

# FAMILY CAREGIVERS OF DEPENDENT ELDERLY: SAME NEEDS, DIFFERENT CONTEXTS – A FOCUS GROUP ANALYSIS

Cuidadores familiares de idosos dependentes: mesmas necessidades, diferentes contextos -muma análise de grupo focal

Carla Sílvia Fernandes<sup>a</sup>, Ângelo Margareth<sup>b</sup>, Maria Manuela Martins<sup>c</sup>

## ABSTRACT

**OBJECTIVE:** The present study aimed to identify the needs of the family caregiver of dependent elderly in a different cultural dimension, integrating the social, political and economic reality of each community. **METHODOLOGY:** This phenomenological study was carried out with two groups of caregivers of dependent family members from Portugal and Brazil, using focus group as a data collection instrument. **RESULTS:** From the analysis of the narratives of the 12 caregivers who participated in the study, a set of categories emerge: the need to learn alone, the need for time to maintain the roles, the need for a support network, resilience in imbalances family, and the resources to care for them. **CONCLUSION:** In this work it was possible to highlight similarities in the needs of the caregivers of the two countries.

**KEYWORDS:** family caregivers; elderly; needs assessment; nursing.

## RESUMO

**OBJETIVO:** O presente estudo pretendeu identificar as necessidades do cuidador familiar do idoso dependente numa diferente dimensão cultural, integrando as realidades social, política e económica de cada comunidade. **METODOLOGIA:** Este estudo fenomenológico foi realizado com dois grupos de cuidadores de familiares dependentes, tanto de Portugal quanto do Brasil, utilizando o grupo focal como instrumento de colheita de dados. **RESULTADOS:** Da análise das narrativas dos 12 cuidadores participantes no trabalho emerge um conjunto de categorias, que são: a necessidade de aprender sozinho, as necessidades de tempo para a manutenção dos papéis, a necessidade de uma rede de suporte, a resiliência nos desequilíbrios familiares, e os recursos para o cuidar. **CONCLUSÃO:** Neste trabalho foi possível evidenciar as semelhanças nas necessidades dos cuidadores dos dois países.

**PALAVRAS-CHAVE:** cuidadores familiares; idoso; determinação de necessidades de cuidados de saúde; enfermagem.

<sup>a</sup>Universidade Fernando Pessoa – Porto, Portugal.

<sup>b</sup>Escola de Enfermagem, Universidade de São Paulo – São Paulo (SP), Brazil.

<sup>c</sup>Escola Superior de Enfermagem do Porto – Porto, Portugal.

### Correspondence data

Carla Sílvia Fernandes – Rua do Cidral, 28 – CEP: 4490-562 – Póvoa de Varzim, Portugal – E-mail: carlasilviaf@gmail.com

Received on: 01/05/2018. Accepted on: 03/20/2018

DOI: 10.5327/Z2447-211520181800008

## INTRODUCTION

Population aging will lead to an increasing prevalence of persons with chronic illness or disability who need care, and, in the vast majority of cases, the responsibility for care will rest with a family member.<sup>1</sup> Although relatives have always borne the primary responsibility for providing care to older members of the family, adult caregiving was not a generalized phenomenon until few generations ago, because few people needed care at the end of life.<sup>2</sup> The lengthening life course and associated morbidity have given rise to a greater need for care. Due to a lack of support structures, it often falls on family caregivers to meet this need.

Family caregivers struggle daily not only with their tasks, but also with key life issues, such as their own mortality and the status of the relationships with loved ones who may be suffering and dying. Caring for a parent is a major challenge for adult children, who must renegotiate roles, relationships, and support until the death of those who have given them life and livelihood.<sup>3</sup> Positive and negative aspects may arise from caregiving, to which caregivers may respond actively or passively. Caregivers seem to fluctuate between different states of mind, influenced by variables such as resilience, burden, reward, and needs,<sup>4,5</sup> in addition to exhibiting a particular set of needs, which should be a privileged focus of nurses' attention and intervention.<sup>4</sup> Caregivers take on multiple responsibilities that can overburden them, particularly when their own needs are inadequately met.<sup>6</sup>

Greater recognition of the complexity and variety of family caregiver needs is essential throughout the transition to the caregiver role.<sup>3</sup> As family caregiving is greatly influenced by the cultural, political, and economic contexts of society, understanding it requires analysis of this complex scenario, which involves the family context and the meaning of care.<sup>7</sup>

The onset of a disease in the family and the dependence that follows create a need for replacement of some self-care activities, a role that is usually taken on by the caregiver. This new role is experienced through a multiplicity of feelings and needs, which are often contradictory and antagonistic due to the tension, competence, and conflict involved. Experience with illness in the family includes how the affected people, their relatives, and members of their social network perceive, live with, and overcome the physical and psychosocial challenges posed by painful symptoms, disability, and treatments.<sup>8</sup>

Nurses play a preponderant role in this context, as they are responsible for training the caregiver to provide care to his or her charge, namely, by being available to offer information, training, support, and respite care, while meeting their actual needs. The absence of such action may culminate in

an unhealthy transition and thus result in harm to the health of both the family caregiver and, consequently, the dependent individual.<sup>4</sup>

Countless studies have been conducted on this topic, with caregivers of dependents with different diseases<sup>1,5,6,9,10</sup> many reported similar results.<sup>11,12</sup>

Needs have been described in several areas: knowledge and learning for self-care, emotional, formal support, as well as social, financial, and structural support for care, information, and communication are all necessary.<sup>4,12</sup> Although some social initiatives to help in this setting do exist, they are still highly focal and are not enough to meet the needs of family caregivers. There is a pressing need for studies to investigate the profile, needs, and implications of family caregiving in the sense of developing policies to construct a support network that can contribute to the quality of life of such caregivers.<sup>9</sup> Assessing caregiver needs is a key step, as it is at the heart of the issue of caregiver support. At the population and regional levels, such research allows the design and implementation of tailored support schemes and, thus, rationalizes the supply of services. At the individual level, a detailed understanding of each caregiver's needs and of the dynamic nature of the caregiving role is an integral part of providing support, and is a prerequisite for directing caregivers to the most appropriate support venues.<sup>11</sup>

The present study stands out in relation to those already carried out insofar as it seeks to address the *needs of family caregivers* in different social, political, and economic contexts, in a search for similarities or discrepancies.

## METHODS

This was a qualitative, phenomenological, and cross-cultural study. We sought to establish what the phenomenon of interest means, in an attempt to understand and explain the meaning of experience, without focusing on quantification of results.<sup>13</sup> The cross-cultural nature of the analysis allowed us to glean knowledge about the meaning participants ascribed to the life event studied herein. In this particular case, this allowed us to compare and integrate the values, beliefs, and practices inherent to the studied cultures themselves as they pertain to the needs of caregivers. The data collection instrument used was the focus group, a strategy that allows researchers to gather rich data, because participants are more likely to share their experiences authentically.<sup>14</sup> Family caregivers were identified by nurses who were aware of their experiences. The focus group consisted of 12 caregivers (eight Portuguese and four Brazilian). Participants were recruited intentionally according to their availability

and willingness to participate, as long as they met the following inclusion criteria: being caregivers of family patients; being older than 18 years; and having cognitive and communication skills. During data collection, for analysis and interpretation, we sought to suspend the phenomenon of interest – the “*needs of the family caregiver*” –, its meaning, and the trajectory of each participant.

Two focus groups were held, one in Portugal and the other in Brazil. Each meeting lasted 90 minutes, was moderated by one of the investigators, and was recorded (audio only). The focus group scripts were designed to collect elements that could identify each caregiver’s needs. The data obtained were transcribed from the group discussions and annotated with remarks and reflections made by the observer. Then, the discourses of each sample were compared by looking for evidence from individual and group discussions to establish points of convergence and divergence.

Throughout the study, all ethical research principles were safeguarded. Data collection was approved by the relevant ethics committees. The study was approved by the ethics committees of the health care facilities in which it was conducted, with opinion nos. 1,553,398/2016 and 12542014.

## RESULTS

The focus groups consisted of 12 caregivers, all of whom were female, aged between 30 and 67 years. The duration of caregiving ranged from 1 to 21 years. In most cases, the dependent was the caregiver’s father or mother. Regarding marital status, most were married (n=4) or single (n=3). As for occupational activities, most were homemakers (n=4) or unemployed (n=3).

A systematic analysis focusing on the topic of interest of the study was carried out, in which similar, interconnected, overarching themes of needs emerged from the focus-group discussion transcripts, yielding the following categories (Figure 1): the need to learn alone; the need for time to maintain one’s roles; the need for a support network; resilience when facing family imbalances; and resources for caregiving. Over the course of the next paragraphs, we will present these different categories, attempting to highlight the phenomenon as it is experienced: a complex, multifaceted reality, which can only be appropriated through the wealth of information provided by the participants.

### The need to learn alone

The transition to the role of family caregiver is a complex process, which comprises different stages. The need to be self-aware and to develop certain know-how skills was

highlighted by caregivers in both contexts, as was a sense of being alone in this process.

So, I feel there really is a great need for people, for caregivers, to have training... There’s no training (C1-Portugal).

I learned at my own expense (C2-Portugal).

They just fall into our arms and we’re left not knowing what to do (C3-Portugal).

I didn’t have any training, I learned along the way (C5-Portugal).

I’d make the bed with her still in it... There you go! That’s something you must learn to do (C1-Portugal).

For many years, I cared... by myself (C5-Portugal).

At first, it was very hard, we didn’t know a thing (C9-Brazil).

I got home and I was lost (C10-Brazil).

I thought: How am I going to take care of my mother at home? (C11-Brazil).

I didn’t know how to change my mother. I was used to changing babies, but doing it on my mother was very difficult at first (C12-Brazil).

### The need for time to maintain one’s roles

The role of caregiver adds to, and compromises, a multitude of preexisting roles. This change in the caregiver’s life when the duty of care imposes itself triggers tension and conflict, due to the lack of time to maintain other, previously existing roles. This aspect was endorsed by participants mainly

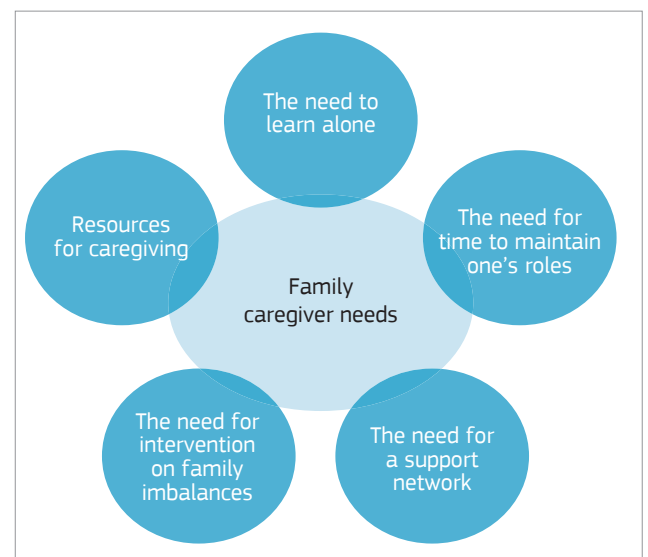


Figure 1 Categorization of caregiver needs, 2017.

with relation to the spousal subsystem and the maintenance of social relationships.

There's no vacation, there's nothing. It's a prison (C2-Portugal).

At first, I was taking care of her. But towards the end, as soon I left her side, I was already tired (C3-Portugal). Then, it's like this, the way they see it... You have to do everything right away, and there's no time left for anything... (C6-Portugal).

Because to take care of an old man, you die with him. I say I died without dying... I lost many years of my life given to that old man, didn't I? (C1-Portugal).

I didn't have the time to go out anymore (C8-Brazil).

It's like, my life is really hectic, it's all on me (C9-Brazil).

I'm there nearly 24 hours a day. If I don't at least set aside part of the morning to have a cup of coffee with my husband, I can't even talk to my husband (C9-Brazil).

### The need for a support network

The need for a support network was mentioned by caregivers, who highlighted the lack of formal (especially social) help for caregivers, such as financial and material requirements, support for instrumental care, and a support network for caregivers, among others.

In this category, caregivers also stressed the importance of informal support, namely from families and neighbors, which was considered a facilitating condition throughout the process. This need involves the caregiver's expectation of receiving help from family members for some activities of daily living, including some associated with caregiving tasks.

No one ever came over to see how my mother-in-law was doing, to find out what I needed (C1-Portugal). The services provided may not be very expensive, but in proportion to the state pension, it's a lot of money! (C2-Portugal).

I had to take my mother, in the state she's in... I had to drive her in my car or call an ambulance to take her in for an appointment when she caught a cold (C3-Portugal).

I think if the support services worked better, it would be safer (C5-Portugal).

This isn't right, you can't ask someone who has a job to stop working and come take care of her mother, we have to find other support structures... (C7-Portugal).

Caregivers should get psychological counseling themselves (C8-Portugal).

There was the possibility of [someone from the] center coming in to give a bath. But they were asking 130€, and that money goes a long way... It's the usual story! (C8-Portugal).

There are lots of people in need, I tried to get support, but there were no openings. So I took over care without any help (C10-Brazil).

I had an angel come down from the sky... my neighbor (C11-Brazil).

### Need for intervention on family imbalances

Caring for a family member involves changes in family relationships, which generates tension and conflict within the household; these extend over time, further isolating the caregiver. Family members distance themselves, leading to experiences hurtful to the caregiver, as highlighted below.

I urge families... because it's not even about money. All the money in the world can't pay for that, and families have to be aware of that. And that, families don't take that into account. "There you go, she's the one, let her work it out" (C1-Portugal).

People would ask, "but you have your sisters!" But they were all far away. What was I supposed to do? Make them? If I had to wait for them, it would be noon before anyone gave my mother a bath... (C3-Portugal).

Being there alone, without anyone even saying hello, people are there, but no one comes around... (C7-Portugal).

We're all friends, we're all sisters and we're very close friends, but sometimes only one of us is the daughter. I think I've said it all... This is what upsets me... it upsets me, if you need something, tell me, tell me if you need anything. I don't need anything, do I...? The others do it if I ask them, but when I ask they make excuses... as if to say, you're the one who's supposed to be here. The others are earning money, while I'm not making a dime... As though it were a job... No, it's an obligation (C12-Portugal).

When I called the family and said, this is unbearable, let's all take responsibility, because it's getting to be unbearable to me. "Oh, ask the center for help", and you pay them, ask and pay... Nobody was willing then... This is very complicated... There you go, sometimes some outside help was important to bring the family together... (C2-Portugal).

I called the family and said I needed them to come by every other week, on Sunday, so I could go out.

That led to a huge feud. They said I was taking money from my mother. We got into a really big fight. No one ever came back (C11-Brazil).

### Resources for caregiving

Countless resources are needed for caregiving, some of which are unknown to the caregiver. On the other hand, access to these resources, including information, equipment, and support, is described by caregivers in their narratives as difficult. Difficulty in accessing information and in overcoming obstacles to accessing these resources – namely, bureaucratic processes that wear out the caregiver – are reported as factors that complicate the transition to the caregiver role, often leading to abandonment, given its complexity.

The house isn't prepared for someone who can't move. You need help, materials... how can I arrange the room so that I can stand up, move to the chair, from the chair to the bed, then to the bathroom (C2-Portugal). But there was no adjustable bed, just a massage mattress... While she was bedridden, she went through six or seven mattresses... Before you knew it they were full of holes... A hundred euros... The last one I bought lasted a month (C4-Portugal).

I fought a hard battle to get everything I needed (C9-Brazil).

I kept trying to get someone to help me pay for the diapers, but every time I went there... Say they asked for 10 documents, I had a really hard time getting those 10 documents. I'd bring them these 10 documents, and when I got there, they asked for five more, and so on. One day, I just couldn't take it anymore and gave up (C10-Brazil).

I got all the supplies I needed through major sacrifices (C11-Brazil).

## DISCUSSION

The role of caregiver for dependent family members is traditionally assigned to women, as shown in the present study. Historically and as a result of the logic of family socialization, care is delegated to the female figure. Within any family, the role of caring for a dependent member could be shared by more than one person; however, most caregiving tasks are carried out by only one person, who is usually a woman.<sup>9</sup> It is common in families for a single member to take on most of the responsibility for care. Division of care-related tasks would be important to keep caregivers from feeling overwhelmed.<sup>15</sup>

As reflected in this study, facing up to a new role requires new knowledge and skills on the part of caregivers.<sup>10</sup> The period of transition into this new role is viewed as a time of particular importance in acquiring new skills appropriate to the level of care needed.<sup>16</sup> Caregivers highlighted the need to learn this new role by themselves. The knowledge domain represents one of the most important needs of family caregivers, as meeting knowledge needs allows them to better understand the whole situation and, consequently, their new role and relevance.<sup>4</sup>

You learn on your own. We don't have any training on anything, not hygiene, not anything. There's no training (C6-Portugal).

In a prior study of family caregivers, the authors stressed that initial training needs are many<sup>5</sup> and can change over time.<sup>12</sup> The importance of providing support to caregivers themselves, thus preventing them from becoming overburdened with tasks, cannot be overstated.<sup>17</sup>

In addition to acquisition of new skills, the transition to the role of caregiver requires a redefinition of existing tasks and incorporation of new ones. The need for time, brought about by the difficulty in maintaining preexisting tasks, was prominently featured in the discourse of caregivers who report being completely absorbed by their new role as such. Caring for a dependent family member requires time, family organization, and personal organization, which, coupled with the other demands faced by caregivers in their different social roles, creates an overload that can affect the caregiver negatively.<sup>18</sup>

We forget about us because I... As I didn't have any children, my husband and I would go out for every holiday, we'd go the beach. But then my life stopped in its tracks. I didn't go anywhere anymore. I only focused on my mother (C12-Brazil).

According to a study carried out with caregivers, an average of 10.9 hours are devoted to caring for the dependent subject, which makes it impossible to continue other roles.<sup>5</sup>

The need for a support network, including formal and informal support, is considered essential by caregivers. Support plays a key role in adapting to and discharging the functions of this new role, in a period of great vulnerability.<sup>4,9,16</sup> The family is reported as a major source of support, as are some close friends. Caregivers reported feeling alone and abandoned when these informal support sources disappear completely, and hoping that it would be offered without their having to ask.<sup>9</sup>



I had to put my foot down and say: “I need help, I need somebody down there” (C9-Brazil).

Participants also highlighted the need for intervention on family imbalances. One of the most common issues of coping and resilience in illness and family caregiving is conflict and separation among family members. The challenges of caregiving can be overwhelming, but can also become an opportunity for family members to mend tense relationships.<sup>8</sup>

We had a feud in the family, my brother wouldn't speak to me anymore, my niece, my brother-in-law, everyone, no one would speak to me, no one did for several years (C12-Brazil).

Family support, assistance, and sharing of responsibilities for caregiving have been shown to promote family resilience.<sup>15</sup> Family intervention is especially necessary when the disease is found to have generated conflicts and tensions among relatives that have not been adequately resolved; these are a substantial burden on the family as a whole, but especially for the caregiver.<sup>19</sup>

The narratives also highlighted the need for resources for caregiving, especially to procure supplies needed for this new role. Many caregivers have limited access to information and little knowledge about support mechanisms available in their communities.<sup>18</sup>

We need to know what's out there, because often this equipment is easy to get a hold of and we don't know about it, because we're not in the health field (C5-Portugal).

Furthermore, even if these resources are available, obtaining access to them is so complex that many caregivers give up on their use.

Nurses should continually assess caregiver needs, providing information as the need arises and guiding caregivers to the appropriate resources.<sup>20</sup> Caregivers' reports of the need for self-learning highlights the essential importance of nurses providing caregivers with knowledge and skills to take better care not only of their family members, but also of themselves. Caregiver education and support lead to a reduction in overload and promote quality of life for family caregivers.<sup>21</sup> By understanding caregiver needs and identifying sources of stress, as well as by mobilizing the necessary sources of support and information, nurses can provide the help caregivers need to stay healthy.<sup>20</sup>

In a review of nursing interventions for patients and family caregivers, the authors stressed that family caregivers should also be targeted for care, which should extend to the wider family context. It bears stressing that support and teaching interventions should be reviewed at various time points, over several weeks, involving a combination of in-person visits and telephone contact. Interventions should be based on the involvement and active learning of participants, because they must create their own individual strategies for action. On the other hand, interventions should not be designed to achieve economic goals, such as reducing the use of health services.<sup>22</sup>

Family caregivers lack interventions in training, information, support, and continuity of care, which should help care recipients remain healthy, but also ensure that caregivers receive care.<sup>20-22</sup>

This study has some limitations regarding the comparability and discussion of its findings. The fact that all subjects were female, in particular, precludes generalization of the results. On the other hand, the fact that the duration of caregiving varied so widely means that different needs can arise over time. It also bears stressing that the samples differed between the two countries.

## CONCLUSION

Giving caregivers a voice, through a focus-group design, allowed us to identify the needs of caregivers of dependent patients. From these discussions, many needs emerged that should be a focus of nursing intervention. This study shows that, despite different social and political contexts, the needs of caregivers are similar and converge on the same problems and challenges.

The use of focus groups is a very useful qualitative research method, especially when designed to facilitate the collection of data that is enhanced by participant interaction and which would be more difficult to obtain through one-on-one interviews. Throughout these narratives, it became clear that talking about caregiving means delving into the history of the family, because everything is intermingled; and that, although family life goes on, often at too high a price, the impact of this process on all family members must be taken into account. Health facilities should rethink new strategies to support caregivers, as well as consider the need to evaluate the effectiveness and efficiency of training programs offered by different institutions.

## CONFLICT OF INTERESTS

The authors declare no conflict of interests.

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