American Journal of Alzheimer's
Disease & Other Dementias®
2016, Vol. 31(3) 223-230

DOI: 10.1177/1533317515603818
aja.sagepub.com
SAGE

Perspectives About Health Care Provision in Dementia Care in Spain: A Qualitative Study Using Focus-Group Methodology

Ester Risco, MNSc[1], Esther Cabrera, PhD[2], Marta Farré, MNSc[1], Carme Alvira, MNSc[3], Susana Miguel, MNS[4], and Adelaida Zabalegui, PhD[1]

Abstract

Background: The aim of this study is to identify the barriers and facilitators in dementia care with respect to information provision, communication, and collaboration from the perspectives of the person with dementia, family caregivers, and health care professionals over the course of the illness. **Methods:** A qualitative study using Focus-Group methodology was carried out in people with dementia, family caregivers, and health care providers. **Results:** The categories that emerged from the analysis were *insufficient information provided, specific dementia care needs, and acceptance of long-term care institutionalization* from the people with dementia and caregivers' groups and *insufficient communication between health care providers, differential information according to disease stage, and home care coordination from* the health care providers' groups. **Conclusion:** The family is a key element in successful care coordination during dementia care provision. New effective strategies including self-management and emergent roles, such as case managers, could bring great benefits to people with dementia, caregivers, and health care providers.

Keywords

dementia care, communication, information, collaboration, focus group

Introduction

Dementia is considered to be one of the principal causes of incapacity.[1] The way this disease affects individuals makes them highly dependent on care from the early stages of the disease, causing elevated levels of burden, anxiety, and depression in family members and leading to greater demands on the health care system than other chronic conditions associated with the elderly patients.[2] Sometimes, this is due to a lack of information, or even conflicting information, from health care providers. Furthermore, various health care providers are involved during the progression of the disease, so it is essential to establish good coordination strategies to ensure continuum of care.[3] Physicians, staff nurses, and social workers may be from different settings such as acute hospitals, primary care, or social services. Thus, there is a need to establish effective means of communication and information exchange among these health care professionals as well as between health care professionals and people with dementia and their families.[4,5]

International literature supports the idea of adapting dementia care provision to cultural norms in terms of communication with family caregivers, coordination between health care providers offering a variety of services, and information disseminated.[6-8] Although some national dementia guidelines based on international evidence have been developed over recent decades in Spain, these have not been fully implemented due to the fragmentation of the health care system across the country. Each autonomous community has a distinct and independent health care organization.[9] Furthermore, there are 3 main health care areas dealing separately with different aspects of dementia care: acute hospital care, primary and community care responsible for monitoring the chronic condition, and long-term institutional care. This type of long-term care is not an option for all patients as places in public institutions are limited and demand in recent years has grown considerably. Current waiting lists for

---

[1] Department of Nursing, Hospital Clínic de Barcelona, Barcelona, Spain
[2] School of Health Sciences TecnoCampus, Pompeu Fabra University, Mataró, Spain
[3] Department of Nursing, Comte Borrell Primary Care, Comte Borrell, Barcelona, Spain
[4] School of Health Sciences Gimbernat i Tomàs Cerdà, UAB. Av. de la Generalitat, Barcelona, Spain

This article was accepted under the editorship of the former Editor-in-Chief, Carol F. Lippa.

Corresponding Author:
Ester Risco, MNSc, Hospital Clínic de Barcelona, Villarroel 170, 08036 Barcelona, Spain.
Email: erisco@clinic.ub.es

state-run, long-term care institutions are around 2 years.[9] It should also be borne in mind that acute hospital care, primary and community care, and long-term institutional care have varying organizational arrangements, and they face numerous challenges to optimal care delivery during transitions, such as care fragmentation among institutions or a certain degree of controversy regarding medical recommendations that can lead to a breakdown in confidence in health care providers among our population.[10] Moreover, central and regional governments handle serious economic problems that may influence public health care and social service provision to people with dementia and their family members.[10] Despite the near-universal coverage provided by the Spanish health care system, there is still insufficient provision of social services to support dependent individuals and their families compared with other more comprehensive social care systems such as those found in some other European countries.[11,12] Few resources exist for the improvement in care quality for dependent people such as free home care services, rehabilitation centers, monitoring of dependent individuals, or support for overburdened family caregivers. Consequently, situations that could have been managed with a simple, early intervention become crises that result in high demand for expensive emergency services.[12]

Thus, the aim of this study is to identify the barriers and facilitators in dementia care with respect to information, communication, and collaboration from the perspectives of the person with dementia, family caregivers, and health care professionals over the course of the illness. The evidence obtained could then be used by policy makers to improve and reorganize dementia health care provision in Spain.

Methods

Study Design

A qualitative study using focus-group methodology was conducted. This study design was chosen as it is a means of collecting research data through moderated group discussion based on participants' perceptions and experience.[13] It was considered that a group discussion would encourage participants to share experiences and that, in group dynamics, it is the group, rather than the constituent individuals, that is front and center. This study was part of a larger European research project aiming to improve health services for European citizens with dementia.[14]

Population and Sample

The study population was selected to represent the main stakeholders in the dementia care process: people with dementia and their family members and those health care professionals responsible for dementia care decision making (physicians, registered nurses, and social workers). Participants were categorized into 2 types: (1) people with dementia and family caregivers and (2) health care professionals with expertise in dementia care.

Between September and October 2011, 25 health care professionals, 20 informal caregivers, and 15 people with early-stage dementia (with a Mini-Mental State Examination score between 19 and 24 points)[15] were recruited from separate health care centers (hospitals, primary care, long-term care homes, and day care centers). The inclusion of participants from different institutions ensured maximum variation within the sample. Four master's degree nurses, with a broad expertise in elderly and dementia care, did the recruitment of people with dementia and family caregivers. They spoke to a wide range of health care providers regarding the aims of the study and the population of interest. These health care providers, following institutional guidelines, then gave the nurses details on people they considered would be suitable study participants. Contact with these potential participants was made by phone to set up a visit to explain the project, their possible participation and, in cases where they agreed to take part, obtain written informed consent (people with dementia and family caregivers). The health care experts were recommended by the health care center (hospital or primary care center) and, following contact by e-mail to explain the aims of the study, those who met the criteria were identified and recruited by the same 4 nurses. Regarding the number of participants, it was determined that each focus group should consist of a minimum of 8 people and a maximum of 10.[16] Fifteen informal caregivers, 10 people with dementia, and 22 health care professionals first agreed to participate. Afterward, 4 informal caregivers declined due to caregiving schedules or health-related problems, 3 people with dementia declined for unspecified reasons, and 3 health care professionals decided not to take part due to work commitments. Nevertheless, the number of participants included remained consistent with the methodology.

People With Dementia and Family Caregivers

To ensure that the groups were representative of people with dementia and family caregivers, each contained representatives of both. A minimum of 2 people with dementia were required in each of the focus groups, although these participants could not exceed 50% of the total number of group members. Taking into account that participation could be more difficult for these individuals as they had to be able to understand the study aims and be capable of participating in the meeting, only people with early-stage dementia were included.[17] Family members were excluded when the selected participant with dementia was related to them. The family members were selected according to health care professional criteria, and they had to have been caring for a person with dementia for at least 1 year.[17]

Health Care Professionals

Health care professionals were chosen according to the usual composition of teams involved in dementia care in Spain,[18] and all had extensive expertise in this type of care. They needed to be working in the distinct settings: acute hospitals, primary care or social services and come from separate disciplines (physicians, registered nurses, and social workers), and type of center (acute or chronic). Strategic sampling of health care professionals was performed to obtain comprehensive variation in experiences and perspectives on dementia care.

Data Collection

Data collection took place during November 2011. The researchers conducting the focus-group sessions were nurses with expertise in care of the elderly patients, a master's degree in Nursing Science and special training in focus-group methodology. Before the focus-group session began, demographic data were collected to obtain profiles of the various stakeholders taking part. One nurse led each focus group and a second acted as an observer to document relevant contributions that would not necessarily have been picked up by the audio recordings such as nonverbal reactions. A focus-group interview guide, based on a review of the literature, was previously developed and consisted of 5 open-ended questions about their experience of being part of the dementia care process within the health system. Questions regarding any deficiency in the chain of care were included, exploring barriers and facilitators with respect to information, communication, and collaboration (Appendix A). To facilitate the participation of the people who attended the meetings and prevent any of the participants from monopolizing them, people took it in turns to express their opinions without interruption at the beginning. This was carefully monitored by the focus-group moderator. The sessions, of a maximum of 90 minutes, were audio-recorded and transcribed verbatim. All meetings were conducted in the Spanish language. Prior to study commencement, 8 different health care professionals from hospitals and primary care centers were invited to participate in a pilot focus group. After this session, they provided feedback on the methodology used and they all agreed that the study aim, instructions, and guidelines were easy to understand as well as reporting satisfaction with the chance to share opinions and experiences.

Data Analysis

Qualitative content analyses of the interview transcripts were performed.[19] Texts were previously read to get a general sense of content. Subsequently, quotations of relevance to the study aim were identified and divided into meaning units. Then, these units were condensed at a descriptive level while taking care to remain faithful to the original text. These condensed forms were then abstracted and labeled with a code. Researchers used the general viewpoints expressed in the sessions as a point of reference during the analytical process, in particular when seeking a deeper understanding of the meaning units and code. To ensure the reliability and quality of data analysis, 4 members of the research team individually compared codes to identify similarities and differences. The overall data analysis process was coordinated by 3 PhD nurses. Three meetings, attended by the 4 nurses with master's degrees responsible for data collection and the 3 PhD nurses coordinating the process, were held to refine the list code and to organize the codes into categories that emerged from the data. Saturation point was reached when no new themes were identified in data collection.[20,21]

Ethical Aspects

Ethical approval was obtained from the institution's legal authority for research on human beings to conduct the study in accordance with national standards and regulations: Ethics Committee, Hospital Clinic, Barcelona (2010/6031). All focus-group participants were asked to provide written consent.

Results

Four focus-group sessions (with 2 types of groups) were conducted: (1) 2 focus groups with 18 people with dementia and family caregivers ($n_{a1} = 10$; $n_{a2} = 8$) and (2) 2 focus groups with 19 health care professionals ($n_{b1} = 9$; $n_{b2} = 10$). Results are explained separately:

People With Dementia and Family Caregivers

Of the participants in these 2 groups, 7 were people with dementia living at home (3 men and 4 women) and 11 were family caregivers taking care of people with dementia either living at home or in a long-term care institution. The mean age of people with dementia was 74.2 years (from 63 to 81), and the mean age of informal caregivers was 78.3 years (from 65 to 92), 7 family caregivers were wives, 3 were husbands, and 1 was a son.

Three categories emerged from analysis of the texts concerning participants' views on dementia care provision: insufficient information provided, specific dementia care needs, and acceptance of long-term care institutionalization (Table 1).

Insufficient Information Provided

Participants explained that people with early-stage dementia usually receive information first from primary care physicians or outpatient clinic specialists. Many individuals described this information, as well as the communication with professionals, as insufficient (Table 1, Quotation 1). One aspect that contributes to this failure of communication and information dissemination, in the participants' opinion, is short visits (Quotation 2) and, consequently, family caregivers are forced to look for information wherever they can (books, online, advice from friends, etc; Quotation 3). Moreover, when people are in a long-term care institution in advanced stages of the illness, the families want to receive information directly from the professionals who take care of their relatives. However, as contact is usually with health care assistants, rather than the physicians or registered nurses who are qualified to provide this information, it does not reach the relatives. Moreover, as mentioned above, the lack of home care visits by health care workers means that information is not provided to people at home on the late stages of the disease nor is information provided on social service availability until it is urgently needed.

Table 1. Examples of Representative Quotations of People With Dementia and Family Caregivers' Focus Groups.

Themes	No	Quotation (representative)
Insufficient information provided	1	"The problem is that if I don't demand information ... I can't know how my mother is if I'm not told anything"
	2	" Doctors have ten minutes available per patient and have to explain to you everything about senile dementia"
	3	"Most of the people surf the internet and look for information"
Specific dementia care	4	"There should be a specialized centre for all these people."
	5	"The fact of going to a specialized institution or to the same healthcare professional, where that person already knows it, reduces the distress of the caregiver."
Long-term care institutionalization	6	"It's hard to remove a person from home. It was very hard for me and I would return him home every single day. It seemed that I was getting rid of him because he would rush me"
	7	"... I visit my husband, I am with my husband in the morning and in the afternoon, everything runs smoothly"

Specific Dementia Care Needed

An aspect that participants highlight is the need for specialized spaces or services for people with dementia and their families (Quotation 4). For instance, people living at home consider the dementia day care centers as an important resource for families, especially in the early stages, because they have the opportunity to share care experiences with others. Another aspect that informal caregivers valued as positive was the caregivers' support group, although there is currently a scarcity of such groups (Quotation 5).

Physicians are usually in charge of diagnoses and pharmacological treatment. Disease monitoring is generally performed by registered nurses and social workers in the primary/community care setting, giving support through home visits or phone calls, and this is deemed positive by most participants. Both people with dementia and informal caregivers like to have a single health care professional as a reference expert over the course of the illness, but this is not always feasible. From the families' perspective, too many health care professionals offering advice on what constitutes the best care can lead to confusion or conflict. Families also feel that hospital admission due to acute conditions, and subsequent discharge, cause a breakdown in the care continuity provided by the primary care center. It is at this point that a health care professional such as care-liaison expert is needed to minimize disruptions to agreed care plans.

Long-Term Care Institutionalization Acceptance

Participants explained that in the advanced stages of dementia, a long-term care institutionalization is the preferred resource as it is considered a positive service for people with dementia and their family members, although some specific cultural aspects make this decision very difficult (Quotation 6). In general, family caregivers value the attention they receive from health care professionals at long-term care institutions although they emphasize that only at home can a person receive personalized care. Another important characteristic of this care context is the fact that the family members feel that they are not reducing their commitment to care of the patient even when they are institutionalized as they continue to visit them for several hours each day (Quotation 7).

Health Care Professionals

Mean participant age in both groups was 41.2 years (ranging from 31 to 53). There were 4 primary care physicians, 4 geriatricians, 2 neurologists, 5 registered nurses (3 primary care nurses and 2 hospitalization nurses), and 4 social workers (2 from primary care and 2 from hospitals). The analysis of the text revealed 3 categories: *Insufficient communication between health care providers, differential information according to disease stage, and home care coordination* (Table 2).

Insufficient Communication Between Health Care Providers

The participants stated that poor communication between professionals and institutions is common when people with dementia change from one provider to another; interrupting the care continuum (Table 2; Quotation 1 and Quotation 2). Participants think that a computerized system to share medical records between health care providers would improve collaboration (Quotation 3). They know these systems exist but their perception is that they are not integrated, and that up-to-date services and a more modern way of handling and exchanging information is needed.

Differential Information According to Disease Stage

Professionals stated that the information given must be matched with the stage of the disease that the person is going through to provide a better response to their needs (Quotation 4). In the early stages of the disease, there are usually more worries and insecurity, so people need to understand what exactly is happening and receive emotional support. Although some professionals explained that care recipients often complain about the insufficient information given on future behavioral disorders and resources or services that will be available (Quotation 5), an aspect that participants highlight as positive is the advance directives document, which should be provided during the early stages of the disease (Quotation 6). This document offers those with dementia and their caregivers the opportunity to make decisions regarding action to deal with future stages of the disease.

Table 2. Examples of Representative Quotations of Health Care Professionals' Focus Groups.

Themes	No	Quotation (representative)
Insufficient communication between health care providers	1	"When the communication is not fluent and there is not feedback everyone does what they want and then we do the same things twice. One says something and another says otherwise."
	2	"We have to work in a multidisciplinary and interdisciplinary way but always in a coordinated way."
	3	"New devices would save time because when you admit a patient you ask them everything again . . . if you already have the data . . . "
Adequate information	4	"I think that the information on this disease and its impact not only on the patient but on the caregiver and the family is very important."
	5	"By giving expectations that are not real you get the patient and family against you immediately."
	6	"I understand that in advanced stages the patient is not able to decide but in incipient stages it is very important that he may make some kind of decisions for their future."
Home care coordination	7	"It's different the person who has an adequate social support, because apart from the public resources that may be present, if there's no family behind, there's no way to control everything."
	8	"The home attention is vital because you better know what's going on beyond the diagnosis."
	9	"The communication between the family and the professionals fails."

Home Care Coordination

Good coordination between the primary care health care team and the main family caregiver is very important when the person with dementia is still cared for at home, so the engagement of the caregiver is essential when developing care plans (Quotation 7 and Quotation 8). Professionals stated that communication between the family and the home care team is sometimes difficult due to the lack of information provided in the early stages of the disease and many participants referred to this during sessions (Quotation 9). Participants explained that there is not enough information regarding possible problems or needs associated with home care of patients with dementia that will arise in later stages of the illness. They also stated that information on services and resources specific to dementia stages is consistently inadequate.

Discussion

Results show that health care and social service systems have several aspects that should be readdressed according to current actual needs. Both groups are in general agreement regarding barriers and facilitators in dementia care provision, and many overlapping aspects have been identified from the 2 types of focus groups studied.

People with dementia and family caregiver profiles reflect the traditions and strength of the family unit in Spain where people with dementia live at home while their families can afford to take care of them and still maintain a relative degree of independence.[22] When the complexity and burden of care or the family situation makes it impossible for the person with dementia to continue living with them, they start thinking about taking him or her to a long-term care institution.[23] This decision is generally hard, and study participants sometimes stated that they have the feeling that they are abandoning a loved one.[24] Although health care professionals came from various care settings and from distinct disciplines, some important health care professionals, such as psychologists and physiotherapists, were missing from those groups. This occurs as these professionals are not usually involved in standard dementia care in Spain unless special interventions are needed or prescribed. International evidence also shows that other professionals' interventions, such as those by case managers,[25] occupational therapists, or liaison nurses,[26] compared well with interventions carried out by physicians or registered nurses. As such, these should probably be reorganized within the health care system.[27]

In Spain, there is still a need for improvements in communication including the use of electronic devices or other IT systems in daily practice, as these have been shown to work in other studies.[28] Moreover, care recipients are aware of the inefficient communication between institutions, and this may affect their adherence or trust. Communication is a dynamic process and prompt, useful, personalized information should be provided throughout the progression of the disease.[29] The main difficulties are seen when specific acute problems appear, and the person being cared for at home needs to be admitted to a hospital. As there are still no well-established care plans linking primary care teams with acute hospitals, the family dynamic can be negatively impacted. Evidence also indicates that family caregivers in Spain are the most burdened compared with other European countries.[30,31] Again, other health care professionals, such as case managers, seems to be very effective in ensuring better collaboration although specific professional training is still lacking in our country.[32] To ensure an adequate response from the health care professions, continuous specialized training has to be a priority within the health care system.[33]

From the categories that emerged, we can say that the informal caregivers still want to assume the carer role, but they are demanding more information and education to manage unexpected situations and avoid unnecessary hospitalizations. This occasionally raises ethical issues: how to determine the appropriate amount of information people should receive and how to enrich patient understanding and involvement.[34] Some current research indicates that several components of self-management, including people with dementia and their family caregivers, have been incorporated into group-based interventions for this population and have been beneficial and effective.[35,36] Health care providers should promote a culture of actively supporting self-management as a normal, expected, monitored, and rewarded aspect of care. Alternative methods of communication between health care professionals and families could be used where appropriate such as consultation by e-mail rather than telephone for simple and nonurgent conditions. Previous studies[37] show that it is a useful addition to the conventional method of consultation, being easy to use and improving communication, although it would not be appropriate for urgent queries, which require professionals to use other methods such as telephone or face-to-face consultation.

Fortunately, there is optimism that the increasing use of new technologies will help to overcome some difficulties in the monitoring of patients and provision of information. Patients, family, and health care professionals highlighted the lack of information and how this leads to deficiencies in care, interruptions to the care continuum, and increased use of emergency services that could have been avoided with effective, early interventions. Community initiatives may also have a role to play in the context of health service budget cuts. Volunteer networks and support groups for people with dementia and their caregivers can complement services provided by public institutions. It is hoped that the evidence contributed by this study will help government and policy makers to target interventions and make information available in the most cost-effective way. It has to be considered that this study was performed in a particular area of Spain, Barcelona, and results may not be completely generalizable due to differences in health care systems. A small qualitative study cannot identify the frequency of each category but rather provides a framework when organizing new dementia care interventions that can be validated in future research.

Considering the barriers and facilitators in dementia care with respect to information provision, communication, and collaboration from the perspectives of the person with dementia, family caregivers, and health care professionals over the course of the illness, our findings suggest that a new practice framework could be implemented to improve the quality of information provided in each dementia phase according to specific care needs. The adoption of new communication platforms has the potential to revolutionize communication and collaboration between health care providers and bring tangible benefits to everyone involved in dementia care.

Appendix A

Focus-Group Interview Guide

(a) People with dementia and family caregivers

1. How are the communication, information, and collaboration between care providers' working in relation to you?
2. Thinking about it as a process and in particular about collaboration, information, and communication, please share your experiences about this process.
3. Thinking about when the service works at its best; tell about situations when it works really well and what characterizes the service.
4. Thinking about when the service works less good; tell about situations when it works not so good and what characterizes the service then.
5. Taking your perspective and having the opportunity to tell the government about how this care should be along the disease process should be carried out—what would you tell them.

(b) Health care professionals

1. How the communication, collaboration, and information between you, as different care providers and between you and the care recipients, is working currently? Think and discuss about it from the phase of diagnosis and until the end-stage of life.
2. Thinking about when care provision and service works at its best; tell about situations when it works really good and what characterizes the service then.
3. Thinking about when the service works less good, tell about situations when it works not so good and what characterizes the service then.
4. Thinking about collaboration, communication, and information, what would you improve between different providers and between you and people with dementia and family?
5. What would you like to see improved to provide very good care and service and really live up to the idea of best practice, in particular in relation to communication, collaboration, and information?

Acknowledgments

We would like to express our gratitude to all the participants in this Focus Group study; the people with dementia, family caregivers, and the health care providers who voluntarily agreed to participate and give accounts of their experiences.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was supported by a grant from the European Commission within the 7th Framework Program (Project 242153), as part of a larger European project, the RightTimePlaceCare, aiming to improve health services for European citizens with dementia.

References

1. Burock J, Naqvi L. Practical management of Alzheimer's dementia. *R I Med J*. 2014;97(6):36-40.
2. Holtzman DM, Goate A, Kelly J, et al. Mapping the road forward in Alzheimer's disease. *Sci Transl Med*. 2011;7(7):114-148.
3. Bass DM, Judge KS, Snow AL, et al. Caregiver outcomes of partners in dementia care: effect of a care coordination program for veterans with dementia and their family members and friends. *J Am Geriatr Soc*. 2013;1377-1386.
4. Brown LJ, Bond MJ. Transition from the spouse dementia caregiver role: A change for the better?[published online June 16, 2014] *Dementia (London)*. 2014. pii: 1471301214539337.
5. Callahan CM, Schubert CC. Dementia: the complexities of comorbidity in dementia. *Nat Rev Neurol*. 2014;10(4):184-186.
6. Kales HC, Gitlin LN, Lyketsos CG. Assessment and management of behavioral and psychological symptoms of dementia. *BMJ*. 2015;350:h369. doi:10.1136/bmj.h369.
7. Risco E, Cabrera E, Jolley D, et al. The association between physical dependency and the presence of neuropsychiatric symptoms, with the admission of people with dementia to a long-term care institution: a prospective observational cohort study. *Int J Nurs Stud*. 2015;52(5):980-987. pii: S0020-7489(15)00059-0. doi:10.1016/j.ijnurstu.2015.02.013.
8. Hallberg IR, Leino-Kilpi H, Meyer G, et al. Dementia care in eight European countries: developing a mapping system to explore systems. *J Nurs Scholarsh*. 2013;45(4):412-424.
9. Jódar-Sánchez F, Martín JJ, López del Amo MP, García L, Araújo-Santos JM, Epstein D. Cost-utility analysis of a pharmacotherapy follow-up for elderly nursing home residents in Spain. *J Am Geriatr Soc*. 2014;62(7):1272-1280.
10. Gil-Gregorio P, Regidor-García J, Arriola-Manchola E, García Navarro JA, Ruipérez-Cantera I. Concerns of the Spanish society of geriatrics and gerontology regarding care received by patients with dementia. *J Am Geriatr Soc*. 2007;55(8):1314-1315.
11. Costa-Requena G, Espinosa Val M, Cristòfol R. Caregiver burden in end-of-life care: advanced cancer and final stage of dementia. *Palliat Support Care*. 2015;13(3):583-589.
12. Hallberg IR, Cabrera E, Jolley D, et al. Professional care providers in dementia care in eight European countries; their training and involvement in early dementia stage and in home care[published online September 2, 2014]. *Dementia (London)*. 2014. pii: 1471301214548520.
13. Carlsen B, Glenton C. What about N? A methodological study of sample-size reporting in focus group studies. *BMC Med Res Methodol*. 2011;11:26.
14. Verbeek H, Meyer G, Leino-Kilpi H, et al. 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.
15. Folstein M, Folstein SE, McHugh PR. Mini-mental state a practical method for granding the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975;12(3):189-198.
16. Gill P, Stewart K, Treasure E, Chadwick B. Methods of data collection in qualitative research: interviews and focus groups. *Br Dent J*. 2008;204(6):291-295.
17. Kress HG, Ahlbeck K, Aldington D, et al. Managing chronic pain in elderly patients requires a CHANGE of approach. *Curr Med Res Opin*. 2014 30(6):1153-1164.
18. Mateos R, Franco M, Sánchez. Care for Dementia in Spain: the need for a nationwide strategy. *Int J Geriatr Psychiatr*. 2010; 25(9):881-884.
19. Moss H, Donnellan C, O'Neill D. A review of qualitative methodologies used to explore patient perceptions of arts and healthcare. *Med Humanit*. 2012;38(2):106-109.
20. Leech NL, Onwuegbuzie AJ. Qualitative data analysis: a compendium of techniques for school psychology research and beyond. *School Psychol Q*. 2008;23(4):587-604.
21. Denzin NK, Lincoln YS, eds.The SAGE Handbook of Qualitative Research. Third edition. Thousand Oaks; 2005.
22. Afram B, Stephan A, Verbeek H, et al. Reasons for institutionalization of people with dementia: informal caregiver reports from 8 European countries. *J Am Med Dir Assoc*. 2014;15(2):108-16.
23. Alvira MC, Risco E, Cabrera E, et al. The association between positive-negative reactions of informal caregivers of people with dementia and health outcomes in eight European countries: a cross-sectional study. *J Adv Nurs*. 2015; 71(6):1417-1434.
24. Saks K, Tiit EM, Verbeek H, et al. Most appropriate placement for people with dementia: individual experts' vs. expert groups' decisions in eight European countries. *J Adv Nurs*. 2015;71(6):1363-1377.
25. Schoenborn NL, Arbaje AI, Eubank KJ, Maynor K, Carrese JA. Clinician roles and responsibilities during care transitions of older adults. *J Am Geriatr Soc*. 2013;61(2):231-236.
26. Aldeen AZ, Courtney DM, Lindquist LA, Dresden SM, Gravenor SJ. Geriatric emergency department innovations: preliminary data for the geriatric nurse liaison model. *J Am Geriatr Soc*. 2014; 62(9):1781-1785.
27. Eggenberger E, Heimerl K, Bennett MI. Communication skills training in dementia care: a systematic review of effectiveness, training content, and didactic methods in different care settings. *Int Psychogeriatr*. 2013;25(3):345-358.
28. Turkal N. The value of robust geriatric programs to integrated health systems. *J Am Geriatr Soc*. 2013;61(6):1022-1023.
29. Salvador-Carulla L, Costa-Font J, Cabases J, McDaid D, Alonso J. Evaluating mental health care and policy in Spain. *J Ment Health Policy Econ*. 2010;13(2):73-86.
30. Verbeek H, Zwakhalen SM, van Rossum E, Ambergen T, Kempen GI, Hamers JP. Effects of small-scale, home-like facilities in dementia care on residents' behavior, and use of physical restraints and psychotropic drugs: a quasi-experimental study. *Int Psychogeriatr*. 2014;26(4):657-668.

31. Bleijlevens MH, Stolt M, Stephan A, et al. Changes in caregiver burden and health-related quality of life of informal caregivers of older people with Dementia: evidence from the European Right-TimePlaceCare prospective cohort study. *J Adv Nurs*. 2014. doi: 10.1111/jan.12561.
32. Iliffe S, Robinson L, Bamford C, et al. Introducing case management for people with dementia in primary care: a mixed-methods study. *Br J Gen Pract*. 2014;64(628): e735-e741.
33. Jaglai S, Cockerill R, Lemieux-Charles L, Chambers LW, Brazil K, Cohen C. Perceptions of the process of care among caregivers and care recipients in dementia care networks. *Am J Alzheimers Dis Other Demen*. 2007;22(2):103-111.
34. Barnes M, Henwood F, Smith N. Information and care: a relational approach[published online March 24, 2014]. *Dementia (London)*. 2014.
35. Zabalegui A, Hamers JP, Karlsson S, et al. Best practice interventions to improve quality of care of people with dementia living at home. *Patient Educ Couns*. 2014;95(2):175-184.
36. Warrick N, Peckham A, Watkins J, Padjen M, Williams AP. Caring for caregivers of high-needs older persons. *Healthc Q*. 2014;17(3):24-29.
37. Kerssens C, Kumar R, Adams AE, Knott CC, Matalenas L, Sanford JA, Rogers WA. Personalized technology to support older adults with and without cognitive impairment living ay home. *Am J Alzheimers Dis Other Dement*. 2015;30(1):85-97.