

Assessment of the Workload of Caregivers of Patients Under Palliative Care

Avaliação da Sobrecarga Laboral de Cuidadores de Pacientes Sob Cuidados Paliativos
Evaluación de la Carga de Trabajo de los Cuidadores de Pacientes en Cuidados Paliativos

RESUMO

Introdução: O envelhecimento populacional e o aumento das doenças crônicas geram desafios aos sistemas de saúde, especialmente na oferta de cuidados paliativos. Nesse cenário, cuidadores assumem papel central, muitas vezes sem preparo ou suporte adequado, resultando em sobrecarga física e emocional. **Objetivos:** Avaliar os fatores que contribuem para a sobrecarga dos cuidadores na região metropolitana de Belo Horizonte- MG, e impactos na qualidade de vida e no cuidado prestado. **Métodos:** Trata-se de uma pesquisa qualitativa, descritiva e exploratória, realizada por meio de entrevistas com sete cuidadores formais e informais. **Resultados:** Evidencia-se sobrecarga persistente, destacando a necessidade de ampliar estudos e implementar políticas públicas que garantam suporte e melhores condições aos cuidadores. **Conclusão:** Os relatos evidenciam sobrecarga física e emocional persistente, indicando a necessidade de mais estudos e políticas públicas que garantam suporte e melhores condições aos cuidadores.

DESCRIPTORES: Cuidadores; Sobrecarga do cuidador; Cuidados paliativos; Estresse Psicológico; Saúde Mental.

ABSTRACT

Introduction: Population aging and the rise in chronic diseases pose challenges to healthcare systems, especially in the provision of palliative care. In this context, caregivers assume a central role, often without adequate training or support, resulting in physical and emotional overload. **Objectives:** To evaluate the factors that contribute to caregiver overload in the metropolitan region of Belo Horizonte, Minas Gerais, and the impacts on quality of life and care provided. **Methods:** This is a qualitative, descriptive, and exploratory study, conducted through interviews with seven formal and informal caregivers. Results: There is evidence of persistent overload, highlighting the need to expand studies and implement public policies that guarantee support and better conditions for caregivers. **Conclusion:** The reports highlight persistent physical and emotional overload, indicating the need for more studies and public policies that guarantee support and better conditions for caregivers.

DESCRIPTORS: Caregivers; Caregiver burden; Palliative care; Psychological Stress; Mental Health.

RESUMEN

Introducción: El envejecimiento de la población y el aumento de las enfermedades crónicas plantean desafíos a los sistemas de salud, especialmente en la prestación de cuidados paliativos. En este contexto, los cuidadores asumen un papel fundamental, a menudo sin la preparación ni el apoyo adecuados, lo que genera una sobrecarga física y emocional. **Objetivos:** Evaluar los factores que contribuyen a la sobrecarga de los cuidadores en la región metropolitana de Belo Horizonte-MG y sus repercusiones en la calidad de vida y la atención brindada. **Objetivos:** Evaluar los factores que contribuyen a la sobrecarga de los cuidadores en la región metropolitana de Belo Horizonte, Minas Gerais, y sus repercusiones en la calidad de vida y la atención prestada. **Métodos:** Se trata de un estudio cualitativo, descriptivo y exploratorio, realizado mediante entrevistas con siete cuidadores formales e informales. **Resultados:** Existen indicios de sobrecarga persistente, lo que subraya la necesidad de ampliar los estudios e implementar políticas públicas que garanticen apoyo y mejores condiciones para los cuidadores. **Conclusión:** Los informes ponen de relieve la sobrecarga física y emocional persistente, lo que indica la necesidad de más estudios y políticas públicas que garanticen apoyo y mejores condiciones para los cuidadores.

DESCRIPTORES: Cuidadores; Carga del cuidador; Cuidados paliativos; Estrés psicológico; Salud mental.

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INTRODUCTION

Population aging has accelerated, requiring specialized care and support. According to the World Health Organization, by 2030, one in six people will be 60 years of age or older, as noted in the 2021 Baseline Report. This demographic trend poses complex challenges to health systems and increases the burden on family caregivers. In Brazil, the 2022 Census showed a significant 57.4% increase in the number of older adults in just 12 years. This demographic scenario intensifies the pressure on health services and highlights the fundamental role of informal caregivers, especially in cases

of chronic and advanced-stage diseases that require continuous care.¹

In light of this significant growth in the elderly population, major challenges arise for healthcare systems, requiring reforms in public health and social assistance policies to meet the demand for palliative care, particularly due to the rise in chronic degenerative diseases.²

Based on this understanding, the Ministry of Health established the National Palliative Care Policy in 2024 within the Unified Health System (SUS), which aims to ensure more accessible and humane palliative care, improve the quality of life for people suffering from incurable

diseases in advanced or even terminal stages, and provide pain relief, symptom management, and emotional support for patients and their families.³

By definition, palliative care is understood by the National Academy of Palliative Care as a healthcare approach that seeks to alleviate pain and suffering, whether of physical, psychological, social, or spiritual origin.⁴

Although the National Academy of Palliative Care recommends that palliative care be provided by a multidisciplinary team, in practice, the responsibility for care falls largely on informal caregivers, usually family members or individuals close to the patient receiving palliative care. And

these caregivers, without adequate institutional support, end up facing emotional, physical, and financial overload, and the literature shows that this reality of neglect and overload for caregivers compromises their well-being and quality of life.^{5,6,7}

In the context of caregiving, overload can be understood as a multifaceted phenomenon involving physical, psychological, emotional, social, and financial consequences perceived and experienced by those who assume responsibility for care.^{6,7} Given this scenario, understanding the factors that contribute to the burden on caregivers becomes essential to inform interventions that promote their well-being and the quality of care.

In this context, this study aims to evaluate the factors contributing to caregiver burden among caregivers of palliative care patients in the metropolitan region of Belo Horizonte, Minas Gerais, and their impacts on caregivers' quality of life and the care provided to patients. The relevance of the study lies in its potential to inform public policies, improve training and support strategies, and contribute to enhancing the quality of palliative care.

METHOD

This is a qualitative study, descriptive and exploratory in nature, conducted with formal (health professionals) and informal (family members or close relatives) caregivers of palliative care (PC) patients in the metropolitan region of Belo Horizonte, in the state of Minas Gerais.

Data collection took place through semi-structured interviews from May to July 2025 and involved seven participants. Minayo⁸ considers this the primary strategy in fieldwork, as it facilitates direct contact and brings the researcher closer to the respondents' world, allowing for an understanding of their perceptions, beliefs, values,

experiences, and meanings attributed to reality.

Secondarily, a methodology based on phenomenology was also adopted, aimed at understanding the participants' lived experience, using the snowball sampling technique. The inclusion criteria selected formal or informal caregivers with experience in (CP), over 18 years of age, who agreed to participate in the study voluntarily with consent through the Informed Consent Form (ICF). The interview was recorded and included data on the workload, the support received, and the caregivers' health conditions and emotional impact. For data analysis, the content analysis method proposed by Laurence Bardin was used.

According to Bardin⁹, the term "content analysis" refers to a set of systematic and objective techniques for describing the content of messages, aimed at drawing inferences about the conditions under which these messages are produced and received. The content analysis was conducted in three stages: (1) pre-analysis, which involved organizing and skimming the material; (2) exploration of the material, with coding and categorization of units of meaning; and (3) processing of results, inference, and interpretation, in which the data were analyzed in light of the research objectives and the theoretical framework adopted.

This study complies with the guidelines established for research involving human subjects, as recommended by CNS Resolution No. 466, dated December 12, 2012. The research project was duly submitted to Plataforma Brasil and received approval from the Research Ethics Committee (CEP) of the Pontifical Catholic University of Minas Gerais (PUC Minas), as per the opinion documented under CAAE No. 83568224.1.0000.5137.

RESULTS

The profile of the seven participants revealed a female predominance, with five women and two men, which leads to reflection on a socio-cultural construct that historically associates caregiving as one of women's roles. This distribution is consistent with studies indicating that caregiving, especially in palliative contexts, falls disproportionately on women, considering them "natural" caregivers^{2,5}.

The study by Corrêa et al.¹⁰ confirms this reality by demonstrating that the responsibility for care still falls predominantly on women, especially wives and daughters, even when they are elderly and often also in need of care. This double burden can compromise mental health, as the overload of caregiving has been associated with the emergence of depressive and symptoms. Therefore, it is essential that health services begin to pay closer attention to older adults who care for others. Psychosocial care for this population is a frequently neglected need, yet one that has direct implications for overall well-being and the quality of care provided.

The age range of the interviewees was between 28 and 57 years, with an average age of 43. This age diversity reflects different ways of perceiving and coping with the challenges of caregiving. Research suggests that younger caregivers may be less emotionally and socially prepared, while older caregivers, although they have more experience, face more severe physical strain⁴.

Regarding education, the caregivers in this study have different levels of education and, consequently, different ways of understanding care and managing challenges. In terms of experience, the group of interviewees ranged from caregivers with 3 years of experience in the role to professionals with a long career spanning up to 28 years. During the interview, participants reported a lack of ongoing pro-

Qualitative Article

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fessional support, such as psychological counseling or frequent technical training, which can compromise the quality of care provided and the caregiver's own health

Regarding work hours, it was observed that most caregivers work full-

time, with workloads ranging from 40 to 60 hours per week. This extensive dedication points to a scenario of potential physical and emotional overload, especially when combined with a lack of time for rest and self-care. Overload was one of the most recur-

rent themes in the participants' accounts (Table 1). Caregivers reported psychosomatic symptoms, such as forgetfulness, difficulties with social interaction, and feelings of anxiety and depression.

Table 1. Participants' statements regarding physical and emotional overload are summarized in Table 1.

Caregiver A: "Mild forgetfulness and difficulty socializing."

Caregiver B: "I feel that, over time, this burden builds up and weighs heavily on me. I've had episodes of anxiety and, at times, signs of depression. Even though I love what I do, I can't deny the impact on my mental health."

Caregiver C: "The emotional burden of caregiving varies, right? Depending on the environment and how the elderly person is cared for, this influences the caregiver's life positively or negatively. As for the physical burden, it's very tiring. Depending on the patient, it requires a lot of skill and physical strength."

Caregiver D: "It affects me a lot. Sometimes I get stressed, anxious, and there are days when a heavy sadness hits me. I've had anxiety attacks because of exhaustion. We keep building up feelings and worries, and before you know it, you're at your limit, you know."

Caregiver E: "Well, the emotional burden—it's significant, right? It manifests in various ways. There's, like, stress, depression, irritability, right? So... we have to deal with that, right? Knowing how to handle this situation, because we can feel guilty—I myself sometimes feel guilty for not being able to complete a task, you know? So we have to know how to cope very well so as not to be harmed or end up in any of those states of stress, depression... I avoid that a lot."

Caregiver F: "I see a lack of psycho-spiritual support. In old age, people think a lot about death, and not everyone is prepared for that moment. In this context, the caregiver for the elderly isn't prepared to handle this situation."

Caregiver G: "It's a responsibility involving daily tasks and care, which can lead to an emotional and physical burden, often without the necessary support and without recognition."

These narratives confirm that the burden extends beyond physical limits, affecting the caregiver's emotional and spiritual well-being, reinforcing the need for systematic support and interventions to protect mental health.

In addition to the burden, a prevalence of informal professional relationships was observed among the interviewees. A significant portion of caregivers work without an employment contract or legal protections,

which reinforces the vulnerability of the role and hinders access to basic labor rights.

The informality associated with the high degree of responsibility required in the role contributes to a sense of professional devaluation and insecurity regarding financial stability and social recognition of the caregiver's role (Table 02). These structural aspects directly impact the motivation, well-being, and retention of these professionals in

the field of palliative care.³

A study conducted with informal caregivers of hospitalized older adults in Brazil revealed that the lack of support and the absence of formal recognition of the role increase the stress and emotional burden of these professionals. Furthermore, the absence of labor benefits, such as vacation time and sick leave, exacerbates the precarious situation of these caregivers.³

Table 2. Lack of social recognition and informal employment relationships as central factors contributing to feelings of devaluation and insecurity among caregivers.

Caregiver B: "Even though I love what I do, I can't deny the impact on my mental health, especially due to the lack of recognition and support."

Caregiver C: "Psychosocial support is severely lacking in the caregiving field. In most of the institutions where I've worked, we had no support, and this negatively impacts the caregiver's well-being and mental health."

Caregiver D: "Look, it could be so much better. There's a lack of appreciation, a lack of information, a lack of structure. Most institutions don't offer adequate support—neither for us, nor for the patients. And as for a support network... it depends a lot on the patient's family or our own. If there's no one to help you, you're really on your own."

Caregiver E: "The lack of adequate support intensifies the emotional strain on both the elderly and the caregivers."

These accounts demonstrate that caregivers' motivation depends not only on personal affinity with the role but also on social and professional recognition.

These structural challenges directly impact the environment in which care is provided—whether at home, in long-term care facilities, or in hospitals—contributing to the burden felt by caregivers.

In this study, the home emerged as the primary setting for care, although some participants reported experiences in Long-Term Care Facilities for the Elderly (ILPIs) and in hospital settings, highlighting a variety of practice areas. Palliative care can be provided in different contexts; both home-based care and care provided

in ILPIs or hospitals present distinct advantages and challenges. Support networks—whether family, social, or institutional—help reduce caregiver burden by offering emotional support, assistance with tasks, and protection of mental health.

A study conducted by Dalkirane, Silva, Banaco, and Miyazaki¹¹ with informal caregivers of palliative care patients showed an inverse relationship between burden and social support, particularly material support. This indicates that the greater the support, the lower the perceived burden.

Faced with emotional burden and a lack of institutional support, caregivers developed their own strategies to cope with stress, preserve mental he-

alth, and balance their personal and professional lives (Table 3). Among the main practices reported are physical activity, leisure time, routine planning, conversations with family members or coworkers, and seeking informal emotional support. Self-care strategies, both individual and social, reveal the importance of encouraging supportive and well-being practices in daily professional life.

Analysis of the interviews (Table 4) identified three main themes related to the experience of caregivers of palliative care patients: physical and emotional over , lack of institutional support and social invisibility, and individual coping strategies.

Table 3. Caregivers' own strategies for coping with stress, preserving mental health, and balancing personal and professional life.

Caregiver A: "You always have to try to spend time with people during your free time, de-stress, and not let your mind dwell on work. To lighten the load, you can't isolate yourself from the social world."
Caregiver B: "I try to set aside small moments of the day for myself, even if they're brief. Sometimes listening to music or just taking deep breaths for a few minutes helps. I also try to talk to people I trust when I'm overwhelmed."
Caregiver C: "What helps us cope with stress is recognizing when we're overwhelmed. I exercise, I've started reading again, and I try to talk to someone I trust. Sometimes just talking about what happened during my shift is a huge relief."
Caregiver D: "I do what I can... I listen to music, try to take a little time to go for a walk or watch a movie, even if I'm tired. Talking to other caregivers or close friends helps, but it's not always enough."
Caregiver E: "Family leisure time and moments of healthy conversation really help relieve emotional tension. It's not formal care, but it's where we can express how we feel."
Caregiver F: "I try to rest and get some exercise. These activities help me stay calm and clear-headed so I can care for the elderly safely."
Caregiver G: "I maintain healthy habits, seek rest, and exercise. I also value contact with family and friends, who are my emotional support."

In addition to personal strategies, Table 4 offers a comparative summa-

ry of the caregivers' individual experiences and responses, highlighting

similarities and differences in how they cope with burnout

Table 4. General comparison of interviews with caregivers.

Subject	Caregiver A (APSM)	Caregiver B (MLP)	Caregiver C (ACS)	Caregiver D (CAS)	Caregiver E (AOS)	Caregiver F (EMS)	Caregiver G (BFD)
1. Emotional and physical strain	Tiring, exhausting, requires constant attention; greater burden in ILPIs.	Emotionally intense; physically exhausting.	Varies depending on the environment; very tiring.	Physically and emotionally demanding; involves suffering.	Manifests stress and irritability; tries to avoid impacts.	More emotional than physical; begins with insecurity.	High responsibility without recognition; frequent fatigue.
2. Hours of care per day	12-hour shifts; overburdened in ILPIs.	12 hours/day, may double.	12x36 in ILPIs; up to 72 consecutive hours in home care.	Average of 12 hours, may exceed.	Varies; depends on the patient.	12 hours or up to 24 hours.	It should be 44 hours per week, but it always exceeds that.

Qualitative Article

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3. Work-life balance	I manage to balance it thanks to time off.	No, personal commitments take a back seat.	Difficult at first; better balance over time.	No, personal life is compromised.	Yes, I manage to keep them separate.	Yes, good management.	Yes, considers it essential.
4. Psychosocial support received	No formal psychological support.	Little support; depends on friends/family.	Outdated; institutions do not offer it.	Almost none; only talks with colleagues.	Support from family (children/relatives who are psychologists).	Patients' family members provide support.	Receives family support.
5. Institutional support and support networks	Insufficient; lacks recognition.	Flawed; few public policies.	Very outdated; institutions are profit-driven.	Lacks recognition and structure.	Considers it crucial, but does not formally participate.	Fragile, especially in the spiritual aspect.	Considers it essential, but insufficient.
6. Difficulty with personal commitments	Yes, rigid schedules and lack of time.	Yes, has already missed important commitments.	Yes, has sacrificed academic performance and social life.	Yes, you have missed appointments and events.	You can't keep your commitments.	No, you plan to balance it all.	Yes, you lack time and energy.
7. Impacts of burnout on mental/emotional health	Emotional exhaustion, grief, and lack of support.	Anxiety and signs of depression.	Affected by family neglect and long shifts.	Anxiety, stress, deep sadness.	Able to avoid significant impacts.	Emotional discomfort around the elderly.	Fatigue, difficulty concentrating, and insomnia.
8. Psychological support considered essential	Regular psychological counseling.	Free access to specialized therapy.	A psychologist available to caregivers.	Therapy or support groups.	Formal professional support would be welcome.	Training courses.	Group therapy/support network.
9. Impact on family and personal relationships	Difficulty maintaining a social life and commitments.	Loss of social contacts and family tensions.	Losses in relationships and family life.	Friends have drifted away; family conflicts.	You are able to keep these areas well separated.	Strengthened family relationships.	Generates gratitude and reciprocity.
10. Strategies for coping with stress	Seeks leisure and social interaction.	Short breaks, music, conversation, sharing tasks.	Physical activity, reading, and psychotherapy.	Music, walking, talking with colleagues.	Family leisure, conversations, meditation.	Rest and physical activity.	Rest, healthy habits, exercise.

DISCUSSION

The emotional and physical burden of caregiving

In the context of palliative care, a caregiver is defined as a family member or close relative who assumes responsibility for physical care. This role is typically performed on an ongoing basis and, in many cases, without prior training or specific preparation. Becoming a caregiver requires adaptation and can have a significant physical and emotional impact on those who take on this role.¹²

Palliative care is a specific area of care that emerged in response to a technocratic model of medicine, which focused on the disease rather than the patient. The term, coined in 1974, originates from the Latin *pallium* ("cloak") and

refers to the idea of protecting or supporting.¹³ Patients of all ages facing severe and progressive chronic illnesses, or physical or mental limitations that do not respond to curative treatment, can benefit from palliative care.

In palliative care, caregiver burden is understood as a multidimensional phenomenon, encompassing physical, emotional, psychological, and social aspects, resulting from the continuous care of a person with a serious or terminal illness. In the study by Teixeira et al.⁽¹⁴⁾ conducted with caregivers of elderly cancer patients, it was observed that 75% of participants exhibited moderate-level burden, often accompanied by mild to moderate depressive symptoms.

The participants' accounts of how work overload affects their mental and emotional health confirm this reality:

"Mild forgetfulness and difficulty socializing" (Caregiver A)

"I feel that, over time, this burden builds up and weighs heavily on me. I've had episodes of anxiety and, at times, signs of depression. Even though I love what I do, I can't deny the impact on my mental health." (Caregiver B)

"It affects me a lot. Sometimes I get stressed, anxious, and there are days when a heavy sadness hits me. I've had anxiety attacks due to exhaustion. We keep accumulating feelings and worries, and before you know it, you're at your limit, right?" (Caregiver D)

Psychosomatic disorders manifest through the conversion of emotional stress into physical symptoms such as

mental fatigue, difficulty concentrating, memory lapses, feelings of indifference, and apathy. These signs are also observed in cases of anxiety and depression, reinforcing the need to pay attention to the emotional changes experienced by caregivers.¹⁵

Data analysis revealed that caregivers recognize burnout as an intrinsic part of the caregiving routine, often normalizing symptoms of exhaustion and psychological distress. The perception of burnout is not limited to physical exhaustion but is strongly linked to the emotional impact of continuous involvement with another person's suffering, the lack of institutional support, and the social isolation resulting from exclusive dedication to caregiving. This subjective experience demonstrates how the role of the caregiver goes beyond the technical aspect, involving profound emotional and social implications that demand recognition and specific interventions by health services and public policies focused on palliative care.

Thus, the findings reinforce that caring for palliative care patients poses challenges, especially for informal caregivers, who generally lack specific training for the role. Therefore, strategies that promote emotional and technical support and a welcoming environment are essential. The absence of effective public policies contributes to feelings of emotional and physical overload and negatively impacts the well-being of those providing care.

This burden is not limited to the physical demands of care but is exacerbated by the lack of institutional support and social invisibility, which intensify emotional exhaustion.

Lack of institutional support and the invisibility of the caregiver;

Resolution No. 41, dated October 31, 2018, which sets forth guidelines for the organization of P.C.s within the SUS, establishes that P.C.s must be offered at all points of care within the network, including Home Care (HC),

in order to make the home an appropriate and welcoming place.¹⁶ In this sense, the home environment serves as a space for integration between health interventions and the life context of people in palliative care and their families.¹⁷

Home care, one of the central elements of dehospitalization, is provided mostly by family members, who perform this role on a voluntary basis, driven by emotional bonds and a sense of responsibility. However, this dedication, often without adequate support, can lead to physical, psychological, and emotional overload for the caregiver.¹⁸

The qualitative study by Garcia et al.¹⁹ revealed that many caregivers did not assume this role voluntarily, reporting physical and emotional overload, as well as frustration, guilt, and social isolation. Given these experiences, family and social support networks prove essential for supporting the caregiver and mitigating the negative impacts of caregiving.

The act of caregiving among the elderly, as evidenced by the findings, is permeated by ambivalence: it is simultaneously an expression of affection and commitment, but also a burden imposed by circumstances and the limitations of the family context. In this scenario, psychosocial support emerges as a fundamental protective factor, capable of mitigating the adverse effects of emotional and physical overload. The results further reinforce the need to strengthen public policies and institutional strategies aimed at supporting and valuing caregivers, recognizing the centrality of their social and family ties in sustaining care.¹⁹

Furthermore, the study by Rocha et al.²⁰, conducted with caregivers of older adults in palliative care, reveals that the lack of institutional support for caregivers of older adults in palliative care has a significant impact on mental health, manifesting in symptoms such as anxiety, insomnia, and feelings of isolation. According to the study, caregivers without access to support networks or psychological support experience more

intense emotional distress, which affects the quality of care provided.

This lack of support is evident not only in the quantitative and qualitative data but also in the statements of the interviewees, who express the feelings of abandonment and invisibility experienced by caregivers:

"The lack of adequate support intensifies the emotional strain on both the elderly and the caregivers" (Caregiver E)

"Look, it could be so much better. There's a lack of appreciation, a lack of information, a lack of structure. Most institutions don't offer adequate support—neither for us, nor for the patients. And a support network... it depends a lot on the patient's family or our own. If there's no one to help you, you're really on your own." (Caregiver D)

"I see a weakness in psycho-spiritual support. In old age, people think a lot about death, and not everyone is prepared for that moment. In this context, the caregiver is not prepared to deal with this situation." (Caregiver F)

Although the philosophy of the Care Centers recommends comprehensive care for the patient, family, and caregiver, reality reveals a deficiency in addressing and supporting the biopsychosocial needs of the caregiver.²⁰ There is a gap between what is advocated and the reality experienced by caregivers in different settings, reinforcing the urgency of effective public policies that recognize the importance of this role and offer ongoing support, not only to the patient but to the entire network that sustains end-of-life care.

The caregivers' testimonies reveal a scenario marked by neglect and institutional invisibility. Although they are engaged in a practice that requires not only technical skills but also emotional availability, caregivers often find themselves neglected by formal healthcare

structures. The absence of psycho-spiritual support, mentioned by one of the participants, reveals the limitations of traditional care approaches, which often fail to address the complexity of the suffering faced by those accompanying the terminal process. These accounts point to a critical gap between the humanized discourse of palliative care and the concrete experience of caregivers, who end up assuming an essential role, yet one devoid of adequate support and recognition. In this context, it is essential to propose actions that promote the quality of life and work of caregivers

Personal coping strategies and emotional resilience.

Research indicates that the palliative care approach, whether in hospital or non-hospital settings such as the home, is associated with high levels of stress, emotional exhaustion, and health impairments. When the caregiver focuses exclusively on their role, ignoring the need for leisure activities and social interaction, there is an increased risk of mental health issues and feelings of being overwhelmed, which are frequently associated with this role.^{13,15,18}

Constant exposure to the suffering, pain, and lack of a favorable prognosis of the person being cared for can lead to emotional distress in the caregiver. Given this, it is essential that the caregiver knows how to balance their dedication to caregiving with attention to their own needs. When asked about the strategies they adopt to cope with the stress and emotional burden associated with the work, the caregivers interviewed reported personal coping mechanisms aimed at promoting physical and mental well-being:

“I try to set aside small moments of the day for myself, even if they’re brief. Sometimes, listening to music or just taking deep breaths for a few minutes helps. I also try to talk to people I trust when I’m overwhelmed. And, whenever possible, I accept help

from family members to share some tasks. Recognizing that I can’t do everything alone was an important lesson I’ve learned over these 10 years of experience as a caregiver.” (Caregiver B)

“What I used to do and continue to do, which does me good and helps me manage my anxiety and stress, is physical activity. I also started reading again, because I had stopped reading. I started reading again. I believe it’s a big step toward helping us manage our emotions, fatigue, and anxiety.” (Caregiver C)

Similarly, Caregiver G considers that, in addition to healthy habits such as physical activity, it is important to maintain emotional bonds:

“I try to rest and engage in physical activity. I maintain my healthy habits, stay in touch with my family and friends. I exercise and always try to stay in good spirits.” (Caregiver G)

The statements reveal that the act of caregiving poses significant emotional challenges, and it is necessary to be mindful of this, making it essential to seek coping mechanisms such as healthy routines and strengthening social connections and relationships.

It is evident from the testimonies that caregivers reveal a process of individually constructing coping strategies in the face of the emotional impacts generated by the practice of caregiving in end-of-life contexts. It is observed that, in the absence of systematic institutional support, these individuals resort to personal mechanisms aimed at preserving mental health and reclaiming autonomy over their own time and bodies. The search for moments of introspection, the cultivation of pleasurable activities such as music, reading, and physical exercise, as well as the value placed on being listened to by trusted individuals, are indicative of an awareness of the importance of

self-care as a tool for resilience.

Furthermore, the narratives highlight the reflective capacity acquired through accumulated experience in the role, as evidenced by the recognition of one’s own limits and the appreciation of sharing responsibilities with the family network. This stance demonstrates not only emotional maturity but also an expanded understanding of care, which includes the caregiver as a person equally deserving of attention and support. These practices, though spontaneous and unsystematic, demonstrate the transformative potential of self-care as an essential pillar for the sustainability of palliative care providers’ work, reiterating the urgency of public policies that recognize, guide, and strengthen these initiatives.

In this context, the healthcare system must recognize the personal strategies adopted by these caregivers, while simultaneously offering effective support to promote the emotional well-being and quality of life of those who care.

FINAL CONSIDERATIONS

The results of this study highlight the emotional and physical burden in the daily lives of palliative care caregivers. This strain is related to caregiving demands without adequate institutional and social support, leading to negative impacts on caregivers’ sense of well-being and quality of life.

Furthermore, the study showed that caregivers are able to recognize these challenges and therefore develop personal coping strategies, such as maintaining healthy habits, engaging in physical activity, and valuing emotional and social bonds.

However, these individual mechanisms are insufficient; further research is essential to broaden our understanding of the phenomenon, and the healthcare system must recognize this by creating and strengthening existing public support policies so that palliative care caregivers feel properly supported and

equally cared for.

In light of these findings, the urgency of incorporating the caregiver as a subject of care within palliative care guidelines becomes evident. The invisibility that permeates this role causes significant harm to the physical, emotional, and social health of individuals who assume this role, often in an informal and unsupported manner. Recognizing the caregiver as an integral part of the patient–family–caregiver triad, as proposed by palliative care philosophy, requires more than mere rhetoric:

it demands concrete actions focused on training, psychosocial support, and ongoing assistance. Furthermore, the role of the State and health institutions is reinforced in the development of public policies that guarantee dignity and quality of life for those who dedicate their time and affection to caring for others in the final stages of life.

However, this study has limitations that warrant consideration. The small sample size and the geographical scope limited to the Belo Horizonte Metropolitan Region restrict the generaliz-

ability of the results to other sociocultural contexts.

Furthermore, the qualitative approach does not aim to extrapolate statistical data but rather to deepen the subjective understanding of caregivers' experiences. Thus, we recommend conducting broader investigations using different methods and in diverse contexts to strengthen the knowledge base regarding caregiver burden and support more effective and context-specific interventions.

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