have trouble performing such activities, as described by Russel (2007). However, husbands taking over these responsibilities have expressed pride at achieving activities while caring for their partner (Sanders & Power, 2009), and experienced well-being when cooking (Kullberg et al., 2010). A study including men caring for their wives revealed that both partners in the couple were sliding into new food roles. For the caregiving husbands, this meant that they gradually performed more preparation and ultimately came to be in control of these activities, whilst the partners with dementia moved towards doing less (Atta-Konadu et al., 2011). In Paper II a majority of the interviewed persons with dementia were females, and when it was no longer possible for them to perform foodwork they missed doing it (II). This is in accordance with results from other studies, which have shown that older women link the inability to perform foodwork with feelings of
sadness (Sydner et al., 2007) as well as guilt and frustration (Sidenvall et al., 2001). Perhaps females find these activities important, which might be related to their thinking of foodwork as part of their identity. Foodwork has traditionally been connected to female roles (DeVault, 1991), and a recent study showed that women preferred to engage in activities related to cooking/eating more often than men did (Menne, Johnson, Whitlatch, & Schwartz, 2012). A Canadian study also revealed that interviewed older women with dementia found household chores, such as foodwork, extremely important since such activities constituted their personhood and helped them retain a sense of their personal identity (Phinney, Chaudhury, & O’Connor, 2007).

Meal routines were also transformed, and for some this meant that less foodwork was carried out in the home and instead that meals-on-wheels, day care centres and restaurants came to be more frequently used (II, III). It has previously been described that changes in routines were due to the healthy partner not finding it appropriate to take on activities formerly performed by the person with dementia, or the healthy partner not having an interest in these activities but instead finding other ways to manage (Atta-Konadu et al., 2011). Eating out can be one way to reduce foodwork and demands, not least for the person who has taken over the foodwork. For single-living persons with dementia, moving meals outside the home can help them increase their social interaction (Cassolato et al., 2010). However, family caregivers have regretted simplifying and changing routines, expressing that it made them feel like their meal standards were slipping (Keller et al., 2007). Single-living persons have also associated changes in routines with feelings of a negative nature, e.g. dependence and loneliness, even though they were grateful to receive meals-on-wheels (Pajalic, Persson, Westergren, Berggren, & Skovdahl, 2012).

Relationships and social interaction with others are highlighted in the meal concept (Oltersdorf et al., 1999; Sobal, 2000). According to LNT, meals create opportunities to relate to and connect with the self, as a couple and also within a wider perspective, i.e. within social networks. Further, they can make it easier for families to stay together as a unit and be connected (Keller et al., 2010). However, this can be troublesome as the ability to speak sometimes changes due to the disease (Alzheimer's Association, 2013).
Partners of people with dementia expressed that the communication during meals was not the same as it used to be; the person with dementia became quieter or was not always able to follow on-going dialogue (III). Loss of conversation has previously been found to change the pattern of daily life within couples (Walters et al., 2010), and has been considered to be one aspect that can make a partner see his/her loved one with dementia as a different person than before, which could lead to a disruption of marital closeness (Boylstein & Hayes, 2012). In previous studies, partners have described that the relationship changes from an equal situation to one in which the healthy spouse becomes more of a caregiver than a partner (Walters et al., 2010). Partners learned ways to help the person with dementia participate in a dialog when he/she had trouble communicating (III), which is also described in the LNT. However, verbal communication is not the only way to be connected; things like hugs and laughter can also be helpful in connecting (Keller et al., 2010). Non-verbal communication has also been previously described as useful in helping persons with dementia remain part of the communicative world when they lost the ability to converse (Hubbard, Cook, Tester, & Downs, 2002).

Foodwork and meals worked quite well, according to persons with dementia as well as their partners (II, III). Perhaps performing these activities can serve as a hub for preserving relationships in everyday life, as this is actually something that has not changed. The LNT describes that sharing foodwork and meals can promote connections (Keller et al., 2010), and it has previously been described that foodwork includes shared activities that can help couples stay engaged with one another (Hellström, Nolan, & Lundh, 2005). However, when changes occurred, persons with dementia and their partners adjusted and found strategies for managing foodwork and meals (II, III). Using different strategies to compensate for memory loss is common, and has previously been described as helping persons with dementia to manage (Nygård, 2004; Öhman et al., 2008). This is similarly described in the LNT, which further explains that these strategies can be something the person with dementia and their families obtain through both experience and research. Further, trial and error are commonly used to learn how to deal with changes (Genoe et al., 2012). Hence, passing along results from studies like this one can help other couples in similar situations increase their
knowledge, and the LNT advocates that support groups and networks can be helpful for families (Genoe et al., 2012).

The importance of staying independent

It was important for persons with dementia to remain independent (II), and formal caregivers also expressed that the person’s own abilities and independence should be preserved (IV). In a study on healthy eating, including older persons from several European countries, a strong desire to manage oneself was expressed (Lundkvist, Fjellström, Sidenvall, Lumers, & Raats, 2010), and similar results have been found among older women in Sweden (Andersson & Sidenvall, 2001; Sidenvall et al., 2001). Actually, doing things oneself has previously been described as being so important that people have tried to manage themselves even though they actually needed support, which resulted in deficient food intake (Gustafsson, 2002). An explanation for why foodwork is so important for older persons might be related to the results of a study by Haak, Fänge, Iwarsson, and Ivanoff (2007), i.e. that being able to perform daily activities is one way to preserve your image as independent. Further, Porter (2007) found that older women associated the ability to cook with the ability to live on their own. The desire to be independent can also be related to current policies reflecting that independence is something to strive for (Ministry of Health and Social Affairs, 2003:91), and people of today have likely been socialized to value independence. Dependence, on the other hand, is a stigmatized concept (Fine & Glendinning, 2005; Munnichs, 1976) and can create a fear of not being seen as a respected member of society.

Support from partners or formal caregivers during foodwork and meals is sometimes necessary (III, IV). As capacities decrease (WHO and Alzheimer’s Disease International, 2012), dementia affects the ability to stay independent and increases the need to rely on others (Steeman et al., 2007). However, according to the LNT, focusing on foodwork and meals can preserve one’s own identity and dignity as it provides an opportunity to choose what to eat and with whom, and how foodwork should be managed, which can help a person with dementia gain control over life when his/her capacities change (Genoe et al., 2010). Furthermore, in health care
independence is more than just the competence to perform daily activities; it instead includes autonomy and the ability to have control and make one’s own decisions (Tamaru et al., 2007), which strengthens the results suggesting that the person should do as much as possible him/herself (IV). Perhaps becoming more and more dependent results in a need to feel useful and that one is contributing in some way, as highlighted in the LNT (Genoe et al., 2010). Staff mentioned that including the person with dementia, instead of just taking over, could help the person feel like he/she was competent and needed as well as that participating and contributing (IV). The LNT explains that it is a balancing act between respecting the person and making foodwork safe (Genoe et al., 2010). Fjellström and Mattsson Sydner (2013) also highlight the problem of providing autonomy and at the same time protecting the person, as independence could endanger his/her health and quality of life. Technical devices were described as something that could make it possible to maintain foodwork, like using a timer for the stove (II, IV), which also increased the person’s safety. Hence, independence should be understood as a continuum including several levels and one might need assisting devices, for instance; but this decreases the independence of others, which was also found in a review by Bonikowsky et al. (2012). This is important from a partner perspective as well, since they might struggle with changes themselves, and by upholding the person’s functions it might actually be possible to decrease the burden on the partner. Hence, as described in the LNT, the partner can be the one who becomes dependent (Genoe et al., 2010) as he/she needs help from the person with dementia to perform foodwork, as mentioned in Paper III. This also highlights what Munnichs (1976) writes about dependence and independence: that there is a social world in which people meet and relationships are created, i.e. in some ways we are all dependent on each other. Instead, the focus should be on creating care that has its starting point within the person, which is in accordance with person-centred care (Edvardsson et al., 2008).

Using a person-centred care approach is essential in foodwork and meals

In Paper IV, staff described several means for improving foodwork and meals for persons with dementia who were in need of support, including
supporting the person at home, eating at restaurants and providing pre-packaged food (IV). These findings are significant; there is little knowledge about how to support persons with dementia and their families at home, as most research has been carried out in special housing or hospitals (Aselage & Amella, 2010). However, as more older persons tend to live at home longer more of them develop dementia (Ferri et al., 2006), and an increased need of home care is to be expected (Genet et al., 2011). The problems and support needed may differ between persons with dementia living at home and those cared for in special housing or hospitals (Jackson, Currie, Graham, & Robb, 2011). However, one might argue that some of the interventions can be applicable to both home-living persons and those in special housing and hospitals; such results have been found by Keller et al. (2008). According to Amella, Grant and Mulloy (2008), who tested interventions for persons with moderate- to late-stage dementia, the ultimate goal is to enhance their meal experience and quality of life, preserve their independence and dignity, engage them in social interaction, and give meaning to every meal. For this to be possible, the person must be understood based on his/her context and experiences, which is in agreement with the meaning of person-centred care. The quality of the relationship with the person with dementia may also increase when spending time in the person’s home, which is significant in person-centred care as well as nursing care (Edvardsson et al., 2008). Further, a benefit when working in the home environment is that the chances of getting to know the person are enhanced since being in the person’s own context offers an understanding of his/her life and routines (Öresland, Määttä, Norberg, Jörgensen, & Lutzén, 2008). Having access to such information probably makes it easier to offer support based on the person’s individual needs and wishes, which is advocated as the foundation of supporting a person (IV). In other Swedish studies in which older persons have been interviewed, the importance of receiving help on one’s own terms was emphasized (Dunér & Nordström, 2010), and regarding receiving meals distributed by the municipality older persons themselves had suggestions about how the service could be improved (Pajalic, Persson, Westergren, Berggren et al., 2012)). This highlights the benefit of including the persons themselves when designing services, and is in accordance with person-centred care, which underlines personalized care and shared decision-making (Edvardsson et al., 2010). The national
guidelines for persons with dementia also highlight that care and nutritional interventions should be individualized (National Board of Health and Welfare, 2010). The causes of malnutrition can be many; therefore, several interventions can be needed and these should be based on the person’s needs, resources and problems, as this has previously been found to be effective (Lorefält & Wilhelmsson, 2012; Wikby et al., 2009). Yet, there are very few published research studies on person-centred care, and even fewer that identify benefits (McCormack, 2004). Further, even though person-centred care is promoted (National Board of Health and Welfare, 2006a, 2010) it is not always achieved (Docteur & Coulter, 2012). This is also in accordance with the results revealing that there were several means for improving foodwork and meals depending on the individual’s needs and resources, yet meals-on-wheels were often offered (IV). This is supported in the findings by County Administration Boards of Sweden (2009), that food distribution has increased whilst food preparation at home has decreased. Further, what is offered seems to depend on local guidelines rather than the person’s preferences (Dunér & Nordström, 2010). Food distribution, i.e. meals-on-wheels, can naturally be used when suitable. However, a recent Swedish qualitative study among professionals involved in food distribution service revealed that it was a deficient intervention, with staff not knowing what actually happened after they delivered the food, and that a preferable way would have been to stay while the person ate (Pajalic, Persson, Westergren, & Skovdahl, 2012).

Methodological considerations

Validity and reliability

Validity and reliability need to be considered in order to draw clear conclusions from quantitative studies (Kazdin, 2003).

A threat to internal validity is related to the design used when including participants (Kazdin, 2003; Polit & Beck, 2012). The same sample as in the study by Takkinen et al. (2004) was used in Paper I. From a survey including unlike-sex twins (Gold et al., 2002), a sample of 382 twin pairs were invited to participate in in-person testing. Of this sample, a total of 266 persons did
not participate because they: did not want to participate (n=114); had died (n=30); or were excluded because their twin declined participation or had died (n=106); further, 16 persons could not be contacted. Therefore, the sample at OC3 consisted of 249 unlike-sex twin pairs (498 persons) (Taakinen et al., 2004). This indicates that the sample is not similar to the normal population as they were probably healthier. However, many persons decided to take part in the study at all three test occasions; i.e. those participants in Paper I grew frailer over time as a result of ageing. It is fair to believe that in the normal population, a higher rate of people died during the longitudinal data collection as a result of frailty, with the result that the healthiest persons survived. Consequently, the sample (I) and the normal population look more equal over time. Further, the attrition rate can be affected in longitudinal studies, meaning that dropouts may differ to some degree compared to those included in the sample. In Paper I, 60 persons between OC1 and OC2 and another 12 between OC2 and OC3 chose not to participate, which can have affected the results. Even so, many persons decided to take part in the study at all three test occasions. At OC3, 48 persons were excluded because they lacked a complete MNA score or lived in special housing. A comparison of those participating at OC3 (n=258) and those who did not (n=48) showed that those who were excluded had significantly lower MMSE scores and Activity of Daily Living (ADL) functioning, which indicates that those who participated were healthier.

The participants in Paper I were unlike-sex twins, which could be a threat to external validity. However, according to Simmons et al. (1997), twin pairs in older age groups are comparable to non-twins in the same age groups. Further, using statistical analysis for independent or dependent groups, i.e. treating them as matched pairs, gave similar results, which indicates that the relationship between the twins did not affect the results, which can therefore be generalized to other groups of older people as well.

Low statistical power can be a threat to statistical conclusion validity (Kazdin, 2003). In Paper I power was not calculated, but the sample included 258 persons and significant differences were found in the analysis. A recommendation for decreasing the risk of bias includes standardizing procedures, as neglecting to do so can threaten statistical conclusion validity (Kazdin, 2003). Here, a few experienced research nurses collected all data
using standardized questionnaires (I). Further, in-person testing has been proven to have positive effects on response rate (Polit & Beck, 2012).

For the instruments used (I), satisfactory reliability was found for both MMSE (Tombaugh & McIntyre, 1992) and MNA. For MNA this is also true for validity (Guigoz, 2006). MMSE shows good construct validity, and is a commonly used instrument for testing cognitive impairment. Yet, it has low sensitivity regarding mild degrees of cognitive impairment (Tombaugh & McIntyre, 1992). Both MMSE (Grut et al., 1993) and MNA (Guigoz, 2006) are commonly used in a Swedish context. A disadvantage is that the supplementary questions have not been tested for validity or reliability. However, a strength is that the variables have remained basically unchanged over the three occasions of data collection.

The use of parametric tests for MMSE in Paper I can be criticized, as non-parametric tests should be used for ordinal variables and for ratio scale variables that are not normally distributed (Thorne, 2003). Therefore non-parametric tests were used in this thesis. However, this did not affect the results with regard to statistical significance, even though the p-value increased when non-parametric testing was used. For instance, testing for differences in MMSE at OC3 between persons at risk and those who were well-nourished resulted in a p-value <0.001 compared to p-value 0.018. Further, meals-on-wheels were used as an independent variable in the multivariate logistic regression analysis in Paper I. However, one might argue that this is likely a dependent variable. Therefore, this variable was not included in the multivariate logistic regression analysis in this thesis.

Trustworthiness

Lincoln and Guba (1985) describe that trustworthiness in qualitative data can be attained using the four criteria of credibility, transferability, dependability and confirmability, which have been considered in Papers II, III and IV.

Paper II, including persons with dementia, was inspired by ethnography. Using an ethnographic approach means that fieldwork and observations are important in performing a study (Wolcott, 2008). However, here mainly interview data were collected and used in the analysis, which can be seen as
a limitation of the study and could affect its credibility. However, Wolcott (2008) writes that, after observation, interviews are the next best way to gather data in an ethnographic study. Further, he explains that it is better to conduct one in-depth interview than several only on the surface (Wolcott, 2008). However, the dementia disease affected the possibility to gain deep information. Hence, even though the persons with dementia were able to express their views, they seldom gave detailed descriptions. Instead, their answers were often short and they sometimes had trouble remembering words, lost focus or repeated themselves. Even though persons with dementia are able to contribute in a meaningful way in interviews (Moore & Hollett, 2003), they can have trouble distinguishing the present from how things used to be (Edvardsson & Nordvall, 2008), and can normalize or deny problems (Howorth & Saper, 2003). Therefore, it would probably have been good to include observations during foodwork and meals in the data collection. Another way would have been to interview the couples together. However, this could have led to the healthy partner’s voice being given greater importance and regarded as being closer to the truth; also, healthy partners tend to talk for the couple, as described by Hellström, Nolan, Nordenfelt et al. (2007). Besides, the purpose was to hear the person’s own experiences (II, III) and it therefore seemed appropriate to hold individual interviews. Also, those living alone would have been excluded in such an approach.

Papers II and III have similarities, but there is a distinction. It was namely determined that when interviewing persons with dementia, all data should be collected in the home, and this resulted in a greater understanding of the person’s daily life. This is also in agreement with ethnographic methods in which the importance of the context and setting is highlighted (Wolcott, 2008). Further, giving a thick description of the context can strengthen transferability (Lincoln & Guba, 1985). A threat to the credibility is that accessibility determined which persons participated. It was public health nurses who asked about participation in the Food, Exercise and Memory Loss project, and only a few people were asked to participate. Among these, everyone who the researcher considered to be able to communicate verbally about foodwork and meals was included (II). Further, in cases in which the persons in the project had a partner, they were also asked to participate in a
separate interview study (III). However, a benefit of including persons from the project was that several hours were spent at each home and a trustful relationship had been established already before the interviews were conducted, which hopefully allowed the participants to talk openly about their foodwork and meals, and rich information was obtained. This can be understood as prolonged engagement, which is one way to gain credibility (Lincoln & Guba, 1985). Establishing a trustful and relaxed relationship before collecting data is important when including persons with dementia in research (Hellström, Nolan, Nordenfelt et al., 2007).

A similar procedure was used to include staff (Paper IV): it was likely those who were the most interested in the topic who volunteered. However, since the aim was to capture staff views on how foodwork and meals could be improved, this hopefully gave the richest descriptions. Further, the participants in each focus group knew each other before the interviews, which can be an advantage since they shared experiences of incidents and could relate to each other when discussing things (Kitzinger, 1995). The focus group technique is considered to be a good method to use when the purpose is to capture opinions on a specific topic, and makes it possible to include more participants in a short time compared to interviewing one participant at a time (Polit and Beck, 2012). However, using focus group interviews might affect the participants and prevent them from fully expressing their opinions (Kitzinger, 1995; Polit & Beck, 2012), and people can become silent or dominant in the discussion (Polit & Beck, 2012). To avoid this, the moderator tried to include everyone during the interviews, which is in accordance with the method (Krueger & Casey, 2009). Further, to attain credibility and dependability, the assistant summarized the content after each vignette in order to try to prevent misunderstanding (IV). Partners were given a brief summary of the interview during a second home visit to ensure that everything had been understood correctly, and were asked follow-up questions (III).

The researcher’s own experience with persons with dementia was limited before these studies, which might have had an impact on the interviews. However, this might have had both positive and negative consequences, as it probably meant that different questions were asked compared to what someone familiar with the disease and how it affects people suffering from it
would have asked. Interviews with persons with dementia (II) as well as their partners (III) were performed continuously as participants were included, and this therefore should not have affected the interviews. However, the analysis of data from persons with dementia was completed before the analysis including data from partners was conducted. This can have had an influence on the analysis of data from partners, and might have affected the confirmability. To minimize such risks, a dialogue was maintained between the researchers during the whole research process (II, III, IV), and especially during different phases of the analyses continuous discussions were held to ensure that there was agreement regarding the content. The final results were discussed with other researchers as well, at seminars and conferences. According to Lincoln and Guba (1985), this strengthens credibility, dependability and confirmability. In Paper III, a metaphor was used during the analysis. The benefit of using metaphors is that, because of their richness and complexity, it is possible to go further in the analysis to form new meanings and understandings of the data. Moreover, metaphors can also put separate bits together and create a whole (Polit & Beck, 2012). Other researchers have used metaphors in a similar way as in the present study, i.e. to understand processes and relationships in the data (Bonner & Greenwood, 2005; Drury, Francis, Chapman, & Chapman, 2008; Öhlén, Bengtsson, Skott, & Segesten, 2002). There is a risk that the credibility was negatively affected, though, since using metaphors can simplify or overshadow the results. The data in Paper III were not forced to fit the metaphor; instead, it helped the researchers reach an understanding of the data, and hopefully also clarify the partners’ experiences for the reader.

Conclusions and implications

The results revealed that there is an association between cognitive ability and nutritional status, which indicates that for persons with dementia there is a need to assess nutritional status and to intervene early when risk is identified. This thesis has contributed knowledge about what kinds of difficulties home-living persons with dementia and their partners struggle with regarding foodwork and meals. The persons with dementia as well as their partners usually experienced that these activities worked, but as a result of the
dementia transitions regarding roles, routines and relationships were distinguished. This meant that partners took on greater responsibility whilst persons with dementia performed less foodwork and their dependence on others increased. This highlights the importance of supporting both partners in a couple in which one has dementia. Further, deepened knowledge was obtained concerning the importance of formal caregivers helping the person feel independent, autonomous and competent during support. Person-centred care is one approach that can help in accomplishing this, and the person’s own needs, wishes and problems should be the foundation when structuring the support.

Future research should focus on intervention studies aiming to improve foodwork and meals at home. That means designing interventions based on personal needs, wishes and resources, using a person-centred care approach during the whole research process, i.e. including older persons with dementia and their partners when planning and implementing such studies.

The researchers who developed the LNT request that it be tested in different contexts to further develop the theory (Lam & Keller, 2012). Here, the LNT was used to increase the understanding of the results, and it would be interesting to test the theory in a Swedish context using a deductive approach, to further confirm whether the LNT is transferable to this context. Besides, the LNT has its basis in the family, and not every person with dementia lives with someone. Single-living persons are probably more vulnerable than others when their abilities decrease, which means that the formal caregiver has a responsibility to make them feel connected and that their identity is being honoured while helping them adjust to the changed situation. Hence, it would be interesting to investigate how staff can facilitate this.
Svensk sammanfattning


Syftet med denna avhandling var att undersöka och beskriva måltidsrelaterade aktiviteter och måltider för äldre personer med demens och deras partners i eget boende.


Resultaten visade att bland hemmaboende äldre personer finns det ett samband mellan en persons kognitiva förmåga och näringsstatus, d.v.s. låg kognitiv förmåga ger ökad risk för undernäring. Personer med demens och deras partners beskrev att måltidsrelaterade aktiviteter och måltider ibland
hade förändrats, vilket innebar att inhandla, tillaga och äta ibland kunde vara svårt. Förändringar som påverkade den sociala interaktionen beskrevs också, där personen med demens hade svårt att medverka vid samtal under måltider. Detta sammantaget tycktes kunde leda till förändringar i roller, rutiner och relationer. Det fanns måltidsrelaterade aktiviteter som personerna med demens kunde utföra och en önskan om att bevara oberoende och förmågor uttrycktes. Dock behövdes stöd och hjälp ibland och det betonades att detta skulle bygga på personens behov, önskemål och problem.

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# Appendices 1-2

## Appendix 1: Questions Paper I

<table>
<thead>
<tr>
<th>The Questions</th>
<th>Responses</th>
<th>Dichotomized variables</th>
<th>Variable names in Paper I</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>MNA items that have been dichotomized:</em></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Har Du ätit mindre de senaste 2-3 månaderna p.g.a. försämrad aptit, matsmältning, tugg- eller sväljsvårigheter?</td>
<td>Ja, minskat avsevärt (0) Ja, minskat något (1) Nej, ingen förändring (2)</td>
<td>0+1=minskat matintag 2=ingen förändring</td>
<td>Declined food intake over the past 3 months</td>
</tr>
<tr>
<td>(Om minskning) Hur mycket har du gått ner de senaste 2-3 månaderna?</td>
<td>Mer än tre kilo (0) Vej ej (1) Mer än ett mindre än tre kilo (2) Nej, ingen viktförlust (3)</td>
<td>0-2= Viktminskning 3= ingen viktminskning</td>
<td>Weight loss during the past 3 months</td>
</tr>
<tr>
<td>Intar mer än tre ordinerade läkemedel dagligen?</td>
<td>Ja (0) Nej (1)</td>
<td>0=Ja 1=Nej</td>
<td>Takes more than 3 prescribed drugs per day</td>
</tr>
<tr>
<td>Har trycksår eller hudsår</td>
<td>Nej (0) Ja (1)</td>
<td>0=Nej 1=Ja</td>
<td>Pressure sores or skin ulcer</td>
</tr>
<tr>
<td>Frågeställning</td>
<td>Svara</td>
<td>Bemärkningar</td>
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<td>-------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
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</tr>
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</table>
| Äter eller dricker du vanligtvis                                              | Minst en mejeriprodukt dagligen (mjölk/ost/yoghurt) Ja (1), Nej (0) | Noll eller ett ja-svar=lågt intag av protein 
Två eller tre ja-svar=tillräckligt proteinintag |
|                                                                                | Två eller fler ägg per vecka. Ja (1) Nej (0)                         | Small amount of protein intake                                               |
|                                                                                | Fisk, fågel eller kött varje vecka. Ja (1) Nej (0)                  |                                                                           |
| Äter du själv utan problem?                                                   | Behöver mycket hjälp/matas (0)                                      | 0+1=behöver hjälp 
2=åter självständigt More or less assistance during meals |
|                                                                                | Behöver lite hjälp (1)                                              |                                                                           |
|                                                                                | Äter själv utan problem (2)                                         |                                                                           |
| Äter du minst två frukter eller två portioner med grönsaker dagligen?        | Ja (1)                                                              | 0=Nej 
1=Ja Consumes less than 2 servings of fruits or vegetables per day |
|                                                                                | Nej (0)                                                            |                                                                           |
| Hur mycket dricker du dagligen?                                              | Mindre än tre glas/muggar (0)                                       | 0+1=för litet intag 
2=tillräckligt intag Doesn’t meet fluid requirement |
|                                                                                | 3-5 glas/muggar (1)                                                 |                                                                           |
|                                                                                | Mer än 5 glas/muggar (2)                                            |                                                                           |
| Tycker du att du får i dig den mat du behöver?                                | Svårt undernärd (0)                                                 | 0+1= har näringssproblem  
2=har inga näringssproblem Views self as being malnourished or uncertain about nutritional status |
|                                                                                | Osäker om näringstillståndet (1)                                    |                                                                           |
|                                                                                | Har inga näringssproblem (2)                                        |                                                                           |
**Questions asked about aspects that might have an impact on nutritional status:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
<th>Scale</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hur bedömer du din hälsa jämför med för fyra år sedan?*</td>
<td>Bättre (1)</td>
<td>1+2= bra</td>
<td>Health poorer compared with 4 years ago</td>
</tr>
<tr>
<td></td>
<td>Ungefär likadant (2)</td>
<td>3=sämre</td>
<td></td>
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<tr>
<td></td>
<td>Sämre(3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Har du under de senaste två månaderna varit inlagd på sjukhus</td>
<td>Nej (0)</td>
<td>0=nej</td>
<td>Hospital stay during the past 2 months</td>
</tr>
<tr>
<td>(akutvård/rehab)*</td>
<td>Ja (antalet tillfällen)</td>
<td>1=ja</td>
<td></td>
</tr>
<tr>
<td>Har du under de senaste två månaderna besökt/haft besök av läkare</td>
<td>Nej (0)</td>
<td>0=nej</td>
<td>Contact with physicians during the past 2 months</td>
</tr>
<tr>
<td>(exkl. sjukhusvård)</td>
<td>Ja (antalet tillfällen)</td>
<td>1=ja</td>
<td></td>
</tr>
<tr>
<td>Får du någon hjälp i hemmet?</td>
<td>Ja (1)</td>
<td>1=ja</td>
<td>Municipal home-help service</td>
</tr>
<tr>
<td></td>
<td>Nej (0)</td>
<td>0=Nej</td>
<td></td>
</tr>
<tr>
<td>Hemsänd mat</td>
<td>Nej (0)</td>
<td>0=Nej</td>
<td>Meals-on-wheels</td>
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<tr>
<td></td>
<td>Sällan (1)</td>
<td>1-6=Ja</td>
<td></td>
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<tr>
<td></td>
<td>1 gång/månad (2)</td>
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<td></td>
<td>1 gång/14 dag (3)</td>
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<td>1 gång/vecka (4)</td>
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<td></td>
<td>Flera gånger/vecka (5)</td>
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<td></td>
<td>Dagligen (6)</td>
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<tr>
<td>Färdtjänst</td>
<td>Nej (0)</td>
<td>0=Nej</td>
<td>Special transport services</td>
</tr>
<tr>
<td></td>
<td>Sällan (1)</td>
<td>1-6=Ja</td>
<td></td>
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<tr>
<td></td>
<td>1 gång/månad (2)</td>
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<td>1 gång/14 dag (3)</td>
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<td>Flera gånger/vecka (5)</td>
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<td></td>
<td>Dagligen (6)</td>
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<tr>
<td>Tycker du att du har några problem med minnet som försvårar det dagliga livet?*</td>
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<tr>
<td>Nej, inte alls (1)</td>
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<tr>
<td>Nej, knappast (2)</td>
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<td></td>
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<tr>
<td>Svårt att ta direkt ställning till (3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ja, viss utsträckning (4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ja, i hög grad (5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1+2= Nej</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3-5=Ja</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Memory impairment affecting ADL (called MemoryDL in the thesis) |

<table>
<thead>
<tr>
<th>ADL-funktion: Summerad skattning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Totalt nedsatt ADL-kapacitet. Behöver hjälp dygnet runt. (1)</td>
</tr>
<tr>
<td>Starkt nedsatt ADL-kapacitet. Behöver hjälp varje dag men inte nödvändigtvis hela dagen eller natten med många av sysslorna. (2)</td>
</tr>
<tr>
<td>Måttligt nedsatt ADL-kapacitet. Kräver regelbunden hjälp med åtminstone 4 stycken sysslor men klarar någon enstaka utan hjälp, eller behöver regelbundet hjälp med matlagning (3)</td>
</tr>
<tr>
<td>God ADL-kapacitet. Kan utföra alla dagliga sysslor utan hjälp. (5)</td>
</tr>
<tr>
<td>Utomordentlig ADL-kapacitet. Kan utföra alla dagliga sysslor lätt utan hjälp. (6)</td>
</tr>
</tbody>
</table>

1-4=nedsatt ADL-kapacitet  
5-6= God ADL-kapacitet  

Reduced ADL function  

Questions marked with * are included in the thesis
Appendix 2: Interview guides

Interview guide: person with dementia (Paper II)

Opening question: Can you please tell me what you have eaten today? Or: What do you think is really good food?

Areas:
Shopping
Cooking
Eating
Meal environment

Interview guide: partner (Paper III)

Opening question: Can you please tell me what your food and meals look like; what have you eaten today?

Areas:
Shopping
Cooking
Eating
Meal environment
Highlight/problem situations
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