



The care of older adults in the process of frailty: challenges and emotions from the caregiver's perspective

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Abstract

Objective: To comprehend the challenges and emotions within the caregiving process from the perspective of those who care for older adults in situations of frailty within their own homes. **Method:** A qualitative research approach rooted in the theoretical and methodological framework of Interpretative and Medical Anthropology was employed. Nine female caregivers and one male caregiver were interviewed within the homes of the elderly individuals they were caring for. Emic analysis was guided by the model of Signs, Meanings, and Actions. **Results:** Challenges manifest in the absence of caregiver training, constraints related to hygiene routines, the absence of compliance with labor rights, lack of accessibility and material resources, family relationships, and the interpretation of the actions of the care recipients as stubbornness. Emotions described by the interviewees include affection, satisfaction, fatigue, stress, burden, and fear of worsening and making mistakes. **Conclusion:** Caregivers revealed a deep and complex moral, ethical, and emotional involvement in their caregiving roles. They highlight a scenario where it is essential to recognize and acknowledge the work involved in caring for older adults in situations of frailty and to implement caregiving policies with community and cross-sector support actions.

Keywords: Anthropology. Caregivers. Frail older individual.

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INTRODUCTION

The increase in longevity, when coupled with the multifactorial syndrome of frailty^{1,2}, results in a greater demand for care³⁻⁸. The process of frailty is dynamic, encompassing individual, familial, and social factors, and requires an expansion of access to long-term care and informal and formal care networks⁹. It is well-known that caregivers play an essential role in empowering and caring for frail older adults^{1,10}. However, the aging population is occurring with an insufficient number of individuals engaged in caregiving activities, limited support for families, and a lack of preparedness among professionals and services. This is further compounded by the inadequacy of public caregiving policies^{3-7,10,11}.

In Brazil, the majority of caregivers have familial bonds and are over 50 years old^{2,3,5,9}, and when professional assistance is present, it often involves individuals with limited training who work under precarious conditions³. Furthermore, aging with frailty reorients the family dynamic, primarily transforming women into full-time, solitary, and unpaid caregivers^{4,5,10}. Both older adults and those who care for them are affected by individual, social, and programmatic vulnerabilities, leading to a deterioration in living and health conditions^{3,4}. This situation renders them forgotten, undervalued, and invisible^{4,5}. Therefore, there is a need to politicize caregiving on a global scale, moving beyond the distinction between formal and informal caregiving^{11,12}.

Within the field of geriatrics and gerontology, it is considered crucial to comprehend how caregivers experience the intersubjective relationship with caregiving⁵⁻¹⁰, particularly within the context of frailty². There is an interest in exploring the universe in which caregiving takes place and the complexity of this activity, in order to identify the strategies¹³ used to generate information that aims to support^{10,14} caregivers and inform public policies⁵. This is done with the backing of healthcare services^{4,8} to enhance the caregiving conditions² for all individuals involved.

Otherwise, Anthropology inspires us to consider the circuits and various threads that weave the fabric of caregiving, encompassing the multiple forms of concrete work, sociocultural meanings, values, and

emotions in its apprehension¹⁰. However, the analysis of caregiving from the perspective of caregivers of frail older adults¹ is seldom explored. Furthermore, androcentric descriptions fail to comprehensively capture the multifaceted nature of caregiving, as society relies on those who provide care while denying them a place and visibility¹⁵. Thus, this paper aims to understand the challenges and emotions in the caregiving process from the perspective of those who care for frail older adults within their homes.

METHOD

This is a qualitative research anchored in the theoretical and methodological framework of Interpretative and Medical Anthropology^{16,17}, which recognizes that it is through cultural patterns that humans find meaning, interpret, and guide their actions¹⁷. It unveils the social order metaphorically embedded in the biological and interprets the cultural process without being myopic to the social and political dimensions of illness, highlighting power dynamics, the relationship between capitalism and society, the struggle for human rights, and social justice¹⁶.

For participant selection, telephone contacts were made with elderly individuals from the baseline database of the FIBRA study in the Belo Horizonte area, Minas Gerais, Brazil¹⁸. Heterogeneity within the municipality's territory was sought. Interview appointments were made based on convenience. Individuals who agreed to participate in the research were included. Interviews were conducted at the homes of the care recipients, and their preferences to schedule the interviews in accordance with their caregiving routines were accommodated. Data collection occurred in two phases: from January to August 2016 with individuals identified as frail in the database, but due to difficulties in locating surviving individuals or changes in the provided phone numbers, data collection continued from January to May 2018 with individuals identified as pre-frail in the database. There were no refusals to participate. To access perceptions of caregiving in the frailty process, interviews were conducted using a semi-structured script, aiming to understand perceptions of health condition, aging, frailty, caregiving, the strategies employed (community and personal resources), the

difficulties faced in daily life, how they resolve or mitigate them, as well as inquiring about the existence of support from other individuals or institutions and exploring actions they undertake outside the caregiving sphere. The interviews were conducted by psychology and physiotherapy professionals specialized in human aging, lasting an average of 42 minutes. They were recorded and transcribed. The termination of the interviews was based on the quality, quantity, and intensity of the collected data, allowing for the elucidation of the complexity of the phenomenon and facilitating immersion in the sociocultural universe¹⁹.

Data analysis was grounded in the "signs, meanings, and actions" model, starting from actions to access the semantic level as a privileged pathway to cultural systems²⁰. An emic perspective¹⁷ was employed. The analysis commenced with an in-depth reading of the collected material, involving successive readings to identify levels of signs, meanings, and actions related to the theme. Consequently, the content of each interview was segmented and organized, allowing access to interpretations, examination of relationships between the levels, and in-depth analysis, which was compiled into analytical categories.

This research is part of the project "Frailty in Older Adults: perceptions, cultural mediation, coping, and care," approved by the Ethics Committee of the René Rachou Institute - Fiocruz, under opinion number 2141038/15. Prior to the commencement of interviews, participants signed the informed

consent form. Throughout the entire research, the guidelines of Resolutions number 466/2012 and number 510/2016 of the National Health Council were followed. To ensure confidentiality, caregivers were identified by the letter "C" followed by the interviewee's identification number.

DATA AVAILABILITY

The entire dataset that supports the findings of this study is available upon request to the corresponding author, Gislaïne Alves de Souza.

RESULTS

Nine female caregivers and one male caregiver were interviewed, as categorized in Table 1. Seven of the caregivers were single, and three were married (two were spouses, and one was a daughter). The presence of older adults engaged in caregiving activities was noted. Regarding support in caregiving, one family member mentioned daily rotation among children. The other family caregivers reported being responsible for the comprehensive daily management of care, with only occasional support from others. The professional caregivers described this family support in a heterogeneous manner: one family was actively involved, another was passive, and the third had no involvement, but they reported receiving support from other professionals.

Table 1. Characterization of the Interviewed Individuals in the Municipality of Belo Horizonte, MG, 2018.

Caregiver	Sex	Age	Relationship	Description	Condition of the Care Recipient
C1	Fem.	49	Family**	Daughter	Diabetes.
C2	Fem.	24	Professional*	Grandniece	Three falls, fractures, and Parkinson's disease.
C3	Fem.	71	Family**	Daughter	Depression and bronchiectasis.
C4	Fem.	36	Professional*	Caregiver	Nine years on dialysis, eleven surgeries, and femur fracture.
C5	Fem.	65	Family**	Daughter	Alzheimer's disease.
C6	Fem.	33	Professional*	Caregiver	Alzheimer's disease.
C7	Mal.	92	Family**	Husband	Head buzzing, weak leg, and nerve issues.
C8	Fem.	68	Family**	Daughter	Shoulder fracture, back pain, hypertension, and high cholesterol.
C9	Fem.	53	Family**	Daughter	Alzheimer's disease.
C10	Fem.	86	Family**	Wife	Alzheimer's disease.

*Professional = reported receiving payment for caregiving activities, recognized in the literature^{9,12} as a formal caregiver. **Family caregivers are commonly referred to in the literature^{9,12} as informal caregivers.

In the interviews, it was reported that all caregivers had been involved in caregiving for over a decade, except for the youngest caregiver. Various circumstances determined their engagement in this activity, including the worsening of the care recipient's health condition, other family members being employed, unemployment, inability to afford professional caregiving services, and cohabitation with the care recipient. Four caregivers had previous caregiving experiences. All of them resided with the care recipient, except for one professional caregiver.

In the studied scenario, it is observed that caregiving is provided to older adults with varying health conditions, and when asked about frailty, they contextualized it as follows:

"She (my mother) is becoming more fragile; it's a path we have to be more careful on, always watching, whether she wants to do things or not. She is more fragile. (...) I keep an eye on her, watching her all the time. (...) She needs a person like us to take care of her." (C1)

"I believe that (frailty) is the combination of several things (...) because they used to have an active life, had independence from others, but when they have to depend on someone else due to physical or psychological limitations to perform their daily activities, it makes them very fragile. Sometimes they become depressed because they don't feel useful anymore, you know, because they don't have that physical strength (...) their bones are not as strong as they used to be to support their body. So, it's this kind of physical and psychological frailty (...) there are various types of frailties, various aspects of care that you have to work on." (C2)

"Fragile elder? With the fragilities of life? (...) Oh, if they don't have perfect health, if they don't have family support, or if they don't have the financial means to help themselves, or if they don't have the spiritual support to keep them going (...) they can have these physical and mental fragilities (...) she (my mother) had certain fragilities, but she overcame many things. Life wasn't easy for her, especially after my father passed away, so financial fragility is one of the fragilities (...) she didn't give up, she didn't lose heart (...) Aunt M. was a winner; she buried many people and is still alive today, with all she has been through (...) so, one type of frailty is strength (laughs)." (C3)

It is evident that the perception of the frailty process occurs when, due to health conditions, a person needs the care of others to assist in performing basic activities and mobility, as well as the loss of previous independence, decreased energy, and the will to live. The daily caregiving is elucidated, respectively, in the narratives of a family caregiver and a professional caregiver, as seen below:

"Well, I have it all here. A bath? She is dependent. Medication times, lunch, I always have to be there (...) make it clear to her that she has me as a companion. (...) To be honest, I live for her (...) 24 hours in here." (C5)

"She is completely dependent now. I'm the one who gives her baths, I'm the one who administers medication, as she can't see well, I help her with her meals (...) I put her in the wheelchair, and I take her to the doctor. (...) I spend 12 hours with her every day, I just don't stay overnight." (C6)

For an understanding of caregiving relationships, the analysis revealed two categories: "Challenges" and "Emotions."

Challenges

The majority reported challenges in caregiving that impact daily life:

"The time when we had a caregiver, unfortunately, we couldn't afford it, it's not cheap (...) I told them, there will come a point when it will fall on all of us: giving a bath, helping in the bathroom, changing a diaper. 'Oh, but we are men' (referring to the arguments of the children). So what? You are still children (...) The neurologist said, you need someone who can be more assertive with her: 'No means no.' So, when I say 'no,' she says, 'you are angry, you are angry with me'... (gets emotional) (...) Many times, if I go out nearby, there's someone else with her, but she immediately asks me: 'Why did you leave?'" (C5)

"I think the most interfering factor is that there's no room for error, you know!? Because it's a person, it's a life that depends on you (...) mobility is a challenge (...) I arrived at Hospital X, and there was no wheelchair there! (...) It's a hassle, a lack of commitment (...) I carry her in my arms." (C2)

"I had to be with my mom practically 24/7 (...) Someone said, 'Wow! A 71-year-old woman taking care of a 90-year-old person! They are both elderly!' (...) I wanted to sleep at night, but she was awake (laughs) (...) one day, the house collapses, the chubby one falls (referring to herself) (laughs) gets fat because she's very anxious, gains over twenty kilos, but one day, it breaks down!" (C3)

Being unable to afford care, needing to set boundaries, being unable to leave, needing to fight for proper treatment, falling ill, having to cope with the emotional impact of the care recipient, and dealing with the relationship with other family members are some of the challenges that require attention. A summary of the enumerated challenges is presented in Table 2.

Table 2. Summary of the challenges in caregiving from the perspective of those caring for frail older adults. Belo Horizonte, MG, 2018.

Compiled List of Challenges
<p>Structural</p> <ul style="list-style-type: none"> • Limited financial resources (C3, C4, C5); • Lack of accessibility (stairs) (C2, C6); • Limited access to potential prognoses (communication failures by healthcare professionals) (C3); • Need to fight for the elderly person to receive dignified treatment (C2, C3); • Gender stereotypes (C3, C5); • "Stubbornness" of the care recipient (ageism) (C1, C4, C8);
<p>Sociofamilial</p> <ul style="list-style-type: none"> • Inability to care for the elderly person alone (C2, C3, C4, C5, C7); • Limited involvement of other family members in caregiving (C3, C4); • Changes in family relationships (C3, C8);
<p>Adaptations</p> <ul style="list-style-type: none"> • Need for environmental adaptations for mobility and safety (C2, C4); • Need for support in performing transfers (C2, C5, C6);
<p>Neglect of Self-Care</p> <ul style="list-style-type: none"> • Limited time for oneself and for sleep (C3, C4, C5); • Impact on one's own health (C3, C5); • Postponement of personal projects (C1, C4, C5); • Impact of the care recipient's emotions (C2, C3, C4, C5);
<p>Distrust</p> <ul style="list-style-type: none"> • Embarrassment with exposing the body during hygiene activities (C4, C5); • The care recipient lacks trust in another caregiver (C3, C4, C5);
<p>Lack of Professionalism</p> <ul style="list-style-type: none"> • Lack of training (C2); • Failures in complying with labor rights (C4, C6).

Emotions

In the face of these challenges, different emotions are expressed in the narratives of everyday actions that are seen as caregiving and are manifested throughout the interviews:

"Dad was diagnosed (with Alzheimer's) in 2008 (...) there was a phase of paranoia, it was very difficult. (...) It's a loving and physical contact

that I didn't have with him, and now I can have it." (C9)

"Oh, it weighs heavily (...) The fear, not of today, but usually I'm already thinking about tomorrow!? How will she wake up tomorrow? (...) Will I be able to handle it?" (C5)

"I think we have already formed a father-son bond (...) When Mr. A. is unwell, I feel like I'm unwell too (...) I've spent three months here without going

to my own home because of him (...) his daughters say that if I leave, he will die (...) There was a time when I was at hemodialysis with Mr. A., and my brother had a heart attack and passed away (...) so I had to wait, I couldn't show it to Mr. A." (C4)

A summary of the emotions is presented in Table 3.

Figure 1 outlines the main findings of this paper.

Table 3. Summary of Emotions Triggered in the Caregiving Relationship from the Perspective of Those Caring for Frail Older Adults. Belo Horizonte, MG, 2018.

Compiled List of Emotions
<p>Emotions that Favor Care</p> <ul style="list-style-type: none"> • Affection, care, and satisfaction (C2, C3, C4, C6, C8, C9); • Gratitude (C1, C8, C10); • Patience, compassion (C2, C3, C4, C6);
<p>Emotions that Sustain Care, but Intensity Hinders</p> <ul style="list-style-type: none"> • Excessive closeness; emotional dependence, symbiosis (C3, C4, C5); • Being affected by the joys and sorrows of the care recipient (C2, C3, C4, C5); • Feeling responsible for the life of the care recipient (C1, C3, C4, C5, C6);
<p>Emotions that Burden Care</p> <ul style="list-style-type: none"> • Fear of the care recipient's death or what might happen (C2, C4, C5); • Fear of making a mistake (C2, C5); • Being frightened by behavioral changes or deteriorations in the care recipient's condition (C5, C10); • Insecurity, anguish (C1, C2, C3, C4, C5); • Helplessness, anger, and impatience (C5); • Fatigue, anxiety, isolation, and stress (C3, C4, C5).

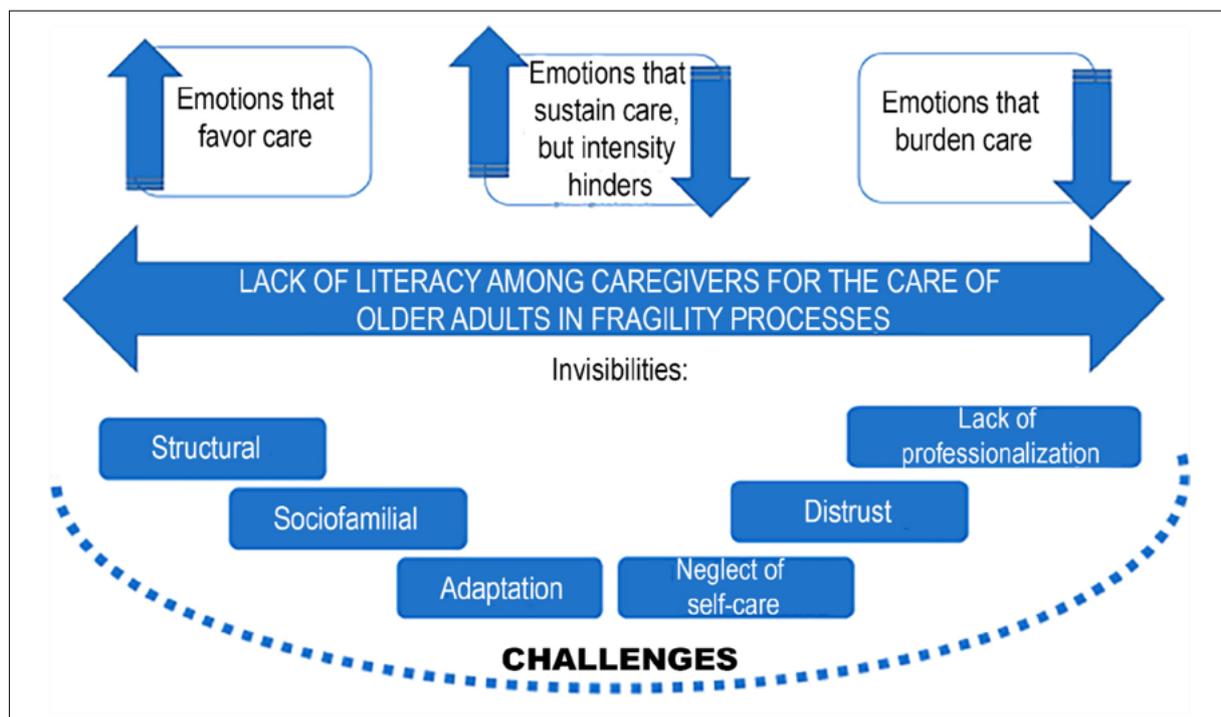


Figure 1. Challenges and emotions in the care process for those caring for older adults in a state of fragility. Belo Horizonte, MG, 2018.

DISCUSSION

In this research, frailty is recognized by the caregivers in various ways: physical, mental, emotional, cognitive, familial/absence of a companion, financial, communicational, and spiritual. The individuals interviewed contribute to the understanding that those who provide care also feel frail when they find themselves unable to meet all the needs of the care recipient. Additionally, this perception of frailty does not exclude "fortility": the strength to sustain life and the caregiving process. However, in the researched literature, no studies were found that explore the process of frailty from the perspective of the caregiver.

In the literature, frailty is characterized as a complex, polysemic, multidimensional, and multicausal concept, influenced by biological, psychological, social and environmental factors²¹. Although there is no unanimity in the definition of frailty, it is generally associated with an increased likelihood of unfavorable clinical conditions, such as susceptibility to diseases, functional decline, dependence in activities of daily living, falls, hospitalization, and early death²¹. It also encompasses issues that go beyond the individual, including the environment and macro aspects that influence the quality of life²², pointing to social, subjective, political, and cultural causes.

Throughout the interviews, there were initially difficulties in naming the limitations of the care recipient, which were overcome after the establishment of a receptive listening space. Similarly, a study reports the initial denial of the caregiving burden, although the presence of physical, psychological, and financial burdens was evident²³. In this research, it was also observed in the field that the interviewed group was concerned with demonstrating that they provide care in the best possible way.

During the interviews, they expressed challenges related to mobility and the need for assistance in taking care recipients to medical appointments, as well as barriers to accessibility, which have also been recognized in other studies²³. Additionally, the caregiving responsibility redefines the existential project of the caregivers, affecting their personal,

family, and professional projects⁷. This leads to physical and emotional exhaustion^{2,4,8}, fatigue, burden, burnout, and a loss of freedom⁴. The caregivers stated that they were unable to sustain the necessary care alone, bearing an overwhelming responsibility for the life of the care recipient. Often, care is provided without social support and without recognition of the work being performed. The literature highlights the decreasing provision of care by the family and their inability to fulfill more than 50% of the care needs of dependent elderly individuals⁸. There is significant pressure on family caregivers, a lack of Public support²³, and a demand for the regulation of these professionals⁶.

The difficulty of involving other family members in caregiving, especially men, highlights gender-related issues and challenges the traditional notion that caregiving is exclusively a female task. The literature has devoted significant effort to this discussion¹², recognizing that women still predominantly perform caregiving activities and that this role remains largely invisible^{4,5,13,23,24}. Unpaid domestic labor continues to be associated with women^{25,26}.

Another reflection of how society perceives old age is the interpretation of certain behaviors exhibited by the person being cared for, which can complicate the caregiving process. Expressions like "old people's quirks," "stubbornness," or "refusing to leave home" appear in the narratives of caregivers, whether they are professionals or family members. These interpretations reveal ageism, where stereotypes about old age are normalized and turned into an individual problem²⁷. The ethics of caregiving present a challenge due to the power dynamics involved in continuous surveillance and the disciplining of actions¹¹.

In the field, a wide range of caregiving relationships and resources are observed, including diverse family and community bonds, varying health conditions, the worsening and manifestation of behavioral symptoms. The constant efforts to access services and secure effective access to resources, including healthcare, conflict with physical inaccessibility, restrictions in accessing treatment, support, and education, as well as the vulnerability of the social condition. These aspects frequently present themselves as challenges

in the caregiving process, and they align with the findings in the existing literature^{7,14}.

Furthermore, when caregiving is prolonged, intrafamily conflicts can arise⁸, and often the willingness to care is sustained at the expense of neglecting one's own Self-care⁸. The sense of lacking support from other family members is identified in this study and in various other researches^{13,23}.

All the interviewees mentioned experiencing impacts on their physical, mental, and emotional health. In line with other research, they faced repetitive, increasing, and varied demands; exhausting schedules with unrestricted dedication. One caregiver mentioned "breaking down," revealing that providing care has psychiatric and somatic consequences^{23,28,29}, as well as repercussions on their overall health. Prolonged caregiving can cause overload¹³, and self-care is reported as being challenging, although it is essential to continue providing care¹⁴.

Family and professional caregivers are willing to sacrifice their well-being to provide care^{7,23} and they have health disadvantages compared to non-caregivers⁷. They experience different degrees of burden across various domains⁷ and scopes^{5,23} (physical, emotional, social, mental, and financial) and have difficulties in preparing to provide care. Additionally, they report that the repetitive behavior, messiness, and aggressiveness²⁸ of the care recipient can be tiring.

The interviewees mentioned that care recipients felt uncomfortable with other individuals assisting them in hygiene routines, which can lead to awkward situations^{14,29}. Having to sleep in the hospital or being the one to provide care became evident in the interview when the care recipient does not accept support from others.

With the exception of one professional who works 12 hours a day and a family member who, with social and economic resources, readjusted their life to maintain care, all other caregivers faced challenges in balancing the caregiving task with other aspects of their lives. All the interviewed professionals mentioned exceeding the eight-hour daily work limit. This overload and the precariousness of employment relationships are observed in other studies⁶.

Therefore, the results highlight that care should not remain hidden and needs support since one of the difficulties experienced is the reversal of roles when it is necessary to exert authority over parental figures or when the care recipient suffers due to the care received. Both forms of suffering have specificities within the field of geriatrics and gerontology.

The interviewed individuals described experiencing contradictory feelings and emotions^{2,5,6,9,24} in the context of care. Caring is redefined as an act of love; an opportunity for closeness and emotional connection; a circumstance to understand oneself as a person with virtues, investing daily to preserve someone's life. In the literature, caring for a family member who has lost autonomy reflects feelings such as gratitude, reciprocity, generosity, justice, dedication, ethical and moral responsibility^{4,5}.

Two professional caregivers mentioned assuming the caregiving role "as a family member." Soares²⁹ discusses that care is considered to be done better when the dedication is similar to that of a family member. This is a relationship in which involvement and love are present, inevitable, essential, and positive, although they are often disregarded and invisible³⁰. While caregiving involves a moral code of self-sacrifice that binds the caregiver to the care recipient⁶, sociocultural values attributed to caregiving by today's society³⁰ expect a balance in the expression of emotions by caregivers. However, the entire group experienced changes in their lives due to the caregiving role and the emotional involvement, leading to complete dedication. The interviewees stated that they forget about themselves, and even symbiotic relationships, where there is mutual dependency⁶, were demonstrated, dedicated to caregiving.

Empathy with the other's pain, sadness in witnessing someone lose a function they used to perform, as well as joy in regaining mobility, were described by the caregivers. This responsibility for someone else's life is part of the ethics of care¹² that requires reflection and goes beyond mere prescriptions²⁹. In this face-to-face work, the emotional expression of the individuals involved²⁹ affects the dynamics of care, and a significant amount of emotional work is done^{14,24,29}. Caregivers

make efforts to ensure that the care recipient emotionally recognizes them as companions. The literature discusses that this compassionate love allows for the well-being of the elderly person, creating a beneficial emotional connection for those involved³¹ and for society^{31,32}.

Nevertheless, other emotions permeate the statements of the interviewed individuals: dealing with the fear of failing in providing care⁵, of not being able to handle the care, and recognizing that the relationship dictated by caregiving is complex and tiring. Caregivers acknowledge the challenges of dealing with self-judgment and the judgment of others⁵, with irritability, and with feelings of loss and helplessness due to the worsening of the care recipient's condition⁸.

It is expected that knowledge about the care recipient's health issue, the longer duration of the relationship⁴, a positive relationship²⁸, and the establishment of a trusting bond²⁹ would provide more security in performing the caregiving role and reduce emotional labor. Conversely, in this research, the fluctuation or worsening of the care recipient's condition and the increasing complexity of demands destabilize this sense of security and require more emotional labor. There is a lack of information when facing new challenges²; there is doubt about whether the care being provided is correct, sufficient, in line with prescriptions, or suitable for the well-being of the older adult. In addition, there is a lack of support, guidance, and care support actions in Brazil⁶⁻⁸. Ultimately, the study highlights the lack of literacy in caring for an older adult in a state of frailty.

Limitations of this research include the fact that it was conducted only with caregivers of participants from the baseline of the FIBRA study, which may have restricted its scope but provided insights into the experience of caring for older adults in a state of frailty. The choice to explore the caregiving universe where it takes place allowed for listening to the voices of both professional and family caregivers, considering their collisions and specificities. This presents a challenge in finding similar literature, but it also introduces the novelty of this research. The understanding that all care is labor³³ underpins

this construction, aiming to shed light on tacit knowledge that is culturally embedded and marked by sociopolitical factors that naturalize and render it invisible. It is considered that the issue of caregiving as employment is one that requires further regulation in the country.

CONCLUSION

In this research, among those who care for older adults in a state of frailty, caregiving is intense, forming a relationship that involves presence and dedication across multiple dimensions. It is a complex endeavor, as it requires various forms of support to assist someone experiencing the loss of their previous independence.

Caregivers revealed a moral commitment ("the person being cared for depends on me"), but also an ethical (of humanity, dedication) and emotional commitment (of interest, affection, and reciprocity), contributing valuable insights to the field of geriatrics and gerontology. Caregiving for caregivers is a subtle and complex relationship, filled with emotions and challenges. The lack of training for caregiving, as well as the lack of accessibility and material resources, is experienced by both family and professional caregivers. Thus, there is a need for public policies to alleviate these difficulties. In the same perspective, the absence of compliance with labor rights is striking for professional caregivers, while the invisibility of caregiving within the home setting as a form of work is notable for family caregivers. For all caregivers, it is evident that support is needed to continue caregiving without neglecting self-care.

Caring for older adults in a state of frailty is an essential task sustained by creations and coping. This implies understanding older adults in a state of frailty and those who care for them as individuals whose humanity and subjectivity must be recognized and respected. For this purpose, the presence and support of the social and family network are necessary, as well as the investment in public policies that offer community and intersectoral care actions, with the participation of all involved: the older adult, the caregiver, the family, society, and the state.

AUTHORSHIP

- Gislaine A. Souza participated in the conception, design, data analysis, and interpretation; paper writing; approval of the version to be published and is responsible for all aspects of the work ensuring issues related to the integrity of any part of the work.
- Karla C. Giacomini participated in the conception, design, and data interpretation; paper writing and critical review; approval of the version to

be published and is responsible for all aspects of the work ensuring issues related to the integrity of any part of the work.

- Josélia O. A. Firmo participated in the conception and design of the data; critical review of the paper; approval of the version to be published and is responsible for all aspects of the work ensuring issues related to the integrity of any part of the work.

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REFERENCES

1. Nan J, Duan Y, Wu S, Liao L, Li X, Zhao Y et al. Perspectives of older adults, caregivers, healthcare providers on frailty screening in primary care: a systematic review and qualitative meta-synthesis. *BMC Geriatrics*. 2022;22(482).
2. Lacerda MA, Silva LLT, Oliveira F, Coelho KR. O cuidado com o idoso fragilizado e a Estratégia Saúde da Família: perspectivas do cuidador informal familiar. *Rev baiana enferm*. 2021;35:e43127.
3. Ceccon RF, Vieira LJES, Brasil CCP, Soares KG, Portes VM, Garcia Júnior CAS et al. Envelhecimento e dependência no Brasil: características sociodemográficas e assistenciais de idosos e cuidadores. *Ciênc. Saúde Colet*. 2021;26(1):17-26.
4. Sousa GS, Silva RM, Reinaldo MAS, Soares SM, Gutierrez DMD, Figueiredo MLF. “A gente não é de ferro”: Vivências de cuidadores familiares sobre o cuidado com idosos dependentes no Brasil. *Ciênc. Saúde Colet*. 2021;26(1):27-36.
5. Gutierrez DMD, Sousa GS, Figueiredo AEB, Ribeiro MNS, Diniz CX, Nobre GASS. Vivências subjetivas de familiares que cuidam de idosos dependentes. *Ciênc. Saúde Colet*. 2021;26(1):47-56.
6. Figueiredo MLF, Gutierrez DMD, Darder JJT, Silva RF, Carvalho ML. Cuidadores formais de idosos dependentes no domicílio: desafios vivenciados. *Ciênc. Saúde Colet*. 2021;26(1):37-46.
7. Diniz MAA, Melo BRS, Neri KH, Casemiro FG, Figueiredo LC, Gaioli CCLO et al. Estudo comparativo entre cuidadores formais e informais de idosos. *Ciênc. saúde colet*. 2018;23(11):3789-3798.
8. Santos SMA, Rifiotis T. Cuidadores familiares de idosos dementados: um estudo crítico de práticas quotidianas e políticas sociais de judicialização e reprivatização. In: Grossi MP, Schwabe E, organizadores. *Política e cotidiano: estudos antropológicos sobre gênero, família e sexualidade*. Blumenau: Nova Letras, Associação Brasileira de Antropologia, 2006. p.95-114.
9. Basu R, Steiner AC, Stevens AB. Long-Term Care Market Trend and Patterns of Caregiving in the U.S. *Journal of Aging & Social Policy*. 2022;34(1):20-37.
10. Kleinman A. Varieties of Experiences of Care. *Perspectives in Biology and Medicine*. 2020;63(3):458–465.
11. Debert GG, Pulhez MM, organizadoras. *Desafios do cuidado, gênero, velhice e deficiência*. 2ª ed. Campinas: Unicamp/IFCH, 2019.
12. Tronto J. *Caring democracy: Markets, equality, and justice*. New York: New York University Press, 2013.
13. Nespolo G, Merhy EE. Trabalho em saúde: biomedicalização de quem cuida. *Saúde em Rede*. 2018;4(2):9-18.
14. Wiles J, Moeke-Maxwell T, Williams L, Black S, Trussardi G, Gott M. Caregivers for people at end of life in advanced age: knowing, doing and negotiating care. *Age Ageing*. 2018;47(6):887-895.
15. Molinier P. Ética e trabalho do care. In: Hirata H, Guimarães NA, organizadores. *Cuidado e cuidadoras: as várias faces do trabalho do care*. São Paulo: editora Atlas, 2012, p.29-43.

16. Nunes MO. Da aplicação à implicação na Antropologia médica: leituras políticas, históricas e narrativas do mundo do adoecimento e da saúde. *Análise Hist. cienc. saude-Manguinhos*. 2014;21(2).
17. Geertz C. *A Interpretação das Culturas*. Rio de Janeiro: Editora Guanabara Koogan, LTC, Antropologia Social, 1989.
18. Vieira RA, Guerra RO, Giacomini KC, Vasconcelos KSS, Andrade ACS, Pereira LSM et al. Prevalência de fragilidade e fatores associados em idosos comunitários de Belo Horizonte, Minas Gerais, Brasil: dados do estudo FIBRA. *Cadernos de Saúde Pública*. 2013;(29):1631-1643.
19. Minayo MCS. Amostragem e saturação em pesquisa qualitativa: consensos e controvérsias. *Revista Pesquisa Qualitativa*. 2017;5(7):1-12.
20. Corin E, Uchôa E, Bibeau G. Articulation et variations des systèmes de signes, de sens et d'action. *Psychopathologie africaine*. 1992;24(2):183-204.
21. Kim Y, Jang S. Mapping the knowledge structure of frailty in journal articles by text network analysis. *PloS one*. 2018;13(4):e0196104.
22. Dury S, Dierckx E, Vorst A, Elst M, Fret B, Duppen D, et al. Detecting frail, older adults and identifying their strengths: results of a mixed-methods study. *BMC Public Health*. 2018;18(1):191.
23. Faronbi JO, Faronbi GO, Ayamolowo SJ, Olagun AA. Caring for the seniors with chronic illness: The lived experience of caregivers of older adults. *Archives of Gerontology and Geriatrics*. 2019;82:8-14.
24. Araújo AB. Cuidado de idosos e emoções na pandemia. In: Angotti B, Vieira RSC, organizadores. *Cuidar, verbo coletivo: diálogos sobre o cuidado na pandemia da Covid-19*. Joaçaba: Editora Unoesc, 2021, p.235-244.
25. Avila MB, Ferreira V. Trabalho doméstico remunerado: contradições estruturantes e emergentes nas relações sociais no Brasil. *Psicol. Soc.* 2020;32.
26. Hirata H. Cuidado: teorias e práticas. In: Angotti B, Vieira RSC, organizadores. *Cuidar, verbo coletivo: diálogos sobre o cuidado na pandemia da Covid-19*. Joaçaba: Editora Unoesc, 2021, p.31-40.
27. Debert GG. O velho na propaganda. *Cad. Pagu*. 2003;(21).
28. Bjorge H, Kvall K, Ulstein I. The effect of psychosocial support on caregivers' perceived criticism and emotional over-involvement of persons with dementia: an assessor-blinded randomized controlled trial. *BMC Health Serv Res*. 2019;9(1):744.
29. Soares A. O trabalho de cuidar e as emoções nos tempos da Covid-19. In: Angotti B, Vieira RSC, organizadores. *Cuidar, verbo coletivo: diálogos sobre o cuidado na pandemia da Covid-19*. Joaçaba: Editora Unoesc, 2021, p.41-56.
30. Le Breton D. *As Paixões Ordinárias: Antropologia das Emoções*. Tradução: Peretti, L.A.S. Rio de Janeiro: Vozes, 2009. 276p.
31. Kahana E, Bhatta TR, Kahana B, Likhak N. Loving Others: The Impact of Compassionate Love on Later-Life Psychological Well-being. *The Journals of Gerontology: Series B*. 2021;76(2):391-402.
32. Horden J. The Dignity of the Frail: On Compassion, Terror, and Social Death. *Literature and Medicine*, Johns Hopkins University Press. 2020;38(2):349-370.
33. Antunes R. Adeus ao trabalho? ensaio sobre as metamorfoses e a centralidade no mundo do trabalho. São Paulo: Cortez, 2021.