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Support Needs and Expectations of People Living with Dementia and Their Informal Carers in Everyday Life: A European Study

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Abstract: The aim of this study was to describe the needs and expectations of support within everyday life among community-dwelling people living well with an early stage dementia and their informal carers. The study employed a qualitative design. Data were collected in 2018, via four focus group interviews with, in total, 17 people with dementia and 21 informal carers, transcribed and analyzed with manifest content analysis. Needs and expectations of support among persons with dementia were expressed as the importance of “Participation in my own care,” “Attitude of the informal carers,” and “Trusting relationships with informal carers.” Informal carers’ needs and expectations of support were expressed as the importance of “Formal care and services,” “Getting out of a carer mindset,” and “Family context.” The findings from this study highlighted that persons with dementia were well aware of their cognitive impairments and tried to maintain their independence, with both formal and informal care to help remain “being themselves.” Health professionals should acknowledge persons with dementia and informal carers’ well-being, and acknowledge the importance of their needs together with an understanding of the importance of continuity of frontline carers to building trusting relationships.

Keywords: ageing; content analysis; dementia; formal care; focus group interview; informal care; neurocognitive disorder

1. Introduction

In recent years, the focus within dementia care research, policy, and practice has moved towards a biopsychosocial (biological, psychological, and social) approach, in which the focus is to improve quality of life and reduce excess disability of the person with dementia, and enable them to live well together with their family or significant other, and in the context of their local community (Spector and Orrell 2010; Revolta et al. 2016; World Health Organization 2017). Person-centred care, based on the needs and preferences of the person with dementia is a central consideration (National Board of Health and Welfare Sweden (NBHWS); Kitwood [1997] 2005). This provides the

setting for an on-going European Erasmus+ funded project, which seeks to gain a more in-depth understanding of the support needs and preferences of people living well with dementia at home, together with their family or informal carers. The knowledge gained will subsequently constitute the framework for a digital training program for frontline care workers who work with people with dementia and their informal carers in the community and in their own homes.

Currently, the majority of people with dementia live in their own homes (Prince et al. 2013) and the main providers of regular help, support, and care are family members, most often spouses/partners or adult children (Winblad et al. 2016). Within a European policy context they are often referred to as informal carers (Eurocarers 2015). Whilst informal carers may find caring satisfying and meaningful, nevertheless providing intensive amounts of care over a prolonged period of time has been found to have a significant negative impact on both the informal carers' physical and mental health status, as well on their social life and financial situation (Courtin et al. 2014). In order to help sustain informal caring and to maintain the health and wellbeing of informal carers, it is increasingly recognized that frontline health and care practitioners need to reach out and provide timely help and support to informal carers (Lethin et al. 2016; World Health Organization 2017).

Frontline care workers who provide care for people with dementia may be licensed practical nurses having finalized upper secondary school and vocational training, or nurse assistants with vocational training of less than six months, alternatively with no formal training at all (Hallberg et al. 2013; National Board of Health and Welfare Sweden (NBHWS)). They provide a variety of interventions in the home to people with dementia and their informal carers based on their needs, such as wound dressing, providing assistance with daily activities and daycare, social-cognitive and sensory stimulation, as well as support for informal caregivers. In a European context, there are more similarities than differences regarding available care and support services throughout the dementia life course, despite the fact that there are differences in health care and social service systems (Hallberg et al. 2013; Bökberg et al. 2015; Lethin et al. 2017). Most often basic home care, such as help with activities in daily living, accompanying service, and home delivered meals, is available, whilst specialized dementia care and services are sparsely available (Bökberg et al. 2015). Herron and Rosenberg (2017) qualitative study of community-based dementia care highlighted that people with dementia tend to seek support that recognizes their own contributions and potential. Thus, it is important that frontline dementia care workers are equipped with the necessary in-depth knowledge and understanding of the support needs, preferences, and expectations of people living well with dementia in their own homes and their informal carers, to enable them to provide appropriate individualized care and support. In order to develop evidence-based training and education programs for direct care workers, the understanding of the needs and expectations of care and support in everyday life among people with dementia and informal carers is crucial. The aim of this study was to describe the needs and expectations of support in everyday life among people living well at home with dementia and their informal carers.

2. Materials and Methods

2.1. Study Context

The study constituted the first stage of an ongoing European Erasmus+ project, "Innovative Digital Training Opportunities on Dementia for Direct Care Workers" (the iDO-project) (2017–2019) that involves the five partner countries Greece, Italy, Lithuania, Portugal, and Sweden. The overall aim of the iDO-project is to develop a comprehensive digital training package for direct care workers that will be free of charge and available in the five official languages of the European Union. An initial key step in the development of the training package was to carry out focus group interviews with people living well with dementia at home and their informal carers, as experts in the needs, preferences, and expectations regarding support within their everyday lives. In this study, four countries participated: Greece, Italy, Portugal, and Sweden.

2.2. Study Design

This initial study had a qualitative design with an inductive approach and employed a focus group interview method (Krueger and Casey 2009) in order to gain a comprehensive picture of the everyday lives of people with dementia and their informal carers. It was considered that focus group interviews would enable participants to disclose their individual support needs, preferences, and expectations in discussions with others in a similar situation to their own.

2.3. Participants

People with a dementia diagnosis and a Mini-Mental State Examination (MMSE) score of ≤ 18 –24 (Folstein et al. 1975), which was measured at the clinic responsible for their treatment and evaluation, who were living at home and cared for by a family member or a significant other (informal carer) were invited to participate in a focus group. The ability to participate and discuss in a focus group was also assessed by their informal care. Potential participants were recruited via existing national networks and ongoing projects. They were contacted by a person already known to them, such as a chairperson of a local dementia association, director of a national center of excellence in the area of informal care, project management assistant, a psychologists, health practitioners, or a registered nurse specialized in dementia care. The national contact person informed them about the study, the aim and procedure of the focus group interviews, and answered any questions potential participants had about the study. In total, 17 people with dementia and 21 informal carers were identified who fulfilled the inclusion criteria and accepted to participate. To reach variation in the sample, participants were selected based on differences in age, gender, and European country of origin. Demographic characteristics of the participants are described in Table 1 below.

Table 1. Demographic characteristics of the participants.

	Greece	Italy	Portugal	Sweden
Persons with dementia				
Participants, n	6	4	4	3
Age, mean (min-max)	92 (71–92)	84 (79–88)	73 (59–96)	78 (75–80)
Gender (male/female)	0/6	2/2	1/3	1/2
Mini-Mental State Examination (MMSE) score	19–21 (mean 20)	18–21 (mean 20)	18–21 (mean 19)	21 (mean 21)
Public support at home	Day care, activity, walking, voluntary organization	Homecare, day care	Home care, voluntary organization	Homecare, day care
Private support at home	-	Private employee (n = 2)	Home care	Family
Technical aids	Internet	Vision device, walking stick, mobile phone, internet	Internet	Mobile phone, internet

Table 1. Cont.

	Greece	Italy	Portugal	Sweden
Informal caregivers				
Participants, n	6	4	6	5
Age, mean (min-max)	73 (66–79)	51 (50–54)	62 (45–69)	67 (49–83)
Gender (male/female)	3/3	0/4	0/6	2/3
Relation (spouse/child/partner)	6/0/0	0/4/0	2/2/0	2/2/1
Years of caring	7.5 (6–10)	3 (2–5)	9 (3–20)	5 (3–9)
Public support at home	Day care, activity	Day care, respite care	Home care, day care, walking, respite care	Day care, nursing home, safety, alarm
Private support at home	-	Private employee (n = 2)	Home care	Day care, daily activities, walking
Technical aids	Mobile phone, internet	Mobile phone, internet	Mobile phone, internet, vision devices	Hearing and vision devices, walking stick

All participants had experiences of the process of early stage dementia, either having the illness themselves or by caring for a person with dementia. There were variations in care needs, as well as type and focus of services provided, including the size of their home municipality.

2.4. Procedure

Focus group data were collected during January to April 2018 (n = 8) with two focus groups per country, and with three to six participants per group. Separate focus groups interviews were carried out with people with dementia and informal carers of people with dementia (four interviews each) in four European countries; Greece, Italy, Portugal, and Sweden. The focus groups with people with dementia were organized in cooperation with existing networks and projects in each country. In order to create a supportive and friendly environment, the moderators organized coffee or lunch together with the participants, which enabled the participants to have an opportunity to talk informally together prior to the focus group interview. A pilot interview was conducted in Sweden to validate the procedure and the interview guide. No changes were necessary after the pilot interview. Prior to the interview, written informed consent was signed by the person with dementia and the informal carer and demographic data were collected (see Table 1), following the interview guide (see Table 2).

The interview guide was developed in Swedish, and in the next step translated into English. Each partner thereafter translated the interview guide to their own native language.

In each of the partner countries a moderator and an observer performed the focus groups interviews. They were instructed to follow the interview guide as well as to visualize keywords of the interview, to think about the support they received or wished to receive in specific situations in their everyday lives, from morning throughout the day. The key words used were: morning situation, shower, dressing, lunch, activities, sports, day care, pay bills, shopping, dinner, and going to bed (see Table 2). When the focus group interview started, the moderator informed the participant about the aim of the interview in an easy way, and guided the session throughout. The observer assisted the moderator in keeping participants on track, and observed the interaction within the group, taking field notes (Krueger and Casey 2009). To gain in-depth experiences and opinions, the moderator asked probing questions as appropriate.

All participants actively discussed the questions and shared their needs, preferences, and expectations. Each interview lasted between 30 and 90 min (for people with dementia the mean time was 55 min and among the informal carers the mean time was 85 min). Interview questions focused on specific areas of daily life such as morning and evening routines, personal care, leisure

activities and sports, shopping, home maintenance and maintenance of personal finances. The needs, preferences and expectations regarding support as expressed by people living with dementia and their informal carers might be related to personal and practical tasks, as well as to information and education and the assistance (if any) provided by professionals (see Table 2).

Table 2. Interview guide for the focus groups interviews.

Interview Guide for Focus Groups Interviews with Persons with Dementia and Informal Carers	
Instructions for the moderator	<p>To guide the participants to the topic, ask them to think about the help they receive in their daily lives, from the morning through to night-time, and throughout the whole week, and how they want this help to be provided.</p> <p>Ask probing questions depending on the direction of the discussion to gain an in-depth discussion, and also about time, patience, and treatment. Ask the participants to give examples of situations in their daily life: the morning situation, shower, dressing, lunch, activities, sports, day care, paying bills, shopping, dinner, and going to bed.</p>
Questions for people with dementia	<p>"Please, try to think about the help you get or you would like to receive in your everyday life, from the morning through to night-time, and throughout the whole week."</p> <p>"How would you like this help to be provided, either if it is a relative or staff helping you." "Think of different situations such as when you wake up, at bedtime, about meals, household or finances but also on activities and day care."</p> <p>"Is there something specific that is important to keep in mind for the one who helps you?" It may be regarding time, patience, and treatment and how you want others to be when they help you?"</p> <p>"Feel free to share your fears and concerns about the future with us. Please help us to understand you, so that people can learn from your experience."</p>
Questions for the informal carers	<p>"Please, try to think about the help you get or receive, or you would like to give or receive, in everyday life; from the morning through to night-time, and throughout the whole week."</p> <p>"How would you like help to you and to your relative to be provided?"</p> <p>"Think of different situations such as morning situations and daily activities, but also on specific caring activities."</p> <p>"Is there something specific that is important to keep in mind within regards to your own emotions or needs, your tasks as a carer, or for the ones who help you? It may be regarding time, practical task, or medical treatments, or how you want others to help you."</p> <p>"Feel free to share your fears and concerns about the future with us. Please help us to understand you, so that people can learn from your experience."</p>

2.5. Data Analysis

With participants' permission, the interviews were recorded and transcribed verbatim in each national language, and thereafter translated in to English by the project team in each respective partner country. Data were analyzed by means of content analysis with manifest interpretation (i.e., by summarizing the interview content without the interpretation of any hidden meaning; Krippendorff [1980] 2004). The first and last author independently read the interview texts and identified meaning units responding to the research question. Condensed meaning units were identified and labelled with codes. The codes were sorted into subcategories and; thereafter, into categories at a manifest content level. Categories and subcategories were discussed within the project team until consensus was reached. The researchers strived to put themselves in the participants' situation when interpreting the text in order to understand it unconditionally and to avoid their own pre-understandings.

2.6. Ethical Considerations

This study followed the ethical principles of the Helsinki declaration ([World Medical Association 2013](#)). The study was approved by the regional ethical review board in each partner country; The Regional Ethical Review Board in Lund, Sweden (Dnr 2017/901; 2017/1007); The Institute's Ethics Committee, Italy (CE INRCA17025/2018); the Scientific Committee of the Athens Association of Alzheimer's Disease and Related Disorders; and the Ethical Board of the City Council in Portugal. Whilst written informed consent was obtained from all participants, in order to ensure that persons with dementia genuinely and fully consented to take part in the focus group interviews, principles of process consent were adhered to as advised by dementia care researchers in which consent is freely and informally negotiated during the research process ([Dewing 2008](#); [Hanson et al. 2007](#)). In the context of the focus group interview study this meant, for example, that if participants were starting to feel fatigued a short break was suggested.

3. Results

In this study, persons living well with dementia were well aware of their cognitive difficulties, which together with the consequences in terms of prolonged processing speed and declining perceptual function constituted the basis/frame for their discussions in the group. They did not explicitly express a “hands-on approach” regarding their needs and expectations for receiving care and support. Rather, they expressed the importance of being able to participate in their own care and of having a trusting relationship with informal as well as formal carers. It was also crucial that the caregiver adopted a positive attitude towards caring for them. Participant informal carers did not express their needs and preferences in detail either, and were more focused on their tasks and emotions regarding their individual caring situation. They highlighted the impact of the dementia disease on their relationship with the person they cared for, and this was acknowledged as being the most challenging aspect to deal with. Nevertheless, formal services and support were acknowledged as being important and enabled them to sometimes get out of a carer mindset, at least for a while. The family context was important for providing compassion and understanding in order to avoid distress and depression. Three categories emerged in each of the two participants groups (see Table 3).

Table 3. Categories and subcategories describing needs and expectations of people with dementia and informal carers when receiving or giving care and support at home.

Categories	Subcategories
<i>People with dementia</i>	
Being able to participate in my own care	Doing things in my own pace Doing things with supervision
Attitude of the carer	Not having too high demands Being present and patient Allowing time and speaking slowly
Having trusting relationships with their informal carers	Giving attention and compliments Having knowledge of likes and habits Staff continuity
<i>Informal carers</i>	
Formal care and services	Participating in voluntary associations Staff continuity Responding to immediate needs Being good and sensitive Having information and knowledge
Getting out of carer mindset	Joining dementia associations Having paid work as a lifeline
Family context	Being protective Sharing responsibility Having compassion and understanding Promoting communication Providing sensitive support

3.1. The Needs and Expectations for Support among People Living Well with Dementia

3.1.1. Being Able to Participate in My Own Care

Being diagnosed with a dementia disease is life changing. As the dementia disease progresses the person's independency declines, a situation that they themselves recognized:

"I was the owner of an important company and I did everything myself. Now it is very different. I do a bit, just to do something. My wife helps me." (Person with dementia, Italy)

To be able to participate in one's own care and to remain independent was important for the participants. This included, for example, being allowed to do things at one's own pace, and taking the time needed when getting dressed. Care and support was considered to relieve the person from exhaustion, and as one participant expressed: "Then you do not have to think" (Person with dementia 2, Sweden). In some activities the participants were still independent, while, in some activities, supervision by both formal and informal carers was appreciated to get things both right and in the correct order, such as grocery shopping. As one participant expressed it:

"I have no difficulties in taking a bath, dressing, or preparing a meal. I am always doing shopping with my daughter, never alone. My children are paying the bills." (Person with dementia, Greece)

"I like cooking, but now I have to wait for my daughter to help me, because I get easily distracted. I cannot follow the recipe through to the end."

(Person with dementia, Portugal)

3.1.2. Attitude of the Carer

Attitudes of formal and informal carers towards them were of utmost importance. Being treated with respect and dignity provided a safe environment where they could be themselves and use their capacities as much as possible. They expressed that they did not want the demands to be too high and impossible to live up to, since this could lead to diminishing of their remaining cognitive faculties and leave them with feelings of failure. *"It is most important that they (the carer) care about you."* (Person with dementia, Sweden). Participants expressed that it was essential for formal and informal carers to be present, not only physically but also in mind, and to be patient when accompanying and giving support in daily activities:

"People who help you should never raise their voices, should remain calm, being understanding when you forget something. Also, they should not talk too fast and choose their words carefully." (Person with dementia, Italy)

Participants also emphasized that they required time to be able to understand what was going to happen and what they were expected to do. To them, it was, for example, necessary that the informal carers spoke clearly so that they had time to process the message and; therefore, could be an active participant in their own life.

3.1.3. Having Trusting Relationships with Their Informal Carers

To be able to build a trusting relationship with both formal and informal carers, persons with dementia expressed their need for full attention by the carer in their daily activities. Compliments from others about their appearance were highly appreciated in general, as well as specifically regarding their clothing, hair, or how things were achieved. Persons with dementia expressed that informal carers had to have knowledge of their personal likes, dislikes, and habits in order to get to know them better. In order for the person with dementia to really feel that they could trust the formal carers it was essential that there was a good continuity of staff; they needed to meet the same staff and familiar faces every day.

“It is nice to have help, with my Ukrainian caregiver we have dinner together and watch television. There must be some feeling, she is very kind, she takes me places, and she pays attention to my movements.” (Person with dementia, Italy)

3.2. Needs and Expectations for Support among Informal Carers

3.2.1. Formal Care and Services

In order for informal carers to fully understand the complexity of the dementia disease and what to expect throughout the dementia trajectory, informal carer participants expressed that they needed information and knowledge about the disease. Some carer participants explained that education and information about dementia were regularly given by the municipalities and were highly appreciated, not only for the knowledge disseminated but also for the opportunity to discuss specific possibilities as well as challenges, and to share experiences with others in a similar situation to their own. Participants acknowledged that this was also possible when attending voluntary associations such as the Alzheimer’s Association.

“To take care of my mother, I have taken many courses organized by the municipality, and I am now participating in an Alzheimer’s cafe. Social support for the family is the most important thing.” (Informal carer, Italy)

Carer participants expected support to be good and sensitive and carried out by the same staff. They also recognized that they needed to know what methods to use to be able to deal with situations that were more challenging to manage, such as aggressive behavior or managing finances:

“My mother was a very active person and now she does not accept her disease. Also, for us it is hard to accept she cannot do things anymore. She feels angry with her family but she is not aware of it. It is a daily struggle for the administration of money, for the use of the ATM.” (Informal carer, Italy)

Informal carer participants acknowledged that they had all seriously considered giving up their caring role from time-to-time, alternatively to try and reduce their amount of care and start using different kinds of support services, such as respite care or even entry into nursing homes. However, at the same time they admitted that to not look after their loved ones was very hard to do. All participants expressed how important good and sensitive support was from other family members, staff, and civil society organizations to help sustain them in their caring role:

“I think it is very good with a dementia support group and, when you are in a situation where you get to know that your wife or husband has got an Alzheimer diagnosis, that it is good to have a professional to take care of you at that time... to be part of a carer group and to start a study circle . . . , it has helped a lot because we wrote down what we wanted to know and then she (the group leader) had the answers the next time we met.” (Informal carer, Sweden)

3.2.2. Getting Out of a Carer Mindset

Depression was a constant threat to the informal carers’ mental health and, for this, paid work could be a respite as well as a lifeline. Additionally, joining associations, choir groups, or going to church was deemed crucial by the carer participants for their own mental health and wellbeing, and a welcome opportunity to get out of the carer mindset:

“In order to get out of my role as caregiver, I usually go to church every weekend and I also participate and belong to the church choir. It helps me relieve the stress I feel throughout the days. It also helps me to cope with what I am going through.” (Informal carer, Portugal)

Carer participants explained that their relative, the person with dementia, often regularly attended a day center or stayed at an institutional respite care setting for a while, which often acted as a good respite for the carer to relax from their carer role. Despite this, informal carers’ thoughts often remained focused on their relative and they visited them frequently to make sure they were all right.

3.2.3. Family Context

Informal carer participants explained that the family context was protective, given that the family was sharing and helping out with caring responsibilities. In particular, without emotional support from the family, distress and feelings of being misunderstood prevailed. Instead, compassion, understanding, and love between family members were highlighted as important issues to avoid distress and depression:

“In the family we share all the tasks. We are three children and we organize for travel, shopping, ATM, and to enable my father to do all the everyday things. Our children also offer to help the grandfather. We have a problem with going outside the home, for transportation. Public service would be useful but is scarce.” (Informal carer, Italy)

Carer participants expressed that everyday activities could sometimes be rather demanding. By supervising their relative with dementia and applying structured daily routines they struggled to maintain independence, both their own and that of the person with dementia. In such situations, participants admitted that the demands could become too high and, as a result, they lost their temper. One caregiver expressed his frustration as follows:

“My wife has dementia and is getting worse over the years. I try to stay calm, but I do not always manage—sometimes I get out of control and I start shouting.” (Informal carer, Greece)

4. Discussion

The main purpose of this study was to achieve an understanding of the support needs and expectations in everyday life among people living well with dementia and their informal carers. Our findings indicate that, for both groups, needs and expectations were related to personal and practical tasks, to information and education, as well as to the attitude and assistance provided by professionals. Overall, for the people with dementia, attitudes and relationships were crucial, while for the informal carer, needs related to practical issues were mixed with emotions (e.g., needs to take care of oneself, to be able to do other things outside the home, to get out of their carer mindset, and to have a supportive family context). That is, in this study the people with dementia expressed their needs and expectations on informal and formal care, while the informal carers highlighted the expectations they had on the formal care provided. To the best of our knowledge, this is the first focus group study illuminating the needs and expectations for support from the perspectives of both people with dementia themselves as well as their informal carers.

The focus of our study was the everyday activities in the person with dementia and informal carer's lives and their needs and preferences for support. The performance of activities requires that the person with dementia remembers the procedures and timing of them (Townsend and Polatajko 2007) which can be problematic when their cognitive capacity is reduced. Since activity and independence increases quality of life (Henskens et al. 2018; Moyle et al. 2015), such supervision is essential. In this context, it is important to note that the persons with dementia expressed a need to manage activities at their own pace, without too high demands, and to be given full attention by the informal carers. It can be argued that, support provided in the right way and at the right time can actually constitute the only way that a person with dementia can be active. Haak et al. (2007) highlighted how being outdoors increases physical and social activity, and health and inclusion, the sense of being an important part of a larger context with the potential to contribute to society. Despite this, people with dementia perceive situations that are confusing and difficult to comprehend as a risk to them (Sandberg et al. 2017), which might lead to inactivity and restricted participation due to fear of exposing oneself to different challenging situations (Sandberg et al. 2017; De Witt et al. 2010).

An important finding of this study was the need of the person with dementia for an emotional and respectful support from both formal and informal carers. Maintaining a loving and respectful relationship with their informal carers enhances the development of strategies to support continued

decision-making for people with dementia (Fetherstonhaugh et al. 2016), which should be promoted to enable people with dementia to participate in their own care. People living with dementia often have a desire and the ability to participate in decision-making about their everyday life, although such desires can be underestimated by both informal and formal carers (Daly et al. 2018). As highlighted in our study, people with dementia need to be able to participate in their own care, and to have a say about what is going to happen. Such issues have been raised in previous research (Haak et al. 2007; Paddock et al. 2018) and in line with this, persons with dementia in this study highlighted the importance of leading an autonomous and independent life, and, despite their cognitive limitations, they persistently strived to remain their identity, self-image, and ultimately their autonomy.

Persons with dementia in this study expressed the need for continuity of informal carers as they expressed that their behavior and capacity may differ from day-to-day, and; thus, circumstances and adverse events can only be understood and adapted to if the informal carers have the possibility to meet the individual over a longer period of time. This is consistent with the results of Low et al. (2013), who explored important characteristics and outcomes for community care. Their study revealed that it was important for community care services to be flexible, reliable, and providing adequate hours of care by well-trained staff. As the dementia disease progresses, the person with dementia will increasingly be more dependent on others, not only informal care but also formal care. In this context, it should be remembered that continuity of formal carers was essential to both the persons with dementia and their informal carers in this study.

From the perspective of the informal carers, continuity of staff has been shown to be positively associated with informal carers' psychological wellbeing (Lethin et al. 2017). The frontline workers can negotiate the needs of the person with dementia and the demands from the context to find the right challenge in specific situations (Sandberg et al. 2017; Ledgerd et al. 2015). Meeting the same formal carers means that a positive and trusting relationship can be established, and; thus, most probably confusing and frustrating situations can be avoided. In order for the informal carer to be able to care for the person with dementia for as long as possible, formal services were important, as they enabled informal carers to sometimes get out of the carer mindset, and to maintain one's own identity. In this regard, the informal carers needed and expected the formal care to be organized at an early stage of the dementia trajectory, responding to immediate needs as well as giving them information and knowledge about the disease. Amieva et al. (2012) reported that informal carers have high to very high expectations on formal care, specifically regarding two main needs; information regarding the disease and learning skills. Informal carers have individual needs of information during the dementia trajectory, and especially adult children need more information, particularly on the disease and how to cope with it (Cova et al. 2018). Most importantly, lack of support and a mismatch of communication and expectations may result in secondary role strain (Lapridou et al. 2018).

The informal carers in our study expressed that caring for people with dementia is burdensome and it is necessary to receive support from the family. The family context acted as a protective and safe zone to be able to share different tasks and appointments, but also a source of relief and someone to talk to that knows the person with dementia and understands their individual situation. Most importantly, the dementia disease may have a significant impact on the relationship between the person with dementia and the informal carer. Caring for a close relative with dementia may lead to a sense of frustration and feelings of hopelessness, and, in such situations, according to our informal care participants the family context was important in order to avoid distress and depression.

Previous research has highlighted that coherence of the family and family satisfaction, as well as the quality of family communication is associated with increased levels of carer well-being. In addition, disengagement is associated with improved carer well-being (Tramonti et al. 2018). To be able to care for people with dementia living at home for as long as possible, as expressed in this study, the informal carers needed to take care of themselves, realizing their own needs instead of only those of the person with dementia. It was apparent from our findings that informal carers used different strategies to minimize stress and address the needs of both themselves and the person with dementia, such as

self-care (Polenick et al. 2018). Professionals should be aware that people with dementia and informal carers put a lot of energy into remaining themselves with different strategies that should be supported by personalized and individualized care.

Strengths and Limitations of the Study

Trustworthiness of the qualitative data collected in the four partner countries was established by ensuring credibility, dependability, conformability, and transferability of the data (Lincoln and Guba 1985). Credibility was established by the use of an interview guide, which enabled the moderators and the observers to follow the same procedure for the focus group interviews and to address the same specific topics. However, we are aware that the questions due to linguistic and cultural reasons were not able to translate verbatim and; thus, they potentially were posed with a slightly different meaning. Despite this, after the data analysis discussions we are confident that all interviews, independently of cultural context, were conducted according to the interview guide.

To ensure that the results were repeatable and consistent, and to strengthen the conformability of the findings (Graneheim and Lundman 2004), the first and last author independently read the interview texts and identified meaning units responding to the research question. Thus, we ensured that the data were dependable. During the data analysis process, the emerging categories and sub-categories were discussed between the authors until agreement was reached. Moreover, illustrative quotes were included to provide evidence for the findings. The data analysis procedure is described in detail, thus enabling the reader to follow the authors' involvement in the analysis. To make the findings transferable, the context and recruitment procedure, as well as the data collection method are described. All authors are researchers in the field of care for older people and informal carer support. However, their professional background, experiences, and cultural context differ, thus multiple perspectives were made visible during the data analysis.

Interviewing people with cognitive difficulties, such as a dementia disease, is challenging. Memory gaps are common, and Nygård (2006) earlier reported that a lack of insight into their problems may lead to a limited amount of information and knowledge being revealed during an interview situation. However, despite the challenges of gaining extensive information, in this study the focus group context encouraged the people with dementia to talk freely and to elaborate on their needs, preferences, and expectations. During the interviews, the person with dementia was accompanied by an informal caregiver (passive attendance). All interviewers were professionals with experience of approaching and handling persons with dementia, the persons felt that they were in a safe environment and no distress during any of the focus groups interviews were reported. Accordingly, despite the challenges, the interviews with the people with dementia in our study were rich and lively, generating significant information.

5. Conclusions

Knowledge of support needs and expectations in everyday life among people living well with dementia and their informal carers is to our knowledge sparse. To conclude this study, people with dementia seem to be aware of their cognitive difficulties, and use different strategies to maintain their independence, autonomy, and self-image. Professional carers should be aware of the importance of personalized support based on aspects related to trust, patience, and time. The family has an important role to support the informal caregiver and the formal support has to take this into account. The care and service system should be aware that the both persons with dementia and the informal carers highlighted the importance of, and the need and expectations for, continuity of staff to build trusting relationships and to relieve stress.

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