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Perceptions of informal caregivers about motivations, needs, and benefits of care for dependent older adults

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Abstract *The informal caregiver provides non-remunerated permanent or regular care to dependent older adults. This qualitative study aimed to identify the perceptions of informal caregivers about motivations, needs, and benefits of caring for dependent older adults. It was conducted with ten Portuguese informal caregivers, based on an instrument with questions about the care provided to older adults and their perceptions about performing this role. The results revealed the following motivations for care: proximity and trust relationship, duty of care, more available family members, home proximity, lack of vacancies, high cost of shelter institutions, and older adults' desire to remain in their homes. The primary care activities for older adults are hydration, hygiene, food, therapeutic administration, companionship, emotional support, comfort, entertainment, and promoting autonomy and dignity. The needs identified by the caregivers were home, social security, and the caregiver's employer support, financial help, psychological support, and training to care for the older adults. The benefits of informal care for dependent older adults were prompt family support, physical and emotional security, affection, and companionship. This study gives voice to crucial citizens.*

Key words *Informal Caregiver, Dependent Older Adult, Care Delivery*

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Introduction

Caring for dependent older adults at home can be complex and involves multiple factors[1]. For example, the multiple tasks performed daily to support dependent people translate into intense overload levels, adversely affecting caregivers' lives, primarily their health, work, and social status, harmful to their well-being[2], which includes care, interpersonal relationships, care expectations, and the perceived self-efficacy in the care provided[3].

Providing comprehensive care to the dependent older adult-caregiver dyad demands specific care resources from the health system centered on home care, enabling access to qualified interprofessional support, health promotion, disease prevention[4,5], and emotional support and learning adequate processes[6] essential for caregivers and those cared for.

The informal caregiver's role has been widely publicized, and several studies show that this function is generally assumed chiefly by women, which corroborates Cronemberger and Sousa[7], when they state that older adult caregivers have a well-defined profile, that is, women aged 30-49 years old and older adults who care for other people. Studies also indicate that caregivers are 50 or over, physically and emotionally close to older adults, provide care in a continuous and isolated manner and do not benefit from public aid, causing distress and personal life restrictions, work overload, illness, unemployment, and weak social and emotional interaction[5,8].

Informal caregivers regularly or permanently care for other dependent people. Friends can assume informal care, but the family usually undertakes this responsibility, self-organizing or assisting in providing care[1]. As older people remain at home, family members, friends, and neighbors not economically remunerated for the care they provide increasingly assume the role of informal caregivers[9].

The relationship between the caregiver and the person cared for is mostly filial and marital[10,11], which perpetuates gender inequality and the lack of remuneration[5,8]. Despite the benefits attached to the caregiver and the person being cared for, the challenges of this role affect the quality of life of caregivers, leading to tiredness, daily physical and psychological effort, sleep deprivation, lack of leisure and time for self-care, besides the burden of additional domestic care generated by family members and older adults, where it is necessary to guarantee the quality of life of the people cared for and caregivers[7].

Several countries have created legislation to mitigate vulnerabilities related to the care process by recognizing the role of informal caregivers. For example, the United Kingdom supports caregiver counseling, registration, and training by requiring hospitals to identify family caregivers who are informed about family patient discharge plans and trained to provide care[12]. Portugal and its Autonomous Regions of the Azores and Madeira also created the Informal Caregiver Statute[13-15].

The informal caregiver is understood as the person, family member, or third party who, outside of the professional or formal scope, takes care of another person in an unpaid manner, preferably at their home, due to chronic illness, disability, dependence (total, partial, transitory, or definitive), in a situation of fragility, in need of care, or without autonomy to take care of their daily lives[13-15]. However, the informal caregiver must cumulatively satisfy the following conditions to be recognized: be over 18, without disabling diseases and physical or mental disabilities, suitable, and not remunerated to perform the caregiver activity of the person cared for[15].

Being someone cared for depends on several requirements, such as being a dependent person, child, young person, or adult who receives care and support to practice activities of daily living due to chronic illness, disability, impairment, dementia, mental illness, post-traumatic sequelae, aging, or frailty duly recognized through a medical declaration[15].

We should underscore the great difficulties that informal caregivers face, which cannot be ignored, thus requiring the implementation of exceptional support and protection measures. Furthermore, the marked aging of the population and the consequent increase in dependence levels calls for the intervention of informal caregivers. The casuistry of the elderly population worldwide has increased in older adults with progressive functional dependence[16]. This problem involves loss of autonomy and independence, limits self-care capacity, compromises quality of life, and triggers dependency relationships that interfere with the older adults' social interaction processes[17].

Given the relevance of the role of informal caregivers in the lives of families and society, the present study aims to identify the perceptions of informal caregivers about motivations, needs, and benefits of care for dependent older adults.

Methods

This qualitative, exploratory, descriptive, and phenomenological study was developed from December 2020 to January 2021 in a demographically aged Portuguese island region – Madeira Island. As human conduct cannot be perceived without referring to the purposes and meanings that individuals give to their actions[18], the methodological option selected this model because it draws on the participants' values, beliefs, and representations, identifying and explaining the essence of an event[19]. This paper is nested in a broader research that addresses a population of utmost importance in today's aging society, informal caregivers of dependent older adults, and gave rise to the publication *Perceptions of Informal Caregivers on the Daily Experience of Caring for Dependent Older Adults*[20] in a publication by New Trends in Qualitative Research, and the chapter *Stress and Coping in Portuguese Informal Caregivers*[21].

The data collection instrument included sociodemographic variables (gender, age, marital status, profession of the informal caregivers, sex, age, length of dependence, and degree of dependence of older adults). The experiences and representations narrated by the participants, which contribute to understanding and identifying the essence of the event, emerged in the answers to the following open-ended questions from the same instrument: Why did you become an informal caregiver for a dependent older adult? What care do you provide to a dependent older adult? What are the informal caregiver's needs to care for a dependent older adult? What are the benefits of "informal care" for a dependent older adult?

The older adult's functional status assessment scale was used to assess the dependence level, which allows for assessing the older adult's autonomy to perform basic activities of daily living[22].

Ten informal dependent older adult caregivers participated in the study. The non-probabilistic and purposeful sampling was built from the snowball strategy[23], which is when a key informant indicates other participants who meet the inclusion criteria. We decided to stop the survey upon reaching data saturation.

Given the constraints, health restrictions, and social distancing from the pandemic situation imposed by COVID-19 for data collection, we adopted the following procedure. We made the first social contact with a critical informant to present the study and requested to indicate other informal caregivers who could contribute to the sample composition. Then, we forwarded the purposes of the study, the informed consent form, and the surveys to 13 informal caregivers. We requested a return in a properly sealed envelope. We achieved a participation rate of 77%.

Ethical procedures were complied with, namely, the protection of participants from physical and mental harm, the right to privacy of their behavior, entirely voluntary participation, and previous information regarding the study's objectives[24].

The Oswaldo Cruz Foundation Ethics Committee approved the empirical study under Opinion No. 1.326.631. The following inclusion criteria were considered: being the primary caregiver of a dependent older adult and over 18, residing on the island of Madeira, and being available to participate in the study freely.

The data obtained were treated anonymously and confidentially, protected under Regulation (EU) 2016/679 of the European Parliament and the Council, of April 27, 2016[25], and Law No. 58/2019, of 8 August 2019[26], which guarantees its implementation under the national legal framework. The surveys were identified by the letter "Q" followed by the number of participants, for example: "Q1" to "Q10", to ensure data anonymity and confidentiality.

We adopted thematic content analysis[27] to analyze the data. This technique considers the participants' statements, whose meaning units were sorted, classified, and analyzed under hermeneutics-dialectics assumptions. Four thematic categories were extracted from the participants' narratives: reasons for taking on the role of informal caregivers for dependent older adults, care provided by the informal caregivers to the dependent older adults, needs to be identified by the informal caregivers when providing care to dependent older adults; and benefits of "informal care" for dependent older adults.

These categories were defined per the theoretical references considered and following extensive discussion and review of references to maximize agreement between coders.

Results

In the analysis of the results and regarding sociodemographic variables, we inferred that the study sample included 10 informal caregivers, most of whom had a partner (77%) and were employed (60%), in the 35-79 years variable age

range (M=53.60; SD=11.52), care providers for dependent older adults for 1-7 years (1 year = 1; 2 years = 1; 3 years = 3; 5 years = 3; 7 years = 2). Regarding older adults' dependence level (mild, moderate, severe, and total), 40% were totally dependent, 30% were moderately dependent, and another 30% were severely dependent. Older adults (9 women and one man) were aged 65-95 years (M=82.90; SD=7.68). The qualitative component that emerged from the content analysis, in an analytical and subjective narrative, sequentially exposes the four established thematic categories.

Reasons for taking on the role of informal caregivers for dependent older adults

Regarding the reasons that led informal caregivers to assume this role for dependent older adults, the representations stated highlight the degree of kinship (9 daughters and 1 wife), the closeness and trust relationship, the duty to care, the family member being more available, the proximity of the residence, cohabitation, the lack of vacancies in institutions that care for dependent older adults, the high cost of these institutions, and the desire of older adults to remain in their homes:

I took on this role because I am the daughter, and I live very close to my mother (Q1).

Because [the elderly woman] became completely dependent on others (Q6).

Because she is my mother and I have more availability [to take care of her] (Q9).

Because I am the daughter, and we have a solid and trusting relationship (Q5).

Because my mother's wish was to spend her old age in her house (Q7).

...because it was not possible to place the elderly woman in a home due to the stipulated price (Q3).

...because no institutions can accommodate people with severe pathologies and manifestations of dementia and nocturnal delirium at affordable prices (Q4).

Care provided by informal caregivers to dependent older adults

Regarding the care provided by informal caregivers to dependent older adults, we found that the participants highlighted multiple care, particularly associated with fundamental needs, such as hydration, personal hygiene, food, therapeutic administration, companionship, emotional support, comfort, overnight stay, tranquility, entertainment, home cleaning, and promoting autonomy and dignity.

I provide all possible care due to the total dependence level [of the older adult], bedridden and unable to speak, bathing, eating in bed, drinking water from a syringe, crushing all the medication. I need to serve 100% because [the older adult] doesn't help at all and is totally paralyzed (Q10).

Personal hygiene, nutrition, medication administration, companionship and reassuring the older adult when they experience nocturnal delirium (Q4).

Take care of and respect their interests [...] comply with the therapeutic regimen, promote autonomy, promote a comfortable and peaceful environment, and ensure good nutrition and hydration (Q5).

...monitoring, medical care [appointments] and others (Q6).

...emotional support (Q7).

...keeping company, staying overnight... (Q8).

Calm is the basis for good care (Q9).

Needs identified by the informal caregivers when providing care to dependent older adults

The participants listed some of the needs felt when providing care to dependent older adults, such as home support, social security, and the caregiver's employer, financial help, psychological support, relief for the caregiver, and training to care for dependent older adults adequately:

Enjoy daily home support (Q1).

Social security and employee support (Q3).

Reconciling professional activity with providing care (Q5).

Due to the dependence severity level, which requires at least one person per day to help provide permanent care, that is, day and night, it is necessary and desirable to include the older adults in an institution where they could receive dignified, adequate, and permanent care [...]. Having financial support to pay for a worker or a nurse and keep the older adults in their homes (Q4).

There needs to be psychological support. Physical and emotional fatigue is often very exhausting or sometimes unbearable (Q7).

Be physically and psychologically fit... (Q2).

Emotional and physical balance; availability... (Q8).

Staying focused is the basis [of care for dependent older adults] (Q9).

The need for periods of rest (Q5).

Receive training to develop capacity and acquire skills to provide adequate healthcare (Q5).

Benefits of "informal care" for dependent older adults

Regarding the benefits of informal care provided to dependent older adults in their homes, some allusions were found to the following aspects: speed of family member support, home support with their belongings, the safety of care for the totally dependent older adults, older adults' emotional security, family affection, and companionship.

Dependent older adults can receive direct support quicker and benefit from the help of a family member (Q1).

Keep [older adults] at home, with their resources/assets and comfort (Q5).

In this case, the care provided allows female older adults to survive. Without it, they could not survive since they are totally dependent (Q3).

Providing a balanced, reassuring, and preventative life, and avoiding loneliness [for older adults] (Q5).

By permanently accompanying him and being a close relative, there is greater affinity and dedication with the older adult (Q6).

The children are always present in my [older adult] mother's life: comfort, smile, and conversations (Q7).

[The older adult] is within the family core, with mutual affection and trust (Q4).

It is, of course, being with our [older adults and family members], and what we do out of love, I would not call them benefits, but rather companionship (Q9).

Discussion

The participants' sociodemographic characteristics support other recent studies[5-7]. This purposeful sample totally comprised informal female caregivers with a mean age of 55 years (Minimum = 35 years; Maximum = 79 years). The eminently feminine task of caring[6,28] is assumed by close family members of dependent older adults, specifically, nine daughters and one elderly wife. This task is invisible, unpaid, and affects the entire society[5,29,30].

Regarding the dependence level of older adults cared for by informal caregivers, the study revealed severe (30%) and total (40%) dependence levels, equivalent to 70% of the sample. These results corroborate data from the National Statistics Institute[31] on the demographic aging of Madeiran society, whose aging rate stands at 129.50%, with a dependency rate of 24.30%. The dependency situation is recognized through the social security system's disability verification system.

Regarding the reasons that determined taking on the role of informal caregivers for dependent older adults, the results indicate some factors inherent to older adults, such as health status and refusal of institutionalization; caregiver-linked factors, such as duty and obligation, gratitude or retribution, financial dependence, degree of kinship, gender, physical and emotional proximity, marital status, employment situation and respect for the older adults' wishes; and, family-related factors, such as family tradition and lack of another response[32].

Therefore, the present study's findings support that the main reason for remaining a caregiver is family/personal obligation[3,33]. Caregivers claim the role is favored by the firm, trusting relationship and respect for fulfilling dependent older adults' wishes. Keeping older adults at home stems from the older adults' clear will, although it often omits the State's delegation of powers to the family[30]. In this sense, families' economic and financial difficulties and providing care in substandard and unpaid fashion[5] justify home care.

The care informal caregivers provide to dependent older adults exceeds support, prevention, and disease surveillance[34]. This service is performed grounded on the dependence level and per the older adults' needs regarding hygiene, food, therapy, and companionship[3]. The study supports the previous literature and adds other reasons, namely, hydration, tranquility, entertainment, home cleaning, and promoting autonomy, which are essential to satisfying fundamental human needs and maintaining a dignified life.

The needs of informal caregivers to provide care to dependent older adults arise associated with the imposing care demands, the insufficient formal and informal responses, financial issues, and restricted personal life[32]. Participants point out the relevance of preserving physical and psychological fitness as a vehicle for availability in facing adversities related to caring for dependent older adults.

The physical and psychological strain is much more significant when caring for older adults with cognitive and behavioral changes. The greater the older adult's dependence level, the heavier the burden on caregivers. The lack of support from other family members and guidance to meet the needs of loved ones, compounded by

the lack of time for oneself, were mentioned by Cronemberger and Sousa[7] as obstacles for informal caregivers.

This study highlights the importance of increased public daily home support, supported by a professional caregiver. In this context, quality of life and the multiple challenges that affect the lives of caregivers, such as tiredness, daily physical and psychological effort, sleep deprivation, lack of leisure and time for self-care, and the burden of additional domestic care, generated by family members of older adults[7] could be mitigated.

The challenges involving care for dependent older adults and social inequalities in health increase the vulnerabilities of caregivers and older adults, primarily with total functional dependence. Thus, faced with the multiple and complex challenges of the role[6,29,35], emerging in situations of conflict, tension, physical and emotional exhaustion, changes in life plans, social isolation, and work overload[32], they also invoke the need for institutionalizing older adults in a home or, on the other hand, they point out work difficulties and request monetary support to cover the costs of a healthcare professional.

Although many of the needs of caregivers of dependent older adults could be met through monetary support and attention to their physical and psychological health, the statements report other determinants intrinsic to the caregivers, based on their availability, keeping their focus, and taking a break from care work.

Challenges experienced by informal caregivers were highlighted, and they can affect their well-being and the quality of life of dependent older adults. Specifically, the compatibility between the role of caregivers for dependent older adults and the need for training to provide care corroborates the following statement. Cronemberger and Sousa[7] purport that the need for adequate training of caregivers on fall prevention, therapeutic administration, nutrition, and hygiene of older adults are essential strategies for guidance and ongoing education for formal and informal caregivers.

Faced with elderly family members who lose their physical autonomy and cognitive, mental, emotional, and social independence[16,30], caregivers develop overload, emotional exhaustion, and lower quality of life, requiring attention, support, and training[6]. This evidence supports the reference literature when it points out the need to care for those who care for dependent older adults as an imperative that needs to be promoted[30] because, in short, caregivers' quality of life contributes to the dependent older adults' quality of life[35].

Regarding the benefits of "informal care" for dependent older adults, the study highlights improved quality of life, staying in one's own home, and a fundamental aspect for survival because informal caregivers are an essential and crucial pillar in supporting dependent older adults[3]. The family member caregiver highlights the importance of affection, comfort, and company from the family member whom the older adult trusts[36]. The testimonies presented, inherent to the family's values and humanized care for older adults[37], clearly highlight the feelings of the participants, indicating that, although the provision of care for dependent older adults remains a fundamental value, the quality of life the person being cared for and the caregiver should be assured[38].

Conclusion

The perceptions of informal caregivers highlighted in this study reveal a daily life concealed by enormous and complex challenges for which they did not feel qualified. In reality, the increasing aging of the elderly population has elevated the dependencies revealed by 70%, often neglected by the public service, leading families to assume the roles of informal caregivers, many without training, resources, and adequate competence. In this sense, we could identify weaknesses arising from the provision of care, which attach negative implications regarding caregivers' physical and psychological health, who manifest positive, beneficial, and rewarding feelings but find themselves in an ambivalence, plagued by an extensive source of negative feelings and emotions.

Thus, older adults benefit from more humanized care in their homes and, above all, in a relationship of trust and affection. On the other hand, this study also reveals the relevance of state home support, the creation of educational technologies for the care of dependent older adults, the reconciliation of professional and caregiver life, financial difficulties, the need for assistance and psychological support, and the vital element of health education, primarily for care and caring relationships with dependent older adults.

The findings emerged from a sample of female informal caregivers living in an island location and cannot be generalized or considered representative of the Portuguese population.

The study identifies situations corroborated by international references. It can be transferred

or re-evaluated in similar contexts in demographically aged countries where public health services are scarce or non-existent. However, this work has some limitations, including that the participant selection procedure was not random, which could hinder generalizing the results in the context itself. Supporting this statement is the small number of participants – all female – and the disparity regarding their respective age groups. We suggest further research on the perceptions of informal caregivers of dependent older adults with more participants and not exclusively female. A more significant number of participants residing in other geographic contexts would add information and contributions to the ongoing theoretical construction. Thus, trans-contextual studies with broader samples are required to grasp informal caregivers' perceptions about motivations, needs, and benefits of caring for dependent older adults, which will contribute to our understanding of this group. However, we recommend that future studies focus on implementing and expanding health policies often neglected in the literature on informal caregivers for dependent older adults.

In short, this study gave voice to a fundamental group, emerging in the hidden face of society, which could contribute to establishing, developing, and implementing social policies to enhance the training of informal caregivers with knowledge and resources to effectively address the provision of care to dependent older adults who are family members.

Collaborations

MRTF Capelo, RMLB Silva and AJOM Quintal participated in the conception, design, research, methodology, and data analysis and interpretation. CCP Brasil, JAF Capelo, LJM Ribeiro, RM Silva and ESF Oliveira contributed to data interpretation, critical review, and final drafting. All authors approved the manuscript's final version.

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