




Specifics of and training needs in the inter-professional home care of people with dementia

A qualitative study

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Editor's
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Abstract: *Introduction:* Successful home care for people living with dementia (PLwD) allows them to live in their own home environment for as long as possible. Current findings indicate a need for further development of medical and nursing knowledge and skills in evidence-based collaborative care for these patients. *Aim:* To identify specifics of inter-professional care for PLwD and training needs of home care nurses and general practitioners involved in care. *Method:* A multi-perspective qualitative study was conducted, comprising focus groups as well as individual interviews. Focus groups and interviews followed a semi-structured topic guide. Interview data was digitally recorded and transcribed verbatim, followed by a thematic framework analysis. *Results:* The sample consisted of nine nurses, one medical assistant, three general practitioners and nine family caregivers of PLwD. Five themes related to inter-professional home care were inductively developed: challenges in outpatient dementia care, challenges in collaboration, insufficient healthcare infrastructure, competencies needed in dementia care, and training requirements. Challenges were a lacking flow of information as well as continuity and organization of care. Home care nurses and family caregivers complained about missing communication skills in health professionals involved in the care of PLwD. *Conclusions:* The interviews revealed heterogeneous training needs of home care nursing staff and general practitioners that can be addressed by an inter-professional training course.

Keywords: dementia, home care, inter-professional training, qualitative research

Spezifika und Fortbildungsbedarfe in der interprofessionellen Versorgung von Menschen mit Demenz: Eine qualitative Studie

Zusammenfassung: *Einleitung:* Eine funktionierende ambulante Versorgung von Menschen mit Demenz trägt dazu bei, dass die Betroffenen möglichst lange in der eigenen Häuslichkeit verbleiben können. Aktuelle Erkenntnisse zeigen einen Weiterbildungsbedarf von medizinischen und pflegerischen Kompetenzen für eine evidenzbasierte, interprofessionelle Versorgung. *Ziel:* Besonderheiten in der Versorgung von Menschen mit Demenz sowie Fortbildungsbedarfe von ambulanten Pflegediensten und Allgemeinmediziner_innen zu identifizieren. *Methode:* Es wurde eine qualitative Studie mit Fokusgruppen und Einzelinterviews durchgeführt. Alle Interviews folgten einem halbstrukturierten Interviewleitfaden, wurden digital aufgezeichnet, transkribiert und mit einer thematischen Framework Analyse ausgewertet. *Ergebnisse:* Die Stichprobe umfasste neun Pflegende, eine medizinischen Fachangestellten, drei Allgemeinmediziner_innen und neun pflegende Angehörige. Fünf Themenbereiche wurden induktiv abgeleitet: Herausforderungen in der Versorgung, Herausforderungen in der Zusammenarbeit, unzureichende Infrastruktur, notwendige Kompetenzen und Ausbildungsbedarfe. Als Herausforderungen wurden der fehlende Informationsfluss sowie mangelnde Kontinuität und Organisation in der Versorgung identifiziert. Pflegende und pflegende Angehörige kritisierten unzureichende Kommunikationskompetenzen der Allgemeinmediziner_innen. *Schlussfolgerung:* Die Interviews zeigten einen heterogenen Fortbildungsbedarf, welcher durch eine interprofessionell ausgerichtete Fortbildung adressiert werden könnte.

Schlüsselwörter: Demenz, ambulante Versorgung, interprofessionelle Fortbildung, qualitative Forschung

Introduction

Dementia is a clinical syndrome, which predominantly arises in old age due to different aetiologies. It is characterized by the progressive loss of cognitive functions (Kopf &

Rösler, 2013). The care and treatment of people living with dementia (PLwD) entails substantial challenges for all people involved, i. e. PLwD, their family members, as well as caregivers and physicians (Feast et al., 2016). Such challenges arise through disease-related behavioral and psy-

What is already known on this topic?

Health professionals are not sufficiently trained to deliver adequate care for people living with dementia.

What this study adds

This study identified – based on interviews with family caregivers, home care services personnel and general practitioners (GPs) – specifics of inter-professional care for people with dementia as well as training needs in the care for people with dementia in the outpatient setting.

chological symptoms in dementia (BPSD) like aggression, sleep disturbances and restlessness (Kales et al., 2015; Foley et al., 2017). PLwD and suffering from BPSD experience more emotional distress, greater functional impairment, and a reduced quality of life (Kales et al., 2015). Health professionals who are frequently confronted with BPSD report more burden with less job satisfaction (Schmidt et al., 2012). Family caregivers are also burdened; BPSD was reported to be one of the reasons why a PLwD has to move to a nursing home (Toot et al., 2017).

The care for PLwD essentially takes place in primary care (Balsinha et al., 2019) and usually requires a close collaboration between family carers, nursing home care services, general practitioners (GP) and possibly other health and social care professionals. Medical and nursing care aims at maintaining the management of daily activities and organizing the best possible care arrangements for patients and family caregivers (DGPPN, 2016). Because of the complex care needs of PLwD, inter-professional collaboration is necessary to provide the best care based on inter-professional assessment, planning and coordination. Successful inter-professional cooperation is seen as an important determinant for the quality of home care by GPs as well as home health nurses (van den Bussche et al., 2011; Stephan et al., 2015) and may help PLwD to live in their own home environment for as long as possible. Furthermore, to be able to provide care based on patient's individual needs, the involvement of family caregivers is essential (Edvardsson et al., 2008).

However, the choice and planning of therapeutic interventions for BPSD were repeatedly assessed as not being sufficient to provide the treatment and care to the level of current recommendations as they lack a patient-centered focus and involvement of family caregivers (Kales et al., 2015). A disproportionate use of antipsychotics (Masopust et al., 2018) as well as uncertainties in the communication with PLwD and their families (Visser et al., 2020) indicates that health professionals are not sufficiently trained to deliver adequate, evidence-based care, i.e. that they are unable to appropriately integrate “best external evidence with individual clinical expertise and patients' choice” (Sackett et al., 1996, p. 71). Communicating with PLwD has been described as a special challenge for home care nurses (Rüsing et al., 2008; Schaeffer & Wingenfeld, 2008). Moreover, GPs reported uncertainties in the diagnosis, the assessment of type and severity of cognitive impairment, in counselling as well as in dealing with cognitive disorders (Foley et al., 2017; Wangler & Jansky, 2021). Altogether,

these findings indicate a need for further development of both physicians' and nurses' knowledge and skills in the care for PLwD and their families (Wangler & Jansky, 2021). This becomes especially important since in Germany nurse practitioners specialized in the care for PLwD are still rare in contrast to other countries where these specialists play key roles for “increasing the capacity of delivering dementia-capable primary care” (Poghosyan et al., 2021, p. 517). Since all health professionals reported similar uncertainties in fields requiring effective inter-professional cooperation (e.g., assessment and management of BPSD), an inter-professional training course would be appropriate.

The research evidence on inter-professional training programs for dementia care is constantly growing but still insufficient. Systematic reviews revealed a variety of evaluated training programs (Brody & Galvin, 2013; Jackson et al., 2016; Scerbe et al., 2019). These programs differed in learning goals (e.g., dementia knowledge, attitudes), target groups, content (e.g., management of BPSD, effective communication), format, delivery mode (e.g., classroom-based, practice-based), and duration. The methodological quality of the studies allowed only limited conclusions about the effectiveness of the training programs (Brody & Galvin, 2013; Jackson et al., 2016; Scerbe et al., 2019). However, some studies reported more positive attitudes towards working in inter-professional teams. In a systematic review of dementia training programs for GPs, potentially beneficial effects were identified. These related to courses that focused on active, practical, and critical-reflective learning (Perry et al., 2011). None of these studies considered the experiences and perspectives of family caregivers.

As person-centered care is considered to be the best practice choice for PLwD (Edvardsson et al., 2008; NICE, 2018), evidence-based training programs should address professionals' competencies in providing person-centered care (Gustafsson et al., 2021).

Following established concepts of person-centered care for PLwD programs for professionals' competences and sufficiently fit the purpose, the needs and experiences of all ambulatory carers, including the family caregivers, and have to be assessed for the curriculum development (Thomas et al., 2016). Beyond that, the identification of needs and experiences of family caregivers informs the development of goals and objectives for training programs.

Aim

The aim of this study was to identify specifics of inter-professional care for PLwD as well as training needs of home care nurses and GPs involved in the care for PLwD at home, both from the professionals' and family caregivers' perspectives. As a needs assessment, this study should inform the development of a training course for home care nurses and GPs within a third party funded project on inter-professional continuing education in evidence-based care for PLwD (KOMPIDEM-2).

Methods

Study Design

A qualitative study consisting of focus groups with home care nurses and medical assistants working in home care services as well as telephone interviews with GPs was conducted. In order to ensure that patient-relevant aspects of care were considered, interviews with family caregivers of PLwD were also conducted. The reporting of this qualitative study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007).

Participants

We included all health professionals involved in home care: GPs, home care nurses, medical assistants (non-medical health-professionals) (Freund et al., 2015), as well as family caregivers.

Home care nurses had to have at least one-year nursing training and experiences in caring for PLwD to be included. We excluded home care nurses and medical assistants who were either still in training or younger than 18 years. For GPs, no exclusion criteria were applied. Interviews were conducted with family caregivers of people with a confirmed diagnosis of dementia. Family caregivers had to be older than 18 years, had to be important for the affected person and primarily responsible for care in the last 6 months. Family caregivers of affected people who recently moved to a nursing home were also included.

For the recruitment of the participants from the home care setting, all registered home care services in the Lübeck Business Directory were contacted in writing and they were informed about the aim and the content of the study, alongside a detailed explanation on the nature of voluntary participation. Since only a small number responded to the written invitation, they were contacted by telephone. In addition to the invitation, they received a thorough explanation of the background, content and aim of the study. GPs were recruited by contacting and informing all academic teaching practices of the Institute of Family Medicine of the University Hospital Schleswig-Holstein via postal service. All participants were informed about the study, its aim and its content as well as its voluntary participation aspect in detailed writing. Since only a small number of the GPs responded to the written invitation, they were contacted by telephone to invite them to the study and inform them about the content and aim.

In order to recruit family caregivers, information about the study was given in care courses for family caregivers of PLwD at the Patient Information Centre of the University Hospital Schleswig-Holstein, as well as at events of the Alzheimer's Association Lübeck. Additionally, an online ad was placed on www.hl-live.de, which is a free of charge regional news platform.

Written informed consent was obtained from all study participants before starting the interviews.

Data Collection

Focus groups with home care nurses and medical assistants, as well as interviews with GPs were conducted in 2016, followed by interviews with family caregivers of PLwD in 2016 and 2017. Focus groups enabled an open discussion by sharing experiences in a group of people (Bohnsack, 2008). However, individual interviews were less burdening for some of the interviewees with regards to time and other organizational aspects. For the focus groups and interviews, a semi-structured topic guide was developed for each target group. Based on the research aim and question, the guidance addressed the following topics: identification of challenging situations in dementia care, information and communication practices and needs, interprofessional collaboration, training needs, and the expectations of interprofessional training in dementia care. The guide was reviewed by a team of physicians and nursing researchers and eventually piloted in two interviews with family caregivers. As it proved itself to be effective, no further adjustments were made.

Focus groups took place at the University of Lübeck and were conducted by three researchers of the research team (DW, KF, KB). Since one nurse was unable to participate in the focus groups, she was interviewed on her own. Individual appointments for the interviews were arranged by telephone with the GPs and the family caregivers. GPs were interviewed by telephone or face-to-face (KF). Interviews with family caregivers took place at the University of Lübeck and were conducted by two researchers (DW, KB).

The specifics of the study were explained by the researchers before the start of the recording, so that remaining questions could be clarified. All focus groups and interviews were digitally recorded and transcribed verbatim. All researchers who conducted the focus groups or interviews had formal degrees in a health profession (DW: advanced nursing practice, KB: nursing, nursing education and nursing science, KF: physician) and are experienced in caring for PLwD. They were also involved in further nursing and health service research projects focusing on care for PLwD and /or inter-professional collaboration.

In addition to the focus groups and interviews, sociodemographic characteristics of participants were collected using a standardized questionnaire.

Data Analysis

A thematic framework analysis was conducted, including the following steps: familiarisation with data, identifying a thematic framework, indexing, charting, and interpretation (Dunger & Schnell, 2018). To get familiarised with the data and early themes, researchers read all transcribed data line by line. After coding the first transcripts, identified key themes were compared within the research team. The thematic framework was applied to index remaining transcripts based on the developed categories. Subsequently, categorised data was charted into a matrix, and finally,

data was interpreted by relating themes and topics (Dunger & Schnell, 2018). Two researchers analysed the transcripts independently following this stepwise approach. Themes and subthemes were generated inductively by each researcher. Intermediate results were compared regularly throughout the analysing process until consensus was reached. In a final step, the research team compared all categories of the three cohorts (home care nurses & medical assistants, GPs, and family caregivers of PLwD), looking for similarities and differences within the data. For publication, the participant quotations were translated from German into English.

Data analysis was performed using the software MAXQDA 2020.

Results

Description of the Study Sample

In total, the study sample consisted of nine home care nurses and one medical assistant from eight different home care services. Two focus groups (FG 1.2016 with five participants, FG 2.2016 with four participants) with eight home care nurses and one medical assistant took place in April 2016 (mean duration 70 minutes) and one telephone interview with a nurse took place in May 2016 and lasted 25 minutes. The characteristics of all participants from the focus groups and the telephone interview are shown in Table 1.

In addition, telephone interviews with GPs ($n = 3$) were performed from March to April 2016. The interview duration varied between 20 to 56 minutes.

Interviews with family caregivers of PLwD ($n = 9$) were conducted from November to December 2016 and March to April 2017. Interview duration varied between 20 to 76 minutes.

Presentation of Themes

Five themes were identified across the focus groups and individual interviews, namely “challenges in outpatient dementia care”, “challenges and specifics within collaboration”, “insufficient healthcare infrastructure”, “training needs and essential competencies in dementia care” and “requirements on training courses” (see Table 2). In the following, the themes and sub-themes will be explained in more detail.

Challenges in Outpatient Dementia Care

GPs felt challenged in the care for PLwD as the care was described as more complex and requiring more time and patience. If there was a suspicion of dementia, the first contact was often not with the person themselves, but rather with family members. As a result, GPs perceived themselves as being exposed to difficult situations, often associated with conflict potential when the PLwD felt that

everything would be alright. GPs stated they were often expected to act as a sort of judge, for example if the decision arose whether the person living with dementia was still allowed to drive or not.

A major problem for home care nurses was the enormous time pressure, which often made it difficult to respond appropriately to BPSD. It got even more difficult if there were no family members to serve as a primary contact person and instead only legal guardians were available. However, home care nurses always had to be mindful of family caregivers in order to recognize signs of overburden. Family caregivers often felt forced to become defensive when this was communicated to them by home care nurses.

GPs and home care nurses reported that they were often confronted with angry and aggressive behavior from patients. Rejecting behavior (e.g., rejection of body care) was not a rare phenomenon.

Moreover, communication with the affected person as well as with family caregivers was experienced as difficult and challenging by GPs and home care nurses.

Challenges and specifics within Collaboration

Home care nurses, GPs and family caregivers reported different challenges with collaboration.

Home care nurses indicated that they would like to get more help from GPs. They particularly pointed to difficulties in their work due to lacking diagnosis with regards to the type and severity of dementia. The statements of home care nurses revealed a distinct desire for clear expert medical advice from GPs. Altogether, the collaboration with GPs was described as successful.

Table 1. Characteristics of participants in focus groups and telephone interviews

Nurses and medical assistants ($n = 10$)	
Gender (female)	9
Age in years, Mean (SD)	42,2 (11,0)
Profession	9 registered nurses (3 head nurses) 1 medical assistant
Work experience in years, Mean (SD)	9,5 (9,5)
Training in dementia care	6
General practitioner ($n = 3$)	
Gender (female)	1
Specialist in family medicine	3
Teaching practice	3
Additional qualification	2 Acupuncture 1 Anaesthesia
Family caregivers ($n = 9$)	
Gender (female)	8
Formal relationship	8 daughter/son 1 spouse
Type of care	5 nursing home 1 home care 1 family member 1 day care

Table 2. Themes and sub-themes

Themes	Sub-themes	Perspective	Anchor examples
Challenges in outpatient dementia care	More time and patience needed	General practitioner	"You need more patience and more time. That's what I think is the challenge. Patience with yourself and with the patient [...]" (T1 2.2016).
	Dealing with aggressive behaviour	Nurses	"[...] You do not have the time you really want to have" (FG 2.2016).
		General practitioner	"Of course it happens that patients sometimes forget things and then [...] become aggressive" (T1 2.2016).
	Lack of disease insight	Nurses	"So the biggest problem and the biggest difficulty is when people living with dementia are aggressive" (FG 1.2016).
		General practitioner	"It's difficult to address the topic. Even to use the word dementia. Patients do not really want to hear this [...] and are very afraid. That's a special situation for us" (T1 1.2016).
	Dealing with family members	General practitioner	"The main challenge is, of course, that we usually do not have the first contact with the person living with dementia, but rather with family members. So that means that we are [...] in such a special constellation" (T1 3.2016).
	Needs for individual approaches	Nurses	"And we also have to point out that family members are overburdened. Especially spouses tend to overestimate and overwhelm themselves [...]" (FG 2.2016).
		General practitioner	"That means we have a lot of different solutions. And therefore there is no standardised course of action" (T1 3.2016).
		Nurses	"General practitioners write 'dementia'. All these different forms of dementia [...] which would also be an important information for us [...] is not considered at all" (FG 1.2016).
	Lack of coordination and communication	Family caregivers	"Too little time. Lack of communication and coordination with each other" (T1 4.2017).
Challenges and specifics within collaboration	Role of family members	Nurses	"If somebody goes home from hospital, we try to contact the social service before the patient is released to home, because there is a lot of information lost" (FG 2.2016).
		General practitioner	"They already play a big role. Well, it often is the case that not the patient is coming, but a family member" (T1 1.2016).
	Collaboration with general practitioner	Nurses	"I think, the care stands and falls with the family members [...]" (FG 1.2016).
		Nurses	"Often, there are no family members or anybody, but only a legal guardian" (FG 2.2016).
		Nurses	"I wish clear expert medical knowledge from the general practitioner, because the fact is that family members are extremely vulnerable to health. General practitioners have to keep an eye on it because [...] under certain circumstances, family members go directly into a depressive episode" (FG 1.2016).
	Role of medical assistants	Family caregivers	"He always talked so much, my mother didn't understand what he had said" (T1 3.2017).
		General practitioner	"Very often, medical assistants are almost more psychological guardian than we as general practitioners, you have to say honestly, because they are... my medical assistants are here for 20 years or more and of course, they also know the patient at the time when they weren't cognitive impaired..." (T1 2.2016).

Table 2. Themes and sub-themes (continuation)

Themes	Sub-themes	Perspective	Anchor examples
	Collaboration with neurologists	General practitioner	"So, the neurologists are still mixing around ... a lot, that's why I am so impressed" (T1 2.2016).
		Family caregivers	"That's just a deficit. General practitioners do not know things exactly, same with the neurologists, that's my experience" (T1 3.2017).
	Collaboration with hospitals	General practitioner	"I think that works well, but that is clearly the commitment of the colleagues from the hospital, who make a short call" (T1 2.2016).
		Nurses	"The collaboration between hospitals and general practitioner [...] it takes too long until the diagnosis or the findings from the hospital arrive at the general practitioner [...]. I think this is very difficult" (FG 2.2016).
		Family caregivers	"I just think there is little time and not enough staff" (T1 7.2017).
Insufficient healthcare infrastructure	Communication between home care services and general practitioners	General practitioner	"Because of the fluctuating staff, that's our experience. Even if you make an appointment for those with a home visit [...] that works not really good" (T1 3.2016).
	Lacking information	Family caregivers	"Actually, from the health system, no information is given, as one should presume" (T1 2.2017).
	Lacking dementia network	General practitioner	"If we, let's say, had a dementia network, uh, which is specifically responsible for home care with certain issues, then I think that would be a very, very big relief" (T1 1.2016).
		Nurses	"[...] we do not have such a network, so no competent support we can call" (FG 2.2016).
	Lacking guide including relevant information	Family caregivers	"Well, that would be good in any case, if there would be build such a network of people who have experiences" (T1 7.2017).
Training needs and essential competences in dementia care		Family members	"If the diagnosis is made, then there should be a sheet of paper that describes point by point what to do, a step chart" (T1 2.2017).
	Sufficiently trained	General practitioner	"Well, honestly, I do not find it difficult" (T1 3.2016).
		Nurses	"All (colleagues) feel well prepared. Nevertheless, I would like to send more to specific training courses" (T1 2.2016).
		Family caregivers	"And what I bothered was when the general practitioner came and diagnosed something, my husband still understood things, but the general practitioner always addressed only me. Him, I don't want to say he ignored him, but he treated him like a child" (T1 7.2017).
	Empathy and attention	General practitioner	"After all, we need time and attention [...] That's not a hocus pocus" (T1 2.2016).
Training requirements		Nurses	"Actually, you have to say, this isn't witchcraft" (T1 3.2016).
			"I think it has a lot to do with interpersonal understanding. How empathic an individual is" (FG 1.2016).
	Interprofessional training	General practitioner	"Yes, of course!" (T1 2.2016).
		Nurses	"I think, it makes sense to team up with the general practitioner, everyone is in the same boat" (FG 2.2016).
	Criteria for participation	General practitioner	"I have to have time, of course" (T1 1.2016).
	Criteria for good training	General practitioner	"Someone who really explains some new things, or tells cases in the field that may not be in guidelines or anything like that" (T1 3.2016)
	Low costs	General practitioner	"So, to be honest, it should be a matter. De facto, it plays a role!" (T1 3.2016).

GPs described the collaboration with neurologists diversely. One said the collaboration worked smoothly, while another reported problems, mainly through prescribing additional medication that would lead patients back to the GPs with side effects, to which the neurologists objected.

GPs mentioned the staff turnover as a reason for a non-successful cooperation with home care services. To ensure good cooperation with other actors in the care process, a lot of time had to be invested by all health professionals involved (e.g., to organize case discussions). With regards to communication with hospitals, GPs did not mention any problems, while home care nurses indicated that information often got lost in the discharge process. They also noted that it usually takes a long time before findings and diagnoses were available to the GPs.

Both the GPs and the home care nurses emphasized the key role of family caregivers in the process of medical care. They reported that they often had more contact with the family caregivers than with the PLwD.

Family caregivers described the care in the hospital as problematic and unsatisfactory. Due to the lack of time and staff, only standard care was delivered. Additionally, family caregivers felt that hospital staff is not adequately trained in dementia care. They also experienced the communication with GPs as being difficult. They reported that GPs often use a lot of medical terms and convey so much information, that it becomes impossible for the affected to understand what GPs say. Similar experiences were described for the communication with neurologists.

Insufficient Healthcare Infrastructure

Home care nurses, GPs and family caregivers complained about the insufficient healthcare infrastructure, detected a lack of information and recommended the establishment of a dementia network.

Family caregivers stated that they had not received any information regarding the care for their family members living with dementia from the GPs or the health insurances. Necessary information was only received upon their own initiative. Family caregivers would have liked to receive a guide directly after the diagnosis of dementia was made, including all relevant and important information (e.g., possibilities for support, applying for financial support).

GPs and home care nurses agreed on the need for more time and improvements in the contextual conditions for home care when asked about requirements that would allow PLwD to stay in their own home environments for as long as possible. GPs, home care nurses and family caregivers discussed that a dementia network would be helpful.

Training needs and essential competences in Dementia Care

Home care nurses and GPs referred to necessary competences in dementia care and gave insights if they feel sufficiently trained. Family caregivers expressed their views about GPs' training needs in dementia care.

GPs said that only time, patience and empathy are needed to ensure adequate care for PLwD. They stated that

they had not attended a training course on dementia. Home care nurses stated that empathy plays a very important role in the care process as well as person-centered care. Both GPs and home care nurses felt well prepared for the care for PLwD; home care nurses pointed out the importance of regular training.

However, family caregivers reported that they had experienced the communication skills of GPs and other medical specialists as particularly problematic. For example, they remembered that physicians stopped speaking with the person living with dementia when the dementia diagnosis was made. Even in the presence of the person living with dementia, they only communicated with the family caregivers. Family caregivers thought that these experiences were not only due to a lack of time, but a lack of skills and competences.

Requirements on Training Courses

For the GPs, the most important attribute of a training course would be the length of time the course lasts. They stated that a mix of theory and practice would be very important as well as the use of case studies beyond the content of published guidelines. An inter-professional design would be welcome. However, one of the GPs said that he would never attend dementia training, regardless of its design.

Regular training in dementia care was considered as very important by home care nurses because they would need to develop competencies to respond appropriately to so-called challenging behaviors. All home care nurses said they had already completed such training and an inter-professional training would be very welcome.

Discussion

Different challenges for PLwD have been identified in home care, such as the need for more time and patience, the importance of individual approaches, dealing with aggressive behavior appropriately, missing insight into the disease and involving family caregivers. These problems have already been described in international reports and guidelines (NICE, 2018; Unwin et al., 2019).

One important issue addressed by GPs, home care nurses and family caregivers relate to an insufficient flow of information as well as fragile continuity and organization of care. One possibility to counteract this problem was already suggested by the interviewees, namely the establishment of dementia networks as well as the development and adaption of a guide, which is handed out to patients and family caregivers after confirmation of the dementia diagnosis. The advantages of such networks have already been described in the literature (Nieuwboer et al., 2017). Regional resources and initiatives should be synchronized with each other and made visible to relevant target groups.

A lack of differential diagnostics and medical information about treatment options turned out to be another critical point in medical care for PLwD, especially in the views

of the family members and the home care nurses. Both groups reported that dementia diagnosis is not always described precisely with regards to type and severity of dementia. This problem has been reported in another study before (Nygaard & Ruths, 2003). Home care nurses and family members articulated a need for better information about medical diagnosis, including type and severity of dementia as well as the treatment. This is seen as a major problem in collaboration with GPs. In contrast, GPs reported difficulties to ensure good cooperation with home care services because of frequent staff turnovers in these care teams.

To diagnose dementia at an early stage or to recognize cognitive abnormalities at the beginning of cognitive impairment, it is necessary for there to be a good cooperation within the medical team (Thomas, 2010). This was also confirmed by our study as GPs stated that medical assistants are very important in this regard. However, experiences of home care nurses as well as family caregivers also indicate that GPs and other medical specialists are not adequately prepared and trained to deal and communicate with PLwD. In contrast, GPs reported no lack of knowledge and no further training needs. This contradicts with other statements they made in the interviews, where they described difficulties and challenges in the communication with affected people and family caregivers. Previous studies suggested that GPs are definitely aware of educational needs in dementia care and are willing to engage in further training (Foley et al., 2017). Recent findings have shown that primary care physicians feel challenged by dementia care and insufficiently prepared by formal education to adequately care for PLwD (Lee et al., 2020).

In comparison, home care nurses in this study considered regular training in dementia care as very important for themselves. Similar results were found in a survey on dementia training needs among staff at community-based outpatient clinics, where home care nurses also reported to be interested in improving knowledge and competencies about dementia care (Adler et al., 2015).

Generally, inter-professional training opportunities were appreciated. Especially home care nurses and family caregivers would welcome this, which is complemented by findings from seminar planning in palliative care (Becker et al., 2010). Findings of this qualitative study can be used as a basis for the development of inter-professional dementia training.

The training should aim to incorporate the necessity to understand the information and decisions of other professions, the knowledge on common challenges in the care process, as well as a patient- and family-centered collaboration (Frost et al., 2020). The training courses should address professional and inter-professional care processes, recommendations for reducing BPSD, regional care services, perspectives of family caregivers as well as inter-professional communication.

Although this study addressed challenges of PLwD at home and training needs of health professionals involved in home care, results are also important for professionals

in other settings, e.g., hospitals. Because of the complex care needs of PLwD, effective inter-professional collaboration is necessary in all settings and all health professionals involved in care for these persons and their families need to be sufficiently trained to deliver adequate person-centered care. Furthermore, the findings indicate a need for improvements in the professionals' communication across different settings to ensure the safety and effectiveness of transition processes. Therefore, the results of this qualitative study provide important information for practice development and continuing education in the care for PLwD at various settings.

Strengths and Limitations

A strength of this study is that the focus groups and individual interviews were conducted and analysed by independent researchers to minimize the risk of bias. Furthermore, a multi-stage analysing process was carried out and each step was discussed by the research team. Another strength is the heterogeneity of home care nurses and family caregivers, as well as the multi-perspectivity of the study. Limitations can be seen in the relatively small study population, especially with the small number of GPs. The results have shown that GPs identified less of a need for action in dementia care than their colleagues in home care and the family caregivers and with a larger sample size that may not have been the dominant view.

Although it cannot be guaranteed that data saturation has been reached, this study provides important insights into the views of the health professionals involved in outpatient geriatric care.

Conclusions

This qualitative study identified specifics in home dementia care, comprising patient care itself, collaboration, insufficient infrastructure, essential competencies, and training requirements. This study reveals that all partners in home care agreed that they were all missing knowledge of existing resources and regional initiatives which needs to be addressed. Furthermore, there are uncertainties in communication with patients and family caregivers and the mutual collaboration between collaboration between all parties involved in the care for PLwD needs to be improved.

Based on the results of this qualitative study, a core curriculum for an inter-professional training course in "Evidence-based home care for people with dementia" was developed and piloted. This curriculum targets home care services personnel and the primary care team. It includes major learning outcomes, content descriptions and recommendations for teaching and learning methods. It enables health professionals, especially home care nurses, nurse and medical assistants and GPs, to provide evidence-based person-centered care for PLwD.

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Ethical Approval

The study was approved by the ethics committee of the University of Lübeck on 4 February 2016 (Aktenzeichen 16–016).

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What was the biggest challenge in your study?

The biggest challenge was the recruitment of study participants.

How could the topic be developed in the future?

We would like professional collaboration to be taught during the training, preferably in an interprofessional approach.

What further reading do you recommend?

Utley, J., Mathena, C. & Gunaldo, T. (Eds.). (2020). *Interprofessional Education and Collaboration: An Evidence-Based Approach to Optimizing Health Care*. Champaign: Human Kinetics.