

Informal carers of people with dementia: How to respond to their need for support and help on different levels?

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Abstract

Social work is constantly evolving and theoretically enriched to meet people's needs in new social situations. Informal carers must balance care with other demands while facing a range of obstacles. Despite research on what informal carers require, a specific typology of their needs has yet to be formulated. The research question considered is "What are the (groups of) needs of individuals who provide informal care for people with dementia?". As part of the research project Long-term Care for People with Dementia in Social Work Theory and Practice, we interviewed a non-random convenience sample of 20 relatives acting as informal carers of people with dementia. The results are presented as a typology of needs on the micro level (personal health—emotional health, physical health), mezzo level (care tasks—support from formal care, planning—information, counselling) and macro level (legislation, system changes). Most obstacles and needs identified were on the micro and mezzo levels. More than on the system (macro level), informal carers see the responsibility and burden of care as lying on the individual (micro level) and institutions and the community (mezzo level).



Keywords: long-term care, social work, informal care, caregiving task, personal health

1. Introduction

The development of social work theories constantly follows the needs of people and new social situations to establish appropriate methods and techniques along with adequate help and support processes. In social work, applicable responses are developed in response to needs on the micro, mezzo and macro levels (Mesec, 2003). In 2013, 13 % of people aged 60 years or older around the world required long-term care (Prince et al., 2013). Care may be provided by formal services, informal carers, or both. Due to the lack of formal care (in the community) and insufficient regulation of the system (although the Long-term Care Act

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was passed, its implementation has been halted and amendments are expected) in Slovenia (Ministrstvo za zdravje, 2016), a considerable share of care work is imposed on informal carers. This is especially the case with informal carers of people with dementia because there are no formal services available for them, notably in rural areas (Rihter, 2022). The focus in this article is on the needs of informal carers of people with dementia. The challenge for all informal carers is to balance the care with other demands on their time like family, paid work, leisure, etc. (Brodaty & Donkin, 2009), but also with their own emotional and psychological state. Family carers of people with dementia are often stigmatised by the disease's invisibility. Research shows (Batsch & Mittelman, 2012) that a key reason for this stigma is the lack of education about dementia in society. Research in the last 20 years on the needs of informal carers of people with dementia in Slovenia in terms of help and support was largely based on collecting data through interviews with carers, partly and less often through observation. In their research, authors Flaker et al. (2008) and Mali et al. (2011, 2018) relied on different typologies of needs focused on the needs of people with dementia and not (or only rarely) on those of carers. Regarding what informal carers need, Queluz et al. (2020) reviewed over 30 studies in this area and determined that the most common needs of carers of people with dementia relate to health (mostly emotional) and the need for support from others. There are a few general theories of needs from which the needs typologies are derived (Bradshaw, 1972; Stufflebeam et al., 1985). Mali and Grebenc (2021) state that social work is primarily concerned with the characteristics of everyday situations in which the conditions and circumstances of a person's life also reveal their needs and obstacles. The following part of the article presents existing typologies of needs developed during research on the needs of older people, people with dementia, and their informal carers. These typologies provide the framework used in the empirical part of the article.

Our research question is accordingly "What are the (groups of) needs of those who provide informal care for people with dementia?". The answer is to be used to develop a preliminary typology of their needs. This typology combines the needs identified and levels on which those needs are expressed (micro, mezzo, macro). Where responses to needs are lacking, we present reflections and make suggestions regarding the level and manner in which this could be regulated. In so doing, we draw on analogies from other areas of social welfare where similar solutions have already been established.

2. Needs of informal carers of people with dementia: From the general to the specific

While exploring needs, the first challenge arises from the fact that needs are defined in various ways. Below, we list some possible definitions and explain the framework used in the presented research when exploring the needs of informal carers of people with dementia.

The Dictionary of the Slovene Literary Language (Fran, n.d.) defines need as: (i) what exists, arises because of its absence (with two subgroups: [a] what is necessary for life or work, and [b] what is required, wants to); (ii) which is caused by circumstances, a state that requires an appearance, the realisation of something; or (iii) excretion of urine, stool. In the Anglo-Saxon world, Webster's definition of needs is well known (Merriam-Webster, n.d.), and is similar to the one above. In this definition, needs are necessary duties, obligations; lack of a certain thing that is desirable, useful; physiological or psychological conditions for the well-being of the organism; circumstances that require provision or remedy; lack of means for survival or poverty.

Stufflebeam (1971) defines needs from several perspectives. The first refers to the gap between what is desired and what we observe as a deviation from it. Here, needs are

determined by a test based on certain criteria and forms to verify that the criteria have been met. The second aspect is the “democratic” view where need is defined as a change desired by the majority of a certain reference group. Such a view is democratic and involves a larger number of people, although one disadvantage is that it mixes needs with preferences, depends on the level of information possessed by the reference group, and allows for false targeting. The third aspect is the diagnostic one where it is assumed that the needs that ensure survival must not be overlooked. This view allows for the discovery of satisfied and unmet needs, while using logic and available research data to determine which differences would be harmful. Still, it is flawed since it focuses only on basic survival needs or omits the harmful effects of deprivation and excludes higher-level needs. The fourth is the analytical aspect where needs are defined as opportunities for improvement that are predicted based on given information about the current state. A disadvantage of this approach is that it is abstract because needs are difficult to operationalise in this way and require highly skilled personnel.

Bradshaw (1972) and Leskošek and Hrženjak (2002) establishes a typology of needs that helps to conceptualise the relationship between individual and social actions in terms of needs. Normative needs are identified when criteria/standards are set in this way and a comparison is made between the standards/criteria and what exists. If an individual or a group does not reach the standard, we speak of the existence of a need. Experts establish normative needs from the top down; they should be objective, scientific and theoretical. They do not necessarily reflect different people’s actual needs. Felt needs are based on knowing people, knowing how they feel about needs, and equating them with wants. They are determined from the bottom up, yet are not always expressed. Expressed needs are feelings followed by action. We refer to them as a demand of people who express the need for a service/help/support. Comparative needs are identified when people or groups receiving a service are used as a reference point for similar people or groups not receiving such services. Although Leskošek and Hrženjak (2002) believe that Bradshaw’s typology is appropriate for social services, we must consider Bradshaw’s caution, “[...] a true need is one in which all four perspectives match”.

In social work and more broadly in social care, the assessment of needs is even more important. Leskošek and Hrženjak (2002) state that social services should be organised on the basis of individuals’ needs. However, even though needs assessment is already acknowledged as an important aspect of programme or service design, the question arises of whether everything that we label as a needs assessment provides a sound basis for designing policies or programmes.

Mali and Grebenc (2021) describe how research on needs in social work focuses on the context of daily life. Such research is particularly important when it considers the setting of practical social work since it reveals what people need for both survival and meaning in life, what they want to change and improve. Information regarding actual needs in everyday life can also be an important starting point for social work science and practice to understand people’s situations and plan appropriate interventions on different levels.

Researchers of people’s concrete needs have often categorised them. In the past decades, focus was given to the needs of people of dementia due to the requirement to develop appropriate programmes and services. Certain typologies were developed (e.g., typology of needs of old people [Ramovš, 2003], typology of long-term care needs [Flaker et al., 2008], typology of needs of people with dementia [Kitwood, 2005]).

Flaker et al. (2008) generally classify needs in two dimensions: expressed-unexpressed and satisfied–unsatisfied. Cross-sections of these dimensions yield more specific combi-

nations: (i) expressed and satisfied needs; (ii) expressed and unsatisfied (called “urgent”); (iii) unexpressed and satisfied (we label them as self-evident); and (iv) unexpressed and unsatisfied. From the perspective of needs research (if we were to explicitly ask people what they need and what they lack), use of the above dimensions would merely reveal the expressed needs, especially the unsatisfied ones, whereas the unexpressed ones would remain hidden.

The needs of informal carers of people with dementia have been studied by several authors. Queluz et al. (2020) summarised them after analysing 31 studies from around the world on this topic. The needs were classified in the following groups: (i) Caregiving tasks: Physical/nursing care; Household work; Supervision/support; Coordination; Help received from others (informal and formal); (ii) Relationship with formal service providers; (iii) Housing; (iv) Juggling responsibilities; (v) Financial costs; (vi) Personal health: Physical health; Emotional health; (vii) Relationships: With the care recipient; With the family; (viii) Planning: Crisis planning; Future planning; Information about dementia and dementia care; Information about professional support and formal services; Information about legal regulation and caring. When using the term “juggling responsibilities”, we refer to the work-life balance of the carers, and how they manage to balance their work and care responsibilities. According to Pitsenberger (2006), the care responsibilities’ interference with carers’ work often causes them emotional, financial and physical stress.

Queluz et al. (2020) also analysed the solutions proposed for meeting the needs by categorising them in two groups, namely education and information; and services. Education and information included the following: educational activities about dementia care in each stage of dementia (practical advice); information about managing behavioural problems and changes in people with dementia; information about dementia and dementia care; information about formal support; information in a central location. With respect to services, they indicated that informal carers should receive formal support pertaining to the health of the person with dementia (e.g., home care, services close to home), that services should be provided to improve carers’ mental health (emotional support), that day centres for people with dementia should be established to give carers time for themselves, and that support for carers’ well-being should vary by the type of dementia involved.

In Slovenia, the needs of people with dementia should be addressed by both social care and health care, especially long-term care. The lack of formal care in the community (most formal care is provided in institutional care settings) (Ministrstvo za zdravje, 2016) and insufficient regulation of the system (postponement of the Long-Term Care Act in Slovenia) means that already many unmet needs of people with dementia. Notwithstanding various forms of services being available to the elderly, they are not necessarily adapted to the needs of people with dementia, even less to the needs of their informal carers. Filipovič Hrast et al. (2014) list existing forms of community-based care able to partly meet informal carers’ needs: home social care, home health care, day care centres, respite care, clubs for older people, health and nutrition programmes, support services for family carers, technical assistance services, adapted or assisted housing, active aging prevention programmes, mobile and other communication services, etc. Still, there is the question of the extent to which these services are adapted to informal carers of people with dementia.

The fact that the needs of informal carers of people with dementia may occur on different levels also makes it necessary to think about responses on multiple levels. Nagode et al. (2019) note that home social care users and their carers together constitute the micro level of home social care. Yet, this works in conjunction with the mezzo (how the care is organised within the community) and macro levels (how the social policy and legislation

supports/hinders care). All three levels interact with each other, while the latter two have indirect or direct effects on the micro level due to decisions and actions and vice versa, and the micro level gives them feedback and serves as a guide by way of experiences and changing needs. Therefore, in this article we also consider the needs and existing responses and reactions of informal carers from the perspective of the different levels: the micro (direct care of a person with dementia), the mezzo (community forms of help), and the macro (systemic assistance arrangements).

3. A preliminary typology of needs of informal carers of people with dementia

3.1. Research problem and methodology

The different frameworks and starting points for thinking about needs in general (Bradshaw, 1972; Chambers et al., 1992; Isaac & Michael, 1995) and specifically as concerns particular groups of people (Flaker et al., 2008; Queluz et al., 2020; Ramovš, 2003) create challenges in needs research. Chambers et al. (1992) list the levels on which research can be performed: (i) the needs of individuals or groups as potential users of social programmes; (ii) organisational-level needs, which concentrate on organisational functioning (technical assistance, development, training); (iii) studies of community needs, which typically encompass a broader context—neighbourhood development, coordination of services, funding; (iv) studies of societal-level needs consider an even broader context—identification of social problems, demographic indicators, social policy analysis. Nonetheless, this does not answer, for example, the question of how to obtain data on needs that are not openly expressed.

Despite research on what informal carers of people with dementia need, a specific typology of their needs has yet to be formulated. While some classifications of these needs are available (e.g., Queluz et al., 2020), they do not provide additional information about how to respond to the needs emerging on different levels. Therefore, as part of the basic research project Long-Term Care for People with Dementia in Social Work Theory and Practice we conducted qualitative research on a convenience sample selected from the population of carers who are close relatives of the people with dementia for whom they care. Our research question was “What are the (groups of) needs of those who provide informal care to people with dementia?”. We interviewed 20 informal carers on various topics. Since the purpose of the project extended beyond exploring the needs of informal carers, the semi-structured interview guide included the following topics: signs of dementia and diagnosis, recognition of dementia by a relative, knowledge of the disease, communication with a relative with dementia, changes in the life of a person with dementia and their family, experiences with institutional care. We also explored the issue of support and help from the immediate and wider social environment, as well as formal help and associated needs and obstacles.

In this article, we present analysis of the interviews seeking to identify informal carers' support needs and obstacles while caring for a person with dementia. We performed a thematic analysis by groups of needs and obstacles and then open coding (by freely attributing codes) of specific categories within the groups of needs (Mesec, 2023). In the analysis, we assumed that, alongside openly expressed needs, we should also pay attention to possible feelings that had yet to be transformed into expressed needs (as defined by Bradshaw, 1972). The interviewees mentioned their needs mainly while answering questions that explicitly referred to this topic (Did you receive enough support from the environment? How much and what kind of help? What would you need to make caregiving easier, but you have not received? What kind of help and support would you need to exercise certain rights? In which instances? Please describe. What kind of help and support would you need while working with professionals?). The statements made about the obstacles (mentioned

in different parts of the interview) allowed us to infer possible feelings with respect to needs that were not yet expressed. In this case, because we are only interested in inferring that the expressed obstacle might be a need, we listed the obstacles only when both authors responsible for the analysis and this paper agreed. Obstacles perceived as possible felt needs by only one author were excluded from further analysis. Stufflebeam (1971) also describes such a view of needs as an analytical aspect. He views needs as a direction of improvement predicted based on given information about the current state. From the research aspect, a disadvantage of this understanding of needs lies in its abstractness as a need is difficult to operationalise. Accordingly, while analysing the responses of informal carers of people with dementia, we also defined the direction of improvement as a need (when the starting point was a pronounced obstacle), even though the need was not necessarily explicitly stated in their responses. We also paid attention to the level on which needs and obstacles occur: micro, mezzo or macro.

3.2. Results

Based on the above-mentioned classification of needs proposed by Queluz et al. (2020), we identified obstacles and needs as expressed by informal carers of people with dementia in Slovenia and shown graphically in Figure 1. The figure presents a typology of needs of informal carers of people with dementia. Among the eight groups, six were identified in our study. Two (relationships with formal service providers and relationships with care recipients and family members) were not explicitly addressed, with possible reasons for this being discussed in the last part of the article.

In the group of Personal health, one category (also found in Queluz et al., 2020 classification) was addressed as both an obstacle and a need. Namely, under *physical health* carers mentioned obstacles to their own health problems, the burden of care and exhaustion, and expressed the need for a reduced physical burden.

The category of *emotional health* was addressed by the obstacles appearing in different areas of life: due to reasons related to the people with dementia, due to the workload of care, personal response, and due to other factors (relatives' and institutional care, social factors, and others).

Included among the reasons connected to people with dementia were the deterioration of the health of the people with dementia, despair over the disease's progression, and conflicts with the care receiver: "At the beginning, we also argued a lot because she couldn't be convinced of anything. It was very difficult for me then because she often cursed and called me by her sister's name" (S_06_CE¹); the violence of the care receiver, the refusal of help from the care receiver, and the despair of being placed in a home: "At that time, it was really a relief for me. But now I always have a guilty conscience. A guilty conscience is always present. It occurs to me that maybe she could live at home [...] Yes, but the house would have to be completely remodelled" (S_01_CE).

The interviewees state that the stress from the care and lack of confidence as a carer are obstacles arising from the care workload: "With my grandmother, who was 90 years old, the diagnosis was much easier to accept than with my mother, who was 70. She was still physically fit, she could go to Šmarna gora,² but she was so insecure in her body that it

¹The citation label consists of a letter indicating that it is an informal carer; sequential numbers of the interviewee and two letters indicating the region where the interview was conducted.

²Hill near the capital city.

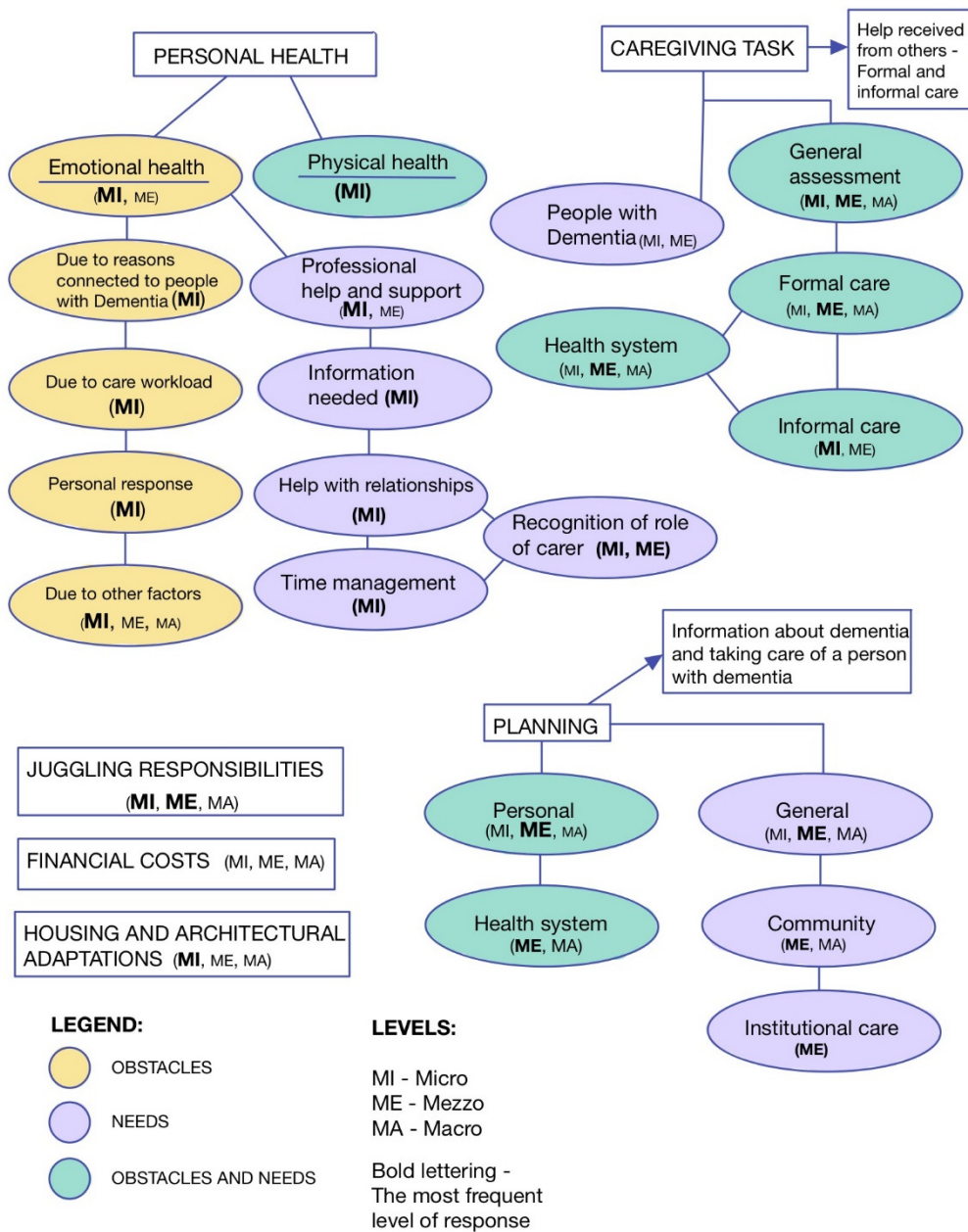


Figure 1. Obstacles and needs of informal carers of people with dementia and levels identified

breaks your heart. It's not nice [...] That's why I also went to Spominčica³ to listen. There they gave me a whole backpack full of information, which is very useful for me. But you still don't know how to do things properly. It's like yoga: you can practise your whole life, but some exercises you'll never get right. Because you start wrong. It's hard. It's hard on the people closest to you” (S_02_CE).

Obstacles categorised as a personal response include psychological distress, guilty conscience, worries about the future, and difficulty with accepting the disease.

Among the obstacles caused by other factors, there were a few that concerned their relatives: disagreement about care with relatives: “Maybe my sister somehow did not want [...] my sister is also strongly against medicine, I am not so much. If you have to, you have to, no? If you know it's bad, or if you can have consequences from it if you hesitate too long. I said you have to get medicine as soon as possible to slow it down. Both my mother and she were very much against it. So, yeah” (S_05_CE), less time for the carer's own family, and changing roles in the family.

Some obstacles were related to institutionalisation: fear of institutionalisation, difficulty with finding a nursing home, and condemnation after the institutionalisation: “Others judge you and say ‘why did you put him in the home?’” (S_03_ZA).

Another group of factors is concerned with social factors: bans on visits during the pandemic, isolation due to the pandemic, and the fact that the informal carer's role is not recognised: “I have not observed much, it seems to me that some people always see it as a taboo subject, but in fact we carers are not visible so much in this role because my mother and I were mostly at home or close by. Of course, the family accepted the changes in my mother, we were all a bit shocked, but I do not think the wider community even noticed our plight, our work” (S_09_ZA).

The needs the carers identified in response to these obstacles listed in the emotional health category were: professional help and support, the information they required, help with relationships, time management, and recognition of the carer's role.

Under professional help and support, they mentioned the need to talk to someone, psychiatric help, help with coping with distress: “When we got the notice that we could go to the nursing home, and when I told my mother, there was a lot of drama. Even though she'd made the application 10 years before. But when the moment came, there was drama, my brother and I were scared” (S_01_CE). The information they needed included help in dealing with the diagnosis and the need for support in the early stages of dementia: “After the diagnosis, at least at the beginning, the biggest changes were with the other family members, who were all coping in their own way” (S_13). Under help with relationships, they mentioned helping to build a relationship with family members and helping to say goodbye to the person in need of care in an appropriate way. In terms of time management, they expressed the need to have time for themselves and the need for their role as (informal) carer to be acknowledged.

In the second group called Caregiving tasks, only one subgroup was addressed—*Help received from others (formal and informal care)*. Most categories in this subgroup were viewed as both needs and obstacles. The following categories were identified: general assessment, informal care, formal care, and health care system. One category (people with dementia) was mentioned as a need.

In the general assessment of caregiving tasks, the carers referred to the (non)availability of help and lack of community support because people with dementia cannot live alone at

³Slovenian Dementia Support Association.

home. Some carers are unfamiliar with the care system: “At the time, it was all new to me and I didn’t know where to turn. I asked my doctor what and how. And even there, they tell you about symptoms and medications, but that’s not all” (S_03_ZA).

When it comes to formal care, the obstacles relate to the high cost of formal care, the rejection of formal care, the hesitation in commencing formal care, and the inappropriate behaviour of social workers: “As I said, the hospital staff didn’t happen to make me angry because she called me to take him home. Even when I was arranging things on the phone, everyone was friendly, except for the one from the hospital” (S_03_ZA), the absence of non-permanent institutionalisation, no companionship for a person with dementia, and no long-term care. Other obstacles mentioned were that the formal carers (in home care) change and that nursing home staff behave inappropriately. In the informal care category, the obstacles were more obvious when the carer was the sole carer and they were unable to provide more care.

In the health care system category, the interviewees described problems with the health care system, dissatisfaction with medical care, slow diagnosis, the fact that doctors do not have time, and that health care workers do not help. This led them to express the need to know the health care system: “A lot depends on how much you inquire. How qualified he is and how much he can research. I don’t think it’s a barrier. For me, it hasn’t been a problem. If a person doesn’t get the hang of it, it can be a very big obstacle” (S_01_CE).

The needs they identified in response to the obstacles listed under Help received from others (formal and informal care) regarding the general assessment, are the need for affordable care and good patient care: “I’ve only one complaint, but it has nothing to do with the home. She waited 9 hours in the emergency room to be transported home. That’s a systemic problem. My brother and I were upset at the time and they invited us to talk, they took it seriously and we agreed” (S_01_CE), help in the case of a violent care receiver, keeping a care receiver busy, and arranging free long-term care. For formal care, they mentioned the following needs: shorter waiting times, the same formal carer, the need for more care, formal care during the night, and the professional and emphatic appearance of formal care: “I’d like to see greater professionalism, human respect, compassion above all” (S_02_CE), more kindness from social workers, and non-permanent institutionalisation. They also asked for enough space in the nursing home and long-term care. In terms of informal care, they also referred to the need for help from family members and friends. Within the category related to people with dementia, they expressed the need to convince a relative (with dementia) to accept help. Regarding the health care system, they mentioned the need for a primary care physician and medical help in the facility, as well as the fact that physicians should take more time per visit.

Under the Planning group, only one subgroup was addressed—information about dementia and taking care of a person with dementia. Obstacles were divided into two categories: personal and health systems.

Under personal obstacles, carers indicated that their knowledge about dementia was inadequate and they were thus poorly informed. They themselves were dependent on learning about it after the diagnosis, and sometimes the carers did not know how to respond: “When my father was hospitalised for a stroke, I asked the social worker there if she could help him find a room in the nursing home because we could not have him at home. A few days later she called me and said that there was no room for him and that he would be taken home by ambulance. Unfortunately, you have to be able to help yourself enough, but some people can help themselves even less than I was able to” (S_03_ZA). They are not familiar with issues involved in establishing the diagnosis.

In the context of the health care system, the following obstacles were identified: the physician's attitude and the physician's lack of knowledge about dementia: "It's going to sound mean, but I think the health care system is just not prepared for these dimensions of dementia. They do not know how to help you, and they do not know how to give advice. They cannot tell you what to do to alleviate the symptoms of dementia. There are several specialists who are available immediately and on a self-pay basis, and I have had good experiences with them" (S_02_CE).

The general needs the carers expressed are the need to plan care and the need for expert support: "A lot is said and written about dementia today, but we are not aware of it. There is also too little 'support', professional help" (S_02_CE), information about formal help, information about the rights of people with dementia, help with finding institutional care, and the need to have all information in a single place. Regarding their personal needs, they noted the need for education about dementia and ongoing carer training. As community needs, they listed the need to educate the community about dementia and to consult with the carer. Needs listed in the area of the health care system related to educating primary care physicians about dementia and the need for more information from health care professionals. In the area of institutional care, they referred to the need for information about placing a relative in a nursing home and information about institutional care: "Looking back, I might have needed someone to educate me about all the options for institutional care" (S_07_CE).

Under the Juggling responsibility group, the following obstacles were mentioned: work demands, adapting paid work to care, and the stress of so doing: "My sister and I alternate visiting days. I have to say that this is quite a challenge since we both work full-time and have three children" (S_07_CE). In response, they noted the need to adjust their work to the care, to secure an exit from work, and to adjust their family life: "The diagnosis came very late, there were problems before. It caused me a lot of trouble. I had a very responsible job, and sometimes I had to drop everything and rush to her. I also moved in with her" (S_01_CE), extra help with care, sharing care between family members, cheaper nursing homes, and recognition of the role of carers.

With respect to the Financial costs group, they mentioned the obstacle of the financial burden (expensive nursing homes) and the need to reduce the financial burden on the family.

In the group of Housing and architectural adaptations, the informal carers stated the following obstacles: barriers and stairs in an apartment. The needs they mentioned were adapting the living space, moving to the ground floor, and moving the care receiver to the carer's home.

Based on the identified obstacles and needs shown in Figure 1, we considered the levels (micro, mezzo, macro) on which the obstacles and needs occur and can be resolved or addressed. Under the Personal health group, we categorised all of the mentioned obstacles mainly on the micro level. Only the obstacles listed under the emotional health group, which are related to other factors (distress in finding a nursing home and community condemnation due to the placement in a nursing home), were also categorised on the mezzo and macro levels. The needs identified in this group were also categorised on the micro level, except for professional help and support (where carers addressed the need for additional psychiatric help in the community) and the recognition of the role of carers (in the community and society), which were placed on the micro and mezzo levels. In the group of Caregiving tasks, the obstacles were listed on all three levels, with the micro and mezzo levels standing out. The obstacles and needs in the category of Planning were also placed on all three levels, but mainly the mezzo one. Both the obstacles and needs in the Juggling responsibilities group were listed on all three levels, mostly on the micro and mezzo levels. The Financial

costs group was placed on all three levels, with none standing out. The group of Housing and architectural adaptations was placed on all three levels, with the micro level being prominent.

4. Discussion and conclusions

Informal carers play a large and important role in care (especially for people with dementia). Mali et al. (2011) note that everyone faces illness in their lives or among those close to them. Alongside their existing daily stresses, they require support at least occasionally to cope with such an experience. Since informal carers are a very important factor in the day-to-day lives of people with dementia (by playing the role of advocates, having an important role and tasks in ensuring the quality of life of the person with dementia), they must be supported and helped while it is still possible (until the weight and burden of the additional loads cause so much disturbance that they need constant help). Flaker et al. (2008) argue that caring for an elderly family member imposes time, physical and emotional burdens on family members. At the same time, carers have doubts about the appropriateness of placement in institutional care and about their abilities. Therefore, on top of researching the needs of people with dementia (which is already widespread and growing), it is necessary to research what their informal carers need and to respond accordingly.

Both the complexity of the needs definitions and methodological issues in exploring the needs of carers of people with dementia have a considerable impact on the results presented above. The analysis revealed that 25 % of the interviewees did not answer questions that expressly concerned needs. Even when we counted the number of statements, it turned out that out of 233 statements in which needs or obstacles were identified, only 28 (about 12 %) openly expressed needs. This low percentage of openly expressed needs may be interpreted by the fact that the interviewed informal carers had already discussed obstacles (felt needs that they did not express) in the other questions, or did not perceive them as such, or felt they cannot change anything and have surrendered to fate (as also noted by Flaker et al., 2008, who describe unsatisfied and unexpressed needs as hidden needs). Another reason could be that they are so emotionally involved in caring for the person with dementia that they do not even think about their own needs. Still another reason could be that the interview was partly standardised and the interviewer did not give as much weight to questions that explicitly referred to needs because the interviewee had talked about obstacles in other sections which the interviewer could understand as needs. Accordingly, it must be noted that the needs we identified based on the obstacles might be a mixture of felt needs and unmet and unexpressed needs. The question is how (with what method, with what formulation of questions/indicators) can we obtain better quality data on needs. Possible suggestions would be to ask informal carers more specifically about needs, using the matrix proposed by Mali et al. (2011), or to think about how to help people articulate their distress and needs—focus groups where each participant can listen to each other.

Existing typologies of the needs and classifications of needs of informal carers of people with dementia (as listed in the Section 2) are quite broad and can provide a general framework for thinking about systems-level interventions. In social work, where the focus is on people's daily lives, we have to be very concrete on the practical level. Therefore, our typology (Figure 1) includes several tangible directions that not only consider the levels on which the obstacles and needs are expressed but can also serve as a guide for social workers while seeking to develop specific interventions. The fact the typology is built on incomplete data means that it must certainly be supplemented by additional research.

Nevertheless, the needs of informal carers of people with dementia identified in the

study and as stated by Queluz et al. (2020) are largely consistent with the needs and obstacles identified by the interviewees in our research. Of the eight groups described, only two groups and some subgroups were not specifically mentioned. However, they are not entirely absent as one group (Relationships with care recipients and family) partly overlaps with the category of other factors by relatives (in the group of Personal health) and another (Relationships with formal service providers) overlaps in part with the health system category in the Caregiving task group. The contribution made by our typology lies in adding categories that are more refined and to reflect the levels on which obstacles and needs emerge.

According to Queluz et al. (2020) research on carers' needs, the following needs occur most frequently: the need for emotional health (help in overcoming emotional distress; the need to recognise the status of a carer; the need for emotional support from family and friends); the need for formal and informal help; the need for information about dementia and caring for a person with dementia (e.g., the need for information about accessible services nearby); the need for physical health (need for time for self; needs related to own health; overcoming physical barriers to care). The needs identified in the articles referred to by Queluz et al. (2020) are mostly consistent with the needs reported by the interviewees in the present study.

The most prominent obstacles for individuals taking care of people with dementia are those we classified in the area of emotional health and lack of support. A major burden on carers is the difficulty of their relative accepting the diagnosis and witnessing the deterioration of the care recipient's health, which is associated with conflict, emotional distress, juggling care and paid work, and care and family life. In this area, carers miss support and especially a key person to accompany and guide them after the diagnosis. It was also suggested that this should be established up in a single place, i.e., someone to inform them about the disease and their rights, refer them to the appropriate facilities, provide psychological support, and give help with the bureaucratic procedures.

The carers pointed out that much depends on the individual and how actively they engage in the search for information (where responsibility is shifted to the individual). The lack of initial information caused many to struggle with a lack of confidence as a carer. They also faced disagreements with their relatives about the care and being judged by others who lacked information about dementia, as well as not having their needs as carers acknowledged. They expressed a need for professional help and support, notably in the early stages after the diagnosis. A major obstacle is that many are unfamiliar with the care system. They also noted the need for more formal and affordable formal home care because care is only available for one or two hours a day and not at night. They also expressed the need for medical staff and social workers to treat themselves and those in need of care with greater empathy and kindness.

Most of the obstacles and needs we detected in the interviews were on the micro and mezzo levels. More than in the system (macro level), carers see the responsibility and burden of care as resting with the individual (micro level) and institutions and the community (mezzo level). Categorising and classifying needs and obstacles on different levels, as with our typology, also allows us to consider what role a social worker can play on which level with informal carers. On the micro level, as Cox (2007) notes, social workers can already enumerate forms of help for people with dementia. Similarly, they can allow informal carers to explore their feelings, fears and concerns related to the diagnosis. Support and assistance processes should aim to reduce stress by planning goals and care that are not as stressful. According to the roles of the social worker described by Mali et al. (2011), a social worker can function as a case manager on the micro level. In this role, they handle the coordination of

programmes and services that informal carers need, establish contacts with various services, and provide assistance with rights. Depending on the needs of the carer, they may also act as a teacher by providing information, knowledge and insights about appropriate and quality care for people with dementia. The social worker can act as a consultant, adopting a holistic approach to offer help to individuals, families and communities, further exploring their needs, identifying different ways to achieve the goals set and co-creating the desired outcomes in a working relationship with the carer and the person with dementia.

Roles in which micro and mezzo level activities are interwoven are: facilitator, connecting informal carers who need help (and cannot find it) with existing services; an advocate, representing the interests of carers (when needs are identified, pointing out that much coordination with employers of informal carers is required due to the heavy burden of coordinating the work life of the carer and care of a person with dementia); and advocating the protection of fundamental rights and dignity. Yet, they can also act as a mediator, a negotiator between people and institutions. Social workers themselves are often in the role of negotiator when helping to interpret the needs of informal carers to others and resolve conflicts.

The role of advocate can also intervene on the macro level, such as to expose and eliminate discrimination, it also addresses the system level and draws attention to the changes that need to be made. In particular, the social worker does this in the role of an activist, advocating for changes in policy and legislation.

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