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The facilitation of user-involvement for people with dementia as experienced by health care professionals: A qualitative study using focus groups

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ABSTRACT

Objective: The main objective of this study was to explore how health care professionals experience adaptation of user-involvement for people with dementia receiving health and social care.

Method: A qualitative explorative design was used with eight focus groups as the method of data collection. A total of 49 health care professionals were included representing a variety of professions, municipal and specialized health services, and all health regions of Norway. The transcribed focus group interviews were analyzed using qualitative content analysis following six steps to identify categories and the overall theme.

Results: Six main categories were identified: 1) facilitation of self-determination, 2) challenges of reduced or lack of awareness, 3) family caregivers' concern and protection, 4) open communication, 5) establishing a trustworthy relationship, and 6) clarifying expectations. To maintain independent lives for people with dementia, health care professionals must facilitate and support shared decision-making using an open and trustworthy communication.

Conclusion: To facilitate user-involvement, health care professionals need to develop and implement strategies that consider the perspectives of people with dementia and support the relationship between people with dementia and their informal caregivers.

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Introduction

Dementia, defined as a clinical syndrome characterized by a progressive decline in cognition and level of function, has an impact on both the person being diagnosed and their family. For some, gaining a diagnosis could be a long and difficult process and a diagnosis is experienced as a relief. For others, receiving a dementia diagnosis is experienced as very difficult and challenging. Most people with dementia express the need and wish to hold on to who they are and to be actively engaged in their own lives (Telenius et al., 2020). However, a dementia diagnosis seems to raise strong feelings of loss, uncertainty and worry about the future (Bunn et al., 2012; Eriksen et al., 2020; Mazaheri et al., 2013). Previous research has shown that people with dementia consider involvement in decision-making to be an important means of affirming self-identity (Caddell & Clare, 2010; Fetherstonhaugh et al., 2013). However, a considerable part of the research in this field reveals the practice of decision-making by proxy on the part of family caregivers (Miller et al., 2016) and frequently exclusion of the person with dementia (Taghizadeh Larsson & Osterholm, 2014).

Autonomy as a human right – which also applies for people with dementia – is determined in the UN's Convention on the Rights of Persons with Disabilities (CRPD). The convention uses a broad definition of the term *disability* that includes people with dementia, stating their right to make their own choices. Additionally, the convention requests health care professionals to help people with dementia to exercise their legal capacity and enable them to make decisions, an obligation with extensive implications for health care professionals.

The term *user* refers to a person receiving services and is the term used in most public documents in Norway as an alternative to *patient*. The users of health and social services have the right to influence their treatment, and, on the other hand, the services are committed to involving the users in decisions. User-involvement is considered essential by valuing the users as an equal partner in the discussions and decisions influencing their own situation.

A systematic review by Wied et al. (2019) revealed that research on shared decision-making in dementia is scarce and the developed support strategies and interventions are not carefully adapted for people with dementia (Wied et al., 2019). The progressive nature of dementia leading to cognitive and functional changes usually affects the capacity to make decisions in the late stages of dementia (Miller et al., 2016). The type of decision – like high-risk decisions about crucial health care and legal matters that involve the consideration of risks and benefits – is central when assessing the capacity for decision-making (van der Steen et al., 2014). The question about long-term care placement is an example of a major decision with a large impact on the lives of both people with dementia and their family caregivers (Miller et al., 2016). Less high-risk decisions, often called *everyday* decision-making, is a concept defined as a person's ability to make decisions about activities of daily living and to solve his or her functional problems (Lai et al., 2008; Lai & Karlawish, 2007). These kinds of decisions occur several times a day in situations where people with dementia express a certain desire, including activities like eating, bathing, dressing, and engaging with others (Delazer et al., 2007; Holm, 2001). Findings from the review of Davis et al. (2017) indicate that people at

an early to moderate stage of dementia desire to influence daily decisions. They are able to state their wishes and find involvement in decisions to be an important part of maintaining selfhood. However, the review identified few interventions to support everyday decision-making for people with dementia and implications for health care professionals should be further investigated (Davis et al., 2017).

In the context of decision-making about healthcare for people with dementia, the person, the family caregivers, and the health care professional form a triadic relationship where each have their own challenges and preoccupations. The possibility for people with dementia to be involved in decision-making is largely dependent on the health care professional's communication skills and timing for introducing conversations about current or future decisions to be made (Lai et al., 2019). As the possibility for the person to be involved and heard is a central prerequisite for person-centered dementia care, health care professionals need to facilitate user-involvement by considering the complex nature of these decisions. As concluded in Bhatt et al. (2020) systematic review, involvement in decision-making relies on good information about the dementia diagnosis and prognosis, the possibilities for support and supervision, and the initiation of conversations about preferences now and in the future (Bhatt et al., 2020). However, the optimal time for initiating discussions about the future especially sensitive topics like the need for health care services, long term care and end of life care is difficult to identify. Health care professionals may be uncertain and resist talking about the future to avoid causing stress and anxiety in the person with dementia and the family (Jones et al., 2019; Lai et al., 2019).

To our knowledge, limited research has been made on the topic of user-involvement for people with dementia from the perspective of health care professionals. Based on these findings we need to further explore health care professionals' experiences and reflections about how to facilitate user-involvement for people with dementia. Hence, the main objective of this study was to explore health care professionals' attitudes to user-involvement for people with dementia and their perception of how such involvement could be facilitated during the course of the disease. This information should be used as a knowledge base for further development of policy, methods, and practical tools to ensure user-involvement for people with dementia.

Materials and methods

The study has a qualitative, explorative design and is part of a larger project named 'The needs of people with dementia'. The project aimed to explore the needs from different angles expressed by people with dementia themselves, their family caregivers and health care professionals (Rokstad, 2020; Telenius et al., 2020). To study health care professionals' experience of user-involvement of people with dementia, focus groups were considered a suitable method. Individual interviews could have made it possible to explore the participants' experiences more in depth. However, using focus groups, comprising people of various professions, provided a framework for participants to mutually reflect upon the questions asked and challenge each other's opinions and statements, thus leading to an extended understanding of the topic (Krueger & Casey, 2015; Morgan, 1997). The focus groups consisted of participants of multiple professions working as clinicians assisting and caring for people

with dementia and their informal caregivers in all stages of the dementia disease.

Participants and recruitment

The participants were recruited by local gatekeepers in the network of the Norwegian National Advisory Unit on Ageing and Health. We included a variety of participants to cover a wide range of experience from both primary and specialized health care and from different professional perspectives. All together eight focus groups were conducted with a total of 49 participants divided into groups of 5 to 10 participants. Four groups consisted of professionals from different services in the municipality, like home-care services, day-care centers, residential care and general practitioners, while the other four groups consisted of participants representing specialized health services working in memory clinics, hospital wards, and outpatient clinics. The participants were recruited from all health regions of Norway. The majority were nurses, as illustrated in Table 1, which presents the professions and numbers of participants.

The focus groups

The focus groups were supported by a semi-structured interview guide based on literature reviews (Bjorklof et al., 2019; Eriksen et al., 2016; 2020; Forsund et al., 2018) and on interviews with people with dementia conducted by our research group (Telenius et al., 2020). The opening questions introduced in the focus groups in line with the main aim of the larger project were: (1) What are the needs of people with dementia in different stages of the disease? and (2) What is important in their everyday life? The main question discussed was (3) What can be done to ensure user-involvement for people during the course of dementia?

The focus groups were carried out by the first author (AMMR). A co-moderator assisted the moderator by taking notes, gave comments during the conversations. All eight focus groups were carried out in meeting rooms in the municipal office or at the workplace of the participants in specialist care. The focus groups lasted for 50 to 70 min and were audio recorded and transcribed verbatim before analysis. Sound files and transcripts were anonymized and stored in a secure database.

Table 1. Participants in the focus groups.

Profession	N
Registered and specialist nurses from primary health care (nursing homes, home based nursing, dementia coordinators)	15
Specialist nurses from hospital care	9
Assistant nurse from primary health care	1
Psychologists from hospital care	5
Psychiatrists from hospital care	4
Geriatrician from hospital care	1
Physicians from primary health care	2
Occupational therapists	6
Physiotherapists	3
Executive officers from primary health care	2
Leader of a day care service	1
Total	49

Preunderstanding

Two of the authors are registered nurses and professors within the nursing field (AMMR and SE), and the third author is a psychologist with a PhD (GHB). All three authors have extensive experience as clinicians and researchers within the field of dementia care, but none of them had had any previous relationship with the participants.

Analysis

The transcribed focus group interviews were analyzed according to qualitative content analysis using six steps inspired by Graneheim and Lundman (2004). In step one, all transcripts were read to provide a sense of the whole and to identify themes discussed in each interview considered a suitable portal for exploring the aims of the study. In step two, meaning units in the text were identified, and in step three, the meaning units were condensed into descriptions close to the text. In step four, the meaning units were extracted and labeled with codes. In step five, the codes were compared based on similarities and differences and grouped into subcategories. Then in step six, the subcategories were grouped and abstracted as categories. Finally, the categories were reflected on to reach an understanding presented as the overall latent theme (Graneheim & Lundman, 2004). The first author (AMMR) made the initial analysis following steps one to four. All authors took part in steps five and six and the final reflection to reach a consensus concerning the overall latent theme. Examples from the analysis process are shown in Table 2.

Ethical considerations

The project was approved by the Norwegian Centre for Research Data (NSD), project number 51712. Participants gave their written, informed consent to take part. Names or other identifying characteristics, except their profession, was not used during the focus groups and information that emerged during the focus groups that could provide identification of participants or their place of work were anonymized during transcription. Hence,

the participants' anonymity was ensured both in the analysis and the publication process. The co-moderator assisted the moderator in making sure that all participants were encouraged to make their voices heard and equally engage in the discussion.

Results

The following six main categories emerged from the analysis: (1) the facilitation of self-determination, (2) the challenges of reduced or a lack of awareness, (3) the family caregivers' concerns and protection, (4) open communication, (5) establishing a trustworthy relationship, and (6) clarifying expectations.

The facilitation of self-determination

The participants mainly expressed their feeling that people with dementia wish to be involved in and have influence on their own lives. Many of their clients state that they would like to live independent lives as long as possible as illustrated in this quote from a psychiatrist: 'It is about the fundamental feeling of being the master of one's own life, and then suddenly it slips away.' Open dialogs are experienced as being important to enhance the influence of people with dementia in making decisions concerning their daily life as illustrated in the following quote. 'One of the important questions to ask repeatedly is: What is important for you?' Making more comprehensive decisions involving receiving professional support or considering transition to a higher level of health and social care assistance, such as day-care centers or residential care, are experienced to require personalized communication as stated by a dementia coordinator, 'There is a large need for trust.... you need a good relation and find the time to raise these questions.'

The challenges of reduced or a lack of awareness

A major challenge experienced by health care professionals is reduced awareness of cognitive impairment and the tendency in many of their clients to trivialize or find a convenient

Table 2. Example of analysis steps from quotation to category.

Quotations	Codes	Subcategories	Categories
<i>I find that astonishing many are focused on being able to be independent, to live their own lives as before as much as possible</i> (occupational therapist)	Many want to live independent lives	Sustain independency	The facilitation of self-determination
<i>It is very difficult sometimes That the patient is not aware of it (cognitive impairment) and some respond with denial and rejection</i> (nurse)	Lack awareness and respond by denial and rejection	Lack of awareness	<i>The challenges of reduced or a lack of awareness</i>
<i>I find it difficult when some family caregivers very clearly ask me not to tell their parent or spouse about the diagnosis. I think they like to protect them from despair</i> (psychologist)	Family caregivers like to protect the patient by requesting staff not to inform about diagnosis	Family caregivers protect the person with dementia by restricting information	The family caregivers' concern and protection
<i>When you are relatively sure about a dementia diagnosis, I think openness to the surroundings is important and that imply a spoken message of a diagnosis</i> (physician)	Information about the dementia diagnosis is important for the patients' to be open to family, friends, and neighbors	Professionals need to be open and give information about the diagnosis	Open communication
<i>There is a large need for trust and to feel basically taken care of. The basic division of power is unbalanced so establishing confidence is alfa and omega</i> (nurse)	There is a need for basic trust to feel acknowledged and good taken care of	Need to establish trust	Establishing a trustworthy relationship
<i>I usually make a structured interview about the client's expectations. We use it as a routine or a method if you like As a starting point I ask: What is important for you?</i> (dementia coordinator)	Clarifying expectations using structured methods	Facilitating user involvement	Clarifying expectations

explanation for their cognitive symptoms. They may not seem to be concerned about their memory loss or functional disabilities but are more focused on living their everyday lives, sharing their life history, and maintaining their close relationships with other persons. Some clients do not recognize their own need for assistance or care and even deny and resist obtaining help from others. 'They don't seem to be concerned about their situation, they have not asked for assistance, and they can't see the need for help' one of the nurses said. The participants expressed a variety of explanations for this observed behavior from their clients. As one nurse explained, 'It could be due to their memory loss. They simply do not remember their cognitive impairment, so they tell me that everything is OK and that they have no problems. Dementia might be experienced like a kind of meta-cognitive impairment, making it difficult to reflect on their own reasoning, which influences their capacity for insight and awareness of their own situation.' Additionally, the participants interpret their clients' lack of openness about their situation as a coping strategy to preserve their self-image. As one of the physicians said, 'Some are very concerned about their façade and reputation and perform the best they can to conceal their disabilities.'

The family caregivers' concern and protection

An additional challenge pointed out by the participants is coping with input from family caregivers on what is best for the person with dementia. Family caregivers are often the ones who take the initiative to assess cognitive symptoms leading to the diagnosis of dementia. They advocate the needs of the person with dementia, which is appreciated by the participants, but they also sometimes suggest restrictions on what kind of information the health care professionals should present for the person diagnosed with dementia. As one of the participants said, 'Some family caregivers are very clear in their message, for example, telling me that their mother, father, spouse or partner must not be informed about the diagnosis.' Often family members are worried about the use of words like *dementia* and *Alzheimer's* and encourage the physician to use alternative and more vague terms like *memory loss* or *memory disease* to avoid sadness and despair in the person receiving the information. This input from family caregivers is mainly seen as an intention to protect their loved ones from anxiousness and worries. 'I think it is a way to protect their family member and a consideration that it would be very painful to know the truth about the disease' one of the physicians said. However, it is experienced as a considerable challenge for health care staff to establish an open and trustworthy relationship with the person with dementia based on these restrictions on information.

Open communication

The participants consider open communication as a crucial condition for user-involvement and collaboration with both the person with dementia and the family caregiver during the course of dementia. Information about the diagnosis and the presumed progress of the disease is an important starting point for the mutual relationship needed to ensure the quality of care. A nurse said, 'I think openness and honesty is very important for developing good collaboration with the patient.' The participants state that the information should be tailored, and staff should be open-minded about meeting the questions and

concerns stated by the clients and their families. The participants described a great need for the families to receive information to face the challenges in everyday situations. They strongly recommend courses or support groups both for people with dementia and for informal caregivers. Openness about being diagnosed with dementia is strongly recommended by the participants and some referred to the positive effect of openness in the society illustrated by the following quote, 'Some of my clients refer to a positive effect of people with dementia being open about their diagnose in public and media.' From the participants' point of view, the need for openness about the dementia diagnosis is crucial as a starting point to ensure active engagement and user-involvement from the people with dementia. However, they recognize that this expectation of openness might also be challenging for some of their clients. Stigma still exists, and one of the nurses refers to a client saying that she does not like the idea of everybody knowing and gossiping about her condition as she mainly does not focus on these symptoms herself. The nurse explained further that 'She [the patient] likes to live as normal as possible as long as she can without having to deal with all the feedback about her dementia diagnosis from her social surroundings.'

Establishing a trustworthy relationship

To ensure user-involvement for people with dementia, a trustworthy relationship with health care professionals is described as essential. The participants broadly underline the need for time and space to establish such a relationship. They state that the clients need a significant feeling of being cared for and, furthermore, that continuity in the relationship enhances the clients' experience of trust and safety. There is an important need for taking the client's worries and opinions seriously, listening actively, and respecting the viewpoints of the client. 'You need to meet them with respect, regardless of what opinion they have' a physiotherapist said. To show interest in the person's life story and meet them in their own home is recommended. User-involvement needs to be based on the emphatic understanding of the person's perspectives on life. As one of the occupational therapists said, 'There is a fundamental feeling of insecurity there [in the person with dementia] that needs to be faced all the time.'

Clarifying expectations

The participants underlined a trustworthy relationship as the basic prerequisite for user-involvement. Based on this relationship, they have experienced successful use of methods and tools to structure and enhance this user-involvement. As part of an early intervention after diagnosis, participants have used a communication tool, with the essential question 'What is important for you?' to structure the conversation and make sure the actions chosen for follow-up are in line with the client's needs and wishes. This tool is often used by coordinators in the group who are following the person as long as he or she is living at home. One of them said 'I use this tool [What is important for you?] in dialogue with the person and ask the next-of-kin to be present ... I find it very useful.' Systematic life story work is also experienced as a useful means of getting to know the person's preferences for future use in planning of care actions. Some clients have already signed a document to authorize a trusted person to take care of their interests in the future. This

document can include stated wishes about how to be treated and how important habits and interests of the person should be facilitated even as the person displays declining ability to take care of their own interests. 'Some clients like to write this authorization to make sure they are well prepared for the future others find it complicated to talk about the need for such a document.' The participants had some limited experience with the use of advanced care planning (ACP), offering people the opportunity to state their wishes for future care and support, including medical treatment, while they have the capacity to do so. The participants describe the challenge of talking about wishes for the future with people with dementia as many of them hesitate to plan for the future and mainly prefer to take life one day at a time. Some participants expressed their feeling that thinking and talking about the future is a threat for people with dementia. Again, they recognize a possible conflict of interests between the person with dementia and family caregivers as illustrated in this quote from a geriatrician, 'The family caregivers are often very eager to establish a power of attorney to be able to cope with economic matters and other crucial decisions. However, the person with dementia might not be so enthusiastic about it.' A main consideration for the participants in using these structured methods and tools is the need to be aware that previously expressed needs and preferences might change during the course of dementia. Hence, the content of information collected by these tools in the past must not be used uncritically to meet all possible future situations.

Overall interpretation

Together, the six categories – (1) the facilitation of self-determination, (2) the challenges of reduced awareness, (3) the family caregivers' concern and protection, (4) open communication, (5) establishing a trustworthy relationship, and (6) clarifying expectations – show that the adaptation of user-involvement for people with dementia depends on health care professionals in all parts of the health care service. User involvement could be facilitated during the course of dementia through open communication in a trustworthy relationship. An overall synthesis of the categories generated from the data material reveals a comprehensive understanding expressed as the latent theme: The need for maintaining independent lives in dementia must be facilitated and supported by professional caregivers through open and trustworthy communication.

Discussion

The main objective of this study was to explore how health care professionals experience the adaptation of user-involvement for people with dementia and how such involvement could be facilitated during the course of the disease. As illustrated in the findings, the participants highly recognize the need for self-determination for people with dementia linked to their professional observations of the users need for practical and medical support on the one side, and the user's and the family caregivers' own perceptions of needs and ways of coping, on the other. Awareness is a complex and multidimensional construct. It may be the recognition of changes related to the decline as dementia progresses, to be aware of a certain deficit, an emotional reaction to the decline and to understand how the decline affects their functioning. Awareness in this respect is a

phenomenon integrating a biological, psychological, and social understanding, and not just a symptom of disease (Clare, 2004; Lacerda et al., 2016). Hence, the participants' preunderstanding of why their clients reject openness and support may to some extent determine how they succeed in developing a trustful relationship both with their clients and with the family caregivers. A longitudinal study exploring the subjective experience of living with dementia described the participants' degree of insight as a non-dichotomous phenomenon, often fluctuating, sometimes fragmented, and often situational (Wogn-Henriksen, 2012). The participants in the current study associated their clients reduced or lack of insight as a possible coping strategy to preserve self-image. Preserving identity and self-image through not wanting to know may be understood as a regulation of disturbing emotions, like threats of loss or a sense of control in life and is in line with findings from a systematic literature review of coping with dementia (Bjorklof et al., 2019). The participants also mentioned the memory loss per se as an explanation to understand why the clients rejected the need for support and involvement from health care professionals. A review of shared decision-making by Miller et al. (2016) revealed that people with dementia are more likely to be involved when the diagnosis has been made recently, when dementia symptoms are less severe, and when the person with dementia is more aware of their condition (Miller et al., 2016). How reduced awareness in the clients is experienced by the health care professionals and how they interpret and understand their clients' reactions and behavior is important for them as they approach and plan their strategies for helping and involving their clients. Reduced awareness as part of the dementia syndrome should nevertheless not disqualify people with dementia from having an entitled opinion about their own situation (Woods et al., 2014).

A second dilemma stated by the participants is how to deal with the concerns of family caregivers and the actions they may take to shield the person with dementia from openness being associated by family caregivers to lead to discomfort and despair in the family member with dementia. Steps are liable to be taken, especially when difficulties are not experienced by the people with dementia themselves. This dilemma, as discussed in the focus groups, was related to the request from some family caregivers to keep information about the diagnosis hidden from the person diagnosed. The participants found these requests challenging as they primarily wanted to initiate and facilitate user-involvement for the person diagnosed as a natural continuation after diagnosis. Informing people with dementia about their diagnosis is important for the above-mentioned reasons but can possibly also be experienced from the family caregiver's perspective as a pressure to inflict unwanted and potentially very disturbing news on their loved ones over and over again. The family caregivers' need for protecting the person with dementia may thus also be understood as a protection of themselves from this deeply conflicting role. Being sensitive and aware of the caregivers' position in this respect may guide the professionals in helping to inform their clients about their condition, in supporting the families, and enhancing the process of user-involvement. A study by Sinclair et al. (2018) revealed that acceptance of the condition by both the person with dementia and the caregiver (his spouse in this case), can lead to a relationship featuring quality, trust, and familiarity, which are important prerequisites for involvement in shared decision-making. Additionally, external factors, like health care

professionals who validated the needs and concerns of both sides and facilitated joint decision-making, were valued (Sinclair et al., 2018).

The health care professionals in our study experienced challenges in introducing conversations with people with dementia about their wishes and preferences for future support and treatment as recommended in advanced care planning (ACP). This is in line with other literature, stating that discussions around end-of-life issues may often not take place or start too late (Denning et al., 2011; Robinson et al., 2012; Vandervoort et al., 2012). The findings could be explained both as a reluctance on the part of the professionals to introduce a challenging theme and causing stress and anxiety for people with dementia and their caregivers. They might also be afraid of not being able to comply with future wishes because of possible changes in the healthcare system (van der Steen et al., 2014; Wendrich-van Dael et al., 2020). It could also be the result of people with dementia primarily wanting to focus on living one day at a time (Eriksen et al., 2020) and a wish to live by the day (de Boer et al., 2012). A review by Sellars et al. (2019) aiming to describe people with dementia and their carers perspectives on ACP, stated that planning for the future while living with dementia make the person confront emotionally difficult conversations and navigate existential tensions. In addition, people with dementia and their carers felt uncertain in making decisions in the context of ACP and end-of-life care (Sellars et al., 2019). Health care personnel plays an important role for initiating ACP (Wendrich-van Dael et al., 2020). It is therefore important that health professionals who are involved in ACP in dementia demonstrate empathy and aim to facilitate acceptance of the inevitable cognitive decline and death in dementia. Additionally, providing an understanding of the decisions that may need to be made along the trajectory of dementia (Sellars et al., 2019).

The participants in this study recognized their clients' important needs for respect and the facilitation of user-involvement. Through information and support in an open dialogue, the participants believe they can develop a trustful relationship and thereby the foundation for user-involvement. The core values of person-centered care, including taking the perspective of the person with dementia, individualizing treatment and care, and facilitating psychosocial support (Brooker & Latham, 2016), can suitably act as a framework to achieve this and should be the basis for facilitation of user-involvement for people with dementia. However, informal caregivers provide the majority of the emotional and practical support for their family members with dementia living at home (McEvoy et al., 2019). This highlights the need for health professionals to use a framework of understanding, including the emotional dimensions of caring for a family member who is living with dementia, in trying to establish trust when openness can obviously be perceived as a threat. The findings also point to the need for further developing the supporting measures for the carers, where a comprehensive focus on these dilemmas also need to be highlighted.

This study includes experiences from a broad sample of professionals representing different regions in Norway. The findings need to be interpreted within the limitation of the Norwegian context. However, our findings are in line with a qualitative study made in eight European countries concluding that contact should be initiated proactively, as early as possible with people with dementia and their family caregivers, to establish a trusting and consistent relationship and facilitate access to and use of formal dementia care (Stephan et al., 2018).

Conclusion

The study reveals health care professionals' perspective on the facilitation of user-involvement for people with dementia. They acknowledge the need for people with dementia to influence decisions concerning their own life. However, they identify barriers like their clients' resistance to openness due to memory loss and ways of coping and experience the complexity in balancing the need for open communication with some family caregivers' actions to shield the person with dementia from negative emotional reactions from information about the disease.

There is need for health care professionals to develop and implement strategies considering both the perspectives of people with dementia, how they experience themselves and the world, and at the same time, facilitate the relationship between the person with dementia and their family caregivers.

More efforts should be made to develop, implement and evaluate systematic tools to enhance user-involvement for people with dementia both in everyday and more high-risk decisions like health care and legal matters.

Disclosure statement

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