DOI: 10.1590/1413-81232020261.30402020

# Subjective life experiences of family caregivers of dependent older adults

Denise Machado Duran Gutierrez (https://orcid.org/0000-0002-0031-3045) [1]
Girliani Silva de Sousa (https://orcid.org/0000-0002-0988-5744) [2]
Ana Elisa Bastos Figueiredo (https://orcid.org/0000-0001-7207-0911) [3]
Maria de Nazaré de Souza Ribeiro (https://orcid.org/0000-0002-7641-1004) [4]
Cleisiane Xavier Diniz (https://orcid.org/0000-0003-4689-6204) [4]
Guiomar Alegria Souza Silva Nobre (https://orcid.org/0000-0001-8672-5106) [1]

**Abstract** *This study aimed to understand the subjective meanings attributed to home care by family caregivers of dependent older adults through a multicenter qualitative investigation that gathered 84 in-depth interviews with family caregivers from eight Brazilian locations. The hermeneutic-dialectic, theoretical, methodological framework was employed. The following categories emerged from the analysis: 1. Movements inhibiting emotions and feelings; 2. Presence of processes of symbiosis and emotional dependence in the older adult-relative relationship; 3. Contentment in caring for the dependent older adult; and 4. Giving up current and future life projects. The results reveal life experiences marked by symbiotic processes, emotional dependence, and psychic stress. Dependence causes suffering and feelings of despair, powerlessness, impatience, but also solidarity and empathy. Withdrawal from the job market, social depreciation of family caregiver's activity, social isolation, neglected self-care, and family conflicts impact caregivers' subjectivity. The elaboration of public policies must consider the social-affective life experiences of family caregivers of dependent older adults in order to include the care of those providing care.*

**Key words** *Family caregivers, Dependent older adult, Care, Subjectivity*

---

[1] Faculdade de Psicologia, Universidade Federal de Amazonas. Av. General Rodrigo Octavio Jordão Ramos 1200, Coroado I. 69067-005 Manaus AM Brasil. ddgutie@ufam.edu.br.
[2] Departamento de Enfermagem Clínica e Cirúrgica, Escola Paulista de Enfermagem, Universidade Federal de São Paulo. São Paulo SP Brasil.
[3] Departamento de Estudos sobre Violência e Saúde Jorge Careli, Escola Nacional de Saúde Pública, Fiocruz. Rio de Janeiro RJ Brasil.
[4] Escola Superior de Ciências da Saúde, Universidade do Estado do Amazonas. Manaus AM Brasil.

## Introduction

When accompanied by cognitive and functional losses, longevity demands special and permanent care, usually provided at home under the responsibility of relatives[1], as is the case of dependent older adults in focus in this paper.

This new reality that reorients family dynamics and turns the relative into an informal caregiver can lead them to experience various feelings and emotions, almost always contradictory and ambiguous, usually marked by depressive states, physical health problems, financial difficulties due to loss or difficulty in reconciling care with paid work, dysfunctional family experiences and insecurity in the way of dealing with the dependent person, due to unpreparedness and lack of technical support[2,3].

Despite this conflicting internal context, as we will see in this text, some caregivers wish to participate in the home care of older adults actively and appreciate when they can interact, receive and exchange information about care with health teams or other professionals[3].

Authors[4,5] point out different cultural realities between countries in monitoring and assisting family caregivers. This task is non-transferable in some Latin American and Eastern countries. Therefore, it is essential to consider how the family caregiver experiences caring for the other, in this inter-subjective relationship intrinsically related to the socio-cultural and economic context. The theoretical perspective of González-Rey[6] is adopted here, and it defines subjectivity as "a complex system that has two permanent and interrelated spaces: the individual and the social, which are established reciprocally while each is established by the other simultaneously".

We consider that the caregiving subjects and their subjectivity is barely addressed in public health. We then defined to understand and analyze the subjective meanings attributed by family caregivers of dependent older adults to home care, enhancing their interpretation of the care experience and multidimensional circumstances that involve this activity as the objective of this investigation.

## Methodological course

This is a qualitative study nested in the "Situational study of dependent older adults living with their families to subsidize a Policy of Care and Support for Caregivers"[7] project conducted in eight Brazilian municipalities in the five regions of the country. The study now in focus gathered data from 84 cases of family caregivers of dependent older adults: daughters, sons, wives, husbands, nieces, granddaughters, daughters-in-law, ex-daughters-in-law, and ex-wives. The set of their statements contributed to portray a vivid picture of their experiences. The hermeneutic-dialectic theoretical perspective[8,9] was adopted through three methodological movements: comprehend (understand), interpret, and analyze. According to Gadamer[10]:

> *Understanding and interpreting the texts... clearly belongs to the whole of man's experience in the world. In its origin, the hermeneutic phenomenon is by no means a methodological problem. What matters to it, in the first place, is not the structuring of a secure knowledge that satisfies the methodological ideals of science – although, without a doubt, it is also about knowledge and truth here. When you comprehend* [...], *you don't just understand texts, but also* [...] *recognize truths.*

Family caregivers of dependent older adults who participated in the investigation were referred for interviews by primary care professionals, outpatient clinics specialized in geriatrics, and other families. The interviews were semi-structured and guided by a roadmap that included initial data (place of birth, ethnicity/color, place of residence, relationship/bond, length of care experience), perception and feelings of family caregivers about their role, themselves, their relationship with the older adults, and emotions and influences on personal life. They were scheduled, recorded, according to the respondents' convenience, and carried out by experienced and trained researchers, with an average duration of one hour, after participants signed the Informed Consent Form (ICF). The Research Ethics Committee of the National School of Public Health/ Fiocruz/RJ approved the project.

The interviews were transcribed and analyzed in-depth, articulating the investigation's objective, the respondents' report, comprehensive inferences – interpretations of the researchers, and discussion of the findings in the face of the literature. The following themes of relevance concerning the subjectivation processes of the interviewed relatives were highlighted: 1. Emotion and feeling inhibition movements; 2. Presence of processes of symbiosis and emotional dependence in the older adult-relative relationship; 3. Contentment in caring for the dependent older adult and 4. Giving up current and future life projects.

## Results and discussion

The results and discussions presented here derive from a hermeneutic elaboration, submitted to criticism and contradictions, from the statements of 71 women and 13 male family caregivers: daughters, sons, wives, spouses, ex-wives, and other relatives. However, only a few statements are presented, giving strength to the caregivers' relevance as a whole. The in-depth analysis of the statements and situations revealed regularities in the subjective experience. However, some singularities and issues were noted in specific groups. People heard from different places did not alter the results, which tend to join by the strength of the same situations experienced.

The age group of caregivers ranged from 30 years to 88 years, and household income from one to ten minimum wages, including earnings from work and retirement of the older adults. Participants who totally and individually dedicate themselves to providing care do not have a personal income. Relatives provide care to older adults with varying degrees and areas of dependence. The length of care provided by relatives ranges from six months to nineteen years. The relevant themes that emerged from the reports of family caregivers are shown below.

### Emotion and feeling inhibition movements

Emotions and feelings are different movements expressed by one individual vis-à-vis the other. Jung[11] affirms that *no intellectual definition will be able to reproduce, albeit approximately, specific to a feeling*[11]. Mauss[12] also presents us with a way to understand emotions and feelings and how they take shelter in individuals:

> [...] *expressions of the feelings of the individual and group are more than simple manifestations. They are signs, expressions understood. In short, a language. The person manifests them to itself on behalf of others.*

Feelings and emotions are interrelated. Just as an emotion arouses a feeling, a feeling can mobilize an emotion corresponding to that feeling, because emotion is a set of responses substantiated by emotional memories and arises when we receive an external stimulus. Feeling is a response to emotion.

The movement of inhibition of feelings and emotions that we seek to highlight here can be seen in the report of VCCS, 34 years old, the youngest daughter living in Brasília who has taken care of her mother for four years:

> *I was not prepared to take care of my mother, and I feel tired of having to control her needs daily. I don't share my anxieties; I prefer to keep it to myself. I don't want to associate my complaints with a feeling of victimization.*

In this case, the inhibition of emotions occurs when her daughter felt the loss of autonomy of the elderly mother as a challenging situation that she must face, without complaining and regretting. Many expressed the same feelings saying that *they must be strong: they do not allow themselves to get sick, keep silent so as not to argue with the older adult, turn a deaf ear to what the older adult says, avoid irritating, seek to distract, redirect the conversations, forgive the attacks suffered, and remain silent in the face of stressful situations.*

When asked about how they became caregivers, in general, the answers show the unusual new situation they had to assume, without listening to their frustrations and anxieties that have invaded them since[13,14]. The expression "*I have to control myself to the extreme*", denounces their ability to inhibit emotions in a context of helplessness or lack of recognition and support. However, respondents who alternate care with other relatives, or with formal caregivers, showed more freedom and time to express affections and emotions.

Investigations carried out in New Zealand and Canada point out that family caregivers often do not receive information necessary to feel safe, especially in the early stages of care[2,3]. Not knowing the real condition of illness of older adults and how to act against it increases tension, insecurity, and fear of failing to provide care.

Conversations with women showed that, while providing care, they reproduced their traditional gender destiny: serving, performing the traditional script at home, in marriage, and assisting the sick older adult up to the physical and psychological resistance limits. This reality is often found in research and is commented on in the literature on countries like China, where women are responsible for care[5,15]. Among the participants, no caregiver has commented or criticized the gender perspective in the exercise of care.

In the name of professional work and everything that is required of them in the male cultural booklet, men reported more difficulties in the relationship with the older adults, as can be seen in the report of EP, 65 years, a son who has been taking care of his mother for eight years in Fortaleza:

> *Living with an older adult is complicated. She fights for anything and puts me down. I forgive her because she is my mother. I have much respect, but I*

*get dejected, tired. Things sadden us. I cannot even get sick. I'm practically forgotten. I'm not living my life...*

This son gave up his work and personal life to dedicate himself to his mother's care with Alzheimer's, which makes him physically and psychically ill. This reality was recurrent in the research and is reported in the literature[2]. However, some single or divorced young men manage to reconcile care for older adults with paid work and rely on relatives or formal caregivers' help. These tend to remotely monitor the person they leave in their place, until, after work, they take on care with devotion and delicacy. Some men can make changes in their routine, sleep beside the older adults, provide affection, and ensure their safety, breaking male stereotypes[16,17].

Having assistant caregivers is a viable alternative for men and women to exercise their profession and have time for themselves and be in the world. However, for most families, the most common solution is leaving care in the hands of one relative only because of financial difficulties or lack of solidarity.

Sons and daughters show that shame and fear also make up the mosaic of emotions that caregivers experience[18,19] and that need to be inhibited for the sake of care. RNM, a 41-year-old single son living in Belo Horizonte who has been taking care of his mother for three years, reports the discomfort he feels when handling the elderly mother's body during daily hygiene care:

*I thought the shower was harder. I was afraid because I was not used to it. I was afraid of hurting her and that she would fall. I was also very ashamed, but we have to forget it all to provide care because there is no other way: isn't that so? Is it going to go wrong on the bed? No! You have to take care!*

This seems to be a sensitive point, as it concerns sexuality and its taboos, although, as indicated by Hogan[20]

*Sexuality must be understood as intrinsic to every individual, at any time in his life, and unique to each person. Sexuality is the fusion of symbolic and physical feelings, such as tenderness, respect, acceptance, and pleasure. It is built progressively and is influenced by history, society, and culture, according to the individual and mental aspects of each one.*

Touching the naked body and genitals of the mother or father is part of an essential social ban. When chronic disease changes the body of older adults, making it weak, it announces its inevitable temporality[21]. Care thus gains a strong dimension of respect for the dignity of others[2,19].

When care is exercised by one of the spouses, witnessing the loved one experiencing pain and functional limitations means facing his helplessness in the face of the finitude of life, as in the account of FAG, 67 years old, living in Manaus, a husband who has been taking care of his wife for four years:

*Sometimes I wonder how it would be. For example, now that we are retired, nobody would stop here, walking with her until the end of life, leaving the boys to take care of the house and travel. I feel sorry for her at night when she is crying in pain. I can't do anything because pain is in the bones, and there is no effective drug for bones.*

This talk of empathy cultivated in a marriage of over fifty years reveals that "*her pain hurts in me*". The loss of health and autonomy becomes part of the husband's history, as both are involved in the same feelings of finitude[14].

## Presence of processes of symbiosis and emotional dependence in the older adult-relative relationship

Contents showing processes of symbiosis and emotional dependence are condensed in this session. Symbiosis is characterized as a close interdependence between two or more people who complement each other to keep a grip and, to a certain extent, satisfy the needs of the most immature parts of their personalities[22]. Four components define emotional dependence: (1) motivational, which refers to the need for support, guidance, and approval; (2) affective, which is related to the anxiety felt by the individual in the face of situations in which he needs to act independently; (3) behavioral, which alludes to the tendency to seek help from others and submission to interpersonal interactions; and (4) cognitive, which refers to the subject's self-perception as powerless and ineffective[23]. Part of these processes - symbiosis and emotional dependence - are marked by an infantile perception of the older adults and the difficulty in recognizing the limits between caring, promoting autonomy, and preserving the older adult's freedom. This risk was reported by PFEM, residing in Porto Alegre, a 36-year-old daughter who has been providing care to her mother for ten months:

*Seeing that she can't do certain things is a little sad, disappointing* [...] *I have to be always controlling myself, so I don't long to do everything and let her do her things with her autonomy, and that's a little difficult for me. I find it hard to have to un-*

*derstand that she has her time and space and that she will do it at her speed.*

The dependence situation can be distressing for relatives, who see their loved ones lose their autonomy gradually or abruptly[2,19]. This is considered by some to be the hardest challenge: witnessing powerlessly the profound bodily and behavioral changes of older adults.

However, it is necessary to escape the temptation of infantilization, which can have several consequences, contributing to erasing the loved one's life history, experiences, and intellectual and cognitive skills[2]. Infantilization also increases the feeling of worthlessness in older adults and reinforces the symbiosis and emotional dependence between them and their caregivers. These risks are admitted by respondents as shown by the report by MPR, 55 years, residing in Manaus, a wife who has been taking care of her husband for five years:

*I would be sinning if I weren't there with him. Sometimes, you end up getting too involved and forget about yourself. It's like having a special baby at home, and you end up not seeing yourself. You just see that person there, and you're afraid to "switch off", and that person has some tantrum, and you blame yourself for the rest of your life because you weren't there.*

Bleger et al.[22] show that older adults' illness can affect family caregivers' life when they do not have room to elaborate on their feelings manifested through their mutual symbiosis. In order to avoid this mutual dependence, it is desirable to alternate care with others to reconcile care with other interactions and professional help, which is something which the caregiver, MPR, residing in Manaus, a wife of 55 years who has been taking care of her stroke sequel-affected husband for five years talks about:

*After the third year, the team became more attuned. I already trust them, and I was able to receive some external invitations for a coffee.*

In the account of TMS, 70 years, residing in Araranguá, a wife who has been taking care of her husband for 54 years, we noticed the manifestation of a previous emotional dependence, which made the caregiver very frail and without reference:

*Life was over for me after he got sick because, when he was well, he took me to the doctor, was going to get my exams, and was scheduling my appointments: he was doing everything!*

The need to assume care and invert the relationship from being a cared person to a caregiver brings about the issues of a dependence structure that was already there in the couple's daily life[23].

## Contentment in caring for the dependent older adult

The feeling of surrender, reciprocity, proving care out of gratitude was found in several statements of caregivers who feel just, generous and happy in the adopted path of giving themselves to what they do[19,24,25]. This is what we see in the statement of 64-year-old LMAS, residing in Teresina, a daughter who has been providing care to her bedridden father for a year, and ICP, 38, residing in Manaus, a daughter who has been taking care of her mother for three years, both below:

*I do everything with great joy. Today, I see that I have the opportunity to give my parents the affection they gave me. I feel it in every diaper I change, every sip of water I offer. I am satisfied and pleased. I feel grateful to be able to repay what they once did to me, and I do for them today.*

*I am happy to take care of my mother. She is a companion for me!*

Care as human essence is only genuine when promoting rapprochement between individuals in such a way that caring for older adults includes and transcends technical actions by sharing affections, feelings of trust, comfort, and satisfaction of the needs of others. The gratifying experiences concern the personal satisfaction of assuming care with attitudes and feelings of devotion, love, affection[19,24,25]. These attitudes refer to robust affective ties and are often associated with a support network that favors either alternating care, affective support for the relative, or the division of tasks[26,27]. Some interviewed caregivers showed that, despite having their personal choices hindered or postponed, they adapted to the new attributions, understanding them as existentially significant.

In summary, for many daughters and sons interviewed, the exercise of care and respect for their elders is a loving obligation. Although they spell out many reasons for providing assistance and caring about their parents' well-being, feelings of gratitude are strongest. Some stated that care is also an investment in the future when they expect to receive care from their respective families[5]. While barely reported, some children commented that the institutionalization of the elderly is not the best way to live in old age and that the place of their loved ones is in the family. This cultural aspect of subjectivities differs from other countries where nursing home-centered care for older adults is a natural thing[5]. Also, older adults with cognitive conditions to answer, when asked, said they prefer to be with their families than in geriatric homes.

### Giving up current and future life projects

The contents that incorporate experiences of abandonment, irritation, complaints about excessive responsibility, lack of support in the care routines, and exhaustion of physical and psychic forces by the caregivers are grouped in this section. As stated by DPFS, 42, resident in Araranguá, a daughter who has been caring for her mother for five years:

*We have a family disagreement, and he* [brother] *refuses to help. This results in an argument. Everything together is a burden, and some days are tough. I have to balance myself. Otherwise, I go rock bottom. It has to be like that, and, unfortunately, it will not change.*

In families where conflicts are part of the relational culture, the burden of care is usually placed on the shoulders of only one person and experienced with feelings of impatience, injustice, anger, and stress. The caregiver's feelings of injustice surfaced in several reports. It was highlighted as a source of great suffering and usually emerged as resentment for not sharing responsibilities of providing care to the dependent older adult[19].

In these cases, there is a kind of change given by life in families marked by loose bonds of affection. Interviews contain reports about children, husbands, and other relatives who, although they may, do not share expenses and hardly visit or hear from the dependent person. In these situations, new and old family wounds become lively and make dependence even more arduous and hard[19,24,25]. This problem is not restricted to Brazil. An investigation carried out in Canada found that husbands, wives, and children who do not choose care for the dependent person at home have worse psychological well-being than relatives who have assumed the provision of care[28].

The personal waiver required by the condition of dependence of the older adult, in many cases, implies a "careless" self-care by the caregiver, as observed in the report by CMSDM, 37 years old, residing in Belo Horizonte, a daughter who has been taking care of the mother for three years:

*There's no such thing of taking care [of yourself]. It's many struggles! At night, I want to sleep. I put my boys to sleep, and I go to sleep, too* [...] *I don't even stop to think, because if one thinks about problems, he doesn't sleep. It's one day at a time. Today she has more difficulty, so I take care of her. Today she is calmer. I am doing my things.*

This statement reveals a multitasking woman – the one who takes care of the family and the older adult – who was recurrent among the respondents, which is another reason for personal "carelessness" because most caregivers cannot balance care for themselves and the other, and end up giving preference to the other[15,19]. "Personal negligence" in favor of meeting family demands was also seen in Spain, where a law provides various types of help. However, many relatives expressed not having time to dedicate themselves to other activities[25]. The real experience of a "life passing by", built chronologically, makes family caregivers feel that they have lost the ability to control their time[26].

The family caregiver's little emotional resistance can increase anxiety due to the burden that means meeting the basic needs of daily living, keeping hours of surveillance, and recovering personally[2,27]. Therefore, it is necessary to have a close look at the suffering of care providers[14]. Several countries have specific psychological support programs for family caregivers in place, helping them to address sadness, pain, loneliness, and helplessness[15,16,24,25,29]. In Brazil, the initiatives are still very specific, and there is no public policy in this sense.

The care situation of the older adult affects, above all, socialization and interaction with others[2,19]. Home confinement is a practical adjustment, with subjective repercussions, commented on by almost all participants, among them MMRS, 60 years, from Fortaleza, a daughter who has been providing care to her parents for three years, and AAS, 71 years, living in Teresina, who has been taking care of the older adult for four years:

*I am 60 years old, and I am no longer a young girl. So, fatigue and stress emerge. I take care of two people with different desires. I have my family, my husband. So, we give up our life in every case. We cannot program anything: I live for them. I have no leisure. I have nothing. I live for them.*

*These days I didn't go to church because I was exhausted, exhausted. I was so tired of spending the day fighting with him.*

Even when care is alternated, management and responsibility often fall on a single relative. Physical and psychological exhaustion, felt as a real "struggle", leads family caregivers to feel that a cumbersome and repetitive task begins every day, consuming them[18,25,30,31].

The reasons that lead caregivers to withdraw at home are practical, and linked to the lack of mobility, access, support materials for care, and social equipment. Feeling alone is also related to the invisibility of care[24,29]. In essence, loneliness can be compared to some mourning where people lose their world as they knew and desired it[29,32].

Several reports reveal an attitude of giving up leaving home by the caregivers and the dependent older adults, which means isolating oneself in a repetitive world with little stimulus. Financial issues weigh heavily in this regard. Several people interviewed have low income, do not have a wheelchair for older adults who need it, and live in mobility-restrictive homes. Consequently, this is another crucial reason for creating initiatives to support family caregivers, especially the poorest[18].

The voluntary or imposed resignation from the world of work is one of the main restrictions and frustrations pointed out by E.M, 48 years old, living in Araranguá, a daughter who has been taking care of her mother for four years:

*I'll start looking for a job when she's doing well. Now, there's no way, because I have to take her to the doctor, shop, and pay. So, she depends on me. I need to find a job that I can reconcile with her care, something that is close by. I want to work. I have my things, and today I depend on her.*

In the above report, the daughter calls into question financially unrewarded care, which, on the one hand, shows the caregiver's impoverishment, and on the other, increases intra-family and personal tension, which can compromise the quality of care. This is a recurring theme in the literature that relates caregiver, older adult, and family. In several countries, caregivers receive a state subsidy[18,32].

Along with the loss or resignation of the post in the formal job market, several caregivers emphasize the social devaluation of the care activity, strongly associated with domestic work, and not considered "real work", which is what appears in the report by MLV, 45 years, residing in Brasília, son, has been taking care of his father for six years:

*I get angry at neighbors and acquaintances who ask me why I'm not working. Sometimes I do some painting services in the neighborhood, but no one understands that I am saddened by not being able to return to the job market, and I am doing everything I can to attend all my father's needs.*

The social perception of the work carried out by caregivers has two sides of invisibility and handicap: on the one hand, they should have an ethical and moral responsibility in fulfilling the silent family contract; on the other, socially, their activity is not recognized as work. Thus, besides emotional, physical, and psychological overload, caregivers are often seen as idle, shying away from "real" work, mainly if they are men[28]. This problem is also mentioned in the international literature. In Portugal, studies show that caregivers say that, when visiting the dependent person, relatives and friends only have access to an apparent reality: their efforts at a heavy routine remain hidden[25].

There are several cases of bedridden older adults told by impatient, tired, and stressed caregivers: they moan, scream, shake, and do not sleep at night. In several situations, caregivers confess that they cannot control irritability and powerlessness in the face of cognitive and behavioral impairments[33]. This is the case of CRS from Fortaleza, 50 years, a daughter who has been taking care of her mother with Alzheimer's for nine years: *I fight, I get stressed and tired. I was supposed to have more patience, but I keep failing. The worst thing is her mood swings!*

In most cases, despite all the difficulties, the research shows that caregivers seek an emotional adjustment, in the face of the existential dilemma of caring or reacting to the voluntary or involuntary provocations of older adults: they try to understand the suffering of those they care for and neutralize feelings of irritation and guilt. A Brazilian study with family caregivers[32] indicated that they fear being judged and judge themselves when angry and tense. However, objectively, an intense and restless workload affects their quality of life. Scholars from all over the world are discussing the situation of this invisible worker called family caregiver[29]. In this sense, most studies advocate that the State and society – and not just the family – must mobilize and produce a policy that benefits those cared for and their caregivers[30,31,34].

## Final considerations

This text aimed to describe and interpret the experience of a group of family caregivers of dependent older adults, most of them women. Some points are worth mentioning:

1. The discovery that an older adult no longer has the necessary autonomy for the activities of daily living and instrumental activities can have an impact on their family.

2. Due to the difficulty of sharing with other relatives, the role of assisting older adults, family caregivers deprive themselves of professional and existential projects and must be recognized and supported.

3. The most different feelings can mark the affective involvement of relatives with care: dedication, compassion and seeking support; isolation, symbiosis, and emotional dependence; anguish, despair, and a feeling of helplessness; impatience and anger. This variety of feelings is often mixed.

4. In the most different affective scenarios, home is the space of care, solidarity or tragedy, and guilt. Most older adults in contemporary Brazil live with their family, and when they are dependent, they are cared for by them, without State support and protection.

5. The reorganization of life plans of those who assume to be caregivers generally includes restrictions and waivers: restrictions to reconcile care with paid work and other activities of daily living, and renunciation of an active social life coupled with the social devaluation of their work.

6. It is worth remembering that having an extended family is not an assumption that caregivers will receive help to accomplish their tasks or to restore their energies. Almost always, only one person assumes the burden of care.

7. The situations of most significant suffering for caregivers occur when there are old and unresolved family conflicts. In general, in these cases, resentments arise, disputes over the right to care for or control the situation, financial problems, and a feeling that the burden of assisting falls unfairly on only one person.

8. Understanding the subjective experiences of family caregivers of dependent older adults is very important so that they are offered adequate support in well-founded interventions, but, above all, to subsidize a specific public policy that takes into account their real experiences and socio-affective experiences.

## Collaborations

DMD Gutierrez, GS Sousa, AEB Figueiredo, MNS Ribeiro, CX Diniz and GASS Nobre participated in the conception of the article's theme, data collection, data analysis and interpretation and text elaboration. All authors carried out a critical review and approval of the final version of the manuscript.

## References

1. Organização Mundial de Saúde (OMS). *Relatório mundial de envelhecimento e saúde*. Geneva: OMS; 2015.
2. Floriano LA, Azevedo RDS, Reiners AAO, Sudré MRS. Care performed by family caregivers to dependent elderly, at home, within the context of the family health strategy. *Texto Contexto Enferm* 2012: 21(3):543-548.
3. Faller JW, Zilly A, Alvarez AM, Marcon SS. Filial care and the relationship with the elderly in families of different nationalities. *Rev. Bras. Enferm*. 2017; 70(1):22-30.
4. Kuluski K, Peckham A, Gill A, Arneja J, Morton-Chang F, Parsons J, Sheridan, N. "You've got to look after yourself, to be able to look after them" a qualitative study of the unmet needs of caregivers of community based primary health care patients. *BMC geriatrics* 2018; 18(1):275.
5. Greenwood N, Smith R. Motivations for being informal carers of people living with dementia: a systematic review of qualitative literature. *BMC Geriatrics* 2019; 19(1): e169.
6. González-Rey F. *O social na psicologia e a psicologia social*. Petrópolis: Vozes; 2004.
7. Minayo MCS, Figueiredo AEB. *Manual de pesquisa Estudo situacional dos idosos dependentes que residem com suas famílias visando a subsidiar uma política de atenção e de apoio aos cuidadores*. Rio de Janeiro: Fiocruz; 2018.
8. Heidegger M. *Ser e tempo*. 3ª ed. Petrópolis: Vozes; 2008. (Parte I e II).
9. Andersen HE, Hoeck B, Nielsen DS, Ryg J, Delmar CA. Phenomenological–hermeneutic study exploring caring responsibility for a chronically ill, older parent with frailty. *Nursing Open* 2020; 7(4):951-960.
10. Gadamer H-G. *Verdade e Método. Traços fundamentais de uma hermenêutica filosófica*. Petrópolis: Vozes; 1999.
11. Jung CG. Fondamenti psicologici nella credenza degli spiriti. In: Jung CG. *Opere*. Torino: Boringhieri; 1976. (vol. 8).
12. Mauss M. A expressão obrigatória dos sentimentos. In: Figueira S, organizador. *Psicanálise e ciências sociais*. Rio de Janeiro: Francisco Alves; 1980. p. 56-63.
13. Pérez-Cruz M, Parra-Anguita L, López-Martínez C, Moreno-Cámara S, del-Pino-Casado R. Burden and Anxiety in Family Caregivers in the Hospital That Debut in Caregiving. *Int J Environ Res Public Health* 2019: 16(20):3977.
14. Santos-Orlandi AAD, Brigola AG, Ottaviani AC, Luchesi BM, Souza EN, Moura FG, Zacarin JF, Terassi M, Oliveira NA, Pavarini SCI. Elderly caregivers of the elderly: frailty, loneliness and depressive symptoms. *Rev. Bras. Enferm* 2019: 72:88-96.
15. Liu H, Lou VW. Transitioning into spousal caregiving: contribution of caregiving intensity and caregivers' multiple chronic conditions to functional health. *Age and Ageing* 2019; 48(1):108-114.
16. Bourdieu P. *A dominação masculina*. 2ª ed. Rio de Janeiro: Bertrand do Brasil; 2002.
17. Baker KL, Robertson N, Connelly D. Men caring for wives or partners with dementia: Masculinity, strain and gain. *Aging & Mental Health* 2010; 14(3):319-327.

18. Shahly V, Chatterji S, Gruber MJ, Al-Hamzawi A, Alonso J, Andrade LH, Angermeyer MC, Bruffaerts R, Bunting B, Caldas-de-Almeida JM, Girolamo G, Jonge P, Florescu S, Gureje O, Haro JM, Hinkov HR, Hu C, Karam EG, Lépine J-P, Levinson D, Medina-Mora ME, Posada-Villa J, Sampson NA, Trivedi JK, Viana MC, Kessler RC. Cross-national differences in the prevalence and correlates of burden among older family caregivers in the World Health Organization World Mental Health (WMH) Surveys. *Psychol Med* 2013; 43(4):865-879.
19. Couto, AMD, Caldas CP, Castro, EABD. Family caregiver of older adults and Cultural Care in Nursing care. *Rev. Bras. Enferm*. 2018; 71(3):959-966.
20. Hogan R. *Human sexuality - a nursing perspective*. 2ª ed. Connecticut: Appleton Century Crofts; 1985.
21. Santos WJD, Giacomin KC, Firmo JOA. Alteridade do corpo do velho: estranhamento e dor na Saúde Coletiva. *Cien Saude Colet* 2019; 24(11):4275-4284.
22. Bleger J. *Simbiosis y ambigüedad: estudio psicoanaítico*. Buenos Aires: Paidós; 2001.
23. Bornstein RF. Illuminating a neglected clinical issue: Societal costs of interpersonal dependency and dependent personality disorder. *Journal of clinical psychology* 2012; 68(7):766-781.
24. Mendez-Luck CA, Anthony KP, Guerrero LR. Burden and bad days among mexican-origin women caregivers. *J Gerontol B Psychol Sci Soc Sci* 2019; 75(8):1719-1730.
25. Moreno-Cámara S, Palomino-Moral PA, Moral-Fernández L, Frías-Osuna A, del-Pino-Casado R. Problemas en el proceso de adaptación a los câmbios en personas cuidadoras familiares de mayores con demencia. *Gac Sanit* 2016; 30(3):201-207
26. Oxfam. *Relatório sobre nós e a desigualdade "tempo de cuidar"*. Davos: Fórum Econômico Mundial; 2020.
27. Anjos KF, Boery RNSO, Pereira R. Quality of life of relative caregivers of elderly dependents at home. *Texto Contexto - Enferm* 2014; 23(3):600-608.
28. Rosas C, Neri AL. Quality of life, burden, family emotional support: a model for older adults who are caregivers. *Rev. Bras. Enferm* 2019; 72(s/n):169-176.
29. Givens JL, Mezzacappa C, Heeren T, Yaffe K, Fredman L. Depressive symptoms among dementia caregivers: role of mediating factors. The American Journal of *Geriatric Psychiatry* 2014; 22(5):481-488.
30. Koumoutzis A, Cichy KE, Dellmann-Jenkins M, Blankemeyer M. Age Differences and Similarities in Associated Stressors and Outcomes Among Young, Midlife, and Older Adult Family Caregivers. *Int J Aging Hum Dev* 2020; 91415020905265.
31. Li L, Lee Y. Caregiving Choice and Caregiver-Receiver Relation: Effects on Psychological Well-being of Family Caregivers in Canada. *Can J Aging* 2020; 1-13.
32. Araújo MGDO, Dutra MOM, Freitas CCSL, Guedes TG, Souza FSD, Baptista RS. Caring for the carer: quality of life and burden of female caregivers. *Rev Bras Enferm* 2019; 72(3):728-736.
33. Ris I, Schnepp W, Mahrer Imhof R. An integrative review on family caregivers' involvement in care of home-dwelling elderly. *Health Soc Care Community* 2019; 27(3):e95-e111.
34. Minayo MCS. O imperativo de cuidar da pessoa idosa dependente. *Cien Saude Colet* 2019; 24(1):247-252.

Article submitted 02/06/2020
Approved 11/08/2020
Final version submitted 13/08/2020

Chief Editors: Maria Cecília de Souza Minayo, Romeu Gomes, Antônio Augusto Moura da Silva. Associate Editor, Elderly Health: Joselia Oliveira Araújo Firmo