



RightTimePlaceCare Report Summary

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Final Report Summary - RIGHTTIMEPLACE CARE (Improving health services for European citizens with dementia: Development of best practice strategies for the transition from ambulatory to institutional long-term care facilities)

Executive Summary:

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Background: Given the increasing number of people with dementia, healthcare services throughout Europe must be prepared to deliver high quality and cost-effective long-term care. Currently, clinical research data on people with dementia and their informal caregivers are not sufficient to develop best practice strategies for long-term care. The RightTimePlaceCare project aimed to develop suggestions on best practice for the transition from formal home care to institutional long-term nursing care facilities. Methods: The RightTimePlaceCare Consortium consists of a multidisciplinary group of researchers from Estonia, Finland, France, Germany, Spain, Sweden, the Netherlands, and United Kingdom. Work Package (WP) 1 aimed at coordinating and managing the project and WP 6 at dissemination of project results. WP 2 described and analysed the European health, social care and welfare systems, advocacy and informal caregiver support systems for people with dementia and their informal caregivers, and intersectorial communication. WP 3 comprised a survey which a) assessed factors influencing institutionalisation of people with dementia and b) investigated their living conditions. The related economic impact was investigated in WP4. WP5 aimed at generating best practice strategies. First, a literature review was conducted and second the Balance of Care approach applied, examining whether people with dementia on the threshold of nursing home entry receive the most appropriate care according to professional judgement, and whether, how and with what consequences the mix of institutional and community services offered by care providers could be improved. Results: The descriptive part of WP 2 for instance indicates that nursing staff skills in dementia care are very heterogeneous throughout participating countries. Early diagnosis and application of non-pharmacological interventions could be improved. Palliative care is not widely implemented for people with dementia. The findings of focus group interviews point to a family-oriented approach and individual adaptation of care but also to the need for proactive care planning. Establishing a trustful relationship and having one person or organisation to refer to throughout the trajectory was regarded as a sign of best practice and tailor-made care indicated compliance with the concept of person-centred care. WP 3 revealed that there is no universal indicator predicting admission of people with dementia to a nursing home throughout Europe. Also, considerable variation in quality of life, quality of care and burden for informal carers was found. WP 4 showed that transition into institutional long-term nursing care seems to increase the total costs of dementia care from a societal perspective. There is pronounced variation related to the country and severity of dementia. Variation is also sensitive to alternative methods for the valuation of informal caregiving and nursing home accommodation. WP 5 indicated that the availability of enhanced community services, could allow at least a quarter of people with dementia currently admitted to a residential or nursing home to be more appropriately supported in their own homes. Thus, the pattern of admissions to institutional long-term care facilities did not regularly correspond with recommendations by experts in WP 5 that were retrieved from structured group discussions of typical case vignettes based on WP 3 data. The findings also provide information about the types of people with dementia in each participating country who would be affected by such re-structuring and the related cost-effectiveness. The results suggest that there could be a potential to save significant resources that could be reinvested in the community. Conclusion: The results of RightTimePlaceCare suggest distinct areas of improvement in practice and also open an agenda for further research. The RightTimePlaceCare recommendations will be directed towards a large target group of policy and decision makers.

Project Context and Objectives:

Given the increasing number of people with dementia, healthcare services throughout Europe must be prepared to deliver high quality and cost-effective long-term care.

At a time of significant financial constraint across Europe, the question of how best to care for people with dementia is of increasing concern. Although institutional long-term care facilities have long formed an important component of care in many countries, current policy guidance is generally focused on reducing the growth of institutional care and on enhancing the provision of home and community services. To date, however, there is considerable variation in the extent to which different countries have achieved this goal.

Currently, clinical research data on people with dementia and their informal caregivers are not sufficient to develop best practice strategies for long-term care. The RightTimePlaceCare project aims were to develop such recommendations for transition from formal home care to institutional long-term nursing care facilities. The

RightTimePlaceCare Consortium consists of a multidisciplinary group of researchers (nursing scientists, geriatricians, old age psychiatrists, psychologists, economists, biostatisticians) from eight European countries. The RightTimePlaceCare project covers the Work Package (WP) objectives mentioned below according to Annex 1 of the Grant Agreement.

WP 1 – “Management”: 1) To ensure timely and qualitative achievement of project results through technical and administrative coordination. 2) To ensure quality control of project results and risk management of the progresses of the project as a whole. 3) To provide timely and efficient administrative and financial control of the project and to meet contractual commitments. 4) To coordinate the management of knowledge and innovation related activities. 5) To support the project coordinator, the Steering Committee and the WP leaders in all management and coordination tasks. The objectives have been fulfilled and the related deliverables were delivered.

WP 2 – “Health Care Structure”: 1) To describe and analyse the European health and social care and welfare systems, advocacy and informal caregiver support systems for patients/ consumers with dementia and intersectorial communication covering the continuum of care from informal care, contribution from the civil society, public home care and the intermediate forms of care to the long-term institutionalised care, including end of life care. 1a) To define and categorise the terminology for description of the entire chain of care from informal care, public or private home care, community and long-term medical, nursing and social care structures and processes available for patients/consumers with dementia. 1b) To analyse and summarise data and information from various available sources. 2) To explore the communication with different care providers and the experiences of patients/consumers with dementia and their informal caregivers with intersectorial information delivery throughout the trajectory of care from diagnosis to end of life care.

The objectives have been fulfilled and the related deliverables were delivered.

WP 3 – “Survey”: 1) To assess the factors influencing the institutionalisation of patients/consumers with dementia at the time of admission to institutional long-term nursing care facility. 2) To investigate the living conditions of patients/consumers with dementia and their caregivers receiving formal professional home care and institutional long-term care. 2a) Quality of care in and quality of life of patients/consumers with dementia in institutional long-term care and home care. 2b) Caregiver burden and quality of life of informal caregivers of patients/ consumers with dementia in institutional long-term care and home care.

The objectives have been fulfilled and the related deliverables were delivered.

WP 4 – “Economics”: Analysis of the data on costs and benefits for the relevant stakeholders in dementia care in the populations investigated in WP 3.

The objectives have been fulfilled and the related deliverables were delivered.

WP 5 – “Best practice”: 1) To develop “Best Practice Strategies” for intersectorial arrangements needed to improve the effectiveness and efficacy of integrated health care in European dementia care systems. 2) To develop recommendations for the “Best Practice Strategies” in long-term nursing care facilities. 3) To achieve consensus on the recommendations among the participating countries.

The objectives have been fulfilled and the related deliverables were delivered.

WP 6 – “Dissemination”: To develop and implement a detailed dissemination plan aimed to effectively deliver the generated knowledge and “Best Practice Strategies” to political and other decision makers in dementia care and the public to ensure a maximum general dissemination of the results.

The objectives have been fulfilled and the related deliverables were delivered. The implementation of the dissemination plan is still ongoing and will take a further several months or a few years.

Project Results:

Description of the long-term formal professional home care and long-term institutional nursing care system and exploration of the intersectorial communication

Work Package 2 covered two objectives, the first of which aimed at describing and analysing the European health, social care and welfare systems, as well as advocacy and informal caregiver support systems for patients with dementia. The description and analyses cover the continuum of care from diagnosis, informal care, contributions from the community, public home care and intermediate forms of care, to long-term institutionalised care, and end of life care.

In a first step, the terminology was developed and meanings of different terms used in relation to dementia care were collected, analysed, defined and categorised. Following this, the terminology was used to develop a graph showing on the Y-axis the course of the dementia disease as described by the OECD in 2004, and on the X-axis the type of care provided, organised in accordance with the process of the disease from dementia screening to end of life care. In addition, each country was asked to provide an overall description of the care system offered there with regard to national directives and financing of the dementia care system. The primary sources of information were written reports from various sources: official documents, epidemiological studies and descriptions of the care system, particularly the dementia care system offered in that country. In addition, interviews with responsible managers, providers or the equivalent in relevant care and service organisations, with persons in consumer/user organisations, with staff, professional employees and purchasers in a municipality or another representative for a civic administrative area were recommended.

Variations and similarities in health care/dementia care systems and the availability and utilisation of services

This descriptive study revealed, as expected, variations in health care systems and dementia care systems between the eight countries. This variation mainly has to do with each country's financial system, the availability of family members and the level of responsibility for care, as well as the access to care and services and including the personal costs to the individual. The underlying political value system in each country may also explain the variation in the views towards developing specific dementia care and service.

The availability of a specific policy for people with a dementia disease varied from no policy at all to clear policies that were either in place or under development. Some of the countries, for example Estonia, Germany and Spain, had policies for care and services directed towards older people in general, whilst other countries had specific policies for dementia care and services or national guidelines for diagnosis and treatment of people with memory disorders, for example England, the Netherlands and Sweden.

Most of the countries have initiatives indicating the awareness of the special needs of people with a dementia disease and their informal caregivers or next of kin. In some countries, for example the Netherlands and England, mental health acts and regulations are also applicable to people with a dementia disease, whilst in other countries the regulations are based solely on care and services for older people.

The findings also point to similarities between the countries, for instance the involvement of the patient's family, despite differences in views about obligation, and also in the distribution of care whether at home or in nursing homes.

All the countries in the study, albeit with some variations, reported that the screening and early diagnosis of a dementia disease was at a low level. From most of the countries, it was reported that usually a diagnosis was not established in the early stage of the disease.

In some countries, it was reported that treatment was terminated when the person entered the moderate to severe stages of the disease, whereas in other countries this was not the case. Non-pharmacological treatment was not generally available or utilised. Some of the responses indicated that the utilisation was dependent on the opinions of the health professionals and their level of engagement and knowledge. Memory clinics and counseling for persons afflicted by dementia were not available very often.

The results of the descriptions of the care and services available and utilised indicated that the application of palliative care as well as end of life care for those with a dementia disease has not yet been implemented to a great extent, although some countries such as England have recognised the need.

There were striking variations between the countries participating in the study in terms of the level of a family member's obligation to care for their next of kin through the course of the disease. In some countries like Estonia and Spain, the obligation of the next of kin, spouses and children to provide care for the family member with dementia was found to be strong, whereas in other countries it was found to be weaker. In some countries, for example Sweden and Finland, there was no obligation at all. In other countries, for example Germany, there were some incentives, such as financial help, to enable family members to take on the role of being primary caregivers. In some countries the family could obtain reimbursement through the state or through the patient with dementia paying the next of kin involved in caregiving. However, despite the differences between the countries, family involvement was shown to be extensive in all of them.

The reports on education, family counseling and support for the next of kin acting as caregivers to a person with dementia showed the use of such activities to be moderate or sparse. This also goes for respite care, which allows caregivers time of their own, and the availability and utilisation of day care activities and the like that also provide caregivers with time and space for themselves.

Some of the countries in the study had less care and social service activity directed towards those being cared for at home. For instance, Estonia and Spain were two countries in this category whereas England, the Netherlands, Finland and Sweden appeared to have more developed care and social service systems for those remaining in their own homes.

There were some variations with regard to care in nursing homes, mainly whether access to this type of care was the choice of the person with dementia or their next of kin or whether it was determined by the authorities providing needs assessment and basing eligibility on the outcome of the assessment. Other types of care facilities like group dwellings were described but generally these facilities were not utilised. Also the specialisation of nursing homes, or wards in nursing homes towards dementia care varied between the countries. In some countries, this was not available and in other countries such options were available, but in most cases perhaps not utilised to a great extent.

There was some variation in terms of the level of competence among the professional caregivers, in particular for care provided on a daily basis. In some of the countries, the professionals involved in daily care had a university level education or the equivalent and in other cases the level was lower. In addition, dementia specific training to improve the care quality also varied between the countries. The report revealed that the most common situation in daily care was that there were professionals who were trained at a lower level or not trained at all.

Methodological limitations

The template used for the study (available on request) asks about availability as well as utilisation, the former being if the kind of care and service is available and the latter being the utilisation of such care. This is without a doubt a

superficial way of getting an overview of a country's care and services system for people with a dementia disease. In addition, the representativeness of the country as a whole can be questioned since there is great variation within different countries depending on the size of the country, the level of decentralisation and the quality assurance systems that are in place. Furthermore, the variations within countries may also be explained by autonomous political geographic areas being responsible for the care and social services to people with dementia. In general, utilisation was reported to be lower than availability. A service may well be available, but is for several reasons not utilised to a great extent.

The descriptions presented in each country's report (available on request) showing, on an overarching level, the care and services available and how they are utilised as well as the providers is a general way of describing the country's care programme for people afflicted with a dementia disease. Thus these descriptions should be interpreted with caution and the great variations within a country acknowledged. The instruction given to each country on how to prepare their report was, however, that they should base their report on the country as a whole. In addition, the descriptions are not based on empirical studies but rather on interviews with experts, reports and other sources of a general nature. Thus, the results should be regarded as general descriptions rather than knowledge derived from valid empirical data. The descriptions do, however, point in certain directions and the descriptions from each country were based on criteria agreed upon before collecting the information.

Work Package 2 also aimed at exploring the communication between different care providers and the experiences of people with dementia and their informal caregivers with intersectorial information delivery throughout the trajectory of care, from diagnosis to end-of-life- care. The plan was to conduct at least four focus groups in each country, two with care providers of different kinds and two with care recipients of different kinds. This was achieved in all the eight countries. Overall, 136 care recipients (group size n=10-27) and 131 care providers (group size n=12 to 26) were interviewed (Table 1).

Table 1: Focus group sample per country.

The data collection aimed at generating potential-oriented rather than deficit-oriented concepts in an attempt to explore how intersectorial information delivery could be improved. It was planned to place the focus groups in communities known to provide high standard dementia care (rural, urban or other depending on the country), defined according to the perspective of the country. Participants were to be professionals working in the dementia care system, patients/consumers with dementia (at an early stage) and patient advocates and caregivers. The focus group discussion was to follow an agreed structure and be tape-recorded. The transcripts were to be analysed according to a predefined thematic protocol based on a preliminary content analysis of the content of the focus group discussions. The results were to be summarised in a report from each country.

Each country has delivered a report on their own focus groups and a synthesis has been developed based on the results from all the countries.

Focus groups on communication and intersectorial information delivery

The results of the focus groups in the eight participating countries reflected a rather consistent view of communication between the countries as well as between the two types of focus groups, those with professionals versus those with patients, family caregivers or stakeholders.

The core findings were that the primary focus of the information, collaboration and communication was on the patient with dementia and his or her family/informal caregivers. Entering and living through the trajectory of the disease and its consequences following the diagnosis was marked by comments particularly on the diagnostic phase and the following phase, but not so much on the end-of-life phase of the disease. The care process in terms of information, collaboration and interaction was addressed on two levels: from a relational perspective, i.e. the emotional quality of the relation between the professionals and the patient and the family caregiver, and from a task perspective i.e. the activities and content of the care process. In addition, the services and care offered to the patients and their informal caregivers as well as staff requirements and the skills needed were addressed. From an information, collaboration and interaction perspective, the findings indicate that information, collaboration and interactions during the care process should center on the patient and the family caregiver. Along the trajectory of the disease communication, collaboration and interaction with professionals were emphasised and spoken about in terms of establishing a trusting relationship, emphasising the relational aspect of the communication and interaction with professionals. Information, communication and collaboration were also addressed in terms of wanting to have one person to turn to and tailor-made care that recognise the patient as well as caregivers and informal caregivers as persons. In addition, it was emphasised that variation in service and care should be offered addressing the personal needs of the patient and the informal caregiver.

The findings point to a family-oriented approach and individual adaptation but also to the need for proactive care planning. Establishing a trustful relationship and having one person or organisation to turn to throughout the trajectory was regarded as a sign of best practice, and tailor-made care indicated compliance with the concept of person-centered care. Figure 1 tries to visualize the main findings.

Methodological limitations

Although the focus groups were set up in a common standardized way, as was the analysis, the results reflect the way in which the groups were actually put together and the way they were conducted. For instance, the number of participants differed among the focus groups from very few to large numbers. In one country only 10 persons participated altogether in the two groups whilst in another country 23 persons participated in the two groups. There was also a large variation in the care providers group, ranging from 12 to 23 altogether in the two groups. In addition, the

participants differed in terms of profession or relation to people with dementia. For instance, it was difficult for most of the countries to include people with dementia and also physicians and thus some perspective may be lacking in most of the focus groups.

Figure 1: Characteristics of communication, interaction and collaboration at its best as discussed in focus groups in the eight participating countries.

Legend: Dotted line indicates that end-of-life care was not addressed although this had been planned. Shaded box means that interprofessional and interorganisational communication should not go through patient and significant others. Survey on long-term formal professional home care and institutional long-term nursing care facilities

Work Package 3 was carried out between November 2010 and April 2012. A study protocol has been published (Verbeek et al. 2012). All countries followed a manual on data collection and methodological procedures. Ethical approval was obtained from country-specific legal authorities for research on human beings. Country-specific consent procedures were followed. Data collection was carried out at baseline and after three months. Not all results could be presented here. Therefore we refer the reader to the published and upcoming papers related to Work Package 3.

The overall sample studied consisted of 2014 dyads of people with dementia and their informal caregivers; n=791 have been recently admitted to institutional long-term care and n=1223 lived at home, but were judged at risk of being institutionalised by formal caregivers (Table 2).

Table 2: Number of participants per country.

Characteristics of participants

The mean age of people with dementia was 83.0 years, the majority was female (67.5%) and married (42.7%). The informal caregivers had a mean age of 62.8 years, the majority was female (67.4%) and married (76.2%). Of the informal caregivers, 32.5% were spouses of persons with dementia.

Table 3 and Table 4 display the characteristics of people with dementia and informal caregivers, respectively.

Table 3: Characteristics of people with dementia.

Legend: Cognitive status assessed by SMMSE, functional status by Katz Index, comorbidity by Charlson Index, neuropsychiatric symptoms by NPI-Q. The underlined score represents the most favourable score.

Table 4: Characteristics of informal caregivers.

Factors influencing institutionalisation

The analyses showed that there is wide variation across countries in factors associated with institutionalisation of people with dementia. A factor influential in one country may be less important in another country and vice versa. Despite this wide variation, caregiver burden appeared the most consistent factor associated with institutionalisation in all analyses. Furthermore, indications for the importance of care dependency (activities of daily living) were found as well, although country differences may be more prominent with regard to this factor.

Living conditions of people with dementia and their informal caregivers

Although self-reported quality of life did not show many differences between settings, proxies evaluated the quality of life of the person with dementia higher when the person with dementia lived in institutional long-term care. Spain was the only country that showed the opposite, with proxies rating the quality of life of people of dementia higher in the home care setting (Table 5).

Table 5: Quality of life of participating people with dementia.

Legend: Quality of life assessed by QoL-AD. The underlined score represents the most favourable score.

There were large country differences between scores on almost all quality indicators, e.g. the use of physical restraints, falls, pain, psychotropic drug use. In the total sample, people with dementia living at home experienced overall more weight loss, pain and depressive symptoms, whereas people with dementia residing in institutional long-term care reported more pressure ulcers and restraint use (Table 6).

Table 6: Quality of care indicators.

Legend: Depressive symptoms assessed by Cornell Scale for Depression in Dementia (CSDD), weight loss by a single item, presence and intensity of pressure ulcer, pain by MDS based indicators, frequency of falls and fall-related injuries. The underlined score represents the most favourable score.

The health-related quality of life of informal caregivers on the whole was acceptable and quite similar for informal caregivers across settings. Transition of persons with dementia from professional home care to an institutional long-term nursing care facility within the three months from baseline to follow-up survey (n=126; 10.3% of the total home care sample) did not result in changes in health-related quality of life of informal caregivers.

The findings of the survey showed a clear distinction in caregiver burden of informal caregivers of those caring for someone at home compared to a person living in institutional long-term care. Informal caregivers of people with

dementia living at home felt more burdened (Table 7). This finding was confirmed in the subsample of informal caregivers of persons with dementia who made the transition to long-term institutional nursing care facility (n=126). They scored significantly lower on the ZBI. Overall informal caregivers in Estonia felt extremely burdened compared to other countries. However, this should be seen in relation to the specific demographics of the Estonian sample, showing that caregivers of people with dementia were younger, had a paid job and performed many caregiving hours. Table 7 displays the informal caregiver experiences and quality of life.

Table 7: Informal caregiver experiences and quality of life.

Legend: Caregiver burden assessed by Zarit Burden Interview, positive/negative reactions to caregiving by Caregiver reaction assessment instrument, health related quality of life by EuroQoL-5D, and psychological wellbeing by GHQ-12.

Methodological considerations

Current findings need to be viewed in relation to the context of the dementia care system within a specific country and the related availability of services for people with dementia available in that country.

This is the first European study which has assessed all known factors influencing institutionalisation and living conditions in a systematic and similar way across countries. This allows for cross-country comparison. However, limitations have to be acknowledged. The study addresses differences across countries, but participants within each country were not sampled to present a representative sample from that respective country. Therefore, results from this study do not necessarily reflect a representative sample of the total population of people with dementia in a country. Furthermore, some limitations regarding the measurements have to be acknowledged. Cognitive status was assessed by means of the SMMSE. In institutional long-term care, fewer people were assessed compared to people living at home, and there was also some country variation. This might exclude people with dementia in institutional long-term care who were not assessed because their dementia was so advanced; therefore there could be a trend for higher mean scores in the current data presented. However, the regression analyses accounted for these missing data.

To provide the most reliable proxy information, the best informed proxy was interviewed.

In home care this would be the informal caregiver and in institutional care it would be the formal caregiver. This could introduce bias in comparing outcome measures and longitudinal analyses for people with dementia who made a transition between settings.

In home care, there was large variation on questions that reflect time spent on caring. Some respondents mentioned '24hours' spent on instrumental activities of daily living which is likely to be overestimated, perhaps including supervision. There also needs to be some caution in interpreting the data on income, especially in relation to income of people with dementia living in institutional long-term care.

In some countries people living in institutional long-term care might receive government funding for their nursing home bed. Based on the data gathered it cannot be determined whether this is perceived as income. In addition, in a few countries, for example England, care records were unavailable and therefore the reporting of the Charlson data depended on the caregiver's knowledge.

Finally, the sample of people with dementia who were admitted during our study period was relatively small (n=126, 10% of the total population living at home at baseline) with large differences across countries. In some countries only four people made a transition, whereas in another country 44 people were transferred to an institutional nursing care facility. This might have been partly influenced by the relatively short follow-up period of three months. However, some countries have collected data at nine months follow-up as well. These data will soon be analysed to validate current results.

Economic evaluation alongside the survey

Work Package 4 was conducted alongside the Work Package 3 survey and aimed at comparing costs for people with dementia receiving professional home care but at risk of institutionalization with costs for people with dementia recently admitted to institutional long-term nursing care in eight European countries. Special emphasis was placed on differences in cost patterns across settings and countries; on the main predictors of costs; and on a comprehensive assessment of costs from a societal perspective. Costs of care were assessed with the instrument Resource Utilization in Dementia. A log link Generalized Linear Model assuming gamma distributed costs was applied to identify the most important cost drivers of dementia care.

On average, costs for institutional long term nursing care amounted to 4491 Euro per month and were 1.8 times higher than professional home care costs (2491 Euro). The relation of costs between settings ranged from 2.4 (SE) to 1.4 (UK). Costs in the institutional setting were dominated by nursing home costs (on average 94%). In the home care setting informal care giving was the most important cost contributor (on average 52%). In all countries costs in the home care setting increased sharply with disease severity. The most important predictor was independency in the activities of daily living in all countries, except in Spain and France where severity of neuropsychiatric symptoms was the most important cost driver. A standard deviation increase in independency in the activities of daily living translated on average into a cost decrease of about 22%.

Transition into institutional long-term nursing care seems to increase the total costs of dementia care from a societal perspective.

Figure 2 shows estimates of mean total costs per month for each country and both settings. The estimates took the heterogeneity across countries, settings and disease severity into account.

Figure 2: Mean (95 % confidence interval) total costs per month by country and setting (adjusted for differences in disease severity and socio-demographics).

However, there is a pronounced variation related to the country on its own and the severity of dementia. It is also sensitive to alternative methods for the valuation of informal caregiving and nursing home accommodation.

Cost estimates entered the Work Package 5 modelling process. Further results of Work Package 4 are available on request.

Generation of best strategy recommendations

In a first step, an extensive systematic literature review on “Best Practice Strategies” for people with dementia was conducted. The final literature review covers 87 pages and deals with pharmacological treatment (for cognitive and neuropsychiatric symptoms), “Best Practice Strategies” in the nursing home care (cognitive and neuropsychiatric symptoms management, physical aspects of care, interventions involving caregivers and structure of dementia care) and home care setting (interventions directed to persons with dementia, interventions directed to informal caregivers, structure of dementia care) and transition from home care to nursing homes care (predictors, interventions to delay nursing home admission, late stage of life care).

Finally, in Work Package 5 the RightTimePlaceCare project applied the Balance of Care approach, examining whether people with dementia on the threshold of nursing home entry receive the most appropriate care according to professional judgement, and whether, how and with what consequences the mix of institutional and community services offered by care providers could be improved.

Briefly, data from the Work Package 3 baseline assessment of n=2014 people with dementia and their caregivers were used for classifying people with dementia into case-types according to functional and cognitive status, behavioural symptoms, caregiver burden and living situation. A total of 14 case-types were selected and vignettes were written as if the person was living at home. At least 15 experts who had the expertise to assess care needs for people with dementia (e.g. case managers, district nurses, geriatric team members, general practitioners and specialist physicians) in each country were invited to group discussions. Participants were divided into small multidisciplinary groups and each group worked with randomly pre-selected vignettes. The experts first made their individual assessment on the appropriate care location and subsequently discussed in the group. Detailed care plans were requested for vignettes where the group’s choice was in favour of home care or assisted living.

Balance of care for people with dementia and their informal caregivers

When individual professionals considered the 14 case type vignettes, their recommendations regarding the most appropriate care setting were relatively consistent across countries for many case types. Decisions were most often in favour of institutional long-term care in the Netherlands, Estonia and France and least often in Finland, Germany and the UK.

In their proposals for alternative care packages of home care, all teams recommended help with personal and instrumental daily activities and day care (either general or dementia specific) in most care packages. Although much of the recommended day care was dementia-specific, most of the recommended home care (instrumental activities of daily living, personal activities of daily living, etc.) was non-specialised or generic. The majority of care packages also included home meals/meals on wheels and transport services.

Whilst there was a degree of consistency regarding the nature of services required within alternative care packages, there was considerable variability regarding the volume of many services (e.g. instrumental activities of daily living, personal activities of daily living support) and, consequently, significant variation in the overall costs of alternative care packages recommended by different professional teams within the workshop sessions. These variations arose between teams within a single country as well as across countries.

A small number of care packages were very different from the others proposed for their case type vignette. The first group had particularly low service inputs and costs. These ‘outliers’ would have generated particularly high levels of savings, but were not used in subsequent modelling as they were felt to represent unduly optimistic assumptions regarding the likely care inputs required for safe and effective care. The second group had particularly high cost care packages.

Estimated cost savings

The estimated potential annual savings across the eight countries were €1,289 million, assuming admissions to nursing homes were prevented, ranging from €364,000 in the smallest country, Estonia, to €365 million in France. The potential saving across the eight countries if admissions to residential homes were prevented was €418 million. Although the contributions of each factor have not been quantified, such as overall population size, the proportion of older people, the numbers with dementia (and with specific case types, based upon our study sample) and the perception of experts from each country regarding the effectiveness and cost-effectiveness of alternatives to institutional long-term care, all have an impact on these estimates. In almost every country (Estonia being the likely exception) there seemed to be significant savings potential (net of any implementation costs), even if diversion of cases was only partially successful. Savings were more limited for Estonia, as only one case type was deemed genuinely marginal (i.e. diversion was both possible and cost effective) and the estimated numbers of cases in that case type were comparatively small, even for

the overall population.

Savings may be dependent on the ability of care systems to support this single case type outside institutional long-term care. More positively, it suggests that, in any particular care system, a significant proportion of realisable savings might be generated by developing services specifically targeted at particularly common, marginal case types. Hence there appears to be the potential for policies of 'downward substitution' to focus upon particular subgroups in dementia care.

Complete results of Work Package 5 are available on request and will be published soon.

Methodological considerations and limitations

A number of assumptions were built into this work. Perhaps the most significant of these is that the sample of cases 'at the margin' of institutional long-term care were representative of the wider population in that situation. As study participants were recruited in a small number of specific localities within each country and recruitment depended upon the identification of cases by existing services, there was potential for bias.

There may be a degree of bias introduced by the level of missing data items. This had its greatest impact in terms of the collection directly from people with dementia of the standardised classification scales, particularly the SMMSE, as a significant number of the most impaired people with dementia were unable to respond meaningfully and the data items were classified as missing. They could not, therefore, be allocated to a case type and included in our key analyses. Although these cases were unlikely to be marginal, this may mean that we have over-estimated the proportion of cases with low or medium levels of impairment, leading to an over-estimation of potential savings.

The standardised vignettes were probably interpreted as though they were in a setting familiar to the expert assessor. They also, intentionally, lacked any information about any existing care package. Both factors might influence any judgement regarding the most appropriate future placement.

The differences in the professional composition of the teams from each country may have limited their collective proposals used as the basis for our costings. Countries had different numbers of professional/expert groups assessing the vignettes; it is likely that those with the most groups considering the vignettes were more likely to identify feasible, cost-effective alternatives to institutional long-term care, potentially biasing the savings, suggesting the potential is greater in those countries.

We have assumed that care packages devised by the practitioner teams in the study were realistic and representative of what was feasible in practice, though some might have proved ineffective following implementation. There was, however, considerable variation across the teams, and both within and between countries, in the extent to which an alternative to institutional long-term care was thought appropriate and the composition (and consequently cost) of any alternative care package. It is possible that some of the more modest care packages proposed for people with dementia with relatively high needs might prove ineffective and some of the more costly care packages might improve excessive.

A further major assumption was that the overall level of health and social services expenditure on older people with dementia was unlikely to vary a great deal from year to year, and that the age structure and associated needs for care of the local population would change little in the short-term. Inevitably, the study was not able to take the broadest possible economic perspective and examine all costs and benefits of alternative care placements and packages (e.g. housing and informal carers' costs are not included within the broader costs of home care packages). The cost perspective was limited to a statutory perspective and benefits are largely assumed to be equivalent for alternative care packages. There was also a degree of uncertainty about service unit costs, particularly between countries, such that the results constitute estimates of expenditure. In particular, the relative prices of complementary and substitute services between countries are a source of uncertainty, despite efforts to allow for relative labour costs.

No account was taken of the transaction costs that might be incurred in reallocating resources between settings or the creation of new services. Where the savings for a particular alternative care package are small and the risk of breakdown high, such alternatives may not prove cost-effective. This is particularly the case because, as the underlying condition deteriorates, the cost of any care package is likely to increase (e.g. as more Instrumental Activities of Daily Living/Personal Activities of Daily Living input, increasing requirements for day or respite care). This will tend to reduce the savings potential of any alternative to institutional long-term care.

Any one-off care costs at the initiation of care were handled similarly over different timescales in our sensitivity analyses, though examination of the data suggested this was not a significant factor for any of the proposed care packages.

Potential Impact:

The potential impact and the main dissemination activities and exploitation of results

The potential impact of the project

The results of the Work Packages suggest defined areas of improvement in practice and also open the agenda for further research.

Work Package 2 indicates that diagnosis of dementia is made mostly in a late stage of the disease. Early diagnosis is likely to have implications for dementia-specific treatment and also for the persons afflicted, and their next of kin, in terms of planning for the future. Careful studies are needed to prove the benefit and absence of harm of an early diagnosis policy. This may be an area for improvement in dementia care.

Non-pharmacological treatment seems to be under-used but must become a priority treatment option as indicated by external evidence on non-pharmacological interventions aimed at reducing sleeping problems, behavioral problems or anxiety in a person with dementia and at avoiding neuroleptic medication.

The palliative care model seems currently to be under-used, but is believed to be well suited for people with dementia. The palliative care model needs to be adapted to the specific conditions that go along with dementia. More research is required in order to develop “best practice” strategies in this phase of the disease.

Family involvement in dementia care seems not to be sufficiently developed. It must be respected more as it is an important issue for many reasons. Knowledge transfer and support for the next of kin, who take over the role as caregivers, should be an essential part of a national policy of dementia care as well an implementation of support systems and interventions.

Since dementia disease is a complicated disease and commonly goes along with other diseases, being part of the aging process, the competence of those providing professional care should be of a high level in order to detect problems that need to be addressed before they have developed too far. The role of registered nurses, as well as staff specialized in dementia care, needs to be explored in terms of cost effectiveness. Cost effectiveness includes care quality and patient outcomes. The impact of non-trained staff on dementia care also needs to be studied further to find out if it is cost effective or if it rather increases the cost of care as well as the suffering of the person with dementia and the next of kin involved in providing their care.

Work Package 3 is certainly an important contribution to the body of knowledge since it cross-nationally compares people with dementia on the threshold between home care and institutional long-term care. The results give insight in many aspects of informal caregiving, the living situation and quality of care of people with dementia. The comparison of quality of care indicators across countries suggests important areas of improvement. Some countries have a lot of scope for improving quality of care for people with dementia in selected quality domains, e.g. Spain with regard to physical restraints. Results of other quality indicators were equally of concern throughout the countries, such as the high prescription frequency of psychotropic medication.

Caregiver burden and dependency in activities of daily living may be crucial in the process of institutionalization and responses to these needs should be targeted in dementia care policy making.

The results by Work Package 5 - which builds on all other Work Packages - indicate that governments seeking to make strategic shifts away from institutional care will each face different challenges and opportunities (including the need to reconfigure services in ways that are appropriate for their particular context and culture). They also highlight a number of common components that will need to be in place for such shifts to occur. These may be seen to constitute an agenda for action, and include:

- An increase in the provision of those community services necessary to enable vulnerable older people to remain in their own homes, including home and day care (either generic or dementia-specific), the delivery of meals, and transport services
- The use of standardised multidisciplinary assessments when making decisions about people with dementia on the margins of care
- The need to co-ordinate care for people with dementia, for example by developing intensive care/ case management arrangements
- The development of staff skills in the management of challenging behavior
- Setting up of information networks that can support both front line staff and service planning
- Contemplation of the different services and systems operating in other countries and their relative strengths and weaknesses

From the perspective of a research agenda, the results and proven methods of RightTimePlaceCare will be perpetuated by an upcoming transnational project within the JPND Call “European research projects for the evaluation of health care policies, strategies and interventions for Neurodegenerative Diseases”. The scientific coordinator as well as members from the RightTimePlaceCare Advisory Board and Consortium will participate in this trial called ACTIFCare (ACces to Timely Formal Care) which is aimed at increasing the understanding of why people with dementia and their caregivers use, or fail to use formal care services (<http://www.neurodegenerationresearch.eu/initiatives/annual-calls-for-proposals/closed-calls/healthcare-evaluation-2012/call-results/actifcare/>).

Main dissemination activities and exploitation of results

The results of the RightTimePlaceCare project have been widely presented at both international and national levels. Up to November 2013, more than 225 dissemination activities other than scientific publications have been conducted across countries. The majority were oral presentations at a scientific event (n=92) and posters (n=31). Oral presentations to the wider public (n=18) and articles published in the popular press (n=39) have appeared less often, as have website applications (n=20), press releases (n=11), and flyers (n=11). Only few interviews took place (n=3). It could be assumed that interview activities might increase with increasing publication activities.

The 20th IAGG Congress of Gerontology and Geriatrics in Seoul, Korea should be highlighted here, since it is without doubt an important event with a wide dissemination effect. In June 2013, the project was presented there by three Work Package leaders and the scientific coordinator (peer reviewed submitted symposium RightTimePlaceCare: Improving health service for European citizens with dementia. The Journal of Nutrition, Health & Aging 2013; 17, Suppl. 1: S212-S213).

Publishing of the RightTimePlaceCare results follows a publication guide which was developed by the Management team and agreed on by the Consortium. In November 2013, first publications dealing with the European results were published in peer-reviewed international journals with impact factor:

- Hallberg IR, Leino-Kilpi H, Meyer G, Raamat K, Soto Martin M, Sutcliffe C, Zabalegui A: Dementia care in eight European Countries: Developing a mapping system to explore. J Nurs Scholarsh 2013 Sep 11. doi: 10.1111/jnu.12046. [Epub ahead of print]
- Beerens HC, Sutcliffe C, Renom-Guiteras A, Soto ME, Suhonen R, Zabalegui A, Bökberg C, Saks K, Hamers JP; on behalf of the RightTimePlaceCare Consortium. Quality of Life of and Quality of Care for People with Dementia Receiving Long Term Institutional Care or Professional Home Care: The European RightTimePlaceCare Study. J Am Med Dir Assoc 2013 Nov 9. doi:pii: S1525-8610(13)00546-X. 10.1016/j.jamda.2013.09.010. [Epub ahead of print]
- Afram B, Stephan A, Verbeek H, Bleijlevens MH, Suhonen R, Sutcliffe C, Raamat K, Cabrera E, Soto ME, Hallberg IR, Meyer G, Hamers JP; RightTimePlaceCare Consortium. Reasons for Institutionalization of People With Dementia: Informal Caregiver Reports From 8 European Countries. J Am Med Dir Assoc 2013 Nov 12. doi:pii: S1525-8610(13)00548-3. 10.1016/j.jamda.2013.09.012. [Epub ahead of print]

For Work Package 3 a study protocol was published in an open access journal:

- Verbeek H, Meyer G, Leino-Kilpi H, Zabalegui A, Hallberg IR, Saks K, Soto ME, Challis D, Sauerland D, Hamers JP; RightTimePlaceCare Consortium. A European study investigating patterns of transition from home care towards institutional dementia care: the protocol of a RightTimePlaceCare study. BMC Public Health 2012; 12: 68

Further four manuscripts dealing with European data from Work Package 3 and 5 have been submitted to international journals and are currently under peer review.

The Consortium is currently working on a series of papers for submission to the Journal of Advanced Nursing which has offered a RightTimePlaceCare Special Issue. All Consortium members will contribute and 11 papers are planned for submission dealing with Work Packages 2, 3, and 5.

RightTimePlaceCare national data could be published either in national language journals or in international journals. First national papers have been published which do not interfere with the European data:

- Stephan A, Renom A, Juchems S, Meyer G: Der Balance of Care Ansatz zur Generierung passgenauer Versorgungsangebote für Menschen mit Demenz zwischen Häuslichkeit und Pflegeheim: Anwendungserfahrungen in Deutschland. Z Evid Fortbild Qual Gesundh wesen 2013 (in press)
- Stephan A, Mayer H, Renom Guiteras A, Meyer G: Validity, reliability and feasibility of the German version of the Caregiver Reaction Assessment scale (G-CRA): a validation study. Intern Psychogeriatr 2013; 25: 1621-1628

Important steps for further dissemination activities beyond publishing are ongoing, such as local conferences for practice partners (nursing homes and ambulatory care providers, consulted experts), which already took place in Germany and the Netherlands, and mailing of brief written reports on the study results for the participating institutions. A summary of main findings representing a deliverable of Work Package will be mailed after accreditation by the EC to addresses collected systematically throughout the project. The dissemination database of the RightTimePlaceCare project comprises local, national and international interested addressees, decision makers and policy makers. The summary of main findings booklet will also be positioned on the RightTimePlaceCare homepage in the English language and made available for translation to all countries. The homepage will be kept updated and the publication list will be updated continuously.

The scientific coordinator will attend a workshop on "Mental Health Research - bridging the gap between evidence and policy", to be held in Brussels on 22 January 2014. The workshop will seek to create a dialogue and build a network between the different players. This includes identifying strategies and overcoming barriers, in which the best evidence can move into action in practice, through inter-sectoral and multi-stakeholder collaboration.

List of Websites:

<http://www.uni-wh.de/en/health/pflegewissenschaft/department-pflegewissenschaft/righttimeplacecare/>

Related information

Result In Brief

- [European healthcare services for dementia](#)

Documents and

- [final1-rtcp-publishable-summary.pdf](#)

Publications

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