







Artigo original

Experiences of family caregivers of dependent older people in the care process*

Vivências de familiares cuidadores de idosos dependentes no processo de cuidado
Experiencias de cuidadores familiares de personas mayores dependientes en el proceso de cuidado

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Abstract

Objective: to understand the experiences of family caregivers of the older people in relation to care. **Method:** a descriptive study with a qualitative approach, conducted in a city in southern Brazil with 14 family caregivers of dependent older people. The interviews carried out between October and November 2022 were audio recorded, fully transcribed and submitted to Content Analysis, a thematic modality. **Results:** Family members take care unexpectedly. Although it is little shared, the family, especially in the early days, reorganizes to support the older adult. With the continued experience of home care, family members perceive the burden, however, they are able to (re)signify their role and demonstrate that the experience is a source of learning and retribution. **Conclusion:** Health professionals should be attentive to the way in which the process of caring for the older people is established in the lives of family members and develop interventions that support them, reduce overload and expand their strengths.

Descriptors: Caregivers; Caregiver Burden; Family; Aged; Perception

Resumo

Objetivo: compreender as vivências de cuidadores familiares de idosos em relação ao cuidado. **Método:** estudo descritivo, de abordagem qualitativa, realizado em um município do Sul do Brasil com 14 cuidadores familiares de idosos dependentes. As entrevistas realizadas entre outubro e novembro de 2022 foram audiogravadas, transcritas na íntegra e submetidas à Análise de Conteúdo, modalidade temática. **Resultados:** os familiares assumem o cuidado de forma inesperada. Apesar de ele ser pouco compartilhado, a família, especialmente nos primeiros tempos, se reorganiza para apoiar o idoso. Com a vivência continuada da assistência domiciliar, os familiares percebem a sobrecarga, contudo, são capazes de (re)significar seu papel e demonstram que a experiência é fonte de aprendizagem e retribuição. **Conclusão:** profissionais de saúde devem estar atentos à forma com que o processo de cuidar de idosos se estabelece na vida dos familiares e desenvolver intervenções que os apoiem, diminuam a sobrecarga e ampliem suas fortalezas. **Descritores:** Cuidadores; Fardo do Cuidador; Família; Idoso; Percepção

Resumen

Objetivo: comprender las experiencias de cuidadores familiares de personas mayores en relación al cuidado. **Método:** estudio descriptivo, con abordaje cualitativo, realizado en una ciudad del sur de Brasil con 14 cuidadores familiares de personas mayores dependientes. Las entrevistas realizadas entre octubre y noviembre de 2022 fueron audiogravadas, transcritas íntegramente y sometidas al análisis temático. **Resultados:** los familiares asumen el cuidado de manera inesperada. Aunque rara vez se comparte, la familia, sobre todo en los primeros días, se reorganiza para apoyar al paciente. Con la experiencia continuada del cuidado domiciliario, los familiares perciben la sobrecarga, sin embargo, logran (re)significar su rol y demostrar que la experiencia es fuente de aprendizaje y retribución. **Conclusión:** los profesionales de la salud deben ser conscientes de la forma en que el proceso de cuidado del anciano se establece en la vida de los familiares y desarrollar intervenciones que los apoyen, reduzcan la carga y amplíen sus fortalezas. **Descriptor:** Cuidadores; Carga del Cuidador; Familia; Anciano; Percepción

Introduction

Currently, in the Brazilian context, population aging is part of reality, and projections indicate that the older population will continue to grow. For example, the percentage of people over 60, which was 5.8% in the 1970s, in 2020 reached 18.8%, and life expectancy is projected to increase from 77.1 years in 2022 to 81 years in 2050.¹ These changes relate to the increase in the level of socioeconomic and educational development, in addition to the increasing urbanization and improvements in health care that have occurred in the country in the last 30 years.²

The creation of the Unified Health System (SUS), in the early 1990s, allowed access

to full and free care for the entire population. The SUS is configured as one of the largest public health systems in the world, which focuses mainly on health promotion and disease prevention in all life cycles.³ However, although there are public policies that value the promotion of active and healthy aging,⁴⁻⁵ older people often develop/acquire demands related to chronic noncommunicable diseases (CNCDs) cardiovascular diseases, cancers and dementias, which can cause disabilities, decrease quality of life and trigger the need for a family caregiver.²

In the home context, women are usually directly responsible for the management of older family members who need assistance. These women, in general, are middle-aged or older women; wives or daughters; they live with the older people or welcome them into their homes; and sometimes receive help from other family members.⁶ In addition, many family caregivers leave their jobs, their social life and their personal relationships to dedicate themselves fully to the assistance of their loved one, including without adequate technical preparation and minimal skills to perform the activities inherent to care,³ which known changes the dynamics and functioning of family life.⁷

Thus, experiencing family care in the role of caregiver entails unique experiences, which cannot be measured, but can be known. By experience is meant the fact of existing and living, bringing together feelings and knowledge acquired by experience in one or several situations of everyday life. In this sense, the experience is composed of the fleetingness of the human being in the world, the significance that the person gives to the totality of his existence and the incommensurability of the content of the experience itself, which gives it an aesthetic dimension.⁸

Experiencing the process of caring for the older people, especially those with disabilities or limitations for the development of activities of daily living, implies being prepared and willing to assume this commitment. However, it is important that this person can reconcile the new role with his own personal, work and family demands and needs. It is necessary to be attentive to the maintenance of health, the prevention of diseases, biological and emotional changes, stress, anxiety, depression and family conflict, which may arise as a result of social isolation and/or abandonment of work activity.⁹ The various changes that can occur in the health, social relations and life of this person are often related to the performance of the role of caregiver and the experience of overload.¹⁰

Overload refers to the objective and/or subjective impact caused by the need to

provide prolonged care in the family context, involving economic, biological and emotional aspects, to which caregivers can be submitted.¹¹ Due to this complex context of experiencing the burden of family caregivers, knowing their personal experiences enables health professionals in Primary Care – especially nurses because they are the professionals closest to the reality of families in their homes – to understand how they can plan care in a holistic perspective, considering the dependent person and the family – especially the caregiver.¹² This is because families, when considered systems, when they experience a CNCD in their midst, have repercussions that reverberate the experiences of all other members and, therefore, need to be cared for in their entirety.¹³

In the meantime, this study is justified by the need to recognize and value the experiences of family caregivers of dependent older people, so that nursing interventions at home are directed to the real demands experienced in daily life regarding biological, social and emotional aspects. Although the burden of older people caregivers is a recurring theme in the literature,^{6-7,12-13} discussing it remains necessary, as professionals are still unable to have a performance capable of effectively interfering with it. Thus, assuming that caregivers with less burden and with satisfactory physical and emotional health tend to provide more qualified care to the elderly, this research was proposed with the aim of understanding the experiences of family caregivers of the elderly in relation to the care provided.

Method

This is an exploratory and descriptive study with qualitative approach. Qualitative research was chosen when considering the possibility of describing, recording, analyzing and understanding people's reality, daily life and worldview, interconnected to socioeconomic and cultural aspects, in the face of a specific phenomenon or problem situation.¹⁴ The criteria of the Consolidated Criteria for Reporting Qualitative Research (COREQ) were used as a guide to improve the presentation of the research report.¹⁵

The investigation took place in the medical and surgical clinics of the University Hospital linked to the State University of Maringá (UEM), which is a reference in high complexity care for the 30 municipalities that make up the 15th Regional Health of the state of Paraná, Brazil. The medical and surgical clinics are intended for the hospitalization of

adult patients with clinical, surgical, orthopedic and traumatic diseases, and have 78 beds distributed in rooms with three beds. Only patients under the age of 18, those over the age of 60 or those with special needs can have a companion, usually a family member.

The following inclusion criteria were: being 18 years old or older and being the primary family caregiver of an older adult dependent on care, admitted to the Medical or Surgical Clinic. Dependence on care was considered when the family member claimed to provide daily care to the older adult, and when the nursing team reported that the older adult presented dependence for basic activities of daily living, which included food, hygiene and locomotion.¹⁶ We did not include family caregivers who were tearful (01 case) and those with speech problems that hindered communication (01 case).

Data were collected between October and November 2022, through an open interview, using a semi-structured questionnaire, composed of two parts: the first returned to seek sociodemographic data to characterize the participants; the second was composed of a guiding question: Tell me how the experience of taking care of your relative has been? There were also supporting questions: Do you think your life project has changed since becoming a caregiver? Did you have any difficulties with care or family relationships? Are you worried about something related to caring for your family member? How would you describe the care provided to your relative so far? What are your wishes for the future?

The interviews were conducted in person, in the mornings and afternoons, by a student from the last period of the nursing course, who was previously trained to conduct qualitative interviews. Family members were approached in the hospitalization room, where they were invited to participate in the study and, if accepted, were directed to a reserved room. The interviews lasted an average of 30 minutes and were recorded in full audio.

After transcribing the interviews and editing the speeches to remove grammatical errors and language addictions, the methodological framework of Content Analysis was used, a thematic modality,¹⁷ applying its stages of pre-analysis, exploration of the material and treatment of the results obtained. Pre-analysis began with the organization of the material, followed by floating reading of the documents and systematization of preliminary ideas, with formulation of the first hypotheses and indicators. The exploration of the material aimed to codify and categorize the text of the interviews. This occurred from the use of different colors that highlighted the similarities and semantic differences in the

content under analysis. Subsequently, the different codes generated were grouped to form the units of meaning in the text. In the phase of treatment of the results, inference and interpretation, the researchers analyzed, in a reflexive and critical way, the units previously identified, producing a logical understanding for the interpretation of the results and construction of the thematic category and its subcategories.¹⁷

The analytical process led to the identification of the category "Experiences of family caregivers of the older people with the care process", composed of three subcategories: "The need for care as a crossing in family life and its consequences"; "Experiencing the burden and suffering resulting from continued family care"; and "Family caregivers reframing care and thinking about the future".

To obtain methodological rigor in the investigation, the analytical and interpretation process of the information was carried out independently by two researchers guided by the exercise of reflexivity. That is, the previous assumptions of both about the theme were recognized and put into suspension. During the analysis, when there were inconsistencies, the team of investigators met by video call and discussed the analysis and interpretation of the data, in search of consensus. Finally, reliability and confirmation were ensured by maintaining an audit trail, ensuring that all necessary and supporting documentation (field notes and analytical/reflective notes) was available for further consultation, if relevant.¹⁸

The research was developed according to the ethical aspects indicated in Resolution 466/2012 of the National Health Council and its complements. The project was approved by the Standing Committee on Ethics in Research with Humans of UEM (Opinion: 5,715,372, approved on October 21, 2022). The interview was conducted in person, in a reserved room, inside the hospital, which allowed the privacy of the participant. And to protect the identity of the interviewees they were cited with codenames that represent their degree of kinship with the older adult, the order of entry into the study and the length of care. Example: (Wife 01, 3 months).

Results

The study included 14 family caregivers, with ages ranging from 37 to 78 years, 11 women and most of whom were white. One caregiver did not study; five had elementary

school; six, high school or post-high school; and two had complete or incomplete higher education. One caregiver did not study; five had elementary school; six, high school or post-middle school; and two had completed or incomplete higher education. As for the family relationship, nine were daughters; three were wives, one was a sister, and one was a grandson. Dedicated care time ranged from 15 days to 30 years, and male caregivers had been caring for their family member for a few days (Box 01).

Box 01 - Characteristics of family caregivers participating in the study. Maringá, Paraná, Brazil.

Codename	Age	Education	Occupation	Race/skin color	Time of care and context
Wife 01	53 years old	Elementary School	Daily hired maid	Brown	Three Months Caregiver; she left the daily activities to take care of her husband. She feels it has been a difficult experience.
Wife 02	65 years old	Post-high school	Nursing Technician	White	30 years. The old man is diabetic and had a Stroke eight years ago, and currently uses a wheelchair to move around. The caregiver is hypertensive and has recently had spinal surgery.
Wife 03	78 years old	Elementary School	Retired	White	09 months The old man is hypertensive and has difficulty getting around. The caregiver says she has a problem with her spine.
Daughter 01	42 years old	Post-high school	Nursing Technician	White	17 years The caregiver is divorced and has seven siblings. She quit her job to take care of her mother. She refers to feeling pain in her spine.
Daughter 02	59 years old	Post-high school	Environmental Management Technician	Brown	10 years. The caregiver is married and is the oldest of five siblings. She suffers from arthrosis and back pain. Her father is in palliative care.
Daughter 03	55 years old	Elementary School	Housewife	White	12 years She is the oldest of four siblings, but her mother, now bedridden, has lived in her home since she became a widow. The caregiver

					suffers from osteoarthritis.
Daughter 04	42 years old	Elementary School	Unemployed	White	A month. The caregiver has financial and emotional support from her wife. She says she feels pressured by her mother, because she is the only woman of three brothers, because the mother says that she must take care of her and the brothers must work.
Daughter 05	36 Years old	High School	Self-employed seller	White	15 days Caregiver is married and has three children. She tries to make the mother not feel that care is a problem. She feels frustrated that she has to leave her children with her husband, because she realizes that he can't do everything, like she did at home and at school.
Daughter 06	42 years old	Elementary School	Housewife	White	Three years. The caregiver has two children (one autistic and one hyperactive). She lives with older parents, the mother is diabetic and father since 2020 had complications with stroke and recurrent pneumonia; he is currently bedridden.
Daughter 07	55 years old	High School	Freelancer	Brown	12 years The caregiver is divorced, childless, she lives with her older parents and takes care of them. She suffers from heart disease while undergoing treatment.
Son 01	53 years old	High School	Night security guard	White	17 days The caregiver is married and hypertensive. He refers to working every night and coming straight to the hospital to be with his mother who suffered a fall and fractured her femur.
Son 02	33 years old	High School	Civil servant, public officer	White	15 days The caregiver is the oldest of three siblings and is married. The mother lived alone, but reveals that the family will have to reorganize to take care.
Sister 01	68 years old	No education	Housewife	White	Four years. Caregiver is caring for the only sister who is obese and has locomotion

					restrictions. She says she is already anxious, tired and sad about the time of care.
Grandson 01	28 years old	Incomplete higher education	Student	Brown	26 days. The caregiver says that the grandmother, after the worsening of Alzheimer's, is not the same and that she will need care at home, requiring the support of the whole family.

Experiences of family caregivers of the older people with the care process

From the results it was possible to observe that some assume the role of caregiver of an older person unexpectedly, even in chronic conditions, from complications, limitations and sequelae that may arise. In these cases, despite being a little shared task, in the early days, especially, the family reorganizes itself in order to support the sick family member. However, with the passage of time, the main caregivers begin to feel the physical and mental burden resulting from a home care that is continuous, repetitive and unfinished.

Suffering is a common feeling at this stage of the care process, with which caregivers need to learn to cope. By advancing in this trajectory, the family members (re)signify their role with the one with dependence, coming to realize that providing care, in addition to being a source of learning, is a way to reciprocate the affection received from him previously. They also justify that, with their attention, they want to sow positive feelings, create family ties strong enough to overcome the crises and adverse situations common in the family system. This is so that other family members, especially younger ones, can recognize the importance of reciprocal relationships, the appreciation of the older people and see the caregiver as an example to be followed.

The need for care as a crossing in family life and its consequences

Caregivers reveal that the chronic illness of their older family member associated with the need for home care and, at some point, hospitalization, crosses the daily life of the family system. This causes suffering, especially for the one who assumes the role of primary caregiver.

Caring for my family member has been a very difficult, painful, very painful experience for us. Suddenly he lost his memory, he didn't recognize us. Now everything changed, it was a situation he had never experienced. It was a shock to our family. (Wife 01, 3 months)

The experience of taking care of my husband started 30 years ago. He had an accident and the physicians had to amputate his leg; it was a very sad situation; I had to do the dressings, I had to teach him to walk, I had to encourage him and take him home for care. (Wife 02, 30 years)

My husband has been sick for nine months already, at first during the first three months I started to notice him strange, he forgot things, he started to undress, he did his physiological needs anywhere in the house, I put a diaper on him. It was very sad to accept that he was sick, people [in the family] couldn't take it anymore and I had to take him to the hospital and that's how he was admitted. (Wife 03, 9 months)

Although it is not an experience shared by all family caregivers, some report that household chores, especially during hospitalization, are divided among different family members. They even assign activities to the extended family.

We organized ourselves at home, in the first week [of hospitalization] they [the children] came to stay in the hospital, on Monday I asked for a certificate and I spent the whole week with him. He has three children from his first marriage and with me we have one child and so we start to share the chores. (Wife 01, 3 months)

My daughter sometimes helps me stay in the hospital and my son helps me clean the house, not financially because he can't afford it. (Wife 03, 9 months)

Although the act of caring at home is difficult, hospitalization produces important changes in the daily life and routine of families.

I have two brothers who are bedridden, another is a truck driver, my other sister can't stand to see him in the hospital and my last sister works all day. So, people are doing what they can, paying a caregiver and leaving her alone. I'm on leave from work, but I have to return the following week, this hospitalization brought many changes in our daily lives. (Daughter 02, 10 years)

Our family is very close, my father passed away 12 years ago, now everyone here wants to take care of her, so we communicate very well, let's talk and one asks the other to go replacing in the hospital, that's what we do. (Daughter 03, 12 years)

In addition to the family organization and the use of the social support network, several family caregivers employ, to provide higher quality care, their skills and knowledge, bringing as baggage previous experiences with the care of other family members.

My experience of taking care of a family member started with my first marriage, there I took care of my husband until the end, he had cancer, I never left him and I took care of him alone in those four and a half years, the truth was a lot of suffering, but I did not give up. (Wife 03, 9 months)

The crossing of the need to care in the life of the family system is understood as a priority. Thus, caregivers repress their demands and feelings and sometimes seem to wear a protective shield to hide suffering and gather strength to continue caring for the older family member.

I have to move on, hide my sadness, cry when I'm alone; God only knows what I cry. (Wife 01, 3 months)

I'm sick of diabetes, but I'm taking care of myself, I keep my mind busy, there's no time to be sad. Now if I have an economic problem or I get sad, I leave all these problems out the door, I forget everything and I just look at it, while I focus on taking care of her. (Grandson 01, 26 days)

But sometimes I'm not always well, I take controlled medicine when I'm too loaded too, I have high blood pressure, I have pain in my knees, I have surgery scheduled on my spine, but I still take care of him. (Wife 02, 30 years)

Experiencing the burden and suffering resulting from continued family care

Suffering proved to be an inherent feeling in the process of caring for a family member who lives with chronic conditions. Different caregivers said that such suffering, in part, is caused by the fact that they identify that their loved one, as a result of the underlying diseases and their complications, suffers physically and emotionally.

There are many situations that bother me, he has many secretions that do not improve, wounds that do not heal, his suffering also bothers me. (Wife 01, 3 months)

Seeing him so sick hurts me. My heart is very sad and it hurts a lot to have to live like this. (Wife 03, 9 months)

When she is in pain it bothers me a lot, they give morphine that is very strong and in the end her body is not responding, it bothers me because I feel powerless to help her. (Daughter 01, 17 years)

Suffering is intensified when the caregiver himself presents physical and/or mental health problems, resulting or not from the care provided to the family member. Consequently, in some cases, harmful habits, including smoking, are amplified in the routine of caregivers and, in other cases, there is a risk of not complying with their own treatment by prioritizing care for the older adult.

Now there are times when I get tired of taking care of so much. I do not see well, it bothers me and I also take medicine for high blood pressure, this all makes it difficult for me to take care of my family member. (Child 01, 17 days)

I'm tired, but I'm not giving up. Despite having high blood pressure, spinal problems, I'm in treatment for all of this. (Wife 03, 9 months).

I'm worried that I'm not getting my treatment because I can't sleep and, on

the other hand, I'm afraid of getting sick. There are times when I go out to smoke, I'm smoking about 20 cigarettes a day. (Daughter 04, 1 month)

It is also verified that the context of home and hospital care favors the burden of family caregivers. Caregivers who cannot count on the support of other family members and/or are unable to pay a formal caregiver have intense care routines associated with other stressful everyday situations. Therefore, they show a greater burden on family care.

I have to keep working. So, to take care of my mother, I chose not to come home and when I leave work I come straight to the hospital, because I work all night as a security guard, and I come straight to the hospital, it's a tremendous effort, but I do it for my mother. (Son 01, 17 days)

The truth is that I am exhausted, tired, overwhelmed, because my family does not help take care of my mother, I think if it were another caregiver they would pay, but as I am, they do not pay and do not help me. (Daughter 04, 1 month)

I know there are other people who can afford a caregiver, but I can't afford it, I manage on my own. It tires me too much, I'm overwhelmed. (Wife 03, 9 months)

Family caregivers resignifying care and thinking about the future

Family caregivers, as they live with home care, (re)signify their experiences in providing care to the loved one. Thus, they come to understand that care is a source of learning and use this experience as a way to reciprocate the affection previously received. In addition, they make it clear that they want to be present in the care process.

We are learning more and we are caring, with love and affection. He needs someone who will do things for him with love. We've gotten used to it, it's been a great learning experience. (Wife 01, 3 months)

To take care of my husband, I do what I can, as far as my strength lets me go, is my love. I talk to him every day: "I'm here, I'm not going to abandon you." (Wife 03, 9 months)

As my father is bedridden, he is totally dependent, I received instructions from the nurses to bathe him in bed, change positions and other things, they helped me, I am learning and I am grateful for it, because I will continue to take care of him, as he did with me. (Daughter 06, 3 years)

Caregivers also report that they care for the sick family member because they want to sow positive feelings, create strong family bonds that can overcome crises and adverse situations in the family system; and they want other family members, especially children, to see the caregiver as an example to be followed.

I think so, I put myself in her place, I have to have references, I want my children to see this, not out of obligation, but above all out of love. I had this

reference and I thank these people. I don't want it to be an obligation to take care of me. But I want my kids to watch it and talk about it. (Daughter 01, 17 years)

I feel like we've built strong family ties, so we help each other out as much as we can. It is a gift of time and love. At this point I want my mother to be calm, so I'm here and I took care of my grandmother during the hospitalization. (Grandson 01, 26 days)

Finally, family caregivers, in some cases, are prepared for the moment of death of the loved one, because they recognize that he is in palliative care, and, therefore, they wait resigned to the future.

My father is in palliative care, the physician explained to the family, I will always ask for the best for him, we are preparing for his departure, and it also hurts us that he suffers. (Daughter 02, 10 years)

No one knows what might happen tomorrow, we know that the state is delicate, but God only knows. So I leave it all to Him. (Sister 01, 4 years)

Discussion

The participants of this study have a sociodemographic profile composed mostly of women, with low education, no paid occupation, close kinship and who dedicate themselves exclusively to the care of the older adult. This profile of family caregivers has long been identified in studies conducted in Brazil¹⁹⁻²¹ and in other parts of the world,²²⁻²³ demonstrating that gender, education and degree of kinship influence the designation of family caregivers of older people dependent on care. In fact, it is noteworthy that the three male participants were in this role a few days ago, and it is likely that, if the dependence on care is maintained over time, another family member will take responsibility.

The results listed here reveal that family caregivers experience the beginning of care unexpectedly. Although care is a task little shared among the different family members, the interviewees revealed that, especially in the early days, the family needs to reorganize to take care of the sick family member together. A phenomenological study carried out with nine family members of older people with Alzheimer's disease identified that the needs of caregivers started abruptly, because, although the disease presented initial signs and symptoms, the diagnosis was not quickly reached because, sometimes, families postpone seeking professional help or even because of the difficulty in accessing health services.²²

Another qualitative investigation carried out with eight family caregivers of patients with stroke sequelae pointed out that, although the participants accompanied the family

member during the hospitalization period, when they arrived at home they encountered various difficulties and feelings: despair, sadness, anxiety and helplessness.²⁰ In addition, the participants experienced, already in the first days at home, insecurity for the execution of home care, fear of worsening of the clinical condition, the need for adaptations in the infrastructure of the residence, financial difficulties and decreased social relations with extended family and friends.²⁰ Thus, it is observed that the beginning of care for the older people is a crossing in the daily life of families. Changes in habits and adaptations are necessary, which, to some extent, already starts the process of overloading the family caregiver, especially when the social support network is not structured.²⁴

In the present study, with the passage of time, the main caregivers reported experiencing an intensification of overload due to daily and prolonged home care. Suffering was a common feeling at this stage of the care process. Similarly, a review of the literature that analyzed the impacts on health and quality of life of family caregivers of older people with Alzheimer's disease identified that their quality of life was increasingly impaired, as, increasingly, studies reported feelings of stress, frustration, loneliness and impotence among family caregivers.²⁵ Research carried out in Thailand also showed that sociodemographic factors impacted the quality of life of family caregivers of people who had suffered a stroke. And more: that the burden on caregivers continued to be a problem, especially for those in advanced age and with low income who cared for severely dependent elderly people.²²

It is known that overload has an intense impact on the health of caregivers and exposes them to vulnerabilities. This is because most caregivers prioritize the care of their dependent family member and, therefore, fail to perform care for their own health, abandon work activities and even move away from social relations.²⁶⁻²⁷ Thus, nurses and the health team should be aware of these determinants and develop a family intervention program that supports them in order to improve their quality of life. This is because well-informed, oriented and more experienced caregivers are less anxious and more secure in providing care, which is reflected in more capacity and availability to care for the family member.²⁵ And, consequently, a lower frequency of adverse situations resulting from inadequate care.

By advancing in the care trajectory, family members (re)signify their own role as caregivers and demonstrate that the provision of care is also a source of learning, in

addition to a way to reciprocate the affection previously received. In this sense, the process of caring for an older person is described as ambivalent, permeated by feelings that confront each other.¹⁹ A study conducted with 20 family caregivers of the older people showed that they felt tired and overwhelmed with long-term care. However, the perception of overload with care was mitigated by the strong affective bond established between caregivers and the older people, which was expanded as the time of care also increased.²⁷

The caregivers of the present study also indicated that they took care of the family member because they wanted to sow positive feelings, create strong family ties that could overcome crises; and they wanted other family members perceived the caregiver as an example to be followed. In this sense, studies 21, 27-28 have shown that among caregivers there is a perception of positive aspects with the provision of home care: satisfaction with the role of caring; reciprocity in relationships with the person being cared for; recognition of the existence of emotional rewards; personal growth; development of new skills and competences; spiritual growth and increased religiosity; gains in interpersonal relationships; and sense of accomplishment.

Even with the important findings identified, this study has limitations. The first is related to the fact that most of the interviewees are female, which may circumscribe the findings from a gender perspective. However, this is an aspect commonly found in research with family caregivers. Another limitation refers to the fact that the interviews were conducted within the hospital unit, during a time when, certainly, there is an amplification of negative feelings and the perception of overload among family members resulting from the changes faced. But this was a strategy employed to expand the location and facilitate the approach of family caregivers of older people.

However, it is noteworthy that the study is relevant in demonstrating to nurses in clinical practice, especially those who work in primary care services and researchers in future investigations, that the development of family interventions is necessary. Such interventions should seek strategies to reduce the feeling of suffering and physical and mental burden among caregivers of older people and, at the same time, expand competencies and abilities for continued care. This is important for families to feel supported in the provision of care, reduce the experience of overload and expand their strengths and potentialities. Therefore, family nursing references for evaluation and interventions with families can be used both in practice and in research.

Conclusion

Based on the results of this study, it was possible to understand the experiences of family caregivers of the older people related to the care process, which is an experience that often materializes unexpectedly, and, although care is a task little shared between the different family members, they need, especially in the early days, to reorganize to support the older people.

With the continued experience of care, family members report feeling physical and mental overload. Suffering seems to be inherent in the process of caring, especially in its beginning. However, when advancing in the care trajectory, family members (re)signify their own role as caregivers and reveal that the provision of care is a source of learning. In addition, they affirm that they take care of the family member because they want to sow positive feelings, create stronger family ties to overcome crises and adverse situations in the family; and expect other family members to perceive the caregiver as an example to be followed by them.

References

1. Instituto Brasileiro de Geografia e Estatística (IBGE). Esperança de vida ao nascer 2022. Rio de Janeiro (RJ): IBGE; 2022 [acesso em 2023 jan 12]. Disponível em: <https://sidra.ibge.gov.br/tabela/7362#resultado>
2. Scwarcwald CL, Stopa SR, Malta DC. Status of the main noncommunicable diseases and lifestyles in the Brazilian population: Brazilian National Health Survey, 2013 and 2019. *Cad Saúde Pública*. 2022;38(Supp 1):51-4. doi: 10.1590/0102-311xpt276021
3. Barreto MS, Carreira L, Marcon SS. Envelhecimento populacional e doenças crônicas: Reflexões sobre os desafios para o Sistema de Saúde Pública. *Rev Kairós*. 2015;18(1):325-39. doi: 10.23925/2176-901X.2015v18i1p325-339
4. BRASIL. Lei nº 8.842. Dispõe sobre a Política Nacional do Idoso, cria o Conselho Nacional do Idoso e dá outras providências. Brasília (DF): Presidência da República, 1994. Disponível em: https://www.planalto.gov.br/ccivil_03/leis/l8842.htm. Acesso em: 10 jan. 2023.
5. BRASIL. Lei nº 10.741. Dispõe sobre o Estatuto do Idoso e dá outras providências. Brasília (DF): Presidência da República, 2003. Disponível em: https://www.planalto.gov.br/ccivil_03/leis/2003/l10.741.htm. Acesso em: 10 jan. 2023.
6. Viesenteiner JL. O conceito de vivência (Erlebnis) em Nietzsche: gênese, significado e recepção. *Kriterion*. 2013;54(127):141-55. doi: 10.1590/S0100-512X2013000100008
7. Mendes PN, Figueiredo ML, Santos AMR, Fernandes MA, Fonseca RSB. Physical, emotional and social burden of elderly patients' informal caregivers. *Acta Paul Enferm*. 2019;32(1):87-94. doi: 10.1590/1982-0194201900012
8. Cunha JVB, Reiners AAO, Azevedo RCS, Cardoso JDC, Cunha CRT, Silva KM. Funcionamento de famílias com idosos totalmente dependentes. *Cienc Cuid Saúde*. 2019;18(2):e48825. doi: 10.4025/ciencuidsaude.v18i2.48825
9. Monteiro JKM, Sá SPC, Bezerra DRC. Sobrecarga e qualidade de vida do cuidador familiar do idoso da quarta

idade. *Res Soc Dev.* 2021;10(10):e478101018931. doi: 10.33448/rsd-v10i10.18931

10. Alvarez AM, Sandri JVA. Population aging and the Nursing commitment. *Rev Bras Enferm.* 2018;71(suppl 2):770-01. doi: 10.1590/0034-7167-201871Sup201

11. Eloia SC, Oliveira EN, Lopes MVO, Parente JRF, Eloia SMC, Lima DS. Family burden among caregivers of people with mental disorders: an analysis of health services. *Cienc Saúde Colet.* 2018;23(9):3001-11. doi: 10.1590/1413-81232018239.18252016.

12. Bernabéu-Álvarez C, Faus-Sanoguera M, Lima-Serrano M, Lima-Rodríguez JS. Revisión sistemática: influencia de los Grupos de Ayuda Mutua sobre cuidadores familiares. *Enferm Glob.* 2020;19(58):560-74. doi: 10.6018/eglobal.392181

13. Dadalto EV, Cavalcante FG. The place of family caregivers for older adults with Alzheimer's disease: a literature review in Brazil and the United States. *Cienc Saúde Colet.* 2021;26(1):147-57. doi: 10.1590/1413-81232020261.38482020.

14. Morse J. The changing face of qualitative inquiry. *Int J Qualit Method.* 2020;19:1-7. doi: 10.1177/1609406920909938

15. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349-57. doi: 10.1093/intqhc/mzm042

16. Soares MFN, Maia LC, Costa SM, Caldeira AP. Dependência Funcional em idosos assistidos por equipes da Estratégia Saúde da Família. *Rev Bras Geriatr Gerontol.* 2019;22(5):e190147. doi: 10.1590/1981-22562019022.190147

17. Bardin L. *Análise de conteúdo.* São Paulo: Edições 70; 2016.

18. Velloso ISC, Tizzoni JS. Critérios e estratégias de qualidade e rigor na pesquisa qualitativa. *Cienc Enferm.* 2020;26(28):1-10. doi: 10.29393/CE26-22CEIS20022.

19. Almeida NC, Dalla-Vechia ADR, Montini LLC, Lima CM. Narrativas sobre conviver com um idoso dependente: perspectiva do cuidador familiar. *Rev Kairós.* 2020;23(3):199-214. doi: 10.23925/2176-901X.2020v23i3p199-214

20. Fisher MMJB, Barreto MS, Marcon SS, Batista VC, Marquete VF, Souza RR, et al. Caring for a family member with stroke sequelae: the first days at home after hospital discharge. *REME Rev Min Enferm.* 2021;25:e-1385. doi: 10.5935/1415.2762.20210033

21. Mattos EBT, Kovács MJ. Alzheimer's disease: the unique experience of family caregivers. *Psicol USP.* 2020;31:e180023. doi: 10.1590/0103-6564e180023

22. Kongkar R, Pinyopasakul W, Pongthavornkamol K, Dajpratham P, Orathai P. The determinants of quality of life in Thai family caregivers of stroke survivors. *Siriraj Med J [Internet].* 2019 [cited 2023 Jan 10];71(4):290-6. Available from: <https://he02.tci-thaijo.org/index.php/sirirajmedj/article/view/205219/142863>

23. Pérez-Cruz M, Parra-Anguita L, López-Martínez C, Moreno-Cámara S, Del-Pino-Casado R. Coping and anxiety in caregivers of dependent older adult relatives. *Int J Environ Res Public Health.* 2019;16(9):1651. doi: 10.3390/ijerph16091651

24. Silva MS, Beuter M, Benetti ERR, Bruinsma JL, Donati L, Girardon-Perlini NMO. Situações vivenciadas por cuidadores familiares de idosos na atenção domiciliar. *Rev Enferm UFSM.* 2019;9:e10. doi: 10.5902/2179769232528

25. Silva ALO, Santos BA, Santos CTL, Santos VSO, Oliveira JKP, Santos JS, et al. Impacts on the health and quality of life of caregivers and family members of individuals with Alzheimer's disease: integrative review. *Res Soc Dev.* 2022;11(9):e46211932245. doi: 10.33448/rsd-v11i9.32245

26. Palma DA, Magalhães AS, Monteiro MC. Cuidadoras familiares de idosos dependentes: convivendo com perdas. *Rev Kairós.* 2019;22(4):395-415. doi: 10.23925/2176-901X.2019v22i4p395-415

27. Garcia GMF, Imoto PH, Bernuci MP, Yamaguchi MU, Massuda EM. Sobrecarga de cuidadores informais de

idosos. Rev Interdiscip Estud Saúde. 2020;9(1):115-30. doi: 10.33362/ries.v9i1.1724

28. Lindeza P, Rodrigues M, Costa J, Guerreiro M, Rosa MM. Impact of dementia on informal care: a systematic review of family caregivers' perceptions. BMJ Supportive Palliat Care. 2020;15(6). doi: 10.1136/bmjspcare-2020-002242

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