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Living at home with cognitive impairments

Risks during daily living and support from home care service

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Living at home with cognitive impairments
Risks during daily living and support from home care service

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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‘As soon as there is life, there is danger.’
Ralph Waldo Emerson, 1803–1882

ABSTRACT

The overall study's aim was to increase knowledge of conditions for older, home-residing persons with cognitive impairments – with focus on risks during daily living and support from home care service.

To disclose conditions for persons with cognitive impairments, four studies used different methodological approaches. **Studies I and II** applied a qualitative design; here focus was on daily living risks for persons with dementia. **Study I** explored experiences of 12 persons with dementia by interviewing them; data were processed using qualitative content analysis. **Study II** explored experiences of home care staff via 12 individual interviews and 2 focus group discussions (n=11); data were analysed using a constant comparative method.

Studies III and IV applied a descriptive correlational cross-sectional design. **Study III** focused on describing the range of municipal-granted home care services and examined associations between services granted to persons with cognitive impairments and demographic characteristics (from records for 131 older persons). **Study IV** documented perceived job strain among home care staff members (n=69) and investigated if job strain correlated with personal and organisational factors.

Study I contributed knowledge about (i) how home-residing persons with dementia experienced risky situations as being unfamiliar and confusing and (ii) how they dealt with these situations and sought recognition and clarity to reduce risk.

Study II showed how home care staff reasoned – regarding risks for persons with dementia – and how they struggled with dilemmas when (i) tracking risks, (ii) deciding when to act on a risk, and (iii) acting upon risks.

Study III acquired knowledge about the range of home services granted to older persons and found that these persons receive a wide range of services including support for basic needs such as eating and drinking. This study also found that persons with cognitive impairments, and persons who live alone, were granted a higher number of home care services than other home care service applicants.

Study IV generated knowledge regarding job strain, namely, (i) home care staff perceived high job strain, particularly dementia care specialists, (ii) employees who don't have Swedish as their first language perceived higher job strain regarding understanding and interpreting work situations with older persons, and (iii) organisational climate is crucial because a more creative organisational climate is associated with lower job strain.

In conclusion, these findings provided better understanding of how persons with dementia experienced risk-filled situations and showed that risks should be accounted for because they can affect how individuals engage in activities of daily living. Home care staff members are challenged as they face dilemmas when managing situations fraught with risk for persons with dementia, and they often work alone. Staff members encountered persons who were granted a wide range of services and staff perceived high job strain. Therefore, it's important to ensure that home care staff members have appropriate support and work under appropriate organisational conditions so they can take safety into account while supporting persons with cognitive impairment to engage in daily life – despite presence of risks.

SAMMANFATTNING

Avhandlingens övergripande syfte var att öka kunskapen om situationen för äldre personer med kognitiv nedsättning som bor hemma – med fokus på risker i det dagliga livet och stöd från hemtjänst.

För att studera situationen för personer med kognitiv nedsättning som bor hemma så användes olika metodologiska angreppssätt i de fyra studierna. **Studie I** och **II** hade en kvalitativ ansats och fokus i dessa studier var risker i det dagliga livet för personer med demenssjukdom. I **Studie I** utforskades erfarenheter hos personer med demenssjukdom genom 12 intervjuer med personer med demenssjukdom. Data bearbetades med kvalitativ innehållsanalys. I **Studie II** utforskades erfarenheter hos hemtjänstpersonal genom 12 individuella intervjuer och 2 fokusgrupper (n=11). Data analyserades med en konstant komparativ metod.

Studie III och **IV** hade en kvantitativ ansats och designades som beskrivande tvärsnittsstudier som studerade samband. I **Studie III** var syftet att beskriva utbudet av kommunalt beviljade hemtjänstinsatser samt att undersöka associationer mellan insatser som beviljats och: att ha en kognitiv nedsättning och demografiska karaktäristika (från dokument för 131 äldre personer). I **Studie IV** studerades upplevd påfrestning i arbetet hos hemtjänstpersonal (n=69) och hur påfrestning i arbetet korrelerade med: personliga och organisatoriska faktorer.

Studie I bidrog med kunskap om (i) att personer med demenssjukdom som bor hemma erfor riskfyllda situationer som obekanta och förbryllande och (ii) hur de hanterade dessa situationer genom att exempelvis söka efter igenkänning och klarhet.

Studie II visade hur hemtjänstpersonal resonerade gällande risker för personer med demenssjukdom och hur de kämpade med dilemma när de (i) spårade risker, (ii) när de övervägde om de skulle agera och (iii) när de agerade utifrån risker.

Studie III bidrog med kunskap om (i) vilka typer av hemtjänstinsatser som beviljades till äldre personer och visade att de beviljades ett brett utbud av insatser, inklusive stöd för grundläggande behov som att äta och dricka. Resultatet visade även att (ii) personer med kognitiv nedsättning och (iii) de som bor ensamma hade beviljats fler hemtjänstinsatser än de andra deltagarna.

Studie IV genererade kunskap om påfrestning i arbetet. Där visade det sig att hemtjänstpersonal upplevde hög påfrestning i arbetet, särskilt (i) personal som var specialiserad att möta personer med demenssjukdom, (ii) personal som inte har svenska som sitt första språk upplevde högre påfrestning i arbetet när det gällde att förstå och tolka arbetssituationer med de äldre personerna, och (iii) organisationsklimat var avgörande, då ett mer kreativt organisatoriskt klimat var associerat med lägre påfrestning i arbetet.

Sammanfattningsvis så bidrar dessa resultat till en ökad förståelse för hur personer med demenssjukdom erfar riskfyllda situationer och att risker bör beaktas då de kan påverka hur individer engagerar sig i aktiviteter i det dagliga livet. Hemtjänstpersonal har en utmanande arbetssituation då de ställs inför dilemman när de försöker att hantera riskfyllda situationer för personer med demenssjukdom och de arbetar ofta ensamma. I sitt arbete möter de även personer som är beviljade ett brett utbud av insatser och de kan också uppleva hög påfrestning i sitt arbete. Baserat på dessa resultat är det av vikt att försäkra att hemtjänstpersonal erhåller lämpligt stöd och att de ges förutsättningar som innebär att de kan ta hänsyn till säkerheten samtidigt som de stödjer personer med kognitiv nedsättning att vara aktiva i sin vardag – trots att det finns risker.

LIST OF SCIENTIFIC PAPERS

- I. Sandberg, L., Rosenberg, L., Sandman, P.-O., & Borell, L. (2017). Risks in situations that are experienced as unfamiliar and confusing – the perspective of persons with dementia. *Dementia*, 16 (4), 471-485.
- II. Sandberg, L., Borell, L., & Rosenberg, L. Risks as dilemmas for home care staff who care for persons with dementia. Unpublished manuscript, Karolinska Institutet, NVS.
- III. Sandberg, L., Nilsson, I., Rosenberg, L., Borell, L., & Boström, A.-M. (2018). Home care services for older clients with and without cognitive impairment in Sweden. *Health & Social Care in the Community*. 1-12. doi: 10.1111/hsc.12631. [Epub ahead of print]
- IV. Sandberg, L., Borell, L., Edvardsson, D., Rosenberg, L., & Boström, A.-M. (2018). Job strain: a cross-sectional survey of dementia care specialists and other staff in Swedish home care services. *Journal of Multidisciplinary Healthcare*, 11, 255-266.

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LIST OF ABBREVIATIONS

ADL activities of daily living

CCQ Creative Climate Questionnaire

CI cognitive impairment

CI confidence interval

IADL instrumental activities of daily living

MoHO Model of Human Occupation

PCC personal care category

ρ Spearman's rank correlation coefficient (rho)

r Pearson's correlation coefficient

SC service category

SD standard deviation

SDCS Strain in Dementia Care Scale

SE standard error

SPSS Statistical Package for Social Sciences

t Student's t-test

1 INTRODUCTION

1.1 PERSONAL INTRODUCTION

I've worked as an occupational therapist at a geriatric clinic. And over time, I've seen how hospital stays have become shorter and how it has become harder for older persons to get residential care placements. Consequently, they could return home from the hospital and face significant limitations in managing daily living.

The occupational therapist's role in a team at the geriatric clinic was to do assessments and support older persons carry out daily activities. I worked with older persons who were hospital in-patients and with home-residing persons. A doctoral project I had heard about captured my interest because it focused on risks for home-residing persons with dementia. As an occupational therapist, I had met many persons with dementia and observed their daily living challenges and risks that could arise. For example, using the cooker can be a fire hazard and having difficulty finding the way home when taking a walk can be risky. During the doctoral project, I also focused on home care services and job strain among home care staff. I know from my experience as a practitioner that considerations for home care staff are essential, because they face huge challenges when providing care for older persons with complex limitations during daily living.

Thanks to this doctoral project, I've had opportunities to thoroughly study risks for home-residing persons with dementia. Listening to their stories and home care staff stories gave me better understanding of their perspectives and experiences.

My hope is that better understanding of risk-filled situations – as seen from perspectives of persons with dementia and home care staff – will mean we're better able to support individuals with cognitive impairment as they participate in daily living activities, while accounting for risk. Identifying various types of granted home care services and disclosing perceived job strain might promote public discussion on the provision of appropriate services. This knowledge could enable better working conditions for home care staff and thus improve the services they provide when supporting home-residing older persons.

1.2 POINT OF DEPARTURE

Have you ever gone out and then wondered if you really did turn off the cooker or pulled the plug on the iron?

Everyone faces daily living risks, and persons with cognitive impairment (such as dementia) are especially at risk (Douglas, Letts & Richardson, 2011). For those who live with dementia, doing daily activities can be difficult; one challenge they face is making appropriate decisions in different situations – which can put them at risk. So risks can be related, for example, to cooking, getting lost when walking outdoors (Douglas et al., 2011; Gilmour, Gibson & Campbell, 2003), managing money (Gilmour et al., 2003) and driving (Hunt, Brown & Gilman, 2010).

It's public knowledge that the number of older persons in Sweden is growing and that they remain living at home a longer time – including persons with cognitive impairment such as that resulting from dementia (Schön, Lagergren & Kåreholt, 2016). In 2012, about 92,000 persons in Sweden had dementia and lived at home (Wimo, Jönsson, Fratiglioni, Sandman, Gustavsson & Sköldunger, 2014). Persons with dementia often need daily living support from family and friends (Bakker et al., 2013; Wimo, von Strauss, Nordberg, Sassi & Johansson, 2002) and from home care services (National Board of Health and Welfare, 2018a). Sweden has an *aging-in-place* policy; consequently, individuals may be able to remain living at home despite their impairments, activity limitations and participation restrictions (Henning, Åhnby & Österström, 2009; SFS 2001:453). The policy states that home-residing persons, who have needs, may be provided with tax-funded home care services such as help with showering and shopping. The rise in older, home-residing persons with comprehensive impairments and activity limitations requires extensive expertise for those who deliver home care services. For example, home care staff have to manage daily living risks for these persons.

The first two studies within this overall study placed particular focus on risk for persons with dementia as seen from the perspectives of those with dementia (Study I) and home care staff (Study II). Study III investigated home care services that are granted to older persons with or without documented cognitive impairment. Study IV examined job strain experienced by home care staff. Accordingly, the aim was to increase knowledge of conditions for older, home-residing persons with cognitive impairments – with focus on risks during daily living and support from home care service.

2 BACKGROUND

2.1 RISK CONCEPT – DAILY LIVING RISKS FOR PERSONS WITH DEMENTIA

Knowledge about perceived risks might trigger improvements in health care system services for home-residing persons with dementia (Clarke, 2000). In relation to dementia care, no standard definition of risk exists (Stevenson, McDowell & Taylor, 2018). Depending on context, risk (as a concept) is defined in varying ways (Althaus, 2005). Although quantitative definitions are more common, a non-quantitative definition occurs in everyday language, for example, when speaking about something undesirable that might or might not occur (Boholm, Möller & Hansson, 2016).

In line with qualitative interpretations of risk, the studies described in this thesis chose a *social constructivist* approach (Lupton, 2013), i.e., that which is seen as risk depends on the person's interpretation of the situation and the context in which risk arises. This choice is aligned with the focus within this thesis on situations that involve risk as experienced by persons with dementia and home care staff. To explore and understand experiences of situations involving risk, the studies adopted a broad definition of the risk concept, namely, 'issues of uncertainty of future outcomes from actions' (Clark et al. 2009, p. 90). Stevenson, Savage and Taylor (2017) investigated risk from the perspective of persons with dementia and stated that the construction of risk, for example, depends on a person's life history and psychological processes such as personality and feelings. And they claimed that risk construction is due to individuals' experiences from situations in which they are continually involved.

Previously, risks for home-residing persons with dementia have been described (Gitlin & Corcoran, 2000; Gilmour, 2004; Lach & Chang, 2007; Lach, Reed, Smith & Carr, 1995). One study contended that the main risk areas are cooking, falling, getting lost and managing money (Gilmour et al., 2003). Other studies did not focus on various types of risk but instead focused on specific risks such as driving (Hunt et al., 2010), or on risks that arise with wandering behaviour (Robinson et al., 2007). In a literature review, Stevenson et al. (2018) synthesised risk concept research regarding persons with dementia and accounted for carers who support these persons. The authors noted that while psychological risks have been described, dominant focus has been on physical safety risks.

Most studies that investigated risks for persons with dementia adopt an outsider perspective. That said, some qualitative research exists and gives persons with dementia a voice. In one qualitative study, persons with moderate dementia expressed no concerns about risk (Gilmour et al., 2003), while in another study, participants with mild-to-moderate dementia identified a wide range of actual or feared risks associated with factors such as daily activities and medications (Stevenson et al., 2017). The authors pointed out that several persons (with dementia) associated risk with danger and vulnerability and some persons expressed feelings of being frightened, scared or worried about risk. This illustrates that different approaches exist for describing the way these persons perceive risks in their daily lives.

Note, however, that some research includes the subject of risk-filled situations – even if the term risk wasn't used. One study, for example, reported grocery-shopping experiences of persons with Alzheimer disease. This study discovered and described *critical incidents* (Brorsson, Öhman, Cutchin & Nygård, 2013). Here, *risks* might be equated with *critical incidents* because both concepts include activity-related uncertainty.

Some studies examined how persons with dementia manage various situations. Others explored the way life – as a whole – changes with the onset of dementia (Clare, 2002; De Witt, Ploeg & Black, 2010; Harris, 2006; Nygård, 2004). And others extensively studied specific areas such as use of everyday technology (Rosenberg, Kottorp, Winblad & Nygård, 2009). While these studies didn't specifically report ways in which risk-filled situations are managed, to some extent, they dealt with management of potentially risky situations. Here are several examples that document ways in which persons with dementia handle risk: receiving help from those around them (Clare, 2002; Harris, 2006; Nygård, 2004; Stevenson et al., 2017); writing down what they need to remember (Clare, 2002; Nygård, 2004); checking that what they were meant to do has actually been done (Brorsson et al., 2013; Nygård, 2004; Stevenson et al., 2017); using their sense of touch to reinforce their impressions (Nygård, 2004); and using devices such as dosette boxes for medication (Harris, 2006; Nygård, 2004; Stevenson et al., 2017). Harris (2006) reported that when persons with dementia felt unsure about a situation, they applied these types of strategies to manage the situation. The literature indicates that persons with dementia reason and negotiate with themselves regarding whether or not risks are worth taking – and doing so might be necessary to continue carrying out certain activities, which ensure that they retain their identity (Clarke et al., 2009; Harris, 2006).

In summary, others have researched risks for persons with dementia but primarily from an outsider perspective – not from the persons' perspectives. Having better understanding of their experiences facilitates greater opportunities for supporting them.

2.2 REDUCING RISKS FOR PERSONS WITH DEMENTIA

To reduce risks for home-residing persons with dementia, family members, close friends and care staff support them via supervision. Ledgerd et al. (2015) reported that the presence of another person was one of the most important factors for preventing undesirable things from happening to home-residing persons with dementia. This study included various stakeholders and found that wandering behaviour and falls were considered to be risk-filled situations. Other studies reported on how family members and close friends said that they needed to stay at home with them and 'keep an eye on them' (p. 1002) to avoid risks (Lach & Chang, 2007). One study mentioned the importance of being attentive while caring for persons with dementia who demonstrated wandering behaviour (Bowen, McKenzie, Steis & Rowe, 2011). This study found that family members and close friends often had difficulty

understanding what had led up to the person's disappearance, i.e., it was difficult to predict when a risky situation might arise. Care staff emphasised importance of supervision and risk of injury when gaps occur during supervision (Horvath et al., 2005).

Lach and Chang (2007) described a more informal form of supervision; persons with dementia are less vulnerable when they live in a place in which nearly everyone knows them, e.g., neighbours, who watch out for them to some extent. If the culture of care in the neighbourhood is good, i.e., if people in the community show concern for each other, then social support constitutes a safety net (Wiersma & Denton, 2016).

As described in the literature (Bowen et al., 2011; Coracoran et al., 2002; Gitlin, Kales & Lyketsos, 2012; Horvath, 2005; Lach & Chang, 2007; van Hoof, Kort, van Waarde & Blom, 2010), modifying the person's environment is another, often-used way to reduce risk. For example, an occupational therapy intervention used strong colours for reinforcing presence of objects. Other intervention examples include support handles in the bathroom to avoid falls (Lach & Chang, 2007) and sufficient lighting to compensate for visual problems (Coracoran et al., 2002). Motion detectors might help manage wandering behaviour (Coracoran et al., 2002; Lach & Chang, 2007). And door/drawer locking might prevent hoarding among other undesirable behaviours (Coracoran et al., 2002). Family members and close friends removed objects to prevent potentially harmful activities, for example, they hid car keys (Bowen et al., 2011; Lach et al., 1995).

Studies have investigated activities in relation to risk. The literature emphasises the importance of carrying out an activity in relation to risk. Participation in leisure-time activities to stave off feelings such as restlessness and boredom have, for example, been found to be helpful to reduce risk of wandering behaviour (Coracoran et al., 2002). Clark et al. (2010) stress the importance of activity so that persons with dementia can 'maintain a sense of self and identity'. To improve opportunities for doing things; an activity can be divided into simple steps, a person can be given verbal or tactile cues and can be encouraged to carry out structured daily routines that are predictable (Gitlin, Kales & Lyketsos, 2012).

To establish a calm situation in meetings with persons with dementia, the carers can find different strategies helpful such as a calm attitude and gentle voice (Coracoran et al., 2002; Gitlin et al., 2012). In order for the carer to create and maintain a good relationship with a person with dementia, Haak (2002) emphasises the significance of spending time with that person and getting to know the individual – an approach that is at the heart of person-centred care (Kitwood & Bredin 1992; Leplege, Gzil, Cammellin, Lefevre, Pachoud & Ville, 2007). This is a way of ensuring that the individual is comfortable. Another strategy is to choose an appropriate time and place for a particular intervention when the person is rested and not distracted (Coracoran et al., 2002). Ledgerd et al. (2015) emphasised that training for home care staff, who work with persons with dementia, is a critical success factor for

ensuring that nothing undesirable happens to the persons they support.

In summary, studies reported strategies for reducing risks during daily living for home-residing persons with dementia from the perspectives of family members, close friends, and professional caregivers. Given that persons with dementia often receive services from home care staff, understanding of the ways in which home care staff manage risk in the persons' daily lives is highly relevant. But to my knowledge, no studies addressed ways in which home care staff identify and act upon risks for persons with dementia.

2.3 SUPPORT FROM HOME CARE SERVICES FOR OLDER PERSONS

Most older people remain living in an ordinary home environment as long as possible (Schön et al., 2016; Swarz & Nord, 2015), and home is the centre of daily life (Haak, Dahlin-Ivanoff, Fänge, Sixsmith & Iwarsson, 2007). Some need assistance to do everyday activities. A report published in 2018 stated that a high proportion of persons (ages 65+ who were discharged from hospital to their homes) needed personal care help. In 2017, in Stockholm County, 82% needed help with a bath or shower, 52% needed help with toilet visits, and 47% with moving around (Stockholm Gerontology Research Center, 2018).

As per Sweden's *Social Services Act* (Government bill 1979/80:1), the objective of care for older persons is to enable them to remain living at home in comfort – rather than being forced prematurely to move into residential care units. The number of places in residential care in Sweden has gradually declined. Between 2001 and 2012, the number of persons living in residential care fell 24%, while the number of older persons receiving home care services rose 33% (Ulmanen & Szebehely, 2015). In 2016, just over 166,300 persons, who had turned 65, were granted home care support (National Board of Health and Welfare, 2017a).

In Sweden, a local municipal assessor does an assessment when a person applies for home care support. The individual applies for home care support, and a local municipal assessor assesses the individual's needs and decides which services should be granted. The National Board of Health and Welfare (2009) described this process and noted that assessors receive necessary information from individuals and, when appropriate, from their families and from professional staff (National Board of Health and Welfare, 2009). As per the *Social Services Act*, home care staff must support individuals during their daily life when their needs cannot be met in another way, and this support is to ensure that they attain a reasonable standard of living (SFS 2001:453). The *Act* does not define a reasonable standard of living and because the *Act* is a regulatory document, municipalities have the freedom to base the support they choose to provide on local circumstances. Consequently, granted home care support can vary in Sweden.

The granted services fall into these categories: service and personal care (Hjalmarson, 2014). Services in the service category can include cleaning the home, shopping, laundry and running errands at the post office and bank. Services in the personal care category can include supervision, going for a walk, assisting with dressing and undressing, showering, toilet visits and preparing meals (Hjalmarson, 2014). The municipality can offer mental health and social support, such as day-care (SFS 2010:427). When an applicant is granted home care services, a care plan is developed to stipulate a more detailed description of how the home-care-delivering agency should provide the services. Care plans are based on collaboration between home care service agencies and individuals who receive support.

Because older, home-residing persons can have comprehensive activity limitations, home care services were developed to be more advanced, which places high demands on staff competence in terms of care provision and also medical duties (Gransjön Craftman, Grundberg & Westerbotn, 2018; Hjalmarson, 2014). Nurses can, for example, delegate medical duties such as dressing wounds, administering medicine and giving injections (insulin) to home care staff – even when these staff members have no training. As per the law, staff members can take on delegated duties on a voluntary basis. But when uncertainty exists on how a specific duty should be carried out, they have an obligation to report this to a nurse (SOSFS 1997:14). Gransjön Craftman, Hammar, von Strauss, Hillerås, and Westerbotn (2015) believe that the judiciousness of staff members' work situations is questionable, because the assumption is that home care staff should perform certain duties – despite their not having competence to do so. The study notes, for example, that home care staff are expected to provide medication to older persons who need assistance – even if the staff might not have adequate medical care qualifications.

Doubts exist regarding the *aging-in-place* policy objective to enable older persons to remain living at home. Some stakeholders contend that the policy has gone somewhat overboard and that many individuals who apply for residential care do not receive it (Ulmanen & Szebehely, 2015). Applicant rejection might occur because municipal assessors believe that home care services can meet applicants' needs – regardless of their wishes. Economic incentives might motivate this belief, because up to a certain cut-off point, it is less costly for older persons to remain living at home (Gens, Hjalmarson, Meinow & Wånell, 2015). The following factors were studied in relation to the population of older persons: the rise in home care services between 2001 and 2012 and the fall in granted residential care. Study results showed that the percentage of those receiving home care rose from 7.9% to 9.9%; the percentage of those receiving residential care fell from 7.7% to 4.9%. Ulmanen and Szebehely (2015) contend that the rise in home care recipients does not make up for the fall in the number of places in residential care. Szebehely and Trydegård (2012) believe that those in charge of assessing home care needs have become more restrictive and that this is due to limited resources in many municipalities.

Criticism targets the degree to which persons applying for home care actually can influence and agree to the type of support provided for their individual needs and wishes (Berglund, Dunér, Blomberg & Kjellgren, 2012; Szebehely & Trydegård, 2014). A Norwegian study investigated the problem of municipalities offering a variety of home care services as standard packages, whereby older persons are transformed into passive recipients who must address their needs in relation to this standard package (Vik & Eide, 2012). To tackle these types of problem, the Swedish National Board of Health and Welfare advocates an approach that puts individuals' needs first. So local municipal assessors start assessments by finding out what older persons want to achieve, what is important to them, and what is supportive or obstructive in their daily living. Proposed services should not be offered until needs are investigated and identified (National Board of Health and Welfare, 2016).

A nationwide investigation in Sweden of the way older persons perceived the quality of home care found that most respondents were generally satisfied with the services but that considerable differences existed among municipalities. But some respondents (who had been granted home care hours above the average number) reported that they were *less* positive about their health and *less* positive about the provided care. Many respondents reported that loneliness troubled them and that they felt rather or very unsafe living at home – even with support from home care services (National Board of Health and Welfare, 2018b).

In summary, Sweden has a body of regulations and an organisation for granting assistance in the form of public funding to ensure that older applicants have what is called a reasonable standard of living. Home care services that include personal care and other services can be granted to individuals as daily living support. Ongoing discussions take up whether or not older persons are granted appropriate means of support, i.e., whether they are receiving the help they need and whether it has become too difficult to be granted other housing accommodations. The situation in which older persons with comprehensive activity limitations remain living at home places heavy demands on home care staff.

2.4 INFORMAL AND FORMAL SUPPORT FOR PERSONS WITH DEMENTIA

It's well known that family members and close friends to persons with dementia can experience significant strain (McCabe, You & Tatangelo, 2016; Singh, Hussain, Khan, Irwin & Foskey, 2015; Tyrrell, Hillerås, Skovdahl, Fossum & Religa, 2017). Caregivers who participated in a focus group study provide examples of strain when they reported that they were scared something would happen to the person with dementia, such as suffering a fall. Some of the family members reported that they were scared for their own safety because of aggressive and violent behaviour (Lach & Chang, 2007). Regarding overall support given to these persons, their families and friends provided informal support that's considerably greater than formal support from other sources such as home care services (Bakker et al., 2013; Wimo et al., 2014).

Despite the increase in the number of home-residing persons with dementia, a comprehensive Swedish study found that only 41% of persons with a dementia diagnosis were granted home care support (Odzakovic, Hyden, Festin & Kullberg, 2018). This finding is in line with a study from the Netherlands; here, other types of care did not compensate for the decrease in residential care for persons with cognitive impairment (Aaltonen, Raitanen, Comijs, van Groenou, 2018). Studies reported that persons with dementia were more likely to be granted home care services to a higher extent if they lived alone (Larsson, Thorlund & Forsell, 2004; Miranda-Castillo, Woods & Orrell, 2010). Another study including persons with Alzheimer's disease who lived alone reported that; lower IADL capacity and more medications were associated with more home care services. In the case of persons with Alzheimer's disease who were living with family members; higher age, lower basic ADL capacity and more medications were associated with more home care services (Wattmo, Londos & Minthon, 2014). No studies examined *types* of available home care services provided to persons with cognitive impairment.

Swedish residents with dementia must get a dementia diagnosis to access tailor-made care such as day care and home care services from staff specialized in caring for persons with dementia (Bökberg, Ahlström, Karlsson, Rahm Hallberg & Janlöv, 2014). The National Board of Health and Welfare found that support of a dementia team has positive effects, such as improved quality of life for persons with dementia and fewer negative consequences, such as emergency hospital visits, and greater continuity in encounters between these persons and staff (National Board of Health and Welfare, 2017b). But in other parts of Europe, persons with dementia seem to be given a more general, basic level of formal care and services, and provided services are seldom adapted to individuals' needs (Bökberg et al., 2015). Moreover, persons with dementia can have difficulty expressing their needs and wishes when applying for home care services because of reduced cognitive capacity, such as impaired memory and ability to communicate (Österholm & Hydén, 2016). Although these persons can have difficulty expressing their needs, a review reported that they still wish to be involved in decisions regarding their care (Miller, Whitlatch & Lyons, 2016). Having their needs met is key. For example, one study shows that those who had care needs met at home reported more positive psychosocial benefits than those whose needs were unmet (Kadowaki, Wister & Chappell, 2015).

In summary, persons with cognitive impairment receive support from home care services even though a significant proportion of the support comes from other sources such as families and close friends. Research shows that it can be difficult for persons with cognitive impairment to express their needs and wishes when applying for home care services. Few studies considered home care services granted to persons with cognitive impairments (e.g., dementia). To the best of my knowledge, no study attempted to document *(i)* various types of support that is granted and *(ii)* variation among types of granted services for persons with or without cognitive impairment.

2.5 JOB STRAIN AMONG HOME CARE STAFF – PARTICULAR FOCUS ON THOSE WHO SUPPORT PERSONS WITH DEMENTIA

How care staff feel about their situation is naturally of importance, and their well-being is linked to quality of care, i.e., staff well-being has significance for the quality of care they provide and thus for older persons who receive that care (Edvardsson, Sandman, Nay & Karlsson, 2008). Given that carers' well-being is key, the overall study also focused on job strain among home care staff. To measure job strain, I used the *Strain in Dementia Care Scale (SDCS)* developed by Edberg, Anderson, Orrung Wallin and Bird (2015). This instrument is based on an empirical study of staff experiences (Edberg, Bird, Richards, Woods, Keeley & Davis-Quarrell, 2008), and is thus not based on any specific definition of job strain or theory (see section '5.4.4.1 Instruments' for more information about the *SDCS*). Because the instrument was used in the overall study, no specific definition of job strain was given, but the instrument is described in detail. That said, the *job strain* model (Karasek & Theorell, 1990) is one model that is closely related to job strain; the model illustrates how psychosocial environments affect health. This model associates intense workplace stress with burdensome work demands combined with minimal control.

Job strain studies of care staff primarily targeted nursing homes, and these studies reported that staff work situations are stressful (Edvardsson et al., 2008; Edvardsson, Sandman, Nay & Karlsson, 2009; Knopp-Sihota, Niehaus, Squire, Norton & Estabrooks, 2015; Mc Vicar, 2003; Orrung Wallin, Jakobsson & Edberg, 2015).

Orrung Wallin et al. (2015) reported that nursing-home-related job strain is related to personal and organisational factors. Two studies, which investigated personal factors, reported that higher job strain levels were associated with younger staff members (Edvardsson, Sandman, Nay & Karlsson, 2009; Orrung Wallin et al., 2015). Orrung Wallin et al. (2013) found that higher job strain levels were associated with staff members who had studied at a university or college. While Edvardsson et al. (2009) reported the opposite: lower educational levels were associated with higher job strain (Edvardsson et al., 2009). These studies used various instruments, and this variation impedes direct comparisons between the results. Orrung Wallin et al. (2015) used the *Strain in Dementia Care Scale* (Bird, Edberg, Anderson & Orrung Wallin, 2012). Edvardsson et al. (2009) used a questionnaire on demands and control (based on the job strain model, Karasek & Theorell, 1990). Lower work experience levels were associated with a higher job strain levels (Orrung Wallin et al., 2015). One personal, job-strain-related factor *was not* considered in these studies, namely, the staff's first language. No thorough studies exist regarding ethnic differences in Sweden among professionals working in elderly care (Olt, Jirwe, Saboonchi, Gerrish & Emami, 2014). In a nursing-home-based Canadian study, English was not the first language of more than 50% of the staff. The authors noted that that ethnicity and culture must be considered – to improve staff planning and thus improve

situations for care recipients (Estabrooks, Squires, Carleton, Cummings & Norton, 2015).

Regarding organisational factors, shortcomings in management and support were related to higher job strain levels (Orrung Wallin et al., 2015). Perceptions of the climate of care and opportunities to discuss difficulties and ethical dilemmas were associated with job strain (Edvardsson et al., 2009). Not being able to provide appropriate care is one of the main causes of job strain. One study claimed that not being able to provide appropriate care can be related to instances when staff members do not have the abilities, time and appropriate resources (Edberg et al., 2008). In a literature review on workplace stress, Mc Vicar (2003) listed these factors as stressors: workload, relationships with other staff members, management and management style, dealing with patients' and relatives' emotional needs, shift work and insufficient pay.

Situations whereby older persons with cognitive impairment live at home challenge home care staff. Some studies reported on the stressful nature of dealing with behavioural and mental health problems in persons with reduced cognitive capacity (Edvardsson et al., 2008; Schmidt, Dichter, Palm & Hasselhorn, 2012). For example, dealing with aggression and unpredictable behaviour is difficult (Boström, Squires, Mitchell, Sales & Estabrooks, 2011; Brodaty, Draper & Lee Fay, 2003). Results from research in this area are contradictory; some studies found that staff members, who work on dementia units, reported significantly lower stress levels and fewer behavioural symptoms among the residents (Morgan, Stewart, Dárcy, Forbes & Lawson, 2005). Morgan et al. (2005) suggested that staff education and training levels determine their chances of avoiding stressful situations.

While stress and job strain, among nursing home staff, were previously studied, stress and job strain were not studied among home care staff. Of course, many similarities occur between working in home care services and working in a hospital or nursing home – and so do substantial differences. For example, home care staff face additional challenges because they often work alone in older persons' homes and must thus manage various situations on their own (Gransjön Craftman et al., 2018; Quinn et al., 2015). Lundgren, Ernsth-Bravell and Kåreholt (2015) contended that (i) non-existing collaboration opportunities for home care staff hinder collegial support opportunities and (ii) nursing home staff work under conditions that facilitate collegial support *more so* than home care staff. So home care staff must rely on their own capabilities (Hanson, Perrin, Moss, Laharnar & Glass, 2015). Working on their own in an individual's home was considered emotionally stressful (Hansson & Judith, 2008). Physical distances between home service recipients can mean that managers have fewer opportunities to supervise, organise and optimise staff members' work situations (Lundgren et al., 2015).

Staff members who provide care in individuals' homes can be exposed to stress in various ways. Although *job strain* – as a specific term – was not studied, research exists in this area. For example, one US study reported various risks to health and safety – including musculoskeletal injuries, violent

behaviour, exposure to contaminants plus cleaning agents and disinfectants that contain chemicals (Quinn et al., 2015). Another US study that focused on violence in the workplace against home care staff found that a proportion of no less than 61% of female staff had experienced violent behaviour on at least one occasion during the past year (Hanson et al., 2015). A Norwegian study described a typically stressful working day for staff members; they felt that the nature of their jobs went against their own professional norms and that they were being pushed to the limit of what they could cope with (Vik & Eide, 2012). In another study, the feeling of not being able to meet individuals' care needs was associated with depression among staff members (Kim, Noh & Muntaner, 2013).

Some studies report problems associated with strain among home care staff, and others report high-level job satisfaction among home care staff. This satisfaction is primarily related to close relationships that they develop with persons they support – and to the ability to work independently and enjoy job flexibility (Quinn et al., 2015). It is interesting to note that providing person-centred care is a key factor in job satisfaction (Orrung Wallin et al., 2012; Sjögren, Lindkvist, Sandman, Zingmark & Edvardsson, 2014). Staff members, who participated in a training programme in person-centred care, reported that ‘... they become proud of their work and consider it important’ (Berglund, Gillsjö & Svanström, 2018, p.7). Although job strain in the context provided here has been looked at primarily regarding its negative aspects, it can be a sign of commitment (Edberg et al., 2015).

In summary, the aforementioned studies reported that working in a nursing home can be stressful and that personal and organisational factors are associated with job strain levels. The studies reported that challenges occur when dealing with persons with cognitive impairment and caring for them in their home. Home care staff work varies from institutional care staff work. Literature on home care staff work situations and job strain assessments is limited.

2.6 THEORETICAL FRAMEWORK

Daily life for home-residing persons with cognitive impairments forms the foundation for the overall study, which adopted a person-centred approach to avoid focusing on diagnosis and overshadowing individuals' stories (Kitwood & Bredin, 1992; Leplege et al., 2007). A person-centred approach seeks to find out who a person is, and to understand the person through his or her life story – a story that exists between a person's memories and expectations (Ekman, 2014). Person-centred care might be understood as an approach that focuses only on a person. This overall study, however, focuses on persons' situations. Thus, a person-centred approach is adopted via experiences of individuals with dementia (Study I) – and experiences of home care staff (Studies II and IV). In addition, studying the range of granted home care services is included because these services affect the life stories of persons who receive the services (Study III).

The theoretical framework of the overall study is based on the idea that *occupation* (activity) is central to human beings in their daily lives, so an occupational perspective was applied. This perspective offers a way of looking at and thinking about 'human doing' (Njelesani, Tang, Jonsson & Polatajko, 2012, p. 228). One of the fundamental assumptions in an occupation (activity) perspective is the relationship between doing and health and well-being (Hemmingsson & Jonsson 2005; Wilcock, 1998; Wilcock, 2001). Another assumption is that doing (in terms of being engaged in activities) contributes to being, becoming and belonging (Huot & Rudmans 2010; Wilcock, 2007). Consequently, doing contributes to who we are and who we wish to become – and to how we engage in occupations (activities) with other persons.

The above assumptions emphasise importance of increasing knowledge about daily living for home-residing persons with cognitive impairments. For example, ways in which they experience risks and manage the risks and ways in which support is provided to them are of importance for their doing and well-being in daily life – but yet sparsely researched.

Applying an occupational perspective (*i*) contributed to focusing the studies on occupations (activities) in the daily lives of persons with cognitive impairment, (*ii*) contributed to the overall design of Studies I-III and (*iii*) guided development of the interview guides, by focusing on occupation (activity) in daily living (Studies I-II).

From an occupational perspective, *occupation* is a key concept, and this definition of occupation was selected: ‘doing culturally meaningful work, play or daily living tasks in the stream of time and in the context of one’s physical and social world’ (Kielhofner, 1995, p. 4). This definition is appropriate because it embraces experiences of persons with dementia and experiences of home care staff. In this thesis, the word occupation is used interchangeably with activity. Kielhofner (2008) points out that culture is always present – shaping and defining the physical and social environment. Consequently, occupation cannot be disconnected from the context in which it is performed. This guided my understanding, for example, when studying experiences of persons with dementia regarding risk-filled situations within the context of precarious, uncertain circumstances in various life situations (Study I).

But the interplay of different aspects of daily living situations is difficult to address. To facilitate understanding of the interaction between a person, the environment and an occupation in relation to risk, the *Model of Human Occupation (MoHO)* was applied (Kielhofner, 2008). The *MoHO* is based on dynamic systems theory and demonstrates how doing can be understood in a dynamic interaction between the person, the environment and the occupation – making every situation unique (Kielhofner, 2008). Highlighting uniqueness in each situation throughout dynamic interactions can expand understanding of risk-filled situations – risks can, for example, be hard to predict and manage because interaction is continuously ongoing.

3 RATIONALE OF THE OVERALL STUDY

This is the overall study's rationale: many older persons live at home with cognitive impairment, which may affect their activities during daily living. Because the number of beds in residential care has decreased, this implies that, with support from home care staff, a higher number of older persons live at home with complex health care needs. These persons are as all persons, exposed to various types of risks in their everyday lives, but persons with cognitive impairment might be even more vulnerable. Home care staff members who support older persons mostly work alone. They must rely on their own skills and abilities and thus land in a demanding job situation. Based on the research presented in the background section, the overall study intended to contribute with new knowledge – to fill in these knowledge gaps:

1. Earlier studies described risks to which persons with dementia are exposed. Yet a knowledge gap exists regarding how persons with dementia experience and manage risk-filled situations during daily living.
2. Even if it's common for older persons to have home care services, research on how home care staff care for older persons with cognitive impairment is sparse. A knowledge gap exists regarding how home care staff identify daily living risks for persons with dementia and how they reason and act upon these risks.
3. Regarding home care services, previous reports described the amount of support such as the number of service hours, but a gap exists regarding types of home care services that persons with and without cognitive impairment are granted.
4. Knowledge exists regarding how nursing home staff report job strain, but little is known about perceived job strain among home care staff.

Taken together, through deepened understanding of how risk-filled situations can be experienced by persons with dementia and home care staff, appropriate support to persons with dementia can be designed based on new knowledge. An overview of types of home care services granted to persons with and without cognitive impairment can contribute to better understanding situations for these older, home-residing persons. Moreover, in this context, it is relevant to study work situations of home care staff regarding job strain – to learn more about how to enhance their well-being and to give them more opportunities to be able to offer high-quality services.

In conclusion, it is important to add valuable knowledge to be able to support older persons and those with cognitive impairments such as dementia – thus advance their opportunities to receive services that support their participation in daily living activities.

4 RESEARCH AIMS

4.1 AIM OF THE OVERALL STUDY

The overall study's aim was to increase knowledge of conditions for older, home-residing persons with cognitive impairments – with focus on risks during daily living and support from home care service.

4.1.1 Specific aims of each study

Study I: explore and better understand how people with dementia, living at home, experience risks in their daily life and how they handle these situations.

Study II: explore how home care staff identified risks in the everyday lives of persons with dementia and further investigate how they reasoned about, and acted on, these identified risks.

Study III: identify and describe the range of granted home care services and service hours; compare services granted to persons with and without documented cognitive impairment; and examine associations between the range of granted home care services and factors related to cognitive impairment and demographic characteristics.

Study IV: describe perceived job strain among home care staff and examine correlations between job strain, personal factors and organisational factors.

5 METHODS

5.1 STUDY DESIGNS

Various methodological approaches were used to enhance knowledge about conditions for older, home-residing persons with cognitive impairments. Studies I and II aimed to explore experiences of persons with dementia and home care staff members; thus, explorative qualitative methods were used. Studies III and IV aimed to describe variables and examine associations and correlations between the described variables; therefore, a cross-sectional study designs was used. Table 1 displays an overview of research methods used in the studies.

Table 1. Overview of the focus, design, participants and research methods in the studies

	Study I	Study II	Study III	Study IV
<i>Focus</i>	Explore risk-filled situation via experiences of persons with dementia	Explore how home care staff reason regarding how they identify risks in daily lives of persons with dementia & how they handle these identified risks	Describe the range of granted home care services & associate the services to CI ¹ & demographic characteristics	Describe perceived job strain among home care staff & correlate job strain with personal & organisational factors
<i>Design</i>	Explorative qualitative approach based on content analysis	Qualitative grounded theory approach	Descriptive correlational cross-sectional study design	Descriptive correlational cross-sectional study design
<i>Participants</i>	Home-residing persons with dementia	Home care staff: Dementia care specialists n=20 Other staff n=3	Older persons with home care services: Persons with CI ¹ n=43 Persons without CI ¹ n=88	Home care staff: Dementia care specialists n=34 Other staff n=35
	Total n=12	Total n=23	Total n=131	Total n=69
<i>Data collection</i>	Open-ended individual interviews	Open-ended individual interviews & focus group discussions	Need assessment forms & care plans	Self-reported survey
<i>Instruments</i>				SDCS ² & CCQ ³
<i>Data analysis</i>	Qualitative content analysis	Qualitative grounded theory approach	Descriptive & inferential statistics	Content analysis Descriptive & inferential statistics

¹cognitive impairment, ²Strain in Dementia Care Scale, ³Creative Climate Questionnaire

5.2 SETTING AND PARTICIPANTS

The overall study focused on older persons with cognitive impairment and on home care employees.

5.2.1 Study I: setting, participants and inclusion criteria

Persons with dementia were recruited via a memory assessment clinic in Stockholm, Sweden, where individuals are diagnosed, treated and provided with guidance and support.

The study recruited 12 participants based on these criteria: (i) participants had to be diagnosed with mild-to-moderate dementia as per established criteria for dementia: DSM-IV (American Psychiatric Association, 2000) and ICHD-10 (World Health Organisation, 1993); (ii) participants had to communicate in Swedish, (iii) participants had to reside in their own domiciles and not within institutions.

To include individuals with varying experiences regarding risk-filled situations, the concept of purposeful sampling (Patton, 2002) was applied. This enabled the study to achieve variation in participants' gender, age and living conditions (living alone/cohabiting).

Of these 12 participants (Table 2), gender was equally divided between men and women (6 females and 6 males). Participant age varied from 67 to 87 (m=79). Living conditions consisted of 8 individuals who cohabited, while the 4 lived on their own. The locations in which they lived varied. Five participants lived in a city in Sweden, while 7 lived in suburbs. The most common diagnosis among the participants was Alzheimer disease (n=9). Two persons were diagnosed with vascular dementia, and 1 person with Lewy body dementia.

Table 2. Overview of the 12 participants in Study I

Gender	n	Age	Years	Living conditions	n	Location	n	Diagnosis	n
Male	6	Mean	79	Living alone	4	City	5	Alzheimer disease	9
Female	6	Range	67-87	Cohabiting	8	Suburb	7	Vascular dementia	2
								Lewy body	1

5.2.2 Studies II, III, and IV: setting

Studies II, III and IV were mainly conducted via one home care service agency. This agency is centrally located in a city in Sweden and had 5 units in various areas. The agency provides 24/7 services and employs about 400 persons to provide home care services to about 1000 persons. Annually, the agency received about the same number of need assessment forms from municipal assessors, i.e., one for each person. Persons who received the services had varying types of functional limitations. The director at the agency estimated that 20–30% of the persons had cognitive impairment and/or dementia. In Study II, participants were also recruited from a second agency in a suburb; it

provided services 24/7 but with a smaller number of employees and persons to whom they provided services. The agencies were invited to participate in these studies via convenience sampling (Polit & Beck, 2016).

In Studies II and IV, the participants were home care staff. All participants, except for 4 persons in Study II, worked at the main home care agency, and the records (need assessment forms and care plans) used in Study III were collected at this main agency.

Both agencies, from where participants were recruited, had staff members who were specialized in dementia care. Dementia care specialists from those teams participated in Studies II and IV. Being a dementia care specialist at the agencies meant that they had dementia care education. The agency recommended that they complete a web-based course and additional dementia care education. The specialized staff at each unit had a one-hour meeting allocated every week for reflection and guidance regarding caring for persons with dementia. Providing guidance is in line with the Swedish National guidelines for care and nursing in dementia 2010 (National Board of Health and Welfare, 2010). Other employees (hereafter called *other staff*) were not required to have dementia care education. All staff members at all agencies provided services to persons with varying types of limitations, but the specialized staff worked more extensively with persons who had a dementia diagnosis and with those persons who had increased special needs.

5.2.2.1 Study II: participants and inclusion criteria

In Study II, a total of 23 persons participated – all were employed as home care staff at the two previously described agencies. Inclusion criteria were (i) participants should be home care staff members who cared for persons with dementia; (ii) they should have at least 6 months working experience as home care staff employee, and (iii) work day shifts.

Participant recruitment for individual interviews was conducted so that the home care staff at the two home agencies could be informed about the study during a staff meeting and about what it meant to participate. Then they were asked to self-report if they wanted to participate in the study. For focus group discussions, staff members were recruited from two of the units in the centralised agency.

Of the 12 persons who participated in the individual interviews, 7 were nurse assistants and 5 were care assistants. Nine participants worked as specialists who provided services for persons with dementia and 3 worked in other capacities. All had experience working with persons with dementia; 9 participants were women and 3 were men. The length of time that they had worked with persons with dementia in home care ranged from 6 months to 17 years. Some staff members had other experience in working with persons with dementia, such as working at a nursing home. On average, the participants had worked for 10.5 years; the median was 10.0 years.

Eleven persons participated in 2 focus group discussions (n=6 and 5) – 4 were nurse assistants and 7 were care assistants (8 women and 3 men). They had been employed in home service between 4 and 24 years, and they had varying experience working with persons with dementia. On average, the participants had worked for 9.7 years; the median was 8.0 years.

Table 3. Overview of the 23 participants in Study II

Participants	Individual interviews n=12	Focus group discussions n=11	Total n=23
<i>Working as, n (%)</i>			
Nurse assistant*	7 (58)	4 (36)	11 (48)
Care assistant	5 (42)	7 (64)	12 (52)
Specialized in caring for persons with dementia	9 (75)	11 (100)	20 (87)
<i>Gender, n (%)</i>			
Male	3 (25)	3 (27)	6 (26)
Female	9 (75)	8 (73)	17 (74)
<i>Working with persons with dementia in home care services, years</i>			
Mean	10.5	9.7	10.1
Median	10.0	8.0	10.0
Range	0.5-17.0	4.0-24.0	0.5-24.0

* Requires 1.5 years of secondary school education

5.2.2.2 Study III: participants and inclusion criteria

Study III used 131 personal records that contained need assessment forms and care plans. The inclusions of records were based on fulfilling three criteria's for the need assessment forms: (i) applicants had to be age 65+; (ii) they had to be living in their homes – not in institutions; and (iii) they had to have a care plan developed by agency staff members.

Most persons were women (n=101; 77.1%). Their mean age was 85.3 years (SD=6.7). Most were living alone (n=110; 84.0%) and most had children (n=100; 76.3%); see Table 4.

The sample was divided into 2 groups: persons with documented cognitive impairment (n=43; 32.8%) and persons without documented cognitive impairment (n=88; 67.2%). Of the 43 persons in the group with documented cognitive impairment, dementia diagnoses were entered on 16 forms. The other 27 personal records for this group contained notes, e.g., memory problems, on the waiting list for tests at a memory clinic, or indicating cognitive impairment. Table 4 displays characteristics of the 2 groups. No significant differences in gender, age, living conditions and number of children were found when comparing the 2 groups. A p-value of ≤ 0.05 was considered statistically significant.

Table 4. Characteristics of the total sample – plus a comparison of groups in Study III

Variable	Total sample	Persons with CI*	Persons without CI	Test statistics	p-value
Older persons, n (%)	131 (100)	43 (33)	88 (67)		
Gender, n (%)				$\chi^2=1.142$	0.163
Male	30 (22.9)	13 (30.2)	17 (19.3)	d.f.=1	
Female	101 (77.1)	30 (69.8)	71 (80.7)		
Age, years				$t=-0.449$	0.654
Mean (SD)	85.3 (6.7)	84.9 (6.8)	85.5 (6.6)	d.f.=129	
Range	67.0 to 103.0	67.0 to 96.0	68.0 to 103.0		
Living conditions, n (%)				$\chi^2=1.142$	0.285
Living alone	110 (84.0)	34 (79.1)	76 (86.4)	d.f.=1	
Cohabiting	21 (16.0)	9 (20.9)	12 (13.6)		
Children, n (%)				$\chi^2=0.006$	0.939
Yes	100 (76.3)	33 (76.7)	67 (76.1)	d.f.=1	
No	31 (23.7)	10 (23.3)	21 (23.9)		

*cognitive impairment

5.2.2.3 Study IV: participants and inclusion criteria

Study IV engaged 69 home care staff members. The inclusion criterion was that home care staff members had to provide care and services for older persons. Dementia care specialists and other staff were invited to participate in 2 data collection phases. Consequently inclusion involved an indirect criterion, i.e. being a dementia care specialist (phase 1) or not (phase 2). Working night shifts only was the sole exclusion criterion.

Participants included women (n=56; 81%) and men (n=12; 17%); 1 person reported *other* for the gender item. Ages ranged from 21 to 64; the mean was 46.3 (SD=11.5). Current educational status was high school (n=58; 85%), course at university (n=20; 29%) and education in dementia care (n=39; 57%); see Table 5. Among these participants, 55% (n=38) had Swedish as their first language. Length of employment in home care services ranged from 1 to 40 years (m=14.7; SD=10.7). The mean for length of time working with persons with dementia in home care and/or in nursing homes was 15.2 years (SD=10.6). Most were permanently employed (94%; n=64) and worked daytime and weekdays (n=42; 61%).

The sample was divided into 2 groups: staff specialised in caring for persons with dementia (n=34; 49%) and other staff (n=35; 51%). Table 5 displays characteristics for the employees within the groups. Two significant differences were found when comparing dementia care specialists with other staff. Dementia care specialists (n=27; 79%) had education in dementia care to a greater extent compared with other staff (n=12; 34%; $p<0.01$), and a higher percentage of dementia care specialists (29%; n=10) worked evenings compared with non-specialized staff (6%; n=2; $p<0.01$).

Table 5. Characteristics of home care staff members in Study IV; significant values in **bold** (≤ 0.05)

Variables	Total sample	Dementia care specialists	Other staff	p-value
Number	69	34	35	
<i>Gender, n (%)</i>				
Female	56 (81)	29 (85)	27 (77)	
Male	12 (19)	5 (15)	7 (23)	0.499
<i>Age, mean (SD)</i>				
Year	46.3 (11.5)	47.9 (9.9)	44.8 (12.8)	0.272
<i>Education, n (%)</i>				
High school	58 (85)	29 (88)	29 (83)	0.559
University course	20 (29)	11 (32)	9 (26)	0.491
<i>Dementia care education, n (%)</i>	39 (57)	27 (79)	12 (34)	<0.01
<i>Swedish as first language, yes, n (%)</i>	38 (55)	17 (50)	21 (60)	0.404
<i>Length of employment in home care service year, mean (SD)</i>				
	14.7 (10.7)	14.7 (10.3)	14.7 (11.2)	0.976
<i>Length of time working with persons with dementia in home care or in institutional care year, mean (SD)</i>				
	15.2 (10.6)	14.8 (10.7)	15.5 (10.7)	0.777
<i>Employment, n (%)</i>				
Permanent	64 (94)	32 (94)	32 (94)	1.00
<i>Working hours, n (%)</i>				
Daytime-weekdays	42 (61)	15 (44)	27 (77)	
Daytime-weekends	15 (22)	9 (27)	6 (17)	
Evenings	12 (17)	10 (29)	2 (6)	<0.01

5.3 ETHICAL CONSIDERATIONS

Persons with dementia participated in Study I and home care staff members participated in Studies II and IV. My starting point was to show respect for each participant's autonomy, that is, individuals' right to decide about their own person (Lynøe & Juth, 2009). Informed consent was acquired for the studies. Informed consent is a prerequisite for a person to be able to make a rational decision as to whether or not he or she wants to participate in the study.

Study I participants had a dementia diagnosis so informed consent was obtained with extra sensitivity. Great care was taken to provide information that was understandable and that contained relevant details. The information was provided on the phone and in writing before the session, and it was reiterated before the interview's start. Oral consent was obtained with sensitivity – using an explicit strategy. This strategy is based on not including persons who seem to have difficulty understanding what consent means or who, upon inclusion in the study, later express or signal discomfort.

All participants in Study I, II and IV received oral and written information, which explained that participation was voluntary and that they could discontinue their participation without having to give any explanation. Since many home care staff members did not have Swedish as their first language, the information was provided in easy-to-understand Swedish – with opportunities to ask questions about what participation implied.

Study III studied personal records (need assessment forms and care plans). Before processing the data, social security numbers and names – except for birth date and gender – were erased. All collected personal records were treated with confidentiality, and the documents were kept in a locked cabinet that was only available to the research group.

Findings were presented in a way that ensured that it was impossible to identify participants; fictitious names were used to present Study I participants.

The Regional Ethics Committees in Stockholm, Sweden approved all four studies (Study I: No. 2009/1540-31/2 and 2011/1011-32); (Study II: No. 2009/1540-31/2 and 2014/1014-31/4); (Study III: No. 2014/1014-31/4 and 2015/1176-32); and (Study IV: No. 2014/1014-31/4 and 2014/1894-32).

5.4 DATA COLLECTION

Data collection is reported separately for each study because different procedures were used.

5.4.1 Study I: data collection

Data for Study I were collected in 2011 via individual interviews (Kvale, 2009) and each of the 12 participants were interviewed once. The setting for 11 of the interviews was their participants' homes and 1 was conducted at the memory assessment clinic (which they preferred). To allow study participants to narrate their own experiences of risky circumstances, the interview guide included open-ended and follow-up questions (Kvale, 2009). The interviews started with questions related to whether individuals had experienced accidents during daily living, which could be considered an example of a situation fraught with risk. The *MoHO* served as support during the interviews; it helped me stay focused on how risks might influence a person's everyday life. For example, to note a person's values, interests, roles and habits (Kielhofner, 2008).

Because having dementia can affect the ability to express oneself, the interviews were adapted to facilitate active participation – to increase the likelihood of participants sharing their individual experiences. For example, Nygård (2006) contends that time constraints should not burden participants, and questions can be tangible and based on daily living activities. To increase participants' answering/responding capabilities, *risk* was not the only term that was used. This prompt is an example of how their individualized experiences were obtained: 'Please tell me how you get on when you go grocery shopping'.

A pilot interview was done to facilitate practice using the aforementioned guide (Dahlberg, 1993). Subsequently, minimal changes were made, which helped improve the guide. During the pilot interview, appropriate data were collected and subsequently included in this study.

Interview length varied – depending on the individual's circumstances. For example, one interview lasted only 12 minutes, while the other 11 interviews lasted between 29 and 59 minutes. The average time for all interviews was 42 minutes, and the median was 41.5 minutes. But note, however, that visit length exceeded interview length. Because the sessions were without time constraints, opportunities to establish trust between myself and the participants increased. I was able to answer their questions, and we could discuss the study without time pressure. All interviews were transcribed verbatim.

Thereafter, the text was validated against the audio recordings (Kvale, 2009).

5.4.2 Study II: data collection

Data collection began with 12 individual interviews with home care staff during 2011. The interviews were semi-structured and followed an interview guide (Kvale, 2009). They were designed to collect

data on (i) how home care staff reasoned regarding identifying risks during daily living for persons with dementia and (ii) how they act upon these risks. During the interviews, the *MoHO* was a support, for example, for formulating follow-up questions regarding the dynamic interaction between the person, the environment and the occupation – thus highlighting the uniqueness of the situation (Kielhofner, 2008). To deepen understanding of participants' experiences, the interview guide was continually updated. Interview length varied between 25 and 61 minutes; the median was 48 minutes.

To further explore the areas of interest regarding how staff reasoned about risks, 2 focus group discussions (Kitzinger, 1994; Morgan & Krueger, 1997) with home care staff were held in the spring of 2015. Analysis of the previously conducted individual interviews enabled formulation of topics and questions that were asked. Because focus group methodology was new to me, one of my supervisors (LR) moderated the first focus group, and I had the role as a facilitator. In the second focus group session, we changed roles. The moderator introduced the purpose of the study and encouraged focus group participants to discuss the topics with each other during the session. The moderator led and guided focus groups' discussions. The facilitator kept field notes and contributed with follow-up questions when needed. Each focus group lasted for about 110 minutes.

All interviews – individual and with the focus groups – were transcribed verbatim. The written text was validated against the sound recordings (Kvale, 2009).

5.4.3 Study III: data collection

Personal records (need assessment forms and care plans) used in Study III were collected from the main home care agency in January and February 2015. During this period, an agency employee collected 135 records; of these, 131 met inclusion criteria.

For Study III, the second author and I extracted this information from personal records:

- Gender (male/female), age (years), living conditions (living alone/cohabiting), and children (yes/no)
- Documented cognitive impairments
- Types of home care services and service hours (hours per month) that were granted to each person.

5.4.4 Study IV: data collection

In Study IV, survey responses from home care staff members at a centrally located home care agency were collected in 2014. Data collection occurred in these phases:

- Phase I: Dementia care specialists were invited to participate, and the surveys were distributed at a meeting
- Phase II: Other home care staff members were invited to participate, and the surveys were distributed within the agency's units. Data collection ended when the number of participants in phase II was comparable to the number of respondents in phase I.

The study used two instruments: the *Strain in Dementia Care Scale (SDCS)* and the *Creative Climate Questionnaire (CCQ)*. See section '5.4.4.1 Instruments' which presents reasons for selecting these instruments and descriptions of the instruments.

The survey contained questions about:

- Gender, age, educational level (high school and university course), dementia care education (yes/no), Swedish as first language (yes/no)
- Length of employment, length of time working with persons with dementia, employment (permanent/temporary), and working hours (day shifts, and day shifts including weekends and evenings).

5.4.4.1 Instruments

Study IV participants filled in the *SDCS* and the *CCQ*, which were selected because they investigate the area of interest for this study, i.e. job strain and organisational climate. The instruments had been developed, validated and used in a similar context in Sweden. Previous studies reported adequate validity and reliability for the *SDCS* (Edberg et al., 2015; Orrung Wallin, Edberg, Beck & Jakobsson, 2013; Orrung Wallin et al., 2015) and for the *CCQ* (Ekvall, 2004, Carljford & Festin, 2015; Orrung Wallin et al., 2015; Söderlund, Norberg & Hansebo, 2014; Wallin, Jakobsson & Edberg, 2012). Here are short descriptions of the instruments.

Strain in Dementia Care Scale (SDCS)

The *SDCS* was used to assess job strain (Edberg et al., 2015). The *SDCS* has an empirical foundation; this instrument is based on staff's experiences (Edberg et al., 2008). Their experiences were obtained through focus groups including staff from Sweden, England, Wales and Australia. The participants in the focus groups were involved in direct nursing care of patients with dementia, but they could have experiences from adult day care, home care and residential care. The *SDCS* was originally designed for employees working with persons with dementia in institutional care. So the text in the survey in Study IV was slightly revised; the terms residents and clients were replaced with older persons.

The *SDCS* consists of 27 statements divided into these factors:

Factor 1: Frustrated empathy (7 statements)

Factor 2: Difficulty understanding and interpreting (7 statements)

Factor 3: Balancing competing needs (5 statements)

Factor 4: Balancing emotional involvement (4 statements)

Factor 5: Lack of recognition (4 statements).

Table 12 displays all statements to give increased clarity to the meaning of the 5 factors. Respondent rates each statement using two, four-point Likert scales. The first scale deals with how often the situation occurs and the second deals with level of stress the situation causes when it occurs.

Regarding frequency, for the first scale, the response options range from 1=never to 4=very often. The

response options regarding stress level for the second scale range from 1=none to 4=high. When calculating the total score and the score for the 5 factors, the response options for each statement are multiplied (range 1–16) before summarizing the scores. Mean values are calculated from the summarised scores, i.e. the total and factor scores. A high score indicates high job strain level.

Currently, no cut-off scores are set for the *SDCS* that describe various job strain levels. In a previous study, mean values between 2.7 and 3.7 were reported for the 5 factors (Orrung Wallin et al., 2015).

Creative Climate Questionnaire (CCQ)

The *CCQ* was used to assess organisational factors (Ekvall, 1996). This instrument focuses on the person and the social psychological environment in the organisation. The *CCQ* consists of 50 statements, which generate a total score and these 10 dimensions (5 statements are in each dimensions):

1. **Challenge:** Emotional involvement of members in the operations and goals of the organisation
2. **Freedom:** Independence in behaviour demonstrated by organisation members
3. **Idea support:** Manner in which new ideas are received
4. **Trust/openness:** Degree of trust that is conveyed and experienced in the relationship
5. **Dynamism/liveliness:** Eventfulness and dynamics of the organisation
6. **Playfulness/humour:** Display of an informal, spontaneous, relaxed atmosphere
7. **Debate:** Occurrence of encounters and clashes concerning differences of opinions, ideas, experiences, and knowledge
8. **Conflicts:** Presence of interpersonal conflicts and emotional tension (in contrast to conflicts between ideas) in the organisation
9. **Risk-taking:** Ability to tolerate uncertainty in the organisation
10. **Ideas time:** Time individuals can use for introduction or suggestion of new ideas.

Respondents rated the statements on a 4-point Likert scale, which ranges from 0=not at all to 3=to a high degree. A high score indicates a creative organisational climate for the dimension, except for dimension number 8: **conflicts**. Here, a high score indicates the opposite, i.e., a stagnated organisational climate.

5.5 DATA ANALYSIS

5.5.1 Study I: data analysis

A qualitative content analysis approach (Graneheim & Lundman, 2004) was used to analyse the interview transcripts. Data processing began during data collection to determine when sufficient rich data were collected in relation to the study's purpose (Patton, 2002) and ensure that no ambiguity existed, which might require additional clarification questions, e.g., during preparation for the upcoming interview (Creswell, 2000).

These steps were followed during analysis:

- Interviews were transcribed and then read multiple times to grasp the entirety of the data; collected recorded materials were listened to.
- The transcribed text was divided into two domains, based on risk-filled situations and how these situations were managed.
- The text was further divided into meaning units – depending on content.
- The meaning units were then condensed and assigned suitable codes; condensed text and codes were formulated so that they reported the original texts as clearly as possible.
- The codes were compared and divided into categories and subcategories by scrutinizing their similarities and differences.

As illustrated in these steps, analyses of the transcribed interviews in the beginning remained close to the text. Later, the analyses became more interpretative to be able to describe experienced meaning from interviewees' narrations. Data were analysed to investigate if underlying meanings permeated the condensed meaning units, codes or categories to determine if it was possible to create an overarching theme.

During content analysis, the authors alternated discussions with each other. But note that analysis was not done in a linear manner through these specified steps. Constant alternation between the whole and the parts of the transcribed interviews characterised the analysis. Context was considered throughout analysis.

5.5.2 Study II: data analysis

As per a grounded theory approach (Charmaz, 2014), data analysis was continuously carried out throughout data collection; preliminary analysis guided data collection. Transcribed interview text was coded; here open coding was applied, i.e., similar text segments were assigned codes that captured the essence of their content. Constant codes comparison occurred for merging codes with similar content into categories. When the focus groups were held, transcribed text from these sessions was coded using focused coding, i.e., codes from previous analyses of individual interviews were used – but we were open to the data to ensure that new findings could emerge. Analyses of emerging findings

continuously alternated between the whole and the parts of the transcribed interviews.

When analysing the data, I used mind maps to enable a clearer content overview of emerging categories and ways in which they were aligned with each other. In order for the analysis to reach a more theoretical understanding based on the purpose of the study, memo writing was done in parallel with the coding. For example, I wrote questions related to the data and about how data could be understood and how different codes could be merged. During data analysis, participants' metaphors facilitated further understanding of the data. In addition, I worked with metaphors to grasp the meaning of the data related to the aim of the study. During analysis of the emerging findings, I went back and forth between the data and the emerging findings to ensure that the findings were well grounded in the collected data.

5.5.3 Studies III and IV: data analysis

Data in Studies III and IV were analysed using *SPSS* version 22.

5.5.3.1 Statistics

Table 6 displays an overview of the statistical tests used in Studies III and IV for which a p-value of ≤ 0.05 was considered statistically significant.

Table 6. Statistical tests used in Studies III and IV

Purpose of analysis	Statistical test	Study
Describe frequencies & distributions	Frequency (n), mean (m), percentage (%), standard deviation (SD), range, median & quartiles	III, IV
Assess internal consistency of scales	Cronbach's alpha test (α)	IV
Assess difference in proportions between independent groups (nominal data)	Chi-square test (χ^2) & Fisher's exact test	III, IV
Assess difference between 2 independent groups (interval, ratio data, normal distribution is required)	Student's t-test (t)	III, IV
Assess difference between independent groups (interval, ratio data, normal distribution is not required)	Mann-Whitney U test (U)	III
Examine correlation between 2 variables (interval/ratio data)	Pearson's product-moment correlation (r)	IV
Determine if a correlation is different from zero (that a relationship exists; ordinal data)	Spearman's rank correlation (ρ/rho)	IV
Examine correlation between 2 or more independent variables & 1 dependent variable to predict probability of an event (dependent variable is binary)	Logistic regression models	III
Examine correlation between 2 or more independent variables & 1 dependent variable to predict probability of an event (dependent variable is continuous)	Multiple linear regression model	IV

5.5.3.2 Study III

Descriptive statistical analyses captured characteristics of participants in the total sample. Bivariate analyses were conducted to compare characteristics of persons with and without cognitive impairment. Student's t-test was used for interval data, such as age, and Chi-square test for nominal data, such as gender.

Services that were identified and extracted from personal records (need assessment forms and care plans) were labelled as per the National Board of Health and Welfare's terminology database definition (National Board of Health and Welfare, 2008). Home care services were divided into two categories: personal care and service. Hjalmarson (2014) inspired this grouping, which was done to examine associations between the range of home care services and cognitive impairment and demographic characteristics. The second author and I performed this content analysis separately. If discrepancies arose between our results, then we discussed and resolved them.

Descriptive statistical analyses were used to describe various types of home care service for the total sample. To compare granted services across the sample, the persons were divided into 4 groups, depending on whether they had few or many services in the personal care and service categories. The medians in the categories served as cut-off points. *Few* services was set to 0–2 in the personal care category and to 0–4 in the service category. *Many* services in the personal care category was set to ≥ 3 services and to ≥ 5 services in the service category. Figure 1 illustrates the groups, based on whether the persons had *few* or *many* services in the personal care and service categories. Descriptive statistical analyses were used to describe distribution of services across the sample.

To compare services granted to persons with and without cognitive impairment, bivariate analyses were used. The numbers of services in the personal care and service categories, and total hours for home care services were analysed with the Mann-Whitney U test (instead of Student's t-test), because these data were not normally distributed. Various types of home care services were analysed with Chi-square test. If the number of services in the groups was expected to be less than 5, then Fisher's Exact test was used.

persons was set to ≥ 40 in each group. The reason for using arbitrary cut-off points was that previous research could not guide the authors regarding these values.

5.5.3.3 Study IV

Descriptive analyses were used to describe characteristics of the total sample (n, %, mean, and SD). To compare characteristics of dementia care specialists and other staff members, bivariate analyses were conducted. For interval data, such as length of employment, in home care service, Student's t-test was used, and for nominal data, such as employment (permanent or not), Chi-square test was used.

As in previous studies, the *SDCS* and the *CCQ* were treated as interval data – even if the scales provide ordinal data; that way, the results could be compared with these prior findings (Orrung Wallin et al., 2015).

Imputation was performed before data from the *SDCS* and the *CCQ* were analysed. If $\leq 50\%$ of the values for each factor on the *SDCS* or dimension on the *CCQ* was missing, the missing value was substituted with the calculated mean for the actual factor/dimension.

The '5.4.3.1 Instruments' section describes scores calculation for the *SDCS* and the *CCQ*.

Descriptive statistics were used to describe (n, m and SD) perceived job strain with the *SDCS* and organisational factors with the *CCQ*. The Student's t-test was used to investigate if differences existed between dementia care specialists and other staff regarding job strain ratings (with the *SDCS*) and organisational factors (with the *CCQ*).

Cronbach's alpha was used to test internal consistency for the *SDCS* and the *CCQ*. Analyses were conducted for (i) total score of the instruments and (ii) scores for the 5 factors on the *SDCS* and for the 10 dimensions on the *CCQ*.

Multiple linear regression models were used to investigate correlations between job strain ratings and personal and organisational factors. Job strain (*SDCS* total score and the 5 factors) was the focus in this study and was thus used as a dependent variable. Personal factors (gender, age, education, dementia care education, Swedish as first language or not, length of employment in home care services, length of time working with persons with dementia in home care or in institutional care, type of employment, working hours) and organisational factors (*CCQ* total score and its 10 dimensions) were regarded as potential independent variables.

Considering the small sample size, not all independent variables could be included in the multiple linear regression models. So data analyses was done in the following phases:

Phase 1: Differences and correlations were investigated between dependent (*SDCS* total score and the 5 factors) and independent variables (personal factors and organisational factors). Student's t-test was used to assess differences between two independent group means, e.g., whether differences existed between dementia care specialists and other staff regarding how they rated job strain on the *SDCS*. Pearson's correlation coefficient was used to examine correlations between scores on the *SDCS* (job strain) and the *CCQ* (organisational factors) and other continuous variables, e.g., age.

When the analyses showed a difference or correlation between the dependent variable and an independent variable, the independent variable was included in phase 2.

Phase 2: To examine multicollinearity, i.e., if a relationship exists between independent variables, Spearman's rank correlation coefficient was used. A rho value >0.85 indicates whether a co-varying variable should be excluded (Tabachnick & Fidell, 2013).

Phase 3: Multiple linear regression modelling was done on the independent variables selected from phase 2. The independent, dementia-care-education variable was included in the regression models (although no differences were detected), because this variable was of special interest for this study.

Six multiple linear regression models were set up to examine correlations between these dependent and independent variables:

Dependent variables:

- ***SDCS* total strain**
- **Factor 1: frustrated empathy**
- **Factor 2: difficulties understanding and interpreting**
- **Factor 3: balancing competing needs**
- **Factor 4: balancing emotional involvement**
- **Factor 5: lack of recognition.**

Independent variables:

- *Dementia care specialisation* (specialists/other staff)
- *First language* (not Swedish/Swedish)
- *Dementia care education* (no/yes)
- *Organisational climate* (total *CCQ* score).

Because a correlation existed between **factor 2: difficulties understanding and interpreting** (dependent variable) and *first language (not Swedish/Swedish)* (independent variable), the authors decided to study this further. Descriptive statistics (n, m, and SD) were used to describe **factor 2** for the 2 groups, i.e., persons who did or did not have Swedish as first language. Student's t-test was used to investigate the difference for these 2 groups regarding **factor 2: difficulties understanding and interpreting** and the 7 statements within this factor.

6 FINDINGS

6.1 FINDINGS, STUDY I

The aim of **Study I** was to explore and better understand how people with dementia, living at home, experience risks in their daily life and how they handle these situations.

The Study I analysis resulted in an overarching theme describing how persons with dementia experienced risky situations to be unfamiliar and confusing. This theme consisted of 2 categories. The first focused on being in situations in which individuals faced risks. The second focused on how they managed these risks in their daily lives (Table 7).

Table 7. Overview of the theme, categories and subcategories in Study I

Theme	Category	Subcategory
Risks in situations that are experienced as unfamiliar & confusing	1. <i>Being in unfamiliar & confusing situations that are difficult to comprehend</i>	<u>The unfamiliar place</u> <u>The details don't come together</u> <u>Uncertainty about what has actually happened</u>
	2. <i>Handling unfamiliar & confusing situations in order to reduce risk</i>	<u>Seeking something recognisable</u> <u>Convincing oneself that a situation is as it should be</u> <u>Refraining from or exposing oneself to situations fraught with risk</u> <u>Accepting assistance from one's environment</u>

6.1.1 Being in unfamiliar and confusing situations that are difficult to comprehend

The first category presents how participants experience risk-filled situations as *being in unfamiliar and confusing situations that are difficult to comprehend*. This category includes 3 subcategories that are briefly described here through illustrative examples and quotations from participants.

The unfamiliar place. Participants explained how places that were previously familiar had subsequently become unfamiliar. They said that these changes could arise suddenly and unexpectedly. For example, Arthur described when a risky situation arose while driving his car ‘... suddenly I was not sure where I was. ... It was frightening, very frightening’.

Participants expressed impending risk of getting lost when being outside their home.

The details do not come together. Another experience of a risk-filled situation was when details did

not come together. Participants told how it could be difficult to understand how details were related to each other and formed an overall picture. When being exposed to risk of getting lost, Mark said: 'I do not know what that street is called ... and where it stops and starts and ends ... so lack of details is what you're suffering from, details that enable an overall picture'.

Uncertainty about what has actually happened. Participants said that they experienced uncertainty about what actually had happened in relation to daily situations with exposure to risk – especially when they did not get the feedback they needed to clarify it. Peter, for example, described risk of not taking the correct amount of medication; he was unsure whether he had actually taken it as prescribed: 'If I forget, I feel nothing strange'.

6.1.2 Handling unfamiliar and confusing situations in order to reduce risk

The second category focused on how participants *handled unfamiliar and confusing situations in order to reduce risk*. Even though participants were challenged in these situations, they seemed to face these situations with confidence that they would work out. This category includes 4 subcategories, which describe various ways of managing situations in which participant were exposed to risk.

Seeking something recognisable. This subcategory describes how participants managed the situation by seeking something recognisable. For example, some participants had difficulties finding their way outdoors and managed this by searching for something that was recognisable to them. For example, to find his way home, Mark looked for something familiar within the environment, which he could recognize and use as a starting point.

Convincing oneself that a situation is as it should be. This subcategory illustrates how participants tried to convince themselves that situations were as they should be. This was sometimes done by repeatedly checking the same thing. Christina, for example, described how she struggled to avoid errors when paying her bills. She told how she checked her calculations multiple times: 'back and forth and back and forth'.

Refraining from or exposing oneself to risk-filled situations. Sometimes risks were managed by refraining from or exposing oneself to risky situations. Participants said that a risk could be experienced as being so great that they chose to *not* expose themselves to it. Some said that they chose to expose themselves to situations – even when they knew that risk was probably involved.

Participants described how they negotiated risk-taking with themselves, namely, potential benefits were weighed against negative consequences.

Accepting assistance from one's environment. Accepting help from a partner or a neighbour or using technical aids were ways of managing risk-filled situations. Participants said that it was important to have someone available who could assist them, because often, it was problematic to predict when risks might arise. Christina described how her neighbours provided her with great comfort because they lived nearby and were often available in case she needed some type of assistance: 'it's reassuring to know that there's a door you can knock on'. Besides personal assistance, participants used aids such as timers on stoves and coffee makers to reduce uncertainty and risk of causing fire.

Ways in which participants managed risk-filled situations led to varying outcomes and sometimes had negative consequences. When participants, for example, managed exposure to risk by refraining from performing a specific activity, they often missed other activities that they had hoped to be involved in. Harry, who was afraid of getting lost in the subway system and thus refrained from using public transportation, consequently was unable to move around freely outdoors. This resulted in missing out on various activities that took place outside of his home: '... yes, it means that I lose contact with life so to speak' Participants described how they felt 'handicapped' and 'constrained'.

6.2 FINDINGS, STUDY II

The aim of **Study II** was to explore how home care staff identified risks in the everyday lives of persons with dementia and further investigate how they reasoned about, and acted on, these identified risks.

The findings illustrate how home care staff reasoned regarding identifying and acting upon risks in the daily lives of persons with dementia. Home care staff noted risks – such as risk of fire when they couldn't deal with a gas stove and when they were outdoors and couldn't find their way home. The staff highlighted the importance in always paying attention to a person's abilities, because these could decrease over time and new risks could arise from that. To be able to detect these changes, staff members implied that continuity was essential. They saw themselves as an alarm system, because they could detect risks and signals if something needed to be done to reduce risks. The data analysis resulted in these categories that focus on dilemmas that home care staff faced when identifying and acting upon risks for persons with dementia: (i) strategies for tracking risk; (ii) dilemmas concerning where to draw the line and deciding when to act; and (iii) dilemmas when acting upon risks.

6.2.1 Strategies for tracking risk

Home care staff described how they tried to track risks for persons with dementia by constantly paying attention to changes that might imply risks. This was challenging because risks could appear suddenly and unexpectedly.

Another factor that was challenging and important to notice is that participants tried to avoid risks to persons with dementia – when they were present with these persons and when they were not present (their presence was based on the time that was granted for each person). When staff members were present, they could see risks for tripping on a carpet edge and subsequently falling, among other risks.

Staff members could track risks by detecting traces of previous situations, such as burn marks in pans and the smell of burned plastic from when a person had heated a plastic package directly on the stove. Because it can be difficult for some persons to tell about situations in retrospect, staff members described how they sometimes made observations. For example, if they were uncertain of whether the older person had eaten, they said that they looked in a person's refrigerator to see if food was still there and in waste containers to see if food had been thrown away.

6.2.2 Dilemmas concerning where to draw the line and deciding on when to act

In the focus groups, participants discussed where to draw the line and decide on when to act on a risk – these decisions were not always obvious. For example, they interpreted situations differently regarding if a person with dementia needed a locked medications cabinet. The analysis showed how home care staff weighed risk against consequences of taking action; consequently they faced difficult dilemmas regarding where to draw the line and say 'this is too risky'. The findings showed that making difficult decisions on where to draw the line regarding risks fell on the individual staff member's shoulders because they often worked alone.

During focus group discussions, home care staff talked about how they were faced with dilemmas regarding if, and in what situations, they should act. For example, they expressed concerns about a relationship an older woman with dementia had with a much younger man; they had no evidence but they had a feeling that he might be taking advantage of her financially. They wanted to protect her, but they had not observed any improprieties that required them to intervene and investigate the situation, which further exacerbated the dilemma about whether or not they should act.

6.2.3 Dilemmas when acting upon risks

The findings showed how participants described their actions when trying to reduce risks for persons with dementia and how home care staff tried to reduce risks when they were not present in the person's home. To reduce risks, they made re-arrangements in a person's home, for example, by trying to make certain objects visible and accessible – to guide persons with dementia to use these objects. One example is that they placed a walker close at hand for the person to use – thus reducing risk of falls.

Another example when acting up on risks is that the staff put up written reminders in the persons' homes. In the home of one person, the staff had put a written reminder on the front door saying that the person should not go out on her own without her son or home care staff; this action was taken to reduce risk of her going out and getting lost. Participants said that influencing actions of persons with dementia could result in dilemmas about their integrity.

Participants described how they removed objects so that persons with dementia would not see them and use them (e.g., matches and candles). They also restricted access to space, for example, by locking basement doors to reduce risk of falling down the stairs. To remove objects and access to space resulted in dilemmas associated with the persons' autonomy. The participants described how they tried to balance persons' wishes against necessary actions that reduced risks. They were protective of the persons' sense of autonomy – so they would not be deprived of things they wanted to have in their lives. Home care staff mentioned, for example, how they made sure persons with dementia had access to a smaller amount of money – despite having money management difficulties.

Although staff members stressed importance of a person's rights, they mentioned serious risks that could not be permitted. One is risk of fire. If persons with dementia did not use a gas stove in a safe way, then staff members said that the gas stove had to be disconnected – even if it was against a person's will. Another serious, recurring risk that could not be permitted was when persons went out repeatedly and didn't find their way home. When this risk occurred, participants believed that persons with dementia needed another accommodation in which they could receive constant supervision.

6.3 FINDINGS, STUDY III

Study III aimed to identify and describe the range of granted home care services and service hours; compare services granted for persons with and without documented cognitive impairment; and examine associations between the range of home care services and factors related to cognitive impairment and demographic characteristics.

These research questions were investigated:

- What types of home care service are older persons granted, and to what extent are they granted these services and service hours?
- How are the types of services distributed among older persons with fewer granted services and with many granted services?
- To what extent are persons with and without cognitive impairment granted various home care services, and are there differences between these 2 groups?
- Are there associations between the range of granted home care services (in personal care and service categories, and service hours per month) and these factors: cognitive impairment, gender, age, and living conditions?

The following sections present findings based on the research questions.

6.3.1 Range of granted home care services

In Study III, a range of granted home care services were identified from need assessment forms and care plans (Table 8).

Thirteen types of services were identified in the personal care category (median=3; range 0-12) and 11 types of services were identified in the service category (median=5; range 0-10); see Table 9. In the personal care category *shower* was the most common granted service (n=69; 52.7%). In the service category, *cleaning* was the most common service (n=103; 78.6%). Regarding service hours, the median was 27 hours per month (quartile 1=9 to quartile 3=67), and the hours ranged from 2.5-127.5.

Table 8. Types of services on need assessment forms and in care plans in Study III

Service types	Helping with for example . . .
Personal care category	
<i>13 services:</i>	
Shower	Getting in & out of bathtub
Dressing/undressing	Clothing; motivating the person to dress, giving oral guidance, providing/pointing to handrail, putting on support socks
Personal hygiene	Shaving or cutting nails
Supervision	Protection (day & evening); ensuring that everything is OK & that no accidents occurred
Walk	A walk around the vicinity; ensuring that the person finds the way home
Follower/escort	Doctor, dentist, & hairdresser visits
Toilet visits	Toilet visits; emptying urinal/bed pan & catheter bag
Movements inside	Getting out of bed
Eat & drink	Encouraging eating & drinking; providing meal-time companionship
Medicine	Medications or eye drops
Social support	Diminishing isolation through walks or conversations
Moving outdoors	Getting from the residence to a taxi
Safe & sound	Personal alarm, i.e., home care staff call the person to ensure that everything is as it should be & that the person feels safe & secure
Service category	
<i>11 services:</i>	
Cleaning	Household cleaning
Shopping	Buying groceries & other necessities
Window washing	Various types of windows
Laundry	Washing machine & dryer
Household tasks	Bed changing, watering flowers, tossing garbage, sorting for recycling
Food preparation	Preparing breakfast & cooking meals
Washing dishes	The dish washer, rinsing & drying dishes
Distributing meals	Food that's delivered to the home
Errands	Pharmacy visits or fetching packages
Shopping together	Grocery shopping (accompanying the person)
Other efforts	Hearing aid, fetching mail, reading mail, making phone calls, running CD player, book circle participation
Service hours	Number of hours/month the person was granted

6.3.2 Distribution of different types of services among older persons with fewer granted services and with many granted services

To describe how services were distributed across the sample (n=131), personal records were divided into 4 groups depending on how many services each person had been granted (Figure 1).

In group 1 (n=43), for example, which included persons who were eligible for the lowest number of services in the personal care category (0-2) and in the service category (0-4), the most common service in the personal care category was *shower* (n=7; 16.3%) and in the service category, *cleaning* (n=29; 67.4%).

Persons in group 4 (n=53) were granted the highest number of services (personal care category ≥ 3 and service category ≥ 5). In this group, the 2 most common services in the personal care category were *dressing* (n=45; 84.9%) and *shower* (n=44; 83.0%), and in the service category, *cleaning* (n=49; 92.5%) and *shopping* (n=47; 88.7%), see Table 9.

Table 9. Home care services in the total sample & comparison between persons with few & many services in the personal care category (PCC) & service category (SC); description of cut-off points for few PCC ≤ 2 ; many PCC ≥ 3 ; few SC ≤ 4 ; & many SC ≥ 5 , in Study III; significant values in **bold** (≤ 0.05)

	Total sample n=131	Group 1, few PCC, few SC n=43	Group 2, few PCC, many SC n=21	Group 3, many PCC, few SC n=14	Group 4, many PCC, many SC n=53
Personal care category					
<i>13 services:</i>					
Mean (SD)	3.44 (3.04)	0.72 (0.83)	1.19 (0.93)	4.29 (1.27)	6.30 (2.28)
Range	0 to 12	0 to 2	0 to 2	3 to 6	3 to 12
Median	3	0	2	4	6
Quartile 1	1	0	0	3	5
Quartile 3	6	1	2	6	8
	n (%)	n (%)	n (%)	n (%)	n (%)
Shower	69 (52.7)	7 (16.3)	9 (42.9)	9 (64.3)	44 (83.0)
Dressing/undressing	59 (45.0)	2 (4.7)	3 (14.3)	9 (64.3)	45 (84.9)
Personal hygiene	52 (39.7)	1 (2.3)	3 (14.3)	8 (57.1)	40 (75.5)
Supervision	42 (32.1)	4 (9.3)	1 (4.8)	5 (35.7)	32 (60.4)
Walk	40 (30.5)	3 (7.0)	3 (14.3)	3 (21.4)	31 (58.5)
Follow/escort	39 (29.8)	4 (9.3)	5 (23.8)	6 (42.9)	24 (45.3)
Toilet visits	30 (22.9)	1 (2.3)	0 (0.0)	4 (28.6)	25 (47.2)
Movements inside	24 (18.3)	0 (0.0)	0 (0.0)	4 (28.6)	20 (37.7)
Eat & drink	21 (16.0)	2 (4.7)	0 (0.0)	1 (7.1)	18 (34.0)
Medicine	22 (16.8)	2 (4.7)	1 (4.8)	4 (28.6)	15 (28.3)
Social support	22 (16.8)	1 (2.3)	0 (0.0)	3 (21.4)	18 (34.0)
Moving outdoors	15 (11.5)	2 (4.7)	0 (0.0)	1 (7.1)	12 (22.6)
Safe & sound	15 (11.5)	2 (4.7)	0 (0.0)	3 (21.4)	10 (18.9)
Service category					
<i>11 services:</i>					
Mean (SD)	5.00 (2.50)	2.51 (1.26)	6.29 (1.15)	2.93 (1.44)	7.06 (1.45)
Range	0 to 10	0 to 4	5 to 9	0 to 4	5 to 10
Median	5	3	6	4	7
Quartile 1	3	2	5	1.75	6
Quartile 3	7	4	7	4	8
	n (%)	n (%)	n (%)	n (%)	n (%)
Cleaning	103 (78.6)	29 (67.4)	20 (95.2)	5 (35.7)	49 (92.5)
Shopping	92 (70.2)	18 (41.9)	19 (90.5)	8 (57.1)	47 (88.7)
Window washing	80 (61.1)	18 (41.9)	17 (81.0)	3 (21.4)	42 (79.2)
Laundry	79 (60.3)	14 (32.6)	18 (85.7)	3 (21.4)	44 (83.0)
Household tasks	71 (54.2)	2 (4.7)	18 (85.7)	7 (50.0)	44 (83.0)
Food preparation	66 (50.4)	5 (11.6)	12 (57.1)	5 (35.7)	44 (83.0)
Washing dishes	49 (37.4)	0 (0.0)	8 (38.1)	3 (21.4)	38 (71.7)
Distributing meals	35 (26.7)	8 (18.6)	5 (23.8)	3 (21.4)	19 (35.8)
Errands	35 (26.7)	1 (2.3)	11 (52.4)	2 (14.3)	21 (39.6)
Shopping together	29 (22.1)	10 (23.3)	4 (19.0)	0 (0.0)	15 (28.3)
Other efforts	16 (12.2)	3 (7.0)	0 (0.0)	2 (14.3)	11 (20.8)
Service hours (h/m)					
Mean (SD)	40.8 (36.6)	10.7 (11.9)	23.0 (14.9)	42.4 (33.1)	71.8 (32.1)
Range	2.5 to 127.5	2.5 to 63.5	7.5 to 63.0	5 to 117.5	12.5 to 127.5
Median	27	7.5	18.5	32	77.5
Quartile 1	9	4	11	16.8	45
Quartile 3	67	10	30.5	67.0	95.5

6.3.3 Differences regarding range of home care services when comparing persons with and without cognitive impairment

The analysis showed differences when comparing the 2 groups: persons with (n=43) and without (n=88) cognitive impairment, regarding the range of home care services (Table 10).

Persons with cognitive impairment (m=4.26; SD=3.23) were granted a higher number of services than persons without cognitive impairment (m=3.03; SD=2.88) – in the personal care category (p=0.049) and for 5 of the 13 services in this category (Table 10).

No difference was found between the groups regarding numbers of services in the service category. But 2 differences occurred among the 11 services in this category.

Persons with cognitive impairment were granted *household tasks* (67.4% vs. 47.7%; p=0.033) to a higher degree than persons without cognitive impairments, and persons without cognitive impairment were granted *errands* to a higher degree than persons with cognitive impairment (33.0% vs. 14.0%; p=0.021).

Regarding service hours per month, a significant difference (p=0.013) occurred, which indicated that persons with cognitive impairment (m=52.8; SD=40.8) were eligible for more hours than persons without cognitive impairment (m=34.9; SD=33.1).

Table 10. Home care services for persons with and without cognitive impairment (CI) and a comparison between these groups in Study III; significant values in **bold** (≤ 0.05)

	Persons with documented CI, n=43	Persons without documented CI, n=88	Test statistics	p-value
	n (%)	n (%)		
PC* category			U=1494.00	0.049
<i>13 services</i>				
Mean (SD):	4.26 (3.23)	3.03 (2.88)		
Range:	0 to 11	0 to 12		
Median:	5	2		
Quartile 1:	1	1		
Quartile 3:	6	5		
Shower	26 (60.5)	43 (48.9)	$\chi^2=1.560$	0.212
Dressing & undressing	26 (60.5)	33 (37.5)	$\chi^2=6.154$	0.013
Personal hygiene	24 (55.8)	28 (31.8)	$\chi^2=6.948$	0.008
Supervision	20 (46.5)	22 (25.0)	$\chi^2=6.137$	0.013
Walk	14 (32.6)	26 (29.5)	$\chi^2=0.124$	0.725
Follower/escort	12 (27.9)	27 (30.7)	$\chi^2=0.106$	0.744
Toilet visits	11 (25.6)	19 (21.6)	$\chi^2=0.261$	0.610
Movements inside	9 (20.9)	15 (17.0)	$\chi^2=0.291$	0.589
Eat and drink	11 (25.6)	10 (11.4)	$\chi^2=4.338$	0.045
Medicine	12 (27.9)	10 (11.4)	$\chi^2=5.657$	0.017
Social support	9 (20.9)	13 (14.8)	$\chi^2=0.784$	0.376
Moving outdoors	3 (7.0)	12 (13.6)	Fisher Exact=1.364	0.383
Safe & sound	6 (14.0)	9 (10.2)	$\chi^2=0.385$	0.529
Service category			U=1637.00	0.208
<i>11 services</i>				
Mean (SD):	5.40 (2.23)	4.81 (2.62)		
Range:	1 to 9	0 to 10		
Median:	6	5		
Quartile 1:	4	3		
Quartile 3:	7	7		
Cleaning	35 (81.4)	68 (77.3)	$\chi^2=0.292$	0.589
Shopping	31 (72.1)	61 (69.3)	$\chi^2=0.106$	0.744
Window washing	30 (69.8)	50 (56.8)	$\chi^2=2.037$	0.153
Laundry	31 (72.1)	48 (54.5)	$\chi^2=3.716$	0.054
Household tasks	29 (67.4)	42 (47.7)	$\chi^2=4.523$	0.033
Food preparation	26 (60.5)	40 (45.5)	$\chi^2=2.604$	0.107
Washing dishes	18 (41.9)	31 (35.2)	$\chi^2=0.543$	0.461
Distributing meals	12 (27.9)	23 (26.1)	$\chi^2=0.046$	0.830
Errands	6 (14.0)	29 (33.0)	$\chi^2=5.326$	0.021
Shopping together	10 (23.3)	19 (21.6)	$\chi^2=0.046$	0.829
Other efforts	4 (9.3)	12 (13.6)	Fisher Exact=0.527	0.579
Service hours, h/m			U=1386.50	0.013
Mean (SD):	52.8 (40.8)	34.9 (33.1)		
Range:	2.5 to 127.5	2.5 to 127.5		
Median:	46.5	22.0		
Quartile 1:	11.5	7.6		
Quartile 3:	85.0	59.9		

* personal care

6.3.4 Associations between range of home care services and cognitive impairment and participant characteristics

Three statistically significant associations occurred after analysing correlations between the ranges of home care services and cognitive impairment and participant characteristics in logistic regression models (Table 11).

In summary, the associations pointed to these results (odds ratios in parentheses), namely, persons:

- With cognitive impairment were granted a higher number of services in the personal care category (2.73)
- Who lived alone were granted a higher number of services in the service category (3.87)
- With cognitive impairment were granted a higher number of service hours per month (2.31).

Table 11. Associations between home care services (no. of services in the personal care category and service category and service hours) and cognitive impairment and demographic characteristics (logistic analysis) in Study III; significant values in **bold** (≤ 0.05)

Dependent variables	Independent variables	Odds ratio	95% CI*	p-value
Personal care category Cut-off ≥ 5 , n=46	<i>Cognitive impairment:</i> No (0) vs. Yes (1)	2.73	1.255 to 5.955	0.011
	<i>Gender:</i> Female (0) vs. Male (1)	1.88	0.763 to 4.612	0.170
	<i>Age, years</i>	1.05	0.986 to 1.110	0.133
	<i>Living conditions:</i> Cohabiting (0) vs. Living alone (1)	0.84	0.305 to 2.309	0.735
	Logistic whole model fit: $\chi^2 = 5.948$, d.f.=8, p=0.653 Likelihood ratio=158.83 $\chi^2 = 10.99$, d.f.=4, p=0.027			
Service category Cut-off ≥ 7 , n=41	<i>Cognitive impairment:</i> No (0) vs. Yes (1)	1.61	0.715 to 3.614	0.250
	<i>Gender:</i> Female (0) vs. Male (1)	1.86	0.729 to 4.769	0.193
	<i>Age (years)</i>	1.05	0.993 to 1.119	0.084
	<i>Living conditions:</i> Cohabiting (0) vs. Living alone (1)	3.87	1.023 to 14.635	0.046
	Logistic whole model fit: $\chi^2 = 13.806$, d.f.=8, p=0.087 Likelihood ratio=153.396 $\chi^2 = 9.427$, d.f.=4, p=0.051			
Service hours Cut-off ≥ 51 h/m, n=44	<i>Cognitive impairment:</i> No (0) vs. Yes (1)	2.31	1.060 to 5.029	0.035
	<i>Gender:</i> Female (0) vs. Male (1)	1.83	0.746 to 4.502	0.187
	<i>Age (years)</i>	1.04	0.981 to 1.103	0.186
	<i>Living conditions:</i> Cohabiting (0) vs. Living alone (1)	1.27	0.446 to 3.610	0.656
	Logistic whole model fit: $\chi^2 = 7.864$, d.f.=8, p=0.447 Likelihood ratio=159.475 $\chi^2 = 7.750$, d.f.=4, p=0.101			

* confidence interval

6.4 FINDINGS, STUDY IV

The aim of **Study IV** was to describe perceived job strain among home care staff and examine correlations between job strain, personal factors and organisational factors.

These research questions were investigated:

- To what degree, do home care staff members perceive job strain?
- Are there differences among home care staff when they rate job strain (i.e., do dementia care specialists rate job strain differently compared with other staff)?
- Are there correlations between job strain ratings and other factors (personal and organisational factors)?

The following sections present the findings for the research questions.

6.4.1 Perceived job strain among home care staff

The mean score for home care staff members perceived job strain (*SDCS* total score) was 5.22 (SD=1.86).

Factor 3: balancing competing needs (m=5.95; SD=2.97) had the highest mean score of the 5 factors. **Factor 2: difficulties understanding and interpreting** (m=4.43; SD=2.13) had the lowest.

The range for the 27 *SDCS* statements varied between 7.50 and 3.11; these had the highest mean scores:

- I want to do much more for the older persons than my employers will allow (m=7.50; SD=4.24).
- Older persons do not receive the care I feel they are entitled to (m=7.48; SD=3.71).
- I feel that older persons are highly dependent on me (m=7.33; SD=3.70).

Table 12 displays all statements and numbers.

Table 12, SDCS (total, factors 1-2 & statements) for total sample, for dementia care specialists, and for other staff, in Study IV; significant values in **bold** (≤ 0.05)

SDCS	Cronbach's <i>alpha</i>	Total sample		Dementia care specialist		Other staff		p-value
		<i>n</i>	Mean (SD)	<i>n</i>	Mean (SD)	<i>n</i>	Mean (SD)	
Total strain	0.92	57	5.22 (1.86)	29	5.70 (2.18)	28	4.71 (1.32)	0.04
Factor 1: frustrated empathy	0.85	64	5.41 (2.38)	32	6.15 (2.63)	32	4.67 (1.86)	0.01
I see other staff behaving toward an older person in ways that show they don't understand effects of dementia		64	6.69 (4.09)	32	8.22 (4.48)	32	5.16 (3.00)	<0.01
I see that an older person is suffering		66	6.61 (3.37)	33	7.33 (3.65)	33	5.88 (2.93)	0.08
Older persons don't receive the care I feel they are entitled to		64	7.48 (3.71)	32	8.19 (4.08)	32	6.78 (3.22)	0.13
I see the families of older persons suffering		65	4.97 (3.08)	32	5.47 (3.35)	33	4.48 (2.75)	0.20
I see older persons being mistreated by their families		64	3.80 (2.76)	32	4.25 (2.90)	32	3.34 (2.59)	0.19
I see other staff treating older persons badly		64	3.11 (2.48)	32	3.72 (2.56)	32	2.50 (2.27)	0.05
Other staff tries to change what I have done for an older person		64	5.23 (3.37)	32	6.00 (3.84)	32	4.47 (2.66)	0.07
Factor 2: difficulties understanding & interpreting	0.90	64	4.43 (2.13)	33	4.76 (2.30)	31	4.07 (1.91)	0.20
I have difficulties understanding what older persons are thinking		66	5.02 (2.76)	33	5.45 (3.28)	33	4.58 (2.08)	0.20
I have difficulties understanding what older persons are trying to communicate		65	4.55 (2.49)	33	4.79 (2.63)	32	4.31 (2.36)	0.45
I have difficulties understanding older persons' needs		64	4.03 (2.44)	33	4.55 (2.40)	31	3.48 (2.39)	0.08
I find it difficult to know what is best for older persons		64	4.30 (2.93)	33	4.70 (3.42)	31	3.87 (2.26)	0.26
I worry I might upset or hurt older persons because I don't understand their needs		64	4.23 (2.84)	33	4.52 (3.33)	31	3.94 (2.22)	0.42
I cannot understand why older persons behave the way they do		66	4.27 (2.30)	34	4.44 (2.00)	32	4.09 (2.59)	0.54
I find it difficult to explain to older persons what is happening in situations which may upset them (e.g. showering, bathing or toileting)		68	4.57 (3.27)	34	5.24 (3.83)	34	3.91 (2.47)	0.10

Possible range for the SDCS 1–16. High scores indicate high level of job strain.

Table 12 continued, factors 3-5. Significant values in **bold** (≤ 0.05)

<i>SDCS</i>	<i>Cronbach's alpha</i>	Total sample		Dementia care specialist		Other staff		p-value
		<i>n</i>	<i>Mean (SD)</i>	<i>n</i>	<i>Mean (SD)</i>	<i>n</i>	<i>Mean (SD)</i>	
Factor 3: balancing competing needs	0.85	61	5.95 (2.97)	31	6.85 (3.46)	30	5.02 (2.01)	0.01
I must balance the needs of the older person against the needs of his or her family		63	6.17 (3.70)	31	7.42 (4.42)	32	4.97 (2.33)	0.01
I must balance the needs of the older person against the needs of other older persons		61	5.87 (4.10)	31	7.29 (4.81)	30	4.40 (2.55)	0.01
I must prioritize on the basis of urgency rather than fairness or the needs of older persons		62	6.27 (3.51)	31	6.84 (3.68)	31	5.71 (3.29)	0.21
Older persons resist the care I want to provide		64	6.00 (3.57)	31	6.74 (3.92)	33	5.30 (3.12)	0.11
I must balance the safety of older persons against their quality of life		64	5.39 (3.87)	32	5.91 (4.15)	32	4.88 (3.56)	0.29
Factor 4: balancing emotional involvement	0.75	63	5.18 (2.51)	30	5.68 (2.79)	33	4.72 (2.17)	0.14
When an older person dies or must move, I feel as though I have lost a relative or close friend		65	4.54 (3.36)	31	4.48 (3.60)	34	4.59 (3.18)	0.90
I feel that older persons are highly dependent on me		64	7.33 (3.70)	31	8.23 (3.75)	33	6.48 (3.50)	0.06
I wish I knew more about older persons so that I could understand them better		63	5.19 (3.13)	30	5.53 (3.38)	33	4.88 (2.89)	0.42
I cannot stop thinking about older persons when I'm away from work		64	3.75 (3.02)	31	4.58 (3.58)	33	2.97 (2.16)	0.04
Factor 5: lack of recognition	0.53	63	5.90 (2.37)	32	6.59 (2.59)	31	5.19 (1.92)	0.02
I feel that my work is not valued by others		64	5.59 (3.86)	32	6.88 (4.16)	32	4.31 (3.11)	0.01
I want to do much more for older persons than my employers will allow		66	7.50 (4.24)	34	8.09 (4.49)	32	6.88 (3.93)	0.25
My employers don't appreciate the work I'm doing		64	3.94 (2.88)	32	4.41 (3.28)	32	3.47 (2.38)	0.20
Families of older persons don't seem to understand how difficult it is to care for their relative		64	6.61 (3.51)	32	7.16 (3.89)	32	6.06 (3.06)	0.22

Possible range for the *SDCS* 1–16. High scores indicate high level of job strain.

6.4.2 Differences regarding perceived job strain for dementia care specialists and other staff

Differences were found regarding rated job strain for dementia care specialists and other staff, which indicated that specialists perceived higher job strain. Dementia care specialists rated a significantly higher total score for job strain ($m=5.70$; $SD=2.18$) than other staff ($m=4.71$; $SD=1.32$; $p=0.04$); see Table 12.

The specialists rated a significant higher mean value for 3 of the 5 **factors (1, 3, and 5)** on the *SDCS* (Table 12). These findings imply that specialists were more frustrated regarding how older persons were treated, had more difficulties in balancing competing needs and felt greater lack of recognition from others (employers and older persons' families).

To illustrate their perceptions of job strain, here are the 6 statements (of the 27 statements on the *SDCS*) for which specialists rated a significantly higher mean score than other staff:

- I see other staff behaving toward an older person in a way that shows they do not understand the effects of dementia ($m=8.22$ vs. $m=5.16$; $p<0.01$).
- I see other staff treating the older persons badly ($m=3.72$ vs. $m=2.50$; $p=0.05$).
- I must balance the needs of the older person against the needs of his or her family ($m=7.42$ vs. $m=4.97$; $p=0.01$).
- I must balance the needs of the older person against the needs of other older persons ($m=7.29$ vs. $m=4.40$; $p=0.01$).
- I cannot stop thinking about the older persons when I'm away from work ($m=4.58$ vs. $m=2.97$; $p=0.04$).
- I feel that my work is not valued by others ($m=6.88$ vs. $m=4.31$; $p=0.01$).

6.4.3 Correlations between job strain ratings and personal and organisational factors

Job strain for total score and all 5 factors on the *SDCS* correlated with being a dementia care specialist in the multiple linear regression models (Table 13). This finding strengthens the previous result, which indicates that dementia care specialists perceived higher job strain than other staff.

Two other correlations were found in the multiple linear regression models:

- **Factor 2: difficulties understanding and interpreting** correlated with Swedish as the first language, which indicates that staff members, who did not have Swedish as their first language, perceived higher job strain regarding understanding and interpreting.
- **Factor 5: lack of recognition** correlated with organisational climate (*CCQ*), implying that higher job strain was associated with a more stagnated organisational climate.

Table 13, Correlations between *SDCS* scores (total & factors 1-2) and personal factors and organisational factors, in Study IV, significant values in **bold** (≤ 0.05)

SDCS	Final model	R²_{adj}	β	B	95% CI for coefficient B	p-value
<i>Dependent variable</i>	<i>Independent variables</i>					
Total strain		.150				
	Dementia care specialisation: Specialists (1) Other staff (0)		1.744	.459	.585 to 2.904	0.004
	First language: Not Swedish (1) Swedish (0)		.571	.143	-.500 to 1.642	0.289
	Dementia care education: No (1) Yes (0)		.999	.258	-.186 to 2.185	0.097
	Organisational climate (total CCQ score)		-.732	-.160	-1.937 to .473	0.228
Factor 1: frustrated empathy		.135				
	Dementia care specialisation: Specialists (1) Other staff (0)		2.353	.498	.968 to 3.737	0.001
	First language: Not Swedish (1) Swedish (0)		.077	.016	-1.195 to 1.349	0.904
	Dementia care education: No (1) Yes (0)		1.320	.272	-.093 to 2.734	0.066
	Organisational climate (total CCQ score)		-.485	-.082	-1.970 to .999	0.515
Factor 2: difficulties understanding and interpreting		.254				
	Dementia care specialisation: Specialists (1) Other staff (0)		1.229	.279	.015 to 2.442	0.047
	First language: Not Swedish (1) Swedish (0)		1.981	.439	.891 to 3.071	0.001
	Dementia care education: No (1) Yes (0)		.741	.165	-.498 to 1.979	0.236
	Organisational climate (total CCQ score)		-.354	-.067	-1.592 to .884	0.568

Table 13, continued, factors 3-5. Significant values in **bold** (≤ 0.05)

<i>SDCS</i>	<i>Final model</i>	R^2_{adj}	β	95% CI for coefficient B	p-value
<i>Dependent variable</i>	<i>Independent variables</i>				
Factor 3: balancing competing needs		.099			
	Dementia care specialisation: Specialists (1) Other staff (0)		2.065	.347 .242 to 3.889	0.027
	First language: Not Swedish (1) Swedish (0)		1.259	.204 -.406 to 2.924	0.135
	Dementia care education: No (1) Yes (0)		.584	.095 -1.274 to 2.441	0.531
	Organisational climate (total CCQ score)		-.181	-.025 -2.102 to 1.741	0.851
Factor 4: balancing emotional involvement		.127			
	Dementia care specialisation: Specialists (1) Other staff (0)		1.768	.341 .251 to 3.285	0.023
	First language: Not Swedish (1) Swedish (0)		1.057	.197 -.365 to 2.479	0.142
	Dementia care education: No (1) Yes (0)		1.393	.266 -.171 to 2.956	0.080
	Organisational climate (total CCQ score)		-1.093	-.171 -2.727 to .540	0.185
Factor 5: lack of recognition		.154			
	Dementia care specialisation: Specialists (1) Other staff (0)		1.921	.391 .500 to 3.342	0.009
	First language: Not Swedish (1) Swedish (0)		.343	.067 -.968 to 1.654	0.602
	Dementia care education: No (1) Yes (0)		.460	.091 -.996 to 1.916	0.529
	Organisational climate (total CCQ score)		-1.775	-.298 -3.262 to -.288	0.020

7 GENERAL DISCUSSION

The aim of the overall study was to increase knowledge of conditions for older, home-residing persons with cognitive impairments – with focus on risks during daily living and support from home care service. The findings contributed new knowledge on how (i) persons with dementia experience and deal with risk-filled situations in their daily lives and on how (ii) home care staff identify and reason about risks as dilemmas in their role as home care providers to persons with dementia. The findings contributed new knowledge about support, namely, (i) types of services and number of service hours for older persons with and without documented cognitive impairment and (ii) perceived job strain among home care staff. Based on the four studies, forthcoming sections address the most interesting findings under these headings: ‘Risk concept’; ‘Living at home with cognitive impairment’; ‘Home care staff’s experience of job strain’; and ‘Being engaged in daily life – despite presence of risk’.

7.1 Risk concept

Risk is one of the main concepts in the overall study, i.e., a situation involving exposure to hazards. Risk is understood and defined in various ways (Althaus, 2005). In Study I, risk was described by persons with dementia and in Study II, by home care staff. Understanding of risky situations was thus explored from two different perspectives. During the overall study period, I found it helpful to apply the Clarke et al. (2009, p. 90) definition: ‘issues of uncertainty of future outcomes from actions’ – because the definition is broad and the aim was to explore experiences of persons with dementia and home-care staff regarding risk-filled situations. Douglas (1994) stated that cultural factors influence a person's perception of risk and that the meaning of risk thus depends on its context. Because risk is a contextual concept, Dickins and colleagues (2017) consider that what can be perceived as risk may vary between and within individuals. Study I reported that risk-filled situations perceived by persons with dementia could be experienced as unclear and unfamiliar, and this experience can inhibit persons to be active in, for example, leaving home and visiting friends. Interestingly, Study I findings regarding experiences of risk-filled situations as unclear and unfamiliar relate to Study II findings, which show how home care staff tried to create clarity and recognition for persons with dementia – to reduce risks in their daily lives. For example, home care staff tried to clarify a situation by making certain objects visible and accessible and by removing objects to ensure that persons with dementia act appropriately in relation to the situation. Earlier studies, for example, reported that environments can be modified to avoid risks (Bowen et al., 2011; Horvath et al., 2005; Lach & Chang, 2007). Ways in which staff members define, identify and act upon risks will have consequences for individuals who receive support. In health care and home care, there have been tendencies to prioritize physical safety before psychological and emotional safety (Gilmour et al., 2003; Morgan 2010; Robinson et al., 2007;

Stevenson et al., 2018), which may cause persons with dementia to have their social and psychological well-being overlooked (Clarke & Mantle, 2016). Because risks are defined and assessed differently, the implication is that it's important for home care staff to repeatedly discuss and reflect on risks in the everyday lives of persons with cognitive impairment – and not assume that consensus occurs.

Studies I and II showed that situations fraught with risk could come suddenly and unexpectedly. Persons with dementia describe, for example, that a familiar situation suddenly may become unfamiliar, which can cause them to not know where they are, and they thus have difficulty finding their way home. Brorsson et al. (2013) reported that even small changes, such as when groceries had been rearranged in a store, could suffice and thus mean that persons with dementia experienced the situation as unfamiliar. Brorsson and colleagues pointed to the fact that in society, awareness about how persons with cognitive impairment manage in public spaces is very low, which may imply that older persons, for example, do not go shopping for food in the local community due to a change in the grocery store. This illustrates that in each situation, dynamic interaction occurs between the person, the environment, and the activity (Kielhofner, 2008). Kielhofner (2008) states that 'volition, habituation, performance capacity, and the environment always resonate together, creating conditions out of which our thoughts, feelings and doing emerge.' (p. 39). Because this interaction is ongoing and because the situation can suddenly change, it becomes even more difficult to know when risk is involved and when a hazardous situation can occur. This unruly nature of risks challenges persons with dementia and the home care staff members who are trying to provide appropriate support for home-residing persons with dementia. But by drawing attention to the uniqueness in each situation, opportunities to understand and thus manage risk-filled situations are increasing.

The new knowledge from Study I can be a valuable source for those who meet persons with cognitive impairment, because it illustrates how persons with dementia – as experts on their own experiences (Harris, 2002) – may perceive a situation fraught with risk. Furthermore, based on findings in Study I, I suggest that it's feasible to invite these persons into this discussion about risks; this might lead to new understanding and maybe new definitions of risks at home for persons with dementia. By paying attention to their experiences, staff and family members can gain in-depth understanding of how hazardous situations can occur and thus have better opportunities to predict and prevent them.

7.2 Living at home with cognitive impairment

In 2016, about 8.4% of older persons (≥ 65) living in Sweden were granted home care services (National Board of Health and Welfare, 2018a), but little has been known about the range of granted home care services. In Study III, different types of home care services were identified and the findings showed that almost half (40%; $n=53$) of those in the sample had 3 or more home care services

involving personal care such as *dressing* and *showering* and 5 or more services, such as *cleaning* and *shopping*. The result indicates that a relatively large proportion of older persons live at home with extensive basic-needs support regarding personal care. A recent report from the Stockholm Gerontology Research Center (2018) put forth similar findings.

Study I described how persons with dementia withdraw from occupations/activities because they perceived the risk to be too high. Other studies reported similar findings (De Witt et al., 2010; Harris, 2006). The findings in Study I offered empirical examples of how not being able to maintain desired activities can contribute to a sense of restricted participation in daily living. To no longer be able to perform activities that you desire to perform might trigger the feeling of not being involved in your own daily life. Being involved in occupations is important because it contributes to who we are, who we want to be and how we interact with other persons (Huot & Rudmans, 2010; Wilcock, 2007). Being involved in occupations can be relevant to the person's health and well-being (Hemmingsson & Jonsson 2005; Wilcock, 1998; Wilcock, 2001).

Regarding opportunities to be involved in desired occupations, I must highlight a result from Study III that shows that persons with cognitive impairment *did not* have more social support services granted than those without cognitive impairment. The result is noteworthy considering that persons with cognitive impairment can have problems with sustaining social relationships (Moyle et al., 2016). Although social withdrawal might occur for several reasons for older persons with dementia, for example (as shown in Study I), it can be hard to even get to social activities – due to risk of getting lost when traveling unaccompanied. The Study III results might indicate that not enough social support services are granted to persons with cognitive impairment – to support social engagement during daily living.

The current situation (in which many home-residing older persons receive many services) is probably a consequence of the *aging-in-place* policy aimed at providing older persons with the opportunity to live at home (Henning et al., 2009; SFS 2001: 453). Compared with the situation 10 years ago, older persons live a longer time in their homes before moving to a residential care unit (Schön et al., 2016). A nation-wide survey (National Board of Health and Welfare, 2018b) reported that older persons, who were granted more home care services hours than the average, rated their own health as bad or very bad, and they were less positive about their services.

7.3 Home care staff's experience of job strain

In Study IV the home care staffs' job strain ratings are considered high – based on a comparison with a previous study that measured job strain among residential care staff (Orrung Wallin et al., 2015).

Because this previous study was done in residential care, it is relevant to account for the fact that the home care staff's work situation varies because they work in home care service. For example, home care staff members work to a greater extent alone and must rely on their own capabilities (Gransjön Craftman et al., 2018; Hanson et al., 2015), which has been demonstrated as a potential source of emotional stress (Hansson & Judith, 2008). A staff members' well-being is of course important to those particular individuals – but their well-being is also important to the persons they support. For example, when experiences of stress and shortcomings increase, then risk of misunderstandings and failures occurs (Edvardsson et al., 2008; Knot-Sihota et al., 2015).

Study III found that persons with documented cognitive impairment received significantly more services compared to those without cognitive impairment, which is in line with previous studies (Larsson et al., 2004; Miranda-Castillo et al., 2010). Despite this finding that older persons with cognitive impairment were granted a higher number of services and hours, the findings in Study IV showed that dementia care specialists (who worked extensively with persons with cognitive impairment and those with special needs) reported significantly higher job strain than other staff members. These findings deserve some reflection.

The fact that dementia care specialists reported higher job strain can be related, among other things, to their concerns about the situation for those they cared for with cognitive impairments and with increased special needs. This is in line with previous studies of residential care, which reported that it's a challenge for employees to care for persons with impaired cognition (Edvardsson et al., 2008; Schmidt et al., 2012; Orrung Wallin et al., 2015). Studies I and II illustrated the degree of complexity that situations hold for home-residing persons with dementia. Study II reported, for example, how staff can experience uncertainty regarding what might happen, because a situation fraught with risk may occur suddenly and unexpectedly.

Dementia care specialists reported higher job strain than other staff members regarding this *SDCS* item: *I can't stop thinking about the older persons when I'm away from work*. Uncertainty about how a situation might develop indicates that specialists had found it hard to stop worrying about a person when they were off duty. Their concern is understandable and justified, because as previous research reported, persons with dementia can be vulnerable. For example, a systematic review that investigated injuries, found a trend, which suggested that medication self-administration errors and wandering were more frequent among older persons with dementia – compared to older adults without dementia (Douglas, Letts & Richardson, 2011).

Another factor that could have been perceived as extra burdensome for dementia care specialists was to leave persons with dementia alone because they can be vulnerable – and most persons, who receive home care services, live alone (National Board of Health and Welfare, 2016). Study III reported that persons with cognitive impairment were largely granted supervision ($p=0.01$); so staff visited them to

ensure that everything was in order. Being granted the service supervision more often can be interpreted to mean that situations for persons with cognitive impairment are more uncertain – that something undesirable might occur – and that the persons will not be able to contact staff when they are alone.

Interestingly, in Study IV, no significant relationship was found between job strain among the home care staff and degree of dementia education. Previous studies in residential care for persons with dementia have presented positive relationships (higher education, higher job strain; Orrung Wallin et al., 2015) and negative relationships (lower education, higher job strain; Edvardsson et al., 2009). These contradictory outcomes regarding educational level give reason to reflect more deeply on the non-significant findings regarding job strain and dementia education level in Study IV. Perhaps staff job strain was more related to the needs they observed and how they acted, than to their level of education about dementia? A person-centred approach (National Board of Health and Welfare, 2010; 2017) among the specialized staff might have led to more extensively identifying older persons' needs and wishes. But the findings suggest that the needs of persons with dementia were found to be difficult to fulfil because staff members had to balance these needs against the needs of other older persons for whom staff members also cared for.

Drawing on the stress theory of demand and control (Karasek & Theorell, 1990), one can assume that the specialized staff in the present study put high demands on themselves in caring for persons with dementia – using a person-centred approach. At the same time, they had low control of the overall situation for these persons and their own work situation. The combination of high demands and low control often lead to stress (Karasek & Theorell, 1990). A person-centred approach might therefore be related to increased job strain for home care staff, which is in line with previous research (Edberg et al., 2008). But it's important to emphasize that providing person-centred care is regarded as being one of the most important factors for job satisfaction (Orrung Wallin et al., 2012). Staff members who participated in an educational program in person-centred care for persons living with dementia expressed how they had become proud of their work and considered their work to be important (Berglund et al., 2018). This indicates that increased job strain does not necessarily always have to be seen as something negative; it can demonstrate that staff members are empathetic and committed to supporting older persons in their care (Edberg et al., 2015). From this, I must emphasize the importance of the context in which home care services are delivered so that the staffs' positive qualities, such as empathy and commitment, will not lead to negative consequences.

Based on the finding that dementia care specialists reported higher job strain (Study IV), it is relevant to reflect on the extent to which services were granted to persons with cognitive impairment. Although Study III results showed that those with cognitive impairment received significantly more services in the personal care category and more service hours, the dementia care specialists reported that the older

persons did not receive the services they were entitled to. Dementia care specialists had higher scores on the *SDCS* than other staff members regarding this item: *I must balance the needs of the older person against the needs of other older persons*, which indicates that they did not find granted time sufficient for caring for persons with dementia.

Previous research reported that it is challenging for persons with cognitive impairments to communicate their needs and wishes when applying for home care (Österholm & Hydén, 2016). It is crucial for older persons to get a correct assessment of their needs – regardless their ability to communicate; previous studies reported that older persons, who had their care needs met at home, reported more positive psychosocial benefits (Kadowaki, Wister & Chappell, 2015). So it's also reasonable to assume that correct need assessments benefit home care staffs' working situations.

Study IV showed that the organisation has an effect on how staff members rated their job strain – a more stagnated organisational climate was correlated with higher job strain, which indicated the importance of stimulating and supporting a creative climate in the organisation. Other research found that leadership and support can influence how staff members rate their job strain levels (Orrung Wallin et al., 2015). But support for home care staff may vary. Study IV revealed that those, who did not have Swedish as the first language, reported higher job strain regarding **factor 2: difficulties understanding and interpreting**. This relationship is not very surprising, and it emphasises the importance of perceiving staff members as individuals who may have different needs for different types of support.

7.4 Being engaged in daily life – despite presence of risk

Study I reported that persons with dementia sometimes decided that they were willing to accept a risk in daily living because the advantages outweighed the disadvantages. Clarke et al. (2010) reported that persons with dementia actively negotiated their decision-making. This situation can create dilemmas for staff members as they strived for keeping the older person safe. Huge responsibility is placed on staff member when they work alone in a person's home – when it comes to decision-making regarding risk management for persons with cognitive impairment. Study II reported that home care staff struggled with dilemmas that concerned where to draw the line and to decide on when to act. Clark and Mantle (2016) emphasised the importance of a person-centred approach for understanding persons with dementia and what facilitates purpose and meaning in their lives; these authors contend that person-centred care means accepting and enabling risks – to improve quality of life. Managing risks means that staff members face different situations in which they must assess what's acceptable in terms of risk (Dickins et al., 2017). So it's important that staff members can share decision-making – regarding risks – because sole decision-making responsibility might be a great burden for one

individual (Edvardsson et al., 2009; Morgan & Williamson, 2014). Based on Studies I and II findings and previous research, I must emphasise the importance of home care staff having opportunities to discuss with colleagues and get support when needed, because they face difficult dilemmas.

Based on the four studies, it's clear that home care staff members face challenging work situations regarding how to deal with risk for persons with cognitive impairments. In view of this, and that training and education for staff is one of the most important efforts to prevent unwanted situations to happen for the persons they are supporting (Ledgerd et al., 2015; Morgan et al., 2005), I think it is worrying that the number of dementia teams in Sweden's health care system has decreased (National Board of Health and Welfare, 2018c). The Swedish National Board of Health and Welfare (*i*) emphasised that the quality of life can increase for persons with dementia who receive services and care from a dementia team and (*ii*) gave this service the highest priority in its recommendations. The same priority is given to long-term and continuous education in combination with practical training in person-centred care (National Board of Health and Welfare, 2017b). This overall study indicates that continuing education for home care staff members, who care for persons with cognitive impairments, is vital – as is the opportunity to reflect together on the balancing act that enables persons with cognitive impairments to be engaged in daily living activities – despite presence of risks.

Study II findings showed how home care staff tried to enhance feelings of autonomy. For example, rather than taking money away when risk existed for losing it or being cheated, staff members could ensure that persons with dementia had access to smaller amounts. That way, persons with dementia could retain a sense of being in charge – a sense of autonomy – and not feel deprived of everything. Such staff actions can increase participation of persons with dementia in daily living activities and thereby strengthen the older person's occupational identity (Christiansen, 1999). Ways in which home care staff members should perform their services are not specified in detail in care plans (Study III), which seems to be reasonable because situations change, and they must constantly be responsive and adapt their actions. But this implies greater demands on the staff members who provide the support.

In Study II, home care staff members described how they faced dilemmas and had to make decisions about how to act in risky situations. They asked themselves questions such as: How high is the risk? What are the consequences if the unwanted occurs? What type of impact can inhibiting and eliminating risks have? Previous research found that staff members often perceived it as their duty to protect persons with dementia from risks (Stevenson et al., 2017). That said, there is a danger that there may be too much focus on reducing risks rather than supporting them in taking daily living risks (recall that dementia care specialists reported high job strain on this item: *I can't stop thinking about the older persons when I'm away from work* and that in Study II, staff members took on huge responsibility for reducing potential risks to protect persons with dementia).

MacLeod and Stadnyk (2015) reported that health and social practitioners, who worked with older persons, tend to focus on negative consequences of risk. When balancing and making decisions regarding how risks are addressed, stakeholders should attend to the benefits – and not just focus on hazards. They must recognise strengths that persons with dementia have or strengths around them that can be used to reduce risks (Morgan & Williamson, 2014). Also crucial: home care staff members should be able to share decision-making in risk-filled situations with colleagues and other health care professionals, because this can be helpful for understanding situations from various perspectives. Furthermore, in these discussions, it might be favourable to use a definition of risk that is more neutral – rather than focusing on negative outcomes – to acknowledge positive and negative consequences (MacLeod & Stadnyk, 2015).

7.5 METHODOLOGICAL CONSIDERATION

During the overall study, various methodological approaches were used to explore and investigate conditions for older, home-residing persons with cognitive impairments – with focus on risks during daily living and support from home care service. Each methodological approach has strengths and limitations that influenced the findings. This section highlights and discusses the main methodological considerations, namely, the sampling, data collection, and data analysis used in the four studies in the overall study.

7.5.1 Sampling

A main methodological consideration (for all the studies) is sampling of participants and records. Even though the number of participants in the qualitative Studies I (n=12) and II (n=23) can be considered low, it's important to note that the richness and content of the data matters – not the number of participants (Polit & Beck, 2016). Studies I and II are strengthened by rich data that corresponds to the studies' purposes. By analysing the content of the data in parallel with data collection, it was possible to determine when it was sufficiently rich, and the recruitment of new participants could draw to a close (Charmaz, 2014). So the number of participants was not decided beforehand.

In Study I, it was important to recruit participants with varying characteristics, because the intention was to include individuals with varied experiences of situations fraught with risk. This was achieved through purposeful sampling (Patton, 2002), which contributed to variation in, for example, gender (6 male/6 female) and living conditions (4 living alone and 8 cohabiting). But the criterion that participant had to be able to communicate in Swedish might have limited the variation of the experiences of risk-filled situations because risks are cultural embedded (Douglas, 1994). Study II participants were included through convenience sampling from two home care agencies in a larger city

in Sweden. One of the agencies was in the city centre and one in suburban parts of the city. Purposeful sampling (Patton, 2002) could have contributed to including home care agencies in rural areas and a greater variety of participant characteristics, for example, most participants were women (n=17; 74%). Because context is crucial, this may affect transferability of the findings to situations for home care staff members who work in smaller cities or rural areas. Although convenience sampling was used in Study II, it is a strength that staff members, who participated, had extensive working experience with persons with dementia in home care service (on average, they had worked for about 10 years).

To achieve a representative population sample from a quantitative perspective, randomized sampling is preferred (Polit & Beck, 2016). Considering current financial conditions and time constraints, this was not possible. Instead, sampling of convenience was used. Even though a sampling of convenience was used, a strength of the sample in Study III is that it appears to be representative of the older persons who receive home care services in Sweden. Here, participant characteristics are aligned with other studies and reports (National Board of Health and Welfare, 2014; Odzakovic et al., 2018). If a sample is representative, then this increases results generalisability to other places that have similar home care service systems.

An additional strength of the quantitative studies (Studies III and IV) is that the groups within the studies are comparable as per their characteristics. But something that I reflected on in retrospect is whether or not a confounding factor exists regarding participants who were specialised in Study IV. It seems reasonable to assume that these persons who actively chose to educate themselves to be specialized are more committed to their work. Perhaps this factor (that they were committed staff) could have been significant for the outcome. Then the question is whether specialized staff members correlate with higher job strain or whether engaged staff member correlate with higher job strain.

In quantitative studies, power calculation should preferably be conducted beforehand to help determine an appropriate sample size. Power calculation indicates the number of participants needed to detect changes regarding assessed outcome (Polit & Beck, 2016). For Study III, no studies existed (on various types of home care services) that could have guided decisions for cut-off scores. For the same reason, no power calculation was used regarding the sample in Study IV. Because the *SDCS* is a new instrument, no cut-off scores exist for high and low job strain levels, so it was not possible to make a power calculation.

In conclusion, due to small sample sizes, the purposes of the studies were more exploratory and hypothesis-generating than conclusive. But in each of the studies, the intention was to present the context and describe the participants using sufficient information that would enable readers to determine if the findings are transferable or generalizable to other situations that are of interest to them (Creswell, 2000; Graneheim & Lundman, 2004, Polit & Beck, 2016).

7.5.2 Data collection

To achieve the purposes of Studies I and II, a qualitative method was appropriate, because this made it possible to share participants' experiences (Creswell, 2000). Within Studies I and II, I collected data through open-ended interviews (Kvale, 2009).

To facilitate the sharing of experiences from persons with dementia in Study I, flexibility and attentiveness to the respondent characterised the interview sessions. For example, the time for the interview was not limited and the questions were tangible and accounted for risk-filled situations in their daily lives (Nygård, 2006; Stevenson et al., 2017). I was surprised about the detail with which persons with dementia described their experiences of risky situations and how they managed them. Besides the flexible, attentive interviews, it may be that risk-filled situations evoked strong emotions that made them recall these situations. That said, research shows that persons with dementia may have varied awareness of their abilities to report on their everyday functioning (Frank, Lenderking, Howard & Cantillon, 2011). So readers should remember that the study investigated persons' experiences of risk and that their experiences need not be aligned with other person's observations.

The same applies in Study II, which reported staff members' descriptions of how they identified and acted upon risks for persons with dementia – not how they managed in practice. The findings are based on what staff members chose to tell in the interviews or in the focus groups. So some might have left out things that are uncomfortable to talk about. That said, during individual interviews and focus group discussions, various dilemmas emerged, which indicates that staff members seemed comfortable in sharing inconvenient situations that they experienced as difficult and problematic. In the focus groups, participants appeared to be comfortable in expressing their assessments of risk-filled situations – even if the assessments were inconsistent with other participants' assessments in the focus group.

In Study III, the time of the year could have been significant due to data collection in January and February 2015 when temperatures in Sweden are cold and roads and sidewalks are icy and it's harder to get out and about. Because no other reports exist for comparison, there is no way to determine whether or not data collection is representative of the entire year. In retrospect, it could also have been of interest to examine differences, if any, among the needs assessors regarding their assessment of granted home care services for older persons.

To assess job strain and organisational factors, Study IV used the *Strain in Dementia Care Scale* (*SDCS* [Edberg et al., 2015]) and the *Creative Climate Questionnaire* (*CCQ* [Ekvall, 1996]).

Reflections on the *SDCS* and *CCQ* are under the next heading, yet it's noteworthy to mention that the

instruments were written in Swedish – even though 45% of the staff did not have Swedish as their first language. This might be a possible source of bias. However, *SDCS* and *CCQ* statements are short and clear. To reduce risk of misunderstandings when interpreting *SDCS* and *CCQ* items, staff members had opportunities to ask questions when they filled in the *SDCS* and *CCQ*.

7.5.2.1 Reflections on the data collection instruments

As mentioned above, Study IV used the *SDCS* (Edberg et al., 2015) and the *CCQ* (Ekvall, 1996).

Previous studies reported that the *SDCS* has adequate validity and reliability (Orrung Wallin et al., 2013; Edberg et al., 2015), and it is a strength that the *SDCS* was developed and validated in Sweden, because context is critical. But unlike previous studies, the present study took place in the context of home care – rather than residential care – and the *SDCS* addresses persons with other functional limitations – not just persons with dementia. That said, Study IV reliability tests indicated acceptable Cronbach's alfa values, i.e. acceptable internal consistency of the scales. The total *SDCS* score had a Cronbach's alfa value of 0.92, enforced by 4 of the instrument's 5 factors (0.75-0.90). ***SDCS factor 5: lack of recognition*** had a low Cronbach's alfa (0.53), which suggests caution when interpreting results for this factor. The Cronbach alpha value for **factor 5** was reported in a previous study to be low ($\alpha = 0.65$) (Orrung Wallin et al., 2015). But results for **factor 5** seems to be reasonable, because associations were identified between this factor and *CCQ* variables' **total** and two dimensions, namely, **ideas support** and **conflicts**. These findings correspond with the Orrung Wallin et al. (2013) study in which ***SDCS factor 5: lack of recognition*** was associated with organisational climate (*CCQ total*) measured by the *CCQ*.

It is relevant to reflect on what the reported *SDCS* scores mean. Because no cut-off scores exist, interpretations were made in relation to previous studies. Some of the *SDCS* scores in Study IV are interpreted as high, such as the *SDCS* total score ($m=5.22$), because this score is higher than in a previously published study ($m=3.3$ [Orrung Wallin et al., 2015]). Because no cut-off scores exist for various levels, knowledge is insufficient, and it's questionable as to whether the statistically measured significant differences in Study IV are of clinical relevance. The findings in Study II underpin clinical relevance of the difference found in Study IV, which indicates that dementia care specialists perceive high job strain, because Study II demonstrated how challenging their work situations were, which might lead to job strain.

It was appropriate to use the *CCQ* in Study IV because it had been used previously to examine associations in relation to the *SDCS* (Orrung Wallin et al., 2015), which was the main outcome measure in this study. The *CCQ* has adequate reliability and validity and was developed in Sweden (Ekvall, 2004). Reliability tests for the total sample in Study IV indicated acceptable reliability – for

the total *CCQ* and for 6 of the 10 dimensions. But 4 of the dimensions had a Cronbach's alfa score <0.70, which indicated that these dimensions are not completely reliable and must thus be interpreted with caution.

7.5.3 Data analysis

Different methods were used in the two qualitative studies. Study I used a qualitative content analysis (Graneheim & Lundman, 2004) and Study II used a qualitative grounded theory approach (Charmaz, 2014). Method instructions guided the analyses. Applied procedures are presented to show how the work was performed for each study. Several similarities occurred between how I used the analytical methods in Studies I and II. For example, in both studies, I tried to grasp the content of the data and to understand it from its context. I assigned codes to the data depending on its content, and I merged codes with similar content into categories. But differences existed. For example, in Study II, I worked with memo writing, which supported me in the process of understanding how data could be interpreted and how different codes could be merged. Credibility of the results in Studies I and II is strengthened by presence of descriptions and quotations from the transcribed text, which shows similarities within the categories and differences between them (Graneheim & Lundman, 2004). Agreements among authors and other researchers' reviews strengthened the credibility.

The findings should be understood based on a *social constructivist* approach, which implies that the findings are an interpretative understanding – rather than an objective truth. So risk-filled situations can be interpreted in various ways, i.e. understanding depends on interpretation of the individual (Charmaz, 2014). So it's vital for researchers to report, for example, their theoretical framework – to clarify their preunderstanding. I elaborated upon my preunderstanding in this thesis, but in publications of Studies I and II, the description of my preunderstanding is insufficient. Given my clinical background and occupational perspective, my preunderstanding has been a strength for gaining deeper understanding of participants' experiences. For example, support from *MoHO* (Kielhofner, 2008) contributed to being attentive to participants' described experiences. But preunderstanding can also be seen as a limitation, because it may, for example, have steered interpretation, and other findings might have remained undiscovered. It seems reasonable to assume that the work with Study I contributed to my' preunderstanding before performing Study II, which most likely affected the analyses and consequently, the study's results.

Regarding the interpretation, Graneheim and Lundman (2004) stated that it involves a balancing act for researchers: On one hand, it's impossible and undesirable for researchers to not add a particular perspective to phenomena under study. On the other hand, researchers must 'let the text talk' and not 'impute meaning that is not there' (p.111). Graneheim and Lundman (2004) and Charmaz (2014)

report that research findings are the result of collaboration between researchers and participants – the findings arise within a context. To strengthen credibility of the findings, researchers have reflected on their own influence during the process.

Here are some reflections regarding missing data in Study IV and how this was managed by using a method for imputing values. The amount of missing data in Study IV was similar to previous studies (Boström, Wallin & Nordström, 2007; Edberg et al., 2015; Orrung Wallin et al., 2015). A systematic method for imputing values was used (Tabachnick & Fidell, 2013). Imputation was performed if $\leq 50\%$ of the values for each factor on the *SDCS* or dimension on the *CCQ* were missing. Between 4 and 7 persons completed less than 50% of the response scale for the 5 different *SDCS* factors, and between 5 and 7 persons for the 10 different *CCQ* dimensions; thus, imputation could not be done for 6-10% of the total sample. So a consequence of imputation with mean values could be reduced variance (Polit & Beck, 2016).

Considering the skewed distribution of some data in Study III, non-parametric statistical tests were the convenient choice. Non-parametric statistical tests would also have been appropriate in Study IV because the *SDCS* and *CCQ* have Likert scales, which are ordinal (Polit & Beck, 2016). But to be able to compare the findings in Study IV with a previous study, parametric statistical tests were used. Non-parametric statistical tests were also conducted to examine differences vs. the parametric statistical tests in Study IV. The non-parametric statistical tests showed similar results as the parametric tests.

Consideration must be given to the small sample size in Studies III and IV, which probably contributes to differences, associations and correlations remaining undiscovered (Type II error). But significant differences that were found must be interpreted with caution – partly because many statistical tests were conducted. If many statistical tests are run, then risk increases for tests results to erroneously indicate difference by chance. In retrospect, I think that more participants should have been recruited in Studies III and IV, fewer variables should have been used, hypotheses should have been formulated, and the p-value should have been lowered to increase generalisability of the studies' results.

8 CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

Findings from the overall study contribute new knowledge with useful implications for practice that involves older persons with cognitive impairments; home care staff and their managers; and organisations that support persons with cognitive impairments.

Study I showed that persons with dementia experienced risk-filled situations as unfamiliar and confusing, and they tried to reduce these risks by seeking recognition and clarity. This implies that ways in which persons with dementia experienced these situations seemed to be linked to the way in which they managed them. Because risky situations might occur unexpectedly, risks can be difficult to predict.

Knowing that persons with dementia can experience risk-filled situations as unfamiliar and confusing is potentially helpful for caregivers, for example, home care staff, who struggle to keep persons with dementia safe. This new knowledge may increase their understanding of how persons with dementia perceive different situations and may thus facilitate detection and management of risk-filled situations.

The findings in Study I described how risk affected daily living – directly and indirectly. If a person, for example, no longer wanted to use public transportation due to risk of getting lost, this could mean that the person could not attend activities he or she wanted to participate in. So that person's roles and habits could be affected. Sometimes persons with dementia stated that they were willing to take a certain risk, which could lead to ethical dilemmas for family and staff who tried to keep the person safe.

Because risk-filled situations can be perceived in various ways and have varying impact on individuals, it cannot be emphasized enough that it's crucial for caregivers to be sensitive to the situation and to the wishes of persons with dementia. The findings in Study I demonstrated that home-residing persons with dementia can express themselves regarding the topic of risk and described ways in which risks affected activities in daily living. They deserve to be heard.

Study II described how staff reasoned regarding ways in which they identified and acted on risks in daily living for persons with dementia. By constantly paying attention, staff members tried to track risks, but this was challenging because risks could occur suddenly and unexpectedly. Home care staff members pointed out that staff continuity is critical for enabling opportunities to note changes and track risks in their work with persons with dementia.

Continuity is something to strive for because it can facilitate risk detection. If the same staff members regularly visit older persons, then they are more likely to discover if something has changed, which can contribute to risk.

Based on the fact that home care staff often meet older persons regularly and may notice changes in their needs for support, home care staff members must have opportunities to collaborate with other professionals such as dietitians, nurses, occupational therapists, psychologists, physicians, physiotherapists, and speech therapists – if these competences are needed.

Home care staff in Study II described how they faced dilemmas when identifying and acting upon risks. Where to draw the line and decide on when to act upon a risk was, for example, not always obvious for them, and it was found that staff members could make different assessments of the same situation. Home care staff described how they weighed risk of not taking action against the consequences of taking action. Because they worked alone most of the time, they often faced, and struggled with, these difficult dilemmas on their own.

Accordingly, home care staff should be given opportunities to discuss what a risk is, because staff members can assess a situation fraught with risk differently – so risk assessment shouldn't depend on which home care staff member a person with dementia happens to have. Staff members should have opportunities to increase their knowledge regarding how to identify and act upon risk-filled situations for persons with dementia, for example, through experiences exchanges with colleagues. Given that staff members may face ethical dilemmas and often work alone, there should be opportunities for them to discuss and receive guidance, so they need not make decisions and deal with these dilemmas by themselves.

Study III found that older persons with and without documented cognitive impairment were granted a wide range of services – and some of them to a great extent (quartile 3=67 h/month; highest 127.5 h/month). A proportion as large as 40% of the sample was granted several services in the personal care category (i.e., ≥ 3 services, e.g., *shower*) and in the service category (i.e., ≥ 5 services, e.g., *cleaning*). These findings indicate that many older persons live at home with complex daily needs.

Because fulfilling these needs puts heavy demands on home care staff, advanced knowledge and skills are required. So staff members need training and support in their daily work to be prepared for work situations. This implies that home care staff managers are crucial for enabling proper work environments.

The findings in Study III show that persons with documented cognitive impairment were granted services to a greater extent – regarding personal care and service hours – than persons without

documented cognitive impairment. But no difference was found between persons with and without documented cognitive impairment regarding social support services.

Because no differences were found between persons with and without cognitive impairments regarding social support, municipal assessors (who are involved in granting home care services) might have to be even more responsive to need for social support among persons with cognitive impairments. This was evident in previous research, which showed that persons with cognitive impairment might have greater difficulties in maintaining social contacts.

Study IV indicated that home care staff perceived high job strain – higher than previous studies have shown for staff in residential care. This may be related to the work situation. Home care staff often work alone and need to rely extensively on their own capacities and competence.

Accordingly, it is vital that the organisation offers natural meeting places in which home care staff can discuss topics that are relevant to them daily.

Home care staff members perceived high job strain – particularly dementia care specialists and staff who did not have Swedish as their first language. Staff members, who did not have Swedish as their first language perceived higher job strain regarding understanding and interpreting work situations with older persons. A more creative organisational climate, on the other hand, was associated with lower job strain.

Consequently, it's important that staff members are seen as individuals who may need different types of support. For example, staff who are not completely familiar with the language and culture of older persons might need support to improve their ability to communicate with the older person. Furthermore, it's crucial for the organisation to strive for a creative organisational climate. Home care staff manager must pay attention to, and work for, an open, creative workplace climate – to enable employees' competence to flourish.

In conclusion, based on new knowledge from the four studies within the overall study, it is relevant to reflect on the fact that persons with dementia are living longer at home with a great degree of support from home care service that is granted for basic needs. Given the challenges that may exist for persons with dementia and for home care staff members, public discussions must continue regarding support that can be offered when remaining in the home and opportunities to change housing when this would enable prospects of offering person-centred care for persons with dementia.

9 FUTURE RESEARCH

Based on the overall study's findings, I suggest new topics for future research.

Study I showed how risks are experienced by persons with dementia and Study II showed how home care staff identify and act upon risks for persons with dementia. Both studies used interviews to capture (from different perspectives) subjective experiences of situations for home-residing persons with dementia. In future research, it would be interesting to further expand understanding of risk-filled situations for home-residing persons with dementia by using an observations-based format of data collection. For example, an ethnographic fieldwork approach might be feasible for exploring in more detail how persons with dementia try to manage risk-filled situations and how home care staff act when facing dilemmas that involve risks. Furthermore, participatory action research could deepen understanding regarding persons with dementia and their experiences of participating in the community – despite risk presence. Such knowledge might help our understanding of how to provide useful support to older persons with cognitive impairments. More continuing and professional education opportunities should be investigated so that home care staff can better account for safety, while supporting older person as they engage in daily living activities – despite presence of risks.

Services identified in Study III raise further questions, e.g., did provided services correspond to older persons' needs? The findings indicate that it might be particularly interesting to investigate how to ensure that persons with cognitive impairment receive the social support they want and need.

Findings in Study IV showed that home care staff reported higher job strain than staff in residential care and that dementia care specialists reported higher job strain than non-specialized staff. To reduce job strain for home care staff in general, and for dementia care specialists in particular, it is important to study why these differences occur. Are the differences regarding job strain scores, for example, associated with home care staffs' work situation and working methods? Based on the finding that personal factors, such as first language, correlated with job strain, it is relevant to further investigate how home care staff can be offered more individualised support that meets their needs – what kind of support is appropriate for reducing the staff's perceived job strain? The finding that home care staff members reported high job strain was interpreted by comparing scores with a previous study. But to better understand various job strain levels on the *SDCS*, it would be desirable to have cut-off scores.

Further studies are needed for confirming or rejecting the findings in the four studies – considering use of convenience sampling and small sample size. But all four studies point in the same direction regarding presence of risks and challenges when living at home with cognitive impairments or when supporting persons who do. Future research should focus on how home care staff can gain greater opportunities to facilitate safety for persons with cognitive impairment while still supporting them as they participate in meaningful daily living activities.

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