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ARTIGO ORIGINAL

“NOT A BED OF ROSES”: A QUALITATIVE EXPLORATION OF THE PERCEPTIONS OF INFORMAL CAREGIVERS

"ISTO NÃO É UM MAR DE ROSAS": UMA EXPLORAÇÃO QUALITATIVA SOBRE AS PERCEÇÕES DE CUIDADORES INFORMAIS

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Resumo

Objetivos: O cuidado informal acarreta tarefas e responsabilidades que podem dar origem a uma sobrecarga mental e física para o cuidador. Este estudo procurou explorar as perceções sobre a prestação de cuidados informais a pessoas idosas em [localização]. Métodos: Os dados foram recolhidos com base em trabalho de campo de inspiração etnográfica, por meio de sete entrevistas semiestruturadas com cuidadores informais, grupo focal com representantes de instituições-chave, análise documental de atas das reuniões interinstitucionais e observação direta, por um período de seis meses. A Condensação Sistemática de Texto, uma abordagem qualitativa desenvolvida por Malterud, permitiu a triangulação dos dados recolhidos e uma compreensão mais aprofundada dos tópicos em estudo. Resultados: Os cuidadores informais referem sentir-se "invisíveis" aos olhos dos organismos públicos, uma vez que consideram que as suas reais necessidades não são atendidas nas políticas atuais. A maioria dos participantes depende de serviços comunitários para lidar com complicações relacionadas com as comorbidades das pessoas idosas, não tendo sido referido nenhum apoio institucional direcionado aos cuidadores. Esta lacuna é identificada como possível motivo para uma multiplicidade de problemas de saúde física e mental. Os cuidadores mencionam ignorar continuamente a sua estabilidade mental, em prol da prestação de cuidados à pessoa idosa. Conclusão: A mitigação do impacto negativo do cuidado pode ser alcançada por meio de esforços adicionais por parte de instituições públicas e organizações do terceiro setor, para a criação e/ou melhoria da cooperação intersectorial.

PALAVRAS-CHAVE

Envelhecimento; Carga de Cuidado; Cuidador Informal; Colaboração Intersectorial; Investigação Qualitativa.

Abstract

Objectives: Informal caregiving implies inherent tasks and responsibilities that may lead to both mental and physical overload for the caregiver. This study sought to explore the perceptions of informal caregivers in [location]. Methods: Data was collected based on ethnographically inspired fieldwork, through seven semi-structured interviews with informal caregivers, a focus group with representatives of key institutions, documentary analysis of the minutes of inter-institutional meetings and direct observation, over six months. Systematic Text Condensation, a qualitative approach developed by Malterud, made it possible to triangulate the data collected and gain a deeper understanding of the topics under study. Results: Informal caregivers say they feel ‘invisible’ in the eyes of public bodies, as they feel that their real needs are not addressed in current policies. Most participants rely on community services to deal with complications related to the elderly's comorbidities, and no institutional support for caregiving was mentioned. This gap is identified as a possible reason for a multiplicity of physical and mental health problems. Caregivers mention continually ignoring their mental stability in favour of caring for the elderly. Conclusion: Mitigating the negative impact of caregiving can only be achieved through the development of additional efforts by public institutions and third-sector organisations to create or improve intersectoral cooperation.

KEYWORDS

Ageing; caregiver burden; caregivers; intersectoral collaboration; qualitative research.

1 Introdução

Ageing is a human phenomenon seen worldwide given that currently, 830 million people are aged 65 and older (Nações Unidas, 2024). By 2030, it’s expected that one in every six persons in the world will be 60 or older and by 2050, the global population of those aged 60 and above will double, reaching 2.1 billion. (Organização Mundial da Saúde, 2024). Social and economic modernisation, the improvement of jobs, working and living conditions, and the advances in medical care have contributed to an increase in life expectancy (Estevens, 2017; Kirkwood, 2017; Brown, 2015). However, this growth is not equally visible worldwide due to inequalities driven by factors such as disease burden, health behaviours, (Arora et al., 2016) and disparities in social and economic development (MEDICI, 2021).

Additionally, ageing is a multidimensional and complex construct (Rivadeneira et al. 2021), underpinned by social and biological processes which result in changes in physical abilities, social activities, and status (Cox et al., 2014). Ageing leads to a reduction in physiological resources, an increased risk for various diseases, and a general decline in abilities over time (Organização Mundial da Saúde, 2015; Zhang et al., 2020). It can be characterised by a high prevalence of physical limitations, cognitive losses, depressive symptoms, sensory decline, accidents, and social isolation (Ramos, 2003; Maresová et al. 2019). These changes may affect mood, environmental attitude, and social activity, influencing one's place in the family and society (DZiechciaz & Filip, 2014; Leung et al., 2021). Feelings of loss of status and anxiety, a degradation of relationships, and exclusion from participation in decision-making are, at times, a ramification of physical and psychological dependence (Schröder-butterfill & Fithry, 2014), derived from one’s inability to perform the necessary tasks to be an active member of the community (GRAF, 2008). When old age is accompanied by physical restrictions, chronic diseases, and loss of cognitive and social skills, a change in the routine and the reorganisation of the environment are necessary to make up for these conditions (de Brito et al., 2022).

If in the past, age was closely related to the notion of experience and knowledge, and older people had social recognition, respect, and power (Gonçalves, 2006), currently, a society marked by a culture of stereotypes that mostly values the symbols of youth prevails (Alves & Novo, 2006), leading to the devaluation and marginalisation of older people (Campante, 2021). Although the process of ageing is a significant civilisational achievement (Haverland & Marier, 2008) as a direct result of the population's quality of life and longevity (GBD, 2019; Ageing Collaborators, 2022), it also raises challenges that demand significant efforts, for which existing resources quickly become insufficient, resulting in an overload in primary health care (Martins, 2006). Furthermore, changes in priorities become apparent, posing unique challenges for policymakers, and service providers (Etters et al., 2008).

Residential structures rise to meet the needs of older adults (Guedes, 2007), even though they may express fear and aversion to institutional care, manifesting feelings of loneliness, loss of individuality, idleness, and inactivity (Vaz & Gaspar, 2011). In this context, care provided by family members, friends, or other informal caregivers tends to represent a significant part of care provision (Kluzer et al., 2010).

Caregiving can be defined as ‘activities and experiences involved in providing help and assistance to relatives who are unable to provide help for themselves’ (Etters et al., 2008). In some cultural settings, it is regarded as a family duty whose non-compliance carries negative consequences (Lavoie & Membrado, 2014; Stein et al., 1998). The pressing need to care for older people may be associated with a feeling of obligation (Serrano-gemes & Serrano-del-rosal, 2024), rising from a need to compensate for the effort that older people employed in the life of the caregiver (Lavoie & Membrado, 2014). As it can be challenging to assign caregiving responsibilities to people outside of the family to preserve self-respect and dignity (Lavoie & Membrado, 2014; Mallon, 2009), families end up caring for older relatives due to filial responsibilities, societal or generational obligations (Apesoa-verano et al., 2015; Luichies et al., 2019).

Understanding how informal caregivers interpret the effects of the care they provide is critical (Martin et al., 2021). Some may give up their jobs and hobbies, as well as deeply focus on the needs of the person they are caring for, putting themselves at risk of poverty and social exclusion (Comissão Econômica Das Nações Unidas Para A Europa, 2019). Caregivers frequently imagine themselves as full-time providers of physical, affective/emotional, and social support through the provision of safety, comfort, and care (Lavoie & Membrado, 2014). Unfortunately, caregivers' quality of life, self-esteem, and self-care suffer as a result, leaving them vulnerable to overload, low life satisfaction, isolation, depression, burnout, lack of concern for their health, and changes in their professional and family lives (de Brito et al., 2022; Teixeira et al., 2020; dos Santos et al., 2022). To lessen the negative effects of caregiving, public and social policies that make social support networks accessible to older people and informal caregivers have been developed (Verbakel et al., 2017). These social networks, together with close relationships with friends and relatives, the social role that older people play in society, and both real and perceived health status, are important factors that affect how older adults assess their quality of life (Campante, 2021).

In Portugal, as of 2024, there are approximately 3 million people aged over 65 years, with the ageing index registering an increase of 56.7% between 2012 and 2023 (Instituto Nacional De Estatística, 2024). Portugal is the second European country with the highest percentage of older people (24.1%), and the third European country with the highest dependency ratio, counting 38.2 older adults per 100 people of working age (Eurostat, 2025). The country’s ageing population has led to growing research on informal caregiving and its associated burden. Studies indicate that caregiving often reduces social contact and free time, contributing to the deterioration of caregivers' physical and emotional health (de Carvalho et al., 2021; Teixeira et al., 2020). This decline is exacerbated by the misalignment between social and health sectors, particularly when caregivers require additional support. Beyond systemic constraints, some caregivers also report a general lack of knowledge on accessing necessary services (Barbosa et al., 2020; Teixeira et al., 2020).

The current study proposes to explore the experiences and perceptions of informal caregivers in [location], expanding on previous studies that identified the need to further analyse informal caregiving so that adequate support systems can be developed (Barbosa et al., 2020; Pimenta et al, 2009). Thus, the current study aims to: characterise the reality of informal caregivers and older adults; explore the implications and perspectives of the caregivers on their burden; analyse the perceived needs of the caregivers in terms of training, psychosocial condition, health, and work; and explore the local context in which support is provided by non-governmental organisations.

2 Método

This exploratory study was anchored in an ethnographic-inspired approach, using multiple data collection tools to ensure a comprehensive and holistic perspective that could respond to the study's objectives. Data was gathered through semi-structured interviews with informal caregivers, one focus group with institutional representatives, direct observation in the participants' natural life context, and documentary analysis of interinstitutional meeting minutes.

This methodological approach allowed the researchers to familiarize themselves with the contextual dimensions of the study settings, capturing both the existing dynamics in the field and how these changed during the observation period (Whitehead, 2015). This approach enabled us to obtain a systemic understanding of the processes, systems, and meanings relevant to the participants (Whitehead, 2015). Ethical approval was obtained from the institutional ethics committee and informed consent was obtained from all participants.

Thirty-five third-sector organizations, universities, and other institutions were contacted to facilitate the recruitment of informal caregivers assisting people aged 65 and older with, at least, moderate dependence, as assessed by the Lawton-Brody Index (Sequeira, 2007). This index evaluates functional independence in instrumental activities of daily living, including telephone use, shopping, meal preparation, housework, laundry, transportation, medication management, and financial autonomy. The index varies between eight and thirty points according to the following cut-offs: eight points - independent; nine to twenty points - moderately dependent; more than twenty points - severely dependent (Sequeira, 2007).

In the first phase, twelve caregivers were approached for participation, with seven agreeing to act as key informants. Interviews were primarily conducted at the caregiver's house, while some took place via telephone due to fear of exposure to COVID-19 from in-person interactions. The interviews lasted approximately 60 minutes. The semi-structured interview guide was developed in Portuguese, based on the Handicap Santé (2009a, 2009b), supplemented with discussions with relevant stakeholders. The interview script comprised open-ended and closed questions exploring five intrinsic dimensions of caregiving: (1) conditions of informal caregiving; (2) relationship with the older adult; (3) daily life; (4) experiences as an informal caregiver; and, lastly, (5) social and healthcare of the older adult. The guide was developed by three researchers and reviewed by a senior psychologist and a senior social worker to ensure that all relevant topics were included, as well as social and cultural appropriateness.

Thirteen key informants who work directly with the informal caregivers were invited to participate, and seven accepted the invitation. This diverse group, composed of professionals from different sectors, was selected to provide a multifaceted perspective on caregiving. Five participants attended the virtual focus group session, which lasted approximately 90 minutes. The discussion followed a structured guide developed to explore the experiential knowledge of professionals who interact with caregivers, helping to contextualize and enrich the findings from semi-structured interviews.

To complement data from the interviews and the focus group, we conducted direct observation of the participants and relevant stakeholders in their natural context of life, systematically documented in field journals. An observational guide oriented the observation according to two main dimensions: (1) spatial and contextual elements, including observation of perceived needs and caregiving demands; and (2) interactions between caregivers and older adults, emphasizing verbal and nonverbal interactions. This exercise was limited by the COVID-19 pandemic. Most of our interactions with informal caregivers occurred over the phone due to concerns that the research team might introduce the infection into their households. At the institutional level, public policies restricted the entry of external individuals and required a negative COVID-19 test within the past 48 hours. These measures made it impossible to conduct direct observations with all partners, requiring some conversations to take place via online meeting platforms.

This last aspect was included to further contextualize the reality of caregiving within the study setting, primarily from an institutional perspective. We prioritized networking, leveraging the resources of twenty-seven local institutions in various ways to achieve different objectives. To gain a preliminary understanding of the situation, we engaged with services and institutions in the area, identifying key stakeholders essential due to their work with the target population and their accessibility. Meetings with institutions and services supporting informal caregivers were instrumental in indirectly characterizing the population, allowing for continuous adaptation of the data throughout the project. Regarding inter-institutional collaboration, there was a notable disparity in participation between formal and informal institutions, as the latter demonstrated greater willingness and availability to engage and collaborate in this study. This contrast may be attributed to the heavy workload of professionals in formal institutions, exacerbated by the challenges posed by the COVID-19 pandemic.

Data consisted of meeting minutes and other relevant records obtained from interinstitutional meetings with key informants (e.g., social workers, healthcare professionals, and community representatives). These documents provided insight into the existing support systems and interventions available to caregivers.

The analysis followed Systematic Text Condensation (STC), a qualitative analytical framework developed by Malterud (2012) that allows for thematic cross-case synthesis of qualitative data. This approach is particularly suited for exploratory studies, as it ensures methodological rigour while maintaining flexibility in uncovering patterns across diverse data sources. The STC approach was implemented in four distinct steps: (1) gaining an overall impression of the data by reading through the material to identify preliminary themes; (2) decontextualizing the data by identifying meaning units relevant to the research questions and coding them into thematic groups; (3) systematically condensing and synthesizing meaning units into a narrative that preserves participants' original expressions; and (4) recontextualizing the findings by developing comprehensive thematic descriptions that integrate data across different collection methods.

To ensure robust triangulation, data from interviews, focus groups, field journals, and documentary sources were systematically compared and integrated within the STC framework. The final thematic synthesis was validated through iterative discussions within the research team, ensuring that the findings accurately reflected participants' experiences and contextual realities. Additionally, an auxiliary quantitative analysis was conducted using SPSS Statistics 28.0.1 to complement the qualitative insights.

3 Resultados

All seven participants are female (100%), with ages ranging between 50 and 79 years old (most falling within the range of 60-69 years old). Most caregivers only have basic education (72%) and are married (57%). Only one caregiver reported being employed, albeit in a precarious situation as an independent worker. The rest mentioned being retired (43%) or being in a situation of long-term unemployment (43%). Most caregivers reported that, at a certain point in their professional lives, they had to make adaptations and/or changes to their work as a result of caregiving. Three caregivers referred to taking care of more than one person (i.e., monitoring medical appointments, helping with medication, providing moral and instrumental support in daily life, participation in household chores, administrative support and decision-making, night and/or day surveillance, and financial support).

The main themes that emerged from the STC analysis include caregiver characterization, conditions of the older person, dimensions of caregiving, constraints derived from caregiving, and links with social and healthcare services. Each theme is presented with supporting synthesized narratives enriched by quotations, which were translated while preserving their original meaning.

Caregivers reported that care is provided on a full-time basis, 365 days a year. There appears to be a very close relationship between the older adult and the caregiver, which is closely linked to the latter's responsibility to provide the best possible care to the former. The analysis revealed that this close relationship influences the caregiver's perception of the importance of caregiving, resulting in a sense of 'obligation' towards care, with caregivers unable to seek external help, overloading their daily lives with tasks inherent in caregiving.

> "I don't even want anyone in there. I don't. Even she doesn't want anyone there." (Interview, Female, 53 years old)

The relationships are mostly defined as very good or good. It should be noted that one of the most important factors (seemingly with the greatest impact) is described as being the moral support and physical presence/companionship that the caregiver provides. Only one caregiver reported having a difficult relationship, in this case, with her husband.

> “She doesn't do anything without seeing me. [...] As I'm attached to her, she's attached to me.’ (Interview, Female, 63 years old)

> “She doesn't do anything without seeing me. [...] As I'm attached to her, she's attached to me.” (Interview, Female, 63 years old)

Caregivers reported feeling recognized and valued for their work, though at times some mentioned a feeling of generational obligation of care towards the older adult.

> “It's a mother-daughter relationship. She raised me and now... I pretend I'm raising her too” (Interview, Female, 63 years old)

This was one of the major constraints identified by the professionals, as there is a need to change the paradigm of caregiving as ‘an extension of family responsibilities’, allowing, in the long term, for these caregivers to seek additional support. This change is advocated as essential for an improvement in their condition and involves a double effort on disseminating the role of the caregiver, the services available, and their rights.

Most caregivers didn’t identify specific or immediate needs other than greater instrumental support, especially if the health condition of the older adult worsens. This was further justified by the caregivers, who refused to participate because they did not recognize any immediate change that would lead to an improvement, either in living conditions or in caregiving. The professionals also mentioned the need to improve current services and, consequently, the quality of care, as well as to develop more adaptive strategies focused on the real needs of caregivers rather than the perceived ones.

Despite the caregivers' extreme exhaustion, the obligation and personal responsibility—as they perceived it—appear to be connected to the rejection of third parties’ support. Though there are some external factors involved, most of the care is the caregiver's responsibility. Moreover, in some cases, no family backup was mentioned, either for the older adult (neglected by the family and left to the care of others, with no family connection) or for the caregiver (who must balance the time dedicated to family and caregiving, culminating in an overload).

> “But there's not a phone call, there's not a visit to find out if their dad’s okay, if their mom's okay. There's nothing. Nothing.” (Interview, Female, 73 years old)

It was also found that the feeling of shame about the need to ask for support influences the search for essential services. On this note, professionals identified two main reasons that seem to influence the search for support by caregivers: (1) lack of knowledge about the existence of these services; and (2) constraints in terms of financial resources. Regarding this last point, some participants argue that there are cultural factors related to financial management which translate into an added difficulty in seeking and paying for possibly vital services.

Regarding the degree of (in)dependence, the composite results Lawton-Brody Index show that all older adults from this study are severely dependent, needing all the help that can be provided, similar to the results reported by de Carvalho et al. (2021). Their health is mostly characterised by comorbidities that require continuous attention and care. Although there is, in some cases, some degree of autonomy, it is conditional and confined to specific tasks, resulting in a generalised dependence on the caregivers.

> “He already had surgery on his right ear…but the thing is, he never got well again! He hears very badly and... and that's it. And then there's the heart.... Look, he just doesn’t have any issues in the lungs and liver.” (Interview, Female, 73 years old)

The caregivers mentioned having general and sufficient knowledge of the health condition of the older adult, being able to guarantee the necessary care in daily life, and admitting the possibility of, in critical situations, doubt or lack of knowledge, resorting to specialized healthcare services.

However, when asked about their involvement in training sessions on healthcare and caregiving, they mentioned that they had never participated, though some were open to participating in the future as long as some focal points were ensured, as they were determinants of their participation. This issue was further reinforced by the professionals, as they also identified training as an immediate need, though it would be crucial: (i) to ascertain the caregivers' availability to participate; (ii) to ensure care during the training period, and (iii) to involve services in the active search for solutions.

> “It's essential to have several different sessions, due to distances. [...] Then, have different modules because, if we're going to mix everything up... Everybody gets confused! If it’s to give a bath, it’s a module on how to give a bath. If it's to heal a wound, it’s to heal a wound. If it’s to make lunch, it’s to make lunch.” (Interview, Female, 60 years old)

Due to the severe dependency of the older people in this sample, caregiving is provided in several categories, ranging from administrative tasks to more instrumental tasks. The degree of support differs according to their psychophysiological condition. Older people with no cognitive impairments require less assistance in making decisions (medical or otherwise) as well as less support from caregivers. When they are physically capable, the caregiver has only the role of supervision. Even though some of the older people maintain some degree of autonomy, sometimes it seems necessary to pay extra attention. Older people, with deep physical problems, need immense help in carrying out simple tasks.

> “For dressing, he doesn’t [need any help]. But, at times, one has to fix it. He puts on some clothes, but one has to, for instance, press the shirt button. (...) Nothing that serious.” (Interview, Female, 66 years old)

On the other hand, those who experience cognitive loss end up transferring the responsibility of decision-making to the caregiver, including the management of their financial resources, managing specialised healthcare (e.g., scheduling appointments, managing medication), managing household chores, helping with hygiene and food preparation (and in some cases, with eating). These tasks, when accumulated, present themselves as a burden with a major impact on the caregivers, restricting, in many cases, their daily lives, which is only mitigated by domestic support provided by local organisations, which are ‘a great answer but not nearly enough.

> “I’m the one who dresses her. I’m the one who puts on her shoes. I’m the one who feeds her.” (Interview, Female, 53 years old)

All caregivers reported feeling the need to respond on their own, with few of them reporting having someone to replace them. As such, a central part of caregiving is the constant presence or companionship, which seems to promote an improvement in the mental health of older adults and is seen as indispensable to their relationship with the caregiver. When there is a need for the caregiver to be absent, the replacement is precarious, being performed by a close relative (e.g., a son or daughter, a sibling).

The impacts deriving from caregiving can be organised into three general groups: (1) health (mental and/or physical); (2) economic; and (3) daily management around caregiving, including routine disruptions.

The caregivers generally reported a decay of their physical and mental health, marked by extreme fatigue that sometimes has repercussions on their mental health, generating sleep problems, depressive and anxious symptomatology. In most cases, the difficulty in getting a restful sleep is related to the constant preoccupation with the older person, as well as the possibility of any nightly occurrence.

> “I feel very tired. At the end [of the morning], when I lie down if I could just stay a little longer (...) because I can't stand my bones. I can't even stand up by that point. I get tired of getting up, changing them, making them breakfast… I feel really, really tired. This is not a bed of roses. It's not easy” (Interview, Female, 63 years old)

Most caregivers have some health problem that hinders the provision of care. There seems to be an acceptance of their condition and a disregard for their well-being.

> “It's always the same. The same life. But then I try to turn it around, right? That's what I have to do! That and nothing else.” (Interview, Female, 63 years old)

Regarding the financial impact, results showed that caregiving entails high expenses that significantly influence the caregivers' finances. Most caregivers reported having difficulties related to a lack of financial resources to meet their expenses, to which those related to caregiving are added. Therefore, there is an added concern with conscious financial management.

> “Oh dear, the financial part. I'll be honest. With his retirement, I pay for the day centre and his and mine medication, which, unfortunately, is a lot. Then I pay for the electricity. Sometimes I have €50, €60, €70 left... it depends. I also have to pay for the water, (...) and I pay €25 for a storage unit, which is where I keep some things, to be tidy. And the rest is for food, dear. I can't afford to spend it. I never had any help (...). So, I can't stray from the path, because the money is not much. We have to always count it, and the month is quite long, right?” (Interview, Female, 73 years old)

Finally, it was found that the daily activities of a caregiver are developed around care provision and planned according to the immediate needs of the older adult. Some caregivers reported work constraints, as a result of the impossibility of being absent from caregiving. Difficulties in time management that translate into a lack of activities outside caregiving, essential for the promotion of one’s mental well-being, were also mentioned.

> “It's like this... I’m always out of time because by dedicating myself to a person like this, one doesn't have time for themselves. But I'm used to it. As long as I can, I'll continue doing it.” (Interview, Female, 63 years old)

Most caregivers reported that they have no time for themselves and feel socially isolated, reporting that caregiving has negatively affected not only their social life but also their family life. However, it is mentioned that sometimes the family itself ends up adapting to the constraints that come with caregiving.

As far as specialised services are concerned, contact with them is frequent, particularly with day centres, which are considered to be beneficial as a means to relieve the caregiver’s burden; and healthcare services are valued for their proximity.

It’s important to emphasise the caregiver’s lack of knowledge regarding the total number of available services and support that intervene in the field of caregiving. However, this seems to stem from a lack of dissemination of these services and a poor adaptation of the available information to the characteristics of the population (e.g., health literacy level), originating, in some cases, a lack of adherence to them.

The caregivers recognize the need for these services but identify some gaps, such as the lack of personalised and close monitoring by the professionals belonging to social mediation structures. Some of the caregivers claim to feel invisible, reporting a lack of understanding of their difficult reality.

> “You know, they [social workers] don't come to the field (...). because the social workers, the ones from the parish, know that this man lives alone, they know that he has no one except me, and he’s not even related to me. They never ask how he is, if he’s well, if he’s not.” (Interview, Female, 66 years old)

The perspective shared by the professionals it’s not the same as the caregivers, as they identify three central dimensions as to why caregivers’ realities are not something known and explored. First, they mentioned the "invisibility" of the population, who doesn’t seek the support of these professionals recurrently, requesting support only in disruptive moments, to respond to more immediate needs. Secondly, the characteristics of social work, which articulate the needs of the caregivers with the services in the territory to provide answers to these immediate needs, and not on a continuous approach. Lastly, the lack of information sharing by the specialised services weakens the general knowledge of the caregivers’ realities and, consequently, prevents an adaptation of services.

> “Regarding caregivers, they are almost invisible. We don't see them, as they are not on the street with a sign saying ‘I am a caregiver.’ And that is a huge problem.” (Focus Group, Parish Council Board Member responsible for Social Action)

These professionals recognized the value of personal and intimate relationships with this population, stating that part of the caregivers' openness with them derives from continuous and close case monitoring.

> “Because the personal, professional - personal relationship with people is very important and it has to do, really with the long haul, especially for those who have worked for many years, which is my case (...) it is natural that I know people and with me they say, they do.” (Focus Group, Social Worker).

4 Discussão

The ageing process entails physical and cognitive transformations that influence daily life and may lead to various degrees of dependence, which appear to be covered by informal caregivers (Pereira and Duque, 2017; Campante, 2021). Through its ethnographically-inspired approach, this study substantiates the experiences and perceptions of informal caregivers in the [location], by offering a holistic understanding of the caregiving burden, the support systems in place, and the needs of the caregivers. The findings reinforce the literature on the multidimensional nature of informal caregiving, highlighting the social, emotional, and economic constraints caregivers face.

One of the key findings highlights the sense of obligation among caregivers, where they feel an intergenerational obligation to take care of the ones who took care of themselves as they grew up, often deriving from cultural norms and personal responsibilities. This aligns with previous research, which suggests that caregiving is frequently viewed as an extension of family duties (Martins, 2006; Luichies et al., 2019), and a role mostly played by women (Pereira e Duque, 2017). In many cultures, caregiving is not only an expectation but also a deeply ingrained tradition, often passed down through generations. Caregivers often perceive their role as a moral responsibility rather than a choice, which can lead to emotional distress when they feel they are not meeting perceived obligations (Serrano-gemes e Serrano-del-rosal, 2024).

The results also confirm the presence of caregiver burden, which manifests in physical exhaustion, emotional distress, and financial strain, as documented in prior studies (Teixeira et al., 2020; dos Santos et al., 2022). Caregivers report experiencing extreme fatigue due to the continuous and demanding nature of caregiving responsibilities, leading to deteriorating physical health and emotional well-being, as caregivers often neglect their own health needs while prioritizing those of the older adult (Verbakel et al., 2017).

The study further reveals a significant gap between caregivers and available support services. While caregivers acknowledge the existence of services such as day centres, many express a lack of awareness or difficulty accessing these resources. This echoes previous research (Barbosa et al., 2020), which suggests that the dissemination of information regarding available support structures remains insufficient. The reluctance of caregivers to seek external help due to feelings of shame or obligation highlights a major barrier to improving their quality of life (Martin et al., 2021), as some caregivers expressed a strong desire to maintain autonomy in caregiving, even in personal hardship.

Despite their willingness to improve caregiving skills, most of our caregivers have not received formal training on essential caregiving tasks such as administering medication, personal hygiene, and financial management. The participants reported that the lack of training contributes to increased anxiety and uncertainty regarding their ability to provide adequate care. Prior research (de Brito et al., 2022), has advocated for structured training programs to equip caregivers with the necessary skills to provide better care while mitigating personal stress. Addressing this gap through structured educational initiatives could significantly enhance caregivers' confidence and efficiency.

Financial constraints were another prevalent issue identified in the study. Many caregivers reported struggling with the financial burden of caregiving, which includes medical expenses, household costs, and sometimes lost income due to the inability to maintain employment. This financial stress further compounds the emotional and psychological burden experienced by caregivers, leading to higher levels of distress and burnout, often resulting in economic strain, particularly for individuals who reduce their working hours or leave the workforce entirely to provide care (de Carvalho et al., 2021).

Social isolation emerged as another critical theme, with caregivers reporting that their responsibilities limit their ability to engage in social activities or maintain relationships outside of caregiving (Pereira and Duque, 2017; dos Santos et al., 2022). The lack of social interaction exacerbates the emotional toll of caregiving, contributing to feelings of loneliness and depression. Addressing this issue requires implementing social support networks and respite care services to enable caregivers to maintain a balance between caregiving and personal well-being.

Notwithstanding the essential role informal caregivers play in sustaining healthcare and social support systems, their work remains largely uncompensated and unprotected by labour regulations. Unlike formal employment, caregiving lacks remuneration, social security contributions, and legal protections, leaving caregivers financially vulnerable and socially invisible. This aligns with broader discussions on the gendered nature of unpaid labour, as caregiving is predominantly undertaken by women (Pereira & Duque, 2017), reinforcing economic inequalities. Furthermore, existing policies often fail to provide comprehensive solutions, offering only limited financial support and recognition. Addressing this structural issue requires rethinking caregiving not just as a private, family obligation but as a societal responsibility that demands legal, financial, and institutional backing.

In the end, caregivers expressed frustration regarding the lack of personalized support and individualized attention from institutional services. While various programs and services exist, many caregivers feel that these are not sufficiently tailored to their specific needs, often offering only generalized solutions that fail to address the complexities of their daily realities. The absence of structured support exacerbates their already precarious conditions, as caregiving remains an unrecognized form of labour, lacking remuneration, defined working hours, legal protections, and access to essential benefits such as paid leave or social security contributions. The lack of societal recognition further compounds caregivers' distress, as their work—despite being physically and emotionally exhaustive—is often perceived as a natural familial duty rather than a valuable social contribution. The resulting cycle of self-reliance and burden accumulation not only compromises their well-being but also jeopardizes the sustainability of informal care as a whole, highlighting the urgent need for institutional reforms that formally acknowledge and support caregivers.

The main strength of this study lies in its methodological approach, which integrates multiple data collection techniques with participatory approaches, conducted in the natural life contexts of the participants thus, translating into grounded empirical data. The combination of semi-structured interviews, focus groups, direct observations, and documentary analysis allowed for the triangulation of data, enhancing the validity and reliability of the findings (Whitehead, 2015). The use of the Systematic Text Condensation method (Malterud, 2012) further contributed to the methodological rigour of the qualitative analysis, ensuring that themes were systematically identified and analysed across different data sources.

Another strength is its focus on an understudied population—informal caregivers, particularly those who provide long-term care to older adults with significant health needs. Though a concerted strategy was defined, recruitment did not go as expected, which resulted in a low number of caregivers being referred by local institutions. However, by examining the perspectives of both caregivers and professionals, the study provides a well-rounded understanding of the challenges and gaps in caregiving support systems. Additionally, the inclusion of documentary analysis strengthens the contextual background of the findings by offering institutional insights into caregiving realities.

Though a selected number of caregivers were interviewed for this study, their experiences cannot reflect the overall picture of informal caregiving in the country and, therefore, should not be generalised. However, the overall analysis and results are supported by previous studies, granting them a degree of feasibility, reliability, and knowledge transfer.

5 Conclusões

Informal caregiving plays an important role in Portuguese society due to the high costs of retirement homes, to which the high rate of poverty in old age can be added since pensions are about a third of the value of private residences. There’s a need for targeted interventions to support caregivers, including improved access to resources, awareness campaigns, and structured training programs. We were able to discern that the social and public response, primordially at a local level, is completely fragmented due to a lack of communication and cooperation. It’s important for these services that provide support to this population to develop a mechanism through which a better response can be provided to caregivers as a means to mitigate the burden of caregiving. Policymakers and service providers must work towards strengthening the bridge between informal caregivers and institutional support networks to alleviate caregiver burden and enhance their well-being.

Future research should expand on these findings by incorporating a larger and more diverse sample, as well as exploring the long-term impacts of caregiving on both caregivers and care recipients. We believe that a snowball strategy could be the best method for the identification of informal caregivers in a specific territory, though this chain referral process might not reach everyone, as there are caregivers that stand outside of this social network and, therefore, will not be identified through this strategy. Other studies that seek to explore the caregiving burden with wider samples or in other territories are needed as a means to understand the consistency of data and, consequently, improve the interventions and policies aimed at informal caregivers.

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