

## **FAMILY CAREGIVERS OF OLDER ADULTS AND PHYSICAL AND PSYCHOLOGICAL HEALTH CONDITIONS AND FAMILY SUPPORT IN CARE**

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### **ABSTRACT**

**Objective:** to analyze the existence of overload in family caregivers of older adults in the physical and psychological health and family support dimensions.

**Method:** a qualitative study conducted with 23 participants from Dianópolis, Tocantins, Brazil. Data were collected through semi-structured interviews in September 2022. Data analysis was performed using content analysis in Minayo's thematic modality, which includes ordering, classification and final analysis of data.

**Results:** the results show that the exercised role of caregiver is related to social representation, which is enhanced: by the context, cultural and family values; by the naturalization of the role of women as caregivers; by increasing the burden due to excessive responsibility and lack of support from other family members; and by the presence of psychological symptoms overlapping physical symptoms in caregivers.

**Conclusion:** it is concluded that the support of professionals is essential to rethink new practices and ways of producing care through individual or collective activities, with a view to preventing caregivers from becoming ill.

**DESCRIPTORS:** Caregivers. Caregiver burden. Older adults. Emotional stress. Psychological exhaustion.

**HOW CITED:** Sartori IFG, Almeida Neto H, Hirdes A. Family caregivers of older adults and physical and psychological health conditions and family support in care. *Texto Contexto Enferm* [Internet]. 2023 [cited YEAR MONTH DAY]; 32:e20230100. Available from: <https://doi.org/10.1590/1980-265X-TCE-2023-0100en>

# CUIDADORES FAMILIARES DE IDOSOS E CONDIÇÕES DE SAÚDE FÍSICA, PSICOLÓGICA E APOIO FAMILIAR NO CUIDADO

## RESUMO

**Objetivo:** analisar a existência de sobrecarga de cuidadores familiares de idosos nas dimensões de saúde física, psicológica e apoio familiar.

**Método:** estudo qualitativo, realizado com 23 participantes de Dianópolis, Tocantins, Brasil. Os dados foram coletados mediante entrevistas semiestruturadas em setembro de 2022. A análise dos dados foi efetuada utilizando-se a análise de conteúdo na modalidade temática de Minayo, que abrange a ordenação, a classificação e a análise final dos dados.

**Resultados:** os resultados evidenciam que o exercício da função de cuidador está relacionado à representação social, a qual é potencializada: pelo contexto, valores culturais e familiares; pela naturalização da função da mulher como cuidadora; pela potencialização da sobrecarga em razão do excesso de responsabilidade e falta de apoio de outros membros da família; e pela presença, nos cuidadores, de sintomas psicológicos sobrepondo-se aos físicos.

**Conclusão:** conclui-se que o apoio dos profissionais é essencial para repensar novas práticas e formas de produzir o cuidado, por meio de atividades individuais ou coletivas, com vistas a prevenir o adoecimento dos cuidadores.

**DESCRITORES:** Cuidadores. Fardo do cuidador. Idoso. Estresse emocional. Esgotamento psicológico.

# CUIDADORES FAMILIARES DE ANCIANOS Y CONDICIONES DE SALUD FÍSICA Y PSICOLÓGICA Y APOYO FAMILIAR EN EL CUIDADO

## RESUMEN

**Objetivo:** analizar la existencia de sobrecarga de cuidadores familiares de ancianos en las dimensiones de salud física y psicológica y apoyo familiar.

**Método:** estudio cualitativo, realizado con 23 participantes de Dianópolis, Tocantins, Brasil. Los datos fueron recolectados a través de entrevistas semiestructuradas en septiembre de 2022. El análisis de datos se realizó mediante análisis de contenido en la modalidad temática de Minayo, que incluye ordenamiento, clasificación y análisis final de datos.

**Resultados:** los resultados muestran que el ejercicio del rol de cuidador está relacionado con la representación social, que se ve potenciada: por el contexto, los valores culturales y familiares; por la naturalización del rol de la mujer como cuidadora; al aumentar la carga por exceso de responsabilidad y falta de apoyo de otros miembros de la familia; y por la presencia, en los cuidadores, de síntomas psicológicos superpuestos a los físicos.

**Conclusión:** se concluye que el apoyo de los profesionales es fundamental para repensar nuevas prácticas y formas de producir cuidado, a través de actividades individuales o colectivas, con miras a prevenir que los cuidadores se enfermen.

**DESCRIPTORES:** Cuidadores. Carga del cuidador. Anciano. Estrés emocional. Agotamiento psicológico.

## INTRODUCTION

The last few decades have been marked by growth in the population's life expectancy and by the drop in birth and death rates in most countries of the world<sup>1</sup>. Older adults currently represent 12.3% of the global population, but it is estimated that the population aged over 60 will reach 2 billion by 2050, which will correspond to 20% of the world's population<sup>2</sup>. This will also increase the number of people dependent on care, which could reach 77 million among older adults and children<sup>1</sup>. Population aging is accompanied by longevity, and with it, the need for care. Thus, governments and society need to review the problem solving strategies of this aging population worldwide<sup>3</sup>.

The aging process and economic development are a reality progressively experienced by the most developed countries in North America and Europe, accentuated after the Second World War. This reality also currently extends to developing countries, such as Brazil, but the accelerated process of population aging occurs in parallel with the slow economic development and the improvement in the quality of life of the population<sup>4</sup>. The expectation is that the number of older adults will reach 25.5% of the Brazilian population by 2060, with the rate being 9.2% in 2018. The proportion of older adults in municipalities in the state of Tocantins is gradually increasing: the aging rate also represents the increase in dependency of this population<sup>5</sup>.

Thus, the demographic and social changes associated with population aging have resulted in much debate about how care is provided to older adults and how the quality of life of caregivers<sup>6</sup> is. With longevity, dependence and physical vulnerability become part of the lives of older adults and their families<sup>4</sup>. In Brazil, the family which (as is already tradition) offers the necessary care to an older adult receives a growing demand in care<sup>7</sup>.

For the Ministry of Health, the caregiver is a person, family member or not, who, with or without remuneration, provides care to the sick older adult or for who is dependent on someone to carry out their daily activities<sup>1</sup>. Such care can be with personal hygiene, food, routine medication, follow-up to health services, as well as help with daily services, except for procedures or techniques specific to legally established professions, particularly in the area of nursing<sup>1</sup>. In the Brazilian Classification of Occupations, the Ministry of Labor defines the caregiver as a person who "takes care of an older adult based on objectives established by specialized institutions or those directly responsible for their well-being, health, food, personal hygiene, education, culture, recreation and leisure of the assisted person"<sup>1:8</sup>.

Research shows that the perception of effort, the greater dependence of older adults, the age of the caregiver and the symptoms of emotional overload are linked with physical overload symptoms and are significantly associated with emotional exhaustion, which can have anxiety and depression as main representations<sup>8-9</sup>. Thus, understanding the physical, emotional and social barriers involved in the act of caring is important to promote better quality of life and less burden on caregivers, and in turn also improve care for the person who is being cared for<sup>10</sup>.

In this sense, considering the aging rates in Brazil and family caregivers, it is necessary to understand the health conditions, needs and difficulties of those responsible for ensuring the quality of life and well-being of older adults.

Therefore, this study had the following guiding question: What is the level of overload in the context of health and well-being, the clinical and psychological conditions and the factors associated with burnout in family caregivers of older adults? That said, the general objective of the study was to analyze the overload of family caregivers of older adults in the physical and psychological health and family support dimensions.

## METHOD

This qualitative study was carried out with caregivers of older adults in the city of Dianópolis, located in the southeastern region of the state of Tocantins, Brazil. The inclusion criteria for the caregiver included: being a family member, being over 21 years old, being the main caregiver for at least one year and not receiving remuneration for this activity. Institutionalized older adults, paid caregivers and older adults with cancer were excluded from the study. The initial sample consisted of 28 participants, but one older adult died, two were not located and two did not meet the inclusion criteria, so there were 23 participants in the final sample.

The field work began with a visit to the seven Basic Health Units (*Unidade Básicas de Saúde – UBS*) in the municipality to present the research to the nurse responsible for the unit and authorization for the random search of four medical records by *UBS* of older adults over 60 years old, men or women, residents of the urban area and dependent on constant care. After selecting caregivers at the *UBS* through randomization and considering the inclusion criteria, the first contact with the caregiver occurred through the Community Health Agent (CHA) of each area. The interviews were conducted at the caregiver's residence by prior appointment via telephone contact. Each lasted about 30 minutes on average. A cell phone was used for recording the interview with the permission of the interviewee. The interviews occurred in the period from September 6 to 20, 2022.

An interview script (semi-structured) previously prepared by the researcher was used for data collection. In addition, a structured script was applied to collect sociodemographic data to characterize the sample, containing variables such as gender, degree of kinship, income, marital status, education, and contamination by Covid-19. The questions in the semi-structured interview were composed of questions which sought to reveal the levels of burden with regard to physical and psychological aspects and receiving support for the care of other family members. The semi-structured interview follows a script previously prepared by the researcher, ensuring that the assumptions will be covered in the conversation<sup>11</sup>. The adequacy of the research instrument (semi-structured interview) was verified through applying a pilot.

The data were processed<sup>11</sup> through content analysis in the thematic modality, which comprises the steps of ordering, classification and final data analysis. The interviews were transcribed in full and the data were organized in the ordering step. Then, an exhaustive reading was performed to classify the data, first horizontally and then cross-sectionally, in order to explore the context and structures of relevance and identify the relevant thematic areas. Finally, the data were analyzed, which included the discussion and interpretation of the data collected from the perspective of recent scientific evidence on the subject in a movement from empirical to theoretical and vice versa.

Regarding ethical aspects, data collection took place after approval by the Research Ethics Committee (CEP) of the Lutheran University of Brazil and signing the Informed Consent Form (ICF) by the participants. The participants were identified by the letter P followed by the interview number as a way of guaranteeing anonymity of the collected information. The communication of the results of this study followed the guidelines of the Consolidated Criteria for Reporting Qualitative Research (COREQ).

## RESULTS

The participants of this study are predominantly female daughters, between 45 and 60 years old. Of the 23 interviewees, 10 have been family caregivers for more than five years. Income mostly comes from the retirement of the older adult or the caregiver themselves, ranging between two and three minimum monthly salaries. Although the caregiver is responsible for administering the resources, there is a reference that they are insufficient for care due to the high cost of medications.

After extracting the structures of relevance from the participants' statements, the data analysis showed three thematic areas, namely: burden on caregivers, physical and mental health conditions and support from other family members.

## **Burden on caregivers**

This thematic area addresses the experience of care and the burden levels experienced by caregivers of the older adults. On the one hand, it points to situations of tiredness, excessive responsibility, lack of time; on the other hand, satisfaction with the care provided. In some speeches, religious beliefs that report care as a divine mission still come to light.

*Not before, but now I'm feeling overwhelmed, there are days when I'm feeling a little tired. Sometimes I wake up with that thought [...] it would be so nice if someone came to take care of them today! Not directly, but sometimes I feel it (P12).*

*[...] there are times when I feel tired, overwhelmed, there are times when I feel "poor thing, you had no mother", so I take care of it properly [...] I think the routine is not normal; I needed to take another break, it's very demanding, I'm about to be 85 years old (P8).*

It is observed among the participants that the overload is not a continuum: there are moments in which the representation of the burden is greater than in others. On the other hand, the following statements demonstrate greater overload, since in addition to the demand for care, there is still the difficulty in dealing with the impulses or the aggressive behavior of the care recipient, caused or not by their health situation and/or clinical condition.

*[...] we feel, yes, too tired because just the tiredness of dealing with him there... it's too rough, aggressive, but we have to endure it! (P17).*

*[...], but sometimes it's very tiring, because my father is very stressed, swears a lot, mistreats me with words. But when he's calm, it's pretty easy to take care of him. The problem is that he is very aggressive, verbally, sometimes even physically (P11).*

It is clear that the relative's aggressiveness level also affects the caregiver's tiredness levels, more than the condition of dependency.

*It was more difficult, I already felt very tired, because that phase of agitation and aggressiveness is over [...], she wouldn't stay quiet, she hit me. [...] today it totally depends, but it doesn't affect my emotions as much as it did back then (P10).*

Another relevant aspect presented which reinforces the burden is the feeling of exploitation reported by two participants.

*It isn't easy, no; and sometimes it demands a lot from us, because an older adult is a lot of work. My mother herself is giving me a lot of work, she's being very difficult. She is very stubborn, everything has to be done her way, and she "keeps score" about everything with me, [...] I feel, I feel, I feel very overwhelmed (P1).*

*[...] he can walk, take a shower by himself, but he doesn't want to, he's prostrated, and what I do never seems to be good, it never pleases him (P3).*

The statements below present feelings of gratitude and surrender, in which the participants experience the care situation as inherent to humans, as an opportunity, privilege and retribution for the bonds of affection and/or previous experience of care.

*[...] I feel happy to take care of her, I feel privileged to be able to be with her. She took care of me, and now I can take care of her (P15).*

*In the affective part [...] I feel accomplished in taking care of him, I like to take care of him. He deserves it, he's always been very good to me. He treated me like a princess, and today I'm reciprocating and I don't complain. Even when I'm tired, I don't change it for something else (P8).*

The ambivalence of feelings arising from care was also evidenced; sometimes solidarity and companionship, sometimes overload and excess responsibility.

*At the same time that I feel privileged to have the time to take care of her, it's also difficult because we don't have time to do anything else and it's very busy. It's a lot of responsibility to take care of someone, too much responsibility (P2).*

Feelings and affective bonds between the caregiver and the person being cared for point to the strengthening of the care relationship and seem to be a protective factor for the demands of the function performed by the caregiver.

*[...] I feel good [emotional] [...] I take care of her with great pleasure, with great pleasure... I want to reach her age (P3).*

*I feel good, I'll take care of him all my life, until the day he dies. I do it with pleasure, me and my girl, very carefully. When he gets sick it is the biggest concern, I do everything possible (P5).*

In the speeches, understanding the care as a mission or divine designation to face everyday situations is present.

*For me it's a mission, and I do it with love. She was always very good with us, so now it's our turn to do it for her, and I'm doing my part and I want to do it the best way (P10).*

*I am the only one responsible for taking care of her. There are times when we get stressed, but I can't stop taking care of her [...]. And my brothers don't care, so I'm like "Isn't that what's left for me?" It was God himself who prepared for me to take care of her (P13).*

The participants refer to personal satisfaction when they see themselves able to reciprocate the care received to fulfill all the daily tasks and also collaborate for the well-being of the family member. They also reported that feelings such as love and gratification were awakened by this experience.

*I feel really good. Thank God I have my mother. It's not an easy task, sometimes it's very stressful, but then I think it's not because she wants to, but because of her problem [...] We try to please, give comfort [...] (P6).*

*I feel good, thank God, I feel good. We who are children have to take care of them. Thank God, the love I have and I feel for her is great, she is the one who brought me into the world, so there is no reason for us to say that we cannot take care of her (P15).*

*I feel good, I like it, I feel good and I ask God to give me health to take care of my parents, that's what I ask God the most. I feel good knowing that my mother took care of me and now I can take care of them both [father and mother] (P12).*

## **Physical and mental health conditions**

This thematic area addresses the physical and mental health conditions of caregivers. The interviews show complaints of physical pain resulting from care, such as low back pain, sleep disorders and the need to use medication. Participants also reported psychological symptoms such as anxiety, fear, non-recognition of the care provided and even lack of self-care due to overload.

*[...] I think that mental is worse, people's minds get much more tired, those who have a husband, a child and works at home, works in the street, just like here at my service. I think the mental fatigue is greater, the overload is more (P16).*

*More mentally, and physically too, because I have a back problem. Sometimes my father is not able to collaborate, so we end up forcing him; this affects the physical aspect, but also the psychological due to verbal aggression (P11).*

Participants try to identify which aspect of burden prevails. Even affirming the physical overload, they mention the emotional issues and the psychological exhaustion suffered.

*Physically, because it's really tiring, you don't rest from Sunday to Sunday [...] And mentally, because I haven't had time for myself for a long time, I don't know what it's like to take care of myself [emotional] (P1).*

*Another noteworthy aspect is the difficulty of prioritizing aspects of personal life and self-care, because the care relationship absorbs most of the time, and it is not possible, at the moment, to dedicate care to oneself.*

*[...] my life is on the sidelines, I'm putting my children on the sidelines, I don't have time for them [...] Being distant from my children [crying], I wanted to do more for them [...]. I feel absent. It's a mother on one side and my children on the other, I do what I can (P3).*

*I don't know what it's like to travel, to go somewhere, from Sunday to Sunday it's me. I have no rest. But I think it's for a good cause (P13).*

Along with the overload experienced, the feeling of exploitation is also present.

*[...] it affects me too much, she exploits me, I feel that she exploits me. And I can't get out of this cycle. I can't get out [...]. (P1).*

*[...], but like, you have to climb the mountain every day. You feel tired, exploited [...] I have five brothers, but nobody helps (P3).*

Some participants reported anxiety attacks, sleep disorders and the use of psychotropic drugs.

*I always talk to God, I feel my head a little troubled, but I ask God for a lot of strength [...] I sometimes get very upset, when he feels bad, I think he won't escape, but when he gets better, it soon passes (P7).*

*It affects me, I felt sick, I stayed here alone for two months, I became very anxious, I started to feel terrible pain, and nothing was going away. And the doctor said it was triggered by anxiety; I did a lot of tests and found nothing (P9).*

*[...] there are times when you think you're going to freak out, the family gets sick together. You get so stuck in this routine that I'm like, "My God, I'm going to have a fit here!" [...] It gave me physical and mental exhaustion [...]. Until then, you're in that rut, and you think you're doing it, but you're not (P10).*

## **Support from other family members**

This thematic area addresses the importance of family support, either through support in alternating care, or in emotional support, in the division of tasks and in financial support. The lack of support mentioned in the speeches enhances the feeling of overload and loneliness.

*[...], but like, I feel like you have to climb the mountain every day. You feel tired... I have five brothers, but nobody helps (P3).*

*I feel overwhelmed when I feel alone, when my sister has to travel I call my brother, he doesn't come, so I get upset (P9).*

*But I feel overloaded, because I have several brothers, but it's all on me. No help (P14).*

The statements show that the non-responsibility and non-involvement of other family members also lead to overload.

*I feel I get a little help from a sister, but only a little. There's this sister who sometimes comes to get them [...], but it's not much. The problem I think is that nobody wants to take responsibility [...]. Because the obligation is mine alone (P12).*

*Our family has eight siblings, but the only one who helps is one sister. One brother even took it, but he only stayed for a week, returned and said he didn't want to do it anymore. He couldn't take that responsibility (P7).*

Burden was also associated with feelings such as loneliness and sadness, especially when the main caregiver cannot count on the help of other family members.

*I feel overwhelmed when I feel alone, when my sister has to travel I call my brother, he doesn't come, so I get upset (P9).*

*There are days when you are happy, but at the same time you are sad, because her situation is not easy. My health is also fragile, but even so I'm fighting, I feel overwhelmed, because I have several brothers, but it's all on me (P14).*

Respondents who rely on alternating care and help from other family members demonstrated more freedom and time to express affections and emotions.

*We are all united, everyone helps each other. My sister works outside, but in the afternoon, three times a week, she comes to get our mother, so we can rest [...] we manage to deal well, it is a pleasure to be with her. Here, one is helping, guiding the other (P6).*

*My brothers always help, our relationship is good, [...] when our mother is hospitalized, if I can't go, they go. And my wife too, she is my support, [...] she helps me a lot. Mom needs help for everything, for a bath, for everything (P15).*

However, in other speeches, the main caregiver feels supported in different ways, emphasizing the importance of collaboration and financial support in care.

*It's just me here, my brothers live far away, but they always help, they help financially, they don't miss anything, the medicines are expensive, they always order them (P16).*

*On a daily basis, it's me and a sister who take turns providing care [...]. But the financial part or depending on taking it somewhere, they contribute (P23).*

*My brothers, nobody; before they helped financially, but now nothing, no one helps. Sometimes they doubt the expense we have, that's why I made a list of everything (P13).*

The interviews demonstrate that caring for an older adult is a process which causes changes in the caregiver's personal and professional sphere due to wear and stress. In the speeches, it was identified that after facing difficulties related to the care routine, some families were able to organize themselves by including other family members in the care provision, thus reporting less burden complaints. It has also been shown that positive feelings and affective bonds towards the person being cared for reduce the burden.

## DISCUSSION

The sociodemographic data found in this study are similar to the findings of another study<sup>12</sup>, in which it is shown that care is provided by family members, usually wives or female daughters in the average age group above 40 years<sup>12</sup>. Thus, it is observed that the family group is empowering in terms of providing care for dependent older adults with various chronic conditions; however, given the challenging task of care, the family is forced to reconcile and reorganize the daily needs of care for other domestic, social and professional responsibilities of their routine life<sup>7</sup>.

The care role attributed to women seems to result from a historical and social construction. Since childhood, girls are taught to perform care tasks and create the expectation that she will fulfill the role of caregiver, whenever necessary, throughout her life. Therefore, one can point to culture as a fundamental element for choosing who will provide care for older adults in their aging process<sup>12</sup>. Responsibility for caring for older adult and sick family members in Brazil has historically been assigned to women<sup>8</sup>. These results are corroborated in another study<sup>7</sup>, in which it was shown that the empirical dimensions show care as an exclusively female and unpaid job.

Family caregivers play a strategic role in the daily activities of those receiving care. Although some caregivers see care provision as conducive and a generator of positive utility and family support,

for others it is perceived that such provision has lost this quality, producing negative consequences for them, such as a high risk of exhaustion, especially when exercising care without external support, leading to worsening in their quality of life<sup>6</sup>. Another study<sup>13</sup> identified that family caregivers have difficulty reconciling their activities as caregivers with those of self-care due to the lack of family support and social and health support networks.

The function of caring over time ends up becoming something extremely stressful and tiring, and this negatively affects self-care, causing various health problems such as: anxiety, depression, recurrent headaches, muscle pain, and/or insomnia<sup>8</sup>. It can be assumed that there is a direct relationship between the greater dependence of an older adult, the time spent on direct care and less time for themselves. This data shows that it is necessary to give visibility to the problem and the way in which the care activities performed by the caregiver are divided and organized<sup>14</sup>.

Studies<sup>9,15</sup> show that the greater the dependency and impairment of the health of the older adult, the greater the physical symptoms and the overload in relation to the care provision, thereby causing worsened quality of life for the caregiver. Overload can also lead to the development of physical, emotional, psychiatric and social symptoms and the use of medication; it can additionally have a negative effect on finances and impair the quality of care provided<sup>16-17</sup>. Even the most resilient caregivers are subject to living with the difficulties arising from the care routine, with some degree of physical and emotional overload and exhaustion from the role of caregiver<sup>13</sup>.

Changes in personal life resulting from overlapping tasks related to the act of caring – so that caregivers give up their own needs and abdicate many of their interests, which then starts to present restrictions regarding their own personal life – can be decisive for the feeling of overload<sup>18</sup>. Exposure to physical and emotional overload and changes in the life routines of family caregivers to dependent older adults are directly related to the quality of life of the members involved<sup>19</sup>.

On the one hand, the act of caring for a loved one can be rewarding and considerable, as it represents a form of retribution for the care once received; on the other hand, if the obligation is the only driver of the task, care generates overload and in turn makes the process exhausting, especially when it is not possible to choose to be (or not to be) a caregiver and when care focuses on only one family member<sup>15</sup>. In this context, faith and religiosity are strategies used as support and a way of coping with negative aspects in the care relationship, being effective strategies for coping with stress, anguish, depression and the burden resulting from the care process<sup>13</sup>.

The meanings given to the caring experience can contribute to reflection by caregivers of older adults on the relationship between the behaviors and habits related to health assumed throughout life and their influence on aging, so that a re-signification of this process is possible<sup>12</sup>. Based on their perceptions and relationships, children feel the duty and obligation to care for and support their parents throughout aging; they feel gratitude for being able to care as retribution for the care received<sup>7</sup>.

Feelings such as love, charity and gratification were identified as a commitment to care and bring a return of affection<sup>20</sup>. Mutual help within the family environment produces trust and well-being for all members; these positive aspects of family life favor an environment of solidarity and union, as well as positively interfere with the state of mind/mood of the members, which considerably contributes to maintaining the physical and psychological integrity of individuals<sup>19-20</sup>.

A scoping review<sup>21</sup> showed that the most frequent need for caregivers of patients with dementia was information regarding health services. Another study<sup>22</sup> showed that the lack of information and support in care contribute to the negative mental health determinants of caregivers. Quality of life, self-esteem and confidence are predictors of positive mental health. The need for information and support for caregivers was also found in a recent national study<sup>23</sup> developed in Japan.

Along this line, a study<sup>24</sup> was carried out with American general practitioners, internal medicine and geriatricians linked to Primary Healthcare with the objective of investigating the approaches, needs and risks of family caregivers. The results showed that few professionals carried out a formal assessment of the family caregiver using a standardized instrument. Among the topics addressed through informal discussions, patient safety management by caregivers, the ability to provide care and the need for support were reported. Most of the interviewees referred the caregivers to other services so that the needs of these users could be met, justifying such conduct due to a lack of time. Regarding Primary Healthcare physicians who assess the needs and risks of caregivers, other researchers<sup>25</sup> have identified factors which contribute to the responsibility of these professionals, such as personal experience with care, being a woman and more mature, and length of outpatient service.

In addition, a group of researchers<sup>26</sup> in Canada developed and validated a new instrument to assess the risk of caregiver burden, the Caregiver Risk Evaluation (CaRE) algorithm. This new instrument is an efficient method for professionals to find out which families need additional care, support or services. CaRE enables both rapid identification of at-risk caregivers and connection to support and services, reducing the need for long-term care admissions for care recipients.

Little by little, studies have been discussing the health of this social actor called “caregiver”, since this is important for guaranteeing, preserving or recovering the health of the person being cared for. Thus, it is of great value that health professionals take this subject into account in their care plans, aiming to provide better support and higher quality care at home<sup>14,20</sup>. However, the existence of actions by the Brazilian State in formulating proposals that benefit dependent older adults and their caregivers is still under construction<sup>3</sup>. Even developed countries such as Japan<sup>23</sup> and the United States<sup>24</sup> which have specific programs and policies in place also have difficulties related to supporting caregivers.

Moreover, health teams need to know the profile of those who are caregivers for older adults and their difficulties, integrating this caregiver in operationalizing their actions. Understanding the vulnerability of the caregiver is the first step towards elaborating care prescriptions covering the needs of this public with a view to reducing risks and raising the quality of life of older adults, the caregiver and the family<sup>8,17</sup>. As observed by another author<sup>27</sup>, the family should not assume the burden of caring for the dependent loved one alone; this care must be divided between the family, the State and civil society.

The limitation of the present study lies in the fact that it was carried out at home, where the dependent family member was present during the interview in some situations, and may have inhibited the participant in answering some questions.

In addition to expanding knowledge about health and burden, feelings and experiences of family caregivers for older adults, this study also enables nursing and health professionals to rethink new practices and ways of providing care. Thus, it is necessary to understand that the caregiver is an important social actor and that their health is related to the health of the care receiver. In this sense, it is up to health professionals to carry out preventive actions for caregivers of older adults, understanding their limitations and weaknesses and to employ support activities and individual or collective guidance through groups of caregivers.

## FINAL CONSIDERATIONS

The present study showed that performing the role of caregiver is not only a task with defined attributions, but also a social representation of being a caregiver related to the context and cultural and family values in which they are inserted. The findings corroborate the evidence in the literature regarding gender issues, specifically the fact that the task of caring is a role naturally attributed to women.

The results showed that the burden is enhanced by excessive responsibility, lack of support from other family members and high demands due to the degree of impairment and physical weakness of the older adult. Furthermore, the influence of religious beliefs and practices was demonstrated regarding the cultural aspect of care, which leads them to believe that care is a divine designation. However, it was observed that caregivers with feelings of gratitude place less emphasis on burden, understanding the care experience as an opportunity to repay the care once received.

Participants who reported psychological symptoms such as anxiety, fear and non-recognition of the care provided complained more about burden than those who reported only physical symptoms derived from routine care; for example, low back pain. The involvement of other family members in alternating care, in emotional support, in dividing tasks and in financial support has been shown to bring more satisfaction in carrying out care, freedom and time to express affections and emotions.

In this sense, it can be said that the relationship between caregiver and the older adult care recipient is permeated by subjective aspects. Thus, it is suggested that managers and professionals, especially from the health and social assistance services network, develop guidance and support strategies for caregivers with a view to sharing knowledge, as well as providing emotional and psychological support to caregivers so that they can take more time and care for themselves.

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## NOTES

### ORIGIN OF THE ARTICLE

Extracted from the dissertation – “*Cuidadores familiares de idosos e condições de saúde física, psicológica e apoio familiar no cuidado*”, presented to the Graduate Program in Health Promotion at Universidade Luterana do Brasil, in 2023.

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Study design: Sartori IFG, Hirdes A.

Data collection: Sartori IFG.

Data analysis and interpretation: Sartori IFG, Hirdes A.

Discussion of the results: Sartori IFG.

Writing and/or critical review of content: Hirdes A, Almeida Neto H.

Revision and final approval of the final version: Hirdes A.

### APPROVAL OF ETHICS COMMITTEE IN RESEARCH

Approved by the Research Ethics Committee of the Lutheran University of Brazil, opinion no. 5.607.510/2022, Certificate of Presentation for Ethical Appreciation 59760122.2.0000.5349.

### CONFLICT OF INTEREST

There is no conflict of interest.

### EDITORS

Associated Editors: Luciara Fabiane Sebold, Maria Lígia Bellaguarda.

Editor-in-chief: Elisiane Lorenzini.

### HISTORICAL

Received: May 08, 2023.

Approved: July 17, 2023.

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