

## **METAMORFOSIS IN THE LIVES OF ELDERLY PEOPLE CARING FOR DEPENDENT ELDERLY IN BRAZIL**

**Girliani Silva de Sousa<sup>1</sup>** 

**Raimunda Magalhães da Silva<sup>2</sup>** 

**Amanda Márcia dos Santos Reinaldo<sup>3</sup>** 

**Christina Cesar Praça Brasil<sup>2</sup>** 

**Maria Odete Pereira<sup>3</sup>** 

**Maria Cecília de Souza Minayo<sup>4</sup>** 

<sup>1</sup>Universidade Federal de São Paulo, Escola Paulista de Enfermagem, Departamento de Enfermagem Clínica e Cirúrgica. São Paulo, São Paulo, Brasil.

<sup>2</sup>Universidade de Fortaleza, Programa de Pós-Graduação em Saúde Coletiva e de Enfermagem. Fortaleza, Ceará, Brasil.

<sup>3</sup>Universidade Federal de Minas Gerais, Escola de Enfermagem. Belo Horizonte, Minas Gerais, Brasil.

<sup>4</sup>Fundação Oswaldo Cruz, Escola Nacional de Saúde Pública, Departamento de Estudos sobre Violência e Saúde Jorge Careli. Rio de Janeiro, Rio de Janeiro, Brasil.

### **ABSTRACT**

**Objective:** to understand the phenomenon concerning the change in life and routine of elderly family caregivers who care for dependent elderly family members in Brazil.

**Method:** qualitative, exploratory and descriptive study, developed with 33 elderly family caregivers, from June to September 2019, in the cities of Belo Horizonte, Rio de Janeiro, Porto Alegre, Araranguá, Manaus, Fortaleza and Teresina. Semi-structured interviews were conducted based on the theme of care, facilitating circumstances and difficulties. The analysis of the information was guided by the theoretical-methodological framework of hermeneutics-dialectics.

**Results:** a comprehensive model of the experience of being an elderly caregiver of a dependent elderly family member. This process was part of two categories: "Assuming care" and "Unmet needs". The facilitating circumstances to assume care were positive emotions and bonds with the older person, acceptance of the disease, stable clinical status and support from health professionals, formal caregivers, domestic employees and family support. The difficulties were when the behavior of the dependent elderly becomes aggressive, experiencing loneliness, poor health, social isolation, financial restrictions and absence of social and health support.

**Conclusion:** elderly caregivers are important agents in the exercise of care for the dependent elderly. When they have support, they can perform the care activities and have time to take care of themselves. However, for the most part, these people give up their lives, withdraw from the labor market, isolate themselves and suffer from the lack of material resources and support from health services.

**DESCRIPTORS:** Qualitative research. Family caregiver. Fragile elderly. Elderly health. Geriatric nursing.

**HOW CITED:** Sousa GS, Silva RM, Reinaldo AMS, Brasil CCP, Pereira MO, Minayo MCS. Metamorfosis in the lives of elderly people caring for dependent elderly in Brazil. *Texto Contexto Enferm* [Internet]. 2021 [cited YEAR MONTH DAY]; 30:e20200608. Available from: <https://doi.org/10.1590/1980-265X-TCE-2020-0608>

# A METAMORFOSE NA VIDA DE IDOSOS QUE CUIDAM DE IDOSOS DEPENDENTES NO BRASIL

## RESUMO

**Objetivo:** compreender o fenômeno da mudança de vida e rotina de idosos familiares que passam a cuidar de idosos dependentes no Brasil.

**Método:** estudo qualitativo, exploratório e descritivo, desenvolvido com 33 cuidadores idosos familiares, de junho a setembro de 2019, nas cidades de Belo Horizonte, Rio de Janeiro, Porto Alegre, Araranguá, Manaus, Fortaleza e Teresina. Realizaram-se entrevistas semiestruturadas norteadas pelo tema de assumir o cuidado, circunstâncias facilitadoras e dificuldades. A análise das informações foi guiada pelo referencial teórico-metodológico da hermenêutica-dialética.

**Resultados:** constituiu-se um modelo compreensivo da experiência de ser cuidador idoso de um membro familiar idoso. Esse processo integrou duas categorias: “Assumindo o cuidado” e “Necessidades não atendidas”. As circunstâncias facilitadoras para assumir o cuidado foram as emoções positivas e os vínculos com a pessoa idosa, a aceitação da doença, o quadro clínico estável e o suporte de profissionais de saúde, cuidadores formais, colaboradores domésticos e apoio familiar. As dificuldades ocorrem, principalmente, quando o comportamento do idoso dependente é agressivo, pois há vivência da solidão, saúde fragilizada, isolamento social, restrições financeiras e ausência de suporte social e de saúde.

**Conclusão:** os cuidadores idosos são importantes agentes no exercício de cuidado à pessoa idosa dependente. Quando possuem apoio, conseguem conciliar as atividades do cuidado e têm tempo para cuidar de si. Em sua maioria, essas pessoas, entretanto, renunciam às suas vidas, se retiram do mercado de trabalho, se isolam e sofrem com a falta de recursos materiais e de apoio dos serviços de saúde.

**DESCRITORES:** Pesquisa qualitativa. Cuidador familiar. Idoso fragilizado. Saúde do idoso. Enfermagem geriátrica.

# METAMORFOSIS EN LA VIDA DE LOS ANCIANOS QUE CUIDAN A ANCIANOS DEPENDIENTES EN BRASIL

## RESUMEN

**Objetivo:** comprender el fenómeno del cambio en la vida y la rutina de los familiares ancianos que comienzan a cuidar a las personas mayores dependientes en Brasil.

**Método:** estudio cualitativo, exploratorio y descriptivo, desarrollado con 33 cuidadores familiares ancianos, de junio a septiembre de 2019, en las ciudades de Belo Horizonte, Río de Janeiro, Porto Alegre, Araranguá, Manaus, Fortaleza y Teresina. Se realizaron entrevistas semiestruturadas, guiadas por el tema de cuidar, facilitar circunstancias y dificultades. El análisis de la información estuvo guiado por el marco teórico-metodológico de la hermenéutica-dialéctica.

**Resultados:** Se constituyó un modelo integral de la experiencia de ser cuidador anciano de un familiar anciano. Este proceso integró dos categorías: “Asumir cuidados” y “Necesidades insatisfechas”. Las circunstancias facilitadoras para el cuidado fueron emociones positivas y vínculos con el anciano, aceptación de la enfermedad, estado clínico estable y apoyo de profesionales de la salud, cuidadores formales, trabajadores domésticos y apoyo familiar. Las dificultades se presentan principalmente cuando el comportamiento del anciano dependiente es agresivo, ya que existe una experiencia de soledad, salud frágil, aislamiento social, restricciones económicas y falta de apoyo social y sanitario.

**Conclusión:** los cuidadores de ancianos son agentes importantes en el ejercicio del cuidado del anciano dependiente. Cuando cuentan con apoyo, logran conciliar las actividades de cuidado y tienen tiempo para cuidarse. La mayoría de estas personas, sin embargo, renuncian a sus vidas, se retiran del mercado laboral, se aíslan y padecen la falta de recursos materiales y apoyo de los servicios de salud.

**DESCRIPTORES:** Investigación cualitativa. Cuidador familiar. Ancianos frágiles. Salud de los ancianos. Enfermería geriátrica.

## INTRODUCTION

The phenomenon of aging is rapidly evolving at the global level. In Brazil, population projections tend to reduce young people and the progression of the elderly contingent in the coming decades<sup>1</sup>. Due to this trend, the occurrence of diseases and the need for long-term care are increasing<sup>2</sup>.

In Brazil, care for dependent elderly traditionally takes place in the home context and is an assignment assumed by a family member, who becomes the caregiver and, consequently, embraces responsibility for the provision of care<sup>2-4</sup>. Demographic transition and changes in family structure, however, lead elderly people to be representative in the segment of caregivers of dependent family components, also elderly<sup>2,4</sup>.

Becoming a caregiver imposes a challenge for an old person, because it means reconciling one's own well-being and self-care with high loads of tasks that the family's health status requires. Studies indicate that elderly caregivers denote fragile health, physical, emotional, financial overload, social isolation and greater self-perception of stress<sup>4-11</sup>. In this context, elderly family caregivers deserve attention in health services, because health problems can precipitate an interruption of care and result in hospitalizations or admissions to Long-Term Care Institutions (LSI).

The role of the caregiver is greatly explored by research in the areas of Gerontology and Nursing. However, there is a gap in knowledge regarding the elderly family caregiver, mainly from the perspective of this social agent. In addition, the lack of public policies and the limited resources and services available to support elderly people who care for elderly family members in Brazil make this reflection necessary<sup>2-3</sup>.

In light of the above, recognizing the needs, challenges and circumstances that involve the process of becoming an elderly caregiver of dependent elderly people is a way for the elaboration of systematic care actions. In these actions, care should be included for the elderly who assist their sick family member.

In this study, by listening to their experiences, we attempt to understand life and routine changes of elderly family members who start caring for dependent elderly people in Brazil.

## METHOD

This is a qualitative, exploratory and descriptive study, carried out from June to September 2019. This investigation is part of a multicentric research called "Situational Study of Dependent Elderly People Who Live with Their Families Aiming to Support a Care Policy and Support for Caregivers". We sought to understand the situation of elderly people who care for dependent family members, who are also elderly. The hypothesis is portrayed in the idea that a better understanding supports actions that support them in their daily routine.

Thirty-three elderly family caregivers participate in this study - in eight municipalities in the five Regions of Brazil: Rio de Janeiro (RJ), Belo Horizonte (MG), Porto Alegre (RS), Araranguá (SC), Brasília (DF), Fortaleza (CE), Teresina (PI) and Manaus (AM), and was called: "Situational Study of Dependent Elderly living with their Families Aiming to Support a Care Policy and Support to Caregivers". The participants had to be the main caregiver of the elderly person; exercise full-time care for at least one month and be oriented in time and space in order to report their experience. This investigation found 43 elderly caregivers, but only 33 were able to describe their situation.

The participant identification occurred upon indication of the health professionals of the Family Health Strategy (ESF) and the geriatric outpatient clinics of these municipalities. The researchers met with health services and explained that the elderly person was dependent on another in order to perform Basic Activities of Daily Living (ADL) and/or Instrumental Activities of Daily Living (IADL).

The semi-structured interview script that served as an instrument for the conversation consisted of open and free questions. It was previously elaborated and improved by researchers with experience in the theme. With the support of this device, the participants were invited to talk about their experiences of taking care of the dependent elderly person, report the changes in their lives due to the care routine, the facilitating circumstances and the difficulties involved in the tasks they perform on a daily basis. A sociodemographic questionnaire was also included to characterize the participants: age; kinship; marital status; length of care; illness and dependence of the elderly.

The interview was previously scheduled with the participants and conducted individually in their homes, with an average duration of 60 minutes. This time was sufficient to establish a comfortable situation and a relationship of mutual trust between researcher and interviewee. The Informed Consent Form (TCLE) was read and signed by the participants, which included the consent for recording on digital media and respect for the stories told by the interviewees, without judgment or criticism.

The theoretical-methodological framework of hermeneutics-dialectics was adopted as the purpose of data analysis<sup>12</sup>. In this framework, the statements must be understood as part of the context in which they are produced. The data interpretation considered the concrete situations that were placed in a reflexive and critical perspective, valuing both empirical data and national and international literature on the subject.

The evaluation of the statements was made by first grouping the interviews, observing similarities and differences in the statements separately by each municipality studied, then grouping them, according to the finding that, regardless of the place of residence, the situations narrated coincided.

The analysis occurred based on levels of interpretation and the data were previously organized, taking into account the following steps: 1) the main question of the analysis - the act of assuming the care of the dependent old person and the facilitating and hindering circumstances of this task; 2) selection of excerpts from the interviews in which the caregivers talked about these aspects; 3) interpretative synthesis of each point, considering all the statements; and 4) interpretative synthesis of the set of data and aspects. As a result of this synthesis, the representative categories described and discussed here were chosen.

In order to protect the identities of the participants, the abbreviation "CI" is used which refers to "elderly caregiver", followed by the numbers from one to 33, in addition to this information: kinship, involvement of the cared person and municipality. Therefore, CI1 represents the first interviewee and so on.

The research was approved by the Research Ethics Committee of the Oswaldo Cruz Foundation.

## RESULTS

Twenty-eight women and five men were interviewed. From the total amount, 18 were between 60 and 69 years old; 11, between 70 and 79 years; and four were over 80 years of age. The degrees of kinship of the respondents were: 15 wives, six daughters, three sisters, three husbands, two sons, two ex-wives, a mother and the wife of a nephew. Regarding the time of care, 18 reported that they performed this activity for between two months to five years; five worked between five to ten years; and ten between ten to 30 years. According to the participants' reports, all the elderly relatives were dependent on ADL's and IADL's.

Regarding the illnesses and dependence, the caregivers reported that 18 elderly people had been affected by stroke, six had developed Alzheimer's disease, four suffered stroke with physical sequelae of alcoholism. The other suffered from multisystemic atrophy, infantile paralysis, head trauma, cancer and depression. Only 12 elderly caregivers alternated the care of their elderly relatives with another person, as five also had a formal caregiver and cleaner. The others had the help of other family members. The majority of the interviewees (28) accumulated the functions of family caregivers

in addition to the execution of domestic activities. Most lived with the dependent elderly person and only five of them lived on their own property.

The category “assuming care” unveils that, for some of the participants, care acquires meaning in marital and filial responsibility and is impregnated with positive emotions - such as dedication, love and gratitude. Thus, the lightness with which the care of the other is attributed to the harmonious relationship with the extension of life is surprising, observing an understanding and acceptance of both elderly people - caregivers and dependents - of the new life situation.

*I give full-time care, I don't see it as an obligation or a burden. Today she sees me as a person who takes care of her, no longer recognizes me as a husband and I am aware that today this is the reality and I seek to live in the best possible way, it is not something she chose and because she knows that she has always been a wonderful person, I care with a lot of love and dedication (IC1, 81 years old, husband, takes care of the wife with Alzheimer's disease, Brasilia).*

According to the above statement, it is inferable that the elderly caregiver was in a marriage and shared dreams, desires and a family, which is the driving force for being a caregiver. Consequently, he associated the attention he paid to his wife with his admiration for her, which made him more resilient and adapted to the situation he experienced.

In general, the statements showed that harmonious experiences are also related to the personal, social and economic conditions of the family. Thus, the participants reported several facilitating aspects, among them: 1) it concerns the social order, because, when there is family support, the caregiver has to share the multiple tasks he/she performs; 2) the elements of emotional content, when the caregiver manages to balance the care of the elderly and their personal desires, that is, care is not the only source of personal fulfillment for the caregiver; 3) Finally, the financial content, because, when the family has the possibility of contracting formal caregivers, rehabilitation professionals and other employees for household duties, the family caregiver's load decreases.

*There's a speech therapist and a physiotherapist who do home visits. Physical therapy every weekday. She has a caregiver, but I help with the dishes, the clothes, the care, the maintenance of the whole house. I realize that it makes a difference to help the caregiver change my mother's diaper, there is a way that she holds onto my arm, then she holds my hand and is calm (IC2, 65 years old, son, takes care of the mother affected by stroke, Rio de Janeiro).*

With the various types of support, the family caregiver is able to manage the tasks, without neglecting the loved one. It is important to highlight that the formal caregiver does not replace the care offered by the family member, but is a fundamental support for the latter to preserve their quality of life, have some time and space for themselves and with a view to socializing, as this participant points out: *I work with artistic restoration to distract myself (IC23)* and others: *I can visit my friends, have an afternoon tea, I go to the country house to rest (IC17)*. However, not all family caregivers have economic and financial conditions and support from other relatives.

Thus, for many interviewees, the exercise of care is something heavy, unsettling and unimaginable. The dark side of this task is experienced as a solitary duty, because there is a lack of support and sharing, and the caregiver suffers the distancing, coldness and neglect of the other family members. Additionally, many of these elderly caregivers report difficulties in the relationship with the person they assist, particularly when they have aggressive behavior.

*I split up with him before he got sick. He was very womanizing. I came home to help take care of his mother. Then he had a stroke and I took care of him. He's the father of my daughter. I think it's my duty, despite the disagreement, I wouldn't let him go without anything. Our coexistence is difficult, because it seems that he does not accept the disease. He gets angry, is very stubborn, complains, throws things at us, when he wants things on time and I cannot give and that's how we go on living, I keep going reluctantly (IC3, 62 years old, ex-wife, takes care of the ex-husband affected by stroke, Belo Horizonte).*

The second type of situation is when the dependent old person does not accept his or her clinical condition.

*I assumed the role of the main and only family caregiver when he had health problems, was unable to perform the activities, did not walk alone and was diagnosed with Parkinson's disease. My daughter worked and soon after she got married. He went on to get very nervous about his life condition, he was very active and now finds himself unable [...] he became stubborn and very angry, it's hard to deal with him, I'm tired of taking care of him alone, I'm on 24 hours, but what can I do? [...] only have me to take care of him (IC4, 64 years old, wife, takes care of her husband with Parkinson's disease, Brasília)*

Although the dark side of care was not directly explained by the participants, they openly discussed the physical, emotional and relational problems they experience. Elderly people who care for the elderly alone have many difficulties. This fact occurs because, in addition to personal renunciations to devote oneself to care, there is a self-demanding factor in the sense of not making mistakes in the exercise of their routine.

The category "unmet needs" gathers the adaptations in life for the exercise of care that lead to physical and mental health problems, associated with tiredness, which impels the elderly caregiver to feel sad, to lose the pleasure of life and to feel isolate socially.

*My routine doubled, I already have several health problems, so it's one patient taking care of the other. At first, I thought I'd take care of it. He's my husband, I've been taking care of him for 54 years, how could I not take care of him now? I didn't think it was going to happen like this and it would be so heavy, to do it all, but after two months I couldn't do it anymore. One day my daughter came and saw me crying, because he was all wet with pee and I could not help, I had no more strength to carry him. Today, I don't live anymore, my life is to live with him indoors. I do not go out, I don't do anything else (IC5, 70 years old, wife, takes care of her husband affected by stroke, Araranguá).*

Several elderly caregivers revealed the worsening of previous health problems, such as chronic-degenerative diseases, hypertension, diabetes, arthritis and the onset of more diseases, such as: back, arm pain and depressive symptoms. The elderly caregiver handles another sick elderly person despite feeling pain, performing basic care with difficulties - such as moving between rooms, bathing and changing diapers. This reality has a course in all the regions surveyed and reflects the need for family, social and governmental support for the exercise of care.

Most participants (28) mentioned restrictions or no longer having a social life to participate in culture and leisure programs, go to church or travel. The loneliness of elderly caregivers is related to home confinement. Some even expressed shame for the situation they experience:

*I miss, sometimes, traveling. I'm sad because I have a daughter who lives in Brasilia. I wanted to go there to see her, [...] she calls me several times, but he (the husband) doesn't like me to travel alone, because he only trusts me to take care of him. If I go out and take longer than planned, he's already in agony. He doesn't want to travel with me either because he doesn't like to go out. So it is difficult (IC6, 71 years old, wife, takes care of her husband affected by stroke, Teresina).*

Some situations are likely to impose embarrassment on the sick elderly people, such as urinary incontinence, oxygen use, wheelchair and others, which restricts them to their home. Dependence on the dependent elderly-caregiver- binomial was also reported as one of the reasons for social isolation. It is important to emphasize that simply leaving the home requires planning and logistics, either due to the difficulty of locomotion of the sick elderly, due to the unfeasibility of using public transport or the fear that the place outside the home does not offer the necessary comfort to the dependent person.

Among the elderly daughters and sons caregivers, the total renunciation of their lives for their parents is also a burden. They are people who withdraw from the labor market and try to reconcile social functions with the activities of the home.

*We give up our lives in everything. We can't plan anything. We live for them [...], I already have my family, I already have my husband, so it's a difficulty. We have no leisure time. We don't have time to go out, go to a beach I like, get out of this routine. We are not able to pay caregivers so we became the caregivers. We had to make sacrifices between us, we had to bear each other. We dedicate ourselves with love, but in the midst of love, we have stress too, we get tired [...] one thing that I gets to me is having left work, I miss it, it was my personal satisfaction (IC7, 60 years old, daughter, takes care of parents affected by stroke and physical sequelae due to alcoholism, Fortaleza).*

This woman reports the alternation of care between the four daughters and all support, instrumentally or in relay on duty, the care to the parents. These women gave up their professional activities to take care of their parents. The participant of the research commented that, when she is not with her parents, she is concerned with the organization of her home and the attention to her husband, showing the feeling of renunciation of personal life. The exit from the labor market is also a circumstance that causes suffering to IC7, reflecting a common reality within several families. She demonstrates it, saying that well-being and pleasure-like leisure activities are no longer part of her life.

The following are some difficulties experienced by elderly caregivers and their family components: financial restrictions to give some kind of comfort to the patient; problems for care in the health system, to have access to medicines, ambulance, among others.

Although Brazil maintains policies for the supply of medicines, equipment, consultations and surgeries, these resources are often not guaranteed on time and according to people's needs. Many complain about bureaucracy to receive them and the lack of public funding for funding:

*He went blind. I took care of him for four years and decided to make a loan to his account to do his surgery privately, because the SUS never worked. They said they'd do it, but they never called. There are nights when he sleeps and has nights that he does not sleep, he is shouting: "oh my God, oh my God" (IC8, 71 years old, wife, takes care of the blind husband, Manaus).*

Many of the interviewees reported an increase in expenses due to the need to purchase equipment and supplies, including hospital beds; wheelchairs and bathing chairs; diapers; medicines, serum and gauze; adaptations at home with ramps and support bars; and in some cases; the cost of surgeries and private consultations with specialists. These facts lead family members to become indebted to bank loans and car sales (among other goods and objects), when there is no other means.

Regarding health care, caregivers highlight the limitations of home visits by health agents or family health physicians, delay in getting appointments for consultations with specialists, unavailability of medications and ambulances for transportation. All this, at the time of crisis, entails significant costs for the family.

*The health center doesn't have physiotherapy. What they have given is medicine for blood pressure, gauze, serum, glove, but other remedies and diapers, they have not. The transportation from the ambulance to the doctor, we are covering everything. I just feel like all of a sudden you can give me something and then how does it look? What's going to happen to her? I have to have surgery on my arm, but how am I going to do it? Then there's physiotherapy, this whole thing, how am I going to do it? Who's going to take care of her? (IC9, 76 years old, husband, takes care of his wife with sequela of stroke, Porto Alegre).*

Among the elderly caregivers living in the various places surveyed, there were complaints about the lack of certain primary care services, such as rehabilitative physiotherapy. In addition, a number of deficiencies were pointed out by elderly caregivers: lack of public funding to support formal caregivers, financial help for expenses due to the consequences of illness, support for home maintenance and leisure activities.

## DISCUSSION

The literature shows that elderly caregivers are mostly women, with a mean age of around 70 years and mean care time provided by ten years<sup>4,8-9,13-14</sup>. Research in Belgium, however, identified that the average age of caregivers is 80 years<sup>15</sup>, which signals the growing reality of spouses and elderly family members as caregivers of older people. In this context, ensuring the health of elderly caregivers should be a priority for all health professionals who care for the elderly.

### Taking over the care

For many elderly caregivers, the positive emotions involved in the feelings of gratitude and pleasure in caring for others results in harmonious affective bonds with the sick elderly person<sup>16</sup>. This is reflected in the increase in the self-esteem of these people<sup>15</sup>. It is positive experience, particularly when the clinical picture of the dependent elderly is stable<sup>8</sup> and care must be exercised with gestures of affection, also counting on the collaboration of the sick person himself, overcoming the fulfillment of basic life needs.

When there is support from the team of health professionals for the provision of physical and mental care, elderly caregivers feel more security in their routine and perceive greater stability in the health status of the dependent elderly relative<sup>13-14</sup>. Regarding this support, however, only those who experience it are a minority of the Brazilian population that has a financial condition to fund professionals with their own resources. In Belgium, care for basic life activities, such as bathing and dressing, are generally provided by a nurse at home<sup>15</sup>, which helps elderly caregivers. Similarly, in other European countries, public policies support elderly caregivers, which is done as part of social security systems, although support modalities are different in each location<sup>3</sup>.

The difficulties that caregivers of the elderly encounter are mainly related to the conflicting and aggressive behavior of the cared person, a previous dysfunctional family experience with the sick elderly and their own challenges in meeting the needs of the dependent elderly - such as turning them in bed, lifting them up, bathing and others. Research conducted in Canada and China relates to the fact that managing and controlling the aggressive behaviors of the dependent elderly and the challenge of dealing with the highest levels of dependence represent the main burden among caregivers<sup>8,13</sup>. The literature indicates that diseases such as dementia, solid tumors, physical disabilities or comorbidities have a direct effect on informal caregiver burden<sup>6,11</sup>.

Particularly in Brazil, the poor social support network weighs on the routine of elderly caregivers. The modification of family arrangements and the migration of elderly people from rural to urban areas tend to distance them from relatives and close friends who would be fundamental at the time of reduction of functional or mental autonomy. Many only have their sick spouses as company at home<sup>5</sup>. What was observed here was also observed in the Netherlands, where elderly caregivers have less social support than adult caregivers<sup>6</sup> and those who care for their spouses alone feel the weight of loneliness, express less hope for the future and enjoyment in life, when compared to independent elderly husbands and wives<sup>8,17</sup>.

Accordingly, the belief and culture, socially imposed in Brazil, that the responsibility of caring for the elderly is family, lead husbands and wives to embrace their function as a social protocol and conformism. Most do not question the negligence and refusal of other family members and public authorities to support this hard, daily and routine task. There was only one case in which the sister of a dependent elderly woman reported to the Public Prosecutor's Office a complaint of mistreatment caused by her husband and daughter, who had assumed care. However, this surveillance is rare and it is known that the main victims of violence in old age are dependent elderly people<sup>2</sup>.

Even when elderly caregivers point out feelings of reward, they associate the act of caring with exhaustion<sup>8</sup>. Positive and negative feelings are part of their daily lives, particularly the weight of the daily routine, when the sick person needs long-term care or has cognitive limitations<sup>6,8</sup>. It is necessary to take into account the notion that these elderly caregivers have almost no time to rest when they are the only ones responsible for the sick person<sup>4,7-8</sup>. The constant fear caused by the advance of the disease of the loved one, as well as the fear of not being able to handle the heavy routine, lead them to neglecting their own needs and physical and emotional pains. What was found in this research was also observed among elderly Canadian caregivers, who feel pressured to bear such complex responsibilities in relation to their patients.

## Unmet needs

The elderly caregivers under study reported health alterations, expressing, in greater proportions, physical and mental health problems, when compared with adult caregivers<sup>4,6</sup>. A research with elderly caregivers identified the fact that 89.1% express moderate, intense and unbearable pain; and 38.7% highlighted moderate, severe and severe physical and mental burden<sup>9</sup>. The prevalence of depressive symptoms among them is, on average, 30%<sup>9,15</sup>. Elderly people who feel alone and those who express depressive symptoms are more likely to become vulnerable because of increased physical vulnerability and, above all, malnutrition<sup>15,18</sup>. The stress perceived by elderly caregivers is associated with high levels of pain, difficulty sleeping and poor self-assessment in relation to health<sup>10</sup>.

Caregivers with poor health or anxiety symptoms experience greater burden<sup>10-11</sup>. Studies conducted in Brazil and Belgium indicate that elderly caregivers have, on average, six chronic-degenerative diseases; they use, on average, three to five medications, including anxiolytics; and have chronic pain in the lumbar region, lower limbs, dorsal, upper limbs and cervical/abdominal/thoracic regions<sup>9-10,15</sup>. In general, the occurrence of depressive symptoms in elderly caregivers is associated with family income, number of diseases, number of medications used, pain intensity, overload and perceived stress<sup>9-10</sup>.

One of the most difficult aspects of the spouse caregiver's experience is loneliness, social isolation, as already mentioned<sup>6,8,13</sup>. The socially constituted identity of family members concerning the dependence of the elderly relative contributes to the real and symbolic removal of children, grandchildren and other relatives. This affective absence results in psychological suffering and lower quality of life, especially for elderly caregivers, when they do not have time for themselves and in order to perform other activities that give them pleasure and joy<sup>4,10-11,13,19</sup>.

The difficult routine and the accumulation of functions also weigh on the health condition of elderly caregivers, when there is no one to help them, as they need to arrange care for the dependent elderly person as well as perform the household chores<sup>4,10</sup>. The attribution of additional responsibilities is certainly more costly for the informal caregiver than the demand for time with care<sup>10-11</sup>. These problems were also found in Canada, where caregivers of the elderly complain of excessive effort and overload, as well as the involvement of multiple chronic diseases<sup>8</sup>. In Portugal, in addition to being overloaded, older caregivers consider themselves less competent to assist the sick person in aspects such as food, mobility, transfers, medication and symptom control and communication<sup>20</sup>.

The physical barriers in the home, the existence of stairs and the lack of accessible public or private transport were also mentioned as limiting factors for leaving the home and for the access of the elderly to health related appointments<sup>8</sup>.

In addition, financial difficulties represent a social burden for elderly caregivers in the care of their loved ones<sup>4-11,13-14</sup>, because both are exposed by them to severe social vulnerability and the risk of worsening diseases<sup>5</sup>. Several studies point to this problem<sup>2-9,21</sup> and to the way some countries have dealt with it. In Germany, for example, there is financial support and a type of reimbursement for the

costs of the dependent person, according to the classification of the severity of the dependency<sup>21</sup>. This type of support is of high relevance and would be very welcome in Brazil.

When the needs are not met by health and social services, the caregiver's burden increases, particularly when he or she is elderly<sup>8-11,13,20-21</sup>. In Canada, which has a policy very focused on the informal caregiver, evaluations show that the elderly, caregivers and health professionals consider that institutional support for this service is fragmented, disjointed and with little coordination<sup>8</sup>. These social groups demonstrate the need for care centered on the person and on better communication between primary, secondary and home care in order to obtain information and provide services in a timely manner<sup>8,20-21</sup>.

Research in 18 European countries found that those with policies to support family caregivers, with training or counseling on the disease and its consequences for care; provision of equipment such as beds and wheelchairs; financial support for unemployed caregivers; and the provision of formal and professional caregivers to perform more complex care all reduce the stress on caregivers<sup>19</sup>.

In Brazil, there is an urgent need to strengthen primary care, geriatric outpatient clinics and home programs for people who are in need of effective coverage. Professionals in the home visit, the flow of referral of exams and the availability of medications are fundamental for elderly caregivers, dishonoring the weight they carry and creating bonds with the services<sup>21</sup>. Few participants pointed out the importance of learning about the disease, while in some countries<sup>13,20-21</sup> this is a recognized and disseminated urgency.

The finitude of life is also a theme highlighted by the elderly caregivers participating in the study. Many said they were afraid of being absent a little and their loved one had a serious problem or passed away. In turn, spouse caregivers represent the most important figure of attachment for the sick and dependent elderly<sup>7-8,15</sup>. For many of these segments of caregivers, the involvement of children is not mandatory, as they have obligations to their families. This finding is quite unique in comparison with other cultures, such as Chinese, in which caregivers in general have the social support of close family members as well as the more extensive family<sup>13</sup>. Elderly caregivers who receive help from relatives denote greater well-being and have fewer negative consequences on their personal, social and professional lives in the exercise of care<sup>13,19</sup>.

The results of this study highlight the reality that the elderly caregivers interviewed passively accept the role of caregiver as natural to the female gender and are overburdened<sup>11</sup>, understanding other family members as people who collaborate, visiting the sick elderly on weekends. Women caregivers who are married or in a stable union have a lower quality of life, because of the additional concern of balancing between the difficulties of providing care and personal investment so that the caregiver routine does not affect their relationship<sup>4,15</sup>. The current Oxfam<sup>22</sup> document, released at the World Economic Forum in Davos in 2020, highlights the invisibility of the work of women caregivers around the world, a work that financially impoverishes them and enriches the capitalist and patriarchal world.

Among the limitations of the study, we highlight the fact that a very small sample is used that does not intend to generalize the results, although there is a broad agreement of local information with the national and international literature. The limited number of participants per studied cities is related to the difficulty in locating these elderly caregivers in the official health services records, which contributes to the invisibility of people and the theme in the Brazilian context.

## CONCLUSIONS

The change in the lives of elderly family members who start to exercise the care of their elderly loved one involves facilitating circumstances that are: rewarding feelings, such as dedication, love and gratitude; harmonious experiences with the sick old person; stability of the patient's clinical status; their acceptance of the disease; alternation between family components in care and having purchasing power to fund a team of health professionals, formal caregivers and domestic collaborators. In this context, elderly caregivers are able to care, have time for their activities and also take care of themselves.

However, for many elderly caregivers the exercise of care is seen as something exhausting and heavy. The difficulties in the routine refer, first, to the degree of physical and cognitive impairment of the elderly person, which causes physical and mental health problems, associated with tiredness, back pain, worsening of preexisting diseases, such as hypertension, diabetes and arthritis. From the emotional point of view, loneliness and social isolation are circumstances pointed out by elderly caregivers who give up their social relationships, withdraw from the labor market and from the previous life context, and begin to devote themselves entirely to the sick relative, without space and time for themselves. Financial restriction is a reality in which the majority, in addition to caring for the sick as well as performing domestic activities.

This article shows that elderly family caregivers are important agents of the care network in the world and in Brazil. However, they urgently need support for the effective exercise of this function. Future research is necessary in order to understand how care is exercised by elderly caregivers from the perspective of health professionals, managers and the dependent elderly themselves and how these social actors are inserted in the agendas of health services.

The results of this study are valuable for nursing care practices, as they indicate that nurses play a very important role in providing comprehensive care, centered on the person and the family, surpassing those that focus on diseases and their repercussions.

As a final point, it is important to express the argument that Brazilian society needs a public policy that covers the large number of people who care for the elderly and other dependent patients in their homes, doing an indisputably necessary job, however invisible and undervalued. In particular, women deserve this support, who make up more than 90% of the total of this segment of workers, most of whom are elderly people taking care of elderly people.

## REFERENCES

1. Instituto Brasileiro de Geografia e Estatística (Brasil). Sinopse do censo demográfico. Projeção da pop. Brasil por sexo e idade 2000-2030; Projeção da população das UF por sexo e idade 2000-2030. Rio de Janeiro, RJ(BR): IBGE; 2013 [cited 2020 Oct 21]. Available from: [http://www.ibge.gov.br/home/estatistica/populacao/projecao\\_da\\_populacao/2013/](http://www.ibge.gov.br/home/estatistica/populacao/projecao_da_populacao/2013/)
2. Minayo MCS. The imperative of caring for the dependent elderly person. *Ciê Saude Colet* [Internet]. 2019 [cited 2020 Oct 21]; 24(1):247-52. Available from: [https://www.scielo.br/scielo.php?pid=S1413-81232019000100247&script=sci\\_arttext](https://www.scielo.br/scielo.php?pid=S1413-81232019000100247&script=sci_arttext)
3. Minayo MCS, Mendonça JMB, Sousa GS, Pereira TFS, Mangas NMR. Policies to support the elderly in a situation of dependence: Europe and Brazil. *Cien Saude Colet* [Internet]. 2021 [cited 2020 Oct 21];26(1):137-46. Available from: <https://doi.org/10.1590/1413-81232020261.30262020>
4. Araujo MGO, Dutra MOM, Freitas CSSL, Guedes TG, Souza FS, Baptista RS. Caring for the carer: quality of life and burden of female caregivers. *Rev Bras Enferm* [Internet]. 2019 [cited 2020 Oct 21];72(3):728-36. Available from: <https://doi.org/10.1590/0034-7167-2018-0334>.

5. Rossetti ES, Terassi M, Ottaviani AC, Santos-Orlandi AA, Pavarini SCI, Zazzetta MS. Frailty, depressive symptoms and overload of elderly caregivers in a context of high social vulnerability. *Texto Contexto Enferm* [Internet]. 2018 [cited 2020 Oct 21];27(3):e3590016. Available from: <https://doi.org/10.1590/0104-07072018003590016>
6. Oldenkamp M, Hagedoorn M, Slaets J, Stolk R, Wittek R, Smidt M. Subjective burden among spousal and adult-child informal caregivers of older adults: results from a longitudinal cohort study. *BMC Geriatr* [Internet] 2016 [cited 2020 Oct 21];16:208. Available from: <https://doi.org/10.1186/s12877-016-0387-y>
7. Pinquart M, Sörensen S. Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychol Aging* [Internet]. 2011 [cited 2020 Oct 21];26(1):1–14. Available from: <https://doi.org/10.1037/a0021863>
8. Ploeg J, Matthew-Maich N, Fraser K, Dufour S, McAiney C, Kaasalainen S, et al. Managing multiple chronic conditions in the community: a Canadian qualitative study of the experiences of older adults, family caregivers and healthcare providers. *BMC Geriatr* [Internet]. 2017 [cited 2020 Oct 21];17:40. Available from: <https://doi.org/10.1186/s12877-017-0431-6>
9. Terassi M, Rossetti ES, Luchesi BM, Gramani-Say K, Hortense P, Pavarini SCL. Factors associated with depressive symptoms in elderly caregivers with chronic pain. *Rev Bras Enferm* [Internet]. 2020 [cited 2020 Oct 21];73(1):e20170782. Available from: <https://doi.org/10.1590/0034-7167-2017-0782>
10. Luchesi BM, Souza EN, Gratão ACM, Oliveira Gomes GA, Inouye K, da Silva Alexandre T, et al. The evaluation of perceived stress and associated factors in elderly caregivers. *Arch Gerontol Geriatr* [Internet]. 2016 [cited 2020 Oct 21];67:7-13. Available from: <https://doi.org/10.1016/j.archger.2016.06.017>
11. Lindt N, Van Berkel J, Mulder BC. Determinants of overburdening among informal carers: a systematic review. *BMC Geriatr* [Internet]. 2020 [cited 2020 Oct 21];20:304. Available from: <https://doi.org/10.1186/s12877-020-01708-3>
12. Minayo MCS. *The challenge of knowledge: qualitative research in health*. São Paulo, SP(BR): Hucitec Publishing House; 2006.
13. Xiao LD, Wang J, He G, Bellis AD, Verbeeck J, Kyriazopoulos H. Family caregiver challenges in dementia care in Australia and China: a critical perspective. *BMC Geriatr* [Internet]. 2014 [cited 2020 Oct 21];14:6. Available from: <https://doi.org/10.1186/1471-2318-14-6>
14. Nunes SFL, Alvarez AM, Costa MFBNAD, Valcarenghi RV. Determining factors in the situational transition of family members who care of elderly people with parkinson's disease. *Texto Contexto Enferm* [Internet]. 2019 [cited 2020 Oct 21];28:e20170438. Available from: <https://doi.org/10.1590/1980-265x-tce-2017-0438>
15. Potier F, Degryse J, Bihin B, Chainiaux FD, Martens H, Saint-Hubert MS. Health and frailty among older spousal caregivers: an observational cohort study in Belgium. *BMC Geriatr* [Internet]. 2018. [cited 2020 Oct 21];18:291. Available from: <https://doi.org/10.1186/s12877-018-0980-3>
16. Greenwood N, Smith R. Motivations for being informal carers of people living with dementia: a systematic review of qualitative literature. *BMC Geriatrics* [Internet]. 2019 [cited 2020 Oct 21];19(1):169. Available from: <https://doi.org/10.1186/s12877-019-1185-0>
17. Adams KB. Specific effects of caring for a spouse with dementia: differences in depressive symptoms between caregiver and non-caregiver spouses. *Int Psychogeriatr* [Internet]. 2017 [cited 2020 Oct 21];20(3):508-20. Available from: <https://doi.org/10.1017/s1041610207006278>
18. Santos-Orlandi AA, Brigola GA, Ottaviani AC, Luchesi BM, Souza EN, Moura FG, et al. Elderly caregivers of the elderly: frailty, loneliness and depressive symptoms. *Rev Bras Enferm* [Internet]. 2019 [cited 2020 Oct 21];72(Suppl 2):88-96. Available from: <https://doi.org/10.1590/0034-7167-2018-0137>

19. Verbakel E. Informal caregiving and well-being in Europe: What can ease the negative consequences for caregivers? *J Eur Soc Policy* [Internet]. 2014 [cited 2020 Oct 21];4:424-41. Available from: <https://doi.org/10.1177/0958928714543902>
20. Dixe MDACR, Conceição Teixeira LF, Areosa TJTCC, Frontini RC, Peralta TJA, Querido AIF. Needs and skills of informal caregivers to care for a dependent person: a cross-sectional study. *BMC Geriatr* [Internet]. 2019 [cited 2020 Oct 21];19:255 Available from: <https://doi.org/10.1186/s12877-019-1274-0>
21. Plöthner M, Schmidt K, de Jong L, Damm K. Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review. *BMC Geriatr* [Internet]. 2019 [cited 2020 Oct 21];19:82. Available from: <https://doi.org/10.1186/s12877-019-1068-4>
22. Oxfam. Report on us and the inequality “time to care”. World Economic Forum 2020, Davos [Internet]. 2020 [cited 2020 Oct 21] Available from: <https://oxfam.org.br/justica-social-e-economica/forum-economico-de-davos/tempo-de-cuidar/>

## NOTES

### ORIGIN OF THE ARTICLE

Extracted from the multicentric research – Situational Study of Dependent Elderly living with their families Aiming to Support a Policy of Care and Support to Caregivers. The research was carried out by the Department of Studies on Violence and Health Jorge Careli CLAVES /ENSP/FIOCRUZ in partnership with universities of Fortaleza, Teresina, Manaus, Porto Alegre, Araranguá, Rio de Janeiro and Belo Horizonte, from 2018 to 2020.

### CONTRIBUTION OF AUTHORITY

Study design: Sousa GS, Silva RM.

Data collection: Sousa GS, Silva RM, Brasil CCP.

Data analysis and interpretation: Sousa GS, Silva RM, Reinaldo MAS, Brasil CCP.

Discussion of the results: Sousa GS, Silva RM, Reinaldo AMS, Pereira MO, Brasil CCP.

Writing and/or critical review of the content: Sousa GS, Silva RM, Reinaldo AMS, Brasil CCP, Pereira MO, Minayo MCS.

Review and final approval of the final version: Sousa GS, Silva RM, Reinaldo AMS, Brasil CCP, Pereira MO, Minayo MCS.

### FUNDING INFORMATION

CNPq Funding, Process No. 405835/2016-7.

### APPROVAL OF ETHICS COMMITTEE IN RESEARCH

Approved by the Ethics Committee in Research with Human Beings of the Oswaldo Cruz Foundation, Opinion 1,326,631. Certificate of Presentation for Ethical Appreciation 44615315.0.000.5240.

### CONFLICT OF INTEREST

There is no conflict of interest.

### EDITORS

Associated Editors: Selma Regina de Andrade, Gisele Cristina Manfrini, Melissa Orlandi Honório Locks, Monica Motta Lino.

Editor-in-chief: Roberta Costa.

### HISTORICAL

Received: December 17, 2020.

Approved: June 15, 2021.

### CORRESPONDING AUTHOR

Girliani Silva de Sousa

girlianis@gmail.com

