

EDSS Focus group interviews about dementia care in eight European countries, from the perspective of people with dementia and their caregivers.

Staffan Karlsson, PhD, RN ¹, Michel Bleijlevens, PhD, PT ², Brenda Roe, PhD, RN ³, Maria Soto Martin, MD ⁴, Astrid Stephan, MScN, RN ⁵, Riitta Suhonen, PhD, RN, FEANS ⁶, Adelaida Zabalegui, PhD, RN, FEANS ⁷, Ingalill R Hallberg, PhD, RN, FEANS, FAAN ⁸ on behalf of the RightTimeCarePlace Consortium*

1) Assistant Professor in Health Care Science, Lund University, Sweden, staffan.karlsson@med.lu.se

2) Researcher, Maastricht University, Department of Health Services Research, The Netherlands, m.bleijlevens@maastrichtuniversity.nl

3) Professor of Health Research, Edge Hill University; Honorary Fellow, PSSRU, University of Manchester, United Kingdom, bhroe@aol.com

4) Geriatrician, Head of Alzheimer Acute care ward, Gerontopôle, Alzheimer's disease Research and Clinical Center, INSERM 1207 in Toulouse University Hospital, France, soto-martin.me@chu-toulouse.fr

5) Researcher, Department of Nursing Science Witten/Herdecke University, Germany, Astrid.Stephan@uni-wh.de

6) Professor, University of Turku, Department of Nursing Science, Turku, Finland, riisuh@utu.fi

7) Upsilon, Director of Nursing, Hospital Clinic of Barcelona, Spain, azabaleg@clinic.ub.es

8) Omega, Senior Professor in Health Care Science, Lund University, Sweden, Ingalill.rahm_hallberg@rektor.lu.se

* The RightTimePlaceCare Consortium partners and their affiliations are listed in Appendix 1

Correspondence

Staffan Karlsson

Department of Health Sciences

Lund University, PO Box 187

221 00 Lund, Sweden

staffan.karlsson@med.lu.se

Abstract

Aim. The aim of the study was to investigate persons with dementia (PwD) and their informal caregiver's experiences of intersectorial information, communication and collaboration throughout the trajectory of dementia care in eight European countries.

Design. Focus groups were applied in eight European countries; Estonia (EE), Finland (FI), France (FR), Germany (DE), The Netherlands (NL), Spain (ES), Sweden (SE) and United Kingdom (UK).

Methods. Participants were 136 in total, and varied between 10 and 27 per country. Participants were PwD and informal caregivers. Structured interviews were provided in each country. Content analysis generated a tentative model of information, communication and collaboration to PwD and their caregivers and in a second step the categories and model was tested.

Results. The core finding was that the primary focuses of information, communication and collaboration was the PwD and the family/informal caregivers. Entering and living through the trajectory of the disease and its consequences was emphasised to be an essential departure. The relation to the professional care was addressed to establishing a trusting relationship; the relational perspective and tailor-made and one person or organisation to turn to; the task perspective. Professional knowledge and commitment, and variation in service and care adapted to needs were important.

Conclusion. Since focus was on the PwD and their informal caregivers seems family-centred care be well suited framework for dementia care. A trusting relationship and a specific person or organisation to turn to seems to be an indicator of best practice as well as adaptation to the needs of the PwD and the informal caregiver.

Key words: dementia, focus groups, older people, informal caregiver, best practice

Introduction

It is well known that living with dementia and being next of kin for a person with dementia (PwD) means having to live through stages that have different characteristics, needs, challenges and requirements (Johnson *et al.* 2009). Thus their view of care quality is of utmost importance as a guidance of how to build up the care chain.

Background

Next of kin is often the primary caregiver for PwD (Schulz & Martire 2004) and knowledge of what they view is of importance in the contact with professional care is needed. Care and service may be in combination with formal care from professionals and to a greater or lesser extent, depending on the stage and the type of symptoms arising along the trajectory of the disease (Hallberg *et al.* submitted). How care and services are organised differ between European countries. Responsibility for health care and social services are often shared between municipalities and counties (Genet *et al.* 2011). Informal care could be a substitute for formal care which is often found in the south of Europe (Bolin *et al.* 2008) as well as in the eastern part (Genet *et al.* 2011), while in the north is viewed more as a complement to formal care (Genet *et al.* 2011, Bolin *et al.* 2008). In addition, legal obligation to provide informal care varies, southern and eastern Europe have such obligation, while the north has no such obligation (Daatland & Herlofson 2004).

Informal caregivers are at risk of developing health problems due to the strain of providing care and coping with the changes in the PwD as the disease progresses (Del-Pino-Casado *et al.* 2011). Meredith *et al.* (2012) and Zabalegui *et al.* (2008) argue for a more preventive orientation in supportive interventions related to informal caregivers. Education about dementia and how to manage the PwD, as well as counselling and respite care have been found to be effective for informal caregivers throughout the disease trajectory. Such interventions have a positive impact on informal caregivers, as decreased burden and depression, improved well-being, ability and knowledge to manage care, and decreased symptoms in the PwD (Pinquart & Sørensen 2006, Zabalegui *et al.* 2014). Providing support to informal caregivers early in the trajectory has also been found to delay or avoid institutionalization of the PwD (Brodsky *et al.* 2003, Smits *et al.* 2007). Thus, it is important to obtain knowledge about care and services provided from the PwD and their informal

caregiver's perspective. Such knowledge will be crucial for the development of tailor made interventions for improvement of quality of life for the PwD and for their informal caregiver

To date there is no curative treatment for dementia but its progressive nature is well known to those concerned; patient, informal caregivers and professionals (Johnson *et al.* 2009). The main problem relates to cognitive deterioration resulting in communication and difficulties in managing activities of daily life. There are particular challenges to informal caregivers who need to understand and interpret the person's needs. Communication difficulties also have implications for the development and handling of behavioural and psychological symptoms of dementia (BPSD) (Edberg *et al.* 2012). Problems of this kind, screaming, wandering, and the like may trigger the inability to continue to provide care at home, or even to abuse of the PwD (Wiglesworth *et al.* 2010). As the disease progresses the PwD may need constant monitoring to ensure safety and help with most activities of daily living. At the end stage the PwD may be totally in the hands of caregivers with respect to these needs and the person's safe (Berg *et al.* 1998). In addition, behaviour problems and complications from other diseases such as cancer may develop (Hallberg *et al.* 1990a, Hallberg *et al.* 1990b). Thus the structure of health and social care and service organization, the trajectory of the disease and the impact it has on the person and informal caregivers, challenges the delivery of information, communication and collaboration.

Aim

The aim of the study was to investigate PwD and their informal caregiver's views of intersectorial information, communication and collaboration throughout the trajectory of care, from diagnosis to end of life care in eight European countries

This study comprises one of the work packages of The "RightTimePlaceCare" (RTPC; the EU 7th framework) project aimed at improving dementia care and services for European citizens with a special focus on the development of best practice strategies for the transition from home care to institutional long-term care facilities. Countries included in the project are Estonia (EE), Finland (FI), France (FR), Germany (DE), The Netherlands (NL), Spain (ES), Sweden (SE) and United Kingdom (UK).

Methods

Design

Qualitative research using focus group methodology was used during autumn 2011.

Sample

The total number of participants in focus groups was 136, and varied between 10 and 27, with a median of 17-18 participants per country (Table 1). Number of participants varied between 4 and 10 per focus group. The sampling was purposeful and included PwD (at an early stage) and informal caregivers recruited from local services or voluntary sector agencies and recruited from municipalities known to provide high standard dementia care (rural and urban), defined from the perspective of the individual country.

Table 1

Ethical considerations

Ethical approval for the study was obtained by the researchers for RTPC in their respective countries from their health services or university review boards as required by each country's law (Verbeek *et al.* 2012).

Procedure

Focus groups applied similar data collection procedure (Joyce 2008) within the eight countries and followed an interview guide (Table 2). The interview guide was developed in collaboration, under the leadership of the last author, with the eight countries representative and first tested in the Swedish context. Professionals interviewing in the eight countries went through a training session prior to conducting focus groups. Two professionals in each country undertook the focus groups, one as a moderator and the other observer/note taker. The participants were informed about the aim of the study and introduced to the format of the focus group, that it was a free discussion between the participants that was of importance. The moderator presented areas for the participants to discuss and encouraged them to share

their experiences . It was the views and experiences of the group and the group discussion that was of interest.. The focus groups were audio recorded and the participants informed how data would be analysed. Participants introduced themselves and the observers made a diagram and placed them with their names around the table on a piece of paper.

Table 2

Data analysis

In each country, the transcribed verbatims were analysed following a predefined thematic protocol that was developed and based on a preliminary content analysis of the focus groups carried out in Sweden. The analysis was carried out in accordance with Graneheim and Lundman (2003) steps (Table 3). Each country provided a summary reflecting on best practice in terms of information, communication and collaboration from the perspective of recipients and in the context of the individual country and the implications of the results. In addition, categories that emerged from the transcribed focus group interviews were described. The analyses in the eight countries were provided in their native languages and after that the results were translated to English. Each country reported the experiences of patients with dementia and their informal caregivers to the Swedish research team, responsible for this part of the project “RightTimePlaceCare”.

Table 3

Method for obtaining a synthesis

The analysis was done in two steps, the first generating a tentative model of information, communication and collaboration to PwD and their caregivers and the second testing the model on the material independently of the first analysis. An interpretative approach (Lincoln & Guba 1985) was taken to arrive at a synthesis (Jensen & Allen 1996). This approach was chosen to extract the characteristics of best practice related to communication with PwD and their informal caregivers. De-contextualisation (Lindseth & Norberg 2004) was a part of interpretation and allowed the identification of findings representative of the eight country reports. The synthesis thus attempted to capture the findings at a level where the

interpretation could be understood outside the specific country characteristics and thus enabled the comprehension of other specific country characteristics through re-contextualisation.

First analysis

The first analysis took place once each country had done their language specific analysis and reported the results. To arrive at an interpretation of the results from all eight countries, the country reports were in a first step read through repeatedly by the last author. In particular the part summarising the results of each report, was read in light of the entire report to ensure that important aspects were covered in the final synthesis. In the second step the categories reported in each country report were listed and their meaning was added as an explanation of the meaning of the terms used. In a third step the categories were sorted for resemblances and differences and those that coincided were labelled according to their content. Finally a tentative model was developed in which the categories were described and this model with categories and synthesis were sent to the principal investigators in each country, for them to validate the interpretation of the whole. The principal investigators discussed the findings and gave feed back to the Swedish team. Their comments were taken into account in order to develop and expand the explanation of the model that emerged.

Second analysis

In the next analysis, the first author independently of the last author read through the country reports repeatedly and did so in the light of the developed categories, testing the justification of the categories in the text from each country. Meaning units were identified in the text from each country and sorted to the associated category. Thus the entire text was sorted into the previous established categories. The meaning units assigned to each category were thereafter discussed between the first and the last author to establish that a meaning unit really supported the category. Within each category the assigned meaning units with a common core formed sub-categories developed by the first author. The categorisation thereafter was validated by the last author and after adjustment sub-categories was decided within each category (Table 4).

Table 4

Results

The results of the focus groups in the eight countries reflected a rather consistent view within the countries of information, communication and collaboration. The core findings were that the primary focuses of information, communication and collaboration was the PwD and their informal caregivers. Entering and living through the trajectory of the disease and its consequences was emphasised to be an essential departure. The relation to the professional care was addressed to establishing a trusting relationship; the relational perspective and tailor-made and one person or organisation to turn to; the task perspective. Professional knowledge and commitment and variation in service and care; adapted to needs were important (Figure 1).

Figure 1

The centre for communication; patient and informal caregiver

The focus on the PwD and the informal caregiver as the hub for all information and communication was evident. The intersectorial information communication and collaboration should work in the interest of the PwD and the significant other. In terms of information, communication and collaboration the PwD and informal caregiver should be addressed as experts on their life situation and this happened when care was at its best. The opposite was also identified and illustrated poor practice. Counselling throughout the trajectory was regarded as a sign of best practice. Overall the informal caregiver and the PwD wanted to be involved and respected. Essentially this concerned the attitudes of the professionals. The PwD and the informal caregiver stated their need of information and knowledge about what living with dementia means, but also support, social as well as task-oriented, throughout the disease trajectory. At the same time their own knowledge and experiences should be taken into account. The first contact was regarded as important as it determined the continuation of the collaboration and interaction. Thus the findings from the focus groups show that the PwD and the informal caregiver should be regarded on the one hand as knowledgeable about the meaning of living with dementia and on the other hand needing information, knowledge and support throughout the trajectory, individually tailored and inviting them to take an active role in the care process.

A woman caring for her husband expressed “*Well our GP was very good. When I took my husband to see the GP and on the second visit...I was going to ask him if he could tell me what I could do if I could go to any special service or anything like that, the memory services, and .. he was asking my husband how he was and could he remember anything now and he said, -“no it seems to be going worse”, so he said, -I think I shall refer you to the memory service, so, you know..., I thought that was excellent, he seemed to be really on the ball, but I know they are not all the same*” (UK)

Entering and living through the trajectory of the disease and its consequences

Entering into the trajectory of the disease and its consequences was addressed as an important point of departure. This entry phase also meant that a first impression was established of professional’s commitment and interest in their situation. Feeling recognised and listened to would have a positive impact on the communication thereafter. This first impression may have implications for the ensuing interaction and collaboration. Best practice in terms of information, communication and collaboration at this entering phase meant, having an early diagnosis and a general practitioner actively involved in that process, not only initially but throughout the process. This was emphasised in most of the countries. It was a problem in the early phase to be taken seriously and this was regarded as a sign of poor practice, as diagnosis was not established despite the problems being presented in the consultation. It was expected that information, adapted to the persons and their needs, would be provided throughout the trajectory and particularly in the initial phase. Thus in essence early diagnosis and tailor-made information, knowledge and communication were addressed as important and signs of best practice. Informal caregivers experienced burden from being the main care provider particularly in home care, but wanted on the other hand to be involved in the care especially when PwD lived in a nursing home. The PwD as well as informal caregiver was forced to cope with the illness of dementia and caring situation throughout the disease trajectory.

A woman caring for her husband expressed “*I tried...Because I understood that we were not going to have another 20 years together as a couple...a life to go out and visit the children and all that.. so I tried to do as much as possible, to do as much as possible in the time that I thought...Would be short and the GPs support withy these adjustments: he dealt me a blow by saying well, now we shall move on to the next phase, we shall do this, we shall do that, and I said to myself.. excuse me, what a bastard! But in fact, it was a good thing. That he told*

everything in advance. So I didn't make the same mistakes, trying to force him to go out, Saying, let's go for a walk...I left him time to rest because that's important. And no one tells you that beforehand, that with this disease you have to have time to rest" (FR).

Establishing a trusting relationship; the relational perspective

Information, communication and collaboration were regarded as being dependent on the establishment of a trusting relationship. A professional approach to create a relationship with the PwD and informal caregiver was identified as best practise. The relationship between professionals, the PwD and informal caregiver was a common topic in the focus groups, mainly in terms of the commitment and involvement of professionals; the emotional aspect of their communication. The professionals were described as available when needed when care was of high quality, i.e. in a relationship where the PwD was regarded as the recipient of care. The need for emotional support, for instance in terms of counselling, should be recognized by professionals. It was also emphasised that there should be a short line of communication between informal caregiver and professionals and that the interaction should be flexible. Thus the emotional aspect of the relationship was emphasised when addressing information, communication and collaboration, in particular recognition of that the informal caregiver and PwD needed support and that their situation can change from one moment to the next and that this can differ widely between individuals.

A child caring for a mother expressed *"If something has changed, even after one week the staff informed whether we were satisfied with the changes. The family is really involved in the decisions made. Every two/three months an evaluation will be conducted. It also takes into account how Mrs X was before. We as a family will also be contacted if there are any problems or questions. I really think that is good. There is also one contact person, you do not need two or three times or persons to call. They provide the information to each other"* (NL).

Tailor-made and one person or organisation to turn to; the task perspective

In addition to the emotional aspect of the relationship, task aspects were addressed as an important part of best practice. These were described in terms of the need for tailored care at all stages of the process and in particular, coordination between providers/settings at a certain

stage and throughout the process. The importance of availability of individualised care and service was stressed, for the PwD as well as for the informal caregiver. Having a reference nurse, a contact person or a key coordinator was brought up as ways of achieving the goal of not having to communicate with too many people. At the same time the need for a multidisciplinary approach was emphasized, using a variety of terminology.

A woman caring for her husband expressed *“it was obvious: he is going to stay there, on Monday morning you could tell he is dying and then everything worked really well between the nursing home, the GP, the palliative care, the physiotherapist came and the cranial sacral osteopathy was very relaxing and I was there from Monday morning until Friday, until he died. All day and all night, and the nursing home was really supportive during that time”* (DE).

Variation in service and care; adapted to needs

The kind of services available and variations in service and care facilities to be used according to needs was particularly emphasised. Care and services specialised in dementia were identified as important for understanding the specific needs of PwD and their informal caregivers. Also providing knowledge and information about available services was regarded as important at an early stage as well as throughout the process. Ensuring safety for the PwD and the informal caregiver was important and required proactive monitoring of their situation. Since care is characterised by the involvement of different providers it was emphasised that roles should be clear and that some sort of centralisation of information should be established. This was to ensure that informal caregivers did not have to repeat themselves over and over again. Access to respite care and day-care facilities ensuring that the informal caregiver had some breaks was important throughout the trajectory and examples such as telephone emergency centres were mentioned. In some countries the existence of a centre of excellence was emphasised. Stage-divided care was suggested as good practice in some focus groups whilst others wanted the same caregivers throughout the trajectory. Since different providers are involved at each stage, as well as in different phases of the trajectory, intersectorial information and communication between levels of care was regarded as a sign of best practice. This in turn however, required a single point of access for the family and PwD.

A family member expressed *“the disease progresses gradually and we try to adapt to the circumstances. They are in a day centre some hours and some others at home. As long as they can keep going on with this I am more than happy”* (ES).

A daughter caring for her mother expressed *“I talked to very nice people over the phone, very positive. They gave me advice, tried to console, talked to me and said that if I really needed help they could take the patient....honestly, I talked a lot, I just had to calm myself down somehow”* (EE).

Professional knowledge and commitment

The professional’s knowledge, commitment and skills were a common theme in the focus groups. They should be experts, specialists in dementia care and have a solid background with experience from the field of dementia. Thus professionals were expected to be specialised and have training in dementia care. Apart from their formal competence, their commitment, ability to imagine what it is like to be the PwD and the informal caregiver, their involvement and ability to initiate interventions were emphasised. Thus they should be flexible and creative, able to imagine and empathise what the situation was like for the PwD and informal caregiver, and to provide individualised care and interventions needed. They should also help to reduce social barriers. Examples of poor practice were described particularly from hospitals emergency departments. The lack of knowledge and ability to provide good care among professionals working in these places were presented as a problem.

A PwD expressed *“I have so competent and good physician. He is a neurologist, who takes care about every small issue, even details”* (FI).

A daughter caring for her father expressed *“Always when I am leaving he gets so sad and it’s so difficult for me and for him but it’s enough that I show myself and some personnel sees me and they step in and take care of him. And that feels so secure”* (SE).

Discussion

As expected the PwD should be at the centre of information, communication and collaboration, and care should be adapted to meet the needs of the person with dementia. However, the emphasis was as much on the informal caregiver and the PwD together, i.e. centred around those involved in the person’s life as a team. It is well known that family

members, or significant others are the cornerstone in providing care for older people (Hellström *et al.* 2004) and in particular of PwD (Schulz & Martire 2004). Despite this the concept of family-centred care is not commonly practiced (Lindhardt *et al.* 2008). The need for a family focus came out clearly in the focus groups which may be explained by that the focus groups consisted mainly of informal caregivers that in one way or the other were involved in providing care for a PwD. They may have experienced being neglected in communication with professionals. A balance needs to be struck between respecting the person's integrity and the informal caregiver's need for support and knowledge. The situation of informal caregivers providing care for PwD is perhaps unique compared to that of other informal caregivers in that the PwD is in the hands of the caregiver, especially in the moderate and late stages of the disease. The informal caregiver has to interpret the fragments of communication as well as guarantee the person's safety and that activities of daily living are maintained. Thus the concept of family-centred care (Rolland 1994) seems well suited to function as a framework for dementia care. Family should, however, be interpreted in a broad sense since the informal caregiver may not be a family member in a traditional sense.

The professional care was addressed from a relational perspective as well as from a task perspective. Information, communication and collaboration were considered to be dependent on establish a trusting relationship with the professionals. Best practice was described when professionals were available when needed. Since the dementia is a progressive disease and on-going for a prolonged time, it implies various needs in PwD and the informal caregiver during the trajectory. Previous studies have shown that informal caregivers experience strain due to the care provided and coping with variations in the PwD along the disease progress (del Pino-Casado *et al.* 2011, McMunn *et al.* 2009, Tolkacheva *et al.* 2011). It was emphasised that the need for emotional support was recognized by the professionals, for instance counselling. Such interventions have been found to have a positive influence on the well-being in the PwD as well as in the informal caregiver (Pinquart & Sörensen 2006, Etters *et al.* 2008, Zabalegui *et al.* 2008). The relational aspect was promoted if the professionals were committed and sensitive to the emotional situation of the PwD and the informal caregiver. Professionals were expected to be specialists in dementia care. However, a previous study from the RTPC project showed that the formal competence in professionals in dementia care varies within Europe and daily care was often provided by staff with no health training (Hallberg *et al.* Submitted). The task aspect in the professional care was emphasised

as an important part of best practice. It was described as a need for tailored care in each stage throughout the process of dementia. Having a reference person or a key coordinator was addressed as ways to avoid having to communicate with too many professionals. The use of case managers have shown to have positive impact on older care recipients and their caregivers. They were more satisfied with the care, experienced less unmet service needs, and stress and burden decreased among informal caregivers (You *et al.* 2012). Altogether, the need for a specific person or organisation for the PwD or informal caregiver to turn to throughout the trajectory of the disease seems to be a marker of best practice.

Communication and coordination between professionals and between organisations should work independently. Interestingly so it turned out that interprofessional and interorganisational communication were rather in the background than in the forefront, as shown in the results. The main message was that interprofessional communication should be in the background and not be the responsibility of the PwD or the informal caregiver. The expectation was that interprofessional communication should work without the involvement of PwD and informal caregivers. This in turn requires a system for knowledge transference between the professionals and organisations involved. However, it has been found barriers for interprofessional communication due to numerous and different professionals involved in the care during the progress of dementia. In addition the responsibility for health care and social services is often shared between municipalities and counties, which may have an impact on interorganisational communication (Genet *et al.* 2011). To promote interprofessional and interorganisational communication, one example is team with various professionals specialised in dementia that includes individualised and flexible package of care, which involve pleasurable social interaction (Gladman *et al.* 2007). Another model is the use of case managers with expert knowledge as a coordinator for effective interorganizational cooperation to deliver integrated care for the PwD and their informal caregivers. High care satisfaction in PwD and their informal caregivers was found in one previous study (Minkman *et al.* 2007). In this study, there were examples brought up regarded having different people to turn to and not knowing who to turn to and the opposite - knowing exactly who to turn and retaining that contact throughout the trajectory - was emphasized as good practice. Thus, well-functioning interprofessional and interorganisational communications are important for PwD and their informal caregivers, and prevented them to be the messenger between different professionals and organisations.

Limitations

The focus group method aims to use experts to initiate a group discussion of the characteristics of a specific theme or problem, in this study were PwD and informal caregivers included. Although the focus groups were set up in a common standardized way as was the analysis, the results probably reflect the way in which the groups were put together and the way they were provided. For instance, the number of participants differed among the focus groups from very few to larger numbers. In one country 10 persons participated altogether in the two groups whilst in another country 18 persons participated in the two groups. In addition the participants differed in relation to PwD. For instance it was difficult for most of the countries to include PwD and thus some perspective may be lacking in most of the focus groups. In addition the meaning of being an informal caregiver may not be comparable across countries. The role and meaning is not only dependent on the level of knowledge and tasks performed but also of the healthcare system of each country. These factors were the main reason for not choosing a comparative but rather an interpretative approach. The ideal best practice mode was the focus of the interpretative approach. Applicability of the interpretation in different countries, however, requires re-contextualisation, meaning that the findings need to be interpreted and adapted to the context in which they are to be applied. The results are based on a secondary analysis of the interviews. Primary the interviews were analysed in each country on their native language and in varying ways that may have influenced the results. However, to minimise the variation in the primary analysis a common thematic protocol was used. Altogether the discussion in the focus groups represented a common view of what was good practice for the PwD and the informal caregiver and thus the findings probably are applicable in many countries.

Conclusions

As information, communication and collaboration were focused on the PwD and their informal caregivers the concept of family-centred care seems to be a well suited framework for dementia care. A trusting relationship with professionals, taking emotial and task aspects into account and a specific person or organisation for the PwD and informal caregiver to turn to throughout the trajectory of the disease seems to be indicators of best practice. A well-functioning interprofessional and interorganisational communications prevent PwD and the informal caregivers to be the messenger between different professionals and organisations.

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Table 1. Sub-samples of the focus groups.

Focus groups	Estonia	Germany	Finland	France	Netherlands	Spain	Sweden	UK
No. of focus groups	2	3	2	2	2	2	4	3
No. of PwD	0	1	6	0	0	5	2	11
No. of informal caregivers	14	16	12	13	10	8	22	16
No. of participants in total	14	17	18	13	10	13	24	27

Table 2. Interview guide

How the communication, information and interaction between care providers works and how it works in relation to the participant.

Thinking about the living in situation as a process and in particular about interaction, information and communication.

Tell us about the situation in terms of the future

Think about when the service works at its best; situations when it works really well and what characterizes the service then

Tell us about what is most valued in terms of the care and service from professionals

Think about when the service works less well; situations when it works not so well and what characterizes the service then

Think about when the service works really bad; situations when it is really poor and what characterizes the service then

What makes the service very good and think about the stages from the diagnosis and on until now. Think in particular on interaction, communication and information and being the person with the disease versus the person standing next by.

Taking the perspective and having the opportunity to tell the government about how this care should be along the disease process should be carried out.

Table 3. Thematic protocol for analysis

Participants' description of contextual situation; Summarizing what the participants say about their own situation and how they reflect on it.

Participants' description of the information and communication with professionals, when it worked best and when it did not work.

Participants' description of the information and communication along the trajectory of dementia from early stage to end stage, if talked about and if it differed over time.

Participants' description of the information and communication depending on whether the care was given at home or in a nursing home.

Participants' description of collaboration with professionals when it worked best versus and when it did not work.

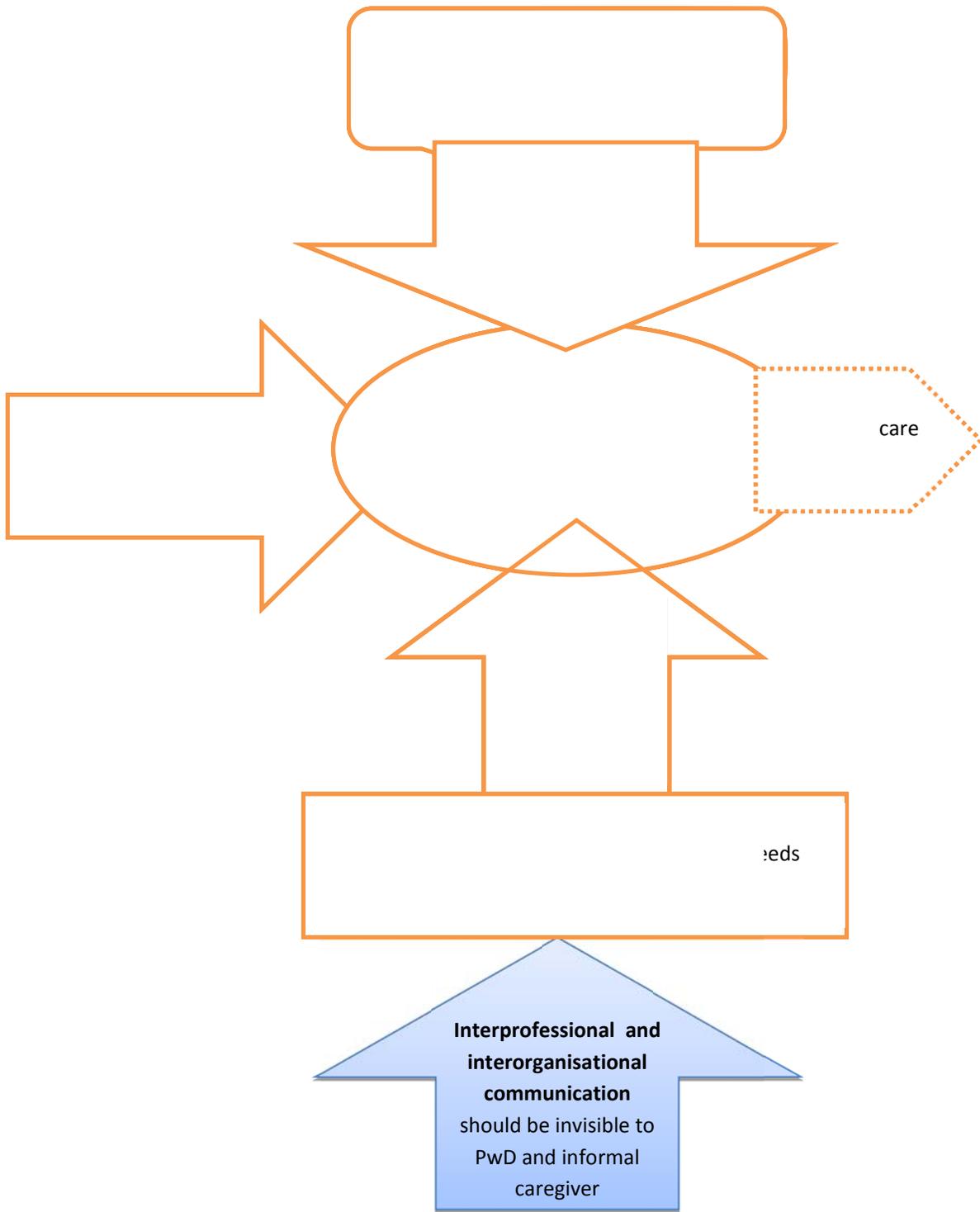
Participants' description of the collaboration with professionals along the trajectory of dementia from early stage to end stage if talked about and if it differed over time

Participants' description of the collaboration with professionals depending on whether the care was given at home or in a nursing home

Participants' overall reflection on care at its best versus not at its best, captured in themes reflecting the content of the participants' talk about the care received.

Table 4. Example of identified meaning units, condensed, subcategories and category

Meaning units	Subcategory	Category
Best with a retain contact with the patient and shows interest in state and treatment (Est)	The need of a key coordinator	Tailor made and one person or organization to turn to; the task perspective
In early stage of dementia un-clarity of whom is giving the information (Fi)		
A place where all necessary information is collected (Fr)		
One contact person or very few professionals of references throughout the process (Ger)		
Difficult to find the right person who can help, especially in the beginning (NL)		
Instead of a number of professionals and means of entry to help and support, a need of single point and contact/case manager (UK)		
Best when social worker provide information about benefits and services (Est)	Availability of individualised care and services	
Best with early diagnosis, support of functional ability and effective arrangement of care and services (Fi)		
Best when care is easy to approach, reasonable costs and services targeted family (Fi)		
Support and training groups for informal caregivers important (Fr)		
Progression of dementia implies a growing network of professionals and the function is especially important in care giving situation at home (Ger)		
Cooperation with professionals is important in order to taking care of their relatives at home (Spa)		
Care with individualized activities, stimulation and closeness to other people (Swe)		
In-patient care need to be more responsiveness to dementia people with nutrition and hydration problems (UK)		
Once diagnosis been stated, the doctor organizes case management (Est)	The importance of coordination between different formal caregivers	
Information coordinated between different care providers (Fr)		
Collaboration in home care challenge of the organization with different care providers involved (Ger)		
Need more time with professionals to make things clearer regarding the disease and its care (UK)		



end of

Appendix 1

The *RightTimePlaceCare* Consortium partners are as follows:

Coordinator:

University of Witten/Herdecke (DE): Gabriele Meyer PhD, RN, professor (scientific coordinator, WP 1 leader), Astrid Stephan MScN, RN, Anna Renom Guiteras, geriatrician, Dirk Sauerland Dr.rer.pol., professor (WP 4 & 6 leader), Dr Ansgar Wübker, Patrick Bremer dipl. oec.

Consortium Members:

Maastricht University (NL): Jan P.H. Hamers, PhD, RN, professor (WP 3 leader); Basema Afram, MSc; Hanneke C. Beerens, MSc, RN; Michel H.C. Bleijlevens, PhD, PT; Hilde Verbeek, PhD; Sandra M.G. Zwakhalen, PhD, RN; Dirk Ruwaard, MD, PhD, professor.

Lund University (SE): Ingalill Rahm Hallberg, professor (WP 2 leader); Ulla Melin Emilsson, professor; Staffan Karlsson, PhD, Christina Bokberg, MSc, Connie Lethin, MSc.

University of Manchester (UK): David Challis, professor (WP5 leader); Caroline Sutcliffe MSc; Dr David Jolley; Sue Tucker, MSc, RN; Dr Ian Bowns; Brenda Roe, professor; Alistair Burns, professor.

University of Turku (FI): Helena Leino-Kilpi, PhD, RN, professor; Jaana Koskeniemi, MNSc, RN, researcher; Riitta Suhonen, PhD, RN, professor; Matti Viitanen, MD, PhD, professor; Seija Arve, PhD, RN, docent; Minna Stolt, PhD, podiatrist; Maija Hupli, PhD, RN.

University of Tartu (EE): Kai Saks, MD, PhD, professor (WP 5 leader); Ene-Margit Tiit, PhD, professor; Jelena Leibur, MD, MBA; Katrin Raamat, MA; Angelika Armolik, MA; Teija Tuula Marjatta Toivari, MA, RN.

Fundació Privada Clinic per la Recerca Biomedica, Hospital Clinic of Barcelona (ES): Adelaida Zabalegui PhD, RN (WP 5 leader); Montserrat Navarro PhD, RN; Esther Cabrera PhD, RN (Tecnocampus Mataró), Ester Risco MNSc, RN; Carme Alvira MScN, RN; Marta Farre MScN, RN; Susana Miguel MScN, RN.

Gerontopole, University of Toulouse (FR): Dr Maria Soto; Agathe Milhet; Dr Sandrine Sourdet; Sophie Gillette; Bruno Vellas, professor.