Title:

Providing dementia care using technological solutions: An exploration of caregivers’ and dementia coordinators’ experiences

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ABSTRACT:

Aim and objectives: To explore the experiences of caregivers of persons with dementia and dementia coordinators regarding their collaboration in care for a person with dementia and the feasibility of using technology in this collaboration.

Background: Caregivers of persons with dementia have a significant risk of developing physical strain and psychological stress due to caregiver burden. Internationally, the use of technology is rapidly evolving in healthcare. Dementia coordinators employed in municipalities in Denmark support caregivers of persons with dementia, thus helping management of life with dementia. The cooperation between dementia coordinators and caregivers is essential, and the use of technology in everyday life is inevitable.

Methods A qualitative, exploratory, descriptive design was used. Data were derived from five focus group interviews in which 13 caregivers and 14 dementia coordinators participated. The participants’ narratives were used to elucidate their experiences and attitudes, and data were analyzed using thematic analysis. The study reports according to the COREQ checklist.

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**Results:** The analysis revealed three themes: the need for creating a safety net in everyday life, the need for moving together in the right direction, and the need for handling technology while preserving relational interaction.

**Conclusions:** Technology might be used as a mediator to help ease some caregiving tasks or the burden of caregiving. However, technology is an area in which the caregivers must rely on their competences and initiatives. Even though the collaboration between caregivers and dementia coordinators was beneficial and supportive, dementia coordinators experienced technology as outside the core elements of their daily work.

**Relevance to clinical practice:** We suggest further discussion regarding who is best suited to support caregivers in making choices regarding which technologies to implement in caring for a person with dementia. If this discussion is not taken seriously, there is a risk of leaving caregivers in a technological quagmire.

**What does this article contribute to the wider global clinical community?**

- In the context of caregiving for people with dementia, technological solutions can be useful as tools in providing person-centered care suited to the individual patient’s physical and cognitive level of functioning.
- Dementia coordinators are willing to use new technological solutions. However, education is needed to keep up with the rapidly evolving developments in this field.
- The nursing profession initiates a discussion regarding who should be updated on possible technical solutions, and who is best suited to support caregivers in making choices regarding which technologies to implement concerning their family member with dementia.
**Keywords:** Dementia, caregiver, caregiver burden, nurse, health personnel, technology, experiences, attitudes, person-centered care.

**INTRODUCTION**

Caregivers of people with dementia have a significant risk of developing both physical and mental health-related stress due to the caregiver burden (Brodaty & Donkin, 2009; Fonareva & Oken, 2014; Gibbons et al., 2014; Papastavrou et al., 2007). Internationally, the use of technological solutions is rapidly evolving in healthcare. Dementia coordinators employed in municipalities in Denmark support caregivers of people with dementia, thus helping in managing life with dementia. This study explores dementia coordinators’ and caregivers’ experiences of their cooperation in caring for a person with dementia and the feasibility of using technology in dementia care.

**BACKGROUND**

As the demographic changes in Europe and the elderly population grows, there is a corresponding increase in the number of people diagnosed with dementia (OECD, 2018). This exerts increased pressure on healthcare services, which require new solutions (Embracing Carers, 2017; Frahm-Falkenberg et al., 2016; Moyle, 2019). Technology in the field of dementia care is in rapid development and is already assisting people with dementia to live a meaningful and fulfilling life with their disease (Astell et al., 2019; Fast, 2019). Technology as a concept, in general, is so extensive that it cannot in a short way be defined in this article. However, technological solutions have been used in the healthcare sector at least from the time of Florence Nightingale when she looked at the wounded soldiers with a lamp in her hand to be able to see better (Friis & Crease, 2015). Today, technological solutions play a central role in several nursing tasks, and nurses have developed new ways of communicating with and supporting patients and their caregivers.

Information and communication technology (ICT) is difficult to define since the term is evolving rapidly. However, ICT can be considered as the use of existing digital technology to help individuals and organizations use information (Rouse, 2019). It is an umbrella term that includes any communication device or application, as well as the various services and applications associated with them (Meiland et al., 2017). Many other assistive technologies (ATs) are present in the daily lives of people with dementia and their caregivers. AT refers to devices or systems that
help maintain or improve a person’s ability to do things in everyday life. ATs can assist with a range of difficulties, including problems with memory and mobility (Meiland et al., 2017). AT can be categorized as safety, health, or enhancing. Safety: AT enables people with dementia to live as fully as possible without putting themselves or others at risk. Health: AT supports people in their efforts to manage, assess, and treat co-morbidities and improve health outcomes. Enhancing: AT covers devices or apps to improve the quality of life of people with dementia (Meiland et al., 2017).

Caregivers of persons with dementia provide the largest share of care and thus substantially support the established healthcare system in relation to the economic costs associated with care (Prince, 2015). While caregivers are taking on an increased share of the social cost of dementia care, their health is suffering as a result of their role as caregivers, and this deserves attention (Fonareva & Oken, 2014).

Caregivers of persons with dementia often become patients themselves due to the stress encountered in caregiving because of a negative impact on their health (Brodaty & Donkin, 2009). A large number of caregivers of persons with dementia are highly burden (68%) and report depressive symptoms (65%) (Papastavrou et al., 2007). Thus, depression is a major consequence of caregiving. It may persist even after the institutionalization or death of the care recipient (Wright et al., 1999). Stress and depression in a family caregiver may even be the triggering cause for the transfer to a nursing home of the person being cared (Fjelløtun et al., 2009).

At the early stage of caregiving, caregivers of persons with dementia are often not aware of the support they can receive, and their need for support remains unrecognized by healthcare and social service professionals (Peel & Harding, 2014; Singh et al., 2014; Stephan et al., 2018). Social services presently available for family caregivers do not seem to ease the consequences of the negative well-being experienced by caregivers (Verbakel et al., 2017). A Danish survey concluded that three out of four family members think that caregiving for a person with dementia has affected their health negatively and four out of ten reports that being a caregiver have an impact on their working life (Alzheimerforeningen, 2020).

Many studies have focused on the older spouses of people with dementia who live with them in their own houses compared to the group of middle-aged caregivers who are still working and who are typically children or a daughter- or son-in-law of the person with dementia. This group of caregivers typically has their own teenage children, jobs, and careers as well as an active leisure life (Huis In Het Veld et al., 2018). It is a group of caregivers who often have multiple responsibilities, particularly if the parent with dementia is single or if both parents are fragile and
therefore needs support in everyday life (Jansson et al., 1998). There may be varying attitudes and understanding of the disease among the family members of the person with dementia, which may give rise to conflicts internally in the family and result in stress and psychological pressure on the caregiver (Tatangelo et al., 2018).

Healthcare systems worldwide are resource-constrained to such an extent that there is increasing pressure on the caregivers in the form of many ad hoc tasks that are not handled by the professional health system or handled only after the caregiver has been involved for a long period (Grigorovich et al., 2016; Jansson et al., 1998; WHO & Alzheimer’s Disease International, 2012).

Support with daily living, navigating the healthcare system, emotional support, and coping strategies have been emphasized as important issues for family caregivers (Etters et al., 2008), as well as the partnership between health professionals and family caregivers (Brodaty & Donkin, 2009). The dementia coordinator in Denmark is typically a nurse trained at the diploma level to carry out the coordination of these tasks and is usually the first healthcare employee to contact the family when the diagnosis of dementia is made. The collaboration between the dementia coordinator and the family develops and continues throughout the disease process, making the dementia coordinator the family's closest contact and a key figure in the healthcare system (DKDK, 2020).

In Denmark, 92% of older people use the internet regularly and are the highest digital users in the European Union (Jensen, 2019). A number of technological solutions exist in helping the caregiving of people with dementia, for example, GPS-enabled tracking and calendar- and life-story-saving apps (Fast, 2019). Telehealth can support caregivers, facilitate significant improvements in caregivers’ coping and positively affect the care of chronic disease in the home because it combines elements of education, consultation, psychological therapy, social support and clinical care (Chi & Demiris, 2015). The current study focuses on the mutual collaboration between the dementia coordinators and middle-aged caregivers, and their experiences and attitudes toward involving technology in care.

AIM OF THE STUDY

To explore the experiences of caregivers of persons with dementia and dementia coordinators regarding their collaboration in caring for a person with dementia and the feasibility of using technology in this collaboration.

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METHODS

Design

A qualitative, exploratory, and descriptive design was used in this study. To study the dementia coordinators’ and caregivers’ experiences and attitudes, focus group interviews were conducted, inspired by the methods described by Halkier (Halkier, 2016). Focus group interviews were used to facilitate dialogues between the participants; hence, the aim was to explore the topic as widely as possible and collect data that showed the groups’ interactions, standards, and interpretations without reaching for consensus on the topic (Barbour, 2018). At first, the participants told their own stories, followed by an open discussion on different experiences and attitudes of the possibility of using technology in dementia care. We also used a small component of the action research method. Action research is characterized by research with actors in the field of practice (Bradbury, 2015). A recommendation from the dementia coordinators on the age of the family caregivers was decisive for the inclusion criteria. In this way, the dementia coordinators became co-determining and thus co-researchers in this field. After transcription of the interviews, thematic analysis guided by the recommendations of Braun and Clarke was used to interpret the data (Braun & Clarke, 2006, 2018). In the thematic analysis, repeated patterns across the dataset were searched for. These were coded and analyzed, and themes were derived inductively from data. This study was guided by Tong et al. (2007) with Consolidated criteria for Reporting Qualitative research checklist (Supplementary File 1).

Participants

Dementia coordinators and caregivers of people with dementia living on the Danish island of Zealand (Capital Region and Region Zealand) were asked to participate. Dementia coordinators were included by identifying them on each municipality’s website. An email was sent to 34 dementia coordinators with an invitation to participate in a focus group interview together with brief information on the study. Eighteen dementia coordinators responded positively and were included. The response from the dementia coordinators was followed up by a personal mail or a phone call from the first author thanking them for their positive response. On the day of the focus group interviews, there were four cancellations due to illness. Fourteen dementia coordinators participated. All 14 were women. There were ten nurses, three nurse assistants, and one psychologist. All 14 dementia coordinators had postgraduate education equivalent to diploma level.
The mean age of the group was 54 years (range 34–63 years), and the average experience of working within the dementia area was 14½ years (range 2–25 years).

Three focus group interviews were conducted with the dementia coordinators. One interview was with six participants and two with four participants. The composition of the groups depended solely on the participants’ ability to participate on the day of the interview.

During the interviews with the dementia coordinators, they pointed out that caregivers in the age range of 28–68 years were an active group of caregivers eager to learn about technological solutions. This led to the inclusion criterion that caregivers should be within this age range. Another inclusion criterion was that the participants were to be either child or spouse of a person with dementia. The dementia coordinators circulated invitations to the caregivers they had contact with and who met the inclusion criteria. A total of 16 caregivers signed up as participants. One was excluded because of age, and two participants canceled on the day of the interview due to other activities. Two focus groups were conducted with the 13 caregivers, one with seven and one with six participants. Both groups included spouses, sons, and daughters, and the mean age of the group was 54 years (range 30–64 years). This mix made the group dialogues dynamic.

Data collection

The interviews were conducted at three different hospitals placed in the two regions to meet the dementia coordinators and caregivers as locally as possible. The interviews were conducted in isolated meeting rooms to avoid interruptions. A semi-structured interview guide was used. An open-ended question started the interview: “What are your tasks as dementia coordinators /caregiver? ” and “What experiences do you have with your role as dementia coordinator /caregiver? ” The open-ended questions were intended to invite the participants to elaborate on their experiences. To keep the discussion focused, specific questions were sometimes asked. To inspire the participants to think broadly on the subjects of ICT and AT, a collage of pictures including various items from the field (e.g. personal computers, cell phones, tablets, electronic calendars) was shown to the participants during the interview when the focus shifted to this topic. In order to maintain a conversational tone during the discussions, the interviewer had memorized the questions in the interview guide. Furthermore, the interviewer was conscious about being present, listening, and appreciative, to help the participants feel safe and comfortable (Kvale & Brinkmann, 2015). An interview guide was developed within the research group. To be open-minded during data collection, the research group shifted roles. This allowed peer feedback and invited reflection on
how the interviews could be conducted. The interviews were audiotaped and transcribed verbatim by the first author.

**Ethical considerations**

This project was approved by the Danish Data Protection Agency (D.nr.: P-2019-316). It was performed in accordance with the ethical guidelines of the Nordic Nurses’ Federation and the Helsinki Declaration (Northern Nurses’ Federation, 2003). The regional ethics committee stated that approval was not needed because the study was not biomedical. The participants were given written and verbal information about the project and informed consent were obtained. They were informed about anonymity and reminded that withdrawal from the interview was possible at any time. To ensure confidentiality, names, and other personal information were anonymized.

**RESULTS**

Three main themes were identified: 1) The need for creating a safety net in everyday life 2) The need for moving together in the right direction, and 3) The need for handling technology while preserving relational interaction.

**The need for creating a safety net in everyday life**

Dementia coordinators described their work as diverse due to the many focus areas within everyday (work) life. These included counseling and guidance of patients and caregivers, home visits, follow-up after diagnosis, information on the services of the municipality and support in connection with clarification of work situations and the future. In addition, emotionally demanding conversations were identified as essential parts of the workload, and the dementia coordinators pointed out that they often found themselves in the midst of a family crisis where they came as problem solver. A dementia coordinator described it like this: “You are always a little wet on one shoulder. There are always traces of someone who needed a shoulder to cry on” (D1). The dementia coordinators were convinced that they constituted a major support for the individual family. The interviews included words like, "They feel that we are their lifeline" (D1, D2), "We provide confidence and security" (D1, D2) and "we are helping to show the way" (D2, D4). They also emphasized that their approach to the patient was crucial to contact with the family. The importance of a person-centered approach was exemplified by "respectful and equal communication" (D1, D3) as well as "giving time and space for the person with dementia to tell what they have in mind” (D2, D3). Administrative tasks

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including legal issues such as legal guardianship and use of force, visitation tasks, and coordination of the efforts in relation to families and staff were discussed. The expert role and being a professional leader in the field of dementia entailed supervision of both the families as well as other healthcare professionals, while also having a role as coordinator or leader in the municipality's many projects within the dementia council. A dementia coordinator described her job as follows:

"I usually have a picture (in my head) of a spider with arms dangling out on all sides because all those sitting at the ends of these dangling arms have a share in the function that I perform" (D5)

As the caregivers described their situations, it was obvious that they were in a difficult situation. They discussed how practical tasks and caring had been overloading them with responsibility and daily work because of the gradual loss of function and cognitive decline of their relative with dementia. Hence, dealing with the practical running of the home, exemplified in tasks such as shopping, cooking, cleaning, laundry, small repairs, changing light bulbs, fixing remote controls, gardening, and so on. At the same time, it was a major task to be the closest contact person in relation to appointments with the social and healthcare system, for example, appointments at the hospital, dentist or bank. Many of the caregivers had to be legally approved as proxies and guardians, which also took up a lot of effort and time. There were so many practical tasks which themselves were time-consuming and strenuous. All stated that it was a demanding endeavor to maintain their jobs and looking after the family member with dementia simultaneously. Some had given up and opted for early retirement from their formal employment. A spouse said:

"... 1½ years ago I had to quit my job, because now he couldn't be alone anymore ... I was otherwise very happy with my job ..." (C4)

A daughter added:

"There are no relatives other than me. So, I feel a little pressured, actually ... I quit working last year ... because I couldn't be in full-time work and at the same time look after a parent with dementia." (C13)

However, it was the emotional and psychological impact of the situation which seemed to weigh most heavily on the caregivers. They described how the experience of helping a person who is becoming increasingly helpless means that the caregiver must take the role as the parent of the family member. A spouse said about her husband:

"... You've just got an extra child, because you're on all the time ... you're on 24/7, right?" (C3)
The caregivers also described their experiences in dealing with the behavioral changes of their family members as being incredibly stressful and difficult. They described how they had to live with a bad conscience by having to lie and to do things "behind the backs of the sick" to avoid conflicts. Moreover, they constantly felt challenged by the fact that communication with the relative was made increasingly difficult because the relative was cognitively unable to understand while at the same time they experienced pressure on their patience and ability to accommodate to their relative. A wife put it this way: "You sit on 'the Bench of the White Lies'." (C1). There was uncertainty because the situation was constantly changing as the dementia disease developed and invaded everyday life. A son said: "... things are slowly falling apart, right? It's from the big to the small, and ... it's just standing on the sidelines watching. It's super reactive. It's super hard to be proactive." (C11). Hence, the families experienced increasing pressure by constantly having to take a new position in relation to their spouse or parents.

The caregivers experienced the dementia coordinator as their entry into the system. A caregiver said: "She pulls in the many threads and helps when it's hard to navigate in the system" (C5). Caregivers used the words “spider” and “octopus” to capture the comprehensiveness of their many functions (C1). Hence the dementia coordinator spread out a "safety net" under the caregivers because the caregivers needed it.

The need for moving together in the right direction

In relation to the use of technological solutions, caregivers dealt with technology to protect the patient's economic or social interests and safety. Banking, letters from the public authorities, and personal e-mails involved tasks that required the attention of the caregiver and they used digital solutions to structure these tasks. However, handling digital or technological solutions was not without frustrations or conflict. A caregiver said: "He forgets the codes all the time: mobile phone, pay-by-phone app, online banking and whatever else he has. I don't know how many times I've had to change them for him. Yes, now they f... blocked it!" (C2). Thus, the caregivers tried out different strategies, such as illustrating codes clearly for the family member. This helped briefly, but as the disease progressed and the cognitive level declined, the relatives experienced that they had to take over and use the power of attorney to safeguard the spouse's or parent's interests and safety.

It was obvious that the relatives were curious and proactive with regard to technological solutions and aids in dementia care. During the interviews, electronic pillboxes, simplified phones to replace the complex mobile phone, electronic calendars, smoke alarms, and circadian lights were mentioned as examples. According to caregivers, all electronic gadgets should
be considered and tried. At the same time there was a recognition that the technological aid had to be individually adapted to the cognitive level, which constantly changed, and at the same time be as simple and concrete as possible for the person with dementia.

The relatives experienced that the support of the dementia coordinators in relation to technological solutions in this area was characterized by a lack of professionalism and knowledge in this area. There was a demand for more active efforts by the dementia coordinator regarding early introduction to technological solutions and tools. A caregiver mentioned that she had to seek information on the municipality's website and the internet. It was the experience that this was not an area that the dementia coordinator had introduced them to. Even regarding problem situations, the dementia coordinator had helped to resolve, help was often given too late in the dementia process.

In the interviews with the dementia coordinators, they also highlighted that they lacked technical knowledge and skills in relation to technology. Many of the dementia coordinators talked about municipal projects in which dementia technology libraries were being tested. The dementia coordinators did not see it as their task to be a part of this, and they were satisfied that there were "staff" who ran this library. A dementia coordinator said: “Development within this area is simply going too fast. We can’t keep up with everything new. Our understanding has been: Others are more knowledgeable, so we need to know where "the others" are" (D14). However, at the same time, it was also revealed in the interviews that dementia coordinators experienced increasing interest and pressure from relatives across age groups in relation to technological solutions. A dementia coordinator said:

"The relatives are very open-minded about it... (ed.: Dementia-technology library). They are absolutely delighted with the catalog and that you can actually do something ... that you should not just sit with your hands in your lap and say: "Well - then we wait” (D3)

The need for handling technology while preserving relational interaction

During the interviews, part of the discussion focused on the general use of ICT. Various digital solutions were discussed. When talking about the use of chatrooms via applications, the dementia coordinators could see opportunities to establish better contact with caregivers who, due to their family member with dementia, could not leave the home. They also mentioned the benefits of being able to communicate with the daughter or son who lived abroad or far away or is bound by his/her work and who therefore does not have the opportunity to participate in activities physically. Finally, there was talk of the possibility of saving time by not undertaking physical home visits if dialogue could take place using ICT. The possibility of creating chatrooms for groups of caregivers and the
dementia coordinator was discussed, where the purpose could be the general opportunity for dialogue and exchange of information, advice, support and guidance both internally and with the dementia coordinator. When asked whether it could negatively impact the dialogue and cooperation, it was agreed that this was not the case. A dementia coordinator said: "No! There will still be many things that we need to be involved in. After all, it should not replace dialogue. It should be a help” (D4). It was emphasized that it was possible that ICT could complement the collaboration, but that it could not replace the personal meeting. At the same time, dementia coordinators emphasized that such ICT solutions (for example chatrooms) could create expectations from the relatives that the dementia coordinators would not be able to meet: "It should be clear that answers are not given 24/7. After all, we cannot be available around the clock” (D10).

In the group of caregivers, some of the same issues were discussed. There were some relatives who joined Facebook groups for relatives, which they were very pleased with. They felt that such a chatroom was a good opportunity to quickly get in touch with others in the same situation. About the caregiver groups on Facebook, a caregiver said: "It is very important to me that it should be when it suits ME! And that’s why I started a Facebook group for relatives, because when I just want to (breathe deeply) ... then maybe it’s 11 o ’clock at night” (C1).

The caregivers agreed that they made great use of the internet, and they could see opportunities in ICT solutions that involved obtaining information of a more practical nature in the area of dementia. However, when the discussion focused on the dialogue and collaboration with the dementia coordinator, there was no doubt among the caregivers. There was broad agreement that technology should not be allowed to replace personal contact. A caregiver said:

“I’m a little afraid that it could be a poor technical replacement for a personal meeting where you profit ten times as much. If that is the intention, then it is Not Good!!... and we ARE people! We see and hear and smell and feel each other as we sit in the same room and it becomes very, very lonely, the other. I don’t think it’s good!” (C11).

The participants emphasized that the caregivers’ need for support and assistance depends on the situation and not on the timing. Thus, there are times during day and night when the caregivers feel left alone. The dementia coordinators, on the other hand, are unable to contribute at these times. Here, the caregivers seek technological opportunities, among other things in the form of Facebook groups.

DISCUSSION

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Our study showed that there was an overlap between the dementia coordinators’ definition of their work and the relatives’ experiences of the dementia coordinator’s help and support. Participants agreed that the dementia coordinators’ job was to provide a safety net for families with dementia. Society and clinicians need to be aware of the extent to which chronic disease affect dementia caregiver. Societal resources must be optimally allocated to maximize the health and wellbeing of the caregiver (Fonareva & Oken, 2014; Hiel et al., 2015). In our study, we found that caregivers’ perception of care referred to a person-centered approach to both the patient and themselves as caregivers. Caregivers’ feelings of loss of their loved one as the person they knew as well as their own growing experience of stress and burden as the disease progressed were illuminated. Caregivers emphasized the importance of adjusting their own approach as well as that of others to the cognitive and behavioral level of the person with dementia. 

Kitwoods’ theory of person-centered dementia care focuses on being able to acknowledge the person with dementia throughout the development of the disease and knowing the person before the dementia disease (Kitwood, 1997; Mitchell & Agnelli, 2015). Long-term counseling and support to family caregivers are important to develop the caregivers’ ability to handle problem behavior and connect them with support services in society (Wright et al., 1999). A healthcare professional should serve as a key contact person to help overcome barriers and gain trust and provide a consistent relationship throughout the progression of dementia (Stephan et al., 2018). The dementia coordinators in our study served as solid support in the everyday life of the caregiver, a role that both parties considered valid. In the interviews with the dementia coordinators, we were able to ascertain that the theoretical basis for the dementia coordinators was in line with the theory of person-centered dementia care (Kitwood, 1997; Mitchell & Agnelli, 2015), because they repeatedly underlined the importance of showing respect and providing sufficient time in their contacts with both patient and caregiver. Other studies (Brooker & Latham, I, 2016; McCormack et al., 2010) emphasize that person-centered care is underpinned by values of respect for persons, individual rights to self-determination, mutual respect, and understanding (McCormack et al., 2010; Xie et al., 2018). Thus, a cohesive collaboration between dementia coordinators and relatives was based on the common position that good care involves person-centered care.

Our study showed that the caregivers welcomed the use of technology in dementia care. They were proactive and curious about technological solutions and had a positive attitude toward the use of the individual technological solutions and stressed that they should be simple and practical to use. At the same time, the choice of individual technological solutions should be adapted to the cognitive functioning level of the individual patient. This is in line with earlier
guidelines for the development of technologies for dementia care (Moyle 2019). In the development of mobile health technology in dementia care, a study found that relatives of people with dementia are often surrogate decision-makers for their relatives (Xie et al., 2018). In this context, it was shown that caregivers were interested in a wide range of information. Most of the relatives were interested in receiving information via smartphones or tablets, and it was concluded that mHealth interventions should strive to provide information tailored to individual caregivers’ specific preferences (Xie et al., 2018). Caregivers to people with dementia demand technologies that are effective, easy to use, and widely disseminated (Ruggiano et al., 2019). The providers of care should be aware of the types of technologies that are available and what technologies may be suggested to meet the needs of patients and caregivers (Ruggiano et al., 2019). A study identified that knowledge about AT usually was gained from personal experience rather than from health and social care professionals (Newton et al., 2016). Our study has similar findings and points to the fact that only when technological solutions fit the need of the individual patient will they be usable as part of the daily care for the patient.

Our study illuminated that caregivers did not feel well supported by the dementia coordinator in the use of technology in dementia care. A study has shown that caregivers of persons with dementia experienced navigating health and social care services as time-consuming, unpredictable, and often more difficult than the caring work they undertook (Peel & Harding, 2014). Optimized support from the dementia coordinator in relation to technological solutions in the context of dementia can help the caregivers to orient themselves more easily with regard to possible technological solutions, because as a key person in dementia care should know many available targeted apps and links.

The dementia coordinators in our study felt that the development of technological solutions was going too fast for them to keep up, and that technological solutions in dementia care were not their responsibility. They were content that the ATs were outsourced to a technological library in the municipality, and that a person who was skilled in the use of technology was employed to do the job. Technical skills are important for handling AT (Guise & Wiig, 2017). Education and training have been shown to bring technology and healthcare together (Gifford et al., 2012), and a study found that training nurses how to integrate information technology into existing care pathways can facilitate its acceptance (Brewster et al., 2014). Nevertheless, our study showed that dementia coordinators experienced that they already had to be experts in many aspects of dementia. This required time and training on a working day that already had a high workload.
Remaining challenges are bridging the gap between these technical experts and the dementia experts so that the new knowledge about AT reaches patients with dementia and their relatives.

Our study revealed that it was important for caregivers to be able to access the various technological possibilities, such as a chatroom or a link with dementia-related information, when they had a quiet moment for themselves. This could typically be when their relatives with dementia had gone to bed. The dementia coordinators, on the other hand, were accessible in the daytime, as their job typically was from 8 in the morning to 4 in the afternoon. This could be one of the potential challenges that can be addressed through technological solutions.

Our study showed that there was a common understanding that technological solutions and tools could not replace the personal meeting between the two partners involved in the care of the person with dementia. Nevertheless, it is expected that the number of people with dementia will grow well in the future, and the integration of technology alongside the human-provided care is inevitable to assist both the person with dementia and to reduce the burden of caregivers (Moyle 2019). Thus, the technology may support the caregiver in the daily care for the person with dementia and give a sense of security and safety.

VALIDITY

To increase the validity and reliability of this study, transparency was sought through reflections, visible choices, interpretations, and discussions (Kvale & Brinkmann, 2015). The participants’ social interaction with each other determines the generation of knowledge in focus groups (Halkier, 2016). The moderator’s ability to create trust with the interviewees is linked to the generation of good data in an interview (Kvale & Brinkmann, 2015). In the focus group interviews with the dementia coordinators as well as with the caregivers, there was lively debate and mutual trust, indicating that the interaction was successful. Confidence and trust were evidenced by the caregivers repeatedly touching on sensitive issues and becoming touched by each other’s stories.

In relation to the dementia coordinators, it was clear that there was a great deal of consensus on what their experiences in their field of work were even though they came from different municipalities. This indicated that their role and tasks were well defined in the healthcare system and that the expectations of a dementia coordinator were roughly the same regardless of the municipality.
LIMITATIONS

Focus group interviews proved to be a valuable data collection method to gain insight into the experiences and attitudes of caregivers and dementia coordinators on using technology in dementia care. However, there were several limitations. We included middle-aged caregivers who all had experience with and used technology daily. There is probably a group of the oldest caregivers who are not well versed in technology and therefore do not match the caregivers in our study. The dementia coordinators in our study had a mean age of 54 years and thus grew up in a time when technology was not part of the school curriculum. They had gained their knowledge of technology on their own, and their experiences might not reflect that of the younger dementia coordinators. The dementia coordinators were all women. A more equal distribution between the sexes might have influenced the data. However, this is probably a representative dataset, since dementia coordinators in Denmark are predominantly women.

CONCLUSION

Being a caregiver to a person with dementia is challenging, and technology might be used as a mediator to help ease some caregiving tasks or the burden of caregiving. Technology is, however, an area in which the caregivers must rely on their own competences and initiatives. Even though the collaboration between caregivers and dementia coordinators was beneficial and supportive, dementia coordinators felt that technological solutions were outside the scope of their work.

IMPLICATIONS FOR CLINICAL PRACTICE

It is difficult to imagine that technology will not be increasingly implemented in caregiving, both to support special caregiving tasks and in the communication between healthcare professionals and patients and their caregivers. Especially in the context of caregiving for people with dementia, it is important that the technology, which is to be implemented, is suitable for the individual patient’s physical and cognitive level of functioning. The development of new technological solutions is rapidly evolving, and according to our study health professionals need to aware of technological developments to enhance caregivers’ needs and wish to interact with technology in everyday life afflicted by a dementia disease. Thus, we suggest further elaboration on how pedagogical and educational solutions can be helpful to update both health professionals and caregivers A discussion

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is, however, needed inside the nursing profession, and outside the nursing profession in collaboration with other healthcare professionals and the surrounding society regarding who should be updated on possible technical solutions, and who is best suited to support caregivers in making choices on which technologies to implement in relation to their family member with dementia. If this discussion is not taken seriously and initiated within a short timeframe, there is a risk of leaving caregivers in a technological quagmire.

REFERENCES


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