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Caring for a person with dementia: The results of a participatory research study

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Abstract

Dementia is a widespread neurodegenerative disease in the Western context, particularly in Italy. It produces significant consequences of various kinds, both for the person who is experiencing the problem and for their caregiver. As the literature shows, the early stages of the disease represent an extremely delicate moment for families. This paper presents a study that investigated the life experiences of people with dementia and their caregivers in the early stages of the disease. Considering its field of investigation and its objective, this study was suitable for the application of participatory research methodology, by directly involving experts by experience. This article discusses the results of the qualitative research carried out by interviewing caregivers of people with dementia/cognitive deterioration. The study results enable us to understand and explore various aspects of this topic: the meaning of caring for a person with dementia; motivations of caregivers; attitudes and emotions concerning the disease; positive aspects related to caregiving; relationships between caregivers and patients, and, in general, how families deal with this situation. The results presented in this paper provide useful considerations and various suggestions for social workers and others involved in the caregiving process.

Keywords

Dementia; participatory research; caregivers' experience; cognitive impairment

Introduction

In the Western context, where different pathologies linked to aging and loss of autonomy are widespread, dementia has particular relevance for three main reasons: 1) it is a syndrome about which we still know relatively little; 2) it involves great psychological, social, and economic consequences; and 3) this disease is one of the major causes of the institutionalization of elderly people (Faggian, Borella, & Pavan, 2013). Furthermore, there is still a gap (which is, on the one hand, disconcerting in terms of caregiving, and on the

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other, interesting from a research perspective) between the onset of dementia and its diagnosis. One of the greatest difficulties is establishing whether the cognitive deficits of an elderly person are due to simple aging or if they represent the onset of dementia; this aspect will be discussed in this paper. The research focused on the early stages of the disease and intended to highlight the experiences of people and families who are affected by it, with the aim of furthering our understanding of how to help people meet their needs at this stage of the disease. In this paper, we focus on the perspectives of the caregivers of people who are suffering from this disease.

The first part of the paper examines the literature on dementia and caregiving. In the subsequent sections, both the research objective and the method used for the implementation of the research are described. At the end of the article, the principal results of the research, a discussion of these results, and the possible implications of the findings are discussed.

Literature review: The caregiver experience

For an informal caregiver, caring for a person with dementia, be it a husband, wife, parent, or other relative, is a source of struggle, stress, and tension (Coen, O'Boyle, Coakley, & Lawlor, 2002; Chiao, Wu, & Hsiao, 2015; Heron, 2002). Research shows that there are multiple factors that influence a caregiver's perception of their burden of care. These factors can be divided into elements deriving from the characteristics of the caregiver, the characteristics of the patient, and the symptoms caused by the disease.

Research shows that the burden of care perceived by the caregiver increases when they care for a person with dementia who has behavioural disorders, such as wandering, aggressive behaviour, and agitation (Berrei et al., 2002; Conde-Sala et al., 2010). High levels of neuropsychiatric symptoms and psychological disorders of the elderly person that the caregiver must confront daily (Berrei et al., 2002; Gallagher et al., 2011) also adversely affect stress and the perception of the burden of care.

Other research shows that the characteristics of the caregiver, as well as those of the assisted elderly person, influence the perception that the caregiver has of the burden of care. Chiao et al. (2015) reported that there are three groups of factors that influence a caregiver's perceptions based on their characteristics: socio-demographic factors (e.g., socio-economic condition, the gender of the caregiver), psychological factors, and factors that concern family relationships and the established relationship between the caregiver and the person with dementia (Andrèn & Elmstahl, 2007; Brown, Chen, Mitchell, & Province, 2007; Chiao, Wu, & Hsiao, 2015; Etters, Goodall, & Harrison, 2008; Kim et al., 2009; Simpson & Carter, 2013).

These elements can lead the caregiver to feel overwhelmed by their burdens and hardships, which often results in the premature institutionalization of the elderly person

(Wolf, 1998). Worse, such frustrations can lead to aggressive and even violent attitudes in the caregiver towards the elderly person (Melchiorre, Chiatti, & Lamura, 2012; Wolf, 1998). If, on the other hand, the relative manages to maintain a positive and proactive attitude thanks to their personal resources and ability to remain optimistic, they may have a lower perception of their care load (Bekhet, 2013; Coen, O « Boyle, Coakley, & Lawlor, 2002).

The sense of caring

A particular feature, which affects different aspects of caregiving, concerns the meaning that is given to it (Quinn, Clare, & Woods, 2015), particularly in the early stages of the disease. In fact, family caregivers find themselves dealing with a completely new situation, with which they must learn to live (Adams, 2008). According to some authors, caregivers experiencing the first stages of the disease tend to feel weighed down, lost, and psychologically overloaded by the changes that the disease brings, as such changes are greater in the early stages (Quinn, Clare, Pearce, & Van Dijkhuizen, 2008). Making sense of what is happening and one's role in the situation is easier when clear information is obtained about it. Previous research has shown that caregivers often feel that they do not have sufficient information and support, neither about the condition of their loved one nor regarding available resources, services, and people they can refer to about the situation they find themselves in (Knapp et al., 2007; Putnam et al., 2010).

Family members, such as children or spouses, are motivated by different factors (Quinn, Clare, & Woods, 2010) when they choose to take care of their loved one with dementia and continue to do so for a long time. Family members are pushed to act in this manner for different reasons, including concern, love, guilt, or a sense of duty or moral obligation (Blandin & Pepin, 2017; Cahill, 1999; Daga, Corvo, Marucci, & Sansoni, 2014; Ducharme, Lévesque, Lachance, Kergoat, & Coulombe, 2011). Moreover, Cahill (1999) highlighted how the type, quality, and intensity of the relationship can affect the motivations that drive caregivers to take care of their loved ones. In fact, a key element of the care relationship according to the literature concerns the connection that existed before the illness between the person with dementia and their caregiver, as this affects the caregiving relationship (Ablitt, Jones, & Muers, 2009). Despite being supported by a strong bond and solid motivation, caregivers of people with dementia, even in the initial stages, find themselves facing a major challenge: balancing their own needs with those of the elderly person. It has also been found that even if caregivers are motivated and convinced that they want to take care of their loved one, they may struggle daily to balance their own needs with those of the elderly person, which often prove to be in opposition (Quinn, Clare, & Woods, 2015).

The caregiver's experiences

The caregiver is faced with a change, gradual or sudden, in their own life and that of their loved one (Hain, Touhy, & Engström, 2010). All this leads the caregiver, over time, to perceive a different relationship with the person they are caring for (Quinn, Clare, Pearce, & Van Dijkhuizen, 2008). Caregivers may perceive that they no longer have an equal relationship with their family member requiring assistance and suffering from cognitive impairment; it can even become difficult to ask him/her for an opinion or advice (Quinn, Clare, Pearce, & Van Dijkhuizen, 2008; Quinn, Clare, & Woods, 2015). The family often perceives that the elderly person with dementia is losing or has lost the role they previously had within the family. All this can create tensions, disequilibria, and difficulties for the different members of the nucleus (Pesonen, Remes, & Isola 2013).

Some family members experience a feeling of loss because they no longer recognize the person in front of them: they do not recognize their personality, character, gestures, ways of doing things, etc. In some situations, this leads to experiencing a deep feeling of mourning, like what a family member may feel after the death of a loved one, precisely because they feel that the person they love is no longer there (Sanders, Ott, Kelber, & Noonan, 2008). The caregiver also perceives a large sense of responsibility. They often feel unique and indispensable: unique because everyone experiences the burden of care in their own way, and indispensable because they perceive themselves to be irreplaceable and essential for their loved one's care. The caregiver realizes that they have new tasks, responsibilities, and burdens, and may worry about aspects of daily life that they had not even considered before (Quinn, Clare, Pearce, & Van Dijkhuizen, 2008). Facing this sense of responsibility and the change of role that the disease imposes, not only for the person with dementia, but also for the caregiver, presents the caregiver with an immense challenge that affects the overall family balance (Pesonen, 2013).

The positive aspects of caregiving

In addition to the many difficulties faced by the caregiver of a person with dementia, the positive aspects linked to caregiving are also highlighted in the literature. Lloyd, Patterson, and Muers (2016) pointed out the satisfying and gratifying aspects of the caregiver role. Research shows that caregivers who can find and experience the positive aspects of caregiving, despite remaining aware of the suffering and difficulties it involves, report lower levels of depression and anxiety, and are less affected by the behavioural disorders of the elderly relative (Pinquart & Sörensen, 2004). Roff and colleagues (2004) demonstrated how high levels of satisfaction with their care task and the ability to see the positive aspects of the situation reduced the likelihood of the institutionalization of people with dementia.

A positive aspect of the satisfaction that the caregiver can feel through taking care of their family member suffering from dementia is the awareness of having done their best and everything possible to care for their loved one (Quinn, Clare, Pearce, & Van Dijkhuizen, 2008). Satisfaction may also derive from a sense of pride in one's role and the tasks performed in relation to it, in contrast to caregivers who might see their role as an obligation and a constraint on their own life (Ribeiro & Paul, 2008). Furthermore, caregivers may derive satisfaction from being recognized for their efforts, especially if the recognition is from the person receiving the help (Ribeiro & Paul, 2008). Different studies have shown how caregivers claim to have grown on a personal inner level thanks to their role (Netto, Goh, & Yap, 2000). In addition, caregivers acquire new skills and competences related to care tasks (Ribeiro & Paul, 2008), problem-solving skills (Sanders, 2005), and those acquired by performing tasks that were previously performed by the care recipient, such as cooking, ironing, and managing the elderly person's finances (Ribeiro & Paul, 2008).

Furthermore, studies have shown how being able to maintain a positive relationship with one's loved one suffering from dementia is a particularly positive and beneficial aspect for both the elderly person and the caregiver (Lloyd, Patterson, & Muers, 2016). What allows the caregiver to face such a challenge is first the acceptance of the loved one's illness, its consequences, and the situation as a whole (Shim, Barroso, Gilliss, & Davis, 2013). Caregivers who manage to do this are those who agree to give up other projects that they had been devoted to, and live their lives one day at a time with the knowledge that the future is uncertain and unpredictable (Quinn, Clare, Pearce, & Van Dijkhuizen, 2008). To take this step, caregivers are often helped by others. The literature highlights how emotional support from other caregivers (Lloyd, Patterson, & Muers, 2016), such as through participation in self-help, mutual aid, and support groups (Anderson, Hundt, Dean, Keim-Malpass, & Lopez, 2017; Gaugler et al., 2011; Quinn, Clare, & Pearce et al., 2008), supports caregivers and people with dementia to accept the disease and implement better strategies to deal with its effects (Moon & Adams, 2013).

The research objective

The aim of the present study was to investigate the experiences of people and families experiencing the first stages of cognitive impairment and dementia to understand how and what type of help can be provided to support caregivers and their families. Emphasis was placed on the caregivers' perspective.

The research methodology

A participatory methodology was used for the development of the study (Bourke, 2009; Cornwall & Jewkles, 1995) in partnership with social workers, people with dementia, and caregivers. The participatory methodology is particularly appropriate for investigating subjects who may be vulnerable and/or marginalized, such as people with dementia and their caregivers. This methodology prescribes the direct involvement of those who were experiencing the topic of investigation first hand. In addition, participatory research provides access to groups that are «hard to reach,» such as people with dementia and their caregivers (Aldridge, 2015; Granosik et al., 2019).

The present study was implemented in Trento, a city with 118,000 inhabitants, and was financed by APSP Margherita Grazioli, a public company that provides services for the elderly. The research began with an exploratory phase in March 2015 and ended in May 2018.

An exploratory survey of the context was developed using the tool of participant observation in a day centre for elderly people in the area, where interviews were conducted with privileged witnesses, that is, family members, social workers, and health workers. The results of the exploratory investigation indicated that it would be interesting to focus on the early stages of the disease.

Once the general purpose of the project had been defined (i.e., focusing on the early stages of dementia), people who had direct experience with the problem (or life condition) being investigated and willing to participate in the research were sought. Therefore, subjects interested in forming what can be called a guidance group were sought; that is, a group of individuals that we interviewed for the study. The guidance group was composed of the following subjects: two people with dementia (a man and a woman), four family caregivers (two daughters, one son, and one wife), two social workers, one nurse, and two professional caregivers.

After training on social research instruments, the group decided to use semi-structured interviews to investigate both the caregivers' experiences and those of the elderly people with dementia. The interviews with caregivers, the subject of this paper, were conducted by caregiver co-researchers.

The sampling was done by selecting elderly people who attended six day-centres in the area thanks to a test administered annually to the subscribers, the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975), which assesses cognitive impairment in elderly patients. From the identification of people with mild cognitive impairment, it was possible to identify their principal caregivers. In summary, 27 people with cognitive impairment were sampled and 27 associated family members. Twenty-five elderly patients and their caregivers agreed to participate in the research as respondents.

The elderly patients interviewed were aged between 71 and 94 at the time of the study, with an average age of 85 years. Most of the elderly patients in the sample were women; the sample comprised 22 women and 3 men. There was also a clear majority of women in the caregiver sample: 18 women and 7 men. It is also necessary to specify that not all of the elderly people in the sample had received a diagnosis of dementia. In our research, we tried to include subjects in our sample who were in the early stages of dementia or had just recently been diagnosed.

Each interview was transcribed and conducted by one of the co-researchers. In this paper, we highlight the results of the interviews conducted with the caregivers, which had a minimum duration of 15 minutes and a maximum duration of 56 minutes.

Study results

The results of the interviews showed that dementia involves different concerns than just healing, and this has different effects on the experiences of family members who, by supporting and assisting their elderly family members, implement an action-based type of care.

The interviewees reported caregiving durations of varying lengths: one caregiver had been assisting their loved one for less than a year, and another had been doing so for over 10 years.

Caregiver struggle, of which there are different types and varying degrees, emerged in almost all interviews. Family members showed and expressed fatigue because, they said, caregiving is an unremitting process. Taking care of a family member with dementia, which requires a lot of time and effort simply to meet the patient's daily needs, leads caregivers to sometimes feel overwhelmed by this commitment that is often added to other responsibilities and burdens.

However, it is not just a matter of time and effort: taking care of a family member with dementia also involves the mental and emotional burden of being preoccupied about them, even when they are not with them. This means that even for family members who do not care for their loved one 24 hours a day, there is a risk that mental energies will be drained by worries that the elderly person may be sick, having trouble, or could get injured when they are not there with them. Other times, in addition to worry, a sense of guilt can arise for not being able to be with the elderly family member all the time. The caregivers reported that they were always preoccupied with their elderly family member, which was expressed by one of the interviewees in the following interview excerpt:

I have so many thoughts for her. In fact, I don't know, sometimes I find myself ..., sometimes it's hard it's hard to do everything, because I have a lot of responsibilities... *(caregiver, interview f3)*

Many respondents talked about the feelings, emotions, and consequences of giving up something to take care of their family member. This aspect is inextricably linked to the difficulty of reconciling various commitments, but it is also closely linked to the perception of fatigue that this entails for the caregiver. Having to renounce many things could lead to a vicious circle in which the caregiver cannot find time for themselves anymore, leading to increases in their perception of physical and mental fatigue.

Furthermore, the interviewees reported a great variety of tasks that the caregivers were responsible for, which differed primarily according to the level of self-sufficiency of the person being cared for.

The tasks that caregivers described included the following: shopping and preparing meals for the elderly person, reminding the family member to eat if necessary, management of administrative and bureaucratic aspects of the family member's life, and activities related to home management. Furthermore, they took care of the hygiene of the family member, the organizational and logistic aspects related to medical visits and the taking of medicines, and ensuring that the elderly person remained physically and mentally active through outings. Becoming a caregiver for some interviewees has meant having to learn to perform tasks that they had never even considered before. The acquisition of new skills and knowledge was acknowledged as a positive aspect by some of the interviews. For example, one caregiver stated:

A*fter [becoming a caregiver], I have had to go to the grocery store to buy groceries. I have even turned into a cook (caregiver, interview gi1).*

This means that for the caregiver, caring for their elderly family member has meant not only learning to perform new tasks and activities, but also learning to live differently. Thus, those who are close to this person suffer the consequences.

Attitudes and emotions of the caregiver

For different interviewees, it was important that the elderly person they cared for recognized their commitment and efforts. The acknowledgement or the lack thereof by the elderly person for the caregivers' efforts led to different responses among the interviewees. There were some who did not feel that their efforts were recognized, and this caused negative feelings and emotions.

Unfortunately, because of her way of being, I don't know what to say. For her, it is always too little. Because even though a cleaning lady comes every so often, I go there too, if only for a short visit. But because I have many things to do, I cannot stay longer. But, my daughter or I are there often to visit her, but for her it is never enough (caregiver, interview gi1).

Another caregiver experience that emerged from the interviews and greatly affected their attitudes concerns the sense of responsibility that drove the caregiver to assume the task of caring for his/her loved one. Some interviewees, in fact, expressed very clearly that the reason why they were taking care of their elderly relative was because of their sense of responsibility or even duty towards the person.

During the interviews, the caregivers expressed the feelings and emotions they experienced by living with a family member suffering from dementia. Some interviewees expressed real desperation regarding the situation, which they faced with great difficulty and weight. Some caregivers displayed feelings of sadness and despair, which conveyed how difficult it is emotionally to take care of a person suffering from a disease of this nature.

Every now and then, I cry myself to sleep over of the situation (caregiver, interview gi1).

Other caregivers, referring above all to the early stages of the illness, told how these moments were tiring because they found themselves faced with an unfamiliar and at times incomprehensible situation, within which they did not know how to orient themselves or cope with its challenges.

Furthermore, some of the caregivers expressed that what made them worry was the feeling of powerlessness in the face of such a situation, especially in the early stages of the disease. Many said that they felt helpless in the face of something for which no possible solution can be found.

An element that produced ambivalent emotions and feelings was making decisions on behalf of the elderly loved one. For some interviewees, it was something that was necessary, because the elderly person was no longer able to make certain decisions or take certain actions. According to several caregivers, their family member was no longer able to make decisions that concerned them, so they were placed in the position of having to make decisions on their behalf to avoid negative consequences for their elderly relative. Other interviewees explained that this was a source of fatigue for them in the past, but they had learned how to manage and understand it as a necessary part of their care responsibility. The interviewees stated that the load related to making decisions on behalf of an elderly loved one could be lightened by the support and involvement of others, usually family members. The decisions were therefore still made on behalf of the elderly person, but by several people through discussion.

However, there is not always collaboration and harmony among family members. Although, to a lesser extent, some of the caregivers interviewed reported a lack of collaboration from family members, but more generally they referred to moments, events, and circumstances in which they decided to express their need for their family members' help. Some caregivers expressed that asking for help from other relatives was not possible, because there was no one else who was able and/or willing to help.

Cognitive impairment and/or dementia

During the interviews, attention was paid to early onset cognitive impairment and dementia.

An important first line of demarcation with respect to the onset of dementia is among family members who have seen a sudden change in their elderly loved one, and among those who have observed slow and gradual change. There were caregivers that pointed out, even as the disease progresses, that the situation is often not a stable one, despite deterioration being certain and constant. On the contrary, the interviewees said they were confronted daily with sudden changes, in which their loved one seemed to be the same person as always at some times, while at other times they failed to recognize their caregiver. There are thus ups and downs that disorient families and make it difficult to manage and control the situation.

The caregivers told us, in a very genuine way, how the moment of onset of the disease, or at least the moment when the symptoms first occurred, is the most complicated and difficult to understand. The caregivers explained to us how many of their reactions, feelings, and emotions were particularly strong at the beginning of the illness, because they were faced with an unanticipated situation that they did not know how to face.

These are reactions that arise from the first signs of the disease, which, according to the caregivers, can be different and very difficult to understand and manage. The interviewees were faced for the first time with a family member who was no longer able to manage his/her money. Some of the elderly relatives had become completely unresponsive, and no longer carried out any kind of activity independently, even the most basic. Another element that triggered a wake-up call in the interviewees was seeing their loved one in a confused and disoriented state. Another initial sign of dementia is getting lost easily. A wife caregiver noticed that her husband was no longer able to drive. In addition to these signals, the element that most often alerted family members that there was something different, strange, or incomprehensible about their loved ones was memory loss. This was not always given the relevance it deserved, but often later, in connection to other symptoms described above, the caregivers knew that there was a problem. These signals in some of the situations encountered led the caregivers, and sometimes even the elderly people themselves, to seek medical help and finally a diagnosis of dementia. Such diagnosis was, some cases, obtained with great difficulty, but brought a sense of relief in that the whole situation was now easier to explain.

I felt total panic, above all because I immediately thought it was Alzheimer's before I had taken her to a doctor, since a friend of mine's mother had suffered from Alzheimer's for years, she had recommended a doctor to me. I took her to this doctor, who told me «in my opinion it is not Alzheimer's, only a loss of concentration,» which was the same thing that a doctor friend of mine had also told me (caregiver, interview g2).

A central finding of the analysis of the interview data concerns the different perceptions that caregivers have when they become aware that this cognitive impairment exists and has an impact on the lives of the people involved.

Some caregivers perceived the cognitive deterioration of their loved one as something that is an unescapable part of life. Cognitive deterioration was perceived by the caregivers as part of the natural aging process, leading to what was perceived as an inevitable decline. Others tended to minimize the problem, trying to make the interviewer understand how cognitive impairment had not affected all of their elderly relative’s abilities. Others instead emphasized the difficulties faced by their loved one, to the point of almost devaluing their abilities and personality, believing them to be incapable of performing even the simplest daily tasks.

Symptoms, difficulties, emotions, and mixed feelings led the caregivers to seeks strategies they could use to help them deal with this difficult situation. During the interviews, the caregivers explained different strategies they used to deal with their situation; in some cases, good results were achieved, in others, not. In addition to adopting more practical tactics, the caregivers adopted strategies focused more on their attitudes towards the situation. The first strategy was to work on themselves by not getting angry, trying to stay as calm and relaxed as possible, and avoiding negative reactions to the elderly relative’s behaviour. In sum, the caregivers explained that they tried to control their own reactions, knowing that what could lead them to lose control were symptoms of the disease.

A common attitude among the respondents was trying to avoid doing too much for the family member by allowing them to do all the tasks they were still able to do on their own, while at the same time being there for them if they needed support. Thus, this means facilitating the actions of the elderly loved one without doing the tasks they could still do on their own for them. Adopting such an attitude allowed the caregivers to maintain and enhance the residual abilities of their elderly loved ones.

Some interviewees told us how they had learned to face situations and obstacles with an awareness of their unpredictability; this means that being aware that everything can change at any moment is fundamental for a caregiver. Thus, the caregivers had to be flexible concerning their own ongoing plans and projects.

The interviewees were asked if they believed that their loved one had lost their former role in the family, and in the event of an affirmative answer, they were asked what they were most nostalgic about. The respondents’ answers were very different from each other and allowed different observations and interpretations. Many of the interviewees said that they had a different person next to them, a person who they sometimes had difficulty recognizing and imagining as the mother, father, husband, or wife they had prior to the onset of the illness. This change in the subject led the caregivers to have different types of nostalgia: nostalgia for the person who was no longer recognizable or there with them. Some of the interviewees described it as a type of grief or mourning. The caregivers nostalgically remember the relationship that once existed between them.

Over the last few years, I have lost both of my parents. One from an illness, and the other from this disease, which is maybe even worse... (caregiver, interview gi1).

Other caregivers, on the other hand, claimed to have gained something positive from their experience with the disease. After their elderly relatives had become ill, they acquired characteristics and put into practice attitudes that the interviewees described as positive elements that improved their relationship.

The relationship with services

One aspect that emerged in most interviews concerns the difficulty caregivers experienced in following the necessary and complicated processes in their encounters with care services and professionals. They said that they found themselves facing procedures that were sometimes highly bureaucratic and long in terms of the time and steps that were required. They recounted very confusing dynamics and passages, in which they felt disoriented and alone. The period in which the caregivers needed the most help and information, even very practical and concrete guidance with respect to the steps to be taken, is the early stages of the disease. The situation was worsened by the fact the caregivers had not even received guidance on the practical and procedural aspects of dealing with a family member with dementia. They expressed the need for clarity and guidance at a time when everything seemed confusing and surreal.

Yes, yes. I... the only thing that maybe I found difficult was when it all started. Then, when one understands the subject a bit better, all is channelled, then the aspects are immediate, but making first contact is always a bit problematic. Afterwards, when one is a little more familiar with how it works, so much assistance is available, so many people are available, but in the beginning I found it problematic and difficult. Sometimes, maybe you don't understand well, then I resort to other caregivers ... (caregiver, interview g3).

What emerged from some of the interviewees was that among family members, there is someone who gives the relationship with the services a meaning strictly connected to the provision. In fact, following this logic, some caregivers said that they had no relationship with the services because they had not requested any kind of services or had not yet received them. Thus, the work of the professional, which goes beyond the individualized provision of social-welfare services provided by the welfare system, risks not being perceived as such and consequently losing its value.

The family

The caregiver is often surrounded by family members who in some cases support and in others hinder their work.

There are situations where the collaboration among family members is so high and valued that there is no main caregiver, and the burdens and tasks associated with the elderly loved one's care are equally distributed. In some cases, there is a clear separation of tasks for everyone: basically, in families with more children, each child tends to have one or more tasks, or there is a division in the hours or days in which the family members take care of the elderly loved one. There are other situations in which the principal caregiver is clearly distinguished, but at the same time, this caregiver knows they can depend on other family members to help them with the elderly loved one's care.

This results of the research confirmed a simple yet essential element of caregiving: the more collaboration there is among family members, the lower the care burden for individual caregivers, regarding both the physical and emotional components of caring.

The interviewees were asked whether and how having a loved one in the early stages of cognitive impairment and dementia affected their relationships with other family members.

Some interviewees described the positive effects on their family, such as positive experiences regarding the necessary collaboration to care for their loved one, and the opportunity to bring the whole family together to confront the problem and express themselves freely.

No comparison is essential and from there one says, «Oh well this is how things are, so let's roll up our sleeves.» The confrontation was more than anything with my husband. Then there are my cousins, who in turn had my aunt, who, poor woman, was also sick a year ago. So, I couldn't ask them for help, but for now I can handle it on my own ... (caregiver, interview g4).

Support from other caregivers

Many interviewees said that they had had the opportunity to talk to other people who were experiencing a situation similar to theirs, and derived some benefits from it. They understood the meaning of the disease and were focused on what to do and what to look for; they found more information and opportunities for discussion and exchange with people with similar experiences rather than with professionals.

Others have simply acquired the awareness that many people have problems similar to their own and that by connecting with them one can obtain information and practical advice which, especially in the early stages of dementia, is essential. The interviewees mentioned work colleagues as a source of such support and information.

Different caregivers clearly explained how communicating with those who had already experienced or were currently experiencing a caregiving situation with an elderly relative was the most useful and authentic source of support. The interviewees were convinced that they could fully understand what was happening to them and could only communicate authentically and deeply with those who fully understood what they were talking about because they had lived through it themselves.

Finally, the interviewees said they had acquired knowledge and skills themselves after having passed through this kind of experience. Acquiring such skills and knowledge based on experience had made them into experts. Thanks to their own experiences as caregivers, they had acquired experiential knowledge and skills that only those who had experienced similar situations could obtain and transmit. These acquired skills, some caregivers said, in turn served to help those who were in similar situations to their own.

Conclusions

Like any qualitative study, the results of the present study cannot be generalized, even within the context in which they were collected, analysed, and discussed. However, the research presented herein confirms various findings in the literature.

The present study confirms that the fatigue and burdens experienced by caregivers are not only physical but also, and perhaps more importantly, emotional (Coen, O'Boyle, Coakley, & Lawlor, 2002; Chiao, Wu, & Hsiao, 2015; Heron, 2002). These hardships do not only concern those providing ongoing, 24-hour assistance to an elderly family member. From the literature (Quinn, Clare, & Woods, 2015) and interview data, it is clear how the caregivers who can understand the importance of balancing their own well-being with that of their loved one experience lower stress levels than those who cannot. It is important for a social worker to be aware that the needs of the person with dementia and those of his/her caregiver do not always coincide; in fact, sometimes they are opposed. It is therefore essential to find a way, and it is certainly not easy, to be able to reconcile the needs of both parties involved. Being able to take this step leads to positive repercussions for the caregiver, the elderly person, and the relationship between them.

Another important finding of the present study is the importance of caregivers recognizing and valuing the positive aspects of their caregiving experience (Bekhet, 2013; Coen, O'Boyle, Coakley, & Lawlor, 2002). The interviewees reported how the change in their loved one caused them to lose something, but it also allowed them to learn about the positive aspects in their characteristics, the attitudes of their loved one, and their relationship with them, which before the illness were not a part of the caregiver or their relationship with the elderly loved one. This finding is consistent with recent research (Lloyd, Patterson, & Muers, 2016). For example, caregivers may succeed in acquiring a different perspective that allows them to recognize the positive aspects of the situation they are experiencing, and the awareness that although the difficulty cannot be eliminated, they can try to see what has been gained in terms of the relationship with their loved one (Netto, Goh, & Yap, 2000; Ribeiro & Paul, 2008). On the one hand, this allows the caregiver to feel less burdened, and on the other hand, it can give the person who is suffering from the illness the feeling of being loved, respected, and valued.

This also allows the caregiver to overcome a major obstacle linked to the difficulties that arise when a caregiver has the perception that the role of their loved one has dissolved and/or that their role has consequently changed to compensate for the deficiencies of the person with dementia (Pesonen, Remes, & Isola, 2013; Ribeiro & Paul, 2008).

Based on the literature and the results of the present study, a clear risk is that the elderly person will lose their former role within the family, will not be recognized as the same person, and the caregiver will not feel recognized by the elderly person for their efforts (Quinn, Clare, Pearce, & Van Dijkhuizen, 2008; Quinn, Clare, & Woods, 2015), and thus they will act only out of a sense of duty towards them (Blandin & Pepin, 2017; Ducharme, Lévesque, Lachance, Kergoat, & Coulombe, 2011). If people can manage to change their perspective, valuing the new and perceiving the positive aspects of the change, they can overcome thinking patterns that debilitate the caregiver, the elderly person, and the entire family (Lloyd, Patterson, & Muers, 2016; Roff et al., 2004).

Furthermore, the results of the interviews with the caregivers show that the weight of the care burden is amplified even more in cases in which the family members do not receive the information and explanations they need (Knapp et al., 2007; Putnam et al., 2010). This means obtaining clarifications that allow the caregiver to face the situation in the best way possible, albeit with struggle and difficulties. Obtaining information and guidance does not lead to the elimination of pain and fatigue, but allows them to acquire the tools they need to cope with a situation that, by its very nature, cannot be addressed through a healing-oriented logic.

An important source of information and support is from people who share the same life experience (Lloyd, Patterson, & Muers, 2016). Consistent with the literature, the present study found that being able to share their experiences with people beyond the boundaries of their own families was an important source of support for the interviewed caregivers (Anderson, Hundt, Dean, Keim-Malpass, & Lopez, 2017; Gaugler et al., 2011; Quinn, Clare, & Pearce et al., 2008). The interviewees placed a high value on the sharing and exchange of information and advice with people who had lived through or were currently experiencing similar situations. The lack of adequate information from services and professionals could be compensated by the advice and support received from friends and colleagues who understood their situation. The knowledge and skills acquired thanks to the experience of caregiving allowed them to become *experts by experience*: a person who by virtue of their experience with a problematic situation has acquired experiential knowledge and skills, which can be obtained and transmitted only by those with similar experience (McLaughlin, 2009). People who have assisted a person with dementia or individuals who are suffering from the disease themselves receive help or provide help to individuals who are in similar situations. The provision of welfare benefits, often indispensable in these situations, is not eliminated, but is part of a broader network of support shared between professionals and family members. On the contrary, an approach of this type must provide for the caregiver and the person with dementia a way to have their say and actively contribute to the situation (Ribeiro & Paul, 2008), as well as a way to use their own abilities to cope with the situation and their own prodigious resistance (Folgheraiter, 2016, 406). The person who asks a professional for help must be encouraged to reflect on the fact that this attitude of the professional is not a symptom of a lack of professionalism or will to help, but is the only useful and valid method to face a challenge of an existential nature such as dementia.

To provide all the parties involved with some benefits, it is essential that a specific process is activated: the person who helps and is helped at the same time need to recognize themselves in the other, to identify the similarities between their own situation and the situation experienced by the other (Anderson, Hundt, Dean, Keim-Malpass, & Lopez, 2017; Quinn, Clare, & Pearce et al., 2008).

The logic of sharing and enhancing experiential skills is the logic that has guided the present study, using a methodology that has made it possible to demonstrate the importance of these experiential skills and how they can be valued also within the research itself. In the research presented here the co-researchers, like the users of the services, were considered experts thanks to their experience of the disease and through their contribution to the study design, implementation, and dissemination (Granosik et al., 2019; Aldridge, 2015). The implementation of such research brings added value both to the research itself, to its process, and to the results obtained through it, thanks to the contribution of family members and people suffering from the early stages of dementia.

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