Care and services at home for persons with dementia. Structure, process, and outcomes.

Bökberg, Christina

DOI:
10.13140/RG.2.2.22397.97764

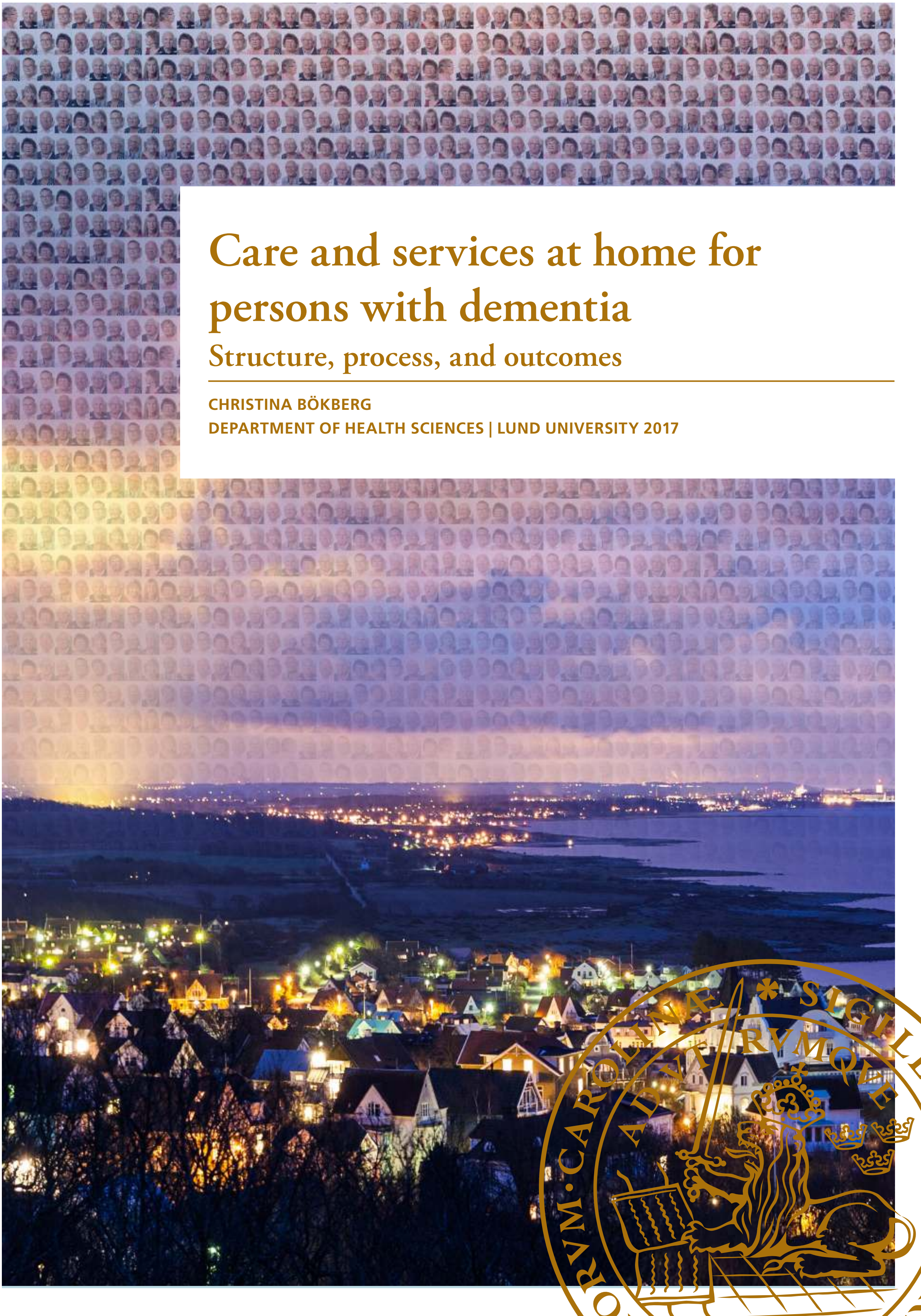
2017

Document Version:
Publisher's PDF, also known as Version of record

Link to publication

Citation for published version (APA):
Bökberg, C. (2017). *Care and services at home for persons with dementia. Structure, process, and outcomes.* Lund University: Faculty of Medicine. https://doi.org/10.13140/RG.2.2.22397.97764

Total number of authors:
1



Care and services at home for persons with dementia

Structure, process, and outcomes

CHRISTINA BÖKBERG

DEPARTMENT OF HEALTH SCIENCES | LUND UNIVERSITY 2017

Care and services at home for persons with dementia

Structure, process, and outcomes

Christina Bökberg

LUND
UNIVERSITY

DOCTORAL DISSERTATION
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To be defended in SSSH-salen, Health Sciences Centre, Baravägen 3, Lund.
16 February 2017 at 09.00.

Faculty opponent

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School of Health Sciences, Örebro University

Organization LUND UNIVERSITY Department of Health Sciences	Document name DOCTORAL DISSERTATION
	Date of issue 16 February , 2017
Author(s) Christina Bökberg	Sponsoring organization

Title and subtitle

Care and services at home for persons with dementia
Structure, process, and outcomes

Abstract

The overall aim of the thesis was to investigate formal care and services at home, regarding structure, process, and outcomes, for persons with dementia (aged 65+ years) at risk of nursing home admission.

Availability and utilization of formal care and services at home for persons with dementia, from diagnosis to end-of-life stage, in eight European countries was described in study I. A mapping form was used to collect data. The results revealed that availability was reported to be higher than utilization, and indicated more similarities than differences among the countries involved. Dementia-specific care and services were sparsely available and even more sparsely utilized.

Study II investigated formal care providers' views on conditions for best practice in terms of collaboration and improvement needs in the chain of care from early to end-of-life stage for persons with dementia in Sweden. Three focus group interviews were conducted to collect data. Data were subjected to content analysis based on three stages of dementia. The results indicated that best practice in terms of collaboration was achieved to a higher degree during the early stage compared with the moderate and end-of-life stages of the disease. Lack of best practice strategies during these stages made it difficult to meet the needs of persons with dementia and reduce burden on informal caregivers.

A cross-sectional study design was used in studies III and IV. Questionnaire-based interviews were conducted with 177 persons with dementia and their informal caregivers. Data were analysed using descriptive and comparative statistics. Study III compared persons with dementia with different levels of cognitive impairment, regarding utilization of formal and informal care and services at home. The results showed that needs relating to activities of daily living and supervision appear to be met first and foremost by the informal caregivers, since the utilization of formal care and services was lower than utilization of informal care. Study IV described self-reported quality of life, different aspects of quality of care and the significance of quality of care for quality of life. The results revealed that pain significantly lowered quality of life in the dimensions behavioural competence and psychological wellbeing, compared with absence of pain. Satisfaction with received care seemed to have a positive effect on quality of life. The overall quality of life was perceived to be high even though one-third of the persons with dementia had daily pain and had had a weight loss of ≥4% during the preceding year. Altogether 23% of the persons with dementia had fallen during the last month and 40% of them had sustained an injury when falling.

The thesis is inspired by Lawton's press-competence model, which provided a deeper understanding of the results and the context of the research.

Key words
Dementia, quality of life, quality of care, home care, nursing, person-centred care, chain of care,
Lawtons press-competence model

Classification system and/or index terms (if any)

Supplementary bibliographical information		Language English
ISSN and key title 1652-8220 Lund University, Faculty of Medicine Doctoral Dissertation Series 2017:17		ISBN 978-91-7619-398-3
Recipient's notes	Number of pages 96	Price
	Security classification	

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Cover photo by Per Birger Olsson

Lund University, Faculty of Medicine, Department of Health Sciences

ISBN 978-91-7619-398-3
ISSN 1652-8220

Printed in Sweden by Media-Tryck, Lund University
Lund 2017

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En del av Förpacknings- och
Tidningsinsamlingen (FTI)

To Anna & Erik
my joy and pride

"One purpose in studying typical environments,
where older people live, is to increase our
ability to serve those in need"

Lawton, 1986

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Paper I-IV

Abstract

The overall aim of this thesis was to investigate formal care and services at home, regarding structure, process, and outcomes, for persons with dementia (aged 65+ years) at risk of nursing home admission. Availability and utilization of formal care and services at home for persons with dementia, from diagnosis to end-of-life stage, in eight European countries was described in study I. A mapping form was used to collect data. The results revealed that availability was reported to be higher than utilization, and indicated more similarities than differences among the countries involved. Dementia-specific care and services were sparsely available and even more sparsely utilized. Study II investigated formal care providers' views on conditions for best practice in terms of collaboration and improvement needs in the chain of care from early to end-of-life stage for persons with dementia in Sweden. Three focus group interviews were conducted to collect data. Data were analysed using content analysis. The results indicated that best practice in terms of collaboration was achieved to a higher degree during the early stage compared with the moderate and end-of-life stages of the disease. Lack of best practice strategies during these stages made it difficult to meet the needs of persons with dementia and reduce burden on informal caregivers. A cross-sectional study design was used in studies III and IV. Questionnaire-based interviews were conducted with 177 persons with dementia and their informal caregivers. Data were analysed using descriptive and comparative statistics. Study III compared persons with dementia with different levels of cognitive impairment, regarding utilization of formal and informal care and services at home. The results showed that needs relating to ADLs and supervision appear to be met first and foremost by the informal caregivers, since the utilization of formal care and services was lower than utilization of informal care. Study IV described self-reported quality of life (QoL), different aspects of quality of care (QoC) and the significance of QoC for QoL. The results revealed that pain significantly lowered QoL in the dimensions behavioural competence and psychological wellbeing, compared with absence of pain. Satisfaction with received care seemed to have a positive effect on QoL. The overall QoL was perceived to be high even though one-third of the persons with dementia had daily pain and had had a weight loss of ≥4% during the preceding year. Altogether 23% of the persons with dementia had fallen during the last month and 40% of them had sustained an injury when falling. The thesis is inspired by Lawton's press-competence model, which provided a deeper understanding of the results and the context of the research.

Abbreviations

ADLs	Activities of Daily Living
BPSDs	Behavioural and Psychological Symptoms of Dementia
CLINT-HC	Client Interview instrument – Home Care
IADLs	Instrumental Activities of Daily Living
IEA	International Epidemiological Association
Katz-ADL	Katz Index of Independence in Activities of Daily Living
NPI-Q	Neuropsychiatric Inventory Questionnaire
OECD	Organization for Economic Co-operation and Development
PADLs	Personal Activities of Daily Living
Q1	First quartile
Q3	Third quartile
QoC	Quality of Care
QoL	Quality of Life
QoL-AD	Quality of Life in Alzheimer's Disease
RTPC	RightTimePlaceCare
RUD	Resource Utilization in Dementia (instrument)
SALAR	Swedish Association of Local Authorities and Regions
S-MMSE	Standardized Mini Mental State Examination
WHO	World Health Organization

Original papers

This thesis is based on the following studies, which are referred to in the text by their Roman numerals.

I Bökberg, C., Ahlström, G., Leino–Kilpi, H., Soto–Martin, M., Cabrera, E., Verbeek, H., Saks, K., Stephan, A., Karlsson, S. (2015). Professional care and services at home for persons with dementia in Europe. Journal of Nursing Scholarship, 47 (5), 407-416. doi: 10.1111/jnu.12158

II Bökberg, C., Ahlström, G., Karlsson, S., Hallberg, I.R., Janlöv, A. (2014). Best practice and needs for improvement in the chain of care for persons with dementia in Sweden: a qualitative study based on focus groups interviews. BMC Health Services Research, 14 (596), 1-10.
doi: 10.1186/s12913-014-0596-z.

III Bökberg, C., Ahlström, G., Karlsson, S. (2016). Utilization of formal and informal care and services at home among persons with dementia: a cross-sectional study. Submitted.

IV Bökberg, C., Ahlström, G., Karlsson, S. (2016). Significance of quality of care for quality of life in persons with dementia at risk of nursing home admission: a cross-sectional study. Submitted.

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Introduction

There is a trend in Sweden, as in many other countries, that the population is ageing and that the country is therefore facing challenges of how to meet the needs of care and services for older people (National Board of Health and Welfare, 2014a). Challenges that are likely to place demands on formal care and services at home are diseases that will have an impact on people's ability to independently manage activities of daily living (ADLs) (Lunenfeld & Stratton, 2013). One of the most important threats to living an independent life is developing any kind of dementia disease. The progressive nature of this type of diseases will inevitably lead to dependency on others (Agüero-Torres et al., 1998; Ferri, Sousa, Albanese, Ribeiro & Honyashiki, 2009). Home care has been put forward as the best way of caring for persons with dementia. This is because it enables a better quality of life (QoL) and is less expensive than institutional care (Moise, Schwartzinger, Um, & the Dementia Experts' Group, 2004; Tarricone & Tsouros, 2008), which means that greater extents of older persons utilize care and services in their own home. Hence, there have been strategies for reducing institutionalization (Knapp, Comas-Herrera, Somani, & Banerjee, 2007; Moise et al., 2004). However, the decreasing availability of informal caregivers (Tarricone & Tsouros, 2008; World Health Organization [WHO], 2012) is likely to challenge the provision of formal care and services at home.

Persons with dementia are, due to cognitive impairment, less able than persons without dementia to express their needs and preferences about how they would like to be cared for and supported (Prince, Prina, & Guerchet, 2013). Person-centred care has become synonymous with best care for persons with dementia (Ericson, Hellström, Lundh, & Nolan, 2001). However, there needs to be continuity between formal care providers, the person with dementia and their families to be able to provide care and services according to each individual's needs, personality and abilities (Edvardsson, Fetherstonhaugh, & Nay, 2010) which might be difficult to achieve in fragmented care systems (Stange, 2009). To provide person-centred care, formal care and services at home need to adapt to individual needs beyond institutional settings. To gain a deeper understanding of the ability of formal care and services at home to adapt to the competences of and needs for help in persons with dementia, at risk of nursing home admission, Lawton's press-competence model was used (Lawton & Nahemow, 1973).

Background

Provision of care and services at home has been put forward as the best way of caring for persons with dementia (Prince et al., 2013; Swedish National Institute of Public Health, 2007). To enable persons with dementia to remain living at home they need access to formal care and services at home adjusted to their specific needs and in line with the progression of the disease (Prince et al., 2013), i.e. person-centred care. The Swedish national guidelines for dementia care specify that all care and services for persons with dementia should be based on a person-centred approach (National Board of Health and Welfare, 2016a). The context in which care and services are provided has the greatest potential to enhance or limit the facilitation of person-centred care (McCormack, 2004). We used Lawton's press-competence model to gain a deeper understanding of the ability of formal care and services at home to adapt to the competences and needs of persons with dementia at risk of nursing home admission (Lawton & Nahemow, 1973). This model describes the balance between individual competences and environmental press. The competences of persons with dementia were represented by ADLs, cognitive impairment, and behavioural dysfunctions, i.e. neuropsychiatric symptoms. A three-part approach was chosen to investigate environmental press based on Donabedian's proposal (1988, p. 1745) that "a good structure increases the likelihood of a good process, and a good process increases the likelihood for a good outcome". Thus, the environmental press was represented by formal care and services at home and investigated in terms of content (structure) and function (process). The outcomes measured were QoL, and satisfaction with and quality of care (QoC) as indicators of the ability of formal care and services to adapt to the competences and needs of persons with dementia at risk of nursing home admission.

Lawton's press-competence model

Lawton's press-competence model describes the importance of balancing individual competences with environmental press (Lawton & Nahemow, 1973). Balance can be achieved by changing one or both components so that, even if the functional capacities decrease, the competences of the individual can increase in a supportive and stimulating environment. The model depicts that environmental press could cause maladaptive behaviour, marginally adaptive behaviour, and comfort, or enhance performance. This means that both too much and too little environmental press can have a negative effect on the competences of an individual. Balance of environmental press is needed to enhance an adaptive level (Figure 1).

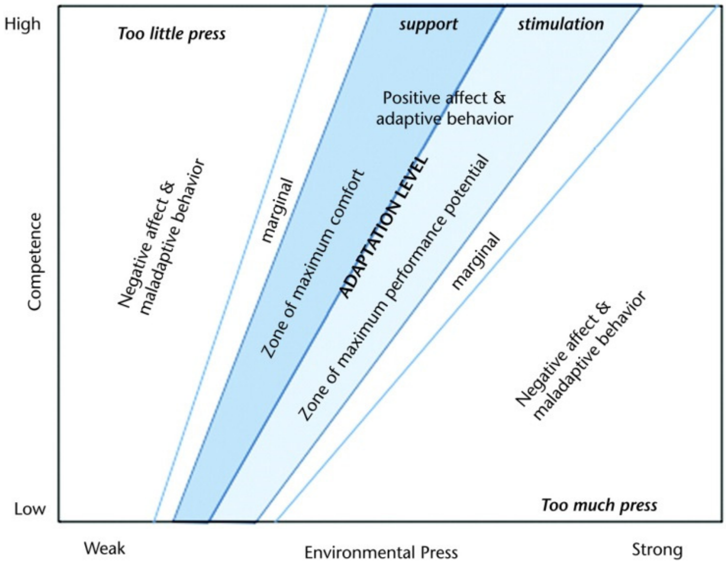

Figure 1. Lawton's press-competence model. Reprinted with permission of the American Psychological Association Source: Lawton MP, Nahemow L. Ecology and the aging process. In: Eisdorfer C, Lawton MP, eds. *The Psychology of Adult Development and Aging*. Washington, DC: American Psychological Association; 1973.

Lawton (1985) suggests that older people must be understood in terms of changes that occur both in themselves and in the world around them. This reciprocal relationship between older people and their environment stems from a simple premise which Lawton & Simon (1968) refer to as the “environmental docility hypothesis”: in terms of this, the less competent and/or the more vulnerable an individual is, the greater the impact of environmental factors on that individual. The principal question is to ensure that there is a balance between the competence of the individual and environmental press, i.e. that there is a fit between environmental demands and individual competence (Izal, Montorio, Marquez, & Lasada, 2005) or how situations or settings accommodate the goals and needs of the individual (Stokols, Clitere, & Zmuidzinas, 2000). Accordingly, a key concept of the “environmental docility hypothesis” is adaptation (Lawton & Simon, 1968); in terms of this, the ageing process itself can be seen as a continual adaptation, a dynamic process in time and space. The individual has to adapt both to the external environment affecting changes in internal capabilities and to functions that take place during the life cycle. Ageing is associated with certain limitations that affect the competences of individuals. It is therefore realistic to expect a gradual process of dependency and increased need for help (Prince et al., 2013; Swedish National Institute of Public Health, 2007). Dementia is strongly related to old age and a serious chronic condition affecting different aspects of competences, implying increased need for care and services.

Competences of persons with dementia

The worldwide prevalence of dementia in 2015 was estimated to be 46.8 million people, approximately 10 million of whom were in Europe, and 160 000 in Sweden. The number is expected to double every 20 years, reaching 74.7 million people worldwide in 2030. This is because of the increasing number of older people in society, and because the average life expectancy is increasing globally. Dementia increases exponentially with age but is not a normal part of ageing (National Board of Health and Welfare, 2014a; 2014b; 2016a; 2016b; Prince et al., 2015; WHO, 2016). In Sweden, it has been estimated that eight percent of individuals 65 years and older, and nearly half of individuals 90 years and older, have dementia. It is not common for dementia to affect people under the age of 65 years (National Board of Health and Welfare, 2016a).

Dementia is a disorder of the brain that is caused by diseases damaging the brain, and is characterized by progressive cognitive and physical impairment, changed behavioural patterns and, often, premature death (McLaughlin et al., 2010). It affects memory, cognition, orientation, comprehension, calculation, learning capacity, language, and judgement, but consciousness is not affected (WHO, 2016). The most common type of dementia is Alzheimer's disease (50-75%), followed by vascular dementia (20-30%). Less common forms are Lewy body dementia, frontotemporal dementia, and combinations of Alzheimer's and vascular dementia (Ferri et al., 2009; WHO, 2016). Due to cognitive impairment, and loss of physical and behavioural competences, the person with dementia becomes increasingly dependent on others. The need for help with ADLs starts early in the dementia disease course and evolves constantly over time (Agüero-Torres et al., 1998; Ferri et al., 2009). The process of requiring help often starts with needing help in instrumental activities of daily living (IADLs) (shopping, cooking, cleaning, washing, transferring, medication, finances) and later on includes also personal activities of daily living (PADLs) (toileting, feeding, dressing, bathing, transferring, continence) (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963; Roe, Whattam, Young, & Dimond, 2001; Sonn & Åsberg, 1991; WHO, 2012). It is expected that the predicted increase in dementia prevalence will put great demands on availability and utilization of formal care and services at home (Swedish National Institute of Public Health, 2007).

Dementia can be divided into different stages or phases based on the progress of the disease (Moise et al., 2004). The diagnosis marks the entry point into the care trajectory for dementia. The diagnosis usually occurs in the early stage, mild dementia, which is characterized by mild symptoms and low impact on ADLs, memory, and social competences. At this stage, the person with dementia is usually still able to handle ADLs and live at home with little support. Intermediate-stage, or moderate, dementia involves increased memory loss, dependency on help with social matters and need for daily assistance with ADLs, often from a combination of informal and formal care and services. Late-stage, severe dementia is marked by severe memory loss and increased demands for continuous assistance in ADLs, safety, and social matters. The person with severe dementia cannot be left unattended. Some sort of special accommodation or advanced care and services at home are usually necessary. The end-of-life stage is reached when the person has a limited time left to live (Huang, 2016; McLaughlin et al., 2010; Moise et al., 2004; National Board of Health and Welfare, 2016a; Prince et al., 2013).

The progression of dementia disease, contributing to disability and dependency, implies not only increasing needs for both informal and formal care and services (Agüero-Torres et al., 1998; Prince et al., 2013) but also risk of institutionalization, when the person is no longer able to remain living at home (Agüero-Torres, Von Strauss, Viitanen, Winblad, & Fragtiglioni, 2001; Luppa, Luck, Brahier, & Riedel-Heller, 2008). No one definitive reason for the institutionalization of a person with dementia has been described, and usually there are multiple factors contributing to institutionalization (Afram et al., 2014; Stephan et al, 2014). The risk of nursing home admission appears to increase when the person with dementia's cognitive, functional, and behavioural functions or competences decrease, combined with inability of formal care and services to meet the person with dementia's needs (Afram et al., 2014; Gaugler, Yu, Krichbaum, & Wyman, 2009; Stephan et al., 2014). Experiences of informal caregiver burden and/or strain also seem to be indicative of persons with dementia moving into institutional care (Afram et al., 2014; Gaugler et al., 2009; Stephan et al., 2014). Therefore, to enable persons with dementia to remain living at home, it is motivating to investigate the ability of formal care and services to adapt to competences and needs in the dementia phase preceding institutionalization.

Behavioural and psychological symptoms of dementia (BPSDs) affect about 90% of all persons with dementia at some point during the disease progress (National Board of Health and Welfare, 2016a). Symptoms may include aggression, agitation, apathy, hallucinations, or sleep disturbances. Behavioural and psychological symptoms of this type cause great suffering, especially for the person with dementia, but also for their family members and formal care providers (James, 2011). Besides being a predictor for institutionalization (Afram et al., 2014; 2015; Stephan et al., 2014) and causing burden in informal caregivers (Gaugler et al., 2009), BPSDs have been associated with lower QoL in persons with dementia (Banerjee et al., 2006; Jing, Willis & Feng, 2016). Because of loss of behavioural competence, persons with dementia may behave in a way considered inappropriate (such as screaming, or urinating in public places) or risky or harmful to themselves (e.g. inability of finding their way home, when going out on their own) (James, 2011) or others (e.g. through aggressive behaviour). This triggers the need for supervision to prevent accidents (McLaughlin et al., 2010). From a person-centred perspective, BPSDs can be interpreted as ways to communicate unmet basic needs such as pain, hunger, thirst, and non-adaptive environments (Edvardsson, Winblad, & Sandman, 2008).

Environmental press

Structure

Structure deals with the content of care and the resources available for delivering care and services, as well as settings in which formal care and services are provided. This includes material resources (facilities and equipment), human resources (the qualifications and number of formal care providers) and organizational structure (Donabedian, 1988; Prince et al., 2013) as well as legislation.

The responsibility for the Swedish welfare system is shared by the central government, county councils (n=20) and municipalities (n=290). The Health and Medical Services Act (*Hälso- och sjukvårdslag*, [HSL], SFS 1982:763) regulates the responsibilities of county councils and municipalities. The role of the central government is to establish principles and guidelines, and to set the political agenda for health and medical care. This is done through laws and ordinances or by reaching agreements with the Swedish Association of Local Authorities and Regions (SALAR), which represents the county councils and municipalities. The county councils are largely divided into hospital care and primary care and are responsible for health care delivery such as assessments leading to dementia diagnosis, treatment, and follow-up. The municipalities are responsible for providing assistance for those older persons who are receiving formal care and services at home, in day care or are living in a nursing home (Swedish Institute, 2017).

Access to formal care and social services is based on assessments of individual needs and is available to all members of society on equal terms (HSL, SFS 1982:763; *Socialtjänstlag*, [SoL], SFS 2001:453; Swedish Institute, 2017). The Swedish national guidelines for care in cases of dementia include recommendations concerning person-centred care, and support to the informal caregiver(s) and multi-professional teamwork

(National Board of Health and Welfare, 2016a). The Swedish welfare system is primarily tax-funded and the main philosophy is that taxes should be paid in accordance with the ability to pay, while the use of care and services should be in accordance with a person's needs (Swedish Institute, 2017).

Formal care providers

It is common to distinguish between formal care and services provided by paid formal care providers and informal care and services provided by unpaid informal caregivers. Formal care providers and informal caregivers coexist, either complementing or substituting for each other, based on the type of dependency (Lipszyc, Sail & Xavier, 2012). Persons with dementia are a heterogeneous group with different impairments and different needs for care and services within the different stages of the disease. Some needs are appropriately met by informal care and services and others are met by formal care and service, but often it is a question of combining formal and informal care (Knapp et al., 2007).

The World Health Organization has defined formal or professional care providers in health care as individuals who provide preventive, curative, promotional, or rehabilitative health care services (World Health Organization, 2010). Formal care providers have an extensive body of theoretical and factual knowledge in diagnosis and treatment of disease and other health problems. A formal care provider may operate within all branches of health care. They may conduct research on human disorders, illnesses, and ways of treating them, and supervise other workers. The knowledge and skills required are usually obtained as the result of study at a higher educational institution in a health-related field for a period of 3–6 years leading to a first degree or higher qualification.

Most of the formal care providers working in home care and services are assistant nurses and licensed practical nurses (National Board of Health and Welfare, 2016b) with upper secondary or post-secondary schooling. These formal care providers provide care and services including help with IADLs, PADLs and minor medical treatments (Lethin et al., 2016). Other formal care providers employed in home care are registered nurses in charge of home nursing care (e.g. administering wound dressings, injections), rehabilitation and needs assessments. Social workers make needs assessments regarding social services and personal safety alarms. Occupational therapists are involved in team-based care, rehabilitation, housing adaptation and PADLs. Physiotherapists are involved with rehabilitation (Hallberg et al., 2016).

Informal caregivers

The Ministry of Health and Social Affairs (2008) defines an informal caregiver as a person who cares for a loved one who is long-term sick, or elderly, or has a disability. Informal caregivers of persons with dementia usually have an existing social relation with the person with dementia. Most informal caregivers are family members and friends - mainly spouses, daughters, and daughters in law (Lipszyc et al., 2012). Care and services provided by informal caregivers are for instance, personal care and supervision, but also include shopping, transport, household chores, and gardening. Informal caregivers may also contact authorities on behalf of the person with dementia, as well as handle finances, mail, bills, and such things (National Board of Health and Welfare, 2012; WHO, 2012).

In Sweden, informal caregivers have no obligation to care for older persons; still, they remain a cornerstone in the care of persons with dementia and assume a great number of responsibilities for the older person's wellbeing (National Board of Health and Welfare, 2012). Since 2009 the Swedish municipalities are obliged by law (SoL, SFS 2001:453) to facilitate for the informal caregivers through support and respite care. Lethin et al. (2016) found that support for informal caregivers was highly available; however, it was utilized by few. This could be related to the finding that only one-fourth of the informal caregivers are aware of the possibility to get relief and support from formal care and services (National Board of Health and Welfare, 2014c).

Developments in provision of formal care and services at home

In the early 1950s care and services at home mostly involved help with IADLs, performed by care providers with no particular training. As the number of frail aged people in Sweden increased, there was an increased need for better health care provision for this group. There was a shift from generic care provision to specific and stricter needs assessments, and questions were raised about what the public welfare system should provide (Thorslund & Silverstein, 2009). Currently, more and more time in formal care and services is focused on personal care, i.e. PADLs, rather than IADLs (Szebehely & Trydegård, 2012), and the available resources have been focused on the frailest older persons with complex care needs (Savla, Davey, Sundström, Zarit & Malmberg, 2008), such as persons with dementia.

In 1992 the *Ädelreformen* (Reform for the Elderly) was introduced with the aim to reduce hospital care. The responsibility for long-term care and services for older people was transferred from the county councils to the municipalities (National Board of Health and Welfare, 2008; Ågren & Axelsson, 2011). The shortening of hospital stays and a reduction in the number of hospital beds (which was reduced by 45% from year 1990 to year 2002) (McKee, 2004) implied that a substantial part of health care was transferred to municipal care and services and to primary health care (National Board of Health and Welfare, 2014d). The reform also implied an increase in the home care sector and a decrease in nursing homes. In 2007, 198 900 (12%) older persons (+65 years) received care and services at home and 97 500 (6%) in nursing homes. In 2012, 219 600 (12%) older persons received care and services at home compared with 90 560 (5%) receiving care in nursing homes. At the same time the numbers of older persons (+65 years) increased by 0.93%, from n=493 113 in 2008 to n=497 717 in 2013

(National Board of Health and Welfare, 2014d). The trend remains, and the possibility to move into a nursing home continues to decline (National Board of Health and Welfare, 2015). The median age for moving into a nursing home is 86.2 years for women and 83.7 years for men. Most (67%) of the elderly moving into nursing homes are women (National Board of Health and Welfare, 2016c). The Reform for the Elderly also implied that older people moving into nursing homes were more frail and dependent, in terms of both functional and cognitive capacity, compared with previously (Karlsson, Edberg, Westergren, & Hallberg, 2008). This means that more and more persons with dementia move into nursing homes only when they are at the end-of-life stage. Additionally, the length of stay after moving into nursing homes (time until death) has decreased. One longitudinal study, (Schon, Lagergren, & Karleholt, 2016) reports a 22.1% decrease in number of days spent in nursing homes. In 2006, 50% of those moving into nursing homes died within 25 months of moving into a nursing home. In 2012 the corresponding figure was 19.5 months (Schon, Lagergren, & Karleholt, 2016). This shift in care and services from hospital care and nursing homes to the own home put great demands on formal care at home to provide care and services of high quality to frail and dependent older people including persons with dementia.

More recently, in 2009, the introduction of the Act on Free Choice Systems (*Lag om valfrihetssystem*, SFS 2008:962) made it easier for municipalities to introduce a customer choice system, where the individual user is able to choose from among authorized care providers. However, this development of additional and different care providers has tended to fragment care provision and have adverse effects on continuity of care (Tarricone & Tsouros, 2008; Ågren & Axelsson, 2011). According to the Organization for Economic Co-operation and Development (OECD, 2013), coordination of care and services between hospitals, primary health care and municipalities is the biggest challenge for Sweden's health and social care system. The main challenge is to be able to continue delivering high-quality as well as person-centred care, since care and services involve several different types of care providers and, hence, require coordination and continuity (National Board of Health and Welfare, 2016a). In fragmented care systems, such as the Swedish, persons with dementia are more vulnerable compared with persons without dementia, because their cognitive impairment may make them unable to express their preferences about how they would like to be cared for and supported (Prince et al., 2013). Additionally, in fragmented care systems, with multiple care and service providers, no-one acknowledges the whole system (Stange, 2009), making it difficult to get a clear picture of what kinds of resources are available and which are utilized through the different stages of the dementia disease. Therefore, there is a need to provide a clearer, more coherent overview of the available care and service activities at home during the process of dementia. This information will provide persons with dementia and their informal caregivers with more control over care and service resources that are available, helping them to make choices in line with their personal preferences.

Process

Process has to do with the function of the care system and the delivery of care, i.e. what is actually happening in giving and receiving care and services such as interpersonal exchanges between the care recipient and the formal care providers. This includes the care recipient's and the informal caregiver's activities in seeking care and services and exchange of information to achieve a diagnosis and appropriate care and services (Donabedian, 1988; Prince et al., 2013).

Best care for persons with dementia

"Best care" for persons with dementia has become synonymous with person-centred care (Ericson et al., 2001), contributing to a positive influence on QoL (Jing et al., 2016). There is no consensus regarding the concept of person-centred care, but Edvardsson et al. (2010) argue that its core aspect is "promoting a continuation of self and normality". A cornerstone of person-centred care is the person's narrative about his/her experiences, feelings, beliefs, and preferences. This narrative gives the formal care providers a good basis for discussing and planning care and treatment options with the person. The telling and listening is a way of creating a common understanding of the illness experience. Documenting the preferences, beliefs, and values, i.e. creating a care plan, facilitates continuity in care (Ekman et al., 2011; McCormack, 2004). Person-centred care highlights the importance of knowing the person behind the care recipient and involves interaction between formal care providers, the person with dementia and their family, according to each individual's needs, personality and abilities (Edvardsson et al., 2010).

The Swedish national guidelines for care in cases of dementia recommend that all care and services for persons with dementia should be based on a person-centred approach (National Board of Health and Welfare, 2016a). The concept of person-centred care means that the person, and not the diagnosis, is in focus on the basis of how the person with dementia experiences its reality. Person-centred care is designed to make nursing and the care environment more personal and to understand behaviours and psychological symptoms from the perspective of the person with dementia. Furthermore, person-centred care acknowledges that the person with dementia is increasingly concealed, rather than lost, offering shared decision-making and interpretation of behaviour from the viewpoint of the person with dementia (Edvardsson et al., 2008). This means that the person with dementia has the right to be informed and to participate in decisions on care and treatment. Persons with dementia should have access to activities on equal terms. Their rights in terms of integrity and self-determination should be respected, and they need to be able to experience security (National Board of Health and Welfare, 2016a).

Current care and services at home for persons with dementia

The context in which care and services are provided has the greatest potential to enhance or limit the facilitation of person-centred care (McCormack, 2004). Provision of care and services at home has been put forward as the best way of caring for persons with dementia (Ericson et al, 2001; Tarricone & Tsouros, 2008), which means that greater numbers of older persons receive care and services in their own home (Swedish Institute, 2017). The majority of persons with dementia in Sweden, about n=93 000 (58%), live in their own homes (National Board of Health and Welfare, 2014a; 2014b). Previous research has found that older people prefer living at home in a familiar environment (Tarricone & Tsouros, 2008) and expected benefits are maintenance of a social network (Luppa, Luck, Brahier, & Riedel-Heller, 2008) and experience of a better QoL (Jing et al., 2016; Nikmat, Hawthorne, & Al-Mashoor, 2011; 2015). Care and services at home have also been found to be more cost-effective compared with institutional care (Moise et al., 2004; Tucker, Hughes, Burns, & Challis, 2008). However, while the person with dementia's sense of identity and integrity is promoted by living in their own home surrounded by well-known objects and continuing their habits in a familiar environment (Tarricone & Tsouros, 2008), the needs for care and services increase as the disease progresses (Moise et al., 2004).

Persons with dementia at risk of nursing home admission require a range of both informal and formal care and services to postpone nursing home admission (Prince et al., 2013). Related to cognitive impairments and decreased functioning or competences, persons with dementia have complex needs for care and services. Compared with older persons without dementia, persons with dementia need more personal care, more hours of care and more supervision (McLaughlin et al., 2010; Norberg, Von Strauss, Kåreholt, Johansson & Wimo, 2005; Wimo et al., 2016), implying multiple contacts with different formal care providers employed by municipalities and county councils across acute care and nursing home settings (Moise et al., 2004). The problem for the persons with dementia in a fragmented care system, with multiple contacts with different formal care providers, is that no-one gets a complete overview of their complex needs, making it difficult to co-ordinate care and service activities (Stange, 2009). The disease also contributes to difficulties in expressing needs and preferences (WHO, 2016) and, thereby, in achieving person-centred care. These circumstances present risks of poor continuity of care, miscommunication, duplication, and/or missed nursing interventions (Callahan et al, 2012), leading to unmet care needs. Therefore, it is important to investigate how transitions in the chain of care are coordinated and how critical information is delivered between formal care providers, and identify communication gaps.

Outcomes

The term "outcome" denotes the experiences, the results, or the consequences of care and services on the health status of care recipients and populations – in other words, what happens to care recipients. Outcomes can be both objective and subjective measurements (Donabedian, 1988; Higashi et al., 2005; Prince et al., 2013). In this thesis, the outcomes QoC, satisfaction with care, and QoL will serve as indicators of the ability of formal care and services to adapt to competences and needs for help in persons with dementia at risk of nursing home admission.

Quality of care

Swedish law stipulates that it is of great importance that care and services be conducted in such a way as to meet requirements for good health (HSL, SFS 1982:763; SoL, SFS 2001:453). This means that the care and social services provided must be of good quality and must meet the care recipients' needs for security in the care. Good care and services should be knowledge-based, appropriate, safe, patient-focused, efficient, and equitable and should be given within a reasonable time. Formal care and services should also be based upon respect for the care recipient's autonomy and integrity (National Board of Health and Welfare, 2009). This approach is in line with the WHO's (2006) definition of QoC including six dimensions of quality: effectiveness (i.e. care must be evidence-based, and improve health outcomes based on needs), efficiency (there must be a maximization of resources, avoiding waste), accessibility (care provision must be timely, and must be geographically accessible, i.e. provided in appropriate settings), patient-centredness (taking into account individual preferences), equitability (equal quality must be delivered irrespective of gender, race, ethnicity, etc.), and safety. Quality of care can also be defined as the degree to which care and services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge (Francis & Netten, 2004).

Quality of care indicators are objective measures that reflect care standards and are used as guides to monitor and evaluate the QoC (Nakrem, Guttormsen-Visnes, Harkless, Paulsen, & Seim, 2009; National Board of Health and Welfare, 2009). These indicators show how structure and processes impact on a person's wellbeing, health and/or QoL. Quality of care indicators can also bring about meaningful understanding that can lead to changes in treatment (Prince et al., 2013). Important QoC indicators in the care of the elderly are pain, falls, pressure ulcers and weight loss, indicating deterioration in chronic conditions such as dementia (Achterberg et al., 2013; Coleman et al., 2013; Higashi et al., 2005; Malara et al., 2016; Payette, Coulombe, Boutier, & Gray-Donald, 2000; Rubinstein, 2006; Stenhagen, Nordell, & Elmstahl, 2013).

There is no universally accepted definition of or measure for satisfaction with care, but a care recipient's satisfaction is none the less regarded as an important aspect of QoC.

While some researchers focus on care recipients' satisfaction with the quality and type of health care services received, others focus on people's satisfaction with the health system more generally (WHO, 2009). In this thesis, satisfaction with care and services is understood to concern care recipients' and informal caregivers' experience of utilized care in relation to their expectations and needs. Finally, satisfaction with care is a person-centred, subjective, holistic outcome indicator that summarizes the impact of structure and care process issues (Prince et al., 2013). Therefore, by investigating both subjective and objective aspects of QoC we may reveal areas for improvement regarding care and services at home. Such information may ultimately enable persons with dementia to remain living in their own homes while maintaining QoL, since QoL in persons with dementia is, in large part, dependent on the QoC they receive (Francis & Netten, 2004; Jing et al., 2016; Vaarama, 2009).

Quality of life

Since there is no cure for dementia (Huang, 2016), the outcomes of dementia care and services should be enhancement and promotion of as good a life as possible and an optimal everyday life (National Board of Health and Welfare, 2016a). Quality of life has been perceived as a positive state and a desirable outcome of health care interventions. Therefore, ensuring QoL is one of the more important outcomes of health care (Holmes, 2005).

To understand QoL in old age, not only the distress and impairments resulting from poor health, but also non-health-related aspects, such as life satisfaction and wellbeing, need to be considered (Bowling et al, 2015; Lawton, 1999). There is no consensus regarding the concept of QoL; however, there seems to be a common agreement that QoL should be viewed and assessed as a multidimensional concept (Bowling et al., 2015; Lawton, 1983; 1991; WHO, 2009) including different domains (emotional, physical, social, and environmental) of a person's wellbeing (WHO, 1997; 2009). One definition of QoL, which was developed for use among older persons, and provided by Lawton (1991, p.6), is that it is "the multidimensional evaluation by both intrapersonal and socio-normative criteria of the person-environment system of an individual in the time past, current and anticipated". This broad definition of QoL includes both a subjective and an objective evaluation. In accordance with this definition, Lawton described a multidimensional model for QoL, where QoL is explained in four subjectively and objectively domains of importance (Figure 2).

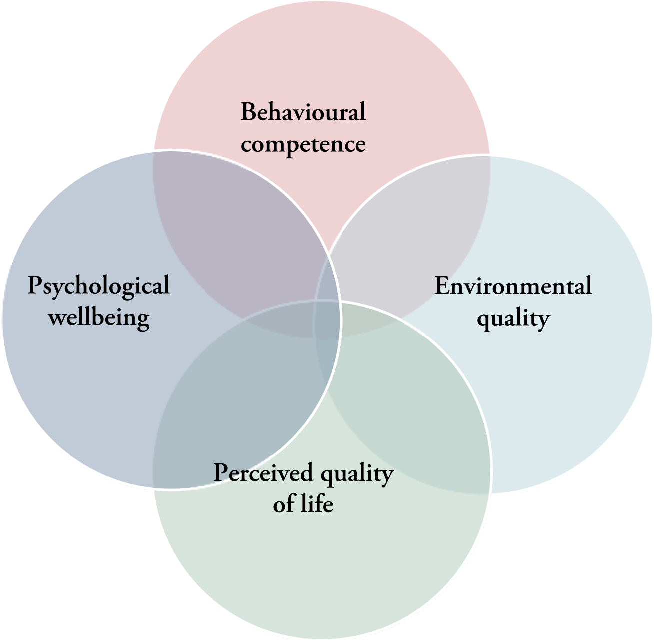

Figure 2. Lawton' s model of Quality of Life

The first domain, behavioural competence, concerns how well a person functions in the areas of physical health (body and organs), functional health (ADLs), cognition (perception and memory), and social behaviour. The second domain, psychological wellbeing, concerns the global aspects of mental health (presence or absence of depression; emotional states; and general life satisfaction). The third domain, perceived QoL, entails the evaluation of one's neighbourhood, family, friends, etc. Environmental quality is the fourth domain, which includes housing quality (Lawton, 1983; 1991). Each of these domains is highly relevant to evaluating QoL in persons with dementia.

Quality of life implies an evaluation, or a subjective rating, by the individual. In dementia research, self-report of QoL is not possible in many cases, as dementia affects cognitive abilities (Moyle, McAllister, Venturato & Adams, 2007), which raises doubts about the ability of persons with dementia to make valid assessments and give reliable answers regarding their QoL. However, there is a growing body of evidence suggesting that persons with dementia can complete standardized questionnaires on self-reported QoL (Logsdon, Gibbons, McCurry, & Teri, 1999; 2002; Trigg, Jones & Skevington, 2007).

Rationale

Since more and more persons with dementia remain at home for as long as possible, increased understanding of the phase preceding institutionalization of persons with dementia is required. Individuals with low competence, such as persons with dementia at risk of nursing home admission, are much more vulnerable to environmental demands compared with persons without dementia and with higher competence (Lawton & Nahemow, 1973). Demanding changes can have a greater negative impact on persons with dementia, but also minor improvements can result in more positive outcomes (Lawton, 1983). Therefore, it is important to gain a deeper understanding of the ability of formal care and services at home to adapt to competences and needs in persons with dementia at risk of nursing home admission. The thesis is inspired by Lawton's press-competence model, which was used to gain a deeper understanding of the results and the context of the research.

Aims

The overall aim of the thesis was to investigate formal care and services at home, regarding structure, process, and outcomes, for persons with dementia (aged 65+ years) at risk of nursing home admission.

Specific aims were:

I To describe available and utilized formal care and services at home for persons with dementia, from diagnosis to end-of-life stage, in eight European countries.

II To investigate professional care providers' views on conditions for best practice in terms of collaboration and improvement needs in the chain of care from early to end-of-life stage for persons with dementia in Sweden.

III To compare persons with dementia with different levels of cognitive impairment, regarding utilization of formal and informal care and services at home.

IV To describe self-reported quality of life in persons with dementia at risk of nursing home admission. Secondly, to describe subjective and objective aspects of quality of care. Thirdly, to investigate the significance of quality of care for quality of life in persons with dementia at risk of nursing home admission.

Methods

Design

For the purpose of investigating formal care and services at home, regarding structure, process, and outcomes, for persons with dementia (aged 65+ years) at risk of nursing home admission, we used various methodological approaches, including qualitative and quantitative study designs. An overview of the study designs is given in Table 1.

Table 1. Design, samples, data collection and analysis used in studies I–IV

Study	**I**	**II**	**III + IV**
Design	Desciptive cross-sectional	Qualitative	Quantitative cross-sectional
Sample	Strategic sample from eight European countries	Strategic sample consisting of 23 formal care providers	Strategic sample consisting of 177 persons with dementia, and their informal caregivers
Data collection	Mapping form Literature review Interviews	Three focus group interviews, using an interview guide	Structured face-to-face interviews Questionnaires
Analysis	Description of types of care and services activities in the different stages of dementia	Content analysis	Descriptive and comparative statistics

Research setting

This thesis was a part of the European research project titled RightTimePlaceCare (RTPC) (the EU 7th Framework Programme for Research, contract number 242153) conducted during 2010-2013. The RTPC project aimed at improving care and services for European citizens with dementia as well as developing best practice strategies for the transition from home to nursing home for persons with dementia. The countries included in the project were Estonia, Finland, France, Germany, the Netherlands, Spain, Sweden, and the United Kingdom (Verbeek et al., 2012).

Sample

In Study I, we described available and utilized care and service activities at home in the eight European countries included in the project (Study I; Table 1). The results from Sweden are presented in this thesis.

In Study II a strategic sample of formal care providers and workplaces was chosen to achieve variation in experiences and perspectives (Krueger & Casey, 2009) on best practice in terms of collaboration and needs for improvement in the chain of care. The recruitment of participants was done through seven contact persons, all of them registered nurses specializing in dementia care in four municipalities in southern Sweden. These contact persons gave oral information about the study to various formal care providers working in the municipalities and the county council. After the formal care providers gave consent, they were contacted by a researcher from Lund University who provided further information about the study process. The total sample (n=23) consisted of a mix of registered nurses with (n=4) or without (n=3) specialization in dementia care, assistant nurses (n=9), occupational therapists (n=4) and social workers (n=3). Their average work experience was 30 years and ranged between 3 and 42 years. The participants mean age was 52 years (range 28–61 years) and all but one were women. The participants were divided into three groups of six to nine participants. The care organizations representing the chain of care were county councils (memory clinic) and municipalities (home care, day care, and nursing homes) (Study II; Table 1).

Inclusion criteria for the face-to-face interviews (studies III and IV) were persons with dementia, aged 65 years or older, with a formal diagnosis of dementia and a Standardized Mini Mental State Examination (S-MMSE) score ≤24 (Folstein, Folstein, & McHugh, 1975; Molloy, Alemaychu, & Roberts, 1991). Further inclusion criteria were, living at home, receiving formal care and/or services, and having an informal caregiver who co-habited with or visited the person with dementia at least twice a month. An additional criterion was being at risk of nursing home admission within six months as per the assessment of their formal nursing caregiver. The risk of nursing home admission meant that the informal caregiver(s) could not manage the situation at home much longer on account of the progress of dementia, implying increased needs for care and services, and/or environmental factors (Stephan et al., 2014). The exclusion criterions were having a primary psychiatric disease and/or Korsakoff's syndrome. The recruitment of participants was done through 15 contact persons, registered nurses specialized in dementia care in twelve municipalities in the south of Sweden. The contact persons asked formal care providers – registered nurses and social workers in home care, who were well known to the person with dementia – to give verbal information about the study to persons with dementia who met the inclusion criteria, and their informal caregivers. If they were interested in the study, the formal care providers also asked them whether a researcher could contact them to give more detailed information about the study and participation. The formal care providers passed the information back to the contact persons, who in turn contacted the researchers. After giving verbal permission, the informal caregivers were contacted by phone by a researcher, who provided detailed information about the study and asked for verbal consent for participation. The time and place for the interviews were arranged.

In total, 243 persons with dementia and their informal caregivers expressed an interest in participating in the study, but when the researchers contacted them 66 dropped out. Twelve had moved in to nursing homes and four had died. The remaining 50 drop-outs were too tired to participate or had changed their minds. Therefore, the total study group consisted of 177 persons with dementia, 92 (52%) of whom were women. The age of the persons with dementia ranged between 65 and 98 years. Sixty-eight percent lived together with their informal caregiver. The spouse of the person with dementia (n=113; 64%) was the most common informal caregiver, followed by an adult child (n=53; 31%). Alzheimer's disease (n=78; 46%) was the most reported dementia diagnosis, followed by vascular dementia (n=56; 33%). Fourteen per cent (n=24) were on a waiting list for nursing home placement (studies III and IV).

Measurement

Socio-demographic data for the persons with dementia included gender, age, living conditions, diagnosis, and information about being on a waiting list for nursing home placement.

Competences of the persons with dementia

The S-MMSE (Folstein et al, 1975; Molloy et al., 1991) was used to assess cognitive impairment. The instrument covers a range of cognitive domains, including orientation to time and place, recognizing objects and recalling three objects, copying a design, spelling backwards, writing a sentence, idiom, and understanding and following commands. For each question, there is a time limit for response of between 10 seconds and 1 minute. The possible score ranges from 0 to 30. Higher scores indicate less cognitive impairment. The total score was noted. Where a person was unable to answer a question, the scoring was given as zero.

To assess the persons with dementia' s ability to independently perform PADLs the Katz Index of Independence in Activities of Daily Living (Katz-ADL) (Katz et al., 1963) was used. The instrument covers the six self-care items of bathing, dressing, toileting, transferring, continence, and feeding. For each item, the person's ability is assessed as "independent", "partly independent" or "dependent". Independence means functional ability without supervision, direction, or active personal assistance. Dichotomizing the items into independency and dependency was made vis-à-vis; "partly dependent" is assessed as dependent in toileting, transferring and continence and as independent in bathing, dressing and feeding (Katz et al., 1963).

Twelve neuropsychiatric symptoms were assessed with the Neuropsychiatric Inventory Questionnaire (NPI-Q) (Cummings, Mega, Gray, Rosenberg-Thomson & Carusi, 1994; Kaufer et al., 2000) namely hallucinations, delusions, agitation/aggression, depression/dysphoria, anxiety, elation/-euphoria, apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviour, sleep and night time behaviour disorders and appetite, and eating disorders. The questions were asked to determine whether the symptom has been present during the last month. The response alternatives were "yes" or "no". The total possible symptom score ranges from 0 to 12. A lower score indicates less presence of neuro-psychiatric symptoms.

Structure

Hallberg et al. (2013) developed a mapping form, describing altogether 50 types of care and service activities, and care providers involved. The care and service activities are sorted into six categories. The 50 activities during the stages of dementia (Moise et al., 2004) are presented horizontally in the mapping form. For each type of care and service activity, estimations of availability, utilization, and information about the care provider are included. The possible responses regarding availability are "for all", "for most", "for few" and "for none". For utilization, the response alternatives are "by all", "by most", "by few" and "by none". An example of the mapping form is shown in Appendix I. Sixteen care and service activities from the category "care at home" were selected in Study I: accompanying service; general technical aids; home-delivered meals; home help/care with IADLs; home help/care with PADLs; housing adaptation; needs assessment; personal safety alarm; transport service; home nursing care; rehabilitation at home; team-based home health care; aid equipment to compensate for cognitive impairment; mobile comprehensive expert team; specialist psychiatric home nursing care; and team-based community mental health for older people (Table 2). Since the data concerning formal care providers involved in the care and services at home were analysed in a previous study (Hallberg et al., 2016) these data were not included in Study I.

Process

An interview guide, presented in Appendix II, was developed to provide the opportunity to obtain formal care providers' experiences and views on conditions for best practice in terms of collaboration and improvement needs in the chain of care (Study II). The interview guide covered questions about the formal care providers' experiences of collaboration, information delivery and channels of communication and about any deficiencies in the chain of care, the participants' visions of best practice, and their suggestions for improvement. To gain in depth knowledge, follow-up questions were asked, such as "Can you tell us a little bit more about that?", and "Can you give an example?"

The Resource Utilization in Dementia (RUD) instrument (Wimo, Jönsson, Karlsson, & Winblad, 1998; Wimo, & Norberg 2000) was used to get an overview of who was addressing the various needs for help of the persons with dementia and to determine the type and amount of utilization of formal and informal care and services (Study III). The RUD is divided into two parts. Part A consists of four sections. The section related to caregiver time was selected for this study to assess type and amount of utilized *informal care and services*. Three questions were asked about how much time on an ordinary day, during the last 30 days, the informal caregiver has spent helping the person with dementia with (1) PADLs, (2) IADLs, and (3) prevention of dangerous situations, i.e. supervision. The response to these questions was given in hours per day and calculated as number of days during the last 30 days.

Part B of the RUD is divided into two sections and the section on health care resource utilization was selected to assess type and amount of *formal care and services* utilized by the person with dementia. Three main questions about utilization of care in county council settings during the last 30 days were asked, regarding: (1) hospital care >24 hours; (2) emergency care <24 hours; and (3) visiting formal care providers (general practitioner, registered nurse, occupational therapist, assistant nurse, physiotherapist, and/or specialist, e.g. geriatrician, neurologist, psychiatrist, psychologist). Response alternatives for these three questions were "yes" or "no". A positive answer to the last of the three questions elicited a follow-up question to establish the number of visits to each formal care provider. Type and amount of formal care and services in municipality settings was assessed by asking questions about utilization of home nursing care, home help, and day care the latest 30 days. Response alternatives were "yes" or "no". Yes, was followed-up by the number of visits and the amount of time.

Additionally, one question about utilization of dementia-specific care and services. Response alternatives were "yes" or "no". Yes, for utilizing dementia-specific care and services was followed by one question: "Please describe the dementia-specific care and services you used." (Study III).

Outcomes

Quality of care

To assess objective perceptions of QoC, QoC indicators including presence of pain, falls, injury when falling, pressure ulcers, and weight loss were evaluated in Study IV. Pain was evaluated by asking informal caregivers how often the person with dementia had expressed signs of pain in the last 7 days. Response alternatives were "no pain", "no daily pain" and "daily pain". The question regarding fall was, "Has the person with dementia fallen in the past month?" Response alternatives were "yes" and "no". "Yes" for fall was followed up with a question to find out if the person had sustained injury when falling, with response alternatives "yes" and "no". In addition, questions about presence of pressure ulcers, and weight loss of ≥4% in the previous year were answered by "yes" or "no" (Study IV).

To assess subjective experiences, i.e. satisfaction with care and services an adapted version of the home care setting, the Client Interview Instrument for Home Care (CLINT-HC), (Vaarama, 2009; Vaarama, Pieper, & Sixsmith, 1992) was used in Study IV (Appendix III). The instrument consists of nine questions relating to the informal caregivers' satisfaction with the care and services received by the person with dementia. The questions are: (1) Do you mainly see the same care workers?; (2) Do the care workers do the things you want done?; (3) Do you think your relative' s care workers are honest and trustworthy?; (4) Is your relative able to keep as clean as you would like?; (5) Is your relative's home as clean and tidy as you would like?; (6) If your relative has a garden, is it as well maintained as your relative would like?; (7) Does your relative get the right amounts to eat?; (8) Does your relative enjoy the meals?; and (9) In general, how satisfied are you with help that your relative receives from home care?" The responses are rated on a Likert scale from 1 to 5. The total possible score ranges from 9 to 45. Higher scores indicate lower satisfaction with the care and services received.

The second way of assessing satisfaction with care was by asking how satisfied the informal caregiver was with received dementia-specific care and services. Response alternatives were: "very dissatisfied", "dissatisfied", "neither satisfied nor dissatisfied", "satisfied", and "very satisfied" (Study IV).

Quality of life

To assess QoL in persons with dementia in Study IV, the instrument Quality of Life in Alzheimer's disease (QoL-AD) (Logsdon et al., 1999; 2002) was answered by the persons with dementia. The instrument consists of 13 items relating to physical health, energy level, mood, living situation, memory, relationship with the spouse, relations with friends, and relations with family, the self as a whole, ability to do chores around the house, ability to do things for fun, the financial situation, and life as a whole. The response alternatives are “poor”, “fair, “good” and “excellent” measured on a 4-point Likert scale ranging from 1 = poor, to 4 = excellent. The total possible score ranges from 13 to 52, with higher scores indicating a higher QoL (Study IV).

Data collection

Data for investigating the structure of formal care and services at home for persons with dementia were collected from 1 November 2010 to 31 January 2011 by researchers from Lund University using the mapping form (Hallberg et al., 2013) (Appendix I). The researchers consulted managers and providers of care and services for persons with dementia in Swedish municipalities and county councils and at the National Board of Health and Welfare. The aim was to collect data representative of the country as a whole. Additionally, a review was conducted of written reports such as official governmental documents and epidemiological data. Then the researchers filled in the mapping form about availability and utilization of care and services at home (Study I).

Three focus group interviews were conducted, led by two registered nurses: a moderator and an observer (A-C.J., C.B.) (Stevens, 1996). The interviews were based on the interview guide presented in Appendix II, and therefore all the interviews followed a similar structure. The interview started with the moderator’s explaining the purpose of the interview, and then posing questions based on the interview guide. The participants were encouraged to bring their views into the open and the observer helped the moderator in ensuring participants’ responses answered the questions and did not digress from the topic. The interviews were digitally recorded and then transcribed verbatim. Each interview took about two hours. Two of the interviews took place in a conference room at Lund university and was held one in a conference room in a nursing home (Study II).

Structured face-to-face interviews with persons with dementia and their informal caregivers were conducted between January 2011 and January 2013. Just before the interview the researcher repeated and clarified the purpose of the interview, both verbally and in writing, to the person with dementia and their informal caregiver, giving them opportunity to ask questions before signing the informed consent. Nine specifically trained researchers interviewed the persons with dementia and their informal caregivers either in the person with dementia’ s own home or at a day care facility. The researchers posed questions based on the questionnaire form starting with the person with dementia who answered the S-MMSE and QoL-AD questions. The remaining questions were answered by the informal caregivers (studies III and IV).

Data analysis

Descriptive analysis

On the basis of a review of the main content, the selected 16 types of care and service activities from the mapping form (Appendix I) were subdivided into three categories: basic care and services; healthcare interventions; and specific dementia care and services (Study I). An overview of the care and service activities, subdivided into the three categories, is given in Table 2.

Lawton's (1991) model of QoL (Figure 2) was used to sort the 13 items of the QoL-AD into four categories: (1) behavioural competence contained the items physical health, energy level, memory, ability to do chores around the house, and ability to do things for fun; (2) Psychological wellbeing contained the items mood, the self as a whole, and life as a whole; (3) Perceived quality of life contained the items relationship with the spouse, relations with friends, and relations with the family and (4) Environmental quality consisted of the items the living situation and the financial situation.

Table 2. Types of care and service activities related to care at home

Basic care and services	Healthcare interventions	Specialized dementia care and services
Accompanying service: Service for accompanying a person to appointments, providing transportation and/or shopping. **General assistive aids:** Assistive devices to compensate for physical disabilities, e.g. aids for: transferring (stick, walking frame, wheelchair), sitting in a chair, personal care, the sickbed, hearing and vision. **Home-delivered meals:** A service that delivers cooked meals to disabled and/or older people in their homes. **Home help/care with IADLs:** Help with IADLs at home provided by paid professionals. **Home help/care with PADLs:** Help with PADLs at home provided by paid professionals. **Housing adaptation:** The person's home adapted to disability, e.g. by removal of doorsteps and/or replacement of the bathtub by a shower. **Needs assessment:** Assessment of needs regarding care and social services from any kind of organization prior to professional care decision and receiving care, including determination of eligibility. **Personal safety alarm:** Technical system allowing the disabled person to call for assistance via the telephone and/or wireless **Transport service:** Transport assistance service for disabled persons.	**Home nursing care:** Nursing care provided at home, including, e.g., wound dressing or injections, by an RN and/or licensed practical nurse/auxiliary nurse. **Rehabilitation at home:** Training at home by an occupational therapist, physiotherapist, and/or RN, and/or licensed practical nurse/auxiliary nurse to improve or maintain functional ability. **Team-based home health care:** Health care provided in the patient's own home by a multi-disciplinary team charged with treating and monitoring the patient with dementia and their informal caregiver.	**Aids equipment to compensate for cognitive impairment:** Equipment to compensate for cognitive functional disability, e.g. equipment to help with time orientation and/or stove alarm. **Mobile comprehensive expert team:** Mobile multi-professional team with expert competence in dementia care, serving as consultants. **Specialist psychiatric home nursing care:** Supervision, support, treatment, and monitoring by a community psychiatric nurse. **Team-based community mental health for older people:** Specialist multi-disciplinary team, including, e.g., a psychiatrist, psychiatric nurse, social worker, occupational therapist, and psychologist, and sometimes "support workers".

IADLs = instrumental activities of daily living; PADLs = personal activities of daily living; RN = registered nurse.

Content analysis

The transcriptions of the focus group interviews were analysed as a conversation, with the participants responding to each other as a group (Krueger & Casey, 2009). The interview texts were analysed using content analysis (Graneheim & Lundman, 2004). As a first step, to get a sense of the whole, the transcripts were read through several times by the first author (C.B.). As a second step, expressions (sentences/paragraphs) of relevance to the study aim were identified and divided into meaning units. Next, the meaning units were condensed at a descriptive level, keeping close to the text. As a fourth step, the condensed meaning units were abstracted and labelled with a code. The interviews in their entirety served as a point of reference throughout the analytical process, in particular when a deeper understanding was required in identifying the meaning units and codes. Fifthly, the codes were thoroughly compared regarding similarities and differences, before categories were created. Four of the authors (C.B., G.A., S.K. and A-C.J.) independently read and critically reviewed the meaning units, codes, and categories in relation to the interview texts, reflected on them, and then discussed them with the other authors in several combined meetings. This procedure was followed to uncover as many qualities as possible within the text and made it possible to reach a consensus concerning the findings (Study II).

Descriptive and comparative statistics

In study III the median total score of 16 on the S-MMSE was used to dichotomize the persons with dementia in to two groups regarding their cognitive impairment: S-MMSE ≤16 (n=92) and S-MMSE 17-24 (n=85). Ten persons with dementia were unable to complete the S-MMSE because of severe cognitive impairments and were included in the group S-MMSE ≤16. The 25th percentile of 9 on the S-MMSE was used to divide the group S-MMSE ≤16 into two subgroups, S-MMSE ≤9 (n=45) and S-MMSE 10–16 (n=47).

In study IV the QoC indicator pain was dichotomized into “no pain” (“no pain” and “no daily pain”) and “daily pain”. The QoC indicators fall, injuries from falling, and weight loss of ≥4% were dichotomized into “present” and “not present”. Since only one person with dementia had a pressure ulcer, this indicator was excluded. The median total CLINT-HC score of 14 was used to dichotomize satisfaction with care into two groups, “high satisfaction” (score 0–13) (n=60) and “low satisfaction” (score 14–40) (n=60).

Not all questionnaires in the QoL-AD and CLINT-HC were completed or answered in full. When the total score was calculated a maximum of one missing item was replaced by the mean score for the remaining items of the individual participant. Where more than one item was missing, no total score for the QoL-AD and CLINT-HC or for any of the individual QoL-AD dimensions was calculated (Logsdon et al., 1999; 2002; Vaarama et al., 1992) (Study IV). Missing values for the NPI-Q and Katz-ADL were not imputed. When one of these items was missing, no total score was calculated for either (Cummings et al., 1994; Kaufer et al., 2000; Katz et al., 1963). For S-MMSE, handling of missing data was not applicable (Folstein et al., 1975; Molloy et al., 1999) (Study III).

In studies III and IV, descriptive and comparative statistics were applied to compare differences between groups. The Mann-Whitney U-test was used to compare ordinal data and Pearson's chi-square test for categorical data. When the expected values in any of the cells were below 5, Fisher's exact test was used to compute the p-value. A p-value of ≤0.05 was considered statistically significant. For data analysis IBM SPSS Statistics for Windows, version 23.0 (IBM Corporation, Armonk, NY, US), was used.

Ethical considerations

The Declaration of Helsinki (World Medical Association, 2013) and the ethical principles of respect for autonomy, non-maleficence, beneficence, and justice (Beauchamp & Childress, 2013) guided the work of this thesis. The studies were designed and conducted in accordance with the Swedish legislation on the Ethical Review of Research Involving Humans (*Lag om etikprövning av forskning som avser människor*, SFS 2003:460), the Swedish Data Protection Act (*Personuppgiftslag*, SFS 1998:204), and the Public Access and Secrecy Law (*Offentlighets- och sekretessförordning*, SFS 2009:400). Permission to perform the studies was obtained from the Regional Ethics Review Board in Lund (reference number: Dnr. 2010/538). The RTPC-project followed the Good Epidemiological Practice guidelines recommended by the International Epidemiological Association (IEA)'s for proper conduct in epidemiological research.

The principle of respect for autonomy

The principle of respect for autonomy obligates the researcher to disclose information, to probe for and ensure understanding and voluntariness, as well as promote adequate decision making. Prior to investigations the researcher must obtain informed consent from participants, which means obtaining an individually autonomous authorization of participation in the research (Beauchamp & Childress, 2013). The 23 participants in the focus group interviews were first given oral information about the study by contact persons in the municipalities. After giving oral consent, the participants were contacted by a researcher from Lund University who gave them further information about the study process. Just before the interviews, the participants were informed about the study, both verbally and in writing, and were given the opportunity to ask questions before signing to confirm their informed consent (Study II). Prior to the face-to-face interviews both the persons with dementia and the informal caregivers were given verbal information about the study so that they could make an autonomous decision about partaking or not in the study. Partaking in the interview was voluntary and participants could interrupt their participation at any time without giving any reason and without incurring any consequences. Just before the interview the researcher repeated and clarified the purpose and design of the interviews to both the persons with dementia and the informal caregivers, verbally and in writing, and gave them the opportunity to ask questions before signing the informed consent form (studies III and IV). Beauchamp & Childress (2013) describe surrogate decision makers who are duly authorized to make decisions for individuals who are no longer able to make decisions themselves, such as persons with dementia. A surrogate decision maker should be very familiar with the person they are making decisions for, so that a particular decision reflects the person's views and values and is in line with the type of decisions the person would have made. Thus, and in line with the Act on Ethical Review of Research Involving Humans (*Lag om etikprövning av forskning som avser människor*, SFS 2003:460), persons with dementia who could not give informed consent themselves were also included in studies III and IV. In accordance with clause 20 of the Act, research was "carried out without the consent" of a person if "illness, mental disturbance, poor health or other similar relationship prevent[ed] his/her opinion from being obtained". Studies III and IV were conducted without the person's consent in line with clause 21 which refers to knowledge "that is not possible to get through research with consent" and "can be of benefit to the subject or anyone else who suffers from the same or a similar disease or disorder" and "means an insignificant risk of injury and a slight discomfort to the subject". In accordance with clause 22, informal caregivers were consulted to obtain permission from the person's relative to participate in the studies (*Lag om etikprövning av forskning som avser människor*, SFS 2003:460).

The principle of non-maleficence

The principle of non-maleficence asserts an obligation to not cause harm, impose risk of harm, or set back the interests of participants (Beauchamp & Childress, 2013). The participants in studies III and IV were vulnerable persons with dementia and their informal caregivers. Steps were taken to minimize the risk of harm to the participants. For instance, during the interviews it was possible that the persons with dementia became aware of their cognitive impairment, and the interviews could also be experienced as a violation of their personal integrity. To minimize these risks and not inflict harm, the interviews were conducted by researchers trained for the task and with experience of approaching older people. Also, if it became apparent that a participant felt uncomfortable during an interview or had difficulty managing an emotion, the researcher contacted the participant's formal care providers in order to acknowledge and address the participant's problems. To cause as few disturbances as possible and so as not to violate the participants' privacy, the time and place of the interviews were determined by the participants. Special attention was paid, during the interviews with the persons with dementia, to their strength and energy level. If they were exhausted or too tired to participate for the length of the interview they had the possibility to rest or leave the room while the interview continued with the informal caregiver. The results from all of the interviews are presented in such a way as to make the participants unidentifiable, thus maintaining their confidentiality. The participants' personal data were replaced by codes and only codes were used during the analysis. The code lists are stored in locked cabinets apart from the questionnaire forms (*Personuppgiftslag*, SFS 1998:204).

The principle of beneficence

The principle of beneficence pertains to doing and acting for the benefit of others. Researchers applying the principle should not only treat persons autonomously and refrain from harming them; they should also contribute to their welfare and embrace public beneficence (Beauchamp & Childress, 2013). In this way, the research can be of benefit. The intended utility of this thesis was to improve care and services at home for persons with dementia, and also to build new knowledge into an already existing knowledge base on the topic. To create as beneficial an environment as possible for the participants, the participants themselves chose the time and place for the interviews. The risks of partaking were regarded as low in relation to potential benefits from the results. The majority of the participants were not likely themselves to benefit personally from the knowledge gained from this research. However, because of these studies persons with dementia and informal caregivers may receive increased attention, contributing to discussions about care and services at home and, in turn, to development and improvements of dementia care. Additionally, the results from the data collection have been fed back to their respective municipalities and have thereby contributed to development of the dementia care locally.

The principle of justice

The principle of justice concerns fairness and includes equal access to various kinds of resources (Beauchamp & Childress, 2013). In this thesis, the principle of justice was considered in randomly selecting the sample. All persons with dementia in the included municipalities in the south of Sweden had the same opportunity to be selected for studies III and IV if fulfilling the inclusion criteria (being a person with dementia and ≥65 years old, having a formal diagnosis of dementia, having a score of ≤24 on the S-MMSE, and being at risk of institutionalization within six months). The sampling of formal care providers and work places was strategic to obtain variation in experience and perspectives on best practice in terms of collaboration and improvement needs in the chain of care. No persons were excluded because of age, gender, sexuality, nationality, political ideology, or social status.

Main results

The overall aim of the thesis was to investigate formal care and services at home, regarding structure, process, and outcomes, for persons with dementia (aged 65+ years) at risk of nursing home admission. To gain a deeper understanding of the ability of formal care and services at home to adapt to competences of and needs in persons with dementia at risk of nursing home admission, Lawton's press-competence model was used (Lawton & Nahemow, 1973) (Figure 1). Thus, the results will be presented in terms of: (1) competences of the persons with dementia; (2) the environmental press (investigating its structure and process); and (3) the outcomes measured, QoC, satisfaction, and QoL as indicators of the ability of formal care and services at home to adapt to competences and needs.

Competences of the persons with dementia

The competences of the persons with dementia, measured in Study III, concerned cognitive impairment, dependence in ADLs, and neuropsychiatric symptoms. For the total sample (n=177), the cognitive function reached a median S-MMSE score of 16 (first to third quartile (Q1–Q3) 11–20) (as per inclusion criteria, no participant had an S-MMSE score >24). The median total Katz-ADL score was 4 (Q1–Q3 = 3–5) and, regarding neuropsychiatric symptoms, the median total NPI-Q score was 5 (Q1–Q3 = 3–7). Dividing the total sample into four groups based on their cognitive impairments S-MMSE 17-24 (n=85), S-MMSE ≤16 (n=92), S-MMSE 10-16 (n=47), and S-MMSE ≤9 (n=45), revealed a decline in the competences of the persons with dementia to perform ADLs, as well as in their behavioural function, as described in Table 3.

Table 3. Competences of the persons with dementia stratified into groups according to their cognitive impairment

Variable	**S-MMSE ≤9 (n=45)**	**S-MMSE 10-16 (n=47)**	**p-value**	**S-MMSE ≤16 (n= 92)**	**S-MMSE 17-24 (n=85)**	**p-value**
Katz-ADL						
Total score (0-6[4])						
Md (Q1-Q3)	3 (2-4)	4 (3-5)	0.059[1]	3 (2-4)	4 (3-5)	<0.001[1]
Dependent in n (%)						
bathing	43 (96)	37 (79)	**0.017**[2]	80 (87)	58 (68)	**0.003**[2]
dressing	36 (80)	32 (68)	0.196[2]	68 (74)	40 (47)	**<0.001**[2]
toileting	24 (53)	17 (36)	0.100[2]	41 (45)	18 (20)	**0.001**[2]
transferring	15 (33)	11 (23)	0.372[2]	26 (27)	12 (14)	**0.030**[2]
continence	23 (51)	22 (47)	0.681[2]	45 (49)	30 (35)	0.067[2]
feeding	7 (14)	2 (4)	0.070[2]	9 (10)	1 (1)	**0.013**[2]
NPI-Q						
Total score (0-12[4])						
Md (Q1-Q3)	5 (3-7)	4 (3-5)	0.893[1]	5 (3-7)	4 (3-5)	0.243[1]
Presence of n (%)						
delusions	18 (40)	12 (26)	0.158[2]	30 (33)	19 (22)	0.116[2]
hallucinations	18 (40)	13 (28)	0.267[2]	31 (34)	13 (15)	**0.004**[2]
agitation/outrage	20 (44)	16 (34)	0.346[2]	36 (40)	29 (34)	0.455[2]
depression/blues	31 (77)	28 (60)	0.411[2]	59 (66)	50 (59)	0.357[2]
anxiety	14 (31)	16 (34)	0.710[2]	30 (33)	27 (32)	0.865[2]
exhilaration/euphoria	6 (13)	3 (6)	0.221[3]	9 (10)	5 (6)	0.337[2]
apathy/indifference	35 (78)	40 (85)	0.365[2]	75 (81)	75 (70)	0.886[2]
disinhibition	8 (18)	14 (30)	0.177[2]	22 (24)	20 (24)	0.987[2]
irritability/lability	13 (29)	19 (40)	0.245[2]	32 (35)	40 (47)	0.097[2]
motor disturbances	21 (47)	21 (45)	0.923[2]	42 (46)	23 (28)	**0.010**[2]
sleep disorders	19 (42)	20 (43)	0.974[2]	39 (42)	34 (40)	0.747[2]
appetite/eating disorders	16 (36)	27 (57)	**0.035**[2]	43 (47)	35 (41)	0.456[2]

[1] Mann Whitney U test [2] Pearson' s Chi square test [3] Fisher' s Exact test [4] Underlined score is the most favorable score

Katz-ADL = Katz Index of Independence in Activities of Daily Living; Md = median; NPI-Q = Neuropsychiatric Inventory Questionnaire; Q1–Q3 = first to third quartile; S-MMSE = Standardized Mini Mental State Examination.

Environmental press

Structure

The structure of care and services at home was described in Study I in terms of types of formal care and services that were available, and that were utilized during the different stages of dementia. The results indicated that basic care and services were available for most or all persons with dementia during all stages of the disease. Exceptions were accompanying and transport services, which were available to few people in the early and moderate stages; however, they were available to all in the late disease stage. Around the time of diagnosis and in the early stage the basic care and services were utilized by few (except needs assessment in the early stage, which was utilized by most). In the intermediate stage, assistive aids, home help with IADLs and needs assessments were utilized by most. Care and service activities utilized in the late stage included, in addition to activities utilized in the intermediate stage, accompanying services, help with PADLs, and the transport service. In the end-of-life stage, help with IADLs was utilized by all and assistance with PADLs and needs assessment were utilized by most (Table 4).

Health care interventions were available for all or most participants in all disease stages. They were, however, utilized by few persons in any of the stages, except home nursing care, which was utilized by most in the end-of-life stage (Table 5).

Specialized care and services regarding aids and equipment to compensate for cognitive impairment, and a mobile comprehensive expert team were available for all, but were utilized by few. Specialist psychiatric home nursing care was available for few, but utilized by most persons to whom it was available for, in all stages of the disease except the end-of-life stage, when few utilized it. Team-based community mental health for older people was available for few and was utilized by few in all stages of the disease (Table 6).

Table 4. Availability and utilization of basic care and services at home, by disease stage

Availability/ Utilization	**Diagnosis stage**	**Early stage**	**Inter-mediate stage**	**Late stage**	**End-of-life stage**
Accompanying service	For few/ By few	For few/ By few	For few/ By few	**For all/** **By most**	For no one/ By no one
General assistive aids	**For all/** By few	**For all/** By few	**For all/** **By most**	**For all/** **By most**	**For all/** By few
Home-delivered meals	**For all/** By few	**For all/** By few	**For all/** By few	**For all/** By few	**For all/** By few
Home help/care with IADLs	**For all/** By few	**For all/** By few	**For all/** **By most**	**For all/** **By most**	**For all/** **By all**
Home help/care with PADLs	**For all/** By few	For few/ By few	**For most/** By few	**For most/** **By most**	**For most/** **By most**
Housing adaptation	**For all/** By few	**For all/** By few	**For all/** By few	**For all/** By few	**For all/** By few
Needs assessment	**For all/** By few	**For all/** **By most**	**For all/** **By most**	**For all/** **By most**	**For all/** **By most**
Personal safety alarm	**For all/** By few	**For all/** By few	**For all/** By few	**For all/** By few	**For all/** By few
Transport service	For few/ By few	For few/ By few	For few/ By few	**For all/** **By most**	For no one/ By no one

By all/few/most/no-one = utilized by all/few/most/no-one; for all/few/most/no-one = available for all/few/most/no-one.
IADLs = instrumental activities of daily living; PADLs = personal activities of daily living.

Table 5. Availability and utilization of health care interventions, by disease stage

Availability/ Utilization	**Diagnosis stage**	**Early stage**	**Inter-mediate stage**	**Late stage**	**End-of-life stage**
Home nursing care	**For all/** By few	**For all/** By few	**For all/** By few	**For all/** By few	**For all/** **By most**
Rehabilitation at home	**For all/** By few	**For all/** By few	**For all/** By few	**For all/** By few	**For all/** By few
Team-based home health care	**For most/** By few	**For most/** By few	**For most/** By few	**For most/** By few	**For most/** By few

By all/few/most = utilized by all/few/most; for all/few/most = available for all/few/most.

Table 6. Availability and utilization of specialized care and services, by disease stage.

Availability/Utilization	**Diagnosis stage**	**Early stage**	**Intermediate stage**	**Late stage**	**End-of-life stage**
Aid equipment to compensate for cognitive impairment	**For all/** By few	**For all/** By few	**For all/** By few	**For all/** By few	**For all/** By few
Mobile comprehensive expert team	**For all/** By few	**For all/** By few	**For all/** By few	**For all/** By few	**For all/** By few
Specialist psychiatric home nursing care	For few/ **By most**	For few/ **By most**	For few/ **By most**	For few/ **By most**	For few/ By few
Team-based community mental health for older people	For few/ By few	For few/ By few	For few/ By few	For few/ By few	For few/ By few

By all/few/most = utilized by all/few/most; for all/few/most = available for all/few/most.

Process

In Study II the findings revealed five categories concerning formal care providers' views on best practice and needs for improvement in the chain of care from the early disease stage to end-of-life care for persons with dementia. Under the first category, *Diagnosis is a prerequisite for specialized dementia care*, the participants discussed the importance of a dementia diagnosis for persons with dementia to get access to dementia-specific care and services (dementia teams, day care and nursing homes specializing in dementia).

In the category *Day care facilitates transition in the chain of care*, the participants described day care as best practice for transitions throughout the chain of care, making transitions smoother and giving the person with dementia a better chance to continue individually living at home despite a gradually increasing need for support. During day care, the formal care providers individually talk to the person with dementia and their informal caregivers, which enables them to put together the person's life story and plan for their care and services. Thus, a good relationship is established, which makes it easier for the person with dementia and their informal caregivers to ask for more help or other care alternatives later in the disease trajectory.

The category *Creating routines in the chain of care* revealed the need for improvement regarding certain critical events in the disease trajectory. In the early stage, formal care providers collaborate with each other and with the person with dementia and the informal caregivers. However, in the intermediate and end-of-life stages, when the disease has progressed and the ability of the person with dementia to express their needs and wishes has diminished, this collaboration may break down. The discussions under this category also revealed that the transition from the own home to a nursing home is sometimes based on a sudden decision, which, combined with shortages regarding information routines, implies that the needs of the person with dementia may not be properly met.

In the category called *Competent staff, a prerequisite for high-quality care*, the participants indicated that formal care providers working in home care often lack specialized dementia education and training, making it difficult for them to correctly interpret symptoms and offer adequate care and treatment.

The category *Next-of-kin participation is a prerequisite for continuity in the chain of care* showed that when the collaboration among formal care providers in the chain of care fails, the participation in the care by informal caregivers as information couriers needs to increase.

Study III showed that the majority of the participants, n=140 (79%), utilized dementia-specific care and services. Sixty-six percent of the persons with dementia utilized day care, 24% utilized respite care and 12% used a combination of these. When comparing utilization of formal and informal care and services at home by persons with dementia at different levels of cognitive impairment it appeared that more participants in the group S-MMSE ≤16 compared with the group S-MMSE 17–24 utilized hospital care >24 hours. The group S-MMSE ≤9 utilized more home help in terms of number of visits (p=0.003) and hours per visit (p=0.029) but visited day care less often (p<0.001), compared with the group S-MMSE 10–16 (Table 7).

The group S-MMSE ≤16 utilized informal care and services with PADLs more often, in terms of number of days per month (p=0.005) and hours per day (p=0.001), compared with the group S-MMSE 17–24. This was also the situation for number of days of utilizing help with IADLs (p=0.032). Regarding the informal caregivers' supervision of the person with dementia to prevent dangerous situations, differences between the groups S-MMSE ≤16 and S-MMSE 17–24 were found in both the number of days (p=0.006) and the number of hours (p=0.008), with more utilization of this service by the group S-MMSE ≤16 (Table 8).

Table 7. Utilization of formal care and services by persons with dementia during the last 30 days

Variable	**S-MMSE ≤9 (n=45)**	**S-MMSE 10-16 (n=47)**	**p-value**	**S-MMSE ≤16 (n= 92)**	**S-MMSE 17-24 (n=85)**	**p-value**
County council n (%)						
Hospital care > 24 h	4 (9)	3 (6)	0.475[3]	8 (9)	1 (1)	**0.041**[3]
Emergency care < 24 h	5 (11)	3 (6)	0.333[3]	8 (9)	3 (4)	0.155[2]
Outpatient care; visits to						
general practitioner	6 (13)	9 (19)	1.000[1]	15 (17)	19 (22)	0.692[1]
registered nurse	9 (20)	6 (13)	1.000[1]	12 (15)	11 (13)	0.405[1]
occupational therapist	3 (7)	1 (2)	1.000[1]	4 (5)	2 (2)	0.121[3]
assistant nurse	2 (4)	2 (4)	1.000[1]	4 (5)	1 (1)	0.172[3]
specialist	1 (2)	2 (4)	1.000[1]	3 (4)	2 (2)	
physiotherapist	0 (0)	2 (4)		2 (2)	2 (2)	0.261[3]
Municipality n (%)						
Dementia-specific care	33 (73)	38 (81)	0.285[2]	71 (78)	68 (81)81	0.632[2]
Visited by:						
home nursing care	5 (11)	8 (17)	1.000[1]	13 (14)	17 (20)	1.000[1]
home help	31 (69)	33 (70)	1.000[1]	64 (70)	54 (64)	1.000[1]
day care	27 (60)	33 (70)	1.000[1]	60 (65)	56 (66)	1.000[1]
	Md (Q1-Q3)	**Md (Q1-Q3)**		**Md (Q1-Q3)**	**Md (Q1-Q3)**	
Number of visits by:						
home nursing care	2 (1-2)	2 (1-7)	0.359[1]	2 (1-3)	2 (1-4)	0.565[1]
home help	60 (12-99)	90 (14-99)	0.346[1]	62 (13-99)	60 (30-90)	0.480[1]
day care	6 (4-8)	8 (8-12)	**0.003**[1]	8 (4-10)	9 (6-12)	0.140[1]
Number of hours per visit by:						
home nursing care	0.3 (0.1-0.5)	0.3 (0.3-0.5)	0.587[1]	0.3 (0.2-0.5)	0.4 (0.3-0.5)	0.529[1]
home help	0.5 (0.5-1.1)	0.5 (0.3-0.7)	**0.029**[1]	0.5 (0.3-1.0)	0.5 (0.2-0.6)	0.202[1]
day care	5.5 (5.0-6.0)	6.0 (5.2-6.0)	**<0.001**[1]	5.5 (5.0-6.0)	6.0 (5.0-6.0)	0.140[1]

[1] Mann-Whitney U-test.

[2] Pearson's chi-square test.

[3] Fisher's exact test.

Table 8. Utilization of informal care and services by persons with dementia during the last 30 days

Variable	**S-MMSE ≤ 9 (n=45)**	**S-MMSE 10-16 (n=47)**	**p-value[1]**	**S-MMSE ≤ 16 (n= 92)**	**S-MMSE 17-24 (n=85)**	**p-value[1]**
	Md (Q1-Q3)	Md (Q1-Q3)		Md (Q1-Q3)	Md (Q1-Q3)	
PADLs[2] (days)	30 (14-30)	30 (1-30)	0.394	30 (7-30)	8 (0-30)	**0.005**
PADLs[2] (h/day)	1.0 (0.4-2.4)	0.5 (0.0-2.0)	0.236	0.6 (0.0-2.0)	0.5 (0.0-0.9)	**0.001**
IADLs[3] (days)	30 (21-30)	30 (15-30	0.150	30 (16-30)	30 (4-30)	**0.032**
IADLs[3] (h/day)	3.6 (2.2–4.8)	2.5 (0.7-3.5)	0.052	3.0 (1.0-4.0)	2.3 (0.6-4.0)	0.227
Supervision[4] (days)	24 (0-30)	30 (0-30)	0.978	30 (0-30)	0 (0-30)	**0.006**
Supervision[4] (h/day)	2.5 (0.0-15)	0.5 (0.0-3.5)	0.119	1.0 (0.0-11.5)	0.0 (0.0-1.0)	**0.008**

[1] Mann-Whitney U-test.

[2] Toileting, feeding, dressing, bathing to get ready.

[3] Shopping, cooking, cleaning, washing, transferring, medication, and finances.

[4] To prevent dangerous situations.

IADLs = instrumental activities of daily living; Md = median; PADLs = personal activities of daily living; Q1–Q3 = first to third quartile; S-MMSE = Standardized Mini Mental State Examination.

Outcomes

Quality of Care

In study IV the QoC indicators revealed that 31% (n=54) of the persons with dementia had daily pain and 29% (n=52) had experienced a weight loss of ≥4% during the previous year. Furthermore, 23% (n=40) of the persons with dementia had fallen during the last month and 40% (16/40) of them had sustained an injury when falling.

Furthermore, in Study IV we found a total median CLINT-HC score of 14 (Q1–Q3= 11–16). Informal caregivers were somewhat more satisfied overall with the formal care and services received, staff being honest, and the size of food portions, compared with the other indicators. Ninety-five per cent among the informal caregivers were either very satisfied (60%) or satisfied (35%) with dementia-specific care and services received (Table 9).

Table 9. Proxy rating of satisfaction with care

Variables		
CLINT-HC score, total (n=150) (range 8–40[1]) Md (Q1-Q3)	14	(11-16)
Personal interaction (range 1–5[1])	2	(2-3)
Staff doing what you want them to do (range 1–5[1])	2	(1-2)
Staff being honest (range 1–5[1])	1	(1-1)
Hygiene (range 1–5[1])	2	(1-3)
Cleaning (range 1–5[1])	2	(1-2)
Food portions (range 1–5[1])	1	(1-2)
Appreciating meals (range 1–5[1])	2	(1-2)
Overall satisfaction (range 1–5[1])	1	(1-2)
Utilizing dementia-specific care and servcies (n=140)		
Satisfaction with dementia-specific care and services n (%)		
Very satisfied	83	(60)
Satisfied	48	(35)
Neither satisfied nor dissatisfied	6	(4)
Dissatisfied	-	-
Very dissatisfied	2	(1)

[1] The underlined score is the most favourable score.
CLINT-HC = Client Interview Instrument–Home Care; Md = median;
Q1–Q3 = first to third quartile.

Quality of life

The persons with dementia in Study IV had a total median score of 36 (Q1–Q3= 33–39) for self-reported QoL. They had a median score of 3 for all QoL-AD items except memory, for which they scored a median of 2. Sorting the items into Lawton's four dimensions of QoL gave a median score of 3 for all dimensions.

Since the QoL in persons with dementia is suggested to be largely dependent on the QoC they receive, comparisons were made between the QoL dimensions and the QoC indicators. The results revealed that persons with dementia expressing signs of daily pain (n=54), compared with those showing no pain (n=121), had lower QoL in the dimensions behavioural competence and psychological wellbeing (p=0.026 and p=0.006, respectively). The results revealed similar differences whether "pain less than once a day" was included or excluded in the category pain (p=0.029 and p=0.006, respectively). No other significant differences were found between the QoC indicators and the QoL dimensions, or the QoL-AD total score.

The group that reported high satisfaction with the care and services received (CLINT-HC score 0–13) showed a higher QoL-AD total score (p=0.006) and higher QoL in the dimension environmental quality (p=0.039) compared with the group with lower satisfaction (CLINT-HC score 14–40). However, there were no significant differences in perceived QoL between those receiving (n=140) and those not receiving (n=36) dementia-specific care and services (Table 10).

Table 10. Quality of life (QoL) self-reported by the persons with dementia, and proxy assessments of quality of care (QoC) reported by their informal caregivers

	QoL-AD Total			Behavioural competence			Environmental quality			Perceived quality of life			Psychological well-being		
	Median	Q1-Q3	p-value[1]	Median	Q1-Q3	p-value[1]	Median	Q1-Q3	p-value[1]	Median	Q1-Q3	p-value[1]	Median	Q1-Q3	p-value[1]
Pain			0.060			**0.026**			0.813			0.658			**0.006**
Yes	35	32-39		2.3	2.0-2.6		3.0	2.5-3.5		3.0	3.0-3.7		2.7	2.5-3.0	
No	37	34-39		2.6	2.2-2.8		3.0	2.5-3.5		3.0	3.0-3.7		3.0	2.7-3.3	
Fall			0.642			0.323			0.264			0.734			0.297
Yes	35	32-40		2.2	1.8-2.8		3.0	3.0-3.5		3.0	3.0-4.0		2.7	2.7-3.3	
No	36	34-39		2.6	2.2-2.8		3.0	2.5-3.5		3.0	3.0-3.7		3.0	2.7-3.0	
Injured when fallen			0.690			0.868			0.645			0.551			0.389
Yes	36	32-42		3.0	2.5-3.5		2.3	2.0-2.8		3.0	3.0-4.0		2.8	2.3-3.6	
No	35	31-39		2.4	1.7-2.9		3.0	3.0-3.5		3.0	3.0-3.8		2.7	2.2-3.3	
Weight loss ≥4%			0.591			0.729			0.273			0.542			0.636
Yes	36	33-38		2.4	2.0-2.8		3.0	2.5-3.5		3.0	3.0-3.7		3.0	2.7-3.0	
No	36	33-39		2.6	2.0-2.8		3.0	2.5-3.5		3.0	3.0-3.7		2.7	2.3-3.0	
CLINT-HC total			**0.006**			0.059			**0.039**			0.067			0.220
High satisfaction	39	34-40		2.6	2.4-2.9		3.0	3.0-3.3		3.0	3.0-3.7		3.0	2.5-3.3	
Low satisfaction	35	32-38		2.4	2.2-2.8		3.0	2.5-3.5		3.0	3.0-3.7		2.7	2.7-3.0	
Dementia specific care and services			0.779			0.824			0.318			0.976			0.794
Yes	36	33-39		2.5	2.2-2.8		3.0	2.5-3.5		3.0	3.0-3.7		3.0	2.7-3.0	
No	36	33-39		2.6	2.2-2.7		3.0	2.5-3.5		3.0	3.0-3.7		3.0	2.3-3.3	

[1] Independent-samples Mann-Whitney U-test. Significant values are given in bold.

CLINT-HC = Client Interview Instrument-Home Care; QoL-AD = Quality of Life in Alzheimer's Disease; Q1 = first quartile; Q3 = third quartile

Discussion

Competences of the persons with dementia

The sample in this thesis consisted of persons with dementia (aged ≥65 years) with a formal diagnosis of dementia and an S-MMSE score ≤24, and at risk of nursing home admission within six months. These circumstances implied specific problems related to cognitive impairment and behavioural dysfunction, making these persons dependent on others in managing ADLs and also making them in need of supervision. Other researchers have found that these specific problems in persons with dementia also predict institutionalization, i.e. not being able to remain living at home (Afram et al., 2014; Gaugler et al., 2009; Stephan et al., 2014).

Environmental press

Structure

The structure of the formal care and services system could, according to Lawton's press-competence model (Lawton & Nehemow, 1973), be interpreted as both strong and weak regarding the ability of the system to adapt to the competences of and needs for help in persons with dementia. The strength of the formal care and services system was the great number of types of care and service activities available to persons with dementia through the progress of the disease. The weakness of the system was that few persons with dementia utilized the available care and service activities. The discrepancy between availability and utilization of formal care and services, described in study I, is probably related to several issues. For instance, there may be a lack of information about and awareness of available care and service activities (Zwaanswijk, Peeters, Van Beek, Meerveld, & Francke, 2013; Robinson, Buckwalter, & Reed, 2013; Graessel, Luttenberger, Bleich, Adabbo, & Donath, 2011; Roe et al., 2001). Other issues for not utilizing formal care and services could be the services were not accessible, or not convenient, or too expensive (Morgan, Semchuk, Stewart, & D'Arcy, 2002; Ward-Griffin et al., 2012).

In Study I, it was notable that few persons with dementia utilized dementia-specific care and service activities at home despite the increasing number of persons with dementia being cared for at home (National Board of Health and Welfare, 2014a; 2014b). Conversely, the opposite was revealed in Study III, where most of the sample, n=140 (79%), utilized dementia-specific care and services. This contradictory result is probably related to the inclusion criterion of having a dementia diagnosis. However, our results demonstrate that the dementia diagnosis is important for getting access to dementia-specific care and services, as supported by the results in Study II and the category *Diagnosis is a prerequisite for specialized dementia care.* Access to dementia-specific care and service interventions adapted to the individual and the specific stage of dementia may enable persons with dementia to remain at home as the disease progresses (Ward-Griffin et al., 2012). Despite the importance of a dementia diagnosis to get access to dementia-specific care and services, it has been estimated that 40–50% of persons with dementia are undiagnosed (Connolly, Gaehl, Martin, Morris, & Purandare, 2011; Prince, Bryce, & Ferri, 2011), meaning that they are deprived of tailored dementia care beyond symptom relief. One reason for people not being diagnosed with dementia may be the stigma associated with the diagnosis (Batsch & Mittelman, 2012), which becomes a barrier to seeking help. Other barriers described are denial of needs, lack of knowledge about the disease, and emotional barriers. Formal care providers may lack knowledge in detecting symptoms and skills in diagnosing (Waldemar et al, 2007).

Process

The process of formal care and services at home could, according to Lawton's press-competence model (Lawton & Nehemow, 1973), be interpreted as both strong and weak regarding the ability to adapt to the competences of and needs for help in persons with dementia. Studies I and III indicated that persons with dementia utilized more help with PADLs and IADLs in the late and end-of-life stages, and home nursing care in the end-of-life stage of the disease. Furthermore, the results in Study III indicated that the needs for help with PADLs and IADLs and also the need for supervision in the persons with dementia seemed to be met first and foremost by the informal caregivers. These results may indicate a strong possibility for formal care and services at home to adapt to the competences of persons with dementia and their needs for help later in the disease trajectory. On the other hand, the results could also be interpreted as indicating a weak ability to adapt, since it seemed like it was only when the informal caregivers were too exhausted or could not manage to provide more care and services that more formal care and services were utilized. However, these results should be interpreted with some caution, since the results report on a specific sample. One of the inclusion criteria was having an informal caregiver who co-habited with the person with dementia or visited them a least twice a month. This exclude persons with dementia living alone or not having an informal caregiver to take care of them. Having an informal caregiver probably makes it more possible to remain living at home without utilization of formal care and services. Hellström, Andersson, & Hallberg (2004) propose that co-habiting may buffer against institutionalization, and may be a precondition for remaining at home, and that formal care and services are mainly provided to those with a smaller social network. This conclusion is supported by Larsson, Thorslund, & Kåreholt (2006) stating that most of those utilizing formal care and services at home are older persons with dementia living alone, and also described by Luppa et al (2008) that a poor social network is a predictor for nursing home admission. Additionally, Taube, Kristensson, Sandberg, Midlöv, & Jakobsson (2014) showed that frail older people who are lonely utilize significantly more outpatient services compared with frail older people who are not lonely. Still, the results from this thesis raise questions and there is a need for further research to investigate how persons with dementia without support from informal caregivers manage to live at home and navigate through the fragmented care system. Another important question to be further investigated is how formal care and services at home adapt to competences of and needs for help in persons with dementia who do not have informal caregivers.

Study III revealed that n=117 (66%) of the persons with dementia utilized day care. Day care could be interpreted both as supportive and as a stimulating environmental activity, since the specific goals of activities in day care for persons with dementia are to create a meaningful day, maintaining independence for as long as possible, and to provide care for the person with dementia to achieve better QoL (Måvall & Malmberg, 2007; National Board of Health and Welfare, 2016a). In Study II the category *Day care facilitates transition in the chain of care* revealed that the formal care providers at day care had a person-centred approach to the person with dementia and their informal caregivers. Early in the disease trajectory the formal care providers at day care put together the life story of the person with dementia based on narratives from the person with dementia and their informal caregivers regarding their past life, and preferences for future care and services. This approach was described as a good start to establishing a good relationship with the person with dementia and their informal caregivers and to planning for future care and service activities. Ericson et al (2001) promotes obtaining detailed information about the individual to be able to provide best care for persons with dementia. Day care was also considered to give the person with dementia a better chance to go on living at home despite a gradually increasing need for care and services.

There are probably several reasons why, in Study III, there was more utilization of informal, compared with formal, care and services. For instance, this finding could be related to shortcomings in the collaboration between the informal and the formal care and services regarding the person with dementia's needs and the disease stage (Lethin, Hallberg, Karlsson, & Janlöv, 2015; Karlsson, et al., 2014). It could also be related to people's desire to manage on their own, as well as being afraid of being a burden to others, not wanting help, and the lack of privacy with formal care providers in the home

(Morgan et al., 2002; Roe et al., 2001). Other possible explanations for not utilizing formal care and services are perceived lack of need and/or lack of awareness of the treatment options that are available (Brodaty, Thomson, Thomson, & Fine, 2005; Morgan et al, 2002; Wolfs, De Vugt, Verkaaik, Verkade, & Verhey, 2010). A further explanation could be that informal caregivers compensate for shortcomings in formal care and services. As described in study II and discussed under the category *Creating routines in the chain of care*, informal caregivers need to increase their participation in the care and services by acting as information couriers when the collaboration among formal care providers fails. It also appeared that the less specialized in dementia care the formal care providers were, the less collaboration there tended to be. Moreover, the competences of the formal care providers could have an impact on informal caregivers' participation in the care and services. The category *Competent staff, a prerequisite for high-quality care* showed that informal caregivers must compensate when formal care providers lack the requisite specialized knowledge concerning dementia, and therefore fail to correctly interpret symptoms and offer adequate care and treatment. It has been described earlier that formal care providers involved in diagnosis and treatment are educated to a higher level (bachelor or above) whilst everyday care and services are provided by formal care providers with lower or no training at all (Hallberg et al, 2016).

Another explanation why informal caregivers put in a great amount of effort to help and support their relatives is that, despite the burden and strain of being an informal caregiver to a person with dementia, it can be a positive experience to care for a loved one (Andrén & Elmståhl, 2005; Bleijlevens et al., 2015) and therefore the informal caregivers have not asked for relief from formal care providers. Peacock et al. (2010) describe caring for a person with dementia as presenting many opportunities such as being able to repay past favours, discovering personal strength, and becoming closer to the care recipient. Furthermore, in this thesis most (64%) of the informal caregivers were spouses to the persons with dementia, which might be an additional reason for not utilizing formal care and services. Previous research has found that older informal caregivers, i.e. spouses to persons with dementia, use less help from formal care compared with younger informal caregivers, such as the adult children or children-in-law of the person with dementia (Graessel et al., 2011; Robinson, Buckwalter, & Reed, 2005). Younger informal caregivers are more likely to be working, implying less possibility to care for a relative (Graessel et al., 2011). Furthermore, it is possible that it is more natural, emotionally, for an adult child to ask for formal care and services than for a spouse whose reasons for caring would include expectations after a long-term relationship, or guilt (Robinson et al., 2005), as well as an opportunity to continue the marital relationship (Peacock et al., 2010).

Transferring the responsibility for the care of and services for the spouse to informal caregivers may increase their burden and make them feel that they are not meeting expectations. It has been found that prior to nursing home admission the burden on informal caregivers increases (Bleijlevens et al., 2015; Stephan et al., 2014) and that the burden on spouses is higher compared with that on informal caregivers who are the person with dementia's children, predicting reasons for nursing home admission (Afram et al., 2014). In most cases, being an informal caregiver is voluntary, but the extent and the forms of caregiving are not always chosen (National Board of Health and Welfare, 2012). Having the main responsibility and performing an increasing amount of care and services could have a negative impact on the wellbeing and health of the informal caregiver (Andersson, Ekwall, Hallberg, & Edberg, 2010; Brodaty & Donkin, 2009; Heejung, Chang, Rose & Kim, 2011). It should be noted that formal care providers can have an impact on the health of informal caregivers, since recognition and appreciation of an informal caregiver's efforts can increase their psychological wellbeing and decrease depression (Carbonneau, Caron, & Desrosiers, 2010).

Transferred responsibilities also make it probable that the person with dementia becomes more dependent on their informal caregivers when formal care and services are not being utilized. This can turn out to be an exposed situation for persons with dementia since rates of abuse, such as neglect, and verbal and physical abuse, by informal caregivers of persons with dementia have been reported to be substantially higher compared with abuse by informal caregivers of older persons in general (Cooney, Howard, & Lawlor, 2006; Hansberry, Chen, & Gorbien, 2010; Lee & Kolomer, 2005; Wiglesworth et al., 2010). This means that formal caregivers must pay special attention to informal caregivers, especially during sensitive periods such as the final period in which the person with dementia lives at home, so that the informal caregivers' burden can be reduced. This includes regular contact and individual support by formal care and services to the person with dementia and the informal caregivers (Lopez-Hartmann, Wens, Verhoeven, & Remmen, 2012; Morgan et al, 2002; Zabalegui et al, 2014) and, a proactive care strategy throughout the disease trajectory (Lethin et al., 2015) as well as clear, coherent information about available care and service activities at home, both for the person with dementia and for the informal caregiver.

Outcomes

In study IV the subjective outcomes, QoL and satisfaction with care and services, indicated that formal care and services at home had a strong ability to adapt to the competences of and needs for help in persons with dementia, as the results indicated an overall satisfaction with received formal care and services and a high total QoL-AD score. However, the objective outcomes (the QoC indicators) could be interpreted as meaning that the formal care and service system's ability for adaptation was weak. The objective outcomes indicated need for improvement of formal care and services, with one-third of the persons with dementia having daily pain and having lost ≥4% weight in the previous year. Furthermore, almost one-fourth of the persons with dementia had fallen in the past month and a substantial percentage of these (40%) had sustained an injury when falling. Registered nurses working in home care settings have responsibility for evaluating care needs, developing care plans, and providing skilled nursing care (Tarricone & Tsouros, 2008; Zabalegui et al., 2014). Moreover, registered nurses have a key role regarding interventions to reduce pain and malnutrition, increase patient safety, and improve QoC. Therefore, from a nursing perspective, the combined results from studies I and III are somewhat remarkable as they revealed that home nursing care was utilized by few before the end-of-life stage (Tabell 5) and that registered nurses simply visited the person with dementia twice (Md) a month, with each visit lasting a mere 0.3 hours (18 minutes) (Md) (Table 7). Furthermore, Study II and the category *Competent staff, a prerequisite for high-quality care* suggest that formal care providers working in home care often lack specialized training in dementia, making it difficult for them to correctly interpret symptoms and offer adequate care and treatment. These results indicate a need for registered nurses to take greater responsibility in the care of persons with dementia at home. The outcomes further revealed that the persons with dementia expressed daily pain had significantly lower QoL in the dimensions behavioural competence and psychological wellbeing compared with those without daily pain. The dimension behavioural competence relates to the individual's functions and capacity for adaptive behaviour (Lawton, 1983) and these functions will probably be further reduced by pain. In the dimension psychological wellbeing, the items mood, the self as a whole and life as a whole were negatively affected by pain. Pain in persons with dementia will probably lead to negative effects such as anxiety, depression, agitation and worrying (Lawton, 1983) and diminished QoL (Jing et al., 2016). A more proactive approach by the formal care providers earlier in the disease course would probably reduce the negative objective outcomes and thereby improve QoL in persons with dementia, since QoL in persons with dementia is, in large part, dependent on the QoC they receive (Francis & Netten, 2004; Vaarama, 2009).

Despite the negative objective outcomes, the informal caregivers reported high satisfaction with the care and services received at home, regarding CLINT-HC as well as dementia-specific care and services. One should bear in mind that satisfaction with care and services concerns care recipients and informal caregivers' experience of utilized care related to their expectations (Prince et al, 2013), and that their expectations have not been investigated in this thesis. Additionally, the results revealed that satisfaction with care and services have a positive effect on QoL total scores and the dimension environmental quality. However, this significance was not found for those receiving dementia-specific care and services. Further research could focus on whether more general or more dementia-specific care and services produce a higher QoC and QoL. One aspect of the reported high satisfaction with care received is that the results reported as well as previously reported results on persons living at home have found that older persons receiving care and services at home are more satisfied with care and services compared with persons living in nursing homes (Karlsson, Edberg, Jakobsson & Hallberg, 2013). Other aspects to consider is that the informal caregivers' dependency on formal care and services at home and hesitations about negatively evaluating formal care and services. These aspects could have affected the results, which may have led to underreporting of dissatisfaction with care and services. However, to minimize this effect the interviews were carried out independently of the care and services delivered to the persons with dementia.

Besides, regarding QoL as assessed by the persons with dementia, a high total QoL-AD score as well as a high score in the four domains was scored. It should be noted that 68% of the study population co-habited with their informal caregivers which may have affected the results. Previous research found that living alone is significantly associated with lower QoL (Hellström & Hallberg 2001; Hellström, Persson, & Hallberg, 2004) while a stronger social network contributes to higher QoL (Keating & Gaudet, 2012). Furthermore, high QoL in these persons with dementia is not an unexpected result; European Commission (2015) report that persons aged 65 years or older in the Nordic countries are generally more satisfied with life compared with the average for for their peers in other European countries.

Methodological considerations

When designing research studies one must be aware of shortcomings of any study design since every methodological choice has its advantages and disadvantages, strengths, and limitations, which may have an impact on the results (Kazdin, 2010; Polit & Beck, 2013). This thesis had various methodological approaches, including both qualitative and quantitative study designs. Consequently, several methodological considerations need to be addressed to evaluate the strength and weakness of this thesis. The quantitative designs in studies I, III and IV will be assessed in terms of validity and reliability. The qualitative design in Study II will be assessed with regard to trustworthiness, which comprises credibility, transferability, confirmability, and dependability.

Validity

“Validity” refers to the extent to which an instrument accurately measures the attributes of a concept. When an instrument is valid, it truly reflects the concept it is supposed to measure (Kazdin, 2010; Polit & Beck, 2013).

Internal validity

“Internal validity” refers to the extent to which the conclusion can be drawn that the independent variable has accounted for the results, the group differences, and the extent to which other, alternative explanations or factors can be eliminated (Kazdin, 2010; Polit & Beck, 2013).

A cross-sectional design is appropriate for gaining deeper understanding of a phenomenon and describing interrelationships among phenomena at a fixed point (Polit & Beck, 2013). Studies using cross-sectional designs usually make comparisons between groups at a given point in time (Kazdin, 2010; Polit & Beck, 2013); they do not investigate changes over time. The threats to internal validity in cross-sectional studies are that no inference can be drawn about the relationships between cause and effect of dependent and independent variables (Kazdin, 2010). The cross-sectional design in Study III made it possible to compare the groups with different cognitive function regarding utilization of formal and informal care and services, dependency in ADLs, and neuropsychiatric symptoms. In Study IV the cross-sectional study design made it possible to compare the differences between the group with high and the group with low satisfaction with received care and services, also in terms of the effect of QoC indicators on QoL in persons with dementia.

One threat to internal validity in studies I, III and IV was that many researchers were involved in the data collection. However, all researchers involved in the data collection were trained in administering and filling in the questionnaires, and received both oral and written instructions. Prior to the data collection for Study I the researchers in the RTPC project conferred on the different types of care and services and agreed on the concepts and terminology. Still, the open and unspecific categories may have affected the results owing to different interpretations and different data sources as well as the great variations between the countries. The descriptions are based on various sources, such as interviews and reports, and not necessarily research in the field. These descriptions should therefore be interpreted with caution and this factor needs to be taken into consideration when interpreting the results of the study. Furthermore, based on the data obtained it cannot be established whether the number and type of activities reported are sufficient in relation to the dementia trajectory; therefore, the availability of a type of care activity was not the same as the activity being offered to and utilized by persons with dementia. Nevertheless, assessing availability and utilization did make sense since the results may have contributed to a clearer and more coherent overview of available care and service activities during the different stages of dementia.

In Study IV we used QoL self-reported by the person with dementia. Doubts have been raised about the ability of persons with dementia to make valid assessments and give reliable answers regarding their QoL, since the dementia disease affects cognitive abilities (Moyle et al., 2007). However, there is a growing body of evidence suggesting that persons with mild to moderate dementia can complete standardized questionnaires on self-reported QoL (Logsdon et al., 1999; Trigg et al., 2007). The QoL-AD is a self-reported, multi-dimensional instrument specifically designed for persons with Alzheimer's disease (Logsdon et al., 1999). It has been suggested to be the most widely used self-report QoL instrument internationally because of ease and rapidity of administration (10–15 minutes) focusing on QoL domains assessed to be important for cognitively impaired older persons (Logsdon et al., 1999; Whitehouse, Patterson, & Sami, 2003). It has been found to be both a reliable and a valid self-report instrument for persons with Alzheimer's disease with MMSE (Mini Mental State Examination) scores >10 (Logsdon et al., 1999; Thorgrimsen et al., 2003) and appropriate to use in persons with dementia with MMSE scores as low as 3 (Thorgrimsen et al., 2003). The sample in this study had a median score of 16 on the S-MMSE. Owing to cognitive impairment ten persons in our study were unable to answer the QoL-AD questions.

In Study IV we used informal caregivers' perceptions of QoC instead of obtaining responses regarding QoC from the persons with dementia, which would have been a more adequate perspective. However, the difficulties described above using persons with dementia as respondents were the reason for using informal caregivers as proxy raters. It should be noted that proxy ratings may be influenced by the proxy's own expectations, burden, and depression (Logsdon et al., 1999) and that this may have affected the results. Furthermore, in Study III we used informal caregivers' assessments of the functional abilities of the person with dementia rather than observations, which would have been a more adequate method (Katz et al., 1963). The reason for using informal caregivers' assessments was out of consideration for the person with dementia's integrity. Using an observation method would be an artificial test situation with elements that could have been perceived as violations of their personal integrity since toileting and dressing are intimate situations as is the question of continence. Interviews were therefore the chosen method, and were conducted in an atmosphere of reliability and openness, which was assessed as important for the validity of the results.

Statistical conclusion validity

"Statistical conclusion validity" refers to demonstrating empirical relationships between the independent and dependent variable, and discloses how well the study can identify existing relationships (Kazdin, 2010; Polit & Beck, 2013). In other words, the term refers to the ability of the statistical methods to detect true relationships between variables or groups (thus avoiding type II (β) errors), and to not detect relationships where there are none (Kazdin, 2010) (thus avoiding type I (α) errors). The *null hypothesis* specifies that there are no relationships between groups. The null hypothesis can be rejected when the methods used find statistically significant differences, or accepted when they do not. The decision-making process is based on selecting a probability level that specifies the degree of risk of reaching a false conclusion (Kazdin, 2010). In a type I error the null hypothesis is incorrectly rejected and there is a "false positive" finding. To minimize type I errors and mass significance in comparisons, a lower p-value must be applied; this is usually set at 0.05, meaning that the size risk of making a type I error is 5% (Björk, 2011).

Another issue related to threats to making valid statistical inferences concerns the statistical power, which means the ability to detect true relationships among variables. Inability to do so is referred to as type II (β) error. Adequate statistical power can be achieved by including a sufficiently large sample (Polit & Beck, 2013). To achieve such a sample, in the RTPC project a power calculation was made for the eight countries included. The calculation estimated that inclusion of 785 participants was needed to estimate mean differences, and 393 participants to demonstrate an effect size with a power of 80% (α=0.05). The drop-out rate was expected to be 15% and therefore 175 participants were planned to be included from each country. In studies III and IV, 177 persons with dementia were included, and therefore the sample size can be assumed to be large enough to detect statistical significances between the groups.

External validity

“External validity” concerns the extent to which the results can be generalized beyond the sample, settings, and circumstances in which the study was carried out (Kazdin, 2010; Polit & Beck, 2013). One threat to external validity concerns the context or setting in which data are collected (Kazdin, 2010). To be able to generalize the results from Study I, data were collected from eight European countries representing different parts of Europe and different welfare systems. It should be noted that data were collected between 1 November 2010 and 31 January 2011 and changes within each country’s welfare system may have occurred since then. The Swedish welfare system is primarily tax-funded and does not rely on private insurance. Furthermore, individuals are protected through regulation of costs for health and social care, services, and medication. This factor limits the impact of an individual’s income level on their access to and utilization of care and service activities. This may limit the generalizability to other countries that have different welfare systems. In studies III and IV, the participants were recruited in a selected geographic area rather than being randomly selected from the national population; therefore, the sample may not be representative for the whole of Sweden. Furthermore, each municipality in Sweden is independent when it comes to decisions about provision of care and services, hence home care can differ between different municipalities.

Another threat to external validity concerns the representativeness of the sample for the population investigated (Kazdin, 2010; Polit & Beck, 2013). Studies III and IV included persons with dementia (aged 65+) at risk of nursing home admission within six months; therefore, the results cannot be generalized to all persons with dementia receiving care and services at home. Another aspect of representativeness concerns those who declined participation. The results from studies III and IV should therefore be interpreted with caution because of some limitations. It is plausible that the 50 persons who declined to participate or changed their mind about participation were more often persons with severe cognitive impairment and more dependency, and therefore would have made the differences between the groups even larger. Thus, it is likely that both the median total score (of 16) and the 25th percentile (score 9) on the S-MMSE would have been lower if these persons had been included. It is also possible that including them would have lowered both the satisfaction with the health care and social services received at home and the self-reported QoL since it is possible that they would have rated QoL and QoC lower and that their data would have affected the results.

Reliability

"Reliability" refers to the consistency with which an instrument measures an attribute. The less variation an instrument produces in repeated measures, the higher the reliability. Reliability also concerns accuracy, meaning that the instrument captures the true state (Kazdin, 2010; Polit & Beck, 2013). The instrument chosen in the RTPC project were selected based on their psychometric properties (validity, reliability), clinical utility, and appropriateness for the targeting settings and populations (Verbeek et al, 2012).

Stability

"Stability of a measure" refers to the extent to which the same results are obtained when the instrument is used in the same people on separate occasions (Polit & Beck, 2013). When developing the mapping form in Study I the researchers from each of the eight countries in the RTPC project agreed on the concepts and terminology. However, the data collection still varied between countries, regions, and organizations as did the data sources. Therefore, it was challenging to compare the availability and utilization of care and service activities. Different interpretations of the categories as well as the response alternatives may have influenced the results, even though all the researchers had been instructed on how to fill in the form (Hallberg et al., 2013).

To ensure quality of the data collection an external audit of data plausibility and management was performed in each of the countries participating in the RTPC project. The audit was performed by an independent external auditor following a checklist and a Standard Operating Procedure (SOP) developed by the RTPC coordinator (Germany). The external auditor visited one or two home care organizations in each country to verify their existence and contribution to participant recruitment. The data check covered at least 20% of randomly selected client files (Verbeek et al, 2012).

Internal consistency

Scales that summarize items are often evaluated regarding their internal consistency, i.e. the degree of homogeneity of the items within a scale. Ideally, scales are composed of items that all measure the same critical attribute and nothing else (Kazdin, 2010; Polit & Beck, 2013). Internal consistency refers to the degree to which items in the scale "hang together". One of the most commonly used measures for assessing internal consistency is Cronbach's alpha. Values above =0.7 are considered acceptable; however, values >0.8 are preferable (Pallant, 2013; Polit & Beck, 2013). To strengthen the construct validity in this thesis, instruments that have been previously psychometrically evaluated were used. Cognitive impairment was assessed using the S-MMSE. The internal consistency for this instrument has been found to be =0.82 (Molloy et al., 1991). The Katz-ADL was used to assess the ability of the persons with dementia to independently perform PADLs. Hamrin & Lindmark (1988) demonstrated a Cronbach's alpha of =0.94 for the Katz-ADL. The NPI-Q was used to assess neuropsychiatric symptoms. This instrument has reported test-retest reliability between symptoms and distress of =0.80 and =0.94 (Cummings et al., 1994; Kaufer et al., 2000). To determine the type and amount of utilization of formal and informal care and services in Study III, the RUD instrument was used. Wimo & Nordberg (2007) evaluated the instrument and report an internal consistency for PADLs of =0.82, IADLs of =0.33, and supervision of =0.81. In Study IV the instrument QoL-AD was used to assess QoL in persons with dementia. Logsdon et al. (1999; 2002) report the internal consistency for QoL-AD for patients to be =0.84. Validity in their research was indicated by low to moderate correlations between QoL and S-MMSE scores, IADLs, depression, and engagement in pleasant events. In Study IV the internal consistency for the QoL-AD calculated for all 13 items on the scale was =0.82. The results for the four dimensions were: behavioural competence (five items), =0.67; environmental quality (two items), =0.70; perceived QoL (three items), =0.68; and psychological wellbeing (three items), =0.59.

To assess satisfaction with care the CLINT-HC was used in this thesis. Beerens, Sutcliff, Renom-Guiteras, & Soto (2014) found the internal consistency to be =0.67. In Study IV the internal consistency for all nine items on the scale was calculated to be =0.59. The item gardening had a high frequency of missing values (n=134) and was therefore removed from the analysis. Cronbach's alpha after the exclusion was =0.70.

Trustworthiness

Even though Study II was designed to obtain trustworthy results, certain aspects need to be reflected on when interpreting the results and transferring them to other settings. Lincoln & Guba (1985) suggested four criteria for establishing trustworthiness in qualitative research: credibility, transferability, confirmability, and dependability. The methodological considerations with regard to Study II concern these criteria.

Credibility

"Credibility" refers to confidence in the truth and believability of the data as well as the interpretation of them (Graneheim & Lundman, 2004; Polit & Beck, 2013). Lincoln & Guba (1985) note that the credibility of the inquiry concerns two aspects that need to be taken into account. The first has to do with carrying out the investigation in a believable way, and the second concerns the ability to demonstrate credibility when reporting the results. Lincoln & Guba (1985) also suggest various techniques for improving and documenting the credibility. One technique is prolonged engagement, which refers to the researcher being familiar with the context in which the study is conducted, but also building trust with the participants so that they feel comfortable to share inner thoughts. Focus group interviews were chosen for the collection of data from the formal care providers. One limitation of this method is that it gives only a picture of the group as a whole, providing the prevailing perceptions of the group, but not the exact number of people for and against this or that perception (Krueger & Casey, 2009). Another issue is that participants in focus group interviews do not always feel free to discuss sensitive and personal experiences and perceptions, especially if some of the other focus group participants are people they know and work with, as was the case here. This could limit the nature and range of data obtained in the study. However, all participants took part in the discussions and spoke openly about the topics of interest, which indicates that they were confident with the interview situation. In the last interview, no new information was obtained and no new insights were gained.

In Study II credibility through prolonged engagement was also assured as the researchers had long experience of caring for older persons with and without dementia. Furthermore, each focus group interview was led by two registered nurses: a moderator (A-C.J.) and an observer (C.B.). The moderator is a researcher in the field of geriatric care and is experienced in conducting focus group interviews. The observer has work experience in different areas of the health care system, including the nursing of persons with dementia. Another technique to improve credibility, as described by Lincoln & Guba (1985), is peer debriefing. Peer debriefing was achieved when the manuscript of the study is presented in seminar groups including senior lectures and doctoral students, prior to submission.

Credibility can also be achieved in qualitative research by choosing participants with different experiences of the phenomena, who shed light on the research question from a number of different angles (Graneheim & Lundman, 2004). The possibility of achieving variation of experiences increases if the sample is heterogeneous (Krueger & Casey, 2009). An appropriate number of data, and also an explanation of the analysis process, further increases credibility (Graneheim & Lundman, 2004). Therefore, in this study a strategic sample of care organizations representing the chain of care, as well as of various formal care providers was obtained. The heterogeneity was reinforced in a number of ways: a variety of age, education, working experiences, and gender was represented in the sample. However, all but one of the participants were female, reflecting the fact that nursing is a female-dominated occupation. Hence, the sample can be said to be representative of the formal care providers' structure in the chain of care for persons with dementia. None of the physiotherapists invited to participate consented to do so. To achieve trustworthiness, the authors independently analysed the material, but interpretations and conclusions were constantly checked and discussed until a consensus was reached regarding the codes and categories.

Transferability

"Transferability" refers to the extent to which the findings can be transferred to other settings or groups (Graneheim & Lundman, 2004; Polit & Beck, 2013). It is the researchers' responsibility to provide sufficient descriptive data about the context and the participants, as well as vigorous presentation of the findings so that the readers are able to evaluate the applicability of the data to other contexts (Lincoln & Guba, 1985). Descriptions of the context, the selection and characteristics of participants, the data collection and the analytical process were given in Study II to facilitate the decision as to whether the findings are transferable to other contexts or not. A detailed description of the analytical process was provided to demonstrate trustworthiness of the categories. To further enhance transferability in Study II, a rich presentation of the findings was provided, and appropriate quotations given.

Confirmability

The term "confirmability" refers to the objectivity or neutrality of the data, i.e. the potential for congruence between two or more independent people about data accuracy, and the relevance or meaning of data (Polit & Beck, 2013). One approach to achieving confirmability and to attaining neutrality of the data was for only two of the researchers to participate in the focus group interviews. Interpretation of the data was carried out by four researchers. The interview texts were subjected to qualitative content analysis by the first author (C.B.), then the other authors (A-C.J., G.A., S.K.) separately read and critically reviewed the meaning units, codes, and categories in relation to the interview texts, reflected on them and thereafter discussed them with each other in several meetings. This procedure made it possible to uncover as many qualities as possible within the text and reach a consensus on the results. Using four researchers in the analysis further reduced the risk of bias due to pre-understanding of the issues, which could have tainted the analysis.

Dependability

The "dependability" of qualitative data is the stability of data over time and across conditions, despite changes in the researchers' perceptions and experiences during data collection, and the researchers' interpretation of the data during the analysis process, and is closely linked to credibility (Graneheim & Lundman, 2004; Polit & Beck, 2013). When the intention is to achieve dependability of data it is important to have the same questions covering the same areas throughout the interviews (Graneheim & Lundman, 2004). To strengthen dependability in this study, all three focus group interviews were conducted within five months and by the same moderator and the same observer. Use of a structured interview guide ensured that all the interviews included the same overall questions, covering the same areas. Additionally, a pilot focus group interview was conducted to test the interview guide. Since no modification was needed, data from the pilot focus group interview were included in the analysis. Involvement of the co-authors (A-C.J., G.A., S.K.) several times during the analysis process also increased the probability to discover and discuss similarities and differences.

Conclusions and clinical implications

This thesis contributed to knowledge of the phase preceding institutionalization of persons with dementia. It also provided a coherent overview of available and utilized care and services activities at home following the dementia disease process. The results revealed that there is room for improvement to strengthen the utilization of formal care and service activities earlier in the dementia disease trajectory. It was found that persons with dementia utilized more formal care and services in the late and end-of-life stages, compared with the earlier stages of the disease. Their need for help with ADLs and for supervision seemed to be met first and foremost by the informal caregivers. Further on, the results found shortages in collaboration and information delivery among formal care providers'. These shortcomings among formal care providers not only mean that informal caregivers need to take great responsibility in the care and services, but also make it difficult to meet the needs of persons with dementia and reduce the burden for informal caregivers. It is possible to assume that improved collaboration among formal care providers, as well as utilization of formal care and services earlier in the disease trajectory might reduce the burden on informal caregivers, and improve their wellbeing and health, as well as reduce the risk for nursing home admission for persons with dementia.

One strength of the care and services provided in the home of persons with dementia is that the persons with dementia are able to participate in day care activity. Day care was described as contributing to continuity in the chain of care, and as a bridge between care and services at home and nursing home. Day care was also described as contributing to the possibility that persons with dementia can remain living at home longer despite decreasing competences and increasing needs for help. Furthermore, day care was the only formal care and service activity that could be interpreted as having a person-centred approach.

The subjective outcomes gave the impression that formal care and services at home have a strong ability to adapt to competences of and needs for help in persons with dementia. However, the QoC dimensions indicated a weak ability to adapt. The QoC dimensions are issues that formal care providers could have an impact on, since they are responsible for interventions related to reducing pain, improving patient safety, and preventing accidents and malnutrition. A more proactive approach by the formal care providers earlier in the disease course would probably reduce the negative objective outcomes and thereby improve QoL in persons with dementia.

Further research

This thesis revealed that many types of care and service activities at home are available to persons with dementia, but that they are utilized by few. This result raises questions regarding the type of care and service activities offered and how appropriate they are and aligned with needs. To delay, or even prevent, institutionalization in persons with dementia is valuable only if the formal care and services offered in the person's home adapt to that person's competences and needs. Therefore, the types of care and service activities that are needed and requested by persons with dementia and their informal caregivers need to be further explored. The results also revealed that satisfaction with formal care and services have a positive effect on QoL. However, this significance was not found for those receiving dementia-specific care and services. It could be of interest to further determine whether more general or more dementia-specific care and services produce a higher QoC and QoL. This knowledge could be helpful how to best structure care and services at home for person with dementia.

The persons with dementia in this thesis had informal caregivers, and the results revealed that the persons' needs for help with PADLs and IADLs and supervision seemed to be met first and foremost by their informal caregivers. The results from this thesis raise the question of how persons with dementia but without informal caregivers manage to live at home. It is also important to find out how formal care providers detect and approach lonely persons with dementia. Further research is needed to find out what lonely persons with dementia's preferences and needs are, their specific requests regarding care and services, and if they differ from the requests of persons with informal caregivers.

The number of lonely persons with dementia is likely to increase because of the worldwide demographic transition. This transition, from high fertility and mortality rates to low fertility and mortality rates, will increase the number of older, lonely, dependent people and lower the number of possible informal caregivers. This development will further challenge formal care and services in the homes of older persons with dementia. However, in 2015 Sweden received 163 000 immigrants. These immigrants mostly came from Syria, Iraq and Afghanistan and were younger people of working age. Therefore, another question of interest would be to explore the impact these immigrants may have on the national provision of care and services. These young people could have a positive impact on the future in terms of possible recruitment and employment of a workforce in the care and services sector.

Swedish summary/ Svensk sammanfattning

En trend i Sverige, liksom i många andra länder, är att befolkningen blir äldre. Hög ålder leder till ökad risk för funktionsnedsättningar samt utmaningar att tillgodose äldre personers behov av formell vård och omsorg i hemmet. Detta gäller speciellt vid sjukdomar som påverkar människors förmåga att självständigt klara av att sköta dagliga aktiviteter såsom personlig hygien och hushållssysslor. Ett betydande hot mot förmågan att leva ett självständigt liv är att utveckla någon form av demenssjukdom, som oundvikligt leder till beroende av andra människor. Vård och omsorg i hemmet beskrivs som det bästa sättet att vårda personer med demens genom att ge en bättre livskvalitet och vara en mer kostnadseffektiv än vård på särskilt boende. Det medför att allt fler äldre personer bor och vårdas i sitt eget hem.

Relaterat till kognitiv nedsättning förlorar personer med demens fysiska och beteendemässiga funktioner eller kompetenser, vilket leder till ett ökat behov av hjälp och stöd från andra människor för att klara av dagliga aktiviteter. Behov av hjälp med dagliga aktiviteter börjar ofta tidigt i sjukdomsförloppet och utvecklas konstant över tid. Personer med demens behöver oftast först hjälp med hushållssysslor såsom inköp, matlagning, städning, tvätt, läkemedel, men också att sköta sin ekonomi. Senare i sjukdomsförloppet behövs hjälp med personliga dagliga aktiviteter såsom toalettbesök, födointag, förflyttning, dusch och påklädning. Personcentrerad vård har blivit synonymt med den bästa vården för personer med demens. Detta synsätt innebär att ge vård och omsorg efter varje individs behov, personlighet och förmåga, vilket kräver kontinuitet mellan formella vårdgivare, personen med demens och deras anhöriga. Kontinuitet kan vara svår att uppnå i komplexa sjukvårdssystem med flera vård- och omsorgsgivare där ingen ser helheten i den enskildes vård. Dessutom behöver de formella vårdgivarna ha förmåga att anpassa sig till individuella behov för att kunna ge personcentrerad vård och omsorg i hemmet. För att få en djupare förståelse för förmågan hos formell vård och omsorg att anpassa sig till minskande förmågor (kompetenser) och ökat hjälpbehov hos personer med demens användes Lawton press-kompetensmodell som inspiration i denna avhandling. Lawton press-kompetensmodell beskriver balansen mellan individuella kompetenser och pressen/stödet i miljön. Det innebär att ju mindre kompetent eller ju mer sårbar en individ är, desto större påverkan har miljön på individen.

Det övergripande syftet med avhandlingen var att undersöka formell vård och omsorg i hemmet, avseende struktur, process och utfall, för personer med demens (65 år eller äldre) med risk att flytta till särskilt boende. Den första studien beskrev strukturen i vården och omsorgen i hemmet genom en kartläggning av tillgängliga och använda vårdformer i hemmet i relation till demensutvecklingen i åtta europeiska länder. Ett specifikt formulär användes för att samla in data (Appendix I). Totalt identifierades 16 vårdformer som delades in i tre kategorier; Basal vård och omsorg, Sjukvårdande insatser samt Specialiserad vård och omsorg för personer med demens (Tabell 2). Resultatet visade att tillgängligheten var högre än graden av användandet. Likheterna vad gällde tillgänglighet och graden av användandet var fler än skillnader mellan de åtta länderna. Flera vårdformer relaterat till vård och omsorg på basal nivå samt sjukvårdande insatser fanns tillgängliga i de flesta länder, men användes av få. Specialiserad vård och omsorg för personer med demens var sparsamt tillgängliga och användes ännu mer sparsamt.

I den andra och tredje studien undersöktes processen i vården och omsorgen. I den andra studien genomfördes tre fokusgruppsintervjuer med formella vårdgivare. En intervjuguide (Appendix II) användes för att undersöka uppfattningar om bästa praktik gällande samverkan och informationsöverföring i vårdkedjan samt förslag till förbättringar i vården och omsorgen för personer med demens i Sverige. Intervjutexten analyserades med innehållsanalys. Analysen resulterade i fem kategorier; Diagnosen, en förutsättning för specialiserad demensvård, Dagvårdsverksamhet underlättar övergångar i vårdkedjan, Skapa rutiner i vårdkedjan, Kompetent personal, en förutsättning för hög vårdkvalitet och Anhörigas delaktighet, en förutsättning för kontinuitet i vårdkedjan. Resultatet visade att bästa praktik (best practice) i demensvård avseende samverkan och informationsöverföring uppnåddes i högre grad under tidigt skede av demenssjukdomen jämfört med senare skeden. Brist på strategier för bästa praktik under senare skeden gjorde det svårt att tillgodose behoven hos personer med demens och att minska bördan för informella vårdgivare. Resultaten visade också på brister hos de formella vårdgivarna gällande kompetens att tolka symptom korrekt, att erbjuda adekvat vård och behandling samt otillräckligt samarbete. Dessa brister hos de formella vårdgivarna medförde att anhöriga behövde ta stort ansvar för vården och omsorgen, men också svårigheter att minska bördan för anhöriga och att tillgodose behoven hos personer med demens. Dagvårdsverksamhet beskrevs ge kontinuitet i vårdkedjan, som en bro mellan vård och omsorg i hemmet och särskilt boende. Dagvårdsverksamheten beskrevs också som en bidragande faktor till att personer med demens kan bo kvar hemma längre, trots minskande kompetenser och ökat hjälpbehov. I studie tre och fyra genomfördes intervjuer med 177 personer med demens och deras anhöriga. Beskrivande och jämförande statistik användes för att analysera data.

I studie tre var syftet att jämföra hur personer med demens med olika grad av kognitiv svikt, använde formell och informell vård och omsorg i hemmet. Resultatet visade att hjälp med dagliga aktiviteter och behov av tillsyn tillgodosågs först och främst av anhöriga. Konsumtion av formell vård och omsorg var mindre än informell vård och omsorg och att formell vård och omsorg användes oftare i slutet av sjukdomsförloppet, jämfört med tidigare skeden. Utfallet av vården och omsorgen i hemmet undersöktes i den fjärde studien.

Syftet med studie fyra var att beskriva livskvalitet hos personer med demens, subjektiva (tillfredställelse av erhållen vård och omsorg) och objektiva (förekomst av smärta, fall, sår samt viktnedgång) aspekter av vårdkvalitet. Syftet var också att undersöka betydelsen av vårdkvaliteten för livskvaliteten. Resultatet visade att livskvaliteten skattades som hög av personerna med demens, trots att en 1/3 av dem hade daglig smärta och hade minskat ≥4% i vikt det senaste året. Dessutom hade 23% fallit under den senaste månaden och 40% av dem hade skadats när de föll. Smärta medförde lägre livskvalitet i dimensionerna beteendekompetens och psykiskt välbefinnande jämfört med dem utan smärta. Tillfredsställelse med den formella vården och omsorgen verkade ha en positiv effekt på livskvaliteten. De subjektiva utfallen kan tolkas som att formell vård och omsorg i hemmet har förmåga att anpassa sig till kompetens och behov av hjälp hos personer med demens, medan resultatet baserat på de objektiva utfallen visade en svagare förmåga av anpassning. De objektiva utfallen (smärta, fall, viktnedgång och trycksår) är faktorer som formella vårdgivare kan påverka, eftersom de är ansvariga för insatser för att minska smärta, förbättra patientsäkerheten, förebygga olyckor och undernäring. En mer aktiv strategi från de formella vårdgivarna tidigare i sjukdomsförloppet skulle förmodligen minska de negativa objektiva utfallen och därmed förbättra livskvaliteten hos personer med demens.

Sammanfattningsvis gav avhandlingen ökad kunskap om fasen före flytt till särskilt boende för personer med demens. Avhandlingen bidrog också till en övergripande, sammanhängande beskrivning av tillgängliga och använda vårdformer i demens-sjukdomens olika faser. Resultatet visade att det finns behov av förbättringar för att öka användningen av formell vård och omsorg i hemmet tidigare i sjukdomsförloppet. Formell vård och omsorg tidigare i demensförloppet kan sannolikt minska belastningen på anhöriga, förbättra deras välbefinnande och hälsa, och på så vis minska risken för flytt till särskilt boende för personer med demens.

Acknowledgements

This thesis was carried out at the Department of Health Sciences, Faculty of Medicine, Lund University, Lund, Sweden. I would like to express my greatest gratitude to everyone who has shared their knowledge and supported me during this work. In no particular order, I would especially like to acknowledge:

The persons with dementia and their informal caregivers, as well as the formal care providers for giving their valuable time during the interviews and to share with me their experiences of care and services in the home of the persons with dementia.

My supervisor and co-author *Gerd Ahlström*, Professor, RN, of the Department of Health Sciences, Faculty of Medicine, Lund University, for sharing your great experience and knowledge in health services research with me. Thank you for critically reviewing my manuscripts, and for your invaluable support and guidance. Thank you for believing in me, and thus helping to make this dream come true.

My supervisor and co-author *Staffan Karlsson*, Associate Professor, RN, School of Health and Welfare, Halmstad University, Halmstad, for inviting me to join the RightTimePlaceCare project. Thank you for many interesting discussions, and for constructive criticism of my work. Thank you also for your support and guiding when I did my first (English) presentations of my work in Toulouse and Seoul. Many thanks for encouraging me when I didn't think I would manage to complete this thesis.

My co-author Ingalill Rahm Hallberg, Professor Emeritus, RN, for giving me the opportunity to be a part of the RightTimePlaceCare project and for critically reviewing and constructively criticizing my manuscript for Study II.

My co-author Ann-Christin Janlöv, Associate Professor, RN, for your great patience and expertise during the content analysis process and for teaching me how to conduct focus group interviews.

Colleagues and friends, PhD students, PhDs, professors, and associate professors in the research group titled "Older people's health and person-centred care", for stimulating discussions and constructive criticism and for knowledge exchange during our Friday seminars. I would especially like to acknowledge *Anna Condelius*, PhD, and *Lina Behm*, PhD, for their excellent pre-midway review. That was the first time I enjoyed talking about my work. Many thanks also go to *Anna Axmon*, PhD, for valuable statistical advice, which I am so grateful for.

The consortium partners and the (former) PhD students involved in the RightTimePlaceCare project, for giving me the opportunity to gain additional, deeper knowledge about nursing, research, and culture as well as care and services from a European perspective. I would like especially to acknowledge my co-authors *Helena Leino-Kilpi*, PhD, *Maria Soto-Martin*, PhD, *Esther Cabrera*, PhD, *Hilde Verbeek*, PhD, *Kai Saks*, PhD, *Astrid Stephan*, PhD, and *Caroline Sutcliffe*, MSc, for good collaboration during the work with and writing up of Study I. I'd like to thank *Hanneke Beerens*, PhD, for inviting me as to act as co-author of her studies. Last but not least, thank you to *Connie Lethin, PhD,* for challenging questions especially regarding the RTPC project. Thank you for being such a good friend, for interesting discussions about research and life and, everything in between. I look forward to future research with you.

The Swedish National Graduate School for Competitive Science on Ageing and Health (SWEAH) for excellent courses on ageing and health. Special thanks to *Professor Susanne Iwarsson*, *Professor Gerd Ahlström*, and *Associate Professor Torbjörn Svensson*, for so openly sharing your knowledge and experiences of science with us. My thanks go to my fellow PhD students at SWEAH for interesting discussions about ageing and health from different professional perspectives. A special thanks to *Ulla Riis Madsen* for endless walks and talks during the courses and conferences at SWEAH.

The European Academy of Nursing Science (EANS) is acknowledged for giving me invaluable knowledge about nursing, research, and complex interventions in health services research during the summer schools of 2014–2016. Thank you to all PhD students, registered nurses, and excellent teachers from all over Europe – I hope we will meet again. A special thanks to my dear friend and colleague *Marianne Holmgren* for listening, discussing, and sharing thoughts on life, while drinking a glass or two of sangria or Prosecco: "What we say in EANS stays in EANS".

The Swedish Research Council, and the Swedish Institute of Health Sciences (Vårdalinstitutet) and the PhD students and PhDs in the seminar group "Elderly health and person-centred care", for critically reviewing some of my manuscripts.

Anna Blomgren for preparing my thesis manuscript before print.

Boel Hovde, my mentor. Without you I would never dared to take the step to leave my job as a public health nurse in home care and start to work as a university lecturer at Lund University. Thank you for your support and guidance, which I hope will continue.

Marianne Ahlner-Elmqvist, PhD, for critically reviewing my framework, but first and foremost for your support and guidance in things large and small.

My former colleagues and friends in primary health care, *Goedele, Birgitta, Barbro, Ann-Kristin, Ann-Britt* and *Kerstin*, and my former colleagues and friends in home care, *Catta, Bennie* and *Per*. Thank you all for your support, for being good role models as registered nurses, for good collaboration and for fantastic coffee breaks, dinners, and after works get-togethers and drinks.

My dearest friends who have known me since childhood and are still VIPs in my life. Thank you for sharing crazy adventures with me – now, back then and always. With you, *Annika*, *Mange*, *Mats*, *Pia*, *Jocke* and *Thomas*, there is never a dull moment. My closest friends since high school, *Anna-Maria*, *Christina*, *Marie* and *Pia*, with you I can share both laughter and tears, joy and sorrow.

My brother *Fredrik* for encouragement, support, and for sibling quarrels. My "sister in law" *Åsa* for language control of the Swedish summary.

My mother, Maria, who always putting other people's interests first. Thank you for your invaluable support during my whole life. You have been my role model as a nurse ever since I was seven years old and accompanied you during your work at Bokelid.

My joy and pride, my children Anna and Erik. Thank you for your emotional support and for so openly sharing your lives and thoughts with me. I love our discussions and I am proud of being your Mom.

My love and friend, *PB*, for dragging me away from the computer to our paradise in the world, Kullaberg. Thank you for taking me to amazing places, for challenging my fears, and for sharing the greatness of nature.

This thesis has been supported by grants from the Department of Health Sciences, Faculty of Medicine, Lund University: the Gyllenstierna Krapperup Foundation: the Swedish National Graduate School for Competitive Science on Ageing, and Health (SWEAH), funded by the Swedish Research Council: the Swedish Institute of Health Sciences (Vårdalinstitutet): the European research project titled RightTimePlaceCare, supported by grants from the European Commission within the EU 7th Framework Programme for Research (project 242153).

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Country:

Template for care and service in dementia care, Part 2

(**A**=availability, **U**=utilization, **P**=provider/s)

Type of care provided	**Course of dementia (Moise et al., 2004)/Care providers**				
	A) Diagnosis stage: Marks the entry when the diagnosis of dementia is determined. Can also be determined in a later stage of the disease.	**B) Early stage/mild cognitive impairment:** When symptoms tend to be mild with a minimal impact on ADLs, memory loss and social affairs	**C) Intermediate stage/moderate cognitive impairment:** Marked by increased memory loss, and dependency on help in ADLs and social affairs.	**D) Late stage/severe cognitive impairment:** Severe memory loss and the person is unable to look after her/himself without continuous assistance in ADL and social affairs	**E) End of life stage:** Final stage of life when it is obvious that the person has limited time left to live
Care provided					
Personal safety alarm/Body carried alarm: Technology system for disabled people calling for assistance via a telephone and/or wireless communication	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**
Mobile comprehensive expert team: Mobile multi-professional team with expert competence in dementia care, serving as consultants.	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**
Team-based home health care: Health care provided in the patient's own home by a multi-disciplinary team. The team is in charge of treatment and monitoring of the patient with dementia and his/her caregiver.	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**

ADLs = activities of daily living.
This template has been reprinted with the kind permission of Professor Emeritus Ingalill Rahm Hallberg.

The focus group interview with staff and stakeholders;

- Start off by welcoming the participants
- Introduce yourself; the interviewer and the observer
- Introduce the aim of the study (also written on a paper placed on the table); We are here because we want to understand better the care for people with dementia when it works at best and in particular the interaction between different care providers, their interaction and information to you as the person needing care and as an informal caregiver. Since living with dementia is a process and different organizations and carers are involved at different stages we would like to know about your experiences in terms of interaction, information and in terms of characteristics when it works at its best or the opposite
- Introduce the idea of a focus group; it is the free discussion between you as participants that is important to us – we will introduce areas and you are to discuss and share experiences with each other.
- It is the views and experiences of the group and the group discussion that is of interest to us
- Introduce the tape recorder and how we will analyse the transcribed text from the tapes
- The participants introduce themselves and the observer shall make a diagram and place them with their names around the table on a piece of paper. Beforehand they have given demographic data to the observer

Best practice

- Tell about your views and experiences about how the communication, interaction and information between you as different care providers and between you and the care recipients is working currently. Think and discuss about it from the phase of diagnosis and until the end stage of life.
- When care and service works at its best; tell about situations when it works really good and what characterizes the service then
- Think about the disease as a process and tell about when the information, communication and interaction work at its best.
- Thinking about when the service works less good; tell about situations when it works not so good and what characterizes the service then
- Thinking about when the service works really bad; tell about situations when it is really poor and what characterizes the service then
- If we would to summarize what you have been talking about; what would you say makes the service very good. Think in particular on interaction, communication and information and being the person with the disease versus the person standing next by.
- If you could wish – what would you like to see then in terms of communication, interaction and information; between different providers and between you and the person afflicted as well as his or her next of kin.
- What would you like to see improved to provide very good care and service and really live up to the idea of best practice, in particular in relation to communication, interaction and information.

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Questions derived from the CLINT on subjective quality of care

We'd like to ask some questions about the care workers and how well the services help you.

1. Do you mainly see the same care workers?

Yes, always	☐
Yes, usually	☐
Sometimes	☐
Seldom	☐
Never	☐

2. Do the care workers do the things that you want done?

Yes, always	☐
Yes, usually	☐
Sometimes	☐
Seldom	☐
Never	☐

3. Do you think your relative's care workers are honest and trustworthy?

Yes, always	☐
Yes, usually	☐
Sometimes	☐
Seldom	☐
Never	☐

4. Is your relative able to keep as clean as you would like?

Yes, always	☐
Yes, usually	☐
Sometimes	☐
Seldom	☐
Never	☐

5. Is your relative's home as clean and tidy as you would like?

Yes, always	☐
Yes, usually	☐
Sometimes	☐
Seldom	☐
Never	☐

6. If your relative has a garden, is it as well maintained as your relative would like?

Yes, always	☐
Yes, usually	☐
Sometimes	☐
Seldom	☐
Never	☐

7. Does your relative get the right amounts to eat?

Yes, always	☐
Sometimes too little	☐
Sometimes too much	☐
Sometimes too little, sometimes too much	☐
Always too little	☐
Always too much	☐

8. Does your relative enjoy the meals?
   - Yes, always ☐
   - Yes, usually ☐
   - Sometimes ☐
   - Seldom ☐
   - Never ☐

9. In general, how satisfied are you with help that your relative receives from the home care?
   - Very satisfied ☐
   - Satisfied ☐
   - Neither satisfied nor dissatisfied ☐
   - Dissatisfied ☐
   - Very dissatisfied ☐

Dereived from the Clint. Vaarama, M. Care-related quality of life in old age. Eur J Ageing 2009:6:113-125.

Care and services at home for persons with dementia

Since more and more persons with dementia remain at home for as long as possible, increased understanding of the phase preceding institutionalization of persons with dementia is required. Individuals with low competence, such as persons with dementia at risk of nursing home admission, are much more vulnerable to environmental demands compared with persons without dementia and with higher competence. Demanding changes can have a greater negative impact on persons with dementia, but also minor improvements can result in more positive outcomes. Therefore, it is important to gain a deeper understanding of the ability of formal care and services at home to adapt to competences and needs in persons with dementia at risk of nursing home admission. The thesis is inspired by Lawton's press-competence model, which was used to gain a deeper understanding of the results and the context of the research.

LUND UNIVERSITY
Faculty of Medicine

Lund University, Faculty of Medicine
Doctoral Dissertation Series 2017:17
ISBN 978-91-7619-398-3
ISSN 1652-8220