



Understanding of caregivers of bedridden older adults about the primary assistance received to their own health care

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Abstract

Objective: To identify caregivers' understanding of healthcare assistance received from primary health care regarding their own health. **Method:** A qualitative study based on Alfred Schütz's phenomenology was conducted. The approach to caregivers of bedridden older adults was carried out by community health agents within their coverage area in a primary health care unit located in the northern region of Espírito Santo, Brazil. The choice of location was convenience-based. Data collection took place between September and December 2022 in households. A questionnaire containing questions about the participants' sociodemographic profile, along with six phenomenological questions to understand the typical experiences of each caregiver of older adults and their intentionality, was administered. Data were analyzed using phenomenological methods. **Results:** Sixteen caregivers of bedridden older adults participated, with fifteen being female, fifteen having a family relationship with the care recipient, and fifteen lacking training qualifying them for the caregiver role. 37.5% of caregivers were aged 61 years or older. Regarding the typical experiences, the following categories emerged from the participants' narratives: 1- Physical, emotional, and social impacts on the caregiver's health; 2- Need for qualification; 3- Support from the healthcare team, with a subcategory: 3.1- Absence of medical and/or nursing professionals. **Conclusion:** It was understood that caregivers are invisible and do not receive healthcare assistance from the healthcare team for their own health. When home visits occur, professionals focus on attending to the older adult, fragmenting the assistance that should be extended to the needs of the family community, including the caregiver.

Keywords: Caregivers. Occupational Health. Primary Health Care. Healthcare Assistance.

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INTRODUCTION

The caregiver is a human being of numerous qualities who is open to tasks that require skill, dedication, and selflessness, as they often sacrifice their own lives to provide care to others. Depending on their age and health condition, this commitment can increase vulnerability to developing illnesses caused by the meticulous attention to the well-being, health, nutrition, personal hygiene, education, culture, recreation, and leisure of the person being assisted. In other words, the caregiver is the individual who provides care to someone in need¹.

All stages of the life cycle require specific care characteristic of each one. Some phases demand greater care, such as infancy and old age. With the increase in human longevity observed in recent decades, various challenges arise for governments and communities to ensure the physical, social, and legal well-being of older adults and their families. Caring for older adults, especially those who are bedridden, can lead to greater physical and mental burden for the caregiver^{1,2}. When assuming this role, caregivers often tend to prioritize the care they provide to the older adult over their own self-care, as the work typically occurs continuously, leading to stress and work overload^{2,4}.

Thus, there are four types of caregivers: family and non-family, laypersons or professionally trained, formal or informal, and primary, secondary, and tertiary caregivers, which refers to the degree of involvement. Primary caregivers are those primarily responsible for the majority of tasks⁵.

In Brazil, the caregiver of an older adult typically has a close physical and emotional relationship with the care recipient, often being a family member. This role is usually taken on abruptly by a family member who is often not psychologically or technically prepared for the task¹⁻³. Authors emphasize the need for training to acquire the necessary knowledge for carrying out care tasks with autonomy, skill, and technique, particularly for more challenging tasks such as bed baths and wound care. This training aims to improve health outcomes and alleviate the burden on the caregiver's body²⁻⁶.

To grasp the magnitude of the issue, according to the Brazilian Institute of Geography and Statistics (IBGE), the number of older adults has been increasing, representing 31.23 million individuals, which accounts for 14% of Brazil's total population in 2020⁷. The aging process brings about changes in the health conditions of the population that worsen with age: functional limitations and diagnoses of chronic diseases increase, among other factors, leading to repercussions on autonomy and independence. Consequently, there is a tendency for older adults to require home care⁴.

Therefore, the caregiver needs support and attention to their own health needs so that they can effectively care for others. A study has shown that the lack of support from family members and family health teams, combined with physical, emotional, and socioeconomic burdens, can affect the health and well-being of individuals who assume the role of caregivers for bedridden older adults⁸. However, there is a lack of studies giving voice to caregivers of older adults regarding the health needs of this population.

Therefore, this phenomenological study gives voice to caregivers of bedridden older adults and aims to identify caregivers' understanding of healthcare assistance received from primary health care regarding their own health.

METHOD

The research is based on Alfred Schütz's sociological phenomenology, which proposes to study how human phenomena are experienced in consciousness, cognitive and perceptual acts, as well as how they can be valued or appreciated aesthetically through understanding the "reasons for" and "reasons why"⁹. The guiding question posed was: "Have caregivers of bedridden older adults been receiving healthcare assistance from primary health care for their own health, according to caregivers' perceptions?"

Caregivers of bedridden older adults who met the inclusion criteria participated in the study: they were

registered as users in the coverage area of the Basic Health Unit (BHU) in the selected neighborhood for the research, had been providing care to the older adult for at least one year, and received regular visits from the Community Health Agent (CHA).

The study was conducted from September to December 2022 in the coverage area of a BHU in the city of São Mateus, located in the northern region of the state of Espírito Santo. The choice of this territory was convenience-based. The BHU consists of a standard Family Health Strategy (FHS) team and serves 2,800 families, with 24 bedridden older adults in the area, which constituted the research sample. Of these, 16 caregivers agreed to participate voluntarily in the study, although data saturation occurred after the eighth interview.

The approach to caregivers initially occurred through the CHA within their coverage area, who extended invitations, and for those who accepted, home visits were scheduled. The semi-structured interviews were conducted individually by the researcher, at a location in the caregivers' homes and at a convenient time. The average duration of each interview was 40 minutes.

A semi-structured questionnaire was used, consisting of questions about the caregivers' sociodemographic profile, along with six phenomenological questions. The questionnaire was developed by the researchers and piloted with a group to verify the reliability and understanding of the questions. After this stage and necessary corrections were made, it was administered to the participants.

The data were recorded on a mobile device and transcribed in full. Several steps were followed to understand the typical action experienced by the participants, with a comprehensive description of their accounts, aiming to capture the differentiated quality of their perceptions about their experiences and their impact on health.

In order to obtain different meanings, the research employed analysis and interpretation categories that varied according to the intersubjectivity of each participant. To achieve the typical action of the subjects, the phenomenological methodology was utilized, namely: apprehension of speech to describe

the lived experience of the subjects; transcription of interviews, excluding Portuguese errors while preserving the subjectivity of the researcher-subject face-to-face relationship; careful and meticulous reading to transform what appeared subjective into objective, with the purpose of grouping the found meanings into categories; the intentionality of the lived experience of the participants, through the "reasons for" and "reasons why"^{14,9}.

Through phenomenological analysis, the "reasons for" and "reasons why" indicate that action interpreted by the subject based on their existential motives, derived from experiences inscribed in subjectivity, constitute guiding threads of action in the social world. Those related to achieving objectives, expectations, and projects are referred to as "reasons for", while those grounded as antecedents in the knowledge repository of lived experience within the biopsychosocial scope of the individual are termed "reasons why"⁹.

Thus, Figure 1 summarizes the stages of phenomenological analysis.

The study was approved by the Research Ethics Committee of the Universidade Federal do Espírito Santo, with opinion number 5,594,220. Participants signed the Informed Consent Form. To preserve the identity of the participants, the abbreviation C (caregiver), followed by a sequential number, was used. For example: (C1, C2... and so on).

DATA AVAILABILITY

All the dataset supporting the findings of this study are available upon request to the corresponding author, Adriana Nunes Moraes Partelli.

RESULTS AND DISCUSSION

Of the 16 caregivers interviewed, 15 (93.75%) were female, and the majority were aged over 61 years, indicating older adults caring for older adults. Most caregivers (43.75%) were married, had incomplete elementary education (56.25%), and 56.25% identified as evangelical. Table 1 provides information on the identification of caregivers' profiles.

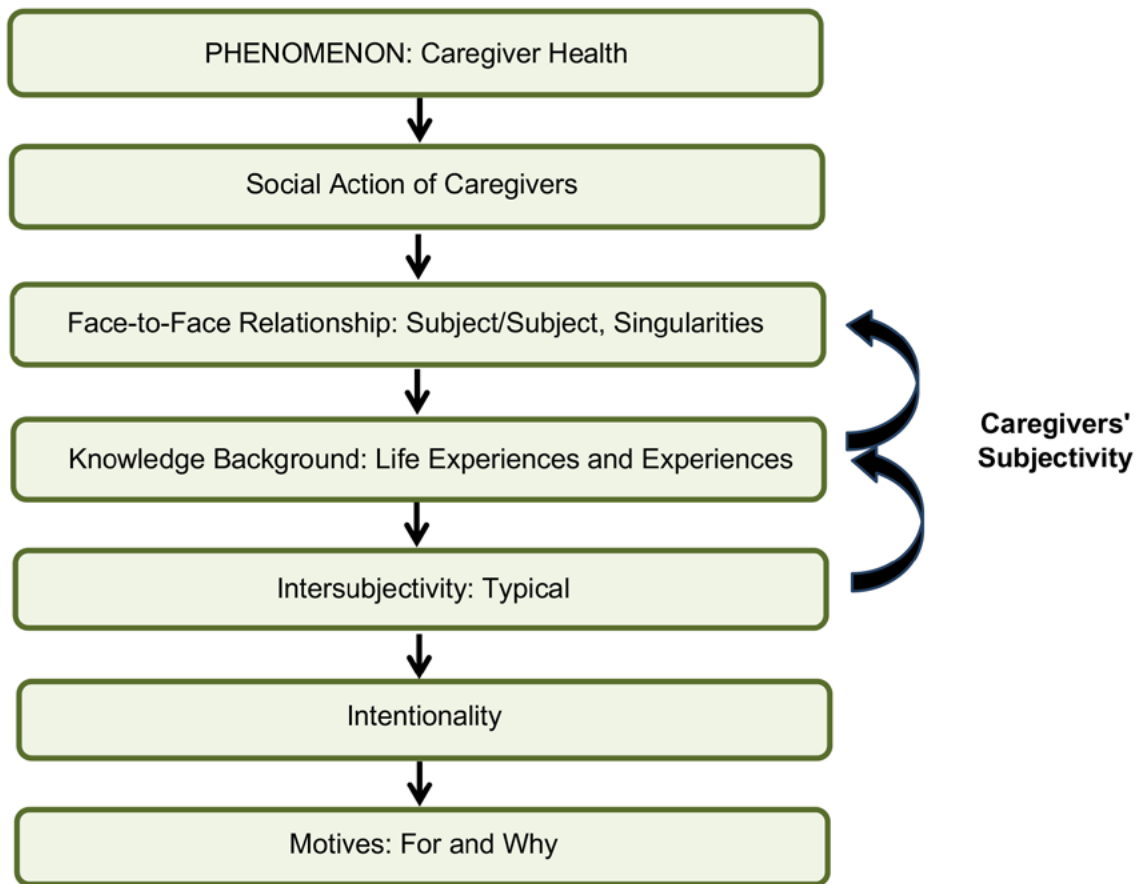


Figure 1. Phenomenological analysis. São Mateus, ES, 2022.

Source: Authors, 2022.

Table 1. Profile and Information on the Role of Caregivers for Bedridden Older Adults (N=16). São Mateus, ES, 2022.

Variable	Absolute Frequency (N=16)	Relative Frequency (%)
Sex		
Female	15	93.75%
Male	1	6.25%
Age		
23 to 30 years	1	6.25%
31 to 40 years	5	31.25%
41 to 50 years	2	12.5%
51 to 60 years	2	12.5%
Above 61 years	6	37.5%
Marital Status		
Married	7	43.75%
Single	5	31.25%
Divorced	3	18.75%
Widowed	1	6.25%
Education		
Illiterate	1	6.25%
Incomplete elementary education	9	56.25%
Complete high school	3	18.75%
Incomplete high school	2	12.5%
Complete higher education	1	6.25%
Religion		
Catholic	7	43.75%
Evangelical	9	56.25%
Degree of Kinship		
Wife	2	12.5%
Daughter	9	56.25%
Granddaughter	3	18.75%
Friend	1	6.25%
Son-in-law	1	6.25%
Formal Employment		
Yes	0	0%
No	16	100%
Remunerated		
Yes	0	0%
No	16	100%
Received instructions or training		
Yes	1	6.25%
No	15	93.75%

Source: Research Data, 2022.

The significant participation of women in the role of caregivers was notable, as they were responsible for feeding, dressing, medicating, hygiene, providing affection, ensuring the health and well-being of the bedridden older adults. Despite cultural and social advancements regarding the role of women in society, this study reveals that the caregiving role performed by women is institutionalized and socially reproduced from childhood, being transmitted from generation to generation, perpetuating the practice of caregiving for family members where women highlight gender differences. Thus, women are responsible for household activities and the care of their family members, while men are expected to provide for the family. The caregivers interviewed also demonstrated a low level of education, which may interfere with their understanding of the care provided for the older adults¹⁰.

When questioned about the caregiver role, it was observed that 15 (93.75%) had a familial bond with the bedridden older adult, with the majority being 9 (56.25%) children. They did not have formal employment nor received compensation for their role as caregivers. When asked about training and qualification, 15 (93.75%) responded that they had never received any training to qualify them for the role.

Similar characteristics were identified in research where caregivers were mostly women, middle-aged daughters, with sons being the main sources of support for the older adults. This can be justified as a way of reciprocating the care provided by parents to their children when they were younger, and as a result, the care is provided on a non-remunerated basis¹¹.

Regarding the "Psychosocial Aspects," the research sought to understand how the caregiver felt about their daily life. Each participant was allowed to select multiple options, and it was observed that 13 (81.25%) caregivers felt depressed, anxious, irritated, and lonely.

Essentially, loneliness can be compared to a kind of mourning in which the person loses the world they knew and desired. There is an attitude of giving up on leaving the house on the part of both the caregiver and the dependent older adult, which means isolating themselves in a repetitive world with little

stimulation. The renunciation of the world of work, whether voluntary or imposed, is one of the main constraints and frustrations for these caregivers¹.

According to Schütz, the resulting categories are termed concrete and constitute objective syntheses of the different meanings of action that emerge from the experiences of the participating subjects. Therefore, after exhaustive reading of the interviews of all caregivers, an analysis based on Alfred Schütz's comprehensive phenomenology was conducted, resulting in three categories (1- Physical, emotional, and social impacts on caregiver health; 2- Need for qualification; 3- Support from the health team) and one subcategory (3.1- Lack of medical and/or nursing professionals).

Category 1 - Physical, Emotional, and Social Impacts on Caregiver Health

In this category, we sought to identify the impacts on the caregiver's life. It was perceived that even amidst expressions of affection towards the older adult being cared for, caregivers revealed exhaustion, feeling overwhelmed, corroborating with some authors who assert that caregiving involves factors that go far beyond affection and love. Becoming a caregiver for an older adult involves meeting needs, whether functional or cognitive¹²⁻¹⁴.

A large portion of the participants stated that their health changed after becoming caregivers. They began experiencing health problems, needing medications, feeling stressed, anxious, and neglecting their own health due to lack of time. The participants' statements corroborate with studies revealing that various diseases that arise with aging can lead to disabilities, and this process of continuous caregiving generates chronic stress, which can affect the physical and mental health of the caregiver to varying degrees^{10,13,15-17}.

"Everything got messed up, my blood pressure is always high, I have constant headaches, I take medication to sleep. Before, I had more free time, I didn't have this burden, now I don't even take care of my health, I don't have time for that anymore my daughter... (tears)." (C9)

"My health used to be good before, but not anymore. I take a lot of medication now, I take 13 different medications. Before I started caring for older person, I didn't take so much medication." (C8)

Another point revealed in the research was the caregiver's restriction at home because the bedridden older adult often cannot be left alone, requiring constant presence of someone by their side. It was also observed that the caregiver feels lonely, and even the healthcare professional during the home visit for the older adult does not inquire about the caregiver's health, highlighting the caregiver's invisibility to healthcare professionals in that locality.

"Today I have depression, anxiety, I don't eat properly. Before, I could take better care of myself, but now I can't anymore, I can't because I live locked up here, I don't open the gate for anything." (C4)

"Caring alone, it feels like I'm forgotten, like nobody remembers me... (tears). When a physician or nurse comes here, it feels like I'm a ghost, nobody asks me how I am, it seems like only my father feels pain. I'm tired, sometimes I feel like dying." (C10)

Studies affirm that most of the time, caregivers of bedridden older adults perform their caregiving role in isolation, where they and the older adult remain confined to the home environment, reducing their leisure and relaxation time, thus contributing to increased distress and stress. Family members and friends are usually present at the beginning of the process, but over time, they tend to drift away, leaving the caregiver feeling alone^{13,16-19}.

The daily activities alongside the older adult encompass various dimensions, depending on the degree of dependency and functional and cognitive limitations of the older adult, bringing emotional, physical, economic, and social difficulties to the caregiver. Therefore, the assistance and support of healthcare professionals from the family health team for both the older adult and the caregiver are necessary. The team feels unprepared for home care, particularly regarding the deficiency of specific human and material resources outside the reference

unit. Thus, nursing and other professionals need support from managers regarding the availability, especially of material resources, to improve the assistance required by the caregiver population²⁰.

It was revealed that despite the impacts caused by the burden, there is satisfaction in caregiving.

"The love I have for him and that he has for me. He raised me, educated me, I'm just doing my duty." (C6)

Despite the stressful situation and the physical and mental efforts involved in caregiving, the caregiver feels pleasure when they can perceive positive outcomes. These outcomes are considered as an opportunity to reciprocate the care they received from the older adult they are caring for^{17,21,22}.

In this perspective, the past relationships between mothers/fathers and daughters, regardless of how they occurred, have generated emotional bonds over the years, and the caregiving category encompasses all these ways of being, allowing for the strengthening of bonds. Alfred Schütz's Sociological Phenomenology is based on experiencing the experience, valuing the unique experience that only the subject of the action can express what they intend to feel in carrying it out, and every intentional action has meaning^{4,23-25}.

In this category, "reasons why" were perceived in the statements when caregivers revealed the past actively lived with more health and disposition, before being in the position of caregiving, recalling the coexistence and love of the older adult towards them.

Category 2- Need for Qualification

Several caregivers affirmed not having the qualification to offer more effective care to the older adult, bringing dissatisfaction and challenges. Through the reports, one can notice the stress that this lack of qualification brings into the caregiver's life.

"Look, I don't know if I'm doing the right thing because my knowledge is very limited, so some training would perhaps give me more confidence." (C4)

"It would help a lot; today I can take care of him better because I did a nursing technician course, but back when it was my mom, I had nothing, I learned everything by myself, the healthcare team never helped me." (C10)

Research indicates that a lack of knowledge about caregiving is one of the main difficulties faced by caregivers and that a well-informed caregiver appears to be more skilled, with less chance of developing anxiety and depression^{13,18,22,25}. The "Practical Caregiver Guide" asserts that the distribution of information assists and prepares the caregiver in their daily life and in the changes that each disease may bring. People who have information are better prepared to manage the situation they are in¹⁷.

It was also noted that caregivers believe that training and qualification should be provided by healthcare professionals, which does not happen, leading to dissatisfaction with the team and the Basic Health Unit (BHU). One participant initially expressed disbelief about the possibility of training, while also expressing interest in participating.

"Training? (laughs) Do you really think so? It's hard enough to get the physician to come here, let alone training... but if it were true, it would help a lot. Dealing with this illness isn't for just anyone." (C13)

Studies assert that a qualified caregiver has more autonomy and skill in caring for the older adult, as there are several activities that require training, such as bed baths, wound care, enteral feeding, among others, which would generate less burden if done correctly^{17,18,26-29}. Public policies provide guidance and biopsychosocial support for self-care actions, improvement of quality of life and well-being; ongoing training, improvement, and monitoring for the caregiver⁵.

In most of the statements, projects and plans were observed in subjectivity, as some participants reported that they would feel more secure in caregiving, or that they would learn to empty and handle the indwelling urinary catheter bag if they received training. Therefore, we have the "reasons for," as they refer to the future, bringing caregivers

the feeling that through qualification, they could provide better care to the older adult.

Category 3- Support from the healthcare team

Caregivers of older adults stated that they received home visits from the Community Health Agents (CHA), who alerted them to the need for exams and vaccination. However, they stated that the Medical and Nursing professionals did not make home visits due to a lack of transportation for this purpose.

"Yes! The agent always reminds me about preventive exams, vaccinations, those things." (C7)

"The agent always comes, it's just that there's no car for the nurse and physician, but thank God the agent is good." (C14)

Studies indicate that caregivers are exposed daily to various situations and factors that demand physical, emotional, financial, and/or psychological efforts²⁹⁻³¹. In this perspective, one of the questions was to understand whether this support from the team makes a difference regarding the caregiver's daily care and the needs they may have.

Subcategory 3.1 - Absence of the medical professional and/or nurse

Participants expressed a negative perception regarding the lack of medical/nursing care, with some caregivers reporting not receiving medical and nursing care for over 2 years due to the absence of professionals at the primary care unit.

"Medical care, because sometimes it's available and sometimes it's not, then we feel underserved." (C2)

"I don't feel supported because there's no physician, only the health agent who always comes." (C6)

Another factor elucidated by caregivers, linked to their non-adherence to the BHU for their own health care, is the lack of someone to care for the bedridden older adult in their absence, as they have no assistance from others for the role they fulfill.

"I stay alone because my children work, so how can I burden them when they are raising their own children and working."

"Well, I feel it because I'm alone, I have no help at all. I have 6 siblings, but they don't help with anything, not even to buy food, let alone stay here so I can go to the physician."

The caregivers also stated that the health of the bedridden older person is a priority and that healthcare professionals could extend consultations to include the caregiver, who has limitations in traveling to healthcare services.

"I know that his health is more important right now; at least I can go out if I want to, but he can't, poor thing." (C6)

"If the physician could come to the house and consult me too, that would be very good. I can't even compare myself to her; in fact, just taking care of her is good enough." (C13)

Studies show that most caregivers do not seek healthcare services for their own health, citing a lack of time for appointments and assuming that the dependent's health is more important, prioritizing it over their own^{23,24}.

Experiences of overload, stress, loneliness, depressive symptoms, and compromised physical health are common in this scenario. According to recent research, these feelings are understandable, considering that many caregivers do not receive help from others in caregiving tasks, have less time for themselves, and may become socially isolated. It is known that any activity requires planning, as caregivers need to reorganize their routines to find someone to stay with the dependent during their absence, and this is not always possible^{9,22,32-35}.

However, an interesting factor is that the family caregiver is usually a user of the same BHU as the older person. Studies indicate that they are not addressed during home visits as users of the unit, with their own problems or complaints, but rather as informants about the health conditions of the dependent older adult^{9,12,23,32-35}.

One can perceive in the statements the intersubjectivity, an experience in the typical lived experience of each caregiver, when questioned about the perspective of improvement, they agree and express the same feeling, even though they have different experiences.

"I think that instead of me going out to see the physician, on the day the physician comes to consult my mother, they consult me too, I really want that." (C4)

"That they have a more sensitive look towards caregivers... The simple fact of the physician or nurse coming and consulting both my mother and me would already help me a lot." (C11)

One can perceive the feeling of abandonment when they express the sentiment of being "left aside".

"No, because when they come here, they just take a look at the older person I care for and then leave." (C9)

"That they see me (laughs), I'm invisible to them. It takes a while for them to come here, and when they do, they don't even pay attention to me." (C10)

In this category and subcategory, both "for" and "why" reasons prevailed. Caregivers expressed different feelings, where some referred to the past when they expressed a feeling of abandonment by stating that they feel invisible to the health team, expressing a feeling they have already experienced. Other caregivers referred their statements to the future when they said that if the physician consulted them, it would help a lot.

One of the main concepts widely discussed by Alfred Schütz is subjectivity and intersubjectivity, which understands that the world is not closed but shared and interpreted at all times by others alike, who, while acting, are also affected by these, leading to the perception of this mutual relationship^{5,6,25}.

The study had limitations due to being conducted with caregivers of older individuals registered in a single primary health care service, thus precluding the generalization of the data. Additionally, the presence of the CHA, at the request of the caregivers,

during two interviews is noted, which may have influenced the participants' responses.

CONCLUSION

By giving voice to caregivers of older individuals, it was identified that they lack support from the multiprofessional team, except for the CHA, thus bringing a negative perception regarding the service provided by the health team. Due to the burden and the various situations faced by caregivers, there are repercussions on their health, requiring health professionals to pay attention to these caregivers, with policies and programs of social support for families and caregivers.

It was noticed that the lack of qualification of caregivers generated overload due to not knowing how to care, thus it was found that they experienced significant changes in their daily routines, which causes physical and mental overload, leading to the need for support networks both from family and from the health team.

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The comprehensive sociological phenomenology of Alfred Schütz enabled the identification of individual understanding through their intersubjectivities, and it became evident that the lack of support from health service professionals and the state, both for guidance on caring for the bedridden older individuals and for self-care, leads to overload, stress, and illness. It was also possible to perceive the lack of support from close family members, such as siblings, highlighting the invisibility of the caregiver.

AUTHORSHIP

- Eliane S. Prates - Conception, data collection, analysis, interpretation, and writing.
- Marta P. Coelho - Conception, analysis, interpretation, writing, supervision, and approval of the final version to be published.
- Adriana N. Moraes-Partelli - Conception, analysis, interpretation, writing, supervision, and approval of the final version to be published.

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