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The demands of care and self-care from the family caregiver's of the elderly with dementia perspective

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Abstract

Objective: Aimed to know the personal demands of family caregivers through conducted roundtables. *Method:* In 2017, two groups were conducted with 6 roundtables each with the following guiding questions: 1) "Who am I? Who do I take care of?"; 2) "What is dementia for me?"; 3) "What is my role in the daily care activities of the person with dementia?"; 4) "What are my thoughts or emotions that are triggered by caring?" 5) "Can I see something positive in this caring experience?"; and 6) "How do I care or could take care of myself?". Inclusion criteria were: to be a caregiver of the elderly with dementia, to have been doing this role for at least 6 months, and to be available and willing to participate in the meetings. The roundtables took place every fortnight with an hour and a half minutes of duration each, with an occupational therapist as facilitator. All the roundtables were recorded, transcribed, and analyzed through the thematic content analysis. *Results:* Fifteen family caregivers participated. From the analysis, nine thematic categories emerged: self-perception of physical and emotional impairment; the search for support; caregiver overload and stress; what I learned from this experience; the mixture of feelings; the losses; valuing the simple aspects of daily life; I already take care of myself; and I need to take care of myself. *Conclusion*: the identification of these personal demands of family caregivers of elderly people with dementia can raise awareness and make health professionals aware of the importance of considering these aspects in proposing interventions focused on caregivers.

Keywords: Aging. Dementia. Caregiver. Occupational Therapy.

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INTRODUCTION

Currently, 47 million people worldwide live with dementia. Approximately 70% of them reside in the community. Most people living with dementia in the community require assistance to perform their Basic Activities of Daily Living (BADL's) such as eating, dressing and cleaning, and to perform the Instrumental Activities of Daily Living (IADL's) that involve financial control and administration of medication, among other activities, as well as the need for help and/or support for rest, sleep and leisure activities[1.]

Care in dementia has been provided mainly by families, represented in the figure of a main family caregiver[1]. Studies have pointed out the negative impacts on the exercise of care regarding changes in the lifestyle, financial and health problems of the caregiver[2-5]. However, more recent research has identified positive aspects related to the role of caring (e.g., personal growth, approximation of broken relationships), which can minimize caregiver burden and stress[6,7.]

This care represents a great burden on the caregiver due to its progressive nature, its long duration, and the absence of disease-modifying treatments. In addition, dealing with the decline in cognitive and functional skills of the person with dementia, offering physical and emotional support, administering medication, dealing with symptoms, with personality changes and with the loss of communication, among other aspects, ends up compromising physical and emotional health, quality of life and well-being of the caregiver.

Many interventions, including occupational therapies, are aimed at family caregivers with a focus on orientation in relation to managing daily activities, handling behavioral changes, and dealing with the the burden of care. Dizazzo-Miller et al.[8] point out that support groups and educational programs are as essential for caregivers as medications are for people with dementia. Nevertheless, a review study with the objective of knowing interventions proposed to caregivers shows that there are few actions that work on the personal aspects of caregivers themselves[9].

Thus, it is essential to know the care and self-care demands of family caregivers of elderly people with dementia, through their perspectives, shared on roundtables.

METHOD

The present research is a pilot and was developed from the realization of two groups with 6 roundtables each, with the main objective of identifying the personal demands for care and self-care of family caregivers of people with dementia.

The study is in accordance with Resolution No. 466/2012 and Resolution No. 510/2016. It was submitted to the Ethics Committee in Research with Human Beings at Federal University of São Paulo (UNIFESP) and divulged on social media in the Baixada Santista region only after approval. The registration of the family caregivers was done by digital means through a disclosed e-mail. The registrants were contacted and invited to participate in the roundtables at a previously scheduled date and place. All participants were informed about the ethical principles and objectives of the research and asked to sign the informed consent form (ICF).

To reach a larger number of relatives, two groups of family caregivers were conducted in the year 2017 (April to June and September to November). The inclusion criteria of caregivers were: to have been exercising the role of family caregiver for at least six months; to be a caregiver of the elderly with dementia; to be interested and willing to participate in the meetings. The exclusion criteria were: being a professional caregiver, not being willing to be present at two or more meetings.

To guarantee the ethical principle of secrecy and non-identification, all caregivers were identified with the abbreviation of the acronym caregiver (C) followed by the ordinal number (1-15).

Morin[10] points out that "the roundtables, from the point of view of complexity, connect seemingly separate issues, so that the parts and the whole are captured as facets of the same object, which is in itself complex and contradictory, hard and utopian: the social conditions and the reality to be (re)constructed ". Each roundtable had an open-ended question that guided the discussions. In each group, six roundtables were held with a fortnightly frequency between each of the meetings, lasting one and a half hours each, facilitated by two occupational therapists, one of them being the responsible researcher and the other being a scientific initiation scholarship student (PIBIC-CNPq).

The guiding questions were: 1) "Who am I? Who do I take care of?"; 2) "What is dementia for me?"; 3) "What is my role in the daily care activities of the person with dementia?"; 4) "What are my thoughts or emotions that are triggered by caring?"; 5) "Can I see something positive in this caring experience?"; and lastly 6) "How do I take care or could I take care of myself?".

All the roundtables were recorded, transcribed, and subsequently analyzed through the thematic content analysis proposed by Minayo[11]. This method presupposes the comprehensive reading of the selected material for the impregnation of the speech, the exploration of the material in order to reach from the "revealed" to the "veiled" and the elaboration of an interpretative synthesis articulating central themes. The meetings were conducted by the responsible occupational therapist. The statements were transcribed by the collaborator and later analyzed by the two of them. In the process, each of the therapists qualified the transcriptions in units of meaning. Then, a consensual analysis of these units was carried out, from which nine thematic categories emerged and which will be discussed in the following results.

RESULTS AND DISCUSSION

Eight family caregivers participated in the first group. Six (75%) were women and two were (25%) men. In the second group, seven (100%) were women. The average age of the participants was 66 years old, ranging from 49 to 88 years old, while 13 (86.66%) family caregivers were over 60 years old. The most common degree of kinship was that of spouse in eight (53.33%) of the participants, followed by six (40%) offspring and one (6.66%) sisters. Regarding the diagnosis, 14 (93.33%) reported that their relative had dementia from Alzheimer's disease. From the previous explanation about the disease phases as well as the main signs and symptoms of the respective phases, the caregivers identified that seven (46.66%) of their family members were in the moderate phase, four (26.66%) in the initial phase and four (26.66%) in the advanced phase.

The thematic categories discussed below emerged from the collected reports.

In the first roundtable, the facilitator presented the group's objectives and participation rules. Henceforth, asked the following question: "Who am I? Who do take care of?", allowing space for each caregiver to present themselves by highlighting the name, degree of kinship with those they cared for and other information deemed important. From the analysis of the caregivers' reports collected, two categories were identified:

1ª) Self-perception of physical and emotional impairment

There is an abundance of literature based on stress coping paradigms, because of the scientific evidence that family caregivers of people with dementia experience stress, overload, depression, and a variety of changes in physical health as a response to their role as caregiver. Duggleby et al.[12] point out that among the changes in physical health are the decrease in immune system response and increase in risk of cardiovascular disease, hypertension, and insomnia.

C9 (Sister) points out, "I don't think she is depressed, but I am." Researchers examined the differences between depression and anticipatory grief in caregivers and observed that the symptoms of separation anxiety or anxiety in general are part of the experience of bereavement, but not of depression[13]. Anticipatory grief (AG) refers to the process of experiencing as phases of mourning (postmortem) before the concrete loss of a significant person[14]. The cognitive focus of depression is on the negative interpretation of self and the world, while in AG the focus is on the experience of loss[15]. Such aspects deserve the gaze of health professionals regarding the specific demands of this care.

2ª) The search for support

Study by Grigorovich et al. identifies that family caregivers, despite searching for information about the disease, largely on the internet, recognize as essential the participation in support groups for the exchange of experiences and guidelines for daily care, as well as for sharing services available in the community, sometimes not well publicized and accessed[15].

> "All I have difficulty with, I seek to understand, because when I understand, I begin to accept". C10 (Daughter).

This statement suggests that the possibility of seeking information, participating in discussions and sharing experiences can be strategies used to assist in the elaboration of the diagnosis and in the developments involved in each stage of the disease. A study carried out with 226 pairs of family caregivers and their elderly relatives with dementia identified 505 unmet needs of these family caregivers. Of these 226 family caregivers, 171 (75.7%) had at least one unmet need. These unmet needs were grouped into 17 categories, 19% of which were related to support groups. This study also points out that factors such as the low level of education and the advanced age of the family caregiver, as well as being the spouse of the elderly person with dementia and the greater degree of functional impairment of this person, as the disease progresses, are associated with higher levels of unmet needs[9].

The second roundtable aimed at answering the question: "What is dementia for me?". Each of the participants spoke about their perceptions and impressions regarding the disease. The third and fourth category emerged in this encounter:

3ª) Caregiver burden and stress

Alzheimer's disease significantly changes the daily lives of families and, especially, the caregiver's. Because it is a chronic and progressive disease that lasts for many years, it carries great emotional and socioeconomic repercussion, besides the physical, emotional, and social demands. Au et al. point out that such aspects may have negative long-term effects on the family caregiver who will carry out a greater number of care tasks besides the need to devote more hours as the disease progresses[16].

> "Almost two and a half years ago, my life completely changed! I do not do what I like to do anymore". C8 (Wife).
>
> "There are times when I totally lose my temper. I sleep very little because I get caught up all the time thinking about the situation we are in. I sleep 2 to 3 hours per night". C12 (Wife).

The care provided to elderly people with dementia becomes very complex, as the family finds themselves involved in feelings that are difficult to manage, which end up imposing a certain isolation on self-care activities, which can affect emotional systems, generate deprivation and changes in the lifestyle in order to include the new needs of their relative.

4ª) What I learned from this experience

Some studies have pointed out the perception of positive aspects related to the experience of caring for dementia. An integrative review developed by Doris, Sheung-Tak and Jungfang identified four central themes that were grouped into personal performance, feelings of reciprocity, greater family cohesion and life purpose. Such findings corroborate with some statements identified in our groups[17].

> "My husband has always been a man who did everything. I've never had any responsibilities. Suddenly I found myself in a situation where I had to take over everything and take care of him. Now I am able to give him the quality of life that he deserves. With patience, I was able to learn things I never thought I would". C5 (Wife).

Peacock et al. in their study identified that wives tended to feel that care was a natural continuation of the marital relationship[18], just as C12 (Wife) puts it: "I think I have an obligation to care of him because we are married. We grew old together, so I have to take care of him". In each one of the reports described, it was possible to identify the recognition of situations in which caregivers mention positive aspects related to care, but that, perhaps, the number of negative situations routinely lived did not allow them to reflect on this matter before the participation in the group[19.]

The objective of the third roundtable was to identify, based on the reports, the difficulties of the caregivers in relation to the demands on the basic activities of daily life of their relatives. Thus, when asked the question, "What is my role in the daily care activities of the person with dementia?" The caregivers' reports have more broadly emphasized the emotions and feelings that come with the activities of care rather than the activities themselves. The fifth category emerged:

5ª) The mixture of feelings

Feelings such as sadness, regret, guilt, emotional pain, anxiety, loneliness and anger are related to anticipatory grief, which is defined as a reaction to the perception of loss, and tends to be a primary reaction to the care of a person with dementia.

While C13 (Wife) realizes that she is isolating herself from her previously performed activities and says: "I need to worry less because it makes me sad. Every time you look at yourself, you become dissatisfied with your attitudes and your isolation", C15 (Wife) feels limited in the sense that she has lost her freedom and says, "I feel angry and stuck on some occasions. I feel a certain limitation."

Still in the face of perceived loss, in the report of C4 (Wife), the loss of relationship and intimacy in relation to her husband and his social role is clear when she says: "I feel very alone. I also feel great sadness, because before he was sick, I had someone to share my problems with, I had my husband."

Studies relate the grief experienced by the caregiver to multiple losses throughout the disease. Research on grief in caregivers has identified that, among the multiple losses that are experienced throughout the illness, are the loss of socialization, intimacy, communication, roles, and relationships[22-25].

The fourth roundtable had as a guiding question: "What are my thoughts or emotions that are triggered by caring?" and gave rise to the following category:

6ª) The losses

The emotional and psychological suffering experienced by family caregivers has challenged the paradigm of overload and stress by recognizing AG as a critical component of this experience. This recognition emerged in an attempt to understand what family caregivers experience during the care trajectory. In the context of dementia, the AG can extend for many years while family members witness the deterioration in the affected person's cognitive, social and physical functioning, as well as experience losses in relation to the past, present and future[27.]

The following statements are from three family caregivers (spouses) in which we can identify aspects related to anticipatory grief respectively, in relation to the present and future losses:

> "When I lie down to sleep, I think about everything. The situation I am in, what I am going through, what will happen...". C12 (Wife).
>
> "I'm very whiny. I'm afraid. I wonder what is going to happen from now on and I am very worried about the future". C4 (Wife).
>
> "I think I'm afraid and I do not even know to what extent. I've been distressed because sometimes I'm worrying by anticipation!". C11 (Wife).

Sanders et al. based on the principles of Bowlby's Theory of Attachment, says that grief occurs naturally in these caregivers because the bonds or feelings of attachment they had with their family member before the start of cognitive decline become tense as memory loss and cognitive impairment progress.

The stronger the attachment, whether it is physical, psychological or emotional, between the caregiver and the person with dementia, the stronger the feelings of grief and loss will be[28].

Marwit and Meuser point out:

> "The anticipatory grief of family caregivers in the context of dementia is more like true grief than the anticipatory grief experienced by caregivers of people with other terminal illnesses" (p.202)[27].

These researchers also sought to differentiate the grief experienced by caregivers based on the relationship status they have with the elderly with dementia and stage of the disease. They also examined the anticipatory mourning experienced by adult spouses and offspring at each stage of the disease (initial, intermediate, and advanced). The results showed that the anticipated mourning experienced by the spouse increased as the disease progressed, corroborating the above-mentioned reports[29].

We began the fifth roundtable addressing the simple aspects of daily life that should be valued. We present the video: "Who, me?"[30] scored by Fernando Aguzzoli. Next, we opened spaces for the caregivers to reflect on the question: "Can I see something positive in this caring experience?". With the analysis of the reports, the seventh thematic category was identified:

7ª) Appreciation of the simple aspects of everyday life

Qualitative research conducted with family caregivers of elderly people with dementia aimed to understand the nature of caregivers' daily occupations about well-being. The results showed that the centrality of occupations in daily life represents for family caregivers a way to monitor the well-being of their family members through some indicators such as: expressions of affection, humor, pleasure and success in performing IADL's[31.]

In fact, these indicators were present in the reports of some caregivers in our roundtables. C5 (Wife) described a well-being situation in the face of her husband showing affection:

> "(...) I asked him (husband) if he wanted to lie down. That was when he turned to me and gave the impression that he recognized me, recognized my voice. I turned to the chair where he was sitting and he gave me a smile... I got up to him, gave him a hug and took him to the room, where I said, "I'm glad you're going to sleep now," and you know what he said to me? "I know you!". Then he put his hand on my face. It had been a long time since he had said anything of that sort".

The sixth and final roundtable aimed to identify and reflect on the activities dedicated to taking care of oneself. With the trigger question: "How do I take care or can I take care of myself?" the last two categories discussed below emerged:

8ª) I already take care of myself

A study on the use of family caregivers' time brought the classification of Chapin's activities into two groups defined as mandatory and/or discriminatory activities. While in the former, the caregiver has a greater degree of restriction of choice because the activities are related to the basic necessities of survival of themselves and of who receives their care, in the discriminatory, the caregiver is more open to the options of activities that involve social interaction inside and outside the family, religious activities, reading, TV, listening to the radio, recreation, relaxation and rest. Factors such as age, education, income, marital status, socioeconomic status, cognition and the environment itself may interfere with the choice, flow and investment in certain groups of activities[32].

In this last roundtable group, it was fundamental to reflect on all the themes developed during our meetings in a way that could bring aspects marked from the experience in the roundtables. Some caregivers have reported to be already dedicating some time from their routines to activities that bring pleasure and satisfaction.

C2 (Spouse) identifies the significant activities already inserted in her daily life when speaking:

> "I go hiking every day and take care of my diet. When I find the time, I do crossword puzzles. Sometimes I use my computer, search the internet, and play games. I visit my children whenever it is possible... Sometimes I think, "If she is (wife) sick I have a problem, but if I also get sick, I'm going to have two problems".

C12 (Wife) uses her hand skill as a way to relax: "I really like doing crafts and sewing. That's how I get distracted.". On the other hand, C5 (Wife), to relax, prefers to leave the environment in which she lives and dedicates care to her husband and points out: "I try to do everything I can to not feel bad. I go out, I go to the cinema, most of the time, alone".

9ª) I need to take care of myself

Although a large part of the activities carried out by the caregivers are related to caring for the other to the detriment of self-care, the groups facilitated awareness and reflection on the importance of (re) inserting significant moments previously abandoned in the daily life.

C6 (Daughter) recognized:

> "To take care of myself I do not need to go to the hairdresser, I do not have to buy expensive clothes, I just need some time for myself. And I have not had that time; time to travel, to meet new people, different places... freedom that I do not have."

The loss of freedom and social contact to the detriment of the accumulation of functions aimed at the care of the other was pointed out as one of the forms of detachment from this look to itself.

C5 (Wife) concluded:

> "It's time to take care of myself. Go back to doing my physical activities and walks. My joys will give me strength to continue to look after him and always be able to offer and say that I love what I do!".

Carvalho draws attention to the importance of organizing the day-to-day care of these family caregivers to ensure that they carry out meaningful activities sufficient to meet their interests, without competing with caregiving activities. Thus, the physical and psychological well-being of the caregivers can increase, benefiting not only them, but also those who receive their care[33].

A study developed with the objective of helping family caregivers to reach their personal goals, through telephone intervention, using the cognitive-behavioral therapy method, identified, as results, three central themes. They are:

- Problem solving (Managing behavior changes, increasing time for your own needs and activities, getting more support with care);
- Cognitive dysfunctions (Reducing the permanent concerns that something might happen to your relative with dementia when you are not around; learning to deal with feelings of guilt by doing pleasant things without the relative; enjoying life more and seeing things in a more positive manner; managing the feeling of guilt when delegating care tasks; reducing the perfectionist standard of care);
- Emotional Regulation (Learning to deal with changes in one's life and increasing the acceptance of the disease; feeling calmer when dealing with behavioral symptoms; learning to accept and deal with feelings of loss; talking about what it feels like to have emotional relief; dealing with the fear of the future and the death of their family member)[34.]

Despite the results of the aforementioned study corroborating the findings of this study, it is important to emphasize the need for an expanded look, which needs to be more personalized to family caregivers. Still, it is worth pointing out some limiting aspects were encountered: the number of groups evaluated was reduced because it is a pilot study; it would be necessary to understand and adapt these thematic categories for other groups in different social, economic, cultural contexts, as well as to different regions from the country.

CONCLUSION

Sensitizing and making family caregivers aware of the need of self-care is an important strategy to facilitate the elaboration of negative aspects arising from the care of others, promoting the expansion of their gaze to the positive perspective of care and valuing simple actions inserted in this daily life.

It is important to consider that, currently, most services and health professionals focus their gaze and their intervention proposals on the care of elderly people with dementia based on the guidelines restricted to this care, with a focus on caregiver overload.

This proposal for differentiated intervention is already described in the international literature, but it is little explored Brazilian literature[9,34,35]. Proposing actions that broaden this view to the care and self-care demands of family caregivers in dementia, in their perspective, can be a more effective approach, as it would allow a space for reception to the central emotional issues involved, which compromise the quality of care, life and well-being of these caregivers.

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