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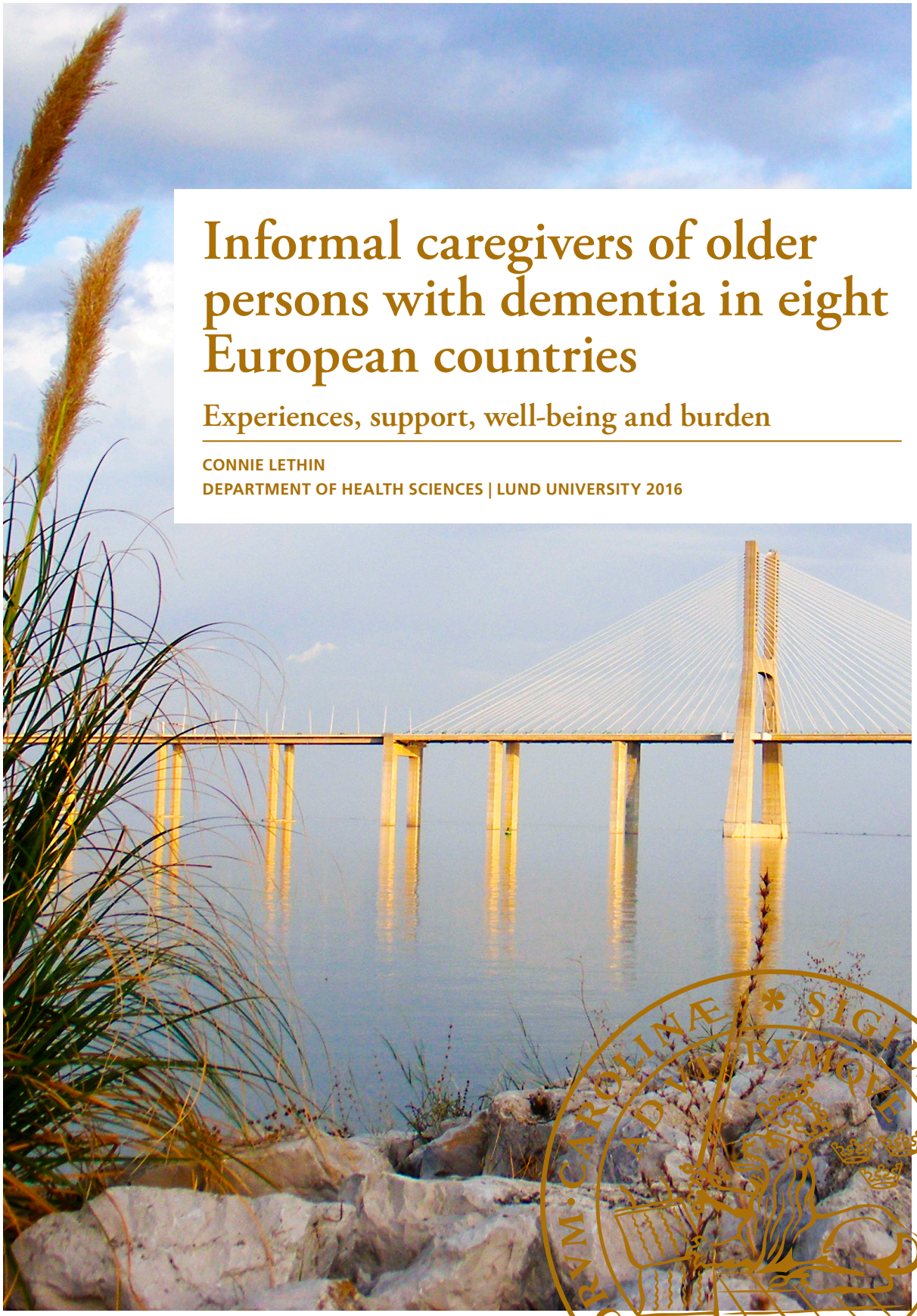

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Experiences, support, well-being and burden

CONNIE LETHIN
DEPARTMENT OF HEALTH SCIENCES | LUND UNIVERSITY 2016

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Connie Lethin

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Abstract:

The overall aim was to investigate informal caregivers providing care for older persons with dementia (≥ 65 years of age) in eight European countries. Focus was on their experiences of formal care, access to support and factors that were associated with caregivers' psychological well-being and burden. Caregivers' experiences of formal care were investigated in a qualitative study with four focus groups interviews with 23 caregivers of older person with dementia living at home or in a nursing home in Sweden (Study I).

The interviews were analysed with content analysis. The result of the caregivers' experiences of formal care when caring for a person with dementia was captured in the theme 'Family caregiving requires collaboration with formal care to get support adjusted to needs specific to the stages of dementia'. Access, i.e. availability and utilization of support including providers of the support was a quantitative, cross-sectional study conducted in eight European countries (Study II). A mapping system was used to estimate availability, utilization, and professional providers of support to caregivers caring for a person with dementia. Data was collected for each country nationally.

The findings showed that counselling, caregiver support, and education were highly available in six of the participating European countries but were rarely utilized. Countries with national guidelines for dementia care seemed to be more aware of the importance of professionals specialized in dementia. In Study III and IV, factors associated with caregiver well-being and burden was investigated, prospectively with 1223 caregivers, caring for an older person with dementia living at home. The caregivers were interviewed based on questionnaires, at baseline and follow-up after three months.

Logistic regression analysis was performed of factors associated with caregivers' psychological well-being and burden at baseline and 3 months later. Factors associated with presence of psychological well-being and burden and over time were the caregivers' experience of caregiving, the quality of care and amount of caregiving for the person with dementia.

This thesis emphasize that formal care needs to be proactive and deliver available care and support early in the course of the dementia disease. Mapping the health care and social service systems is a valuable tool for evaluating existing systems, internationally, nationally and locally for policy making. Professionals should be aware about what factors are associated with caregivers' psychological well-being and burden to provide proper care and support and promote a healthy transition in the caregiving role and through the course of the dementia disease.

Key words: Caregivers, dementia, dependency, Europe, focus groups, health, health services, home nursing, life change events

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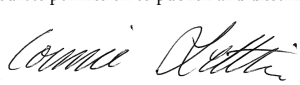
Signature  Date: 2016-08-18

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"*There are only four kinds of people in the world – Those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers.*"

Rosalynn Carter

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Abstract

The overall aim was to investigate informal caregivers providing care for older persons with dementia (≥ 65 years of age) in eight European countries. Focus was on their experiences of formal care, access to support and factors that were associated with caregivers' psychological well-being and burden. Caregivers' experiences of formal care were investigated in a qualitative study with four focus groups interviews with 23 caregivers of older person with dementia living at home or in a nursing home in Sweden (Study I). The interviews were analysed with content analysis. The result of the caregivers' experiences of formal care when caring for a person with dementia was captured in the theme 'Family caregiving requires collaboration with formal care to get support adjusted to needs specific to the stages of dementia'. Access, i.e. availability and utilization of support including providers of the support was a quantitative, cross-sectional study conducted in eight European countries (Study II). A mapping system was used to estimate availability, utilization, and professional providers of support to caregivers caring for a person with dementia. Data was collected for each country nationally. The findings showed that counselling, caregiver support, and education were highly available in six of the participating European countries but were rarely utilized. Countries with national guidelines for dementia care seemed to be more aware of the importance of professionals specialized in dementia. In Study III and IV, factors associated with caregiver well-being and burden was investigated, prospectively with 1223 caregivers, caring for an older person with dementia living at home. The caregivers were interviewed based on questionnaires, at baseline and follow-up after three months. Logistic regression analysis was performed of factors associated with caregivers' psychological well-being and burden at baseline and 3 months later. Factors associated with presence of psychological well-being and burden and over time were the caregivers' experience of caregiving, the quality of care and amount of caregiving for the person with dementia.

This thesis emphasize that formal care needs to be proactive and deliver available care and support early in the course of the dementia disease. Mapping the health care and social service systems is a valuable tool for evaluating existing systems, internationally, nationally and locally for policy making. Professionals should be aware about what factors are associated with caregivers' psychological well-being and burden to provide proper care and support and promote a healthy transition in the caregiving role and through the course of the dementia disease.

Abbreviations

ADL	Activities of Daily Living
CCI	Charlson Comorbidity Index
CLINT-HC	CLient INTerview Instrument – Home Care
CLINT-IC	CLient INTerview Instrument – Institutional Care
CRA	Caregiver Reaction Assessment Scale
CSDD	Depression in Dementia
EQ-5D-3L	EuroQol–5 dimension–3 level (instrument)
EQ-VAS	EuroQol–visual analogue scale
GHQ	General Health Questionnaire
GHQ12	General Health Questionnaire, twelve items
HRQoL	Health-related Quality of Life
ISCED	International Standard Classification of Education
Katz-ADL	Katz Index of Independence in Activities of Daily Living
MMSE	Mini-Mental State Examination
NPI-Q	Neuropsychiatric Inventory Questionnaire
QoL-AD	Quality of Life in Alzheimer's Disease
RTPC	RightTimePlaceCare
RUD	Resource Utilization in Dementia
SMMSE	Standardized Mini-Mental State Examination
VaD	Vascular Dementia
WHO	World Health Organisation
ZBI	Zarit Burden Interview

Original papers

This thesis is based on four studies, which are referred to in the text by Roman numerals:

I **Lethin, C.**, Hallberg, IR., Karlsson, S., & Janlöv, A-C. (2015). Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease. *Scandinavian Journal of Caring Science,* September 8. doi: 10.1111/scs.12275.

II **Lethin, C.,** Leino-Kilpi, H., Roe, B., Soto Martin, M., Saks, K., Stephan, A., Zwakhalen, S., Zabalegui, A., & Karlsson, S. (2016). Formal support for informal caregivers to older persons 1 with dementia through the course of the disease: an exploratory, cross–sectional study. *BioMed Central Geriatrics*. 16:32. doi: 10.1186/s12877-016-0210-9.

III **Lethin, C.,** Renom Guiteras, A., Zwakhalen, S., Soto Martin, M., Saks, K., Zabalegui, A., Challis, DJ., Nilsson, C., & Karlsson, S. (2016). Psychological well-being over time among informal caregivers caring for persons with dementia living at home. *Aging and Mental Health*, July 27, 1-9. doi: 10.1080/13607863.2016.1211621.

IV **Lethin, C.,** Leino-Kilpi, H., Bleijlevens, MHC., Stephan, A., Soto Martin, M., Nilsson, K., Nilsson, C., & Karlsson, S. (2016). Factors predicting burden of informal caregivers caring for persons with dementia at home; a follow-up cohort study. *International Journal of Geriatric Psychiatry*. Submitted 09/06/2016.

Publications not included in the thesis

Publications with results from the RightTimePlaceCare project

I Bremer, P., Cabrera, E., Leino–Kilpi, H., **Lethin, C.**, Saks, K., Sutcliffe, C., Soto Martin, M., Zwakhalen, S., & Wübker, A. (2015). Informal Dementia Care: Consequences for Caregivers´ Health and Health Care Use in 8 European Countries. *Health Policy*, 119 (11), 1459-71. doi:10.1016/j.healthpol.2015.09.014.

II Bleijlevens, M.H.C., Stolt, M., Stephan, A., Zabalegui, A., Saks, K., Sutcliffe, C., **Lethin, C.,** Soto Martin M., & Zwakhalen, S.M.G. (2014). Changes in Caregiver Burden and Health–Related Quality of Life of Informal Caregivers of Older People with Dementia: A RightTimePlaceCare study. *Journal of Advanced Nursing*. doi: 10.1111/jan.12561.

III Stephan, A., Afram, B., Viitanen, M., Bleijlevens, M.H.C., Risco, E., **Lethin, C.,** Sutcliffe, C., Verbeek, H., Saks, K., Hamers, J.P.H., & Meyer, G. (2014). Older persons with dementia at risk for institutionalization in eight European countries: Cross–sectional study on the variation of perceptions of informal caregivers and healthcare professionals. *Journal of Advanced Nursing.* doi: 10.1111/jan.12493.

Introduction

Informal caregivers often have the main responsibility for the care of persons with dementia living at home, with different levels of collaboration with and support from formal care. With the number of people with dementia in European countries on the rise, the demand on informal caregivers to provide care, and on formal care to provide support, is estimated to increase which might place informal caregivers in a vulnerable situation. This raises the importance of the health care and social service systems as they need to provide social and caregiving support for the informal caregiver, and health care and social services for the person with dementia (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011).

A worldwide demographic transition characterized by higher survival rates and lower fertility rates is underway. Increasing age is one of the most important risk factors for developing dementia (Winblad et al., 2016). It is estimated that people with dementia in European countries, aged 60 and older will increase from 6% in 2015 to 8% in 2030, with a further increase to 10% in 2050, which will involve close to 18.5 million persons (Prince et al., 2015). Furthermore, different preconditions, concerning culture, family responsibility and the health care and social service systems that need to be considered apply to informal caregivers in the different European countries, predominantly woman caring for persons with dementia. European countries have different welfare systems with regard to responsibility for the family. In the Nordic countries, the state has a central role, in continental Europe, the family is most important, while in the Anglo-Saxon countries the market is predominant (Esping-Andersen, 2002). As the dementia disease progresses, the person with dementia will have a loss of independence due to cognitive impairment with limitation in performance of activities of daily living such as cooking, washing, getting dressed, shopping, managing household finances, toileting and eating (World Health Organization, 2001). The informal caregiver will, with or without training and caring skills, provide assistance in these activities as well as supervise the person with dementia and deal with behavioural problems (Schulz et al., 2004b). There is a lack of knowledge in European countries about informal caregivers' access i.e. availability and utilization, to support and, experience of formal care, as well as factors that affect their perceived psychological well-being and burden in larger populations, when caring for a person with dementia throughout the course of the disease. This is important in order to develop the health care and social service systems and enable informal caregivers to provide care at home.

Background

Access to health care and social services

Access to health care and social service is essential for informal caregivers caring for a person with dementia through the course of the dementia disease. To understand the complexity of access to health care and social support, as well as the factors that influence the interaction between those who utilize and those who deliver health care and social services, a framework of access might be useful. Levesque, Harris and Rusell, (2013) developed a framework for "Patient-centred access to health care" by synthesizing definitions and dimensions in the published literature, of the concept of access to health care (Figure 1). The conceptual framework was based on the most cited frameworks of access (Bashshur, Shannon, & Metzner, 1971; Donabedian, 1973; Salkever, 1976; Aday & Andersen, 1974; Penchansky & Thomas, 1981; Dutton, 1986; Frenk, 1992; Margolis, Carey, Lannon, Earp, & Leininger, 1959; Haddad & Mohindra, 2002; Shengelia, Murray, & Adams, 2003; Peters, Garg, Bloom, Walker, Brieger, & Rahman, 2008).

Access has been defined by Levesque et al. (2013) as *"the opportunity to reach and obtain appropriate health care services in situations of perceived need for care"*. In this thesis this refers to the informal caregiver's need of social support in the caregiving situation, when caring for a person with dementia. Levesque et al. (2013) emphasize that access should be regarded as an interaction between prospective users and health care resources, in this thesis the informal caregiver and the person with dementia on the one hand and the formal care system in eight European countries, on the other. The interaction may be influenced by the characteristics of those who utilize the services, the informal caregiver and the person with dementia and by those who deliver the resource, the health care and social services. The framework of Levesque et al. (2013) has been rephrased in this thesis to include both the informal caregiver, the person with dementia and the health care and social service systems, as "Person-centred access to health care and social services". The framework was found to be suitable for interpreting the results of the studies included in this thesis regarding informal caregivers of persons with dementia in eight European countries. With present knowledge, this is according to Levesque in a personal communication in March 2016, the first time the framework is applied to informal caregivers.

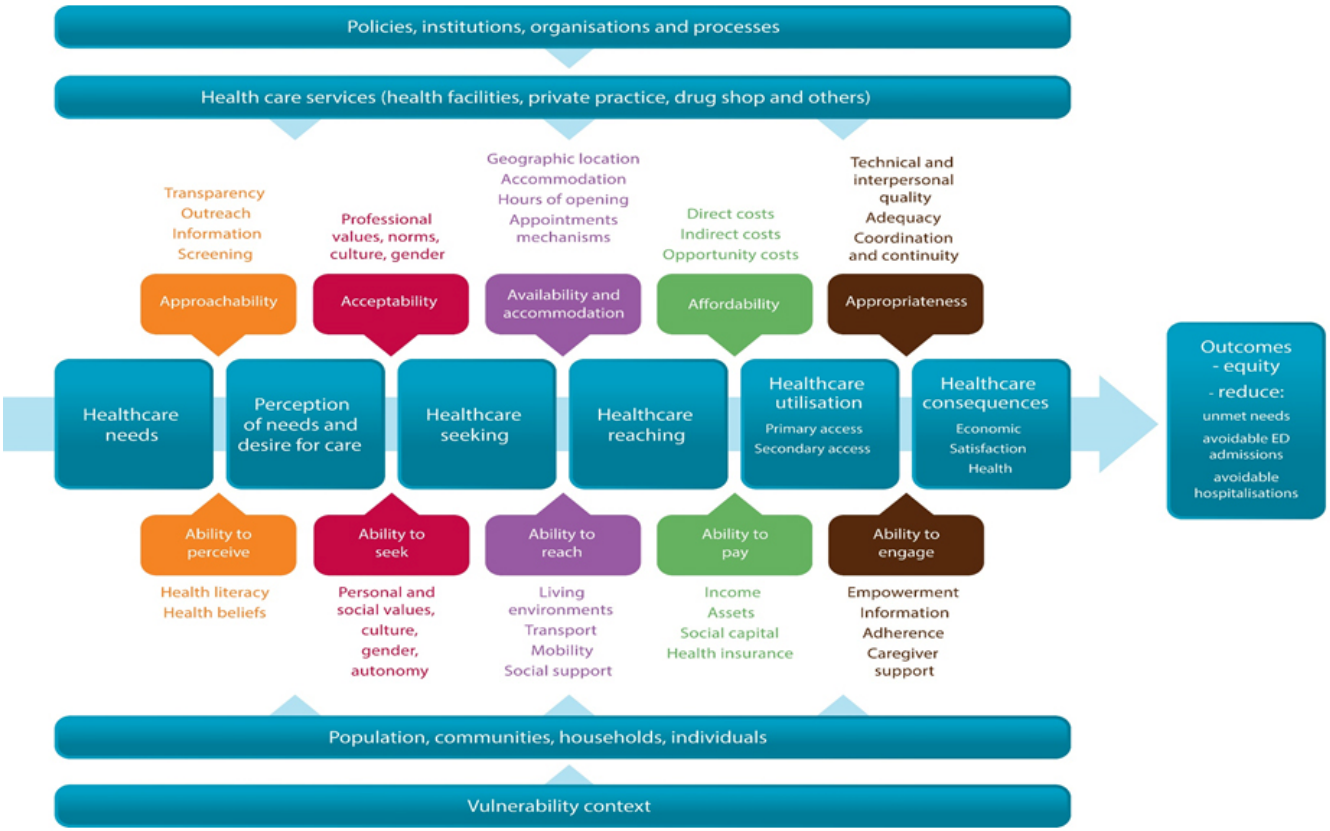

Figure 1. Framework for "Patient-centred access to health care" (Levesque et al., 2013) rephrased for this thesis as "Person-centred access to health care and social services". The updated version of the framework in Figure 1 is provided by the author Levesque.

Access in terms of utilization and availability

Across European countries comparable knowledge about access, availability and utilization and professional providers of the support for informal caregivers is lacking. According to the framework for "Patient-centred access to health care" (Levesque et al., 2013), there are two aspects of access to health care and the social service system, the demand side and the supply side. The demand side has to do with utilization and represents populations, communities, households, and individuals in a vulnerable context, as shown in the lower part of Figure 1. In this thesis the vulnerability context refers to informal caregiving for a person with dementia. Utilization by informal caregivers may depend on their ability to interact with the accessibility based on their ability to perceive a need, seek, reach out, pay, and engage with the services. The supply side has to do with availability and accessibility of the health care in the form of services provided as health care services, private practice, drug stores, and others, as shown in the upper part of Figure 1. These do not operate alone but are part of the services provided by institutions and organizations, each with their policies and processes. Availability may be dependent on the five dimensions of accessibility of health care and social services, namely, approachability, acceptability, availability and accommodation, affordability, and appropriateness as outlined below. The demand side and the supply side are not independent constructs and importantly influence each other.

To understand access, utilization and availability, the five dimensions of accessibility needs to be defined (Levesque et al., 2013). *Approachability* refers to the informal caregiver, realizing their need for support service and identifying that some form of service exists, and further realizing that it is reachable and that it may actually support them. Support service can make themselves recognized by various elements, such as transparency, and information about availability, and by outreach activities. For the individual informal caregiver, it is crucial to have the ability to recognize the need for health care and social services. This need depends on components such as health literacy and their beliefs, related to health and sickness. *Acceptability* refers to the likelihood that the informal caregivers will personally accept the services provided, depending on their gender or social group, or the social group of providers and beliefs associated with the health care and social service system. Acceptability also depends on the appropriateness for the informal caregiver to seek care or service according to their personal and social values, culture, gender and autonomy. *Availability and accommodation* concerns reachability, both physically and in terms of time, and is the result of the characteristics of the facilities (e.g. opening hours), of urban and rural contexts, and the characteristics of the professionals including their ability to make appointments. *Affordability* refers to the financial ability of the informal caregiver to spend assets and their time on utilizing the specific services. This includes both direct and indirect costs, including social capital and health insurance as well as loss of income. Finally, *appropriateness* indicates whether the certain service meets the informal caregiver's needs regarding time and the amount of time spent assessing the service needed and whether the correct service is offered.

This includes technical and interpersonal quality, adequacy, coordination and continuity. The ability to engage refers to the informal caregiver's ability to be involved and participate in decision making, treatment and commitment to completion. This dimension is also dependent on the informal caregiver's ability to communicate, and on their health literacy, self-efficacy and self-management. For the informal caregiver, obtaining access to the most valuable services requires engagement and interaction with the specific services.

Access to support enables informal caregivers to enter formal care with different perception of needs for care regarding health care seeking, and there might be differences in reaching and obtaining or delaying care, and in type and intensity of services sought. Utilization of support may be related to accessibility of the health care and social service system, but is also related to the informal caregiver's ability to interact with the accessibility of services. A survey is needed about access and professional providers of support. This may enable us to understand, interpret, and meet the formal support needs of informal caregivers of the person with dementia. This might further enable health care and the social service systems to provide adequate dementia care and support including professionals with specific expertise and knowledge.

The demand side

Informal caregivers of persons with dementia

Caregiving can be defined as *'...the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting.'* (Schulz et al., 2004b). Informal caregivers can be defined as persons without formal health care education who are caring for, or helping, a person with functional disabilities, prolonged psychiatric or physical illness, or age-related problems (European Commission, 2012). Informal caregivers are predominantly family members, spouses, partners, adult children, but can also be friends, neighbours, or trustees. The primary caregiver is most commonly a woman, often a middle-aged adult child of the person needing care e.g. daughters or daughter-in-law (Moise, Schwarzinger, & Um, 2004; Knapp et al., 2007)

The responsibility and demands as an informal caregiver to a person with dementia is estimated to increase in the future, due to increasing age and number of people with dementia in European countries. During the course of the dementia disease, informal caregivers of the person with dementia often have the main responsibility for health care and social services and assistance with activities of daily living in the home, along

the course of the dementia disease (Janevic, & Connell, 2001; Moise et al., 2004; Ward-Griffin et al., 2012). Informal caregivers have been estimated to provide approximately 75% of the care and service at home including help with activities of daily living, dealing with finances, and supervision tasks among older persons with dementia (Schulz, & Martire, 2004a). This may mean few hours per day, or it may be around the clock. It has been estimated that in Sweden, the ratio of caregiver time to formal care time spent on care (instrumental and personal activities of daily living) for the person with dementia living at home is approximately 4:1 in the early stages of the disease. This time ratio is probably higher in countries with stronger family traditions and multi-generation housing (Moise et al., 2004). Familyism, meaning prioritizing, identifying with and being loyal towards family members, has been shown to be experienced as both positive and negative by informal caregivers (Losada et al., 2010). Hence, informal caregivers have different needs for formal support through the dementia process and more knowledge is needed about their experiences of formal care to be able to develop appropriate health care and social service systems.

Transitions to and in the caregiving

Informal caregiving can be seen as a transitional process, with several factors influencing the transition. A transition is often triggered by an event that constitutes a turning point of change, from a fairly stable state, through a period of experienced instability, uncertainty and distress, to another fairly stable state. When the transition is experienced as positive, this can be an opportunity in life and the transition process can lead to new knowledge and experiences. However, the transition can be experienced as negative, leading to illness. During transition, many people are vulnerable and need support to adjust to a new situation, and to counteract unhealthy transition processes, in this thesis the informal caregiver caring for a person with dementia living at home. Several factors can influence the transition, such as sense of purpose, expectations, level of knowledge and skills. Other factors of importance include the environment, the level of planning, and a person's emotional and physical well-being (Meleis, 2010).

Throughout the life course, people experience different transitions such as becoming a parent or the loss of a close relative or friend. Other transitions are getting married and getting divorced, as well as starting in a new workplace, going into retirement, or having an illness. People's experiences and the responses, and the consequences of transition on individuals' well-being have become increasingly central in nursing. Three different transitions closely connected to nursing have been identified. The developmental transition includes adolescence, parenthood and old age. The situational transition includes educational and professional roles, widowhood, family caregiving and immigration. The transition from health to illness deals with acute and chronic diseases, and includes rehabilitation and transitions between different levels of care in the health care and social service system. In addition, there is the organizational transition

including changes in the environment leading to social, political or economic transition (Chick & Meleis, 1986).

Rose and Lopez (2012) identified several turning points in the course of the dementia and the caregiving transition of which the dementia diagnosis was one. Other turning points were advanced planning for financial concerns and healthcare considerations; loss of driving licence; managing behavioural symptoms; changes in care settings; and preparing for the end-of-life. Informal caregiving has been conceptualized as a series of transitions taking place, while the person with dementia is going through a health-illness transition related to the dementia disease. The informal caregiver has to follow their own transition from the caregiving perspective. In addition, they have to follow the transition of the person with dementia in their health-illness transition perspective to be able to identify needs for both themselves and the person with dementia along the course of the disease. During this transition, to and in caregiving, informal caregivers are in a vulnerable position and it is essential that they have access to adequate knowledge and support from the health care and social service systems. Hence, nursing strategies for caring for, and supporting people to achieve healthy transitions as caregivers through the dementia disease, should be a priority.

Persons with dementia and their care needs

The trend in European countries is that people with dementia should be able to live at home for as long as possible, aging in place, cared for by their family. Persons with dementia have special care needs with regard to their personal care, hours of care and supervision by the informal caregiver, which may be associated with caregiver burden (Prince, Prina, & Guerchet, 2013). Like all neurodegenerative disorders, dementia progresses along a continuum with a series of stages from diagnosis to end of life. A dementia diagnosis is generally the basis for treatment, pharmacological and non-pharmacological, and is a requirement for access to support for both the person with dementia and their informal caregiver. Dementia disease is connected to a large number of underlying brain pathologies. The pathology of the brain is likely to start decades before the first clinical symptom of the dementia. The most common dementia disease is Alzheimer's disease (accounting for 50-75% of diagnosed cases) followed by vascular dementia (20-30%), frontotemporal dementia (5-10%), and dementia with Lewy bodies (< 5%). There are also cases of mixed Alzheimer's disease and vascular dementia pathology, which are believed to be underdiagnosed (Prince, Albanece, Guerchet, & Prina, 2014; Winblad et al., 2016). Pharmacological treatment for Alzheimer's disease is approved and is available in most European countries. There is no cure for dementia and the primary outcomes for pharmacological treatment of Alzheimer's disease are cognitive function; secondary outcomes are function in terms of activities of daily living and behaviour. Non-pharmacological treatment for dementia and mild cognitive impairment is cognitive training and brain-training games with the aim to provide the persons with strategies to improve cognition (Winblad et al., 2016). As the dementia

disease progresses, the person with dementia suffers a loss of independence with increased need for care assistance regarding instrumental activities of daily living (e.g. preparing meals, using the telephone, handling finances) and personal activities of daily living (e.g. functional mobility, dressing, bathing, toileting) and supervision (Schulz et al., 2004b) which in return increases the demands on the informal caregiver. Dependence can be defined as *"the need for frequent help or care beyond that habitually required by a healthy adult"* (Harwood, Sayer, & Hirschfeld, 2004).

In the early stages, there is a slight cognitive impairment, which might impact on activities of daily living, cognition, and social functioning. Most persons with dementia in this stage are still able to live at home, with support from informal caregivers, and in some cases, from health care and the social service. In the intermediate to late stage of the disease, there is increased cognitive impairment and dependency on help with activities of daily living. There also are social needs requiring care from the informal caregiver, often in combination with formal care, occasionally in a nursing home at this stage. There is severe cognitive impairment in the late stage, when the person with dementia is unable to look after themselves without continuous assistance with activities of daily living and social needs. At the end of life stage, when it is obvious that the person with dementia has limited time to live there is a need for palliative care. In most cases the person with dementia will be living in a nursing home (Moise et al., 2004; Sansoni, Anderson, Varona, & Varela, 2013). To enable informal caregivers to care for the person with dementia at home for as long as possible, knowledge is needed about factors associated with informal caregiver psychological well-being and burden. Such knowledge will allow us to predict increased psychological well-being as well as burden for the informal caregivers caring for a person with dementia at risk of moving to a nursing home.

The supply side

Health care and social service systems

Availability and utilization of support for informal caregivers in health care and social service systems through the dementia course is sparsely investigated in the European countries. The long-term care of persons with dementia will be a challenge for the health care and social service systems in the future as the proportion of available informal caregivers will decline, with fewer children being born to take care of an older generation. Also, younger generations are predicted to change their attitude, expectations and work mobility. Women, who currently make up the majority of informal caregivers, will in the future have higher education and more often be working making them less available for informal care. In Europe, these trends will be more notable in the southern and eastern countries, which currently have multi-generation

housing, compared with the western, northern and central European countries (Prince et al., 2013). Simultaneously, the goal is for people to be able to live at home for as long as possible, aging in place, feeling secure and maintaining their involvement in the community, social and family life and when needed, supported by long-term formal care (World Health Organization, 2000). Formal care, the long-term care and service provision for a person with dementia living at home, is a complex system with broad boundaries. It includes both health care and social services and varies from country to country (Prince et al., 2013; Winblad et al., 2016).

The World Health Organization (WHO, 2000) has defined long-term care as: *"the system of activities undertaken by informal caregivers (family, friends, and/or neighbours) and/or professionals (health, social, and others) to ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfilment, and human dignity."* The WHO describes the elements of long-term care, both in terms of arrangement, assessment and evaluation, of health care and social services by professionals and paraprofessionals and in terms of the function of long-term care including support for family, friends, and other informal caregivers. A key priority is to deliver a continuum of care and support as the health condition changes leading to loss of independency which is particularly true in the case of dementia, bearing in mind that the needs of the person with dementia and the family are individual (Prince et al., 2013; McCabe, You, & Tatangelo, 2016). In European countries there are differences regarding support from formal health care and social service systems, as well as regarding families' responsibilities for the older person with dementia. In the Scandinavian countries, the health care and social services are provided based on individual needs for care and service from the municipality or the county council (Genet et al., 2011). In Germany, long-term care insurance only partly covers care dependency, and families are expected to contribute (Dorin et al., 2014). In Estonia, families have a legal obligation towards their sick and impaired relatives, which includes provision of health care and social service and economic security (Colombo et al., 2011). Policies in European countries may include paid care leave (e.g. Finland), providing respite care (e.g. Germany), and counselling and training services (e.g. Sweden) (Colombo et al., 2011). To be able to provide the informal caregivers with individual support and, further, develop the health care and social service system, knowledge is needed about what support is available and how the support is utilized.

Professional providers of health care and social service

Informal caregivers need information and knowledge about dementia through the course of the disease and how to handle the persons' care needs. To provide adequate dementia care and support, professionals need specific expertise and knowledge about the dementia disease. Professional care providers of health care and social services vary across European countries, depending on each country's health care and social service system and reimbursement structure. In the diagnosis stage, some persons with dementia see a general practitioner at the outpatient clinic. Others are referred to specialized centres, memory clinics, connected to large hospitals and universities, or private clinics where they see a neurologist or psychiatrist to get a dementia diagnosis (Winblad et al., 2016). One study performed in European countries with persons with dementia and their informal caregivers (Hallberg et al., 2013) reported that professionals with a Bachelor's degree or above were involved in diagnosis, treatment, and health care, while the everyday care was provided by professionals trained at a lower level or by staff with no formal training at all.

To standardize the classification professionals' educational level in the study by Hallberg et al. (2014), an international comprehensive framework, the International Standard Classification of Education (ISCED, 2013) was used. Professional providers of health care and social services need knowledge and skills to improve the support they provide and the well-being and quality of life of the informal caregiver (Prince et al., 2013; Winblad et al., 2016). Knowledge about professionals' education in dementia care in European countries is sparse. Training professional providers to support informal caregivers with knowledge about the dementia disease and how to provide all types of care may enable informal caregivers to provide care at home for longer. In addition, European countries can learn from each other with regard to provision of health care.

Outcomes of the transition to and within caregiving

Informal caregivers sometimes experience burden, and changes such as shifts in power in the relation to the person with dementia, health, quality of life, and social networks (Wimo & Prince, 2010)), which makes it important to promote their psychological well-being. Caregiving as experienced by informal caregivers may differ from person to person. Some perceive the caring as a positive experience (Bertand, Fredman, & Saczynski, 2006), but it can also be physically and mentally demanding, and some perceive it as unmanageable (Brodaty & Donkin, 2009; Zwaanswijk, Peeters, van Beek, Meerveld, & Francke, 2013). The impact of caregiving on informal caregivers, when caring for a person with dementia living at home, can be divided into a practical, psychological and economic impact, as described by Prince et al. (2013). A practical

impact includes activities of daily living, and supervision time. A review in 30 countries suggested that the average time spent (hours, daily) by informal caregivers assisting the person with dementia in: personal activities of daily living; personal activities combined with instrumental activities of daily living, and supervising, was 2.0; 3.6, and 2.6, respectively with no obvious variation between countries (Wimo & Prince, 2010). A negative psychological impact has adverse effects on informal caregivers' physical health (Schulz & Beach, 1999; Schulz & Martire 2004a). The effect of caregiver burden can reduce the informal caregivers physical and psychological well-being, and shows significantly higher depression symptoms when comparing non-dementia caregivers with dementia caregivers (Pinquar & Sorensen, 2006). Concerning the economic impact, the result of a previous study, not specifically in dementia caregivers, showed that 1% increase of caregiver hours was associated with a reduction of the informal caregivers' employment rate by approximately 10% (Colombo et al., 2011). Having to cut back on work or having to leave or quit work was associated with caregiver burden. This was reduced if hiring a caregiver or having supplementary informal support (Prince et al., 2012). In this thesis, the focus is on the practical and psychological impact of caregiver burden and well-being.

Psychological well-being

Previous research has mostly focused on factors that negatively impact the informal caregiver's well-being. Few studies have focused on positive factors that affect the informal caregivers' psychological well-being (Lyubomirsky, King, & Diener, 2005) Psycho-logical well-being is one part of the multidimensional constructs of health (Ryff & Singer, 2008). Health is defined by the WHO (1948), as "*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*". Psychological well-being may contribute to health (Luybomirsky et al., 2005; Segerstrom, & O'Connor, 2012; Steptoe, Deaton, & Stone, 2015) and higher levels of psychological well-being may improve health and reduce mortality (Chida & Steptoe, 2008; Pressman & Cohen, 2005). Several core dimensions make up psychological well-being, such as self-acceptance, environmental mastery, purpose in life, personal growth, positive relationships, and autonomy (Ryff & Singer, 2008). Emotional and physical well-being should be promoted in transitions to optimize the ability to assimilate new information. During transitions, stress, and particularly emotional stress, is common and might cause discomfort that can influence well-being during the transition (Meleis, 2010).

Indicators for a healthy transition have been identified by Meleis (2010) as a subjective sense of well-being, mastery of new behaviours, and the well-being of interpersonal relationships. This makes it essential for the health care and social support systems to provide informal caregivers with individualized support to reduce the burden experienced and promote their well-being, which also enables the best care for the person with dementia (Winblad et al., 2016). The outcomes for the informal caregiver

regarding psychological well-being and burden might also depend on their access to the health care and social service system. This in turn might depend on how the informal caregiver enters the system and it might also depend on their demands and utilization of the services, and on how transparent the health care and social service system is regarding their supply and availability (Levesque et al. 2013). To understand what factors maintain and improve caregiver psychological well-being and over time, it is essential to investigate factors predicting an increase in psychological well-being.

Challenges in caregiving

Informal caregivers caring for a person with dementia are at increased risk of burden, especially if the person with dementia is at risk of being institutionalized. These caregivers have been assessed to be at increased risk of health complications (Schulz & Martire, 2004a; Wimo & Prince, 2010) and have higher mortality compared with informal caregivers caring for an older person without dementia (Brodaty & Donkin, 2009). The scientific evidence of the effect of different support on informal caregiver burden, well-being, and quality of life is not very strong and in some cases contradictory. Psycho-educational interventions have shown to have some positive effect on caregiver depression, health, subjective well-being, self-efficacy and burden (Parker, Mills, & Abbey, 2008). In addition, it has been reported that it can be beneficial decreasing caregiver burden with support, such as respite care (Pinquart & Sorensen, 2006), multi-component intervention (Zabalegui et al., 2014), information about the dementia disease, prognosis and how to deal with behaviour (de Jong & Boersma, 2009; Prorok, Horgan & Seitz, 2013).

In the caregiving transition, this can be related to expectations such as the individuals' appraisal of an expected experienced transition, and the progress of the effect it might have on that individual's life which can be positive, negative or neutral. The transition can be desired or not desired, and is not necessarily a personal choice of the informal caregiver. Expectations are influenced by former experiences (Reimer, Davies, & Martens, 1991) and the transition may or may not be realistic, and the informal caregiver may not know what to expect. If the informal caregiver knows what to expect of the transition, this might alleviate the stress associated with the caregiving transition. Informal caregivers may have a lack of knowledge (Suhonen, Stolt, Koskenniemi, & Leino-Kilpi, 2015) and often request information about dementia, prognosis, and how to deal with behaviour problems perceived as difficult when assisting the person with dementia (de Jong & Boersma, 2009; Prorok et al., 2013; McCabe et al., 2016). In other words, the informal caregiver's level of knowledge and skill connected to the caregiving transition may often be insufficient to meet the new demands related to the transition. This may also have an influence on the informal caregiver's health outcomes (Meleis, 2010). Respite care for the person with dementia has likewise been shown to relieve caregiver burden (Pinquart & Sorensen, 2006). Multi-component interventions have been reported to have varying impact on depressive symptoms, quality of life, and

caregiver reaction to care recipient behaviour problems and satisfaction (Zabalegui et al., 2014). However, a previous study indicated that interventions for informal caregivers of persons with dementia had little effect on the informal caregivers' level of depression, burden, and subjective well-being of the informal caregiver. The interventions included psycho-educational and cognitive–behavioural interventions, counselling/-case management, general support, and respite care (Pinquart & Sorensen, 2006). In the caregiving transition, respite care can be related to the environment and include external resources such as social support from the family, nurses in formal organizations or therapeutic groups. Support such as this, coming from outside can facilitate the caregiving transition process by helping the informal caregiver to avoid feelings of powerlessness, frustration, confusion, and conflict (Meleis, 2010). Hence, knowledge is needed about factors associated with burden and predicting increased burden for the informal caregivers caring for a person with dementia at risk of being institutionalized. This knowledge might enable the health care and social service system to provide the caregivers with adequate support.

The informal caregiver has a central role in working together with formal care, the long-term health care and social service for a person with dementia living at home; and is to greater or lesser extent supported by formal care (Prince et al., 2013). Informal caregivers have both varying and individual needs for support from formal care as the dementia disease progresses (Moise et al., 2004). The support may help them to relieve the burden and promote psychological well-being, enabling them to care at home for as long as possible. The ability of informal caregivers to participate in the care planning process, both before and during the transition, influences the success of the caregiving transition. Informal caregiver burden often increases prior to moving the person with dementia to a nursing home (Bleijlevens, 2014; Stephan et al., 2015a), which is an important reason for institutionalization (Afram et al., 2014; Sansoni et al., 2013). Effective planning promotes a gentle and healthy transition. As part of the planning, problems and support needs that might occur during the transition, need to be identified. In addition, key persons in the health care and social support system need to be identified and communication with these initiated (Meleis, 2010). Informal caregivers often find it difficult to navigate the system of health care and social service and find the right person to contact for support with different caregiver tasks (Ward-Griffin et al., 2012; Wiles, 2003). Hence, it is important to make the health care and social service system transparent and accessible through the course of the dementia disease to ensure that adequate care and support are offered to informal caregivers caring for persons with dementia to promote the informal caregivers psychological well-being.

Aims of the thesis

The overall aim of this thesis was to investigate informal caregivers providing care for older persons with dementia (≥ 65 years of age) in eight European countries. Focus was on their experiences of formal care, access to support, and factors that are associated to informal caregiver psychological well-being and burden.

The specific aims of the included studies were:

- To investigate informal caregivers' experiences of formal care when caring for an older person with dementia, through the course of the dementia disease (Study I).

- To describe formal support for informal caregivers caring for persons with dementia in terms of availability and utilization, and to examine the educational level of professional providers involved in the health care and social support of informal caregivers of persons with dementia through the course of the disease (Study II).

- To investigate factors associated with informal caregiver´s psychological well-being, related to the informal caregiver, the person with dementia and formal care, when caring for older persons with dementia living at home and at risk of being institutionalised within six months. In addition, factors predicting increased psychological well-being after three months were investigated (Study III).

- To investigate factors associated with informal caregiver´s burden, related to the informal caregiver, the person with dementia and formal care, when caring for older persons with dementia living at home and at risk of being institutionalised within six months. In addition, factors predicting increased burden after three months were investigated (Study IV).

Methods and materials

The RightTimePlaceCare project

This thesis reports on part of a European project called "RightTimePlaceCare-RTPC" (the EU 7th Framework programme for research, contract number 24 21 53), with eight participating countries conducted in 2010-2013. The RightTimePlaceCare project was developed by an established multidisciplinary network of senior researchers in the field of gerontology and geriatrics. In the development of the RightTimePlaceCare project, knowledge gaps were identified in former European project carried out from 2003 to 2009.

The overall aim of the RightTimePlaceCare project was to improve health care service in the European Health Systems for European citizens with dementia and develop best practice strategies for individualized home care. The strategies were also to ensure the best available outcomes for persons with dementia and their informal caregivers at affordable cost-benefit ratios, focusing on the transition from long-term formal professional home care to institutional long-term nursing care facilities. In addition, the project allowed countries to learn from the experience of other health care and social service systems including the sustainability of the systems.

The countries included in the project were Estonia, Finland, France, Germany, the Netherland, Spain, Sweden and the United Kingdom. Seven universities and one University hospital (Spain) participated in the RightTimePlaceCare project. The project consisted of the following six parts: management of the consortium; description of health care structures; clinical data collection; economic evaluation; best practice strategies; and dissemination (Verbeek et al., 2012). Consortium partners for the RightTimePlaceCare project are presented in Appendix I.

Design and sample

This thesis consists of four studies with three different designs. Study I was a qualitative study with focus groups interviews. Study II was a cross-sectional study. Study III and IV were prospective cohort studies, with interviews at baseline and 3-months follow-up. An overview of the design and sample of Study I to IV is presented in Table 1.

Table 1. Description of Study I – IV regarding design, sample, data collection and analysis

Study	Design	Sample	Data collection	Analysis
I	Qualitative, content analysis	Informal caregivers of persons with dementia ≥ 65 years old *n*=23 Conducted in one European country	Focus groups interviews with informal caregivers of persons with dementia ≥ 65 Four focus groups 4-7 informal caregivers in each focus group	Content analysis (Krippendorff, 2004) Methodological description (Graneheim & Lundman, 2004)
II	Quantitative, cross-sectional	Conducted in eight European countries	Mapping system for data collection Manual for data collection (Hallberg et al. 2013)	Analysed for variation
III	Quantitative prospective; cohort followed over time	Informal caregivers of persons with dementia ≥ 65 years old *n*=1223 Conducted in eight European countries	Structured interviews with questionnaires, at baseline and 3-months follow-up	Bivariate regression analyses Multivariate regression analysis
IV	Quantitative prospective; cohort followed over time	Informal caregivers of persons with dementia ≥ 65 years old *n*=1223 Conducted in eight European countries	Structured interviews with questionnaires, at baseline and 3-months follow-up	Bivariate regression analyses Multivariate regression analysis

Demand side

Study I was performed in Sweden. Altogether, 23 informal caregivers participated, 13 spouses and ten adult children of persons with dementia. The recruited informal caregivers, from both rural and urban municipalities, were between 45 and 88 years old. Ten were men and 13 were women. The person with dementia cared for were between 68 and 98 years old. Living conditions for the person with dementia are presented in Table 2. The participants were divided into four focus groups, with four to seven informal caregivers in each group. They represented a range of age and experiences of the process of the dementia disease. The informal caregivers who were caring for a person with dementia in a nursing home consequently had experience of formal care and social services both at home and in a nursing home. Health care and social services used by the informal caregiver and the person with dementia may include accompanying service personnel, home care, day care, respite care and respite care at home. The municipalities were from southern Sweden and the size of the municipalities included ranged from between 10000 to 113000 inhabitants.

The inclusion criteria for the informal caregivers were: cohabiting with the person with dementia at home, or visiting them at least twice a month at home or in the nursing home. Inclusion criteria for the person with dementia they cared for were age ≥ 65 years and having a primary dementia diagnosis, a Standardized Mini-Mental State Examination (SMMSE) score ≤ 24 (Molloy, Alemayehu, & Roberts, 1991) and either living at home with support from formal health care and social services, or living in a nursing home. Recruitment was via a contact person in four municipalities, a registered nurse specialized in dementia care. The contact person was instructed to ask informal caregivers representative of both home care and nursing homes and with range of experiences of all stages in the dementia disease (Moise et al., 2004), whether researchers from Lund University could contact them about participation in focus group interviews.

Table 2. Living conditions for the person with dementia by informal caregiver focus group

	Living at home	**Living in a nursing home**
Group 1, n=4	1	3
Group 2, n=6	3	3
Group 3, n=7	3	4
Group 4, n=6	4	2

Supply side

Health care and social service systems in eight European countries were included. The participating countries were Estonia, Finland, France, Germany, the Netherlands, Spain, Sweden and the United Kingdom.

Outcomes

A total of 1223 dyads of informal caregivers and older persons with dementia living at home were included in Study III and IV. Participating countries contributed the following numbers of dyads: Estonia n=172; Finland n=182; France n=175; Germany n=116; the Netherlands n=177; Spain n=174; Sweden n=146; and the United Kingdom n=81. Sample characteristics of the informal caregivers and persons with dementia included in Study III and IV is presented in Table 3.

The informal caregivers were caring for a person with dementia living at home, either cohabiting with the older person with dementia as a spouse or visiting the person with dementia at least twice a month. In the latter case, the informal caregivers were an adult child or, a friend or had another type of relationship e.g. that of a trustee or neighbour, with the person with dementia. The type of visits was not specified; visits could consist of socialization activities or help with activities of daily living.

Before including the informal caregiver, the person with dementia had to be interviewed first to fulfil the inclusion criteria for the study. Inclusion criteria were that the persons with dementia were ≥65 years old, had been diagnosed with a primary dementia disease, had cognition measured with Standardized Mini-Mental State Examination score ≤ 24 (Molloy et al., 1991) and was living at home with support from health care and/or the social services. The person with dementia was assessed by professionals to be at risk for institutionalization within six months. In Table 3, sample characteristics of the informal caregivers and the persons with dementia included in Study III and IV are presented at baseline and follow-up.

Table 3. Sample characteristics of the informal caregivers and persons with dementia included in Studies III-IV.

Informal caregivers (n=1223)	
Median age, years; (Q1; Q3)	64 (55; 77)
Female gender, %	69
Cohabiting with the PwD, %	61
Relation to the PwD, %	
Husband	18
Wife	24
Adult child, son/daughter	45
Friend	1
Other	12
Persons with dementia (n=1223)	
Median age, years; (Q1; Q3)	82 (78; 87)
Female gender, %	63
Symptoms, years (range)	4 (2; 6)
Cognitive function, (median SMMSE score), (Q1; Q3) (possible score range 0-30)	15 (10; 20)
Dementia diagnosis, %	
Alzheimer disease (AD)	55
AD/VaD	6
Vascular dementia (VaD)	17
Frontotemporal dementia	1
Lewy Body dementia	2
Unknown	16
Other	4

AD=Alzheimer's disease; PwD=Person with dementia; Q1=first quartile; Q3=third quartile; SMMSE=Standardized Mini-Mental State Examination; VaD=vascular dementia. At follow-up, 16% of the persons with dementia (n=274) had moved to a nursing home.

Data collection and assessment

For Study I, data were collected through focus group interviews held in October 2011. Focus group interviews (Krueger & Casey, 2009) was selected as the method to induce participants to disclose positive and negative experiences of formal care in discussion with others, and to gain understanding of differences in perspective between informal caregiving to an older person with dementia, living at home and caregiving for a person with dementia living in a nursing home. The informal caregivers were given both verbal

and written information about the procedure and purpose of the focus group interviews by the researchers. Written informed consent was signed before the interview.

After giving information about the aim of the interview, a moderator conducted the interview based on the interview guide (Appendix II). An observer (the author) helped the moderator to keep participants on track and observed the interaction in the focus group (Stevens, 1996; Krueger & Casey, 2009). The moderator is a researcher in the field of elderly care and psychiatry and are experienced in conducting focus group interviews. The observer has experience in working with persons with dementia and informal caregivers in the municipality and county council. The participants were asked to share their experiences of formal care. The participants all actively participated, discussing the questions with each other and sharing experiences about the process of the dementia disease. The interviews were recorded and thereafter transcribed verbatim. The time per focus group interview varied between 124 and 140 minutes.

Interview guide

An interview guide was developed for all eight European countries with questions regarding informal caregivers' experiences of formal care in the context of caregiving at home or in a nursing home (Appendix II). The interview guide contained questions about interactions, information and communication obtained when caring for a person with dementia, at home or in a nursing home. The participants were asked to describe, if possible, the characteristics of those situations where interaction, information and communication worked the best, or the opposite. To gain depth in the interviews, the participants were asked probing questions such as "What do you mean" or "Can you elaborate on what you are saying?" A pilot interview was conducted in May 2011 to validate the procedure and the interview guide. The interview guide was deemed to fulfil its purpose and consequently no changes were made after the pilot interview.

For Study II, a mapping system was used for data collection (Appendix III). Established researchers with extensive practical and research experience in dementia care from each country contributed to the data collection. The data collection represented each country as a whole. A manual used for the data collection, suggested consulting public reports for sources of information and descriptions of the health care and social service system. The manual also suggested using official statistics and personal interviews with care managers, care providers and civic administrative organizations. For each country data collection was completed by communication with experts (in Germany, the Netherlands, Sweden); nursing staff (England); advisory boards (Estonia, Spain, Finland, Sweden); professional care providers (Finland); and a national Alzheimer's society (Finland) as described elsewhere in detail (Verbeek et al., 2012). Epidemiological studies and literature reviews were used for validation of responses from professionals in each country. Data were collected between 1 November 2010, and 31 January 2011.

The mapping system

A mapping system developed by Hallberg et al. (2013) was used (Appendix III). This mapping system provides a horizontal description of the five stages of the dementia disease, the diagnosis stage, the early stage the intermediate stage, the late stage, and the end of life stage (Moise et al., 2004). Vertically, it gives a description of 50 different types of health care and social services. The different types are divided into seven categories regarding screening, diagnostic procedures, treatment of dementia; and the outpatient care facilities. Furthermore, care at home; institutional care; palliative care; informal caregiving and supportive actions; and civic organizations are described. Each type of health care and social services activities included estimations of availability, utilization, and providers of support, in relation to the five stages of the dementia disease (Moise et al., 2004). Response alternatives for the estimations of availability are "[available] For all", "For most", "For few" and "For no one". For estimations of utilization, response alternatives are "[utilized] By all", "By most", "By few", and "By no one". The term "not applicable" (NA) is used when the health care or social service activity is available, but either it is not suitable for a specific disease stage or it is not suitable at all (Hallberg et al., 2013). For this study, ten different types of support for informal caregivers was analysed for variation. The support was counselling, caregiver support, education, reimbursement, no reimbursement, day care, specialized day care for dementia, residential respite care, specialized residential respite care for dementia, and respite care at home.

Outcomes

For Study III and IV data were collected through face-to-face interviews in eight European countries with persons with dementia living at home and their informal caregiver using a questionnaire including standardized instruments. Data were collected to investigate factors associated with informal caregivers' psychological well-being and burden when caring for older persons with dementia living at home, involving the informal caregiver, the person with dementia, and formal care. Variables that might be associated with psychological well-being and burden in Study III and IV are presented in Table 4. In the eight European countries, a contact person in each municipality or province, contacted possible participants. The contact person could be from different disciplines. The contact person forwarded written and oral information about the study to the informal caregiver and the person with dementia and asked them whether researcher from the universities could contact them. Thereafter researchers contacted the informal caregiver and the person with dementia and repeated the information about the project. If interested, the informal caregiver and the person with dementia gave oral consent to participate in the study. The interviews were mostly performed in the home of the person with dementia, occasionally an interview was held at the day care centre. Prior to the interview, the researcher repeated information about the project and if they agreed to participate the informal caregiver and the person with dementia

signed the informed consent. Prior to the study, permission was obtained for all countries for the use and translation of all the questionnaires (Verbeek et al., 2012). The person with dementia was the first to be interviewed using the Standardized Mini-Mental State Examination, to meet the inclusion criteria. The interview with the informal caregiver concerned socio-demographics, the relation to the person with dementia, experiences and provision of caregiving, caregiver burden, well-being and quality of life. Questions regarding the person with dementia included socio-demographics, diagnosis and symptoms of dementia, comorbidity, cognitive function, quality of life, activities of daily living, neuropsychological symptoms, and depression in dementia.

Table 4. Variables that might be associated with psychological well-being and burden in Studies III and IV.

	Study III, Psychological well-being	**Study IV, Burden**
IC	Age	Age
	Gender	Gender
	Living with the PwD	Living with the PwD
	Number of visits in the last 2 weeks	Number of visits in the last 2 weeks
	Average length of visits, minutes	Average length of visits, minutes
	Relation to the person with dementia	Relation to the person with dementia
	Experience of caregiving	Health-related quality of life
	Health-related quality of life	Psychological well-being
	Informal care provision	Informal care provision
	Caregiver burden	
PwD	Age	Age
	Gender	Gender
	Duration of symptoms, years	Duration of symptoms, years
	Dementia diagnosis	Dementia diagnosis
	Comorbidity	Comorbidity
	Depression in dementia	Depression in dementia
	Activities of daily living	Activities of daily living
	Neuropsychiatric symptoms	Neuropsychiatric symptoms
	Quality of life, proxy rated	Quality of life, proxy rated
	Cognitive function	Cognitive function
FC	Quality of care at home	Quality of care at home
	Use of dementia specific service for PwD	Use of dementia specific service for PwD
	Satisfaction with dementia specific service	Satisfaction with dementia specific service

IC=Informal caregiver; FC=Formal Care; Proxy=delegate, agent; PwD=Person with Dementia.

The questions concerning formal care covered quality of care and dementia specific service for persons with dementia and satisfaction with the service. Data were collected at baseline and follow-up after 3 months (80-100 days). In home care, the drop-out rate was expected to be 15% (informal caregivers and persons with dementia) and when the project was carried through the total number of dyads was 1223 out of the planned 1400 dyads.

Dependent variables

General Health Questionnaire

Psychological well-being was measured with the General Health Questionnaire (GHQ) (Goldberg, 1972; 1978) (Appendix IV). The questionnaire was designed by Goldberg (1972) to detect psychiatric disorders and to investigate four elements of distress: depression, anxiety, social impairment, and hypochondriasis. The questionnaire was originally not designed for informal caregivers but has been shown to be a sensitive instrument to detect those likely to have or be at risk of depression and anxiety (Jackson, 2007). The main General Health Questionnaire consists of 60 items, but four shorter versions are available with 30, 28, 20, and twelve items respectively. For this study, the twelve-item version, GHQ12 was chosen. A 4-point Likert scale was used to measure responses, where 0=better than usual; 1=same as usual; 2=less than usual; 3=much less than usual or 0=not at all; 1=no more than usual; 2=less useful than usual; 3=much less useful. The possible score ranges from 0 to 36, with a higher score indicating lower psychological well-being. Internal consistency has been reported by Cuéllar-Flores, Sánchez-López, Limiñana-Gras, and Colodro-Conde (2014) (α=0.87) and further by Goldberg et al. (1997) (α=0.83–0.95) in a study with 5438 patients in general health care involving 15 centres around the world. Schmitz, Kruse, and Tress (1999) in their factor analysis of GHQ12 used a two-factor structure confirming previous studies in different populations (Politi, Piccinelli, & Wilkinson, 1994; Kilic et al., 1997; & Gureje, 1991). Reliability coefficients have been found to vary in different studies with test–retest (α=0.78-0.95) according to Jackson (2007) and McDowell (2006).

Zarit Burden Interview

The Zarit Burden Interview (ZBI) measures caregiver burden (Zarit, Reever, & Bach-Peterson, 1980) (Appendix V). The Zarit Burden Interview, which was developed in the United Kingdom, is one of the oldest and most used measurements for assessing burden experienced by informal caregivers caring for persons with Alzheimer disease (Zarit, Orr, & Zarit 1985; Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003). Originally, the questionnaire consisted of 29 items (Zarit et al., 1980) but it was later reduced. The Zarit Burden Interview now exists in a short version with twelve items and a longer version consisting of 22 items. The 22-item version of the questionnaire is recommended to be used, due to higher reliability compared with the short version (Bachner & O'Rourke, 2007) and was used for this study. Zarit Burden Interview

consists of five domains: Burden in the relationship (six items); Emotional well-being (seven items); Social and family life (four items); Finances (one item); and Loss of control over one's life (four items). Each item was scored on a 5-point Likert scale, were for 0-4 items 1-2, questions were scored as follow: 0=never; 1=rarely; 2=sometimes; 3=quite frequently; 4=nearly always. For question 22 scores are allocated as follows: 0=not at all; 1=a little; 2=moderately; 3=quite a bit; 4=extremely. The total score was added up with a possible range of 0-88, and a higher score indicates a higher perceived burden by the informal caregiver. Zarit and Zarit (1985) proposed that the burden could be considered as small or absent with a score ≤21, as mild to moderate with a score of 21-40, and as moderate to severe with scores between 41 and 60, while a score of 61-88 is severe. The interpretation of scores should however be considered as guidelines only (Hérbert, Bravo, & Girouard, 1993). The Zarit Burden Interview has in the last 30 years shown test-retest reliability as reported by Gallagher et al. (1985) (0.71) and Hérbert et al. (1993) (0.89). Internal consistency has been reported to be α=0.91 by Gallagher et al. (1985) and α=0.85 by Hérbert et al. (1993). A meta-analysis (Bachner & O'Rourke, 2007) of 102 studies testing reliability and validity of the Zarit Burden Interview reports a test-retest reliability of α=0.59 (range 0.24-0.89) and an internal consistency of α=0.86 (range 0.62-0.95). Regarding the factor structure of the scale, two factors were suggested by Whitlatch, Zarit, and von Eye (1991) personal strain (eleven items) and role strain (six items), which was supported by Hérbert et al. (1993).

Independent variables

Caregiver Reaction Assessment

The Caregiver Reaction Assessment (CRA) scale measures caregiver experiences of caregiving in chronic patients. The questionnaire was developed in the USA by Given et al. (1992) as an instrument to measure the reaction of informal caregivers of older persons with physical impairment, Alzheimer's disease and/or cancer. The Caregiver Reaction Assessment scale is a multidimensional instrument that consists of 24 items in five domains: Caregiver esteem (seven items) with a score range from 7 to 35; Lack of family support (five items) with a score range of 5-25; Impact on finances (three items) with a score range of 3-15; Impact on schedule (five items) with a possible score of 5–25; and Impact on health (four items) with a score range from 4 to 20. For responses in the Caregiver Reaction Assessment scale, a 5-point Likert scale was used, where 1=strongly disagree; 2=disagree; 3=neither agree nor disagree; 4=agree; and 5=strongly agree. A higher score on informal caregiver esteem indicates a positive impact of caregiving on caregiver; for the other domain a higher score indicates a negative impact of caregiving on caregiver's experience. Internal consistency was reported by Given et al. (1992) with Cronbach's alpha for Caregiver esteem being 0.90; for Lack of family support, 0.85; for Impact on finances, 0.81; for Impact on schedule, 0.82; and for Impact on health, 0.80. Construct validity was reported, with dependency

in activities of daily living, Center for Epidemiological Studies-Depression Scale scores and confirmatory factor analysis have been reported as stable for all subscales (Given et al., 1992).

Charlson Comorbidity Index

The Charlson Comorbidity Index was developed by Charlson, Pompei, Ales, and MacKenzie (1987) to classify comorbid conditions that could change the risk of mortality. The Charlson Comorbidity Index predicts 1-year mortality for a patient who may have a range of co-morbid conditions such as heart disease, or cancer. The Charlson Comorbidity Index consists of 19 possible comorbidities. The score ranges from 0 to 37 and a higher score indicate a greater risk to die from comorbid disease (Charlson et al., 1987). Each comorbidity is weighted differently depending on the risk of dying associated with the condition. The total score is calculated by summing up comorbidities multiplied by their weights, either one, two, three or six times. The total score predicts mortality. Frenkel et al. (2014) validated the Charlson Comorbidity Index in acutely hospital admitted older patients (≥65 years old) and showed high accuracy to predict mortality.

CLient INTerview Instrument, experiences of quality of care in home

CLient INTerview Instrument was developed by Vaarama, Pieper, and Sixsmith (2009). It measures subjective experiences of quality of care in institutional care (CLINT-IC) and home care (CLINT-HC). The CLient INTerview Instrument for home care version consists of nine questions as follows: Right amount of food (portions); Enjoying meals; Personal hygiene; Same care workers; Things care workers do; Perceiving care workers as honest and trustworthy; Having a clean home; Garden maintenance; and General satisfaction with formal care. The response alternatives are rated on a 5-point Likert scale, were 1=yes, always; 2=yes, usually; 3=sometimes; 4=seldom; and 5=never except for food portions which are rated as: 1=yes, always; 3=sometimes too little; 3=sometimes too much; 3=sometimes too little, sometimes too much; 5=always too little; or 5=always too much. General satisfaction with formal care is rated as 1=very satisfied; 2=satisfied; 3=neither good nor poor; 4=dissatisfied; and 5=very dissatisfied. The summary score ranges from 9 to 45 and a higher score indicates lower experienced quality of care by the informal caregiver. The CLient INTerview instruments have been tested (Vaarama et al., 2009a and 2009b) and CLient INTerview home care have shown internal consistency as α=0.67 in Beerens, Sutcliffe, Renom-Guiteras and Soto (2014).

Cornell Scale for Depression in Dementia

The Cornell Scale for Depression in Dementia is used to measure depression in persons with dementia and was developed by Alexopoulos, Abrams, Young, and Shamoian (1988). The Cornell Scale for Depression in Dementia contains 19 items covering five

dimensions: Mood related signs (four items); Behavioural disturbance (four items); Physical signs (three items); Cyclic functions (four items); and Ideational disturbance (four items). Each item is rated for severity on a 3-point scale where 0=absent; 1=mild or intermittent; and 2=severe. If the respondent is "unable to evaluate" one symptom this will be scored with 0=absent. The summary score ranges from 0 to 38, and a higher score on the Cornell Scale for Depression in Dementia indicates more depressive symptoms (Alexopoulos et al., 1988). Validity for the Cornell Scale for Depression in Dementia, as well as inter-rater reliability, has been reported to range from α=0.64 to α=0.99. Internal consistency, α=0.84 has been reported by Alexopoulos et al. (1988).

Dementia specific services

Dementia specific services data regarding such services as respite care and day care were collected with a single item question: "Do you or does your relative make use of any dementia specific service?". The response alternatives were "yes" or "no". Satisfaction with dementia specific service for the person with dementia was measured with a single item question: "How satisfied are you with the provided care by the dementia service?" and was rated on a 5-point Likert scale, where 1=very dissatisfied; 2=dissatisfied; 3=neither satisfied, nor dissatisfied; 4=satisfied and 5=very satisfied.

Health-related quality of life

The EuroQoL-5 dimension-3 level (EQ-5D-3L) instrument measure health-related quality of life and self-rated health-related quality of life and was developed by TheEuroQolGroup in 1990 (TheEuroQolGroup, 1990). The goal was to develop an instrument to generate cross-national comparison. One part of EQ-5D-3L consists of questions about five health dimensions: Mobility; Self-care; Usual activities; Pain/discomfort; and Anxiety/depression. Each of the five health dimensions has three levels of response alternatives: 1=no problem; 2=some problems; and 3=severe problems. The EQ-5D-3L score has no arithmetic properties and should therefore not be used as a cardinal score, the score range being -0.594-1. A higher score indicates higher health-related quality of life. Another part of EQ-5D-3L is the EuroQoL visual analogue scale (EQ-VAS) which captures a self-rated state of health. The EQ-VAS is a 20-cm vertical visual analogue scale (VAS) with 100 indicating the best imaginable health state and 0 signifying the worst imaginable health state. A higher score indicates higher self-rated health state (TheEuroQolGroup, 1990). The EQ-5D has shown ability to discriminate between groups using e.g. socio-demographic, health and health service use variables, and has been found to be valid and reliable (Haywood, Garratt, & Fitzpatrick, 2005).

Katz Index of Independence in Activities of Daily Living.

The Katz Index of Independence in Activities of Daily Living is an instrument measuring the ability to independently perform activities of daily living and was developed by Katz, Ford, Moskowitz, Jackson, and Jaffe (1963). It has been used to

accumulate information about prognosis and dynamics of disability in the aging process, but also to assess care need and to evaluate effectiveness of treatment, and as a teaching tool in rehabilitation. The instrument ranks adequacy of performance in the six functions of: Bathing; Dressing; Toileting; Transferring; Continence; and Feeding. Each function is classified as: "independent", "partly dependent", or "dependent on assistance" and dichotomized into 0=dependent and 1=independent. For bathing, dressing and feeding, partly dependent is scored as "1". For toileting, transferring and continence, partly dependent is scored as "0". Summary score ranges from 0 to 6 and higher score indicate more independence in performing activities of daily living (Katz et al., 1963). According to Katz et al. (1963) the Katz Index is reliable, and construct validity indicating that the activities are scalable. Lindmark and Hamrin (1988) report validity with a correlation of 0.95 between motor assessments scores measured on admission of patients at two different periods. The Katz index has shown reliability, ranging from α=0.87 to α=0.94 (Ciesla, Shi, Stoskopf, & Samuels, 1993).

Neuropsychiatric Inventory Questionnaire

The Neuropsychiatric Inventory Questionnaire is used to measure behavioural and neuropsychiatric symptoms in dementia patients and was developed by Cummings et al. (1994). Information about neuropsychiatric symptoms in the person with dementia is obtained from the informal and contains of twelve items: Delusions; Hallucinations; Agitation/aggression; Depression/dysphoria; Anxiety; Euphoria; Apathy; Disinhibition; Irritability/lability; Aberrant motor behaviour; Sleep/night-time behaviour disorders; and Appetite and eating disorders. The instrument measures presence of neuropsychiatric symptoms in the past 4 weeks and on two levels. The first level concerns the severity of the neuropsychiatric symptoms, and the second level concerns the informal caregiver distress caused by the neuropsychiatric symptoms. Severity is scored from 1to 3 where 1=mild; 2=moderate; and 3=severe. The summary score range from 0 to 36 with a higher score indicating presence of more severe neuropsychiatric symptoms. Distress for the informal caregiver is scored on a scale of 0 to 5, where 0=no distress; and 1=minimal; 2=mild; 3=moderate; 4=severe; and 5=extreme or very severe distress. The summary score range from 0 to 60 and, again, a higher score indicates greater distress for the caregiver (Cummings et al, 1994). The Neuropsychiatric Inventory Questionnaire has demonstrated validity compared with a standard instrument (r=0.61-0.62) (Cummings et al., 1994). Test-retest reliability between symptoms and distress has been reported as α=0.80 and α=0.94 respectively (Kaufer et al., 2000).

Resource Utilization in Dementia

The Resource Utilization in Dementia instrument was developed in Sweden by Wimo, Jönsson, Karlsson and Winblad (1998). It was designed to assess resource utilization and calculate monetary costs of a disease such as Alzheimer's disease. Health care resource utilization by the person with dementia and the informal caregiver is assessed,

which makes it possible to determine the level of formal and informal care related to, e.g., Alzheimer's disease. The Resource Utilization in Dementia questionnaire is divided into two parts. Part A consists of four sections for baseline assessment about the informal caregiver: Description of primary caregiver; Caregiver time; Work status; and Health care resource utilization. The section related to Caregiver time consists of six questions and was used for this study, including: personal ADLs hours per day of caregiving; Occasions of personal ADLs during the last 30 days of caregiving; instrument ADLs hours per day of caregiving; Occasions of personal ADLs during the last 30 days of caregiving; Supervision hours per day of caregiving; and Occasions of supervision during the last 30 days of caregiving. In part B there are two sections for the person with dementia: Accommodation; and Health care resource utilization. Part B is the follow-up. Internal validity for personal ADL and supervision was, α=0.82 and α=0.81 respectively and for instrumental ADL, α=0.33. The test-retest reliability for all items in this study was α=0.91-0.98 (Wimo & Nordberg, 2007)

Standardized Mini-Mental State Examination

The Mini-Mental State Examination was originally developed by Folstein, Folstein, and McHugh (1975) to measure cognitive impairment. The Mini-Mental State Examination consists of seven dimensions of cognition: Orientation to time (five items); Orientation to space (five items); Short term memory (three items); Attention and calculation (five items); Recall of three words (three items); Short tasks testing language (eight items); and Visual construction (one item). Reliability and validity have been shown to be satisfactory (Tombaugh, & McIntyre, 1992). The Standardized Mini-Mental State Examination was developed by Molloy et al. (1991) who revised some of the questions, gave more succinct instructions, and set stricter time limits for each question to improve the reliability for the instrument. The Standardized Mini-Mental State Examination consists of: Orientation to time (five items); Orientation to space (five items); Short term memory (three items); Backward spelling (1 item); Recall of three words (three items); Short tasks testing language (seven items); Visual construction (one item). Both the Mini-Mental State Examination and the Standardized Mini-Mental State Examination score range from 0 to 30 and a lower score indicating greater cognitive impairment (Folstein et al., 1975; Molloy et al., 1991). The Standardized Mini-Mental State Examination has shown higher reliability compared with the Mini-Mental State Examination, α=0.92 and 0.69, respectively and for test-retest reliability is α=0.89 and 0.78, respectively (Molloy et al., 1991).

Quality of Life in Alzheimer's Disease

Quality of Life in Alzheimer's Disease (QoL-AD) measure quality of life of persons with dementia and can be both self- and caregiver-reported (Logsdon, Gibbons, McCurry, & Teri, 1999). Quality of Life in Alzheimer's disease instrument consists of 13 items with a score range of 13-52, and a higher score indicates higher quality of life (Logsdon et al., 1999). The Quality of Life in Alzheimer's disease instrument includes

assessment of: Relations with family and friends; Financial concerns; Physical condition; Mood; and Overall experienced quality of life. Each item was scored on a Likert scale from 1 to 4, where 1=poor; 2=fair; 3=good; and 4=excellent. Logsdon, Gibbons, McCurry, and Teri, (2002) have demonstrated that validity was supported by correlation with depression, day-to-day functioning and pleasant events. Test-retest reliability for both persons with dementia and informal caregivers was with α ranging from 0.83 to 0.90. Intra-class correlation for the person with dementia was 0.76, and for the informal caregiver, 0.92 (Logsdon et al., 2002).

External audit

An external audit of data (plausibility and data management) was performed in each of the participating countries to ensure best quality of the data collection. The RightTimeCarePlace coordinator developed a Standard Operating Procedure (SOP) and a data audit checklist, which was followed by each participating country. The audit was performed in all countries by a trained external data monitoring auditor, who had a minimum qualification of a Bachelor's degree in nursing science or a related field, and who furthermore was not involved in the study and had good English language skills. The data check covered at least 20% of randomly selected client record files. Names of participating patients and residents remained concealed from the auditor. Furthermore, the auditor visited at least one or two participating institutional nursing care facilities, and one or two participating home care organizations to verify their participation in the research.

Analysis

Qualitative content analysis

In Study I the interview text was analysed with content analysis (Krippendorff, 2004) as described by Graneheim and Lundman (2004). The transition theory (Meleis, 2010) was used for interpretation of the results concerning the different stages in the dementia disease, and to provide a focus on the participants' answers. Initially the author read each of the four interviews and thereafter repeatedly to get a sense of the whole. Meaning units were identified and later condensed and labelled with codes. The codes were sorted into subcategories based on differences and similarities and, thereafter, into categories, i.e. at a manifest content level. Thus, an overall picture, a latent content and a theme with an underlying meaning emerged. The three co-authors in the paper (Lethin, Hallberg, Karlsson, & Janlöv, 2015) independently reviewed the interviews and discussed the codes in depth with the first author in development of the subcategories, categories and theme, until consensus was reached.

Descriptive analysis

In Study II, availability and utilization of support for informal caregivers caring for a person with dementia living at home were analysed for variation. For each dementia stage, analysis was performed between the participating countries. Thereafter, each author of the research study checked the analysis regarding their own country. For each country, categories of professional providers of support were compiled in the template, the mapping system (Hallberg et al., 2013). For this study, ten different types of support for informal caregivers was analysed for variation. The support was counselling, caregiver support, education, reimbursement, no reimbursement, day care, specialized day care for dementia, residential respite care, specialized residential respite care for dementia, and respite care at home. In order to analyse education systems from a global perspective, a standardized framework, the International Standard Classification of Education (ISCED, 2013), was used to categorize and report data cross-nationally, to ensure comparable data. The framework is categorized into seven levels, as shown in Table 5. In this study professionals were categorized from level three and above. The first author sorted the professionals into levels of education according to the

ISCED's framework. Thereafter, one researcher in each country, co-authors in the paper (Lethin et al., 2016a) checked that the ISCED level was in agreement with their country's educational levels.

Table 5. Level of education according to the International Standard Classification of Education (ISCED) framework (ISCED, 2013).

Level of education	
Level 7	Master's degree or equivalent, vocational education
Level 6	Bachelor's degree or equivalent, vocational education
Level 5	Short-cycle tertiary, vocational education
Level 4	Post-secondary non-tertiary, vocational education
Level 3	Upper secondary, vocational education
Level 1 and 2	Less than upper secondary school

Statistical analysis

For the association analysis (dichotomous data) in Studies III and IV, inclusion of 785 participants was needed and for mean differences, 393 participants was needed to demonstrate effect size with a power of 80% (α=0.05). In home care, drop-out rate was expected to be 15% and consequently 175 informal caregivers and persons with dementia dyads per country were planned to be included with a total of 1400 dyads.

The dependent variable for psychological well-being in Study III, the General Health Questionnaire was dichotomized by using the median value at baseline. The General Health Questionnaire for baseline was dichotomized into "1=psychological well-being" (total score of 0-12: better/same as usual) and "0=low psychological well-being" (total score of 13-36: less/much less than usual). The dependent variable for burden in Study IV, the Zarit Burden Interview was dichotomized by using the median value at baseline. At baseline the Zarit Burden Interview was dichotomized into "0=no burden" (total score of 0-20: never/rarely) and "1=burden" (total score of 21-88: sometimes/-quite frequently/nearly always). At follow up, any change in psychological well-being was dichotomized into "0=no increase" (no change/worse) and "1=increase" (better). Change in burden was dichotomized into "0=no increase" (no change/better) and "1=increase" (worse). For the General Health Questionnaire and the Zarit Burden Interview, missing data were imputed with the mean score if <10% of items were missing.

The independent variables used in the collected data, were expected to explain the informal caregivers increased psychological well-being and burden related to factors of the informal caregiver, the person with dementia, and formal care. All variables are presented in Table 4. One question about formal care "How satisfied are you with the provided care by the dementia-related service?" was dichotomized into "0=dissatisfied" (very dissatisfied/ dissatisfied/ neither satisfied nor dissatisfied) and "1=satisfied" (satisfied/very satisfied). When one item was missing in the Caregiver Reaction Assessment scale and the EQ-5D-3L, no total score was calculated. For both the Standardized Mini-Mental State Examination and the Charlson Comorbidity Index, handling of missing data was not applicable, i.e. no summary score was calculated. For the Quality of Life in Alzheimer's disease, a maximum of two missing items were replaced with the mean score. For the Neuropsychiatric Inventory Questionnaire and the Katz Index of Independence in Activities of Daily Living, no missing values were imputed. For the Katz Index of Independence in Activities of Daily Living, no total score was calculated if one item was missing. Mean score was imputed in the Cornell Scale for Depression in Dementia with a maximum of three missing items. No total score was calculated if more than three items were missing. The answer option "unable to evaluate" was treated as a missing value. For the CLient INTerview Instrument, mean score was imputed if a maximum of one item was missing. If more than one item was missing, no total score was calculated. However, an exception was made if the question about gardening was missed or not applicable, then the mean score was imputed.

The dependent variables for psychological well-being in Study III, the General Health Questionnaire and for burden in Study IV, Zarit Burden Interview were continuous variables so logistic regression analysis was chosen for the bivariate and multivariate regression models. Median values were calculated because the data was skewed. Two different perspectives were analysed in studies III and IV. The studies were, prospectively with 3-months follow-up to identify both factors associated with psychological well-being (Study III) and burden (Study IV) at baseline, and factors predicting change in psychological well-being (Study III) and burden (Study IV) for the informal caregiver caring for a person with dementia living at home. A bivariate regression analysis was performed for each individual associated factor of psychological well-being and burden at baseline, and for increased psychological well-being and burden at follow up. To identify predicting factors for increased psychological well-being in III and burden in Study IV, three multivariate logistic regression models were performed for the independent variables regarding the informal caregiver, the person with dementia and formal care, respectively. Backward stepwise multivariate regression analysis was performed and p=<0.05 was regarded as significant. For all analyses SPSS, version 22.0 (IBM Corp., Armonk, NY, USA) was used.

Ethical considerations

The International Epidemiological Association (IEA)`s guidelines for good practice in epidemiological research (IEA, 2007) were followed in the RightTimePlaceCare project. Furthermore, each country obtained ethical approval from its own country - specific legal authority for research on human beings, as listed in the following, giving approval reference numbers, were appropriate, in paranthesis: the Ethics Review Committee on Human Research of the University of Tartu (196/T-3) and the Ethical Committee of the Hospital District of South-West Finland (8/2010), Finland; the Comité de Protection des Personnes Sud-Ouest et Outre-Mer, Toulouse, France (09 202 07); the Nursing Science Ethical Committee at the University of Witten/Herdecke, Germany; the Medical Ethical Committee of the Academic Hospital Maastricht/Maastricht University, the Netherlands (MEC 10-5-044); the Ethical Committee of the Hospital Clinic in Barcelona, Spain (2010/6031); the Regional Ethical Review Board in Lund, Sweden (2010/538); and the National Research Ethics Service, North West 5 Research Ethics Committee, the United Kingdom (11/NW/0003) (Verbeek et al., 2012). The studies were performed in accordance with the Swedish Act concerning the Ethical Review of Research (SFS 2003:460), The Secrecy Regulation (SFS 1980:657) and the Swedish Data Protection Act (SFS 1998:204). This study follow the ethical principles of the Helsinki declaration (World Medical Association Inc., 2009) and the ethical principles as described by Beauchamp and Childress (2001), regarding respect for autonomy, beneficence, non-maleficence and justice.

The principles of respect for autonomy

The principle of respect for autonomy refers to individuals' rights, enabling them to make reasoned informed choices as autonomous persons. In Studies I-III this was established through information, both verbal and written and informed consent from the participants. The interviews can be perceived as an intrusion into the privacy of persons with dementia and their informal caregivers. To minimize intrusion, the intention was to provide clear and complete information about the study to the participants. When a proxy was used as an agent for service users, there may be an element of uncertainty regarding whether the data are consistent with the answers that would have been given by the person with dementia him-/herself, if able to respond.

The interviews in the home were answered by informal caregivers as proxy. Using a proxy made it possible to get information about a person with dementia, regardless of their cognitive function. This will include information about how they live with the disease regarding depression symptoms, comorbidity, dependency and neuro-psychiatric symptoms. In the studies, the cognitive function of the persons with dementia ranged from a Standardized Mini-Mental State Examination score of 9 to a score of 21.

The principles of beneficence and non-maleficence

The principles of beneficence are to do good with regard to risk versus benefits. Throughout the studies in this thesis, informal caregivers of persons with dementia have received more attention and we hope this will contribute to a discussion of how dementia care works. This can in turn lead to development and improvement of health care and social services, strengthening support to informal caregivers. The studies may also make professionals more aware of factors that increase informal caregivers' burden and psychological well-being. The implication of non-maleficence is to do good and no harm, e.g. not to harm the participants through the interviews. The risk of doing harm in Study I, III and IV was considered low in relation to the potential benefits of the research. Data from the interviews were treated in such a way as that no unauthorized person could access the information. Furthermore, professionals interviewing participants were sworn to secrecy under the Secrecy Regulation (SFS 1980:657). In Study I, III and IV, each participant was assigned a code number. Code numbers were stored separately in locked cabinets, which made it impossible to track any of the participants. Interviews may remind, persons with dementia of their lack of cognitive ability, which can lead to discomfort and a sense of inadequacy. To minimize such experiences for the person with dementia, the interviews were conducted by personnel with experience in interviewing older persons and specific training for the task. Where a person with dementia experienced discomfort during the interview, health care professionals were contacted to acknowledge the person's problem.

The principles of justice

The principle of justice refers to equitable distribution of benefits, risks and costs. Informal caregivers caring for older persons with dementia living at home, and in other similar caregiving situations should be treated equally. The participants were recruited without any discrimination regarding age, gender or relationship to the person with dementia. Participating countries followed the Standard Operating Procedure for the project, an external audit was performed in each country, and data were treated as documented in the Standard Operating Procedure.

Main results

The main results of this thesis indicates that, informal caregivers caring for a person with dementia experience that they require collaboration with formal care to get the needed support, with support adjusted to the stages of the dementia disease. Formal support for informal caregivers caring for older persons with dementia was mostly available, but was utilized by few. Professionals with higher education and specialized in dementia provided support for informal caregivers. Factors associated with presence of psychological well-being and burden and over time were the informal caregivers' experience of caregiving and quality of care, and the amount of caregiving for the person with dementia.

The demand side - informal caregivers experiences of formal care

In Study I (Lethin et al., 2015), informal caregivers' experiences of formal care when caring for a person with dementia, were captured in the theme "Family caregiving requires collaboration with formal care to get support adjusted to needs specific to the stages of dementia". The theme included the categories "The dementia diagnosis – entry into formal care as a novice family caregiver", "Needing expanded collaboration with formal care to continue care at home", and "Being dependent on a nursing home and trying to maintain involvement". In Figure 2 the informal caregivers' three turning points in their transition are presented in relation to the course of the dementia disease, and their needs from formal care.

When informal caregiver´s enter the role of caregiving, they enter a new life situation with new demands, entailing a transition from a novice informal caregiver to an experienced informal caregiver. The dementia diagnosis is the first step into the process of the dementia disease and becomes their formal entry into the role of informal caregiver and of starting collaboration with formal care. The need to be prepared for the caregiving situation becomes urgent, and the need for knowledge, such as information about the dementia disease and available care and support, so that they will be better equipped to handle the person's cognitive impairment, becomes important. Some participants experienced burden when caring for a person with dementia and became aware of their need for support from formal care. They

experienced formal care as accommodating. Other expressed disappointment with formal care and had experiences of isolation. They felt, they had to fight for care and support for both themselves and the person with dementia. Informal caregivers proceed to the next turning point in their transition of becoming a caregiver, from independence to dependency, as the dementia disease progresses. They may need to rely on other family members and relatives to enable them to keep on caring at home and retain independence, for both themselves and the person with dementia. Continuing to care for the person with dementia at home implies having to establish collaboration with various formal care providers, both in health care and in social services. Having a contact person who can facilitate communication with different care providers was expressed as essential by many of the participants. Some participants said that social workers gave them a sense of security and confidence, but others described that the social worker was reluctant to meet their needs. They expressed worry about the future and their own capacity to both continue providing care while struggling for support and some even had had suicidal thoughts. Finally, when the person with dementia moves to a nursing home and becomes totally dependent on formal care, there is a third turning point in the participants' transition as a caregiver as they need to build trusting relationships with the nursing home staff. It was important for the informal caregivers to communicate with the staff and be involved in the care of and the care planning for the person with dementia. When the participants experienced the staff as responsive to their needs, both for themselves and for the person with dementia, both communicating and collaborating, they described being involved in the care and having trust in formal care. Participants who experienced a lack of communication felt excluded and ignored and had no confidence in the staff and formal care.

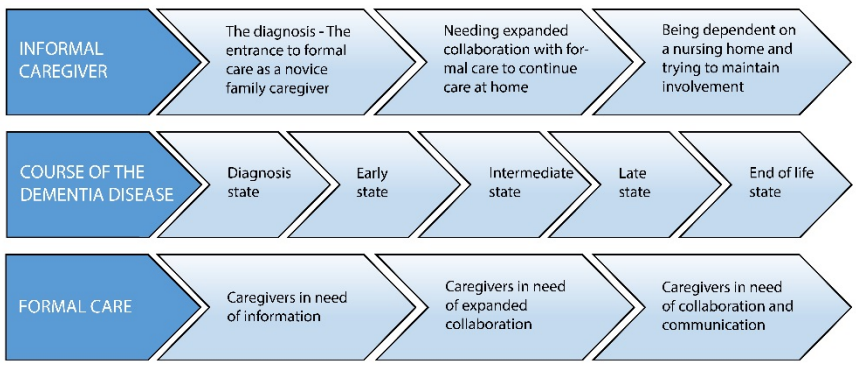

Figure 2. Informal caregivers in transition as caregivers in relation to the stages in the dementia disease and their need for support from formal care.

The supply side - formal support for informal caregivers

The result from Study II (Lethin et al., 2016a), showed that overall there was high availability of the support explored regarding counselling, caregiver support, and education, from the diagnosis to the intermediate stage. The availability of this kind of support decreased in the late to end of life stages. Utilization was low, although there was a small increase in the intermediate stage. Day care and respite care at home were highly available in the diagnosis to the intermediate stage, with a decrease in the late to end of life stage. Both day care and respite care at home were utilized by few or no informal caregivers throughout the different stages of the dementia disease. There were differences between countries concerning both availability and utilization. Independently of the range of availability, the trend was that the utilization was low and/or decreased in the later stages of the dementia disease. Results were slightly different when dividing the support into direct support for informal caregivers (counselling, support, education, reimbursement) meaning that the support was delivered directly to the informal caregiver, and indirect support (day care, respite care, respite care at home) meaning that the support was delivered to the person with dementia as relief for the informal caregiver. Direct support was available in all countries (but only to a limited degree in Estonia); indirect support was less common in Germany, Spain and Estonia. Financial reimbursement was uncommon in all countries except for the United Kingdom (available for all, utilized by few), Germany (available for most, utilized by most), and the Netherlands (available for all, utilized by few). In all countries except Germany, financial reimbursement was not available through all stages of the dementia disease.

In Study II, professionals specializing in dementia (holding a Bachelor's to a Master's degree) provided counselling and education. Regarding counselling these could be geriatricians, psycho-geriatricians, and registered nurses, with or without a Bachelor's degree; regarding education, they were geriatricians. Support for informal caregivers as well as day care, respite care, and respite care at home was provided by professionals specializing in dementia, whose education and training ranged from upper secondary schooling to a Master's degree. A geriatrician, a registered nurse, or a state examined nurse could provide support, while a geriatrician normally provided information. Day care and respite care was provided by professionals specialized in dementia, such as geriatricians, psycho-geriatricians, registered nurses or state-examined nurses. Respite care at home was provided by professionals, such as registered nurses specializing in dementia. Countries with national guidelines for people with dementia seemed to be more aware of the importance of professionals with specialist training in dementia care when providing support.

Outcomes - psychological well-being and burden among informal caregivers

An overview of factors associated with informal caregiver psychological well-being and burden, and predictive factors over time in Study III (Lethin et al., 2016b), and in Study IV is presented in Table 6a and 6b. In Study III, the logistic bivariate regression model showed that factors associated with the informal caregivers' psychological well-being were younger age, female gender, living with the person with dementia and being the spouse of the person with dementia. Furthermore, positive experience of caregiving, less caregiver burden and higher quality of life were other factors associated with the presence of informal caregivers' psychological well-being.

Table 6a. Factors associated with caregiver psychological well-being and predictive factors over time.

	Adjusted R	**Associated factors for well-being**	**Adjusted R**	**Predictive factors for increased well-being**
IC	0.428	Experiences of caregiving Health Caregiver burden Health-related quality of life	0.306	Experiences of caregiving Health Caregiver burden Informal care provision Health-related quality of life
PwD	0.208	Male gender Quality of life Neuropsychiatric symptoms Distress Depression in dementia	0.119	Male gender Quality of life Neuropsychiatric symptoms Severity Distress
FC	0.063	Experiences of quality of care Continuity with staff Clean house Garden maintenance General satisfaction Use of dementia specific care	0.045	Experiences of quality of care Continuity with staff Clean house General satisfaction

Adjusted R=in a logistic regression model, adjusted R is the proportion of variation in a dependent variable, which is explained by the number of independent variables.; FC=formal care; IC=informal caregiver; PwD=person with dementia.

Informal caregiver psychological well-being was further present if the person with dementia was diagnosed as having vascular dementia and had less comorbidity, less cognitive impairment and higher quality of life. In addition, if the person with dementia needed less help in activities of the daily living and had fewer neuropsychiatric and depressive symptoms, informal caregiver psychological well-being was more commonly present. Furthermore, positive experience of quality of care and more often using dementia specific service were associated with informal caregiver psychological well-being. The same factors that were associated with informal caregiver psychological well-being were associated with increased psychological well-being, except for age of the informal caregiver, being the person with dementia's wife, the dementia diagnosis of the person with dementia and use of dementia specific service.

The logistic multivariate regression model showed that factors associated with informal caregivers' psychological well-being were a positive experience of caregiving, less caregiver burden, and higher quality of life for the caregiver. Informal caregivers' psychological well-being was more commonly present if the person with dementia was male, had higher quality of life and fewer neuropsychiatric symptoms. Furthermore, positive experience of quality of care, and more use of dementia specific care were associated with informal caregivers' increased psychological well-being. Factors predicting informal caregivers' increased psychological well-being were the same as the associated factors above, but included less informal caregiving and not including the use of dementia specific care.

In Study IV, factors associated with presence of informal caregiver burden in the logistic bivariate regression model, were female gender of the informal caregiver, and living with the person with dementia as well as relation to the person with dementia. In addition, a greater amount of informal care provision including supervision and less psychological well-being and health-related quality of life of the informal caregiver were associated with informal caregiver burden.

Furthermore, male gender of the person with dementia, more dependence in activities of daily living, lower cognitive function and less quality of life in the person with dementia, and more neuropsychiatric symptoms were associated with informal caregiver burden. Less positive experience of formal care at home and less use of dementia specific service were likewise associated with informal caregiver burden. The same factors as listed above were associated with increased burden, except symptoms of depression and the need for support in activities of daily living.

Table 6b. Factors associated with informal caregiver and burden and predictive factors over time

	Adjusted R	Associated factors for burden	Adjusted R	Predicting factors for increased burden
IC	0.407	Age Relation to the PwD Informal care provision PADL last 30 days caregiving IADL last per day caregiving Supervision last 30 days Psychological well-being Health-related quality of life	0.018	Living with the PwD Psychological well-being
PwD	0.270	Male gender Cognitive function Quality of life Neuropsychiatric symptoms Distress	0.023	Neuropsychiatric symptoms Severity
FC	0.054	Experiences of quality of care Food Continuity with staff Total score	0.008	Experiences of quality of care Total score

Adjusted R=in a logistic regression model, adjusted R is the proportion of variation in a dependent variable, which is explained by the number of independent variables.; FC=formal care; IC=informal caregiver; PwD=person with dementia.

In the logistic multivariate regression model, factors associated with informal caregiver burden were higher age in the informal caregiver, the relation to the person with dementia, low perception of psychological well-being and health-related quality of life by the informal caregiver, and the amount of informal care provision. Furthermore, factors predicting increased informal caregiver burden were male gender of the person with dementia and more neuropsychiatric symptoms, lower quality of life and cognitive function of the person with dementia, as well as lower informal caregiver experiences of quality of care. Factors predicting increased burden in the informal caregiver were the informal caregiver living with the person with dementia and perceiving low psychological well-being. Factors predicting increased informal caregiver burden were more neuropsychiatric symptoms in the person with dementia and lower informal caregiver experience of quality of care.

Discussion

General discussion of findings

The result of the studies in this thesis showed that informal caregivers caring for persons with dementia, experience formal care to be reactive to their need of support, rather than proactive. Support seems to be available in the health care and social service system. However, this support was only utilised to a small degree by the informal caregivers. Several factors were identified to affect the informal caregivers perceived psychological well-being and burden, related to the informal caregivers themselves, the person with dementia and formal care. The findings are discussed in light of the framework for "Patient-centred access to health care" developed by Levesque et al., (2013). The framework includes both the informal caregivers caring for a person with dementia, i.e. the demand side and the health care and social service systems, i.e. the supply side (Figure 1). The framework seems to be suitable for interpretation of the results of the included studies in this thesis regarding informal caregivers' experiences of formal care, and their need for access to support to promote their psychological well-being and prevent burden. Richard et al. (2016) suggestions for future research include examining where in the health care and social service system, improvements are needed to achieve equitable access for vulnerable populations. This means pairing the dimensions of access, i.e. the demand side and the supply side, as they are not independent constructs. This was performed in this thesis by using the framework "Patient-centred access to health care" (Levesque et al., 2013), rephrased to "Person-centred access to health care and social services".

The demand side – informal caregivers experiences of formal care

Informal caregivers caring for a person with dementia are in a vulnerable context, which implies a changing process, a situation where they need to master several transitions at the same time. The transitions includes becoming an informal caregiver in the dementia disease progress and starting to collaborate with formal care, from being independent on formal care when caring for a person with dementia living at home, to being totally dependent on the formal care when the person with dementia moves to a nursing home. As the dementia disease progresses, informal caregivers become increasingly aware of their need for support from and collaboration with formal care. They need support

adjusted to their individual needs and also to the specific stages of the dementia disease. The result from this thesis showed that the informal caregivers experienced a transition process with three main turning points: the dementia diagnosis; the point at which they realized increased need for formal care in order to continue caring at home; and the time when the person with dementia moved to a nursing home. According to the framework by Levesque et al. (2013), informal caregiver access, i.e. utilization of care and support is dependent on their ability to interact with the accessibility. Accessibility is in turn dependent on the informal caregivers' ability to perceive a need, seek, reach out, pay for, and engage with the services. To approach health care and the social service system, the informal caregivers first has to realize the need of care and support. This ability to perceive is dependent on the informal caregivers' health literacy, knowledge and beliefs in health and sickness. This ability might be crucial when the dementia diagnosis is made within the health care system (Winblad et al., 2016). In this thesis, the result showed that the dementia diagnoses was the first turning point which is similar to the results reported by Rose and Lopez (2012). Diagnosis is generally also a requirement for accessing the health care and social service systems (Winblad et al., 2016) and necessary for obtaining suitable care at the appropriate time (Allen, Oyebode, & Allen, 2009; Bakker et al., 2010). At this early stage, the informal caregiver has the main responsibility for the care of the person with dementia and may need formal support such as counselling, education and/or support individually or in groups.

The informal caregivers in this thesis identified their needs for care and support as a need for information and knowledge about the dementia disease and about available care and support, which would enable them to be prepared for the caregiving situation. Some informal caregivers' experienced formal care as accommodating to their needs, while others experienced it as disappointing when they had to fight for care and support. A previous study has shown that families report lack of knowledge and a need for information about the course of the disease and the benefits of social service resources (Gibson & Anderson, 2011; McCabe et al., 2016). This was confirmed in the study, where informal caregivers expressed exhaustion trying to find information about available care and support in a fragmented system with different professionals and organisations responsible for the different types of care and support, as also reported by Wiles (2003) and McCormack, Mitchell, Cook, Reed, and Childs (2008).

In connection with the first turning point informal caregivers usually enter both the health care and the social service system, depending on whether they had any previous needs. The informal caregiver has to seek and have to want to receive formal care; they also have to reach out for the needed care and support. This ability to seek and reach out is dependent on the informal caregiver's autonomy and capacity to seek the care needed and also on the support being reachable, which may be an issue in some rural areas. A previous study showed that the informal caregiver hesitated to seek support which may be due to inner barrier regarding acceptance and decision making for the person with dementia. This may delay the time at which the informal caregiver actually seek care and support (Stephan, Möhler, Renom-Guiteras, & Meyer, 2015b). The

informal caregiver also needs to have financial ability, i.e. to be able to pay for the costs that arise. This includes both money and time and are dependent on the country's welfare system. The support should meet the informal caregiver's needs to motivate them to commit to and participate in the care and enable completion of the agreed care (Levesque et al., 2013).

The second turning point identified in this thesis was when the informal caregiver became aware of an increased need for formal care to be able to continue caring at home. This turning point was also reported by Rose and Lopez (2012) in their discussion of advance care planning concerning health care considerations. The informal caregivers in that study desired guidance with advance care planning for the person with dementia which can be considered as a proactive action. Increased cognitive impairment of the person with dementia increases the demands on the informal caregiver concerning activities of daily living, communication and supervision time. Collaboration with formal care increases as the person with dementia independence gradually decreases. The informal caregivers might need formal care provision such as day care or respite care and help with activities of daily living for the person with dementia. The participants in our study experienced formal care as reactive to their needs, rather than as being proactive and foreseeing their need which is in line with the result of Sutcliffe, Roe, Jasper, Jolley, and Challis (2013).

The third turning point identified in this thesis was when the person with dementia was moved into a nursing home because of extensive care needs. Rose and Lopez (2012) defined this turning point as changes in care settings. At this point the informal caregivers are totally dependent on formal care which has the main responsibility for the person with dementia. However, it was important for the caregivers in our study to be involved in the care of the person with dementia. They felt a need to build trusting relationship with the staff in the nursing home, which is in line with the findings by Karlsson et al. (2015). Being involved in the care of the person with dementia meant the possibility to participate in the care planning and being listened to, also reported by Lopez, Mazor, Mitchell, and Givens (2013).

Developing knowledge about the dementia disease and learning care skills to provide assistance with activities of daily living may promote informal caregivers well-being and a healthy transition into the caregiving role. Conversely, to have to struggle for care and support promotes an unhealthy transition to increased use of formal care and may decrease the informal caregivers' well-being and increase their experienced burden. Informal caregiving requires collaboration with formal care to get support adjusted to the individual's needs and specific to the stages of dementia. Formal care needs to be proactive and share information about and deliver available care and support early on in the dementia course. Interventions should focus on facilitating a healthy transition for the informal caregiver, through the course of the dementia disease to ensure their well-being.

The supply side - formal support for informal caregivers

The health care and social service systems seem to have support available that is not utilised by the informal caregivers of persons with dementia which may be due to issues of accessibility of the system. The result of this thesis show that counselling, caregiver support, and education were highly available in six of the participating European countries from diagnosis to the intermediate stage of the dementia disease, decreasing in the late/end of life stages, but that these services were rarely utilized. In line with the results of this thesis, a study by Bökberg et al. (2015) exploring care and service at home for persons with dementia in European countries also showed that availability was higher than utilization. Formal care access, i.e. availability of health care and social support is dependent on the ability to interact with the accessibility (Levesque et al., 2013). To make health care and social services approachable, proactivity is needed through transparency and outreach activities, and by giving information about available care and support (approachability). The findings of a study by Stephan et al. (2015b) show that professionals in health care and social service expected to be contacted by the informal caregiver.

The support also has to relate to social and cultural factors of the informal caregivers to enable them to accept the support (acceptability). In addition, the support needs to be reachable geographically and at all times in both rural and urban areas and has to be approachable concerning opening hours. The acceptability aspect includes characteristics of the professionals, including their ability to make appointments (availability and accommodation). The findings in this thesis show that countries with health care and social service systems based on national guidelines on dementia care, seemed to be more aware of the need for providing support, the importance of professionals specialized in dementia care and the accessibility of the support.

Six out of eight countries had professionals specialized in dementia care and were able to offer this support to informal caregivers, such as day care and respite care. Professionals had a wide range of education and training, from upper secondary schooling to a master's degree. A previous study reports that implementation of national guidelines for person-centred care, i.e. dementia strategies in nursing homes increased person-centeredness after 12-months which enabled professionals to provide the needed care and activities (Edvardsson, Sandman, & Borel, 2014). Furthermore, McKinlay et al. (2006) showed that adherence to guidelines varied depending on patient´s health conditions and the professional´s length of clinical experience which implies that adherence to specific guidelines may increase awareness in experienced professionals.

Even though support was available, as shown in this thesis, there might be obstacles that prevent the informal caregiver from actually utilizing the support offered. In a review by Phillipson, Magee, and Jones (2013) predisposing factors associated with non-use of services were demographic and social structural variables, beliefs about health, such as perceiving an obligation to care and that the service was regarded as

unreliable by the users. The findings of a previous study of respite care for frail older people showed that the utilization of available support depends on informal caregiver trust and confidence in the support (Stockwell-Smith, Kellett, & Moyle, 2010). The support needs to be affordable and not time consuming when utilized (affordability) which may depend on each country's welfare system and the informal caregivers financial ability. Moreover, the support has to be adequate for the informal caregivers including interpersonal quality, continuity and coordination (appropriateness). It also has to meet individual needs of support that the informal caregivers have through the course of the dementia disease (Moise et al., 2004; McCabe al., 2016).

Informal caregivers have extensive responsibility for health care and for social well-being of a person with dementia living at home and their responsibility will probably increase in the future. This is due to the demographic changes taking place with increased life expectancy, and consequently an increase of people with dementia diagnosis living at home. The increase in numbers of persons with dementia in turn will place great responsibility on the health care and social service systems to be accessible. Accessibility may also be dependent on each welfare regime. Many European countries have up-to-date, national guidelines or policies with recommended treatment, pharmacological and non-pharmacological (Winblad et al., 2016). Mapping health care and social service systems of support for informal caregivers of older persons with dementia may be a valuable tool for evaluating existing systems including professional providers and for policy making, nationally as well as internationally.

Outcomes - psychological well-being and burden among informal caregivers

In the framework for "Patient-centred access to health care", health care and the social service impact include outcomes of personal health and satisfaction with the system (Levesque et al., 2013; Richard et al., 2016). Several associated factors were identified in this thesis. These were related to the informal caregiver, the person with dementia and formal care and affecting the informal caregivers outcomes concerning their personal health, psychological well-being and burden, at baseline and over time, and as well as their satisfaction with formal care.

Caring for a person with dementia living at home is a multidimensional task and a continuous responsibility for informal caregivers. The extent of care that informal caregivers provide when caring for a person with dementia seems to affect their psychological well-being and health-related quality of life as well as perceived burden. In this thesis, informal caregivers' psychological well-being was among others associated with positive experience of caregiving, better perceived health and health-related quality of life. A previous study with both informal caregivers of persons with dementia and informal caregivers of persons without dementia showed that well-being for the informal caregivers was directly affected by perceived social support, burden, self-esteem and hours of caregiving (Chappell & Reid, 2002). The results of this thesis

showed that psychological well-being in informal caregivers was associated with perceived positive experience of caregiving, specifically reflected in the domains of self-esteem, support from family, less impact on finances, ability to schedule spare time, as well as their own perceived health. A previous study including informal caregivers to older people in general showed that less contact with colleagues and friends was associated with high psychological distress suggesting that it is important to keep social contacts (Yiengprugsawan, Seubsman, & Sleigh, 2012). As shown in this thesis, informal caregivers who provided higher amount of care for the person with dementia, regarding personal and instrumental activities of daily living and time supervising the person with dementia, was associated with lower health-related quality of life and presence of caregiver burden which is in line with the findings of Kim, Chang, Rose, and Kim (2012) In addition, the informal caregivers that experienced presence of psychological well-being provided less care for the person with dementia.

A heavy workload in informal caregiving implies a perceived increased burden and negatively affects caregivers' psychological well-being, which has been shown to be the largest differences between caregivers and non-caregivers (Pinquart & Sorensen, 2003). In this thesis, supervision was one factor of importance. A higher amount of supervision time of the person with dementia implied significantly more burden for the informal caregiver compared to informal caregivers with less supervision time. Informal caregivers with perceived psychological well-being performed less supervision time. This was similar to the result of Bakker et al. (2012) and Haro et al. (2014), showing that supervision of a person with dementia was the largest part of informal care. Supervision time of the person with dementia to prevent the person from hurting themselves can be interpreted as a dementia specific factor that distinguishes informal caregivers of persons with dementia from informal caregivers of persons without dementia. In addition, informal caregivers to persons with dementia that perceives psychological well-being provide less supervision compared to informal caregivers that perceive burden. This emphasize the importance for professionals in health care and social services, to identify vulnerable caregivers in order to be able to provide them with support, such as respite care or day care for the person cared for. In addition, by enabling informal caregivers to maintain their social network and encourage families to support each other and share the caregiver responsibility, informal caregiver psychological well-being and relieve caregiver burden might be increased. This could also enable them to continue caring for the person with dementia at home.

Further on, in the dementia process, caring for a person with dementia living at home, requires more extensive informal care provision. The person with dementia has a loss of independence owing to increased cognitive impairment which may influence the informal caregiver´s perceived psychological well-being as well as burden. The result of this thesis show that higher quality of life and fewer depressive symptoms in the person with dementia were associated with psychological well-being of the informal caregiver, while lower cognitive function and neuropsychiatric symptoms in the persons with dementia were associated with informal caregiver burden. A previous meta-analysis

showed that depressive behaviours of the person with dementia were the most distressing behaviour for informal caregivers affecting the informal caregivers' well-being. Agitation and aggression in the person with dementia had less impact on the informal caregivers' well-being (Feast, Moniz-Cook, Stoner, Charlesworth, & Orrell, 2016). The importance of addressing the informal caregivers' psychological health has also been shown in a previous study (McCabe et al., 2016). Professionals need to be aware of the relationship between neuropsychiatric symptoms and informal caregivers' psychological well-being as well as burden, and further studies is needed in this area.

Experience of care provided by formal care for the person with dementia seems to be one important dimension affecting informal caregivers' perceived psychological well-being and burden. When the informal caregiver experienced formal care as positive this resulted in presence of caregiver psychological well-being. Important formal care factors were continuity in care workers, having a clean home, and general caregiver satisfaction with formal care and the use of dementia specific care. On the other hand, the findings in this thesis show that informal caregivers' negative experiences of formal care was associated with informal caregiver burden and regarding the food served, continuity in care workers and the total score. Studies focusing on informal caregivers' experiences of quality of care at home and informal caregiver psychological well-being and burden when caring for a person with dementia living at home are sparse. Previous studies have focused on informal caregiver perception of hospital care. The findings of Janse, Huijsman, and Fabbricotti (2014) showed that satisfaction with formal care decreased if the caregivers did not know which professional to call in case of complaints, problems, or emergencies which might be possible to relate to continuity in care workers.

Dementia specific care for persons with dementia is provided by professionals with specific knowledge and training, assuming that the professionals know how to best care for both the person with dementia and the informal caregiver. A previous study by Goldberg et al. (2013), compared best practice care to standard care for persons with dementia or delirium, in an acute geriatric or general medical ward. The findings showed that patients in the acute geriatric ward were significantly more often in a positive mood or engagement, and they experienced more staff interactions that met their emotional and psychological needs. More informal caregivers were satisfied with the care, and severe dissatisfaction decreased. The result in this thesis showed that informal caregivers' negative experiences of formal care was associated with informal caregiver burden and influenced the total score of quality of care. On the other hand, informal caregivers' perceived well-being was associated with positive experience of formal care and satisfaction with specific dementia care.

It may be assumed that if professionals with specific training and engagement are caring for the person with dementia and make them feel good, the informal caregiver might be more satisfied with the care. In addition, dissatisfaction might relate to other factors such as behavioural and psychiatric symptoms as shown in a previous study included in cognitively impaired patients in hospital settings (Whittamore, Goldberg, Bradshaw,

& Harwood, 2014). Other factors that can affect the caregiver psychological well-being are the informal caregivers' levels of self-esteem, mastery and neuroticism (Brodaty & Donkyn, 2009). Experience of care provided by formal care for the person with dementia seems to be one important factor affecting the informal caregivers' perceived psychological well-being and perceived burden. Professionals in the health care and social services should be aware about the importance of continuity of care workers and provide appropriate care and treatment for both the informal caregiver and the person with dementia.

Pairing the demand side and the supply side

To find determinants to access health care and social service systems, pairing of the demand side and the supply side is recommended by Richard et al. (2016). In this thesis an attempt is made to determine which part of the health care and social service system to target for development of support for informal caregivers of persons with dementia. By pairing the demand-side dimensions of accessibility of support services with the supply-side abilities of informal caregivers to access support services, factors affecting the accessibility may have been identified (Figure 1). In this thesis, when pairing *approachability* with *ability to perceive*, an important factor identified on the demand side was the informal caregivers' realizing a need of support, such as knowledge about the dementia disease and information about available support. Some informal caregivers experienced formal care as disappointing and hard to reach in a fragmented system. The factors identified on the supply side were different health care and social service systems in European countries. Support to the informal caregivers was available but rarely utilised. Pairing *acceptability* with *ability to seek*, the factors identified on the demand side was the informal caregivers' attempt to avoid dependency but needing expanded collaboration with formal care to be able continue caring at home. Factors identified on the supply side was that acceptable and individualised support has to be proactively offered by formal care, proactivity.

For *availability and accommodation* and *ability to reach* factors identified on the demand side was when the informal caregivers experienced disappointment with formal care when they needed to collaborate and building trusting relationships. Identified factors on the supply side was available support but formal care was reactive to the informal caregivers' need of support. When paring *affordability* with *ability to pay*, factors on the demand side include the informal caregivers' social capital and health insurance as well as loss of income. A factor identified on the supply side in this study was the amount of reimbursement, depending on each country´s welfare system. For *appropriateness* and *ability to engage*, one factor identified on the demand side was when the informal caregivers experienced becoming dependent on formal care. They tried to maintain involvement in the care of the person with dementia, but felt ignored and with no confidence for formal care. Identified factors on the supply side was different health care and social service systems in the European countries, different professionals that

provide the required care and support as well as existing National guidelines. Determinants seem to exist in all five dimensions of accessibility. It seems essential to improve each countries health care and support system to facilitate the informal caregivers' access to care and support for themselves and for the person with dementia. This may promote a healthy transition in the caregiving role through the course of the dementia disease and may affect the outcomes for the informal caregiver such as psychological well-being and burden.

Methodology

In Study I, the qualitative study in this thesis, trustworthiness was established by ensuring credibility, dependability, conformability and transferability (Lincoln & Guba, 1985). To ensure credibility, the informal caregivers' experiences of formal care when caring for a person with dementia, living at home or in a nursing home were established by their own descriptions. To achieve variation in the sample, informal caregivers of different ages, gender and experiences of formal care, and from different municipalities in southern part of Sweden, were selected. The researchers performing the study all had knowledge of the context of the Swedish health care and social service systems.

To ensure dependable data, further to ensure repeatability and consistency and to strengthen the conformability of the findings (Graneheim & Lundman, 2004), the authors independently read the transcribed text from the interviews and identified meaning units responding to the research question. Sub-categories, categories and themes were discussed between the authors until agreement was reached. To show similarities and differences and to give an idea of the type of discussions that went on between the informal caregivers in the transcribed text from the interview, quotations have been included in the study. Both the recruitment of participants', and the data collection method and context have been described to make the results transferable. The analysis of the interview texts has been described in detail, to enable the reader to follow the authors' involvement in the analysis. The researchers strived to interpret the text for meaning and essence to understand the statements unconditionally and without pre-understanding. Limitations in this study were the wide range of disease processes in the sample, with persons with dementia having memory problems during a period ranging from 1.5 to 15 years. This might have influenced the results, implying a broader range in length of experience with formal care for some participants'. For some participants their experiences were experienced recently, while for other participants the experience was retrospective which might have been influenced by their recall.

All participants were born and lived in Sweden, which may limit the results. In the pilot group, three out of four participants had experience of home care and one participant had experience of both formal home care and nursing home care, implying that

experience of formal home care was only reflected from one participants view. Both manifest and latent content analysis was chosen to answer the research question. In the study, eleven participants had experience of formal care at home while twelve had experience of formal care both at home and at a nursing home. Our findings may have been different if separate groups had been selected for home care versus nursing home care, to gain a deeper understanding of each group, or if separate spouse and child groups had been chosen.

Transferability of the results to other countries may be limited as other countries may have different care and support systems. The focus groups were carried through in all eight European countries during 2011 and have been analysed with content analysis and the result have been published for Germany (Stephan et al., 2015b), Spain (Risco, Cabrera, Farré, Alvira, Miguel & Zabalegui, 2016), Sweden (Lethin et al., 2015), and the United Kingdom (Sutcliff et al., 2013) which may be considered as primary data and for all eight countries (Karlsson et al., 2015) considered as secondary data. Stephan et al. (2015) investigated the perception of both informal caregivers and health care professionals. The result showed comparable perceptions of successful collaboration among the informal carers and the health care professionals. The major challenge seemed to be the initial contact. The health care professionals expected to be contacted by the informal caregiver, and the informal caregivers hesitated to make contact. In the study by Risco et al. (2016) the result showed among other things that insufficient information was provided and not according to the stages in the dementia disease. Furthermore, there was a need for specific dementia care, and a lack of communication between health care providers. The result of Lethin et al. (2015) study is presented in the present thesis. The findings of the study by Sutcliff et al. (2013) showed that some informal caregivers and persons with dementia experienced difficulties or delays in receiving a dementia diagnosis and also in accessing appropriate care. Karlsson et al. (2015) showed that entering into the course of the dementia disease and its consequences was addressed as important. Establishing a trusting relationship with professional care was required and also care adapted to individual needs.

Using a newly developed mapping system as a first attempt to investigate support for informal caregivers of persons with dementia in terms of access, i.e. availability and utilization, and providers of such support i.e., providers' involvement and educational level in European countries. The strength of this study was that data was mapped for European countries representing different parts of Europe and with different health care and social service systems, related to the stages of the dementia disease. However, eastern and western Europe was only represented by one country each. The findings can serve as a knowledge base and may enable the European countries to learn from each other. When developing the mapping system, the researchers from each country determined the different types of care and support for formal caregivers and agreed on the concepts and terminology. However, the collected information probably varied within organizations, regions, and countries. It was challenging to operationalize and quantify the concepts availability and utilization in a comparable way. The somewhat

open and unspecific categories may have influenced the results due to different interpretations, which may reflect a range of the conditions in each country. Furthermore, data sources varied. The findings are not based on any research in the field and experts consulted were not systematically selected. Moreover, the term "not applicable" provided some problems. Some researchers explained that in some cases, the support was available, but not suitable for a specific stage of the disease or not suitable at all. Occasionally, support was available for most, but was utilized by few. All participants were instructed how to understand the meaning of the concepts availability and utilization as well as how to value the support in relation to the stages of the disease for validation of the data collected (Hallberg et al., 2013).

To establish reliability, each country's researchers were given the same instructions for the data collection. The response alternatives for availability were "For all", "For most", "For few" and "For no one", and for utilization, "By all", "By most", "By few", and "By no one". Responses were estimations, without any statistical basis since the data was not quantifiable. Each country's researchers reported their country's health care and social service systems and policies for dementia care and services if available, assessed and interpreted from each countries cultural and societal perspective, which may have affected the validity of the results. The weakness of this study may therefore be the data collection method, which allowed different cultural interpretations. Data collection was relatively recently performed, but changes in social support systems and the number of professionals specialised in dementia may have been made since then. In future studies when utilizing the mapping system on a national level, cities or provinces, it may be possible to improve inter-rater agreement with fewer data-collectors. National and local mapping may improve the representativeness of samples (e.g. organisations and services providers) and make it possible to collect primary and more precise and statistical data regarding access.

The main strengths of Study III and IV were the large size of the cohort and the comprehensive approach, that is, data were gathered cross-sectional with several factors potentially associated with informal caregivers' psychological well-being and burden as well as over time. Apart from socio-demographic data, such as age and gender, associated and predictive factors were investigated for all involved parties, namely the informal caregiver, the person with dementia and formal care. Furthermore, this study was performed across eight European countries, which enhances generalizability of the results. Sampling between countries may have differed, on account for different health care and social support systems, and this may have influenced the result. Moreover, this study focused on the total sample of informal caregivers in eight European countries. However, to promote internal validity, the same procedures and guidelines were used by all the countries participating in the RightTimePlaceCare project. External validity was promoted by including countries representing northern, southern, central, western and eastern Europe. Each country's sample was n=81-182 which was assessed to be sufficient for the provided analysis (Verbeeck, 2012).

Due to the large total sample (n=1223), the logistic bivariate regression analysis at baseline demonstrated differences in several factor values with little, or no, overlap but with significance (p=<0.05). For quality of care, where values were similar, mean values were calculated to show differences. In addition, the 95% confidence interval was narrow for several factors, suggesting high precision of the studies. Since the person with dementia was at risk for institutionalization within 6 months, it was expected that informal caregiver psychological well-being and burden would be affected, with lower psychological well-being and higher burden. Investigating informal caregiver psychological well-being and burden at baseline and after 3 months allowed to determine factors that could predict increased psychological well-being and burden. The effect of gender on informal caregivers' psychological well-being and increased psychological well-being shows different results depending on the analysis. The logistic bivariate regression analysis showed that most persons with dementia cared for were female and the logistic multivariate regression analysis shows male gender, affecting the informal caregivers' psychological well-being as well as increased psychological well-being. However, more caregivers at follow-up than at baseline rated presence of psychological well-being (58% versus 55%). This was probably due to that some persons with dementia (n=274) being admitted to institutional care during the follow-up period, which may have affected the results.

The main limitation of this study was that the study design, cross-sectional at baseline did not allow establishing any causal relationships, and therefore the results should be interpreted with caution. Further prospective studies are therefore needed. The informal caregivers caring for the person with dementia living in the community receiving home care and being at risk for institutionalization, might differ from the person with dementia who do not receive such services and who would not be judged as being at risk for institutionalization. This would mean that the result may not be representative for informal caregivers of person with dementia in general.

The follow-up period was short, but this was not necessarily a disadvantage because the person with dementia was at risk of institutionalization within 6 months. The changes in informal caregiver psychological well-being within this short time frame should however, be interpreted carefully. In addition, this might imply that the informal caregivers were heavily burdened and that increased burden could be expected. Another limitation of this study was that no data were collected on the duration of daily caregiving at home (in years), which may have had an impact on our results regarding informal caregiver burden. Informal caregiving duration has been suggested elsewhere to be related to the amount of perceived burden (Brodaty & Donkin, 2009), suggesting that this might have an impact on psychological well-being as well. A previous study within the RightTimePlaceCare project by Bleijlevens et al. (2015) showed differences in informal caregiver burden assessed using the Zarit Burden Interview instrument, when comparing informal caregivers caring for a person with dementia living at home and informal caregivers of person with dementia who had recently moved to institutional long term care. Informal caregiver burden decreased after transition to a

nursing home, with large differences between the countries. This study used quality of life for the person with dementia (Quality of life in Alzheimer's disease, QoL-AD), as rated by informal caregivers. Previous studies have shown that the person with dementias quality of life is rated lower by informal caregivers than by the person with dementias themselves ((Logsdon et al., 1999; Thorgrimsen et al., 2003) and it may be possible that informal caregivers' perception of low quality of life of the person with dementias have an impact on their own perceived psychological well-being and burden. This may have affected the associated factors in informal caregivers to perceive low psychological well-being and high burden in connection to whether quality of life rated by the person with dementia had been selected. Quality of life in persons with dementia can be rated by the person with dementia even with a low Mini Mental State Examination score, ≤3 (Thorgrimsen et al., 2003). If the informal caregiver have knowledge about how persons with dementia experience their own quality of life, this might increase the informal caregivers' perceived psychological well-being and decrease their burden.

Conclusions and clinical implications

The informal caregivers experienced that formal care was reactive to their needs of support and this often promoted unhealthy transitions in the caregiving process. Formal care needs to be proactive and provide available care and support early on in the process of the dementia disease.

Support to informal caregivers was found to be available in the eight European countries, but more seldom utilized. Countries with care systems based on national guidelines for dementia care seem to be more aware of the importance of professionals specialized in dementia care and in providing support. Facilitating informal caregivers' access to, and transition within the health care and social service system, should be a priority to enable the informal caregivers to get access to needed care and support.

Informal caregiving for persons with dementia living at home seems to be a complex situation, influenced by several factors associated with the informal caregiver, the person with dementia and formal care. This thesis shows that informal caregiver's psychological well-being and burden is associated with the informal caregivers' experience of caregiving, care provision for the person with dementia and informal caregivers' experience of quality of care. Professionals should be aware about this modifiable factors facilitating psychological well-being and about risk factors for burden in informal caregivers caring for a person with dementia at home.

In conclusion, the accessibility of dementia care services is dependent on the demand side, the informal caregiver, and the supply side, the healthcare and social service system. In each country barriers to access in the health care and social support system are revealed. Consequently, nursing strategies to care for and support informal caregivers to achieve healthy transitions should be a priority.

Determinants seem to exist in all five dimensions of accessibility and are recommended to be further explored in each country in relation to the current health care and social service system. It is essential to improve each system since it may affect the outcomes for the informal caregiver such as psychological well-being and burden, and is important for creating a healthy transition in the caregiving role through the course of the dementia disease.

Future research

In this thesis the result showed that informal caregivers of persons with dementia experienced formal care as reactive to their needs. Interventions should focus on professionals to be proactive and provide available care and support early on in the process of the dementia disease. This may facilitate a healthy transition for informal caregivers through the course of the dementia disease to ensure their well-being.

It is important to explore the health care and social service system nationally to evaluate and detect barriers for access to the health care and social service system. This may enable development of the dementia support system for informal caregivers for persons with dementia according to national guidelines. Dementia research should focus more on visibility, the relation between the educational levels of the health professionals, and their impact on the care for persons with dementia and the satisfaction of care for the informal caregiver. In addition, this may affect the psychological well-being and quality of life of the informal caregiver.

Several factors have been identified in this thesis that was associated with psychological well-being and burden in informal caregivers caring for older persons with dementia. Further studies are needed regarding the modifiable factors such as informal caregiver supervision time and experience of quality of care to develop support from health care and social services. Such knowledge could lead to better adapted health care and social service systems in dementia care provided at home and promote informal caregivers psychological well-being.

More severe neuropsychiatric symptoms in the person with dementia were associated with informal caregivers' decreased psychological well-being. Professionals should provide information about the dementia disease though the course of the disease to the informal caregivers to prepare them for how to handle different behavioural symptoms. In addition, professionals should be aware about health conditions that may affect the presence of neuropsychiatric symptoms in the person with dementia.

Developing quality indicators such as psychological well-being and quality of life in informal caregivers to persons with dementia as well as quality of care seems important. In future studies it may also be important to consider differences between urban and rural areas, populations with different social-economic statues as well as ethnic background.

Summary in Swedish/Svensk sammanfattning

Anhöriga har ofta huvudansvaret för vården av en person med demens som bor hemma, ibland i samarbete med och med stöd från den formella vården. I Europeiska länder förväntas antalet personer med demens öka i framtiden. Hög ålder är en av de viktigaste riskfaktorerna för att utveckla demens. En ökning av antalet personer med demens i framtiden kan öka anhörigas ansvar att vårda och den formella vårdens ansvar att ge stöd. Följaktligen är det av största vikt att vård- och omsorgssystem är välfungerande för att ge stöd till anhöriga, och vård och omsorg till personer med demens för att förhindra att anhöriga hamnar i en utsatt och sårbar position med minskat välbefinnande och ökad belastning. Anhöriga som vårdar personer med demens i hemmet är vanligtvis kvinnor och i Europeiska länder finns det olika välfärdssystem vad det gäller ansvar för familjen, vilket ger olika förutsättningar i vårdandet. Allt eftersom demenssjukdomen fortskrider, kommer personen med demens att förlora sin självständighet på grund av minnesnedsättning med begränsning i vardagen såsom vid matlagning, tvätt, inköp, påklädning, hantering av ekonomi, toalettbesök och att äta. Anhöriga kommer, med eller utan utbildning inom vård och omsorg, att hjälpa och stödja personen med demens i vardagen och övervaka personen för att förhindra olyckor och även hantera beteendeproblem. I dagsläget saknas det kunskap i Europa om anhörigas erfarenhet av den formella vården, tillgång till och utnyttjande av vård och stöd från formell vård, för att både stödja anhöriga och personen med demens. Vidare finns det bristande kunskap om faktorer som påverkar anhörigas välbefinnande och belastning i vårdandet av en person med demens genom sjukdomsförloppet. Denna kunskap krävs för att stödja anhöriga och göra det möjligt att vårda en person med demens i hemmet, och för att utveckla system för vård- och omsorgssystem.

Denna avhandling är en sammanläggningsavhandling bestående av fyra delstudier. Det övergripande syftet var att undersöka informella vårdare som vårdar en person med demens, 65 år eller äldre, i åtta Europeiska länder. Studierna har fokuserat på anhörigas erfarenhet av formell vård, tillgång till stöd, och faktorer som har ett samband med anhörigas välbefinnande och belastning. Samtliga studier var en del av ett Europeiskt projekt ”RightTimePlaceCare” som genomfördes i åtta europeiska länder 2010-2013. De länder som ingick i projektet var Estland, Finland, Frankrike, Tyskland, Holland, Spanien, Sverige och Storbritannien.

Den första delstudien i avhandlingen var en kvalitativ studie med intervjuer i fokusgrupper och genomfördes i fyra kommuner i södra Sverige. Syftet med studien var att belysa anhörigas erfarenhet av formell vård när de vårdar en person med demens, genom sjukdomsförloppet. Totalt deltog 23 anhöriga, fördelade i fyra fokus-grupper, varav 13 anhöriga var make/maka och tio var vuxna barn. Intervjutexten analyserades med innehållsanalys. Resultatet visade med ett övergripande tema att anhöriga upplevde att närståendevård krävde samarbete med formell vård för att få stöd anpassat till de olika stadierna i demenssjukdomen. Temat innehöll tre kategorier som tolkades som viktiga vändpunkter för den anhörig som vårdar en äldre person med demens i hemmet. Den första kategorin var demensdiagnosen som gav tillträde till formell vård för en oerfaren närståendevårdare. Därefter uppstod ett behov av utökat samarbete med formell vård för att kunna fortsätta vårda i hemmet. Slutligen uppstod en situation av att bli beroende av formell vård i särskilt boende och samtidigt försöka behålla delaktighet i vården av personen med demens.

Andra delstudien var en kvantitativ tvärsnittsstudie som genomfördes i de åtta europeiska länderna. Syftet var att kartlägga stöd som erbjuds till anhöriga som vårdar en person med demens i hemmet kopplat till de olika stadierna i demenssjukdomen, från diagnos till livets slut. Syftet var även att kartlägga vilken personal som ger stödet och deras utbildningsnivå. Forskare från respektive land samlade in data för sitt land på nationell nivå. Data samlades in från offentliga rapporter om vård- och omsorgssystem, offentlig statistik och personliga intervjuer med enhetschefer, vårdgivare och tjänstemän i statliga förvaltningar. Datainsamlingen inkluderade beräkningar av tillgänglighet och användning av stöd till anhöriga samt vilken personal som gav stödet. Tio olika former av stöd till anhöriga analyserades för variation vilket var stöd till personer med demens och deras anhöriga i grupp eller enskilt, utbildning, möjlighet till ekonomisk ersättning (förekomst av ersättning eller ingen ersättning), dagverksamhet och korttidsvård (specialiserad och icke specialiserad) och avlösning i hemmet. Resultatet visade att det fanns skillnader mellan länderna avseende tillgänglighet och användning av stöd till anhöriga. Oberoende av hur tillgängligt stödet var, så var trenden att användning var låg och minskade i senare skedet av demenssjukdomen i samtliga länder. Personal, specialiserad i demensvård (med kandidat- eller magister examen) gav stöd i grupp eller individuellt till personer med demens och deras anhöriga. För personal involverad i dag verksamhet och korttidsvård (specialiserad och icke specialiserad) och avlösning i hemmet varierade utbildningsnivån från gymnasieutbildning till magisterexamen. Länder med nationella riktlinjer för personer med demenssjukdom verkade vara mer medvetna om vikten av att erbjuda stöd av personal med specialistutbildning inom demensvård.

Tredje och fjärde delstudierna var kvantitativa och genomfördes i de åtta europeiska länderna. Syftet var att undersöka faktorer hos den anhöriga, personen med demens och den formella vården som hade samband med anhörigas välbefinnande och belastning, när de vårdar en person med demens i hemmet. Vidare undersöktes faktorer sm kunde förutsäga ökat välbefinnande och ökad belastning. Strukturerade intervjuer

genomfördes med 1 223 anhöriga, med uppföljande intervju efter tre månader. Intervjun med anhöriga berörde socio-demografi, relationen till personen med demens, erfarenheter av att vårda, hur mycket anhöriga vårdar, välbefinnande, belastning och livskvalitet. Frågor om personen med demens berörde socio-demografi, diagnos och år med demenssymptom, samsjuklighet, minnesfunktion, livskvalitet, aktiviteter i det dagliga livet, problematiska beteende och depression vid demens. De frågor som behandlade formell vård omfattades av vårdkvalitet och demensspecifik vård för personer med demens och hur nöjd anhöriga var med den specifika vården.

Resultatet i den tredje delstudien visade att anhöriga upplevde välbefinnande när vårdandet upplevdes som positivt, när anhöriga upplevde mindre belastning samt när de skattade sin egen livskvalitet högre. Vidare upplevde anhöriga välbefinnande när personen med demens var en man, hade högre livskvalitet och visade färre problematiska beteende och depressionssymptom. Resultatet visade även ett samband med anhörigas välbefinnande när vårdkvalitén var bättre och demensspecifik vård användes i större utsträckning. Faktorer som kunde förutsäga ett ökat välbefinnande hos anhöriga var samma som faktorerna ovan, inklusive om anhöriga använde mindre tid till att vårda. Vidare var depressionssymptom och demensspecifik vård utan betydelse för ett ökat välbefinnande hos personen med demens.

Resultatet i den fjärde delstudien visade att anhöriga upplevde belastning i vårdandet om den anhöriges ålder var högre, den anhöriga var make, upplevde sämre välbefinnande och livskvalitet och om anhörig ägnade mer tid till att vårda personen med demens, inklusive tid till att övervaka. Vidare, visade resultatet att belastning hos den anhörige hade samband med om person med demens var man och hade mer problematiskt beteende, sämre livskvalitet och minnesfunktion, samt om anhöriga upplevde vårdkvaliteten som sämre. Ökad belastning hos den anhörige kunde förutsägas om den anhörige levde tillsammans med personen med demens och upplevde sitt eget välbefinnande som sämre. Faktorer hos personen med demens som var kopplad till ökad belastning för anhöriga var om personen med demens hade mer problematiskt beteende och om anhöriga upplevde vårdkvaliteten som sämre.

Sammanfattningsvis visade resultatet i denna avhandling att anhöriga som vårdar en äldre person med demens upplevde att formell vård var reaktiva i bemötandet av deras behov av stöd. Detta förhållningssätt påverkar deras redan komplexa situation, att utvecklas i rollen som vårdare till en person med demens med föränderligt vårdbehov genom sjukdomsförloppet. Formell vård behöver vara proaktivt och ge tillgänglig vård och stöd tidigt i demenssjukdomen och stödet behöver vara individanpassat. Stöd till anhöriga visade sig vara tillgängligt, men användes i mindre utsträckning av anhöriga. Länder med vård och omsorgssystem baserade på nationella riktlinjer för demensvård verkade vara mer medvetna om vikten av att ge stöd till anhöriga och personal med specialistutbildning inom demensvården. När stöd inte är tillgängligt kan detta minska anhörigas välbefinnande och öka deras belastning. Flera faktorer som har samband med den anhöriga, personen med demens och formell vård påverkar anhörigas välbefinnande och belastning och även över tid. Detta kan vara faktorer hos den

anhörige själv, så som upplevelsen av att vårda avseende aktiviteter i dagligt liv samt övervakning av personen med demens för att förhindra olyckor och den anhörigas egen livskvalitet. Faktorer hos personen med demens kan vara deras livskvalitet, och minnesfunktion samt problematiska beteende och depressiva symptom. Faktorer hos den formella vården kan vara kvaliteten på den vård som ges till personen med demens så som kontinuitet av personal och användning av demens specifik vård.

Framtida forskning behöver identifiera faktorer som underlättar eller förhindrar anhörigas tillgång till stöd och vård i vård och omsorgssystemen. Personal inom vård och omsorg bör fokusera på faktorer som är påverkbara för att underlätta vårdandet och främja anhörigas välbefinnande så som, stöd och övervakning i vardagen och förbättrad vårdkvalitet. För att minska anhörigas belastning är anhöriga i behov av kunskap om basal vård i hemmet och information om demenssjukdomen för att förbättra kommunikationen med personen med demens. Kvalitetsindikatorer för anhöriga finns inte i dagsläget men hade varit värdefullt för att utvärdera anhörigas välbefinnande och belastning i vårdandet, samt möjliggöra en mer proaktiv formell vård. Vidare bör vårdkvalitet utvärderas eftersom det visade sig vara en viktig faktor för anhörigas välbefinnande och belastning i vårdandet av en person med demens.

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Appendix I

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Appendix II

LUND UNIVERSITY
Faculty of Medicine

RightTime PlaceCare
Improving health service for European citizens with dementia

The focus group interview with patients, proxy and informal caregivers is like this;

- 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 of importance 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 how right now the communication, information and interaction between care providers works and how it works in relation to you.
- You have been living in this situation for longer or shorter times; thinking about it as a process and in particular about interaction, information and communication please share your experiences about this process
- Tell a little about how you think in terms of the future
- Thinking about when the service works at its best; tell about situations when it works really good and what characterizes the service then
- Tell a little bit about what you value most in terms of the care and service from professionals
- 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 in your eyes and think about the stages from the diagnosis and on until now. Think in particular on interaction, communication and information and being the person with the disease versus the person standing next by.
- Taking your perspective and having the opportunity to tell the government about how this care should be along the disease process should be carried out – what would you tell them.

The interview guide was developed by:
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Appendix III

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 ADL, memory loss and social affairs	**C) Intermediate stage/moderate cognitive impairment:** Marked by an increased memory loss, and dependency of help in ADL 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 a person has limited time left to live
Care provided					
Caregiver education: Training for informal caregivers in care and service to persons with dementia disease. Education about needs and symptoms of dementia	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**
Respite care at home: Care at home for relief to informal caregiver who are caring for family member/close friend	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**
Respite care, specialised in dementia care: Residential care around the clock for relief to informal caregiver who provides care for family member/close friend, specialised in dementia care. In a nursing home or residential	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**	**A:** **U:** **P:**

Appendix IV

General Health Questionnaire GHQ-12

Please read this carefully:
We should like t know if you have had any medical complaints, and how your health has been in general, *over the last few weeks*. Please answer ALL the questions simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those you had in the past. It is important that you try to answer ALL the questions.

HAVE YOU RECENTLY:

1 -	**been able to concentrate on whatever you're doing?**	Better than usual	Same as usual	Less than usual	Much less than usual
2 -	**lost much sleep over worry?**	Not at all	No more than usual	Rather more than usual	Much more than usual
3 -	**felt that you are playing a useful part in things?**	More so than usual	Same as usual	Less useful than usual	Much less useful
4 -	**felt capable of making decisions about things?**	More so than usual	Same as usual	Less so than usual	Much less capable
5 -	**felt constantly under strain?**	Not at all	No more than usual	Rather more than usual	Much more than usual
6 -	**felt you couldn't overcome your difficulties?**	Not at all	No more than usual	Rather more than usual	Much more than usual
7 -	**been able to enjoy your normal day-to-day activities?**	More so than usual	Same as usual	Less so than usual	Much less than usual
8 -	**been able to face up to your problems?**	More so than usual	Same as usual	Less able than usual	Much less able
9 -	**been feeling unhappy and depressed?**	Not at all	No more than usual	Rather more than usual	Much more than usual
10 -	**been losing confidence in yourself?**	Not at all	No more than usual	Rather more than usual	Much more than usual
11 -	**been thinking of yourself as a worthless person?**	Not at all	No more than usual	Rather more than usual	Much more than usual
12 -	**been feeling reasonably happy, all things considered?**	More so than usual	About same as usual	Less so than usual	Much less than usual

Appendix V

Zarit scale

Instruction for informal caregivers/next of kin

The questions reflect how persons sometimes feel when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way. There are no right or wrong answers.

	Never	Rarely	Some times	Quite frequently	Nearly always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Paper I

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Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease

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Abstract

Background: Family caregivers' experiences of formal care when caring for persons with dementia through the process of the disease is sparsely investigated.
Aims: To investigate family caregivers' experiences of formal care when caring for a person with dementia, through the stages of the disease.
Design: A qualitative approach with focus group interviews.
Methods: Four focus group interviews were conducted in October 2011 with 23 spouses and adult children of persons with dementia, and analysed with content analysis.
Results: The participants' experiences of formal care when caring for a person with dementia were captured in the theme "Family caregiving requires collaboration with formal care to get support adjusted to needs specific to the stages of dementia". This can be broken down into the categories "The dementia diagnosis – entry into formal care as a novice family caregiver", "Needing expanded collaboration with formal care to continue care at home" and "Being dependent on a nursing home and trying to maintain involvement".
Conclusion: Family caregiving requires collaboration with formal care to get support adjusted to the individual's needs, specific to the stages of dementia. Caregivers experience a transition process with three main turning points: the dementia diagnosis; when they realize increased need for formal care to continue caring at home; and when the person with dementia is moved into a nursing home. The interviewed caregivers experience formal care reactive to their needs and this often promoted unhealthy transitions. Formal care needs to be proactive and deliver available care and support early on in the dementia trajectory. Interventions should focus on facilitating a healthy transition for family caregivers through the trajectory of the dementia disease to ensure their well-being.

Key words: family caregivers, experiences, formal care, dementia, Alzheimer's disease, trajectory, nursing, qualitative research, focus groups, transition theory.

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Introduction

Family caregivers' experiences of formal care when caring for persons with dementia through the process of the disease have been sparsely investigated. Their experiences of formal care are most often investigated separately in different contexts, such as once the diagnosis is set, at home, in day care or in a nursing home (NH). Further, few studies focus on family caregivers´ experiences of collaboration with formal care when caring for persons with dementia throughout the process of the disease. Moreover, studies on the topic are from different cultures, often with different care and service systems, primarily from Australia, Canada, the Netherlands, Sweden and the United Kingdom (1–5). To assist family caregivers (hereafter referred to as "caregivers") and improve formal care and support throughout the process of dementia, more knowledge is needed about caregivers' experiences of formal care through the process of the dementia (6, 7).

The care of persons with dementia through the process of the disease is mainly provided at home by caregivers (8, 9). Caregivers are unpaid individuals who support or provide care to a person who is dependent due to long-term physical or mental illness or disability, or to age-related problems (10). The care of a person with dementia provided at home often involves longer hours and more intense care compared with the amount of formal care provided, and also compared with the care of persons without dementia (11). Of all persons with dementia in Sweden, it is estimated in 2012 that 58% live at home, while 42% live in an NH (12). Caregiving may include helping the person with dementia with activities of daily living (ADL) and coping with changed behaviour (3, 6). Becoming a caregiver to a person with dementia can be seen as a transition through the process of the dementia disease as described in the transition theory by Meleis (13). A transition is characterized by a turning point of change, from a fairly stable state, through a period of experiencing instability, uncertainty and distress, to another fairly stable state.

Caregiving for a person with dementia is sometimes experienced as positive (14, 15) yet it can be both physically and mentally demanding and many caregivers find it more than they can manage (7, 14, 16). Caregivers are at increased risk of stress, strain, depression and other health complications (16) and have higher mortality compared with those caring for persons without dementia (17). Caregivers often request information about the dementia disease, prognosis and how to deal with behaviour they perceive as difficult (3, 18) which has been reported to relieve caregiver strain. Respite care for the person with dementia has likewise been shown to relieve caregiver strain (19). Caregivers often find it difficult to navigate the system of care and service and find the right person to contact for support with different caregiver tasks (9, 20). Furthermore, caregivers can experience strain when caring, and this strain often increases prior to moving the persons with dementia to an NH (21). Moving the person with dementia to an NH does not always mean relief, in terms of stress and strain, for the caregiver. Support during this care phase is also important.

Dementia progresses along a continuum, from early in the dementia disease to the end-of-life stage (22). As the dementia disease progresses the caregiver has different needs for support from formal care. There is a need for knowledge about caregiving when caring for a person with dementia, especially regarding collaboration between caregivers and professionals involved in the care (20, 23). Such knowledge is important for developing and improving formal support for caregivers. To develop best practice, caregivers' own descriptions of how they experience formal care through the process of the disease are essential. The aim of this study was to investigate caregivers' experiences of formal care when caring for a person with dementia, through the process of the disease.

Method

Design

This study has a qualitative approach with focus group interviews, analysed with content analysis. Content analysis was chosen as a flexible method which involves both manifest and latent interpretation (24). This study was a part of a European study, "RightTimePlaceCare (RTPC)", performed in 2010–2013 in eight countries, Estonia, Finland, France, Germany, the Netherlands, Spain, Sweden and the United Kingdom (25). The structure and development of the focus groups in all countries is described elsewhere (26). In this study, focus group interviews were carried out in Southern Sweden. In Sweden, social services are provided at home, covered by the municipality, and regulated by the Social Service Act (27). Home nursing care is provided by county councils and regulated by the Health and Medical Services Act (28).

Sample

A strategic sample of 23 spouses and adult children of persons with dementia, of various age and gender participated. Participants all had experiences of the process of the dementia disease (parts or whole), and there were variations in care and service and municipal size. Inclusion criteria for the person with dementia were age ≥65 years, primary dementia diagnosis, Mini-Mental Test ≤24 (29) and living at home with support from formal care and social services, or in an NH (Table 1). The criterias for the caregivers was that they should be living either with the person with dementia at home or visit them at least twice a month at home or in the NH. Recruitment from four municipalities (10,000–113,000 inhabitants) in southern Sweden was conducted by a contact person in each municipality; a registered nurse specialized in dementia. The dementia nurse contacted likely participants, informed them about the study and the focus group interviews, and asked them to give permission for researchers from Lund University to contact them.

Table 1. Demographic characteristics of family caregivers in the focus groups (n=23).

	Group 1 (n=4)	*Group 2 (n=6)*	*Group 3 (n=7)*	*Group 4 (n=6)*
Gender (man/woman)	1/3	3/3	4/3	2/4
Age of the family caregiver, range, years	50–70*	51–80*	45–88	60–80
Age of the person with dementia, range, years	71–98	73–88	72–92	68–87*
Memory problems for the person with dementia, years	5–15	2–10	1–15	1.5–10
Relation (spouse/child)	1/3	3/3	4/3	5/1
Living condition for person with dementia (at home/ at the nursing home)	1/3	3/3	3/4	4/2
Support from the municipality at home	Accompanying staff	Home care, day care	Respite care, respite care at home	Respite care at home, day care

*One family caregiver who did not answer the question about age

Data collection

Data were collected in October 2011 through focus group interviews (n=4), with one focus group per municipality, and four to seven participants per group. We selected focus group interviews (30) as a method to get participants to disclose positive and negative experiences of formal care in discussion with others, and to understand differences in perspectives. An interview guide was developed with questions about caregivers' experiences of formal care in the context of caregiving at home or in an NH. Further questions covered collaboration, communication and information related to formal care through the process of dementia, and suggestions for improvement. A pilot interview was conducted to validate the procedure and the interview guide. No changes were needed after the pilot interview. Two of the researchers, both experienced registered nurses, conducted the focus group interviews, one as moderator (A.C.J.) and the other as observer (C.L.). The moderator gave information about the aim of the interview, and led the interview using the interview guide. The observer helped the moderator keep participants on track and observed the interaction within the group (30). To gain depth in the interviews, probing questions were asked. The participants were all active, discussed the questions with each other and shared experiences through the process of the dementia disease. The interviews were recorded and transcribed verbatim. The time per focus group interview varied between 124 minutes and 140 minutes.

Quality criteria

Trustworthiness was established by ensuring credibility, dependability, conformability and transferability (31). Credibility was established by descriptions given by caregivers of their experiences of formal care when caring for a person with dementia. To achieve variation, we selected participants with varying age, gender and experiences of formal care, and from different municipalities in southern Sweden. All four researchers have knowledge of the context of Swedish care and service systems. To ensure that results were repeatable and consistent and to strengthen the conformability or the findings (32), all authors independently read the interview texts and identified meaning units responding to the research question, which should ensure that the data are dependable. Sub-categories, categories and themes were discussed between the authors until agreement was reached. Quotations were included to show similarities and differences in the transcribed interview texts. To make the results transferable, the context and sample concerning recruitment as well as the data collection method are described. The procedure of analysis of the interview texts is described in detail, thus enabling the reader to follow the authors' involvement in the analysis. The result may be transferable to other groups, for example caring of persons with fatal diseases with deterioration in cognitive functions.

Analysis

The interview text was analysed with content analysis as described by Graneheim & Lundman (32). The transition theory (13) was used for interpretation in the analysis. Initially the first author (CL) read each interview. Thereafter CL read all interviews several times to get a sense of the whole. Meaning units were identified and later condensed and labelled with codes. The codes were sorted into sub-categories based on differences and similarities and, thereafter, into categories, i.e. at the manifest content level. Thus an overall picture and an underlying meaning, latent content and theme emerged (Table 2). The co-authors (I.R.H., A.C.J., S.K.) independently reviewed the interviews and discussed the codes in depth with the first author in development of the sub-categories, categories and theme, until consensus was reached.

Table 2. Meaning units, condensed meaning units, codes, subcategories, category and theme.

Meaning units	*Condensed meaning units*	*Code*	*Subcategory*	*Category*	*Theme*
"So I have a hard time knowing how to deal with the person in question, with dementia. What you can say, what you can do, what you can't do. That's what I think is a big problem when you don't have any experience." (FG1, son)	Lacking preparedness and knowledge about dementia	In need of preparedness and knowledge	Experiencing strain may need support form formal care	The dementia diagnosis – entry into formal care as a novice family caregiver	"Family caregiving requires collaboration with formal care to get support adjusted to needs specific to the process of the dementia disease"
"She has escaped four times this summer, so that's why I can't go anywhere, you see." (FG2, husband)	Husband can't leave the house/patient	To be a guardian			
"In the past, we used to have a lot of friends. They disappear … the friends. But why do friends disappear? Even the grandchildren have disappeared." (FG3, husband)	Friends and next of kin don't visit anymore	Loss of next of kin	Disappointment of formal care implies experiencing of isolation		
"Then I have two brothers but they live in Stockholm. So it has to be me …" (FG1, daughter)	Daughter feels that it's her responsibility to take care of their mother	Enforced caregiver responsibility by relatives			

FG = focus group

Well aware of the danger of pre-understanding, the researchers strived to put themselves in the caregivers' situation when interpreting the text to understand it unconditionally when searching for meaning and essence. The moderator and co-authors are researchers in the field of elderly care and psychiatry and experienced in conducting focus group interviews. The observer has experience in working with persons with dementia and caregivers in the municipality and county council.

Results

The participants' experiences of formal care when caring for a person with dementia were captured in the theme *"Family caregiving requires collaboration with formal care to get support adjusted to needs specific to the process of the dementia disease"* consisting of three categories: "The dementia diagnosis – entry into formal care as a novice family caregiver", "Needing expanded collaboration with formal care to continue care at home" and "Being dependent on a nursing home and trying to maintain involvement".

When family caregiver´s enter the role of caregiving, they enter a new life situation with new demands, entailing a transition from novice to carer. The dementia diagnosis is a first step in the dementia disease process and becomes their formal entry into the role as caregiver and of starting collaboration with formal care. The need to be prepared and the need for information about the dementia disease, so as to better equip them to handle the persons cognitive impairment, becomes urgent. Caregivers proceed in their transition from independency to dependency as the dementia disease progresses. They rely on other next of kin to enable them to keep on caring at home and retain independence. Continuing caring for the person with dementia at home implies having to establish collaboration with various formal care providers. Finally, when the person with dementia moves to a NH and becomes totally dependent on formal care, there is a new transition for the caregivers as they need to build trusting relationships with the NH staff. It is important for the caregivers to communicate with the staff and be involved in the care of and care planning for the person with dementia.

The dementia diagnosis – entry into formal care as a novice family caregiver
Early in the dementia disease the next of kin to the person with dementia had to enter a new role as a caregiver without being prepared. During this transition they also had to start collaborating with formal care, not knowing their expectations. Awareness of their need for support from the formal care system had increased, including care for the person with dementia and support for themselves. The importance of knowledge about dementia disease and information about available care and services was emphasized. They experienced strain and weariness and realized that they were no longer able to manage the care on their own and had to apply for formal care and services. Some participants emphasized that formal care was accommodating and informative about available services. Others had to fight for care or services, both for themselves and for the person with dementia. Some mentioned that they had not been listened to when requesting aid, equipment or respite care at home. Practical strain was described especially by male participants, who found it hard to meet new demands, such as planning the household and preparing meals. A husband related:

> You are terribly disabled [as a man]. Suddenly you need to do the shopping and planning ... the menu and cooking. It takes such a terribly long time when you have no training. We have to educate ourselves. (Focus group (FG) 4)

In this new role as caregivers, the participants had feelings of being alone and isolated because formal care was not supportive as expected. The participants also experienced increased isolation when relatives and friends no longer came to visit. One husband said, "We used to have a lot of friends. They disappear …" (FG3). To make new friends was a necessity when trying to create a new life. Disappointment related to formal care was expressed when participants themselves had to find out how the formal care system worked and who to contact. Spouses experienced feeling desperate when hospitals had neglected to make care plans before discharge. A wife said: "My husband got a stroke and he couldn't stand on his feet. Two days later, they sent him back from the hospital without any care planning." (FG4). The dissatisfaction over the lack of formal recognition of their importance as caregivers was discussed:

> Son 3: I think I'm the "spider in the net".
> Daughter 2: Yes, that's what we are!
> Son 3: You have to do everything yourself. You have to contact the social worker (SW), the dementia nurse, you have to find out everything yourself. Nobody offers to help.
> Daughter 2: Yes, that's my experience too. Absolutely! (FG1)

Needing expanded collaboration with formal care to continue care at home

Increasing cognitive impairment of the person with dementia implies an increased dependence, a loss of freedom and an expanded need for caregivers to collaborate with formal care. In this transition the caregivers tried to keep their independence for as long as possible, but needed improved collaboration with formal care to be able to continue care at home. When the cognitive impairment of the person with dementia increased, there was an increased need for assistance or supervision to manage ADLs and prevent accidents (for example, when the person with dementia needed assistance in the shower or left the house unattended). The home situation was characterized by collaboration with different care providers. The caregivers utilized formal care (home care, respite care, day care) to support their everyday lives. Having a contact person to facilitate communication with different formal caregivers was essential in this process. Even when they utilized formal care, the caregivers tried to avoid extended involvement from formal care and strived to manage by themselves as much as possible. They complemented formal care with care from relatives and neighbours to keep their independence and avoid "being a burden to society".

> Son 3: I think it has a lot to do with integrity. You want to manage on your own for as long as you can, to keep things the way they are.
> Daughter 4: She [the person with dementia] decides everything herself. She has always done that and she's allowed to do that now as well. (FG1)

Some participants left the person with dementia at home alone when going to work, which became a worry. At times, the person with dementia left the house and could not find their way back home. Then neighbours and friends were described as valuable support. A woman: "Everybody knew her because she went out with the dog all the time and she couldn't find her way home in the last years. Neighbours and friends came with her." (FG2). When the caregiving situation at home became increasingly problematic, communicating with others in dementia associations could be comforting. The struggle to avoid dependence on formal care had consequences for the participants, such as feeling inadequate in the care they were able to

give. These efforts also meant worrying about the future and their own capacity to continue in their role as caregiver. One husband said, "It's really hard and at night you stay awake and think about … for how long can I keep doing this?" (FG2). As the dementia disease progressed, participants needed improved collaboration with different formal caregivers. Responsive social workers were described as giving a sense of security and confidence, as in this quote: "I was exhausted. I had to feel that I could sometimes have time off. I asked for help one day … and got help the next day!" (wife, FG3). SWs were sometimes reluctant to collaborate, for example when they denied a participant a request, such as for extended support in the form of respite care. To have to struggle and fight for care and support was exhausting. Lack of collaboration and repeated resistance to requests for extended care made participants feel pushed to the limit. Some even described suicidal thoughts. On the other hand, participants who got respite care at home expressed feelings of freedom and relief: "This is just respite care. They [staff] just stay with him, you see. But this I appreciate a lot … this help." (wife, FG2)

Being dependent on a nursing home and trying to maintain involvement

The move of a person with dementia to an NH is a difficult time in a caregiver's life, bringing with it separation from their beloved ones which leads into a new transition. Being involved in the care, and being consulted as experts on the needs of the person with dementia make it possible for caregivers to build a trusting relationship with the NH staff. Participants emphasized the importance of still being involved in the person with dementia´s life, and being encouraged to have some influence over the care at the NH. Trust and security were built when staff members were viewed as responsive to both the participant and the person with dementia and their expressed care needs. Having adequate communication with staff at the NH was described as an important prerequisite to being involved. The participants expressed confidence in formal care when they felt the person with dementia was well taken care of and the staff were s engaged and interested in the person with dementia's life and well-being. They also expressed confidence in formal care relating to NH staff requesting communication with the participants if they needed information about the person with dementia. A daughter said: "They even called and asked why he didn't want to have his pyjama pants … [laughter]. They always call and ask, and that feels secure!" (FG3). When, by contrast, participants experienced a lack of communication with NH staff they felt excluded from the care and lost confidence in formal care. Some participants had to call staff all the time, or had to stay at the NH to check the care of the person with dementia. Shortness of NH staff and lacking continuity among staff made the participants feel insecure and concerned about whether the person with dementia was well cared for. Shortness of staff was described as influencing activities for the person with dementia.

> Daughter 3: On their home page, it says that there are two planned activities each day. It's also stated in … [the person with dementia]'s care plan. You are believed to think that this need for stimulation and activities was satisfied in an NH, but that's not the case.
> Daughter 5: The staff have to take care of all practical things and don't have time to take walks with the person with dementia or do puzzles.
> Son 6: It seems to be a problem that there is shortness of staff and so much to do. So even if there's a will there's no time. (FG2)

Discussion

The findings indicate that caregiving requires collaboration with formal care to get support adjusted to individual needs, specific to the stage of the disease the individual is in. Formal care was described to be reactive to caregivers needs instead of having a proactive approach. Experiences of formal care during the process of the disease when caring for a person with dementia can be understood by Meleis transition theory (13). During transition, most people are vulnerable and need support to adjust in order to counteract unhealthy transition processes. In this study the participants seemed to be in an extensive transition process including three marked turning points related to their caregiving and their experiences of formal care in the disease process.

The dementia diagnosis was a first turning point and the first contact with formal care. At this point the caregiver as the main caregiver is responsible for the care of and services to the person with dementia. Caregivers at this point are novices at caregiving, which places them in an unstable position when transitioning into the caregiver role. According to transition theory, healthy transition processes include exploring the meaning of the transition and modifying expectations to make them realistic. Healthy transition processes also mean restructuring life routines in response to the new situation, which allows the caregiver to regain a sense that their life is predictable, manageable and pleasurable. Developing knowledge and skills, creating new choices and finding opportunities for personal growth are included in a healthy transition process (13). Caregivers in this study expressed a need for preparedness through knowledge about dementia which would prepare them for the caring role. They also needed support from formal care to manage the transition in a healthy way. Being prepared for what is in store may protect caregivers from adverse outcomes, such as depression, and may provide help with coping (33). An unstable period during the transition will stabilize when caregivers' needs are met. Caregivers in this study were in need of information, knowledge, care and support. They experienced formal care as reactive to their needs. When care and support were unavailable early in the dementia process, the caregivers struggled with the transition process which was not healthy (13). Several of the caregivers found it exhausting trying to find information, care and services. They did not know who to contact within the formal care system. They also experienced the care system as fragmented, with different professionals and organizations being responsible for different types of care and services, as reported elsewhere (20, 34). With increased caregiver strain, as well as unmet needs for formal care and support, caregivers will lack preparedness to provide care and planning for the future (33), leading to an unhealthy transition not facilitated by formal care. In order to facilitate a healthy transition process it is essential that formal care take a proactive approach, providing structured delivery of available options for care and support early in the process of the dementia disease. Interventions to facilitate the transition may be through reminiscence, to integrate the transition into the life course, and role supplementation, to facilitate development of new knowledge and skills. This can be evaluated by measuring process indicators for caregivers' well-being for early detection of difficulties at critical points in the transition, using various assessment instruments (13). A contact person/case manager (35) who can assist navigation through the care and service system may facilitate and promote a healthy transition process for the caregiver when the diagnosis is set.

As the disease progresses the caregiver has increased need for formal care. This is the second turning point in the transition. The participants and formal care at this point shared the responsibility for the care of their person with dementia's care with formal care, implying compromised independence for the participants. Their needs for care and support changed individually. Collaboration with formal care increased to enable them to continue caring at

home. This turning point, meant a new period of instability in the transition process. In such processes, a healthy transition can be described as creating healthy environments. The environment needs to be safe and secure, as well as enable the caregiver to accomplish daily routines. To accomplish a healthy transition related to compromised independence, a caregiver has to find new meaning in their situation (13). Caregivers in this study became in need of care for the person with dementia, help with ADLs and day care or respite care. Their independence gradually became compromised as they adapted to the new situation. At this point, as previously, the participants experienced formal care as being reactive to their needs rather than foreseeing them. Caregivers also experienced insufficient communication and collaboration between professionals in care and services, as also reported in a previous study (36). At this point, professionals should enable a healthy transition, be proactive and provide tailor-made care adapted to individual needs in the caring situation. Professionals also need to communicate and collaborate about care and services with both the caregiver and the person with dementia in understanding and with each other. This can facilitate a healthy transition and the provision of person-centred and tailor-made care when caregivers experience an increased need for formal care to be able to continue caring at home.

Our study revealed a third turning point, of the process in the dementia disease, when the person with dementia moved to an NH because of extensive care needs. At this point, the caregiver, who has had the main responsibility for the care of the person with dementia, is pushed to leave their loved one in the hands of NH staff. They became dependent on the NH staff but tried to stay involved in the care of the person with dementia. This turning point puts caregivers in a new unstable period of their transition. A healthy transition in this process can be described as mobilization of personal resources. Personal inner resources may change during the transition and new resources may be necessary to promote adaptability, coherence, well-being and a healthy life style (13). A trusting relationship with and confidence in formal care seems to stabilize the transition if caregivers are invited by NH staff to be involved in the care of the person with dementia. Professionals need to be proactive and listen to and consult the caregivers as the experts regarding the needs and habits of the person with dementia. In this study, many participants expressed that they felt involved in and informed about the care of the person with dementia and that they trusted the staff. Being involved in the care meant having the possibility to participate in care planning and being listened to, which made caregivers feel confident in the professionals. This is consistent with the findings of Graneheim et al. (4). By contrast, when NH staff did not respond, and sometimes did not even react, to the caregivers' needs the caregivers felt they were being ignored by formal care. They experienced a sense of being abandoned, exploited and unappreciated by formal care, all of which led to an unhealthy transition. One study showed that the staff and caregivers seemed to find it hard to understand each other's expectations and roles (4). Caregivers in our study who were given the opportunity to build trusting relationships with staff at the NH became confident in formal care. It was most important for them to be involved in the care of the person with dementia to remain confident in formal care, which is in line with the findings of Lopez et al. (37). In summary, it is important that professionals should be proactive to facilitate a healthy transition when the person with dementia is moved to an NH because of extensive care needs. Caregivers need to be involved as experts in the care of the person with dementia to build trusting relationships with NH staff. Interventions should monitor the whole transition and measure caregivers' well-being (13).

This study has limitations. There were a wide range of disease processes in the sample, with memory problems ranging from 1½ to 15 years. This may have influenced the results, since it implies a wide range in caregivers' length of experience with formal care. For some participants their experiences were actual, while the experience was retrospective for

others which may have influenced their memory. All participants were born and lived in Sweden, which could limit the results as knowledge from other countries may be valuable. Transferability of the results to other countries may also be limited as other countries may have different care and support systems. In the pilot group, three out of four participants had experience of home care and one participant had experience of both home care and NH care. Both manifest and latent content analysis was chosen to answer our research question. In the study, eleven participants had experience of formal care at home while twelve had experience of formal care both at home and at an NH. Our findings may have been different if separate groups had been selected for home versus NH care, to gain a deeper understanding of each group, or if separate spouse/child groups had been chosen.

Conclusion

The findings indicate that family caregiving requires collaboration with formal care to get support adjusted to individuals' needs specific to individual disease process. Caregivers experience a transition through the process of the disease, with three main turning points: the dementia diagnosis; the point when they realize increased need for formal care in order to continue caring at home; and the point at which the person with dementia is moved into an NH. The participants in this study experienced formal care as being reactive to their needs, leading to unhealthy transitions for the caregiver. Caregivers need formal care to be proactive and deliver available options of care and support early on in the process of the disease to facilitate a healthy transition. Interventions should focus on facilitating the transition to assure caregivers' wellbeing. This can be evaluated by measuring process indicators for early detection of difficulties at critical points in the transition, using assessment instruments for anxiety, depression, connectedness, empowerment and integrity.

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Author contributions

Study design: I.R.H. , Data collection: C.L., A.C.J., Data analysis: C.L., I.R.H., S.K. and A.C.J., Drafting of manuscript: C.L., Critical revision: I.R.H., S.K. and A.C.J., Supervision: S.K. and A.C.J.

Ethical approval

The study was approved by the Regional Ethics Committee in Lund, Sweden, 2010/538. Family caregivers gave written informed consent before the interview.

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Paper II

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Formal support for informal caregivers to older persons with dementia through the course of the disease: an exploratory, cross-sectional study

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Abstract

Background: In European countries, knowledge about availability and utilization of support for informal caregivers caring for older persons (≥65 years) with dementia (PwD) is lacking. To be able to evaluate and develop the dementia support system for informal caregivers to PwD, a survey of European support systems and professionals involved is needed. The aim of this study was to explore support for informal caregivers to PwD in European countries. We investigated the availability and utilization of support in each of the participating countries, and the professional care providers involved, through the dementia disease.

Methods: A mapping system was used in 2010–2011 to gather information about estimations of availability, utilization, and professional providers of support to informal caregivers caring for PwD. Data collected was representing each country as a whole.

Results: There was high availability of counselling, caregiver support, and education from the diagnosis to the intermediate stage, with a decrease in the late to end of life stage. Utilization was low, although there was a small increase in the intermediate stage. Day care and respite care were highly available in the diagnosis to the intermediate stage, with a decrease in the late to end of life stage, but both types of care were utilized by few or no caregivers through any of the disease stages. Professionals specialized in dementia (Bachelor to Master's degree) provided counselling and education, whereas caregiver support for informal caregivers and day care, respite care, and respite care at home were provided by professionals with education ranging from upper secondary schooling to a Master's degree.

Conclusions: Counselling, caregiver support, and education were highly available in European countries from diagnosis to the intermediate stage of the dementia disease, decreasing in the late/end of life stages but were rarely utilized. Countries with care systems based on national guidelines for dementia care seem to be more aware of the importance of professionals specialized in dementia care when providing support to informal caregivers. Mapping the systems of support for informal caregivers of PwD is a valuable tool for evaluating existing systems, internationally, nationally and locally for policy making.

Keywords: Dementia, Caregivers, Health care services, Home health nursing, Nursing care, Persons, Europe

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Background

Formal support for informal caregivers is crucial for decreasing perceived strain when caring for older persons (≥65 years) with dementia (PwD) through the trajectory of the disease. Support from health care and social services for informal caregivers may improve their well-being as well as ensure improved care for the older PwD [1]. Across Europe, comparable knowledge about availability and utilization of support for informal caregivers caring for older PwD is lacking. It has been suggested that to understand, interpret, and meet the needs for formal support to informal caregivers of older PwD and provide adequate dementia support/care requires professionals with specific expertise and knowledge [2, 3]. Knowledge regarding formal care providers involved in the support to informal caregivers through the dementia trajectory is sparse. To be able to develop and evaluate the dementia support system for informal caregivers of older PwD according to national policies, we need a survey of European support systems and professionals involved, which will provide a knowledge base and enable the different European countries to learn from each other.

Informal caregivers are the main providers of care and services for PwD along the dementia trajectory [4–6]. Among older PwD, informal caregivers provide approximately 75 % of the care at home including help with activities of daily living (ADLs), dealing with finances, and supervision tasks [7]. Informal caregivers may be defined as persons without formal health care education who are caring for, or helping, a person with functional disabilities, prolonged psychiatric or physical illness, or age-related problems [8]. Due to association with neurodegenerative disorders, dementia progresses along a continuum with a series of stages from diagnosis to end of life. Most cases of progressive dementia extend across more than one stage. In the early stage, there is a slight cognitive impairment, which might impact on ADLs, cognition, and social functioning. In the intermediate/moderate stage, there is increased memory loss, and dependency on help with ADLs and social needs. There is severe cognitive impairment in the late stage, when PwD are unable to look after themselves without continuous assistance with ADLs and social needs. In the end of life/final stage, it is obvious that the PwD has limited time to live [9]. The experience of informal caregivers when providing care and service to older PwD may differ from person to person. Some perceive the caring as a positive experience [10] but it can also be physically and mentally demanding and sometimes more than they can manage [10–12]. Informal caregivers caring for older PwD are at increased risk of stress, depression, strain, and other health complications [13, 14] and have higher mortality compared to informal caregivers caring for older persons without dementia [11]. Informal caregivers sometimes experience strain, and changes such as shifts in power, health, quality of life, and social networks [10, 14]. Informal caregiver strain is one reason for nursing home admission for the older PwD [15, 16]. Therefore, support from health care and social service systems is essential to empower informal caregivers to provide care at home for an older PwD through the course of the disease [17].

Significant differences exist between European countries regarding support from formal care and social services and families' responsibilities for older PwD. In Scandinavian countries, the formal care and social support provided is based on individual needs and availability of support from the municipality or the county council [18]. In Germany, long-term care insurance only partially covers the risk of care dependency and the families are expected to contribute. The government covers all expenses in case a family is not able to contribute [19]. In Estonia, families have a legal obligation towards sick and impaired relatives, which includes provision of care and service and economic security [20]. Policies in European countries may include paid care leave (e.g. Belgium), providing respite care (e.g., Austria, Germany, and Denmark), and counselling and training services (e.g., Sweden) [21]. To be able to evaluate and develop the support for informal caregivers of older PwD, exploring the support systems in European countries is essential.

Informal caregivers have varying and individual needs of support from formal care as the dementia disease progresses [9]. The scientific evidence of the effect of different support on caregiver strain, wellbeing, and quality of life is not very strong and in some cases contradictory. In a study by Parker et al. [22], psycho-educational interventions had some positive effect on caregiver depression, health, subjective wellbeing, self-efficacy, and strain. In addition, it has been reported that support might be beneficial in decreasing caregiver strain and that multi-component interventions had varying impact on depressive symptoms, quality of life, and caregiver reaction to care recipient behaviour problems and satisfaction [23]. Another study indicated that interventions for caregivers of PwD had little effect on depression, strain, and subjective wellbeing of the informal caregiver. The interventions included psycho-educational, cognitive–behavioural, counselling/case management, and general support, and respite care [24]. Informal caregivers can have a lack of understandable knowledge [25] such as information about dementia, prognosis, and how to deal with behaviour in PwD that is perceived as difficult [26]. Professional providers of care and support (for example employed physicians, registered and auxiliary nurses) need knowledge and skills to improve the care for older PwD and

the wellbeing and quality of life of the informal caregiver [27]. Hence, it is important to develop and improve the support system from formal care to ensure the wellbeing of informal caregivers. Exploring dementia care and support for informal caregivers caring for PwD through the trajectory of the disease is valuable for development of support and national policies [17].

Aims

The aims of this study were to explore formal support for informal caregivers to older (≥65 years) PwD in terms of availability and utilization, and to examine the educational level of professional providers involved in the care and support of informal caregivers of PwD through the course of the disease across eight European countries.

Methods

Design

This study was an exploratory cross-sectional study conducted in eight European countries (Estonia, England, Finland, France, Germany, the Netherlands, Spain and Sweden).

Context

The study formed a part of the European project "RightTimePlaceCare" (RTPC; the European Commission, 7th framework research project; contract number 24 21 53) with participating countries intended to represent Europe from the north, south, west, east and central [28]. The aim of the RTPC project was to improve health services for European citizens with dementia and develop best practice strategies for transition from professional home care to institutional long-term nursing care facilities. This study was carried out to find out each participating country's health care and social service systems for informal caregivers of older PwD with regard to the country's national regulations, guidelines, and insurances (Table 1).

The sample

Researcher collecting data for this study were RTPC partners from each participating country.

The instrument

The mapping system was developed by Hallberg et al. [29]. It was used to describe care and service activities for PwD and their informal caregivers in the participating countries. Terminology, dementia stages and description of care and services activities for older PwD (≥65 years), informal caregivers and formal care providers involved was developed in consensus between researchers in the eight countries [29]. The mapping system horizontally described five stages of dementia: diagnosis, early stage, intermediate stage, late stage, and end of life. Vertically, different types of care and services activities were described. The mapping system included 50 different activities divided into seven categories: screening, diagnostic procedures, treatment of dementia; outpatient care facilities; care at home; institutional care; palliative care; informal caregiving and supportive actions; and civic organisations [29]. Each aspect of care and services activities, included estimations of availability, utilization, and providers of support, was related to each of the five stages of dementia. Response alternatives for estimations of availability were "[available] For all", "For most", "For few" and "For no

Table 1 Care and support systems for informal caregivers to persons with dementia in eight European countries

	National regulations	National guidelines	Insurances
Estonia	Welfare services for the elderly	No national guidelines	Estonian Health Insurance Fund
Finland	The social and health care system	Under development	National Health Insurance
France	Long-term care	The Alzheimer's disease plan "Plan AD 2008–2012"	National Health Insurance
Germany	Health care and long-term care	Three guidelines from different medical scientific societies	Long-Term Care Insurance
The Netherlands	Within the Health Insurance Act and the Social Support Act	"National Dementia Program"	Exceptional Medical Expenses Act (AWBZ): informal caregivers can apply for needs assessment
Spain	Universal Health Coverage Law 39/2006: promotion of personal autonomy and care of people with dependency	No national guidelines	Cohesion Fund
Sweden	Within the Social Services Act and the Health and Medical Service Act	National guidelines for care and service for dementia	National Health Insurance
England	Within the Community Care Act and the National Health Service Act	The National Dementia Strategy for England	The National Health Service (NHS)

one"; for estimations of utilization, they were "[utilized] By all", "By most", "By few", and "By no one" [29]. The term "not applicable" (NA) was used when the activity was available, but either it was not suitable for a specific disease stage or it was not suitable at all. Providers of each care and service activity were reported in the mapping system and it was possible to state one or more care providers. In the study by Hallberg et al. [29], availability of screening, diagnostic procedures, treatment of dementia; outpatient care facilities; and palliative care was analysed. The result showed that care at home had the broadest range of activities, whilst supportive actions for informal caregiving had the smallest range. Professional care providers involved in the screening, diagnostic procedure and care at home and their educational level have been explored [30], according to the International Standard Classification of Education (ISCED) [31] (Table 2). The result showed that professionals with a Bachelor's degree or above were involved in the screening and diagnostic procedure. Care at home was provided by professionals trained at a lower level or staff with no formal training [30]. Care and services activities available for care at home for PwD were in total 16 and are presented elsewhere [32]. In the present study, ten activities for informal caregiving and supportive actions are presented: counselling, caregiver support, education, reimbursement, no reimbursement, day care, specialized day care for dementia, residential respite care, specialized residential respite care for dementia, and respite care at home (Table 3). Professionals providing the supportive actions for informal caregiving are presented in Table 4.

Data collection

Established researchers with extensive practical and research experience in dementia care from each country, seven universities and one university hospital, contributed to the data collection representing their country as a whole. The mapping system was used for collection of data on support for informal caregivers caring for PwD (≥65 years) at home, including data on availability and utilization of, and provider type for, each support service. A guide was used for data collection, which suggested consulting sources of information for public reports and descriptions of the care system, official statistics, and using personal interviews with care managers, providers, and civic administrative areas. In addition, epidemiological studies and literature reviews were used for validation of responses from professionals in each country. Data collection was completed by communication with experts (in Germany, the Netherlands, Sweden); nursing staff (England); advisory boards (Estonia, Spain, Finland, Sweden); professional care providers (Finland); and a national Alzheimer's society (Finland) and in detail described elsewhere [28]. Data were collected between November 1st, 2010, and January 31st, 2011.

Data analysis

Information was compiled about each country's care and support system for informal caregivers of older PwD. Availability and utilization of support was analysed by the first author for variation, in each dementia stage, between the participating countries; thereafter, each author checked the analysis. For each country, categories of professional providers of support were compiled and documented in the template. In order to interpret education systems from a global perspective, a standardized framework - ISCED, was used to categorize and report cross-nationally to ensure comparable data [31]. The framework is categorized from level 1–7. In this study professionals were categorized from level three and above. The first author sorted the professionals into levels of education/qualifications according to ISCED's framework. Thereafter, each author checked that the ISCED level was in agreement with their country's educational levels (Table 2). The data sets supporting the results of this article are included within the article and its additional files.

Ethical approval

Informed consent was collected from the participants and the study was approved by each countries Ethical Committee (with reference numbers if appropriate in brackets): Ethics Review Committee on Human Research of the University of Tartu (196/T-3), Ethical Committee of the South-West Hospital District Finland (8/2010), Comite de Protection ds Personnes Sud-Ouest and Outre-Mer Toulouse (09 202 07), Nursing Science Ethical Committee University of Witten/Herdecke, Medical Ethical Committee of the Academic Hospital Maastricht/Maastricht University (MEC 10-5-044), Ethical Committee of the Hospital Clinic Barcelona (2010/6031), Ethical Committee Lund University (20120/538), National Research Ethics Service, North West 5 Research Ethics Committee (11/NW/0003) [28].

Results

Counselling, caregiver support, and caregiver education were the support activities with high availability from diagnosis stage to the intermediate stage, with a decrease in the late to end of life stage. Utilization was low, with a small increase in the intermediate stage (Table 3). Day care and respite care at home had the highest availability from the diagnostic to the intermediate stage, with a decrease in the late to end of life stage utilized by no or

Table 2 Categorization of professional providers of supportive actions, according to the International Standard Classification of Education (ISCED)*

ISCED LEVEL: At or above ISCED level	General health care training	Specialized health care training	Specialized training in dementia
7: Master's or equivalent, vocational	Psychologist (psychol), provides counseling and help to people with psychological problems	GP, physician who treats patients within a district for all types of diseases	MD geriatrics (MD-ger), geriatrician or psycho-geriatrician specialized in geriatrics
		MD psychiatry[1] (MD-psych)/ Old Age Psychiatrist, specialized in psychiatry	
	Social worker (SW), provides staff management for residential care or home help service	MD neurology[1] (MD-neuro), specialized in neurology	
	Physiotherapist, provides rehabilitation to identify and improve, e.g., disabled movement and function	MD-internal medicine, specialized in internal medicine	
6: Bachelor's or equivalent, vocational	Social worker, provides staff management for residential care or home help service	Community psychiatric registered nurse, (RN-comm-psych), supports older people at home and in nursing/residential homes. Specialized in psychiatry.	RN specialized in dementia (RN dem), has an overall responsibility for dementia care in an area/municipality. Provides counseling, supervision, and assessments, and mediates contacts. Education at advanced level: Care of the elderly (1 year Master), District nurse (1 year Master), Psychiatric care (1 year Master).
	Registered nurse (RN), provides care and service including help with PADLs, medical treatments, and managing the nursing care team	Home help officer, carries out needs assessment prior to decision about home services and care	
	Occupational therapist (OT), provides rehabilitation to achieve optimum level of functional ability. This may include adaptation of the home and providing aids and equipment to assist with managing everyday activities.	Case manager, professional (nurse or social worker) function that may include finding and outreach, comprehensive assessment and care planning, coordination of service, service provision, monitoring, and evaluation, and, in addition, meeting special needs	
	Physiotherapist[2], provides rehabilitation to identify and improve, e.g., disabled movement and function.		
	Case manager, see "Specialized health care training"		
5: Short-cycle tertiary education, vocational	Registered nurses, not Bachelor's level		State examined nurses specialized in dementia care
	State examined nurse (SEN), not Bachelor's level		(SEN dem), not Bachelor's level
	Occupational therapist, Bachelor's level, provides rehabilitation to achieve optimum level of functional ability. This may include adaptation of the home and providing aids and equipment to assist in managing everyday activities.		
4: Post-secondary non-tertiary, vocational	Licensed practical nurse (LPN)/auxiliary nurse (Aux-N), provides care and service including help with IADLs and PADLs, and, in addition, minor medical treatment. Health care trained at secondary school level.		
3: Upper secondary, vocational	Nurse aid/assistant nurse (Ass-N), provides care and service including help with IADLs and PADLs. Health care trained for <6 months (OECD 2005).		

Table 2 Categorization of professional providers of supportive actions, according to the International Standard Classification of Education (ISCED)* *(Continued)*

	Support worker (Supp-work), home carer, psychological supporter, or home trainer paid at enhanced nursing assistant/home carer rate. Social care/nursing trained at secondary level or trained on the job.
<3	Social worker assistant (SW-ass), performs some similar tasks as the social worker. Not trained, or trained on the job

*International Standard Classification of Education (ISCED), 2011
[1]MD Psychiatry and MD Neurology: training in dementia is normally part of their special training
[2]Registered nurses, occupational therapists, and physiotherapists are trained at different levels in the eight participating European countries
IADL instrumental activities of daily living, *PADL* practical activities of daily living

only few informal caregivers across the disease trajectory. In total, 25 types of professional support providers were identified as being involved in support activities for informal caregivers caring for an older PwD at home (Tables 4).

Availability of support for informal caregivers

Counselling was available during all or most disease stages except in two countries (England and Estonia). Caregiver support was available for all or most stages except in two countries (Estonia and France). Caregiver education was available for all or most informal caregivers in all countries through all stages of the disease. Reimbursement was available for all or most informal caregivers in three countries in the diagnosis and early stage, increasing to five countries in the intermediate stage, and six countries in the late stage. In addition, reimbursement through the trajectory of the dementia disease was available only to few informal caregivers in two countries (Sweden and France), (Table 3). Day care was available for all or most PwD in five countries (England, Estonia, France, the Netherlands, Sweden) in the diagnosis, early and intermediate stage. In the late stage, day care was available for most patients in England and Sweden, and for few in three countries (Estonia, France, Germany). Specialized day care for dementia was available for all PwD in the Netherlands from diagnosis to the intermediate stage and for most in France and England from early stage to late stage. Respite care at home was available for all or most PwD through all stages in four countries (England, Finland, Germany, Sweden). Respite care at home was available for few across the disease trajectory in Estonia and for no one in France and Spain.

Utilization of support for informal caregivers

Counselling was utilized by all or most informal caregivers in the intermediate to end of life stage in three countries (Spain, Finland, the Netherlands) increasing in the early to intermediate stage in four countries (Estonia, Finland, France, Sweden). Caregiver education was utilized by few in all countries except Spain and the Netherlands, where caregiver education was utilized by most informal caregivers through all stages of the dementia disease. Most informal caregivers in Germany utilized reimbursement through all stages. In England and Sweden, few got reimbursement in the early to end of life stage (Table 3). In seven out of eight countries, most informal caregivers provided care voluntarily. Day care was utilized by most informal caregivers in two countries (Finland and France) from the diagnosis to the intermediate stage and by no one or few in five countries (England, Estonia, Germany, Spain, and Sweden). Dementia specialized day care was utilized by most through all disease stages in France, while it was utilized by few or no one in the other countries. Respite care was utilized by all or most in France and the Netherlands from the diagnosis stage to the late stage of the dementia disease. In Estonia, Sweden, and England, respite care was utilized by few from diagnosis stage to the end of life stage. Respite care specialized in dementia was utilized by all informal caregivers in France through all stages of the dementia disease. In Spain, specialized respite care for dementia was utilized by no one. Respite care at home was utilized by few caregivers in England, Estonia, Spain, Germany, and Sweden, across the dementia disease trajectory.

Professionals providing support to informal caregivers and their educational level

Counselling, caregiver support, education, and reimbursement were provided by professionals whose education ranged from upper secondary schooling to a Master's degree in all countries (Table 4). Six out of eight countries had professionals specialized in dementia care and were able to offer this support to informal caregivers. Case managers were professionals with health care training usually at a Bachelor's degree level. They provided support such as counselling, caregiver support, and education in Germany and the Netherlands. In Germany, state examined nurses with a short-cycle tertiary education (not a Bachelor's degree) provided counselling to informal caregivers. In Estonia, counselling

Table 3 Availibility and utilization of supportive actions for informal caregivers in eight European countries

		Diagnosis stage		Early stage: mild cognitive impairment		Intermediate stage: moderate cognitive impairment		Late stage: severe cognitive impairment		End of life stage	
		Available for	Utilized by	Available for	Utilized by	Available for	Utilized by	Available for	Utilized by	Available for	Utilized by
Counseling: Informal and formal, professionals or agency providing support to persons with dementia (PwDs) and their family.	EE	No one	No one	No one	No one	No one	No one	No one	No one	No one	No one
	FI	All	Most	All	Most	All	Most	All	Most	All	Most
	FR	Most	Most	Most	Most	Most	Most	Few	Few	No one	No one
	DE	Most	Few	Most	Few	Most	Few	Most	Few	Most	Few
	NL	All	Most	All	Most	All	Most	All	Most	All	Most
	ES	All	Most	All	Most	All	Most	All	Most	All	Most
	SE	All	Few	All	Most	All	Most	All	Most	Few	Most
	E	Few	Few	Few	Few	Few	Few	Few	Few	Few	Few
Caregiver support: Organization where professionals provide support, such as counseling, individually and/or in groups, and provide home visits to informal caregivers.	EE	Few	Few	Few	Few	Few	Few	Few	Few	Few	Few
	FI	All	Few	All	Few	All	Most	All	Most	All	All
	FR	Few	Few	Few	Few	Few	Few	Few	Few	Few	Few
	DE	Most	Few	Most	Few	Most	Few	Most	Few	Most	Few
	NL	All	Most	All	Most	All	Most	All	Most	All	Most
	ES	Most	Most	Most	Most	Most	Most	Most	Most	Most	Most
	SE	All	Few	All	Few	All	Few	All	Few	All	Few
	E	Most	Few	Most	Few	Most	Few	Most	Few	Most	Few
Caregiver education: Training for informal caregivers providing care and service to PwDs. Education includes needs and symptoms of dementia.	EE	Most	Few	Most	Few	Most	Few	Most	Few	Most	Few
	FI	All	Few	All	Few	All	Few	All	Few	All	Few
	FR	Most	Few	Most	Few	Most	Few	Most	Few	Most	Few
	DE	All	Few	All	Few	All	Few	All	Few	All	Few
	NL	All	Most	All	Most	All	Most	All	Most	All	Most
	ES	Few	Few	Few	Few	Few	Few	Few	Few	Few	Few
	SE	Most	Few	Most	Few	Most	Few	Most	Few	Most	Few
	E	Most	Few	Most	Few	Most	Few	Most	Few	Most	Few
Informal caregivers – reimbursed: Informal caregivers employed by the public to provide care and service.	EE	No one	No one	No one	No one	No one	No one	No one	No one	No one	No one
	FI	No one	No one	No one	No one	Most	Most	Most	Most	All	All
	FR	Few	Few	Few	Few	Few	Few	Most	Most	Few	Few
	DE	Most	Most	Most	Most	Most	Most	Most	Most	Most	Most
	NL	All	Few	All	Few	All	Few	All	Few	All	Few
	ES	No one	No one	No one	No one	Most	Most	All	Most	All	Most
	SE	Few	No one	Few	Few	Few	Few	Few	Few	Few	Few

Table 3 Availibility and utilization of supportive actions for informal caregivers in eight European countries *(Continued)*

	E	All	Few	All	Few	All	Few	All	Few	All	Few
Informal caregivers – not reimbursed: Informal caregivers provide care and service voluntarily.	EE	Most	Most	Most	Most	Most	Most	Most	Most	Most	Most
	FI	Most	Most	Most	Most	Most	Most	Most	Most	Most	Most
	FR	Most	Most	Most	Most	Most	Most	Most	Most	Few	Few
	DE	Few	Few	Few	Few	Few	Few	Few	Few	Few	Few
	NL	All	Most	All	Most	All	Most	All	Most	All	Most
	ES	All	All	All	All	All	All	All	All	All	All
	SE	All	Most	All	Most	All	Most	All	Most	All	Most
	E	All	Most	All	Most	All	Most	All	Most	All	Most
Day care/day activity/day care center/day hospital: Clinic or agency providing social activities and activities to stimulate physical, mental, and intellectual functional ability, daytime.	EE	Most	Few	Most	Few	Most	Few	Few	Few	No one	No one
	FI	Few	Most	Few	Most	Few	Most	No one	No one	No one	No one
	FR	Most	Most	Most	Most	Most	Most	Few	Few	No one	No one
	DE	Few	No one	Few	Few	Few	Few	Few	Few	Few	No one
	NL	All	All	All	All	All	All	All	All	All	All
	ES	No one	No one	Most	Few	Most	Few	No one	No one	No one	No one
	SE	Most	Few	Most	Few	Most	Few	Most	Few	No one	No one
	E	Most	Few	Most	Few	Most	Few	Most	Few	Few	Few
Day care/day activity/day care center/day hospital specialized in dementia care: Clinic or agency with staff specialized in dementia care providing social activities and activities to stimulate cognitive ability, daytime. Only persons with dementia are admitted.	EE	Few	Few	Few	Few	Few	Few	Few	Few	No one	No one
	FI	Few	Most	Most	Most	Most	Most	Most	Most	No one	No one
	FR	Most	Most	Most	Most	Most	Most	Most	Most	Most	Most
	DE	Few	No one	Few	Few	Few	Few	Few	Few	Few	No one
	NL	All	All	All	All	All	All	All	All	All	All
	ES	No one	No one	Few	Few	Few	Few	Few	Few	No one	No one
	SE	Few	Few	Few	Few	Few	Few	For few	Few	No one	No one
	E	Most	Few	Most	Few	Most	Few	Most	Few	Most	Few
Respite care at home: Care at home to provide relief to informal caregivers who are caring for a family member/close friend.	EE	Few	Few	Few	Few	Few	Few	Few	Few	Few	Few
	FI	All	Few	All	Few	All	Few	All	Most	All	Most
	FR	No one	No one	No one	No one	No one	No one	No one	No one	No one	No one
	DE	All	No one	All	Few	All	Few	All	Few	All	Few
	NL	All	All	All	All	All	All	All	All	All	All
	ES	No one	No one	No one	No one	No one	No one	No one	No one	No one	No one
	SE	All	Few	All	Few	All	Few	All	Few	All	Few
	E	Most	Few	Most	Few	Most	Few	Most	Few	Most	Few

DE Germany, *E* England, *EE* Estonia, *ES* Spain, *FI* Finland, *FR* France, *NL* the Netherlands, *SE* Sweden

Table 4 Professionals providing supportive actions for informal caregivers, supportive actions and level of education*

		ISCED level 7: Master's or equivalent, vocational	ISCED level 6: Bachelor's or equivalent, vocational	ISCED level 5: Short-cycle tertiary education, vocational	ISCED level 4: Post-secondary non-tertiary, vocational	ISCED level 3: Upper secondary, vocational
Counseling: Informal and formal, professionals or agencies providing support to persons with dementia (PwDs) and their family.	EE					
	FI		RN, RN dem		Aux-N	
	FR	Psychologist				
	DE	Case manager[2] psychol	Case manager[2], SW	SEN		
	NL	Psychologist	Case manager[2], RN dem			
	ES	MD ger, psych, neuro, GP, psychol	RN, SW			
	SE	MD ger, psych, neuro, GP, psychol				
	E	Psychologist	RN, RN dem, psych, SW, OT			Support worker
Caregiver support: Organization where professionals provide support, such as counseling, individually and/or in groups, and provide home visits to informal caregivers.	EE	Psychologist	SW			
	FI		RN, RN dem		Aux-N	
	FR		SW			
	DE		Case manager[2]			
	NL	Psychologist	Case manager[2], RN, SW		Ass-N	
	ES	GP, Psychologist	RN,SW			
	SE	MD ger, psych, neuro, GP, Psychol			LPN	
	E	Psychologist	RN, RN dem, psych, SW, OT			
Caregiver education: Training for informal caregivers providing care and service to PwDs. Education about needs and symptoms of dementia.	EE	MD	RN, SW			
	FI		RN, RN dem, SW		Aux-N	
	FR	MD-ger	RN, SW			
	DE		Case manager[2]			
	NL		Case manager[2], RN, SW			
	ES	GP, Psychologist	RN, SW, OT			
	SE		RN, RN dem, SW			
	E	Psychologist	RN, RN dem, psych, SW			LPN
Informal caregivers – reimbursed: Informal caregiver employed by the public to provide care and service.	EE					
	FI		RN, RN dem, SW			
	FR	MD ger, GP	SW			
	DE					
	NL	NA[1]	NA[1]	NA[1]	NA[1]	NA[1]
	ES		SW			
	SE		SW			
	E		SW			
Day care/day activity/day care	EE					
center/day hospital: Clinic or agency providing social activities and activities to stimulate physical,	FI	GP	RN, SW, Physio-T			
	FR	MD-ger. Psychologist	RN, SW, OT, Physio-T			
	DE	SW, Physio-T	SW, OT, Physio-T	SEN	Aux-N	Ass-N

Table 4 Professionals providing supportive actions for informal caregivers, supportive actions and level of education* *(Continued)*

mental, and intellectual functional ability, daytime	NL	Multi-prof. team[3]				
	ES	MD-ger, psych, neuro, GP, Psychologist	RN, SW, OT, Physio-T			Ass-N
	SE		SW		Ass-N, LPN	
	E	MD-psych, Psychologist	RN, RN dem, SW, OT, Physio-T		Ass-N	
Day care/day activity/day care center/day hospital specialized in dementia care: Clinic or agency, staff specialized in dementia care providing social activities and activities to stimulate cognitive ability, daytime. Only persons with dementia are admitted.	EE		OT			
	FI		RN, SW		Aux-N	
	FR	MD-ger. Psychologist	RN, SW, OT, Physio-T			
	DE	Multi-prof. team[3]	Multi-prof. team[3]			
	NL	Multi-prof. team[3]	Multi-prof. team[3]			
	ES	MD-ger, psych, neuro, GP, psychol	RN, SW, OT, Physio-T			
	SE		SW		Ass-N, LPN	
	E	MD-ger, psych, Psychologist	RN, RN dem, SW, OT, Physio-T			Ass-N, Support worker
Respite care: For older people, but not specific to those with dementia disease: residential care around the clock for relief to informal caregivers who provide care for a family member/close friend.	EE		RN			
	FI	GP	RN		Aux-N	
	FR	GP, MD-ger	SW			
	DE		SW, OT	SEN, SEN dem		
	NL	Multi-prof. team[3]	Multi-prof. team[3]			
	ES	MD-ger, psych, neuro, GP, psychol	RN, SW, OT, Physio-T			
	SE	GP	RN		Ass-N, LPN	
	E					Support worker
Respite care, specialized in dementia care: Residential specialized dementia care around the clock for relief to informal caregivers who provide care for a family member/close friend. In a nursing home or residential home.	EE		RN			
	FI	GP	RN		Aux-N	
	FR	GP, MD-ger	SW			
	DE					
	NL	Multi-prof. team[3]	Multi-prof. team[3]			
	ES					
	SE	GP	RN		Ass-N, LPN	
	E		RN, RN dem			Support worker
Respite care at home: Care at home for relief to informal caregivers who are caring for a family member/ close friend.	EE					
	FI				Aux-N	
	FR					
	DE					
	NL	Multi-prof. team[3]	Multi-prof. team[3]			
	ES					
	SE				Ass-N, LPN	
	E		RN, RN dem			Support worker

*International Standard Classification of Education (ISCED), 2011
[1]*NA* not applicable, i.e., the support was available, but not suitable in a specific stage of the disease or not suitable at all
[2]Case managers and home health experts had some health care training at ISCED level 6 and, in addition, special training for the task
[3]The multi-professional teams commonly consist of a physician, psychologist, registered nurse, assistant nurse, occupational therapist, and physiotherapist
DE Germany, *E* England, *EE* Estonia, *ES* Spain, *FI* Finland, *FR* France, *NL* the Netherlands, *SE* Sweden
For abbreviations of professional titles and qualifications, see the List of abbreviations

was provided voluntarily by informal caregivers and no professionals were involved. Day care and respite care (specialized and not specialized in dementia care), and respite care at home were provided by a variety of professionals with a range in education, from upper secondary schooling to a Master's degree. In Estonia, day care (not specialized) was provided by informal caregivers and no professionals were involved. In the Netherlands, multi-professional teams were providing respite care, both with and without dementia specialization. Multi-professional teams commonly consisted of physicians, psychologists, registered nurses, assistant nurses, occupational therapists, physiotherapists, and social workers. In Germany and the Netherlands, respite care was provided by informal caregivers, with reimbursement from insurances. In Spain, respite care for dementia was unavailable. Of the four countries with national guidelines for dementia care, two had professionals with specializations in dementia care who worked in (either type of) day care.

Discussion

This study is an innovative attempt at creating an overview and a first use of a classification system to explore support for informal caregivers to PwD through the disease course in terms of availability, utilization, and professional support providers across several countries. In this study, although availability of support for informal caregivers seems to have been high, there was low utilization of support by informal caregivers. This might be understood within the model of patient-centered access to health care. According to this model [33], there are two sides to access to the health care systems: the supply side (i.e., availability), and the demand side (i.e., utilization). Availability may be dependent on five dimensions of accessibility of services, namely: approachability; acceptability; availability and accommodation; affordability; and appropriateness. Utilization may depend on the informal caregiver's ability to interact with the accessibility; and his or her ability to perceive, seek, reach out, pay, and engage. Access can be defined as "the opportunity to reach and obtain appropriate health care services in situations of perceived need for care" [33]. Availability and utilization of support for informal caregivers to older PwD also seems to be related to each country's care and support systems. Four out of the eight participating countries had national guidelines for dementia care (England, France, the Netherlands, Sweden). In two more countries (Germany, Finland) these were under development at the time of data collection. Several determinants may trigger the action of accessing the health systems and utilizing care, both in the health system itself, by providers, and in the persons that need care and support.

The degree of availability of each support might depend on the characteristics of providers, organizations, and health systems. The results of this study showed that formal support for informal caregivers, from the supply side, was available in different degrees, both along the continuum of the dementia disease and across the European countries. In this study, there was high availability of counselling, caregiver support, and education from the diagnosis to the intermediate stage of the dementia disease, with decreased availability in the late to end of life stage. Access to support enables informal caregivers to enter formal care with differences in perception of needs for care, in health care seeking, in reaching and obtaining or delaying care seeking, and in type and intensity of services [33]. In a study, Morgan et al. [34] found that, at 6 months post-diagnosis, informal caregivers experienced relief, validation, and access to support and services. The diagnosis introduced the informal caregivers to support they had previously been unaware of. Even though availability of support for informal caregivers might be high, sometimes it seems that the informal caregivers do not get the information about available support. This may have an impact on the demand side, with low utilization. Low utilization can also be a result of the informal caregiver's ability to interact with accessibility. Our results also showed that utilization of counselling, caregiver support, and education was low in the diagnosis and early stage, but increased in the intermediate stage. Reimbursement to informal caregivers was more available in the intermediate to end of life stages. There can be several explanations for these results. A previous study [35] showed that the utilization, by informal caregivers, of available respite services for frail older persons was dependent on their trust and confidence in the service. In a study investigating beliefs regarding out of home respite services showed that among informal caregivers to older PwD, non-use of respite services was strongly associated with beliefs that using the service would result in negative outcomes for the PwD [36]. It is important for each country to examine the availability of services in their care and service system in cities and provinces in order to develop and increase utilization of support to informal caregivers. A contact person/case manager [37] who can assist the informal caregiver when navigating through the care and service system may promote access and utilization on the demand side of support services. For the informal caregivers, this might build trust and confidence in formal care when caring for an older PwD through the trajectory of the disease.

Low utilization of support may be related to accessibility to the health system and, in addition, may be related to the informal caregiver's ability to interact with the accessibility of the health system support [33]. In our study, even though availability was high, counselling, caregiver support, and education were utilized

by only a few or no informal caregivers through all stages of dementia. Day care, both specialized and not specialized, and respite care at home was utilized by few or no caregivers through the disease stages. Previous studies have shown that there is a discrepancy between availability and utilization of support to informal caregivers of PwD in different stages of the disease [19, 38–41]. This may depend on access to the health system, professional providers, informal caregivers, and both users and non-users of support [33]. One study examined the difference between users and non-users of community service and results showed that the majority of informal caregivers did not participate in support groups (73 %) or use respite services (79 %). The non-users were significantly older, received less social support, and were more depressed [42]. A review [36] found that predisposing factors associated with service non-use included demographic and social structure variables, health beliefs and other beliefs, such as having high perceived duty to care or that the service was unreliable. It is important for each country to explore accessibility of its health system in order to develop and increase utilization of support to informal caregivers. An accessible health system is most important so that the informal caregiver and the older PwD may be able to receive the care and support needed. National guidelines based on current research and experience can be one way to demonstrate the benefits and risks of different interventions. Health care with national guidelines seems to ensure a specific level of care and support to all persons and mediate the health systems and organizations to strive towards established goals. To our knowledge, there are no studies exploring availability and utilization of support for informal caregivers, related to different countries' care and support systems. However, there are studies exploring implementation of national guidelines for person-centered care, dementia strategies, and clinical guidelines for depression. Edvardsson et al. [43] implemented national guidelines for person-centered care for persons with dementia in nursing homes. Their study showed that person-centeredness of care increased from baseline to 12-month follow up. There was also a reduction in staff stress of conscience and the members of staff were able to provide the requested care and activities after the intervention. In a study of physicians in primary care settings, McKinlay et al. [44] showed that adherence to guidelines varies with different patients and the physicians' length of clinical experience. Exploring support systems and developing national guidelines is essential to ensure quality of care and wellbeing for the informal caregiver and the PwD.

It seems that national guidelines regarding dementia care implies more professionals specialized in dementia care who provide support to informal caregivers of older PwD and meet specific needs during the trajectory of the disease. In this study, four out of eight countries had national guidelines in place for dementia care (England, France, the Netherlands, Sweden). Of these countries, two had professionals specialized in dementia care who provided counselling and caregiver support, and three had professionals with dementia specialization who provided education to informal caregivers. Specialized care professionals had education ranging from short-cycle tertiary education to Bachelor's or Master's degrees. Though little research seems to have been done concerning the educational level of professionals specialized in dementia care it can be assumed that higher levels of education and dementia specialization can improve the quality of care and support for informal caregivers and older PwD. One previous study showed that a higher proportion of registered nurses with a Bachelor's degree was related to lower mortality in hospital care in nine European countries [45]. Another study [46] found that educational deficits in dementia knowledge and in knowledge about normal aging made the physicians miss the dementia diagnosis or misdiagnose the disease. They found a considerable variability in primary care providers diagnostic sensitivity (ranging from 0.26–0.60). In addition, it was found that specialists were more accurate, compared with primary care providers, when making a dementia diagnosis. Hence, it appears that to understand and properly meet the needs of older PwD and their informal caregivers, dementia care require professionals with specific expertise and knowledge [2, 3]. It has further been suggested that dementia research should focus more on the relation between the educational levels of the health professionals, and their impact on the care for older PwD, and the wellbeing and quality of life of the informal caregiver [27]. In addition, it is important to explore professional providers' educational levels nationally to evaluate and develop the dementia support system for informal caregivers for older PwD according to national guidelines.

Methodological limitations

This study was a first attempt to explore support for informal caregivers of older PwD in terms of availability, utilization, and providers of support (i.e., providers' involvement and educational level) in European countries using a newly developed mapping system. The strength of this study was that we mapped data about eight European countries regarding the support for informal caregivers of older PwD in terms of availability, utilization, and providers. Our findings can serve as a knowledge base and it is hoped that they will enable the different European countries to learn from each other. The sample represents central, northern, southern, western and eastern European countries and

reflects our aim to include a sample to represent Europe as a whole. However, eastern and western Europe were only represented by one country each. When developing the mapping system, the researchers from each country determined the different types of care and support for formal caregivers and agreed on the concepts and terminology. However, the collected information probably varied within organizations, regions, and countries. It was challenging to operationalize and quantify the concepts "availability" and "utilization" in a comparable way. The somewhat open and unspecific categories may have influenced the results due to different interpretations, which may reflect a range of the conditions in each country. In our study, data sources varied. The findings are not based on any research in the field and experts consulted were not systematically selected. Moreover, the term "not applicable" provided some problems. Some researchers explained that in some cases, the support was available, but not suitable for a specific stage of the disease or not suitable at all. Sometimes support was available for most, but was utilized by few without any relation between availability and use. All participants were instructed how to understand the meaning of the concepts "availability" and "utilization" as well as how to assess the care in relation to the stages of the disease for validation of the data previously collected [29]. To establish reliability, each country's researchers were given the same instructions for data collection. The response alternatives for "availability" were "For all", "For most", "For few" and "For no one", and for utilization, "By all", "By most", "By few", and "By no one". Responses were estimations, without any statistic basis. Each country's researchers reported their country's health systems and policies for dementia care and services, assessed and interpreted from their cultural and societal perspective, which may have affected the validity of the results. The weakness of this study may therefore be the data collection method, which allowed room for different cultural interpretations. Since data used in this study was collected between November 1st, 2010, and January 31st, 2011, it is possible that the result may have been different if data were collected today. Support systems for informal caregivers to older PwD might have been developed in participating countries to improve support for informal caregivers. In addition, professionals with dementia specialization might have increased to improve both support to informal caregivers and quality of care for PwD. Future studies using the mapping system on a national level, cities or provinces, will make it possible to improve inter-rater agreement with fewer data-collectors. National and more local mapping will improve the representative of samples (e.g. organisations and services providers) and make it possible to collect primary and more precise and statistical data regarding availability and utilisation. In future studies it will be important to consider differences between urban and rural areas and populations with different social-economic statues and ethnical backgrounds.

Conclusion

Counselling, caregiver support, and education were highly available from diagnosis to the intermediate stage of the dementia disease, decreasing in the late and end of life stages. These support activities were, however, utilized by few or no caregivers to PwD across the disease trajectory. Estimations of availability and utilization of support for informal caregivers appears to be closely related to each country's care and support systems. Countries with national guidelines for dementia care seemed to be more aware of the importance of having professionals specialized in dementia care involved in providing support to PwD and their informal caregivers. The mapping system used in this study to identify the support for informal caregivers of older PwD is valuable for evaluating this support system, both nationally and locally. Applying the mapping system on a local level (cities and provinces) will make the care and support system through the course of the dementia disease visible and ensure that adequate care and support are offered to informal caregivers to PwD. In addition, the mapping system may also be useful for informing the development of policy for care and services for PwD and their informal caregivers.

Abbreviations

ADL: Activities of daily living; Ass-N: Nurse aid/assistant nurse; Aux-N: Auxiliary nurse; DE: Germany; E: England; EE: Estonia; ES: Spain; FI: Finland; FR: France; ger: Geriatrics; IADL: Instrumental activities of daily living; ISCED: The International Standard Classification of Education; LPN: Licensed practical nurse; MD: Medical doctor; MD-ger: Medical doctor specialized in geriatrics; MD-neuro: Medical doctor specialized in neurology; MD-psych: Medical doctor specialized in psychiatry; NL: The Netherlands; OT: Occupational therapist; PADL: Practical activities of daily living; physio-T: Physiotherapist; psych: Psychiatry; psychol: Psychology; PwD: Person with dementia; RN: Registered nurse; RN-comm-psych: Community psychiatric registered nurse; RN dem: Registered nurse specialized in dementia; RTPC: RightTimePlaceCare; SE: Sweden; SEN: State examined nurse; SEN dem: State examined nurse specialized in dementia; supp worker: Support worker; SW-ass: Social worker assistant; SW: Social worker.

Competing interests

The authors declare that they have no competing interest.

Authors' contributions

The first author (C.L.) drafted the manuscript and was responsible for the data. All authors contributed to collecting the data for the mapping system, and reviewing and critically revising the manuscript. All authors (H. L-K., B.R., M. S-M., K.S., A.S., S.Z., A.Z., S.K.) have approved the final manuscript. B.R. revised the English language and spelling.

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Paper III

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Title: Psychological well-being over time among informal caregivers caring for persons with dementia living at home

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Abstract

Objectives: To investigate informal caregivers' psychological well-being and predicted increase in psychological well-being, when caring for persons with dementia (PwDs) living at home, related to caregiver, PwD and formal care (FC) factors.
Method: A cohort study, at baseline and 3 months´ follow-up in eight European countries. Caregivers included (n=1,223) were caring for PwDs aged ≥ 65 years at home. Data on caregivers, PwDs and FC were collected using standardized instruments. Regression analysis of factors associated with caregiver psychological well-being at baseline and 3 months later was performed.
Results: Factors associated with caregiver psychological well-being at baseline were positive experience of caregiving, low caregiver burden, high quality of life (QoL) for caregivers, male gender of PwD, high QoL of PwD, few neuropsychiatric symptoms and depressive symptoms for the PwD. At follow-up, caregivers with increased psychological well-being experienced of quality of care (QoC) higher and were more often using dementia specific service. Predicting factors for caregivers' increased psychological well-being were less caregiver burden, positive experience of caregiving, less supervision of the PwD and higher caregiver QoL, if PwD were male, had higher QoL and less neuropsychiatric symptoms. Furthermore, higher QoC predicted increased caregivers' psychological well-being.
Conclusion: Informal caregiving for PwDs living at home is a complex task. Our study shows that caregivers' psychological well-being was associated with, among other things, less caregiver burden and higher QoL. Professionals should be aware of PwD neuropsychiatric symptoms that might affect caregivers' psychological well-being, and provide proper care and treatment for caregivers and PwDs.

Keywords: Dementia, caregivers, health professionals, home care services, adaptation; psychological

Introduction

Informal caregivers (hereafter,´caregivers´) are the main care providers for persons with dementia (PwDs) aged 65 years and more living at home. Caregiving for a PwD can be experienced as positive (The National Board of Health and Welfare, 2010) but can negatively influence caregivers´ psychological well-being. Impaired psychological well-being is associated with increased risk for poor health, including depression and life stress leading to chronic disorders (Steptoe, 2006). Therefore it is important to identify factors in caregivers, PwDs and formal care, which might be associated with the psychological well-being of caregivers and predict factors that might improve their psychological well-being.

Informal care is defined by the Organization for Economic Co-operation and Development (OECD, 2004) as care provided by caregivers who can be the spouse/partner, other members of the household, relatives, friends, neighbours or others, usually with an existing social relationship to the person they are providing care for. Informal care at home for PwDs may imply assistance in activities in daily living (ADLs), finances and supervision tasks (Schulz 2004). Caregivers provide approximately 80% of the care for PwDs living at home (Alzheimers' Association, 2010) and can have support from formal care e.g. providing instrumental ADLs (IADLs, personal ADLs (PADLs), day care for the PwD, and other forms of support. As the dementia disease progresses with increased cognitive impairment of the PwD, there is an increase in caregiving needs.

Health is defined by the World Health Organization (1948), as ´a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity´. Health is a multidimensional construct, part of which one is psychological well-being with core dimensions such as self-acceptance, environmental mastery, purpose in life, personal growth, positive relationships and autonomy (Ryff and Singer, 2008). Caring for a PwD can burden caregivers and reduce their physical and psychological well-being (Pinquart & Sörensen 2006). Caregiver burden is an important reason for institutionalization of PwD (Afram 2014; Sansoni 2013) which makes it essential to promote psychological well-being of caregivers.

Psychological well-being may therefore be a facilitating factor for health (Luybomirsky et al., 2005; Segerstrom 2012; Steptoe 2015) and improved health and reduced mortality can be predicted by higher levels of psychological well-being (Chida & Steptoe, 2008; Pressman & Cohen 2005). Few studies have focused on positive factors of psychological well-being (Luybomirsky et al., 2005) as studies of caregivers to PwDs mostly focus on factors that negatively impact the caregiver's well-being. A previous study on both caregivers to Pwd and caregivers to persons without dementia showed that well-being for the caregivers was directly affected by four factors (Chappell and Colin Reid, 2002); perceived social support, burden, self-esteem and hours of caregiving. It is therefore important to investigate factors associated with increased caregivers´ psychological well-being involving the caregiver, PwD and formal care. To understand what factors preserve and improve caregiver psychological well-being over time, it is important to investigate factors predicting an increase in psychological well-being, thus enabling individualized support to caregivers as well as PwD. This knowledge can be used to develop quality indicators for caregivers´ psychological well-being when caring for a PwD living at home. The primary aim of the present study was to investigate which caregiver, PwD and formal care-related factors are associated with psychological well-being of caregivers´ caring for older PwDs living at home. The secondary aim was to investigate which factors might predict an increase in the caregivers´ psychological well-being over time (3months).

Methods

Design

This study was a cohort study. Data were collected at baseline to investigate factors associated with caregivers´ psychological well-being. The study included a follow up after 3 months to investigate changes in caregiver psychological well-being.

Context

The study was a part of the European project ´RigthTimePlaceCare´ (RTPC; the EU 7th Framework programme for research, contract number 24 21 53) including eight participating countries; England, Estonia, Finland, France, Germany, the Netherlands, Sweden and Spain (Appendix 1). The aim of the RTPC project was to describe the health services for European citizens with dementia and to develop best practice strategies for the transition from professional home care to institutional long-term nursing care facilities. The present study followed the same methods and procedures used by the RTPC project without modification (Verbeek et al., 2012).

Sample

Caregivers and PwDs living in the community were recruited by the RTPC study, one county council or province in each country, in total 1,223 dyads (England *n*=81, Estonia *n*=172, Finland *n*=182, France *n*=175, Germany *n*=116, the Netherlands *n*=177, Sweden *n*=146 and Spain *n*=174). A contact person with knowledge about PwDs in the municipality, contacted probable participants. The contact person could be from different health care disciplines and contacts were made most commonly in the home care and in one hospital. Inclusion criteria for the PwD were age ≥ 65 years, official diagnosis of dementia, Standardized Mini-Mental State Examination (SMMSE) score ≤ 24 (Molloy et al., 1991; Folstein et al., 1975), living at home and receiving home care from health care or the social services. PwDs had to be judged to be at risk for institutionalization within 6 months by a professional caregiver responsible for their care. The caregiver had to be visiting the PwD at least twice a month and included both paid and non-paid caregivers. Recruitment in each country was performed by a contact person; these contact persons could be from different disciplines. The contact person informed the caregiver and PwD dyad about the study and the interviews, and asked for permission for researchers to contact them for a face-to-face interview.

Data collection

The study was conducted between November 2010 and April 2012. Standardized measuring instruments used for collecting data are described in detail in Table 1. The caregiver answered all questions except for the SMMSE questions, which were answered by the PwD, as well as a part of the quality of life (QoL) for the PwD. Caregiver data collected that had a potential impact on the caregivers´ psychological well-being included; age, gender, and cohabiting with the PwD, or duration and number of visits to the PwD during the last two weeks. Data on the PwDs included age, gender and dementia symptoms. Data concerning formal care regarded caregivers´ experiences of QoC provided by formal care at home. Information about specialized dementia care regarding respite care and day care was collected with a single item question: ´Are you or your relative using any dementia specific service?´ The response alternatives were ´yes´ or ´no´. Satisfaction with specialized dementia care for the PwD was measured with a single item question: ´How satisfied are you with the care provided by the dementia-related service?´ which was rated on a 5-point Likert scale, where; 1 = very dissatisfied; 2 = dissatisfied; 3 = neither satisfied, nor dissatisfied; 4 = satisfied and 5 = very satisfied.

Table 1. Instruments used for data collection, and measured factors, items, score ranges, interpretation and handling of missing data. The Table also provides references for validity and reliability.

Subject	**Instrument, and outcomes measured**	
Caregiver	GHQ12	General Health Questionnaire, measuring psychological well-being. Score range: 0- 36, a higher score indicating less psychological wellbeing. Handling of missing data: mean score if <10% missing (Goldberg, 1972; Goldberg, 1978).
	CRA	Caregiver Reaction Assessment Scale, measuring caregiver experiences of care giving in chronic patients. 24 items in five domains: *Caregiver esteem*: seven items with a possible score range of 7–35; *Lack of family support*: five items with a score range from 5 to 25, *Impact on finances*: three items with a score range from 3 to15, *Impact on schedule*: five items with a score range of 5–25; and *Impact on health*: four items with a score range from 4 to 20. A higher score on Caregiver esteem indicates positive impact on caregiver experience; for the other domains, a higher score indicates a negative impact on caregiver experience. When one item was missing, no total score was calculated (Given et al., 1992).
	ZBI	Zarit Burden Interview measuring caregiver burden. 22 items in five domains: *Burden in the relationship*, six items; *Emotional wellbeing*, seven items; *Social and family life*, four items; *Finances*, one item; and *Loss of control over one's life*, four items. Score range: 0- 88 with a higher score indicating higher perceived burden. Handling of missing data: mean score if <10% missing. (Zarit et al. 1980; Herbert et al., 2000).
	RUD	Resource Utilization in Dementia, measuring informal care provision and amount of care required from caregivers. *Personal ADLs:* hours per day of caregiving and occasions during the last 30 days of caregiving. *Instrumental ADLs:* hours per day of caregiving and occasions during the last 30 days of caregiving. *Supervision:* hours per day of caregiving and occasions during the last 30 days of caregiving. Handling of missing data: imputed data. (Wimo et al., 1998; Wimo & Nordberg, 2007).
	EQ-5D-3L	EuroQoL, measuring health related quality of life (QoL) and self-rated health-related quality of life. Five descriptive questions about five health dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Score range: -0.594- 1 with a higher score indicating higher health-related QoL.
	EQ-VAS	EQ-VAS, measuring self-rated health. Score range: 0- 100 with a higher score indicating higher self-rated health. No total score if one item was missing. (TheEuroQolGroup, 1990; Brazier, Jones, & Kind, 1993; Oemar & Oppe 2013).
PwD	CCI	Charlson Comorbidity Index. Comorbidity of the PwD. 19 possible comorbidities. Score ranges: 0- 37 with a higher score indicating a greater risk to die from comorbid disease. Handling of missing data was not applicable. (Charlson et al., 1987; D'hoore et al., 1996).
	SMMSE	Standardized Mini-Mental State Examination, measuring cognitive function. 20 items: orientation in time and space, short term memory, short tasks on language, calculation, coordination. Score range: 0- 30 with a lower score indicating greater cognitive impairment. Handling of missing data was not applicable. (Folstein et al., 1975; Molloy et al., 1991).
	QoL-AD proxy rated	Quality of Life in Alzheimer's disease, measuring QoL of persons with dementia (Logsdon et al., 1999). Possible score: 13- 52 with a higher score indicating higher QoL (Logsdon et al., 2002).
	Katz-ADL	Katz Index of Independence in Activities of Daily Living, measuring activities of daily living (ADL). Performance in the six functions of bathing, dressing, toileting, transferring, continence, and feeding. Score range: 0- 6 with a higher score indicating more independence in performing ADLs (Katz et al. 1963; Wallace & Shelkey, 2008).
	NPI-Q	Neuropsychiatric Inventory Questionnaire, measuring behavioural and neuropsychiatric symptoms. 12 items: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, euphoria, apathy, disinhibition, irritability/lability, aberrant motor behaviour, sleep/night-time behaviour disorders, appetite and eating disorders. 1) Screening presence the past four weeks; 2) Severity; 3) Caregiver distress. Severity score range: 0- 36 with a higher score indicating presence of more (severe) neuropsychiatric symptoms. Distress score range: 0 to 60 with a higher score indicating more distress for the caregiver (Cummings, 1994; Kaufer, et al., 2000).
	CSDD	Cornell Scale for Depression in Dementia. The CSDD contains 19 items covering five dimensions: mood-related signs (four items); behavioural disturbance (four items); physical signs (three items); cyclic functions (four items); and ideational disturbance (four items). Score range: 0- 38 with a higher score indicating more depressive symptoms. Handling of missing data: mean score if a maximum of three missing items. The answer option "unable to evaluate" = missing value (Alexopoulos et al., 1988).
FC	CLINT	CLient INTerview Instrument – Home Care, measuring subjective experiences of quality of care in the home. Right amount of food (portions), enjoying meals, personal hygiene, same care workers, things care workers do, perceiving care workers as honest and trustworthy, clean home, garden maintenance, general satisfaction with FC. Score range: 9- 45 with a higher score indicating lower quality of care. Exception: if missing or not applicable in the question about gardening, the mean score was imputed. Mean score if a maximum of one missing item. No total score if >1 item missing (Vaarama, 2009; Beerens et al., 2014).

ADLs = activities of daily living; Caregiver = informal caregiver; EQ-5D-3L = EuroQoL-5 dimensions questionnaire with three levels of answers; FC = formal care; PwD = person with dementia; RTPC = RightTimePlaceCare; QoL = quality of life.

Data analysis

To identify factors that influenced increased psychological well-being we analysed data collected at two different time-points; at baseline and after 3 months. Handling of missing data is described in Table 1. Psychological well-being of the caregiver at baseline as measured by the General Health Questionnaire (GHQ12) (Goldberg, 1972; Goldberg et al., 1978), was the dependent variable for the first analysis and was dichotomized as ´1 = psychological well-being´ (0-12; better/same as usual) and ´0=low psychological well-being´ (13-36; less/much less than usual). Cut-off was decided based on the median value for psychological well-being. For the analysis at follow-up, a new variable was created indicating ´increase in GHQ12 score´, and dichotomized as: ´0 = no increase´ (no change/worse score) and ´1 = increase´ (better score). For each independent variable, a bivariate logistic regression model was applied for the caregiver, the PwD and the formal care respectively, for comparison among caregivers with psychological well-being and low psychological well-being at baseline and increased psychological well-being and no increase of psychological well-being after 3months. Changes were regarded as statistically significant if p <0.05. To identify factors associated with psychological well-being and factors predicting increased psychological well-being, three multivariate logistic regression models were performed backward for the caregiver, the PwD and the formal care respectively. The software program SPSS, version 22.0, was used for statistical analyses (IBM Corp., Armonk, NY, USA).

Ethical considerations

Each participating country obtained ethical approval from country specific legal authority and permission for data collection was obtained for each country, as described in detail elsewhere. Informed consent was obtained from participating caregivers and PwDs for the RTPC study (Verbeek et al., 2012). PwDs, not able to sign the informed consent were asked to assent, and the informal caregiver signed the informed consent for the PwD, if agreed.

Results

Informal caregivers

Psychological well-being was reported by 55% of the caregivers at baseline (median 9; Q1- 7; Q3- 11). At follow up, 58% of the caregivers reported increased psychological well-being (median 10; Q1-7; Q3- 12). Caregivers with psychological well-being were more often male and not living with the PwD; they were predominantly adult children of the PwD and were providing care to the PwD less frequently compared with caregivers with low psychological well-being (Table 2). Table 2 presents results of the bivariate regression analysis for factors associated with the caregivers´ psychological well-being. Caregivers with psychological well-being reported less caregiver burden and more positive experiences of caregiving in all domains compared with caregivers with low psychological well-being. Health-related QoL was higher for caregivers reporting psychological well-being compared with caregivers with low psychological well-being. The same factors were associated with caregiver increased psychological well-being at follow-up were associated with psychological well-being at baseline, except for age.

Influence of persons with dementia on caregiver psychological well-being

Table 3 presents the results of the bivariate regression analysis for PwD-related factors associated with the caregivers´ psychological well-being. Caregivers with psychological well-being at baseline, cared for PwDs who were mostly women, and PwDs with higher comorbidity and less cognitive impairment, higher QoL and less dependency in ADLs compared with caregivers reporting low psychological well-being. Caregivers reporting

Tabel 2. Association between informal caregiver factors and caregiver psychological well-being at baseline at follow-up.

Home care	**Psychological well-being at baseline**					**Increased psychological well-being at follow up**				
Caregivers [a]	**PWB** *n*=667	**Low PWB** *n*=550	**OR**	**CI 95%**	***p* value**	**Increase** *n*=545	**No increase** *n*=401	**OR**	**CI 95%**	***p* value**
Age, yrs; median (Q1; Q3)	63 (54; 77)	64 (55; 76)	0.993	0,986- 1.000	**0.046**	63 (54; 76)	64 (54; 75)	0.996	0.987- 1.005	0.353
Female gender, %	64	74	0.611	0.504- 0.740	<**0.001**	64	75	0.637	0.486- 0.834	**0.001**
Living with the PwD, %	55	69	0.560	0.442- 0.710	<**0.001**	56	70	0.508	0.392- 0.657	<**0.001**
No. of visits in the last 2weeks (range)	6 (4- 14)	7 (5- 14)	0.988	0.974- 1.001	0.074	6 (4- 12)	8 (4- 14)	0.995	0.980- 1.010	0.503
Length of average visit, min (range)	90 (60- 180)	115 (60- 180)	0.999	0.998- 1.000	**0.011**	90 (60- 165)	120 (60- 180)	1.000	0.999- 1.001	0.975
Relation to PwD, %										
Husband	19	16			<**0.001**	19	15			<**0.001**
Wife	20	29	0.620	0.454- 0.847	**0.003**	19	31	0.535	0.364- 0.786	**0.001**
Child	45	45	1.088	0.836- 1.418	0.529	46	44	0.924	0.657- 1.298	0.649
Friend	2	1	1.861	0.743- 4.663	0.185	1	-	6.387	0.801- 50.900	0.080
Other	14	9	1.511	1.075- 2.123	**0.017**	15	10	1.373	0.856- 2.203	0.189
Experiences of care giving (CRA) score, median (Q1; Q3)										
Esteem 7-35	27 (24; 30)	24 (21; 28)	1.080	1.060- 1.100	<**0.001**	27 (24; 30)	24 (21; 28)	1.083	1.056- 1.112	<**0.001**
Support 5-25	10 (8; 14)	13 (10; 17)	0.916	0.899- 0.934	<**0.001**	11 (8; 14)	13 (10;17)	0.920	0.896- 0.944	<**0.001**
Finances 3-15	6 (4; 7)	7 (6; 11)	0.846	0.821- 0.871	<**0.001**	6 (4; 8)	7 (6; 11)	0.856	0.822- 0.891	<**0.001**
Schedule 5-25	13 (10; 18)	19 (15; 21)	0.836	0.819- 0.854	<**0.001**	14 (10; 18)	19 (16; 21)	0.851	0.828- 0.875	<**0.001**
Health 4-20	8 (6; 10)	12 (9; 15)	0.743	0.720- 0.766	<**0.001**	8 (6; 10)	12 (9; 15)	0.774	0.744- 0.805	<**0.001**
Caregiver burden (ZBI), 0-88	24 (15; 33)	41 (31; 50)	0.923	0.916- 0.930	<**0.001**	23 (14; 34)	41 (30; 52)	0.937	0.928- 0.947	<**0.001**
Informal care provision (RUD) median (Q1; Q3)										
PADLs, hours per day of caregiving	1 (0; 3)	2 (1; 4)	0.957	0.934- 0.981	<**0.001**	1 (0; 3)	2 (1; 4)	0.931	0.905- 0.959	<**0.001**
PADLs, occasions, last 30 days of caregiving	24 (0; 30)	30 (8; 30)	0.975	0.966- 0.983	<**0.001**	30 (0; 30)	30 (15; 30)	0.975	0.966- 0.984	<**0.001**
IADLs, hours per day of caregiving	2 (1; 4)	3 (2; 5)	0.945	0.919- 0.972	<**0.001**	2 (1; 4)	3 (2; 5)	0.906	0.876- 0.938	<**0.001**
IADLs, occasions, last 30 days of caregiving	30 (10; 30)	30 (22; 30)	0.975	0.964- 0.986	<**0.001**	30 (12; 30)	30 (26; 30)	0.973	0.961- 0.985	<**0.001**
Supervision, hours per day of caregiving	1 (0; 10)	4 (1; 14)	0.966	0.953- 0.980	<**0.001**	1 (0; 10)	5 (1; 14)	0.955	0.940- 0.970	<**0.001**
Supervision, occasions, last 30 days of caregiving	30 (0; 30)	30 (15; 30)	0.972	0.964- 0.981	<**0.001**	29 (0; 30)	30 (16; 30)	0.966	0.956- 0.975	<**0.001**
Health related quality of life (EQ-5D-3L**),** -0.594-1	0.8 (0.7; 1.0)	0.7 (0.6; 0.8)	18.635	12.085-28.735	<**0.001**	0.9 (0.8; 1.0)	0.7 (0.6; 0.9)	9.591	5.639- 16.313	<**0.001**
EQ5D Visual analog scale (VAS), 0-100	78 (65; 85)	60 (50; 75)	1.046	1.040- 1.052	<**0.001**	80 (69; 85)	60 (50; 71)	1.032	1.025- 1.040	<**0.001**

Caregiver = informal caregiver; CI = confidence interval; CRA = Caregiver Reaction Assessment Scale; EQ-5D-3L = EuroQoL-5 dimensions questionnaire with three levels of answers; IADL = instrumental activities of daily living (ADLs); PADLs = personal activities of daily living (ADLs); OR = odds ratio; PWB = psychological well-being; RUD = Resource Utilization in Dementia instrument; ZBI = Zarit Burden Interview.
$P < 0.05$ was regarded as significant; significant p-values are marked in bold.

Underlining of values indicates a positive result, e.g., 0- 36.

Missing cases at baseline = 0, missing cases at follow up = 3.

[a] PwD moved to nursing home by follow up, n=274.

[b]Imputation of data: PADL last 30 days caregiving n=1- 2, Supervision last 30 days of caregiving n=1- 2, [c] Imputation of data: PADL last 30 days of caregiving n=19- 20, Supervision hours per day n=77, Supervision last 30 days of caregiving n=19- 20.

Table 3. Association between person with dementia (PwD)-related factors and informal caregivers´ psychological well-being at baseline and at follow-up.

Home care	**Psychological well-being at baseline**					**Increased psychological well-being at follow up**				
Persons with dementia[a]	**PWB**	**Low PWB**	**OR**	**CI 95%**	***p* value**	**Increase**	**No increase**	**OR**	**CI 95%**	***p* value**
	n=667	*n*=550				*n*=545	*n*=401			
Age, yrs; median (Q1; Q3)	83 (79; 87)	83 (74; 86)	1.008	0.995- 1.022	0.231	83 (79; 87)	82 (78; 86)	1.013	0.994- 1.032	0.174
Symptoms, yrs (range)	4 (2– 6)	4 (2– 7)	0.986	0.960- 1.012	0.296	4 (2– 6)	4 (2- 7)	0.984	0.949- 1.021	0.388
Female gender, %	68	58	1.480	1.226- 1.787	<**0.001**	70	57	1.740	1.348- 2.246	<**0.001**
Dementia diagnosis (%)										
Alzheimers disease (AD)	57	51			0.190	56	53			0.578
AD/ Vascular dementia (VaD)	5	7	0.637	0.391- 1.039	0.071	7	5	1.246	0.720- 2.156	0.431
VaD	15	18	0.709	0.516- 0.975	**0.034**	15	18	0.790	0.561- 1.112	0.176
Frontotemporal dementia	1	1	1.004	0.223- 4.523	0.995	1	1	0.937	0.208- 4.226	0.933
Lewy Body dementia	2	2	1.507	0.636- 3.569	0.352	2	2	1.305	0.513- 3.321	0.576
Unknown	16	16	0.948	0.686- 1.311	0.748	14	17	0.798	0.560- 1.136	0.211
Other	4	5	0.753	0.432- 1.313	0.317	5	4	1.093	0.591- 2.022	0.776
Comorbidity (CCI), median (Q1; Q3), 0-37	2 (1; 3)[b]	2 (1; 3)[c]	0.909	0.856- 0.966	**0.002**	2 (1; 3)[d]	2 (1; 3)[e]	0.921	0.842- 1.006	**0.067**
Cognitive function, (SMMSE), 0-30	16 (11; 20)	15 (9; 19)	1.023	1.008- 1.038	**0.003**	16 (11; 20)	15 (9; 19)	1.031	1.011- 1.052	**0.003**
Quality of life (QoL-AD, proxy), 13-52	29 (26; 33)	26 (23; 30)	1.089	1.070- 1.108	<**0.001**	29 (26; 33)	26 (23; 31)	1.082	1.055- 1.110	<**0.001**
Activities of daily living (Katz ADL), 0-6	4 (2; 5)	3 (2; 5)	1.096	1.047- 1.148	<**0.001**	3 (2; 5)	3 (1; 4)	1.101	1.033- 1.174	**0.003**
Neuropsychiatric symptoms (NPI)[f]										
median (Q1; Q3)										
Severity, 0- 36	7 (3; 11)	11 (6; 15)	0.941	0.927- 0.955	<**0.001**	6 (3; 11)	8 (4; 12)	0.952	0.933- 0.971	<**0.001**
Distress, 0- 60	7 (2; 13)	13 (7; 20)	0.931	0.918- 0.944	<**0.001**	6 (2; 12)	10 (5; 14)	0.952	0.939- 0.966	<**0.001**
Depression in dementia (CSDD), 0- 38	6 (2; 10)	9 (5; 14)	0.917	0.901- 0.934	<**0.001**	5 (2; 9)	8 (5; 17)	0.938	0.916- 0.960	<**0.001**

CCI = Charlson Comorbidity Index; CI = confidence interval; CSDD = Cornell Scale for Depression in Dementia; NPI = Neuropsychiatric Inventory; OR = odds ratio; PWB = Psychological well-being; QoL-AD = quality of life in Alzheimer's disease; Q1 = first quartile; Q3 = third quartile; SMMSE = Standardized Mini-Mental State Examination.

P < 0.05 was regarded as significant; significant p-values are marked in bold.

Missing cases at baseline = 0; missing cases at follow-up = 3.

Underlining of values indicates a positive result, e.g., 0–36.

[a] PwDs who had moved to a nursing home at follow-up, n=274.

[b] Mean 2.24, standard deviation (SD) =1.8; [c] mean 2.00, SD=1.28; [d] mean 2.18, SD=1.50; [e] mean 2.01, SD=1.25.

[f] Imputation of data for NPI, severity and burden, respectively, n=1.

Table 4. Association between formal care-related factors and informal caregivers´ psychological well-being at baseline and at follow-up.

Home care	**Psychological well-being at baseline**[h]					**Increased psychological well-being at follow up**[i]				
Formal care[a]	**PWB** *n*=667	**Low PWB** *n*=550	**OR**	**CI 95%**	***p* value**	**Increase** *n*=545	**No increase** *n*=401	**OR**	**CI 95%**	***p* value**
Quality of care at home (CLINT) median (Q1; Q3)										
Total score, 9- 45	15.0 (12.0; 18.0)	16.1 (13.1; 18.1)	0.948	0.919- 0.978	**0.001**	14.0 (12.0; 17.1)	16.1(13.1; 18.1)	0.947	0.916- 0.980	**0.002**
Food portions, 1- 5	1.0 (1.0; 1.9)	1.0 (1.0; 1.2)	0.975	0.895- 1.063	0.571	1.0 (1.0; 1.0)	1.0 (1.0; 2.0)	1.042	0.922- 1.177	0. 510
Enjoy meals, 1- 5	1.0 (1.0; 2.0)	2.0 (1.0; 2. 0)	0.875	0.799- 0.958	**0.004**	1.0 (1.0; 2. 0)	2.0 (1.0; 2. 0)	0.848	0.742- 0.970	**0.016**
Personal hygiene, 1- 5	1.0 (1.0; 2.0)	2.0 (1.0; 2.0)	0.867	0.790- 0.952	**0.003**	1.0 (1.0; 2.0)	2.0 (1.0; 2.0)	0.895	0.787- 1.019	0.094
Same care workers, 1- 5	2.0 (1.0; 3.0)	2.0 (1.0; 2.0)	1.150	1.026- 1.288	**0.016**	2.0 (1.0; 2.0)	2.0 (1.0; 2.0)	1.128	0.996- 1.277	0.058
Things care workers do 1- 5	1.0 (1.0; 2.0)	2.0 (1.0; 2.0)	0.837	0.719- 0.975	**0.023**	1.0 (1.0; 2.0)	2.0 (1.0; 2.0)	0.815	0.689- 0.965	**0.018**
Honest care workers, 1- 5	1.0 (1.0; 1.0)	1.0 (1.0; 2.0)	0.766	0.629- 0.933	**0.008**	1.0 (1.0; 1.0)	1.0 (1.0; 2.0)	0.783	0.631- 0.970	**0.025**
Home clean, 1- 5	1.0 (1.0; 2.0)	2.0 (1.0; 2.0)	0.718	0.627- 0.822	<**0.001**	1.0 (1.0; 2.0)	2.0 (1.0; 2.0)	0.719	0.620- 0.833	<**0.001**
Garden maintenance, 1- 5	2.0 (2.0; 2.0)	2.1 (2.1; 2.1)	0.773	0.662- 0.904	**0.001**	2.0 (2.0; 2.0)[d]	2.0 (2.0; 2.0)[f]	0.741	0.625- 0.879	**0.001**
General satisfaction, 1- 5	2.0 (1.0; 2.0)[b]	2.0 (1.0; 2.0)[c]	0.826	0.710- 0.961	**0.013**	2.0 (1.0; 2.0)[e]	2.0 (1.0; 2.0)[g]	0.842	0.715- 0.990	**0.037**
Service to the PwD										
Use of specific dementia service %	43	49	0.736	0.614- 0.881	**0.001**	46	51	0.898	0.702- 1.148	0.389
Satisfaction with dementia specific care, %										
Satisfied, 1- 5	75	71	1.168	0.868- 1.571	0.305	74	68	1.329	0.928- 1.902	0.121

CI = confidence interval; CLINT = CLient INTerview Instrument–Home Care; OR = odds ratio; PWB = psychological well-being; PwD = person with dementia; Q1 = first quartile; Q3 = third quartile.
P < 0.05 was regarded as significant; significant p-values are marked in bold.
Underlining of values indicates a positive result, for CLINT 9–45 and 1-5; for satisfaction with dementia specific care 1– 5.
Missing cases at baseline = 0; missing cases at follow-up = 3.
[a] PwD moved to nursing home at follow-up, n=274.
[b]Mean 1.71, standard deviation (SD)=0.75; [c] mean 1.82, SD=0.80; [d] mean 1.89, SD=0.59; [e]mean 1.72, SD=0.77; [f]mean1.98, SD=0.69; [g]mean 1.77, SD=0.71.
[h]Imputation of data for the CLient INTerview Instrument–Home Care (CLINT), Food portions, n =155, Enjoy meals, n =4, Personal hygiene, n =4, Same care workers, n =4, Things care workers do, n =6, Honest care workers, n =1, Home clean, n =3, Garden maintenance, n =814, General satisfaction, n =3.
[i]Imputation of data for CLINT follow-up: Food portions, n =4; Enjoy meals, n =294; Personal hygiene, n =2; Same care workers, n =1; Things care workers do, n =1; Honest care workers, n =1; Home clean, n =2; Garden maintenance, n =670

psychological well-being cared for PwDs with fewer neuropsychiatric symptoms and symptoms of depression on the depression scale compared with caregivers reporting low psychological well-being. The same factors were associated with increased caregiver psychological well-being at follow-up as with psychological well-being at baseline, except for PwD comorbidity. Type of dementia diagnosis was not associated with caregivers´ psychological well-being at baseline, except for vascular dementia. Neither was it associated with increase in the caregivers´ psychological well-being at follow-up.

The impact of formal care on caregiver psychological well-being

In Table 4 the results of the bivariate regression analysis are presented for formal care-related factors associated with caregiver psychological well-being. Overall, caregivers reporting psychological well-being at baseline, reported higher QoC generally, and explicitly regarding enjoyment of meals, personal hygiene for the PwD, continuity in care workers, tasks care workers do, honesty in care workers, having a clean home, help with garden maintenance and general satisfaction compared with caregivers reporting low psychological well-being. Caregivers reporting psychological well-being at baseline also reported higher use of dementia specific care. The same factors as with psychological well-being at baseline were associated with caregiver increased psychological well-being at follow-up, except for personal hygiene for the PwD, continuity in care workers, and use of dementia specific care.

Factors associated with and predicting caregiver psychological well-being

Table 5 shows the factors that were both associated with, and predicted caregiver psychological well-being, according to the multivariate regression analysis. Caregiver-related factors, in this category were: a positive experience of caregiving in the dimension of health; and less caregiver burden. The PwD-related factors were male gender of the PwD; and the PwD had higher QoL, and fewer neuropsychiatric symptoms causing distress to the caregiver. Finally, formal care-related factors in this category were: a positive experience of QoC concerning having a clean home; garden maintenance and general satisfaction.

Factors solely associated with caregiver psychological well-being at baseline were the caregivers own experience of less caregiver burden; and higher health-related QoL. Regarding the PwD, factors in this category were fewer depressive symptoms on the depression scale. Formal care-related factors in this category were higher rated experience of QoC regarding continuity in formal care workers; and a positive experience of the use of dementia-specific care. On the other hand, caregiver-related factors solely predicting caregiver increased psychological well-being at follow-up were informal care provision concerning less supervision in the last 30 days; and higher health-related QoL. In this category, PwD-related factors were presence of neuropsychiatric symptoms with less severity. Formal care-related factors in this category were experience of QoC: continuity in formal care workers; having a clean home; and general satisfaction.

Discussion

Caring for a PwD living at home is a continuous responsibility for caregivers. To maintain and facilitate caregivers´ psychological well-being it is crucial to support the caregiver. This study has identified several factors associated with caregiver psychological well-being. Positive experiences of caregiving and less burden concerning their own health were associated with the presence of caregiver psychological well-being. Caregivers with psychological well-being reported higher self-esteem, more support from family, and less impact on finances, their own spare time and health compared with caregivers with both low psychological well-being and no increase in psychological well-being. These results are similar to the results of the study by Chapell and Colin Reids (2002) who showed that the psychological well-being for caregivers of PwDs and caregivers of persons without dementia

Table 5. Factors associated with informal caregivers´ psychological well-being and predicting factors for increased psychological well-being.

Associated factors for psychological well-being					
		Adjusted R^{2*}	**OR**	**CI 95%**	***p* value**
Caregiver factors	**Experiences of care giving (CRA)**	0.428			
	Health		0.899	0.856 - 0.944	<**0.001**
	Caregiver burden (ZBI)		0.932	0.920 - 0.945	<**0.001**
	Health related QoL				
	EQ5D Visual analogue scale (VAS)		1.025	1.016 - 1.034	<**0.001**
PwD factors	Gender (male)	0.208	1.562	1.192 - 2.046	**0.001**
	QoL (QoL-AD, proxy)		1.096	1.064 - 1.128	<**0.001**
	Neuropsychiatric symptoms (NPI)				
	-Distress		0.952	0.935 - 0.970	<**0.001**
	Depression in dementia (CSDD)		0.965	0.937 - 0.995	**0.023**
FC factors	**Experiences of quality of care (CLINT**)	0.063			
	-Same care worker		1.270	1.109 - 1.453	**0.001**
	-Having a clean home		0.750	0.647 - 0.870	<**0.001**
	-Garden maintenance		0.840	0.709 - 0.994	**0.043**
	-General satisfaction		0.790	0.659 - 0.949	**0.012**
	Service to the PwD				
	Use of dementia specific care		0.721	0.556 – 0.936	**0.014**
Predicting factors for increased psychological well-being					
Caregiver factors	**Experiences of care giving (CRA)**	0.306			
	Health		0.882	0.838 - 0.928	<**0.001**
	Caregiver burden (ZBI)		0.961	0.949 - 0.973	<**0.001**
	Informal care provision (RUD)				
	Supervision in the last 30 days of caregiving		0.983	0.971 - 0.994	**0.003**
	Health related QoL, EQ-5D-3L		2.684	1.430 - 5.038	**0.002**
PwD factors	Gender (male)	0.119	1.771	1.355 - 2.316	<**0.001**
	QoL (QoL-AD, proxy)		1.073	1.043 - 1.103	<**0.001**
	Neuropsychiatric symptoms (NPI)				
	-Severity		1.069	1.024 - 1.116	**0.002**
	-Distress		0.926	0.899 - 0.953	<**0.001**
FC factors	**Experiences of quality of care (CLINT)**	0.045			
	-Same care worker		1.209	1.048 - 1.396	**0.009**
	-Having a clean home		0.721	0.617 - 0.842	<**0.001**
	-General satisfaction		0.825	0.682 - 0.998	**0.048**

Caregiver = informal caregiver; CI = confidence interval; CLINT = CLient INTerview Instrument–Home Care; CRA = Caregiver Reaction Assessment Scale; CSDD = Depression Scale in Dementia; EQ-5D-3L = EuroQoL-5 dimensions questionnaire with three levels of answers; FC = formal care; NPI = Neuropsychiatric Inventory; OR = odds ratio; PwD = person with dementia; QoL = Quality of life; QoL-AD = Quality of life in Alzheimer's disease; RUD = Resource Utilization in Dementia instrument; ZBI = Zarit Burden Interview.
$p < 0.05$ was regarded as significant; significant p-values are marked in bold.

was directly affected by their perception of social support, self-esteem and burden. Another study including caregivers to older people in general showed that less contact with colleagues and friends was associated with high psychological distress suggesting that it is important to keep social contacts (Yiengprugsawan et al., 2012). For health care and social services, this indicates the need to identify vulnerable caregivers in order to be able to provide them with support, such as respite care or day care for the person cared for (in our case the PwD) and encourage families to support each other and share the caregiver responsibility. Such support has been suggested to facilitate caregiver psychological well-being and relieve caregiver burden. By enabling caregivers to maintain their social network and self-esteem, it enables them to continue caring for the PwD at home.

As the dementia disease progresses the care needs of the PwD increase. With support from formal care, caregiver psychological well-being may remain unaffected and may even increase. The present study shows that caregivers with psychological well-being cared for

PwDs who experienced fewer neuropsychiatric symptoms and less dependency in ADLs. Further, the amount of informal care provision regarding IADLs and PADLs and supervision affected caregiver with psychological well-being. This is similar to results reported in a study by Chappell and Colin Reid (2002) showing that the psychological well-being of caregivers to PwDs and caregivers to persons without dementia was directly affected by hours of informal care, while caregiver burden was directly affected by neuropsychiatric symptoms. A previous study reporting spousal caregiving showed that wives reported higher well-being when providing care to their husbands compared with when carrying out chores such as doing the laundry, preparing dinner and cleaning. For husbands, neither the spouse disability nor her care needs were associated with experienced well-being (Freedman et al., 2014). In the present study, fewer neuropsychiatric symptoms in the PwD were both an associated factor for caregiver psychological well-being and a predicting factor for increased caregiver psychological well-being. It is important for health care and social services to have knowledge about what factors affect caregiver psychological well-being. This enables formal care to provide individualized support to caregivers to promote their psychological well-being.

The way formal care is performed including dementia specific care for the PwD may be important for caregivers and may have an impact on their psychological well-being. The result of our study show that factors associated with caregiver psychological well-being were, positive experiences of QoC overall, and specifically the experience of continuity of care workers and having a clean home. In addition, caregivers with psychological well-being were using dementia specific care. In a previous study, caregivers´ dissatisfaction with formal care was reported to occur when the caregivers did not know which professionals to call for complaints, emergencies and other problems (Janse et al., 2014). In addition, dissatisfaction might relate to other factors such as behavioral and psychiatric symptoms as shown in a previous study included in cognitively impaired patients in hospital settings (Whittamore et al., 2014). Other factors that can affect the caregiver psychological well-being are the caregivers´ levels of self-esteem, mastery and neuroticism (Brodaty, 2009). As shown in this study important factors that influence the psychological well-being of caregivers are their experiences of caregiving and informal care provision; the PwDs neuropsychiatric symptoms and dependency in ADLs, and the caregivers experience of QoC.

The main strengths of our study were the large size of the cohort and the comprehensive approach that is data were gathered on many different factors potentially associated with caregivers´ psychological well-being, including data on all involved parties, namely the caregiver, PwD and formal care. Since the PwDs were at risk for institutionalization within 6 months, we supposed that caregiver burden and psychological well-being would be negatively affected. Examining caregiver psychological well-being both at baseline and after 3 months allowed us to determine the stability of psychological well-being over time, as well as factors that could predict increased or worsened well-being. The gender effect on caregiver psychological well-being and increased psychological well-being shows different results depending on the analysis. The bivariate regression analysis shows that most PwDs cared for were female and the multivariate regression analysis shows male gender, affecting the caregiver psychological well-being and increased psychological well-being. The main limitation of this study was that the study design (cross-sectional at baseline) did not allow us to establish any causal relationships, and therefore the results should be interpreted cautiously, with further prospective studies needed. The caregivers caring for PwDs living in the community receiving home care and being at risk for institutionalization, might differ from the PwDs who do not receive such services and who would not be judged as being at risk for institutionalization. This would mean that the result may not be representative for caregivers to PwD in general. Another limitation might be that the follow-up after 3 months was probably too short to see significant changes, and therefore the changes in caregiver

psychological well-being within this short time frame should be interpreted very carefully. However, more caregivers at follow-up than at baseline rated psychological well-being (58% vs 55%). This was due to some PwDs (*n*=274) having been admitted to institutional care during the follow-up period, which may have affected the results, with higher perceived psychological well-being at follow-up. Caregivers in this study come from different European countries that differ with regard to care and support systems. There may have been some variations in the recruitment process. Nevertheless, to ensure internal validity the same guidelines and procedures were used by the countries participating in the RTPC project. External validity was promoted by including countries representing northern, southern, central, western and eastern Europe. Each country's sample was n=81- 182 which was assessed to be sufficient for the provided analysis (Verbeeck, 2012). In the bivariate regression analysis, several factors at baseline showed large differences in values with little, or no, overlap but with significance (p=<0.05) due to the large sample (n=1,223). Mean value was calculated for equal confidence interval between baseline and follow-up values to show differences (QoC). However, the 95% confidence interval was small for several factors which shows precision of this study. This study used QoL for the PwD (Quality of life in Alzheimer's disease, QoL-AD), as rated by caregivers. Previous studies have shown that the PwDs QoL is rated lower by caregivers than by the PwDs themselves (Logsdon 1999; Thorgrimsen, 2003), and it may be possible that caregivers´ perception of low PwD QoL has an impact on their own psychological well-being. In one study, this may have affected the associated factors in caregivers to perceive low psychological well-being in connection to whether QoL-AD rated by the PwD had been selected. The PwDs QoL can be rated by the PwD even with a very low Mini Mental State Examination (MMSE) score ≤3 (Thorgrimsen et al., 2003). Knowledge about how PwDs experience their own QoL may increase caregivers´ psychological well-being.

Conclusion

Informal caregiving for an older PwD living at home is a complex task that could be influenced by factors associated with the caregiver, the PwD and the formal care. Our study showed that caregiver psychological well-being was associated with less caregiver burden and higher QoL. A higher number of neuropsychiatric symptoms in the PwD was associated with caregivers´ decreased psychological well-being. Higher rated QoC was associated with caregivers´ increased psychological well-being. Professionals should consider the possibility that PwDs neuropsychiatric symptoms may affect their caregivers´ psychological well-being, and provide appropriate care and treatment for both the caregiver and the PwD. Maintaining their social network, and retaining their self-esteem to continue caring for the PwD at home may help caregivers increase their psychological well-being.

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Appendix 1

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Paper IV

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Informal caregivers to older persons with dementia

This thesis emphasize that informal caregivers of persons with dementia needs formal care to be proactive and deliver available care and support early in the course of the disease. Mapping the health care and social service systems is a valuable tool for evaluating existing systems for policy making. Professionals should be aware about what factors are associated with informal caregivers' psychological well-being and burden to provide proper care and support, and to promote a healthy transition in the caregiving role and through the course of the dementia disease.

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