



LUND UNIVERSITY

Care and Service at Home for Persons With Dementia in Europe.

Bökberg, Christina; Ahlström, Gerd; Leino-Kilpi, Helena; Soto-Martin, Maria E; Cabrera, Esther; Verbeek, Hilde; Saks, Kai; Stephan, Astrid; Sutcliffe, Caroline; Karlsson, Staffan

Published in:
Journal of Nursing Scholarship

DOI:
[10.1111/jnu.12158](https://doi.org/10.1111/jnu.12158)

2015

[Link to publication](#)

Citation for published version (APA):
Bökberg, C., Ahlström, G., Leino-Kilpi, H., Soto-Martin, M. E., Cabrera, E., Verbeek, H., Saks, K., Stephan, A., Sutcliffe, C., & Karlsson, S. (2015). Care and Service at Home for Persons With Dementia in Europe. *Journal of Nursing Scholarship*, 47(5), 407-416. <https://doi.org/10.1111/jnu.12158>

Total number of authors:
10

General rights

Unless other specific re-use rights are stated the following general rights apply:
Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Read more about Creative commons licenses: <https://creativecommons.org/licenses/>

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

LUND UNIVERSITY

PO Box 117
221 00 Lund
+46 46-222 00 00

Care and service at home for persons with dementia in Europe

Dementia care at home

Christina Bökberg, MSc, Doctoral student ^{1 §}

Gerd Ahlström, PhD, RN, FEANS ²

Helena Leino-Kilpi, PhD, RN, FEANS ³

Maria E Soto-Martin, PhD, MD ⁴

Esther Cabrera, PhD, RN, FEANS ⁵

Hilde Verbeek, PhD ⁶

Kai Saks, PhD ⁷

Astrid Stephan, MSc, Doctoral student ⁸

Caroline Sutcliffe, MSc ⁹

Staffan Karlsson, PhD ¹⁰

¹ Lecturer, Department of Health Sciences, Faculty of Medicine, Lund University, Sweden

² Professor, Director of the research group Older people's health and person-centred care, Co-coordinator for the Swedish National Graduate School for Competitive Science on Ageing and Health (SWEAH), Department of Health Sciences, Faculty of Medicine, Lund University, Sweden

³ Lampda Pi, Professor and Chair in Nursing Science, University of Turku, Finland, and Nurse manager, Turku University Hospital, Finland

⁴ Medical Doctor, Gerontopôle Alzheimer's Disease Research and Clinical Center, Toulouse University Hospital, France

⁵ Associate Professor, School of Health Sciences, TecnoCampus, University Pompeu Fabra, Mataró (Barcelona), Spain

⁶ Assistant Professor, Department of Health Services Research, Maastricht University, The Netherlands

⁷ Associate Professor, Department of Internal Medicine, University of Tartu, Estonia

⁸ Research Associate, School of Nursing Science, Witten/Herdecke University, Germany

⁹ Research Associate, Personal Social Services Research Unit, School of Nursing, Midwifery and Social Work, University of Manchester, England

¹⁰ Assistant Professor, Department of Health Sciences, Faculty of Medicine, Lund University, Sweden

⁵Corresponding Author:

Christina Bökberg

Department of Health Sciences

Faculty of Medicine

Lund University

P.O. Box 157

SE-221 00 Lund

Sweden

Mobile phone: +46705412770

E-mail: christina.bokberg@med.lu.se

ABSTRACT

Purpose: To describe available and utilized formal care and service at home for persons with dementia, from diagnosis to end-of-life stage, in eight European countries. **Design:** A descriptive cross-country design concerning eight European countries as a part of the European research project, RightTimePlaceCare (RTPC). **Methods:** The research team in each country used a mapping system to collect country-specific information concerning dementia care and service system. The mapping system consists of fifty types of care and service activities. Sixteen of the fifty predefined activities concerning care and service at home were selected for this study and subdivided into three categories, following the stages of dementia. **Findings:** Availability was reported to be higher than utilization and the findings indicated more similarities than differences among the eight countries involved. Even though there were several available activities of *Basic care and services* and *Health care interventions* they were utilized by few in most countries. Furthermore, *Specialized dementia care and services* were sparsely available and even more sparsely utilized in the participating countries. **Conclusions:** The findings indicated that persons with dementia in Europe received formal care and service on a general, basic level but seldom adjusted to their specific needs. **Clinical Relevance:** This study describe the gap between service provision and utilization enabling nurses to develop individually adjusted care plans for persons with dementia during the progress of the disease. The findings do not include matters of quality of care or how to best organize effective care and services. However, the activities of care and services presented here should shed light on what room there is for improvement when it comes to enabling persons with dementia to go on living at home.

Key words: Dementia, home care and services, home health nursing, geriatric nursing

INTRODUCTION

Most countries have policies for reducing institutionalization by developing care and services at home so that persons with dementia shall be able to live in their own homes for as long as possible (Knapp et al, 2007; Moise et al, 2004). Such policies, along with the decreasing availability of persons who are in a position to take on duties of informal care and the increasing proportion of older people afflicted with dementia, will increase the demands for formal care and services at home (Tarricone & Tsouros, 2008; WHO, 2012). Home care is put forward as the best way of caring for persons with dementia, this on the grounds both of it providing a better quality of life for the person afflicted and of it being less expensive than institutional care (Moise et al, 2004; Tarricone & Tsouros, 2008). However, research is contradictory regarding a person's quality of life when remaining at home instead of moving in to a nursing home, since the reasons for transfer differ (Afram et al, 2014; Prince et al, 2013). The World Health Organization (WHO) describes home as a place of emotional and physical associations, memories and comfort (Tarricone & Tsouros, 2008). It can therefore be assumed that persons with dementia prefer to remain living in their own homes with greater ability to retain their social networks (Luppa et al, 2010; Tucker et al, 2008). Persons with dementia are a heterogeneous group with different functions affected and different needs of support within the stages of the disease. Some needs are appropriately met by health care resources, others by social service efforts, but often it is a question of a combination of these (Knapp et al, 2007). The complexity of needs requires knowledge about available and utilized formal care and services at different stages of dementia. Nurses working in home care settings have responsibility for evaluating care needs, developing care plans and providing skilled nursing care (Tarricone & Tsouros, 2008; Zabalegui et al, 2014). To enable nurses to develop individually adjusted care for persons with dementia during the

progress of the disease a structured map concerning available and utilized types of care and service activities during dementia stages may be useful.

European countries vary in terms of health care and social service organizations, demographic patterns and financial systems (Knapp et al, 2007; WHO, 2012), making comparisons difficult. A previous study (Genet et al, 2011) about home care in Europe showed various differences in regulation of care benefits. For instance, allocation of home care and services in Finland and the Netherlands was based on personal needs assessment, financial situation and availability of formal care. Needs assessment was found to be stricter in France than in England and in Sweden. In Spain, availability of public resources for home care seemed to be an important determinant in the decision to assign care, and income was used to allocate care at home. In Scandinavian, countries home care was often independent of income and services were often comprehensive. Another issue was that there were striking variations in terms of the level of family members' obligation to care for their next of kin through the course of the disease. For instance in Estonia and Spain informal care is provided especially by family members due to the preference of the dependent person to remain in their residence, the high cost of the formal resources, and family-oriented character of the society (Gutiérrez et al, 2010; Paat & Merilane, 2010), whereas in Sweden and Finland there was no such obligation (Fukushima et al, 2010; Johansson, 2010). Furthermore, levels of education among formal care providers differ between countries. Hallberg et al (2014) found a wide range of formal care providers involved in dementia home care, often without formal education or specific training in dementia care. Staff with formal education working in home care was common in Sweden and Finland. Thus there is extensive knowledge in the research literature about care and social service organizations, financial issues, assessments and policies (Genet et al, 2011; Knapp et al, 2007; WHO, 2012),

but sparse regarding availability and utilization of formal care and service at home in relation to dementia stages. To the best of our knowledge, this study represents the first attempt to report the range of formal care and social services within a European context in respect of persons with dementia being cared for at home, taking into account not only availability but also utilization.

PURPOSE

The purpose of this study was to describe available and utilized formal care and service at home for persons with dementia, from diagnosis to end-of-life stage, in eight European countries.

METHOD

Design and context

The study had a descriptive cross-country design as a part of the European research project RightTimePlaceCare (RTPC) aimed at improving health care and social services for European citizens with dementia. The countries included were Estonia (EE), Finland (FI), France (FR), Germany (DE), the Netherlands (NL), Spain (ES), Sweden (SE) and the United Kingdom (UK). Thus they represented eastern, western, southern, northern and central Europe, demonstrating variation in terms of health care and social service systems (Verbeek et al, 2012).

Measurement

This study was based on data collected in accordance with a mapping system as a part of RTPC. The development of the mapping system and the definition of the terminology are given elsewhere (Hallberg et al, 2013). The mapping system contained altogether fifty types of care and service activities such as treatment, care and service offered and care providers involved. These activities were sorted into: (1) Screening, diagnostic procedure and treatment in regard to dementia and its complications; (2) Outpatient care facilities; (3) Care at home; (4) Institutional care; (5) Palliative care; (6) Informal caregiving and supportive actions; and (7) Civic activities.

The fifty activities covered the trajectory of dementia according to the OECD (Moise et al, 2004), starting with the diagnosis stage. The early stage was characterized by mild symptoms and low impact on activities of daily living (ADL), memory and social functions. The intermediate stage involved increased memory loss and dependency on help in social matters. The late stage was marked by severe memory loss and increased demand for continuous assistance in ADL, in safety matters and in social matters. The end-of-life stage was reached when the person had a limited time left to live (Moise et al, 2004). The responses possible for availability were “for all”, “for most”, “for few” or “for none”. For utilization the responses possible were “by all”, “by most”, “by few” and “by none” (Hallberg et al, 2013). Sixteen of the fifty predefined activities concerned formal care and service at home and were selected for this study. On the basis of a review of the main content the activities were subdivided into three categories: *Basic care and services*, *Health care interventions* and *Specialized dementia care and services* (Table 1).

Insert Table 1 about here

Data collection

From 1 November 2010 until 31 January 2011 data were collected. The members of the research teams, who were responsible for the data collection in each country, was given the instructions to collect data representative for the country as a whole. The research team consulted other experts and authorities in accordance with the country specific system and authorities. Interviews were conducted with managers, providers or the equivalent in relevant care and service organizations, with persons in consumer/user organizations and with local government officials (including purchasers). They also conducted literature review consisting of written reports such as official governmental documents and epidemiological data. The members of the research teams filled in

the alternatives on the mapping form about availability and utilization of care and service. The data collection was described in a previous study (Hallberg et al. 2013). Data were thereafter reviewed by the first author (CB) and in the event of ambiguity information was clarified by the country's research team.

FINDINGS

The sixteen types of care and service activities in the eight countries were divided into *Basic care and services* (Table 2), *Health care interventions* (Table 3) and *Specialized dementia care and services* (Table 4) and grouped according to each stage of dementia and by country.

Insert Table 2-4 about here

Types of care and service activities available and utilized during dementia stages

In *Diagnosis and Early stage* almost all of the types of care and service activities related to **Basic care and services** (Table 2) were available for all or most in FR, DE, NL, SE and UK. The most reported utilized activity were “General technical aids”, “Needs assessment”, “Personal safety alarm” and “Transport service”. In *the Intermediate stage* almost all types of care and service activities were available in all countries. The utilization across the stages of dementia increased for “Home help/care with IADL” in FI, NL and SE. Also “Home help/care with PADL” increased in FI and FR and “Housing adaption” in FI. “Home-delivered meals” was utilized by all in all stages in FR and by few in the other countries (except FI by most in late stage). In the *Late stage* “Personal safety alarm” was utilized by no one or few in all countries except NL (reported by most). “General technical aids” was utilized by all or most in all countries in all stages (except UK and SE in diagnosis, early and end-of life stage). “Needs assessment” was utilized by all or most in all countries in all stages except for EE (by few) and DE and SE in diagnosis stage. In the *End of life stage* no one or few utilized “Accompanying service”, “Home

delivered meals” (except FR reported by all), “Housing adaption” (except FI reported by most) and “Personal safety alarm” (except NL reported by most). The most commonly utilized activity in **Health care interventions** (Table 3) in all stages were “Home nursing care”. “Team-based home health care” was unavailable in all stages in EE and DE and was utilized by most in FI, FR and NL except the diagnosis stage. The most commonly reported activity in the category **Specialized dementia care and services** (Table 4), being available for all or most in all countries (except EE for few), was “Aid equipment to compensate for cognitive impairment”. None of the other activities in this category were utilized frequently in any country.

Types of care and service activities available and utilized in the eight countries

The availability and utilization of care and service activities varied between countries. For instance, in DE, and UK all types of care and service activities related to **Basic care and service** (Table 2) was available for all or most in almost all stages but utilization varied between the countries. In contrast, only three of the nine activities were available for all in EE. Concerning the activities relating to **Health care interventions** (Table 3) “Home nursing care” was available for all in all countries and in all stages. “Rehabilitation at home” was available for all in all countries (except EE and FI) and in all stages (except end-of life stage). This activity was utilized by all few in all countries (except FR by all in the first four stages and in FI by most in the three latest stages). In the category **Specialized dementia care and services** (Table 4) care and service activities in EE were available and utilized by few or no one and similarly was reported in FR, DE and ES with the exception of “Aid equipment to compensate for cognitive impairment” which was available for all or for most. “Mobile comprehensive expert team” was available in just two countries for all (SE) or most (UK) in all stages but utilized by few. “Team-based community mental health for older people” was available for all in all stages in FI, NL and

UK for most (except for early stage) but utilized by few or no countries. “Specialist psychiatric home nursing care” was reported by SE as being available for few but as being utilized by most of those to whom it was available. In contrast, this activity was reported by UK as available for all but utilized by few.

DISCUSSION

The findings revealed that even if there were several available types of care and service activities related to **Basic care and services** and **Health care interventions** they were utilized by few in most countries. Morgan et al (2002) and Ward-Griffin et al (2012) have shown that utilization of care and service for persons with dementia depends on several factors. For instance persons with dementia or their next of kin were not aware of existing care and services or these were not accessible, not convenient or too expensive. Another explanation for the non-utilization of formal care and service is probably to be found in the large amount of informal care provided by next of kin (Prince et al, 2013). Furthermore, care and services based on symptoms and disability assessment are not always related to an individual’s actual care needs. For example, Hancock et al (2003) have indicated that one person may have fewer unmet needs if they have a supportive care environment, whereas another may have more unmet needs despite receiving greater assistance, because of a low level of personalized care. For the purpose of enabling persons with dementia to remain at home when the disease progresses, there must be access to specialized dementia care and service interventions adapted to the individual and the stages of dementia (Ward-Griffin et al, 2012). However, the findings of this study revealed that **Specialized dementia care and services** were not commonly utilized in any country. This is notable in the view of the increasing number of persons with dementia being cared for at home (Moise et al, 2004). Bökberg et al (2014) found that dementia diagnosis seemed to be an important issue with

regard to gaining access to tailored dementia care, such as dementia teams, day care and nursing homes specializing in dementia. The lack of a diagnosis deprived the persons with dementia of tailored dementia care beyond symptom relief. Moise et al (2004) reported that a large proportion of persons with dementia did not receive any diagnosis and therefore did not obtain support or access to treatment, formal care and service. One reason for people not being diagnosed was the stigma associated with a dementia diagnosis (Batsch & Mittelman, 2012), which became a barrier to seeking help; another aspect was people's desire to manage on their own (Morgan et al, 2002). The most commonly available types of care and service activities related to **Specialized dementia care and service for** was "Aid equipment to compensate for cognitive impairment" but the utilization of specialized technology was limited. Mattke et al (2010) reflect that such technology is not extensive in every country and that innovations and development in home care technology may help to improve home care and services designed to support those living in their own homes. The findings of the present survey indicated that persons with dementia in eight European countries received care and service on a general, basic level, but few received formal care and service adjusted to their specific needs.

This study has illustrated available and utilized types of care and service activities in eight European countries and has pointed to obvious differences between one country and another. Estonia and Spain, for instance, had fewer specialized care directed towards persons with dementia being cared for at home, whereas England, the Netherlands, Finland and Sweden had more (and more specialized ones). This may be related to differences of political systems (Genet et al, 2011). Another difference was in the sense of obligation for family members to provide care for their next of kin through the course of the disease: apparent, for example, in Spain and Estonia (Gutiérrez, 2010; Paat & Meriliane, 2010) but not in Sweden or Finland

(Fukushima et al, 2010; Johansson, 2010). From this survey it is difficult to find best practice strategies for care and services at home, because of the complexity of the dementia disease and the heterogeneity of the support and informal care provided by next of kin. Persons with dementia are a heterogeneous group and it is not only increased availability of dementia care and service that is needed but also person-centred care embracing diversity, flexibility, different choices and supportive services. Person-centred care is an approach to restructuring the delivery of care holistically around the individual, rather than around the impairment that afflicts them, to increase wellbeing and quality of life (Kitwood & Bredin, 1992), and is advocated as a good practice guideline for dementia care particularly in home care settings (Prince et al, 2013). Demands for formal care and services at home are likely to increase because of population ageing. In order for persons with dementia to remain at home, the formal care providers must be able to successfully support them with personalized adjusted access to home care and services. Thus the health care system needs to adapt to ensure high-quality safe care beyond the hospital setting. This means accessibility to the right activities of care and service at the right time to enable persons with dementia to derive the maximum benefit throughout the stages of the disease.

Methodological considerations

The descriptions from each country were based on criteria agreed upon before collecting the information. Thus the information may have identified needs of improvement of dementia care at home. Each country's report were on an overarching level, the types of care and service activities available and how they were utilized during the stages of dementia. Generating knowledge about a country's system of care and services for persons with dementia at a particular point in time becomes inevitably on an overall way. In addition, the great variations within a country need to

be considered when interpreting the finding of this study. Hallberg et al (2013) described some methodological considerations concerning the development of the mapping system. The process of determining the types of care and service activities proceeded without disagreement; however, obtaining the exact meaning of the terms “available” and “utilized” was problematic. Nevertheless, assessing availability and utilization did make sense, thus a type of activity’s being available was not the same as it’s being offered to and utilized by persons with dementia.

Acknowledgements

The RightTimePlaceCare study is supported by a grant from the European Commission within the 7th Framework Programme (project 242153). We would also like to acknowledge the support of the Department of Health Sciences, Lund University, Lund, Sweden. This study was accomplished while Christina Bökberg was affiliated with the Swedish National Graduate School for Competitive Science on Ageing and Health (SWEAH), which is funded by the Swedish Research Council. This research was supported through the authors’ involvement in the European Science Foundation Research Network Programme “REFLECTION” – 09-RNP-049. The views expressed are those of the authors and not necessarily those of the European Science Foundation.

CLINICAL RESOURCE

RightTimePlaceCare: www.righttimeplacecare.eu

REFERENCES

Afram, B., Stephan, A., Verbeek, H., Bleijlevens, M., Suhonen, R., Sutcliffe, C., Raamat, K., Cabrera, E, Soto-Martin, M., Hallberg, IR., Meyer, G., Hamers, J., on behalf of the RightTimePlaceCare Consortium. (2014). Reasons for institutionalization of people with dementia: informal caregiver reports from 8 European countries. *JAMDA*, 15, 108-116.

Batsch, N., Mittelman, MS. (2012). *World Alzheimer Report 2012. Overcoming the stigma of dementia*. Alzheimer's Disease International. London.

Bökberg, C., Ahlström, G., Karlsson, S., Rahm Hallberg, I., Janlöv, AC. (2014). Best practice and needs of improvement in the chain of care for persons with dementia in Sweden: a qualitative study based on focus group interviews. *BMC Health Services Research*, 14, 1-10.

Fukushima, N., Adami, J., Palme, M. (2010). *The long-term care system for the elderly in Sweden. Research Report No 89*. ENEPRI. Retrieved from: www.ceps.eu

Genet N., Boerma, GW., Kringos, DS., Bouman, A., Francke, AL., Fagerström, C., Melchiorre, MG., Greco, C., Deville, W. (2011). Home care in Europe: a systematic literature review. *BMC Health Services Research*, 11, 1-14.

Gutiérrez, LF., Jiménez-Martín, S., Vilaplana, C. (2010). *The long-term care system for the elderly in Spain. Research Report No 88*. ENEPRI. Retrieved from: www.ceps.eu

Hallberg, IR., Leino-Kilpi, H., Meyer, G., Raamat, K., Soto-Martin, M., Sutcliffe, C., Zabalegui, A., Zwakhalen, S., Karlsson, S. (2013). Dementia Care in Eight European Countries: Developing a Mapping System to Explore Systems. *Journal of Nursing Scholarship*, 00, 1-13.

Hallberg, IR, Cabrera, E, Jolley, D, Raamat, K, Renom, A, Verbeek, H, Soto-Martin, ME, Stolt, M, Karlsson, S. (2014). Professional care providers in dementia care in eight European countries; their training and involvement in early stage and in home care. *Dementia*, 00, 1-27.

Hancock, G.A., Reynold, T., Woods, B., Thornicraft, G., Orrell, M. (2003) The needs of older people with mental health problems according to the user, the carer, the staff. *International Journal Geriatric Psychiatry*, 18, 803-811.

Johansson, E. (2010). *The long-term care system for the elderly in Finland. Research Report No 76*. ENEPRI. Retrieved from: www.ceps.eu

Kitwood, T., Bredin, K. (1992). Towards a Theory of Dementia Care: Person-hood and Well-being. *Aging and Society*, 12, 269-287.

Knapp, M., Comas-Herrera, A., Somani, A., Banerjee, S. (2007). *Dementia: international comparisons. Summary report for the National Audit Office*. London: Personal Social Services Research Unit. London School of Economics and Political Science and the Institute of Psychiatry, Kings College. Retrieved from: www.pssru.ac.uk

Luppa, M., Luck, T., Wyerer, S., König, H-H., Brähler, E., Riedel-Heller, SG. (2010). Prediction of institutionalization in the elderly. A systematic review. *Age and Ageing*, 39: 31-38.

Mattke S., Klautzer L., Mengistu T., Gernett J., Hu J., Wu J. (2010). *Health and well-being in the home. A global analysis of needs, expectations and priorities for home health care technology*. RAND HEALTH. Pittsburg: RAND Corporation.

Moise, P., Schwartzinger, M., Um M.Y and the Dementia Experts' Group. (2004). Dementia Care in 9 OECD Countries: A Comparative Analysis. *OECD Health Working Papers*.

Morgan, DG., Semchuk, KM., Stewart, NJ., D'Arcy, CD. (2002). Rural families caring for a relative with dementia: barriers to use of formal services. *Social Science and Medicine*, 55: 1129-1142.

Paat, G., Merilane, M. (2010). *The long-term care system for the elderly in Estonia. Research Report No 75*. ENEPRI. Retrieved from: www.ceps.eu

Prince, M., Prina, M., Guerchet, M. (2013). *World Alzheimer Report 2013. Journey of caring. An analysis of long-term care for Ageing and Dementia Care*. Alzheimer's Disease International, London, United Kingdom.

Tarricone, R., Tsouros, A. (2008). *Home care in Europe*. The Regional Office for Europe for World Health Organization, Copenhagen, Denmark.

Tucker, S., Hughes, J., Burns, A., Challis, D. (2008). The balance of care: reconfiguring services for older people with mental health problems. *Aging Mental Health*, 12, 81-91.

Verbeek, H, Meyer, G, Leino-Kilpi, H, Zabalegui, A, Hallberg, IR, Saks, K, Soto, ME, Challis, D, Saureland, D, Hamers, J. (2012). A European study investigating patterns of transition from

home care towards institutional dementia care: the protocol of a RightTimePlaceCare study.
BMC Public Health, 12, 1-10.

Ward-Griffin, C., Hall, J., DeForge, R., St-Amant, O., McWilliams, C., Oudshoorn, A., Forbes, D., Klosek, M. (2012). Dementia Home Care Resources: How are we managing? *Journal of Aging Research*, 2012, 1-11

World Health Organization. (2012). *Good Health Adds Life to Years. Global Brief for World Health Day 2012*. WHO Document Production Services, Geneva, Switzerland.

Zabalegui A, Hamers JPH, Karlsson S, Leino-Kilpo H, Renom-Guiteras A, Saks K, Soto ME, Sutcliffe C, Cabrera E: (2014) Best practices interventions to improve quality of care of people with dementia living at home. *Patient Education and Counseling*; 95, 175-184.

Table 1 – Types of care and service activities related to care at home.

Category: Basic care and services

Accompanying service: Service for accompanying a person to appointments, providing transportation and/or shopping.

General assistive aids: Assistive devices to compensate for physical disabilities, e.g. aids for transferring (stick, walking frame, wheelchair) for sitting in a chair, for personal care, for the sickbed, for hearing and vision.

Home-delivered meals: A service that delivers cooked meals to disabled and/or older people in their homes.

Home help/care with IADL: Help provided with Instrumental Activities of Daily Living (IADL) at home paid professionals.

Home help/care with PADL: Help provided with Personal Activities of Daily Living (PADL) at home paid professionals.

Housing adaptation: Home adapted to disability, for instance, removal of doorsteps and/or replacement of bathtub by a shower.

Needs assessment: Assessment of needs regarding care and social service from any kind of organization prior to professional care decision and receiving care, including determination of eligibility.

Personal safety alarm: Technical system allowing disabled people to call for assistance via telephone and/or wireless communication.

Transport service: Transport with assistance service for disabled persons.

Category: Health care interventions

Home nursing care: Nursing care provided at home including for example wound dressing, injections, by RN and/or licensed practical nurse/auxiliary nurse.

Rehabilitation at home: Training at home by an occupational therapist, physiotherapist and/or RN and/or licensed practical nurse/auxiliary nurse to improve or maintain functional ability.

Team-based home health care: Healthcare provided in the patient's own home by a multidisciplinary team charged with the treatment and monitoring of the patient with dementia and the caregiver.

Category: Specialized dementia care and services

Aid equipment to compensate for cognitive impairment: Aid equipment to compensate for cognitive functional ability, e.g. equipment to help with time orientation, stove alarm.

Mobile comprehensive expert team: Mobile multi professional team with expert competence in dementia care and serving as consults.

Specialist psychiatric home nursing care: Supervision, support, treatment and monitoring by community psychiatric nurse.

Team-based community mental health for older people: Specialist, multidisciplinary team including for example psychiatrist, psychiatric nurse, social worker, occupational therapist, psychologist and sometimes "support workers".

Table 2. Types of care and service activities related to basic care and services. Availability/Utilization during the stages of dementia.

Basic care and services	Country	Diagnosis stage Availability/Utilization	Early stage Availability/Utilization	Intermediate stage Availability/Utilization	Late stage Availability/Utilization	End-of-life stage Availability/Utilization
Accompanying service	Estonia (EE)	For few / By few	For few / By few	For few / By few	For few / By few	For few / By few
	Finland (FI)	For few/By few	For few / By most	For few / By most	For few / By most	For few/By few
	France (FR)	For all / By all	For all / By all	For all / By all	For all / By all	For no one /By no one
	Germany (DE)	For all / unknown	For all / unknown	For all / unknown	For all / unknown	For all / unknown
	Netherlands (NL)	For all / By few	For all / By few	For all / By few	For all / By few	For no one /By no one
	Spain (ES)	For most / By few	For most / By few	For most / By few	For most / By few	For most / By few
	Sweden (SE)	For few / By few	For few / By few	For few / By few	For all / By most	For no one /By no one
	United Kingdom (UK)	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
General technical aids	EE	For all / By all	For all / By all	For all / By all	For all / By all	For all / By all
	FI	For all / By most	For all / By most	For all / By most	For all / By most	For all / By most
	FR	For all / By all	For all / By all	For all / By all	For all / By all	For all / By all
	DE	For all / By all	For all / By all	For all / By all	For all / By all	For all / By all
	NL	For all / By most	For all / By most	For all / By most	For all / By most	For all / By most
	ES	For all / By most	For all / By most	For all / By most	For all / By most	For all / By most
	SE	For all / By few	For all / By few	For all / By most	For all / By most	For all / By few
	UK	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
Home-delivered meals	EE	For few / By few	For few / By few	For few / By few	For few / BY few	For few / By few
	FI	For all / By few	For all / By few	For all / By few	For all / By most	For all/By few
	FR	For all / By all	For all / By all	For all / By all	For all / By all	For few / By all
	DE	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
	NL	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
	ES	For few / By few	For few / By few	For few / By few	For few / By few	For few / By few
	SE	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
	UK	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
Home help/care with IADL	EE	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
	FI	For few/By few	For few / By few	For few / By most	For all/By most	For all/By most
	FR	For most / By most	For most / By most	For most / By most	For no one /By no one	For no one /By no one
	DE	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
	NL	For all / By few	For all / By few	For all/By most	For all / By all	For all / By all
	ES	For few / By few	For few / By few	For most / By few	For most / By few	For most / By few
	SE	For all / By few	For all / By few	For all / By most	For all / By most	For all / By all
	UK	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few

Home help/care with PADL	EE FI FR DE NL ES SE UK	For few / By few For few/By few For most / By most For all / By few For all / By few For few / By few For all / By few For all / By few	For few / by few For few/By few For few / By few For all / By few For all / By most For few / By few For all / by most For all / By few	For few / by few For few / By most For most / By most For all / By few For all / By most For most / By few For all / By most For all / By few	For few / By few For all / By most For most / By most For all / By few For all / By all For most / By most For all / By most For all / By few	For few / By few For all / By all For most / By most For all / By few For all / By most For most / By most For all / By most For all / By few
Housing adaption	EE FI FR DE NL ES SE UK	For few / By few For most/By few For most / By most For all / By few For all / By few For few / By few For all / By few For all / By few	For few / By few For most/By few For most / By most For all / By few For all / By few For few / By few For all / By few For all / By few	For few / By few For most/ By most For most / By most For all / By few For all / By few For few / By few For all / By few For all / By few	For few / By few For most / By most For most / By most For all / By few For all / By few For few / By few For all / By few For all / By few	For few / By few For all / By most For few / By few For all / By few For all / By few For few / By few For all / By few For all / By few
Needs assessment	EE FI FR DE NL ES SE UK	For all / By few For all / By most For all / By all For all / By few For all / By all For all / By most For all / By few For most / By most	For all / By few For all / By most For all / By all For all / By most For all / By all For all / By most For all / By most For most / By most	For all / By few For all / By most For all / By all For all / By most For all / By all For all / By most For all / By most For most / By most	For all / By few For all / By most For all / By all For all / By most For all / By all For all / By most For all / By most For most / By most	For all / By few For all / By most For all / By all For all / By most For all / By all For all / By most For all / By most For most / By most
Personal safety alarm	EE FI FR DE NL ES SE UK	For few / By few For all/By few For most / By most For all / unknown For all / By most For all / By most For all / By few For all / By few	For few / By few For few / By most For most / By most For all / unknown For all / By most For all / By most For all / By few For all / By few	For few / By few For few / By most For most / By most For all / unknown For all / By most For all / By most For all / By few For all / By few	For no one /By no one For all/By few For few / By few For all / unknown For all / By most For all / By few For all / By few For all / By few	For no one /By no one For all / By few For no one /By no one For all / unknown For all / By most For all / By few For all / By few For all / By few
Transport service	EE FI FR DE NL ES SE UK	For few / By few For few/By few For all / By all For all / By most For all / By most For all / By all For few / By few For all / By few	For few / By few For few/By few For all / By all For all / By most For all / By most For all / By all For few / By few For all / By few	For few / By few For few / By most For all / By all For all / By most For all / By most For all / By all For few / By few For all / By few	For few / By few For few / By most For all / By all For all / By most For all / By most For all / By all For all / By most For all / By few	For few / By few For few / By most For all / By all For all / By most For all / By most For all / By all For no one /By no one For all / By few

Table 3. Types of care and service activities related to health care interventions. Availability/Utilization during the stages of dementia.

Health care interventions	Country	Diagnosis stage Availability/Utilization	Early stage Availability/Utilization	Intermediate stage Availability/Utilization	Late stage Availability/Utilization	End-of-life stage Availability/Utilization
Home nursing care	EE	For all / By most	For all / By most	For all / By most	For all / By most	For all / By most
	FI	For all / By most	For all / By most	For all / By most	For all / By most	For all / By most
	FR	For all / By all	For all / By all	For all / By all	For all / By all	For all / By all
	DE	For all / unknown	For all / unknown	For all / unknown	For all / unknown	For all / unknown
	NL	For all / By most	For all / By most	For all / By all	For all / By all	For all / By all
	ES	For all / By few	For all / By few	For most / By most	For most / By most	For most / By most
	SE	For all / By few	For all / By few	For all / By few	For all / By few	For all / By most
	UK	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
Rehabilitation at home	EE	For few / By few	For few / By few	For few / By few	For few / By few	For few / By few
	FI	For few/By few	For most/By few	For few / By most	For few / By most	For few / By most
	FR	For all / By all	For all / By all	For all / By all	For all / By all	For no one /By no one
	DE	For all / unknown	For all / By few	For all / By few	For all / By few	For all / By few
	NL	For all / By few	For all / By few	For all / By few	For all / By few	For no one /By no one
	ES	For all / By few	For all / By few	For all / By few	For all / By few	For all / By no one
	SE	For all / By few	For all / By few	For most / By few	For most / By few	For no one /By no one
	UK	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
Team-based home health care	EE	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one
	FI	For few/By few	For few / By most	For most / By all	For all / By most	For all / By most
	FR	For most / By most	For most/ By most	For most / By most	For most / By most	For most / By most
	DE	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one
	NL	For all / By few	For all / By most	For all / By most	For all / By most	For all / By most
	ES	For all / By few	For all / By few	For all / By few	For all / By most	For all / By most
	SE	For most / By few	For most / By few	For most / By few	For most / By few	For most / By few
	UK	For most / By most	For few / By few	For most / By few	For most / By few	For most / By few

Table 4. Types of care and service activities related to specialized dementia care and services. Availability/Utilization during the stages of dementia.

Specialized dementia care and services	Country	Diagnosis stage Availability/Utilization	Early stage Availability/Utilization	Intermediate stage Availability/Utilization	Late stage Availability/Utilization	End-of-life stage Availability/Utilization
Aid equipment to compensate for cognitive impairment	EE	For few / By few	For few / By few	For few / By few	For few / By few	For few / By few
	FI	For most /By few	For most /By few	For most /By few	For few / By few	For all /By few
	FR	For most / By most	For most / By most	For most / By most	For no one /By no one	For no one /By no one
	DE	For all / unknown	For all / unknown	For all / unknown	For all / unknown	For all / unknown
	NL	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
	ES	For most / By few	For most / By few	For most / By most	For most / By few	For most / By few
	SE	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
	UK	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
Mobile comprehensive expert team	EE	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one
	FI	For few/By few	For few / By most	For few / By most	For few / By most	For few / By most
	FR	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one
	DE	For few / By few	For few / By few	For few / By few	For few / by few	For few / By few
	NL	For few / By few	For few / By few	For few / By few	For few / By few	For few / By few
	ES	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one
	SE	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
	UK	For most / By few	For most / By few	For most / By few	For most / By few	For most / By few
Specialist psychiatric home nursing care	EE	For few / By few	For few / By few	For few / By few	For few / By few	For few / By few
	FI	For few / By few	For few / By few	For few / by few	For few / By few	For few / By few
	FR	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one
	DE	For few / By few	For few / By few	For few / By few	For few / By few	For few / By few
	NL	For few / By few	For few / By few	For few / By few	For few / By few	For few / By few
	ES	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one
	SE	For few / By most	For few / By most	For few / By most	For few / By most	For few / By few
	UK	For all / By few	For no one /By no one	For all /By few	For all / By few	For all / By few
Team-based community mental health for older people	EE	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one
	FI	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
	FR	For few / By few	For few / By few	For few / By few	For no one /By no one	For no one /By no one
	DE	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one
	NL	For all / By few	For all / By few	For all / By few	For all / By few	For all / By few
	ES	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one	For no one /By no one
	SE	For few / By few	For few / By few	For few / By few	For few / By few	For few / By few
	UK	For most / By few	For few / By few	For most / By few	For most / By few	For most / By few