

“We are humans after all”: Family caregivers’ experience of caring for dependent older adults in Brazil

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Abstract *This paper aims to understand the experiences of family caregivers with dependent older adults in Brazil and the consequences of caring for dependent older adults in the family caregiver’s life. This is a qualitative multicenter study employing dialectical hermeneutics as a theoretical framework. In-depth interviews were conducted with 84 family caregivers in Brasília, Rio de Janeiro, Belo Horizonte, Fortaleza, Teresina, Porto Alegre, and Araranguá, and Manaus. The thematic analysis yielded three categories: motivations for taking on the caregiving role, influences on the family caregiver’s life, coping, and self-care modalities. The care assumed is influenced by affective relationships with older adults and ethical and moral responsibilities. The influences are related to the lack of preparation for caregiving, financial hardship, restricted freedom, and physical and mental health problems. Coping strategies were religion, spirituality, turn-taking between family caregivers, and learning about the tasks. Women predominate in caregiving due to cultural, ethical, and moral reasons. However, family caregivers often lack guidance and require protection and a support network.*

Key words *Family caregivers, Frail older adults, Care, Qualitative research*

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Introduction

The increased longevity started to require a greater need for care for the elderly. Brazil experiences a growing demand on the family, which traditionally provides the necessary care to older adults who are unable to perform activities of daily living¹. This is a cultural situation aggravated in the households' socioeconomic context in locations with a low Human Development Index (HDI)².

The challenge of caring for older adults imposes on the family the dilemma of reconciling and reordering the demands of daily care and other domestic, social, and professional tasks.

The family group is a vital link in providing care for dependent older adults with multiple chronic conditions. National and international quantitative studies have found lower quality of life, physical and mental health problems – such as low back pain, varicose veins, hypertension, decreased sleep, depressive and anxious symptoms – in family caregivers²⁻⁷. They also expressed higher levels of tension and overload, associated with difficulties in performing basic and instrumental activities of daily living and the required care routine^{2,7}.

Qualitative research and more recent reviews advocate the idea that, despite the burden of care routines, the motivations and intersubjectivity of family relationships with the elderly positively influence the adaptation and coping with the situation of assisting them⁸⁻¹¹.

In this line of thought, this paper presents the experience of listening to family caregivers and aims to understand the experience of family caregivers with the dependent older adults in Brazil and understand the consequences of caring for dependent older adults in the family caregiver's life. The focus on relatives providing care to dependent older adults is essential to direct the planning of health services' support to ensure that family caregivers do not feel abandoned.

The study is justified by the invisibility of the theme in public policies, under the assumption that the family alone should not bear the burden of caring for their dependent loved ones, which must be shared between the family, the State and civil society. This responsibility that should be assumed and led by the public authorities already occurs in several countries around the world^{3,12} as a state policy and is required in Brazil, particularly in a reality of social inequality.

Methods

The research aimed to conduct a qualitative study on the situation of dependent older adults living with their families and their caregivers to support proposals for a "Policy on Dependence" in Brazil. The Research Ethics Committee of the Oswaldo Cruz Foundation approved this study under Opinion 1.326.631, which focused on the family caregiver.

A qualitative approach aimed to investigate the meanings that relatives responsible for the dependent older adults assign to experiences, bonds, and family dynamics in their daily care exercise. The theoretical-methodological hermeneutic-dialectic framework was considered the most appropriate to guide in-depth interviews with family caregivers. It was assumed that the statements must be understood in the context in which they are produced. However, at the same time, they are situated in concrete situations, in a culture that transcends and includes these people, making them part of a historical and symbolic contemporary movement^{1,13,14}, and they account for the same issues addressed here locally, with reflection and criticism¹⁵. The research instruments allowed researchers to talk to the respondents about the relationships between relatives and older adults, their opinions about dependence, and how they live, think, and elaborate ways of caring.

The study involved municipalities in five Brazilian regions. In the Midwest, Brasilia; in the Northeast, Teresina and Fortaleza; in the North, Manaus; in the Southeast, Rio de Janeiro and Belo Horizonte; and in the South, Porto Alegre and Araranguá. The cities were chosen to expand knowledge about family caregivers of dependent older adults in the country, in different contexts of life and culture.

Access to participants was intentional and occurred through community health workers' mediation, an indication of geriatricians from specialized services, and an indication of relatives. The 84 family caregivers of dependent older adults contacted and agreed to participate in the study were interviewed at home, from June to September 2019. The number of participants was established by data saturation, that is, through regular information and thematic recurrence to this study's objectives. The following criteria were observed: being family caregivers for dependent older adults and presence at the time of the interview. Relatives

of institutionalized seniors and relatives who did not directly provide care to them were excluded.

The date, time, and place for the interviews were scheduled with the participants. Researchers with higher education in health and human sciences, experience in the subject under examination, and who had been trained to use the study instruction manual conducted the interviews. The “purposeful conversations”¹⁵ were held individually, at the participant’s home, in a reserved place, noise-free, with an average duration of one hour. The Informed Consent Form (ICF) was read, and authorization was requested to record the conversations. Respect for the stories told by the participants was ensured, without judgment or criticism.

A harmonious and trusting climate between interviewer and respondent was assured by explaining the importance of the research to the interlocutor to subsidize the elaboration of a specific policy on “Dependent Aging” that improves health and working conditions of caregivers.

The interviews were transcribed in full, followed by data organization in an analytical corpus. In this logic, the researchers’ comprehensive and interpretive inferences, by reading the empirical material, allowed a general overview and apprehension of the particularities of the contexts of the reality of participants and their socio-cultural environments, identifying the themes on motivations to assume the role of caregivers, influences on the life of family caregivers and modalities of coping and self-care. The analysis of these categories was based on the assumptions of understanding and criticism, supported by national and international literature.

The participants were identified by the initial letters of their civil names, age, marital status, gender, time as caregivers and their municipality of residence to ensure their anonymity.

Result and discussion

General information

Of the family caregivers interviewed, 71 (88.7%) are female, and 13 (11.3%) are male. Of this group, seven (8.3%) were between 20 and 39 years, 44 (52.3%) were in the 40-59 years’ age group, 12 (14.3%) were in the 60-79 years’ age group, and 21 (25.1%) were over 80 years. Of the total caregivers, 39 (46.4%) were daughters or sons, 25 (29.8%) other relatives, such as sisters, nieces, and granddaughters, and 20 (23.8%)

were wives or husbands. We observed that 44 (52.38%) of the people exercised care for two to five years, eight (9.5%) from six to nine years, 22 (26.2%) for more than ten years, and ten (9.5%) for less than a year. Of the total, 46 (54.8%) of the participants did not have anyone else to assist the older adult.

Motivations to assume the role of caregiver

The motivations alleged by people to decide to assume care involve several aspects. Some are focused on the ethics of reciprocity, feelings of gratitude, affection, admiration, and love for the older adult. Other reasons are sustained by affective and harmonious bonds, established throughout life, and finally, those resulting from the lack of choice among relatives to assume care and the moral and ethical responsibility for not abandoning the older adult. Relationships with fathers, mothers, daughters, sons, matrimonial, fraternal-like, and in some cases, with nieces, granddaughters, daughters-in-law, and even ex-wives are recorded. According to a caregiving daughter, her motivation is based on affection.

For everything she did for me. When I was born, I had to receive some more specialized care. She was a very caring mother after she learned about the case [dwarfism]. It’s not just that. It’s love. What makes me be with her is not even because of the disease; it is love (RMRC, 51, single, has been caring for her mother for a year, Rio de Janeiro).

The reports explain the moral and ethical responsibility for providing care. The memories of the times that the older adults dedicated to the family, their affection, and their stories of sacrifice and renunciation to raise and educate their children are the most recalled reasons. Children, therefore, feel a duty and obligation to care and support their parents during aging. They mention reciprocity for the care received and are grateful for the opportunity to provide care. A study in Thailand with family caregivers found that care is associated with feelings of responsibility, gratitude, and pity¹⁶. Another study points out that long-term family relationships, whether by blood or marriage¹⁷, are the reason for care.

Husbands and wives assumed care in the face of certain circumstances, such as children residing in other municipalities, or have their own families and do not want to burden them. The marriage marked by a loving, healthy, and lasting relationship, in which there is a genuine engagement vis-à-vis the other, was also pointed out as a reason for providing care.

For all the years we spent together, I promised to take care of her forever. I provide care with great zeal, affection, fondness, and concern. I do not see it as an obligation. I know that it is not something she chose, and she has always been such a wonderful person. So, I take care of her with great love and dedication (CCA, 81 years old, the husband has provided care of his wife for fourteen years, Brasília)

When the husband received the diagnosis of Alzheimer's disease of his wife, he assumed the role of full-time caregiver. He created a care routine of understanding and writing down the smallest signs shown by the wife to report to the doctor. Similar results were found in Chile¹⁸, where scholars call attention to the fact that the caregiver himself prioritizes meeting the basic needs of the daily life of his loved one, which often ends up limiting the exercise of his self-care.

Respect for the history lived with the older adult in a marriage is also imperative for care even in cases where relationships with older adults have been broken before their illness, as with ex-wives.

I provide care because he is the father of my daughter, although there was a disagreement, I would not leave him in need. I came home to help take care of his mother and him. I took care of his mother. Then he had a stroke. I started taking care of him (AGJ, 60 years, divorced, takes care of her former husband for twelve years, Belo Horizonte).

The former wives explained that they took care of the older adults again because they did not have other relatives to take care of them despite having marriages permeated by violence, betrayals, and conflicts. The situation gave rise to a feeling of pity and respect for the years lived together. These older adults had migrated from rural to urban areas, which caused them to lose contact with relatives of the extended family. This circumstance was also present in a former daughter-in-law who takes care of the former father-in-law for fear of him being abandoned by the family.

In the research, we identified some situations of relatives' resistance to provide care, especially with large families, conflicts over the distribution of tasks in the face of the older adults' dependence, and overload of women.

Seriously? Everyone disappeared, and I ended up with full responsibility. I take care, give love, and give affection. She was widowed at the age of thirty-nine. She could have lived her life, married, have other children, another life. She lived only for

the children. We have to pay her back. She did not request us to do so. Morally, I believe it is our duty (ARS, 49, married, daughter has taken care of her mother for three years, Belo Horizonte).

In the above report, as the older woman was discharged, the six children got together and opted for institutionalization. However, one of the daughters took care of the mother, because she said *her suffering bothers me more than my own life*. Here it is evident that the affective and emotional dimensions influence the decision to take care of the older adult. In this specific case, it was observed in other countries, regarding the care assumed by only one relative¹⁹⁻²¹.

Family caregivers feel ashamed to verbalize that they exercise care due to the lack of options and do not always speak openly about family dysfunctionality. Family conflicts that occur between relatives in order not to share the role of caregivers are usually associated with how painful and costly this is and disrupts caregivers' life^{5,6,8,11,13}. In this case, the family component that assumes the role with solidarity, solitude, devotion, and the duty of responsibility emerges, thus fulfilling the traditions of the countries of Latin culture, in which adult children are responsible for their parents when they age^{11,19,22}. Other ethnic groups, such as Orientals, also maintain the culture of relatives taking care of each other^{17,22,23}. In Brazil, the absence of public power¹⁹ weighs on family caregivers.

Noteworthy is the fact that most family caregivers are women. The role of family caregiver appears as a fate:

In Brazilian culture, women have always been the ones taking care of the house, staying close, with more sense of responsibility, and staying and taking care of their parents. [...] We women were created to take care of the offspring. When we have our parents, our parents become our children. Men marry, take care of, and dedicate themselves to their family (LMP, 58 years old, daughter has taken care of her father for five months, Porto Alegre).

Traditional gender roles are identified in this statement, including maintaining the home, marriage, and caring for parents and children rooted in contemporary society^{17,19,22}. The task of caring for older adults falls on wives, daughters, daughters-in-law, nieces, and granddaughters. In Canada²⁴ and European countries^{21,25}, the struggle of family caregivers is for social recognition and economic support from the State for the fulfillment of their role^{5,26}. These issues were not raised in the research reports. Oxfam's document¹³ released at the Doha Meeting denounced the invisibility of

female caregivers' work around the world. This work impoverishes them financially and enriches the capitalist and patriarchal world.

In this study, in the same sense as the previous arguments, it is pointed out that men are not the first option to assume care. They do it when there is no alternative:

I stayed away for a while. My sister and niece took care of her, but my niece got her son, and my sister was coming in very late. I left my night work shift to stay home, and I will stay until God wishes me to take care of her (RNM, 40 years old, single, the son has taken care of his mother for three years, Belo Horizonte).

Unmarried children and spouses looking after older women were identified in this study. Men's full dedication to caring is usually motivated by the fact that they are single. When they are married, in general, daughters-in-law assume this responsibility. Regarding husbands, a study in Germany²⁷ considers that the situation of men taking care of their wives cannot be generalized for all age groups. In old age, the care they provided usually occurs when they have already retired from the labor market²⁷.

Men providing care tend to receive more external help with domestic chores, which is supported by a longitudinal study in Germany²⁷, which revealed that male caregivers are significantly more likely to receive external support (29.6%) than women (17.7%)²⁷.

Influences in the family caregiver's life

The changes in the lives of caregivers when faced with an unexpected situation of the dependence of a relative are massive and, in general, arouse concern about the difficulties they will face, with their inexperience and the unpredictable situation:

The health service could improve with the availability of priority medicines for older adults, and geriatric clinics in the SUS should receive training and guidance for caregivers. The beginning is challenging. There is much insecurity about what to do, how to do it. Before in Brasilia, besides the appointment with the older adult, the caregiver also went to the general practitioner, and this was great, as many caregivers cannot get treated. Older adults and the caregivers should be treated with more respect and dignity (MVL, 45 years old, has taken care of his father with Parkinson for six years, Brasília).

Insecurity in dealing with this new context and the limits of care are common issues among

respondents in all the cities surveyed. Virtually everyone talks about the need to learn about aging and the disease that made their family dependent to understand their behavioral changes and provide them with well-being and satisfaction.

These circumstances can increase the burden of those providing assistance and give rise to feelings of anguish and stress^{10,16,18}. The lack of educational support and training to help, especially in the initial stages of care, can last a long time, mainly if there are complex and often unpredictable comorbidities and symptoms^{8-10,16,21}. All the cases heard indicate the need to promote care to the family caregiver, with special person-centered care, considering the particularities of older adults and those who assist them^{3,8,19}.

Most family caregivers express their desire to lead in assisting older adults, which is yet another reason for establishing links with health professionals for more adequate and effective care. The appreciation of family caregivers can facilitate the clinical management and assertive behaviors of professionals who begin to understand situations better. Collaborative work can reduce family caregivers' stress and relieve the care services, because, when feeling valued, they are involved in care^{10,19,20}. A current trend considers family caregivers' work as an integral part of health systems^{21,24}.

The participants considered reconciling health care with older adults' care demands as the most challenging part. These findings are exacerbated when there is no care alternation or in cases where older adults require intermittent care. As a result, caregivers are forced to sacrifice various dimensions of their life, giving rise to negative repercussions on their physical and mental health:

I got my share of cursing last week at the doctor because it's been two years since I took any medicine. I stopped for a while when my mother was hospitalized. When my mother is unstable, one cannot leave her side. How can I take pressure medicine that makes people pee a lot? No way! I was going to take fluoxetine, which makes people sleep, and stay calm. I couldn't. I had to be always turned on (GPRD, 55 years old, widow, has taken care of her mother for six years, Belo Horizonte).

Other caregivers who take care of themselves talked about their situation in a similar way, pointing out that their loved ones' demands lead them to physical and mental exhaustion and deprivation of their freedom. These people must reconcile care with other tasks. In a study with Mexican female caregivers, women express the same feelings of tiredness, exhaustion, and

overload¹¹. The care routine is too tiring, especially for people who need to assist relatives daily, leading them to emotional stress³ and sometimes burnout syndrome. The latter case occurs mainly with family caregivers of older adults with dementia^{2,7,8}. The time spent on caring for older adults and the lack of space to carry out personal activities burdens caregivers, as there is a clear relationship between greater elderly dependence, time spent for direct care, and less time for themselves. This data shows the need to give visibility to the problem and promote ways of dividing and reorganizing care activities, seeking the caregiver's balance and well-being^{3,19}.

A study in Spain found that 39% of caregivers had depressive symptoms²². The family obligation to provide care alone and the dysfunctional thoughts about this responsibility act indirectly in depressive symptoms^{22,28}. The negative psychosocial repercussions on relatives are more significant when they believe that they are unable to provide care as it should be^{22,28}.

The absence of a social-family network for sharing care in dependence interferes with the experience of the family caregiver who experiences the activities of daily living with physical and mental fatigue and financial difficulties. In this context, the caregiving daughter recognizes:

I get stressed and tired. Sometimes I feel wronged. I think a person "freaks out" with everything. Sometimes it becomes unbearable, and what tires are not just taking care, giving food and bathing. I think it's worse to deal with her behavior: the most significant stress is humor. I am losing my smiling nature. It affects me, and I miss working, living, having time for myself. The lack of money makes it even worse (CRS, 50 years old, daughter has taken care of her mother with Alzheimer's for nine years, Fortaleza).

For some participants, dealing alone with the older adults' mood swings led to mental exhaustion^{2,7,8,22,28} in which the ability to address them with patience was exhausted, giving rise to contradictions, conflicts, and tensions in the role of caregivers. They weigh on the daily needs of family caregivers, their desire to work, and moments of freedom and better financial conditions.

Heidegger²⁹ points out that it is necessary to realize that care providers take risks, have limitations, make mistakes and get it right, and require care to provide care to the other. One cannot care without considering the human condition's ontological determinations, human's own identity built on the coexistence and interrelationship that, in this study, reveals the limitations of care

with dedication and concern for the other. Care is only authentic when it joins reality and possibility, but a possibility as a human condition that takes into account human behavior and attitudes.

Cases of young and economically active men and women who had to leave work to care for the elderly relative were found. In other situations, relatives assumed care because they were unemployed and commented that they were unable to return to the job market because they did not find any alternative in the family or the government. Only in one family did the brothers pay the minimum wage to the sister who takes care, socially acknowledging her work. Most caregivers then depend on their families to cover personal and older adults' expenses. This tension of economic bias has also been found in other countries^{6,9,10}.

Some people still face the challenges to reconcile professional work with the demands of care: *I have to learn to separate things, or else I will fail at my job* (RMRC, 51, single, has been caring for her mother for a year, Rio de Janeiro). This reality is similar in other countries, and in some of them, as in Germany^{5,27}, in the policy in favor of the dependent person, arrangements are made for hours, time, and flexible wages that facilitate care. Of the respondents in this research, many caregivers held essential positions in the organizations⁶ and were unable to give up their jobs. They point out that even having someone at home, the concern with medicines, food, and other tasks related to the loved one, means tiredness to reconcile with the occupational demands^{2,6,8}.

Given this situation, elderly caregiver programs are available from the Canadian and Danish governments to provide family caregivers with time to reconcile work and other activities^{5,10,30}. It is a feasible alternative for those who cannot or do not want to pay for formal caregivers.

Coping and self-care modalities

Most caregivers consider that they require help to have a little control over their personal lives, such as a support network that allows them to take care of themselves, someone to share their feelings with, without judgment or criticism, being physically and mentally connected with others¹¹, learning about the person's illness, and the presence of religion and faith.

Among the support strategies, the research mentioned the search for help within the family to alternate in the role: *We are humans after all, and I get tired. If I need to go to the doctor, I go, and my sister stays there. One helps another, and*

I end up venting a lot to her. There are many conversations. I spend the day talking (JMA, 54 years old, the daughter-in-law has been caring for the elderly for two years, Manaus). This alternation was also mentioned by other caregivers, who mentioned the need to have pleasant moments, leisure, travel and walks, giving a little lightness in their life and the necessary self-care:

When I want to go out, I go out, walk, and travel! Last year I traveled. I visit my colleague's country home now and then. When I want, I ask someone to stay with her. I send my sister to come and stay with her. Furthermore, I go, I spend Sunday, and come back in the afternoon (GMS, 71 years old, the sister has taken care of the older woman for four months, Manaus).

Moving away from the care situation curbs stress momentarily. Some caregivers reported that they had to overcome their apprehensions of leaving the older adult with other people. Then they organized themselves to have some moments of rest without feeling guilty. However, some family dynamics preclude alternating care^{11,17,19,20}, either due to the distance and pre-existing tensions in the family members' relationship, the lack of commitment of relatives to care, geographical distances, and many children, especially in the northeast, where several families migrated to other cities, which hinders the provision of support to family caregivers. It should be noted that, although 46.2% of the participants reported that they receive help with care, this support only happens on weekends and timely. Care is exercised in a shift format and effective relay between the brothers only in four households. Several caregivers mentioned that they seek to learn about the health problems of the people they care for, which makes them safe and confident in performing their role:

I talked a lot to doctors and the psychologist at the hospital, where he was admitted to understand his illness. The psychologist guided me in several ways to deal with him. The Home Doctor program [Better at home] is fantastic, excellent. The older adult feels welcomed and receives guidelines that not even relatives knew, and we learn every day with the doctor, a physiotherapist, nurses. It is very significant support for the family (LMP, 58 years old, the daughter has taken care of her father for five months, Porto Alegre).

After diagnosis, knowing and learning about the nuances of the disease, since some pathologies demarcate significant impairments, affecting the motor, behavioral and affective part of older adults and their relationship with family caregiv-

ers may favor an adaptation, so that wear and exhaustion are minimized in the provision of care. The need for care in geriatrics and gerontology is unanimous in this study among the participants. Initiatives such as the *Melhor em Casa* (free translation: Better at Home) Program with home care for older adults requiring long-term care are necessary for family caregivers. Belo Horizonte has the *Maior Cuidado* (free translation: Greater Care) Program, which provides formal caregivers for low-income people: *I cannot physically provide care to her. Having the girls here at home is a blessing. They bathe, exercise, and interact with older adults. It's just two hours a day, but that helps (MJS, 60 years old, has taken care of the bedridden mother for four years, Belo Horizonte).*

The transition to the role of caregivers must be understood (and supported) in several ways. There is a time for learning to care, which may involve the development of management strategies for clinical, psychological, and relational aspects, expressed daily. Some emotional and interpersonal needs are imposed on the relationship besides several guidelines that can be generalized, providing support from other people and, almost always, social, financial, and structural support³¹.

Family caregivers in all municipalities make financial sacrifices to have a health plan and ensure specialized care in geriatrics. Relatives also pay for speech therapists and private physiotherapists. Formal caregivers for older adults are hired when a relative is unable to care 24 hours/day because he/she does not have flexibility in the work environment or a person to share the care, and do not have the physical conditions to care for the older adult.

Everyone likes her. The brothers got together to pay caregivers and nurses to take care of her directly. I just follow up, because I don't have the strength to provide care. I think she must feel better here than there at the hospital. Their brothers always visit her, I caress her head and talk to her (MHSM, 85 years old, she has taken care of her daughter with a stroke sequel for eight months, Teresina)

Deep social inequalities mark the Brazilian reality. Few relatives can organize themselves financially to provide the best care to the older adult. In this research, only a small number of family caregivers took care of themselves, valuing their affections, with the possibility of a unique production of holding their places in the world when establishing an effective care routine.

Foucault³² argues that the notion of self-care shows ethics in itself, in which self-care can be characterized as an elaboration of the subject

through a subjective transformation and the consequent establishment of new ways of life, which are manifested by acts and conduct and a set of practices and techniques that are exercised from oneself to oneself.

Physical activity, religion, and spirituality have often been described as a means of self-care:

I engage in my physical activity daily. The spiritual part is also fundamental. It is as important as material food, so I do not miss going to church. I am the minister of the Eucharist. I have to attend to some people once a week and thank God I can do that. I can reconcile (MCMAM, 59 years old, Teresina)

Many caregivers say prayers, go to church, receive religious groups at their homes, looking for strength to help endure difficult days. For many, faith is a mechanism for relieving tension. Religious beliefs and faith-related creeds were mainly positive for caregivers, giving them meaning for the tasks of caring. According to the literature, Latin culture caregivers tend to value religiosity as support for coping with care procedures^{11,22}.

A limitation of this study is the lack of registration of family caregivers in the health information system, which resulted in a convenience sample.

Final considerations

The empirical dimensions underlying the experiences of family caregivers of older adults point

out that caring is an eminently female and unpaid job. Attention is drawn to the number of young men taking care of older adults, and the lack of questioning about the role of caring among the respondents. For most, taking on the role of caregiver involved positive feelings, gratitude, ethical and moral responsibility towards older relatives who lost their autonomy. There is a sense of reciprocity in the care received, in a movement of renouncing oneself in a pre-established moral code that links the subject in the care of the other.

The daily needs of family caregivers are characterized by insecurity due to the lack of guidance in care in geriatrics and gerontology, psychosocial repercussions for the drudgery and repetitive work, social deprivation, difficulties in reconciling care and work, suspension of professional life and financial embarrassment. Noteworthy is the percentage of older adults taking care of other older adults. This data is of concern due to the increased vulnerability of older caregivers in the face of routine and permanent workload.

It is necessary to draw the attention of the Brazilian State to the situation of caregivers. While the Brazilian legislation considers care for the dependent older adults to be the responsibility of the family, the state, and civil society, specific policies supporting family caregivers are weak or non-existent. The country does not financially invest in family caregivers. Studies that consider family caregivers' experience can be a way to integrate them as part of the health system, valuing their demands, and assuring their rights and adequate protection by the State.

Collaborations

GS Sousa, RM Silva, DMD Gutierrez, and MLF Figueiredo participated in the conception of the paper's theme, data collection, analysis, and interpretation of indicators and drafting of the text. AMS Reinaldo and SM Soares participated in the drafting of the paper. All authors performed a critical review and approval of the final version of the manuscript.

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