NEEDS OF INFORMAL CAREGIVERS IN END-OF-LIFE SITUATIONS: A SCOPING REVIEW

Necessidades dos cuidadores informais perante a finitude: a scoping review

Necesidades de los cuidadores informales ante la finitud: a scoping review

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ABSTRACT

Background: he aging population has led to a significant increase in the number of people at the end of life, making it essential to thoroughly identify the specific needs of informal caregivers. **Objective**: to map the literature relating to the needs of informal caregivers of people at the end of life. **Methods**: a scoping review was conducted using CINAHL Complete (via EBSCOHost), Medline Complete (via EBSCOHost), PubMed, Cochrane Library, and Scopus. The data extraction tool was developed based on the model proposed by the Joanna Briggs Institute. **Results**: a direct search in the databases resulted in 826 articles, of which 30 were included in the study. The data were organized into six main categories: physiological and physical health needs, informational needs and decision-making, emotional and psychological support, cultural, spiritual, and religious needs, social and community support, and self-care and quality of life; these categories address the study's objective. **Conclusion**: this research is crucial for improving the quality of life and personalizing care. The study provides a solid foundation for future research and interventions, highlighting the importance of an integrated and multidisciplinary approach.

Keywords: caregivers; terminal care; terminally ill; needs assessment

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RESUMO

Enquadramento: o envelhecimento populacional resulta num aumento expressivo do número de pessoas em fim de vida, tornando-se fundamental proceder a uma identificação exaustiva das necessidades específicas dos cuidadores informais. **Objetivo**: mapear a literatura relativa às necessidades dos cuidadores informais de pessoas em fim de vida. **Metodologia**: foi realizada uma scoping review na CINAHL Complete (via EBSCOHost), Medline Complete (via EBSCOHost), PubMed, Cochrane Library e Scopus. O instrumento de extração de dados foi elaborado com base no modelo preconizado pelo Joanna Briggs Institute. **Resultados**: pela pesquisa direta em bases de dados resultaram 826 artigos, dos quais 30 foram incluídos no estudo. Os dados foram organizados em seis categorias principais: necessidades fisiológicas e de saúde física, necessidades de informação e tomada de decisão, apoio emocional e psicológico, necessidades culturais, espirituais e religiosas, suporte social e comunitário, e autocuidado e qualidade de vida; que permitem dar resposta ao objetivo do estudo. **Conclusão**: esta investigação é fundamental para melhorar a qualidade de vida e personalizar os cuidados. Este estudo fornece uma base sólida para futuras investigações e intervenções, destacando a importância de uma abordagem integrada e multidisciplinar.

Palavras-chave: cuidadores; assistência terminal; doente terminal; avaliação das necessidades

RESUMEN

Marco contextual: el envejecimiento de la población ha llevado a un aumento significativo del número de personas en fase terminal, lo que hace esencial identificar exhaustivamente las necesidades específicas de los cuidadores informales. **Objetivo**: mapear la literatura relacionada con las necesidades de los cuidadores informales de personas al final de la vida. **Métodos**: se llevó a cabo una scoping review con base en el modelo recomendado por The Joanna Briggs Institute. Las bases de datos electrónicas consultadas fueron: CINAHL Complete (via EBSCOHost), Medline Complete (via EBSCOHost), PubMed, Cochrane Library e Scopus. **Resultados**: la búsqueda directa en las bases de datos resultó en 826 artículos, de los cuales 30 fueron incluidos en el estudio. Los datos se organizaron en seis categorías principales: necesidades fisiológicas y de salud física, necesidades de información y toma de decisiones, apoyo emocional y psicológico, necesidades culturales, espirituales y religiosas, apoyo social y comunitario, y autocuidado y calidad de vida; estas categorías permiten responder al objetivo del estudio. **Conclusión**: esta investigación es fundamental para mejorar la calidad de vida y personalizar los cuidados. El estudio proporciona una base sólida para futuras investigaciones e intervenciones, destacando la importancia de un enfoque integrado y multidisciplinario.

Palabras clave: cuidadores; cuidado terminal; enfermo terminal; evaluación de necesidades

INTRODUCTION

Promoting the health of informal caregivers of individuals in terminal stages requires a profound understanding of their needs, given the growing importance of supporting these caregivers to ensure the provision of quality care. Ensuring their biopsychosocial well-being is essential, highlighting the importance of targeted interventions to maintain their own health (Kent et al., 2020).

The process of recognizing the prognosis of the cared-for individual and maintaining hope is influenced by personal, environmental, and cultural factors (Araújo & Remondes-Costa, 2018). The informal caregiver, defined as the individual who provides the most frequent care over time, plays a central role in supportive care. This role is fundamental in balancing caregiving responsibilities with the preservation of their own identity. Their needs generally focus on the skills and resources required to care for a family member (Zhang et al., 2023). Variables such as age, gender, education level, and socioeconomic status of caregivers significantly impact their well-being (Yakubu & Schutte, 2018). Furthermore, situational factors such as the extent of involvement in decision-making, the duration of the individual's illness, and the type of treatment also influence the caregivers' valuation of different types of information (Lindt et al., 2020), potentially leading to physical and emotional exhaustion (Teixeira, 2018). These findings underscore the need for a personalized educational approach, tailored to the condition of each individual and the specific characteristics of each family (Ullrich et al., 2021). Additionally, in the development of policies and supportive interventions, it is crucial to consider these variables to ensure solutions that address the diverse realities and needs of informal caregivers.

In the Health Sciences Descriptors (DeCS), the term "health needs" refers to the systematic identification of the needs of a population or the assessment of individuals to determine the most appropriate level of service requirements.

Within nursing theories, the term "informal caregiver" also refers to a non-professional agent, often a family member, friend, or community member, who assumes unpaid responsibility for providing care to an individual facing health challenges or requiring assistance. From the perspective of Virginia Henderson's Theory of Basic Needs, these caregivers focus on addressing the fundamental needs of care recipients, such as nutrition, hygiene, and mobility (Ferrari et al., 2014). Collaboration between informal caregivers and nursing professionals is essential to optimize care, ensure the fulfillment of basic needs, and promote well-being.

In DeCS, the term "caregiver" encompasses individuals who provide care to someone in need of supervision or assistance due to illness or disability. Caregivers may operate in home, hospital, or institutional settings; while the term includes healthcare professionals such as doctors and nurses, it also extends to parents, spouses, other family members, friends, teachers, social workers, among others.

The Portuguese Social Security Institute (2024), in its "Practical Guide to the Informal Caregiver Statute," defines the primary informal caregiver as the individual who permanently accompanies and cares for the cared-for person, shares the same living space, and receives no financial remuneration for the care provided.

In the context of Orem's Self-Care Deficit Nursing Theory, informal caregivers play a crucial role in addressing the self-care deficits of the person being assisted. These caregivers provide support in activities that the individual cannot perform independently due to health limitations (Queirós et al., 2014). The theory emphasizes the importance of nurses providing guidance and support to empower informal caregivers, enabling them to deliver effective care while promoting the autonomy of the individual whenever possible.

The concept of "end-of-life" refers to a stage where an individual's life expectancy is significantly reduced due to advanced, chronic, or terminal health conditions. This stage is characterized by disease progression that is either incurable or has a limited prognosis. According to the DeCS descriptor, the terms “Terminal Care” or “End-of-Life Care” refer to medical and nursing care provided to patients in the terminal phase of a disease. Promoting health within the sphere of informal caregivers of individuals at the end of life requires a deep understanding of their needs, aiming not only to prevent adverse outcomes but also to ensure access to excellent care. This involves fostering supportive environments and targeted interventions to optimize conditions and improve the quality of life for all involved, with biopsychosocial well-being identified as a significant factor influencing caregiving activities, as noted by Fernandes et al. (2016).

Thus, it becomes imperative to adopt a comprehensive approach in which both the person at the end of life and their family/caregivers play crucial roles in managing and meeting needs. This focus is the essential starting point for this study, which aims to map the literature on the needs of informal caregivers of individuals at the end of life, as understanding these needs is critical to ensuring adequate support in end-of-life care contexts.

To achieve this aim, a scoping review methodology was selected, providing a comprehensive and inclusive approach to analyzing the needs of informal caregivers within the context of end-of-life care.

The PCC framework (Participants, Concept, Context) was used to formulate the following research question: What are the needs of informal caregivers of individuals at the end of life? The primary objective of this review is to map the literature on the needs of informal caregivers of individuals at the end of life.

REVIEW METHODOLOGICAL PROCEDURES

The present study followed the most current methodology for scoping reviews proposed by the Joanna Briggs Institute (Khalil et al., 2016; Peters et al., 2020a; Peters et al., 2020b). This review aims to map the evidence on the needs of informal caregivers facing end-of-life care across various domains—emotional, psychological, physical, and social—to identify research gaps and provide directions for future investigations. This document was prepared in alignment with the guidelines of the *Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR)* (Tricco et al., 2018).

i. Eligibility Criteria

Following the recommendations of the Joanna Briggs Institute for conducting scoping reviews, eligibility criteria were defined using the mnemonic Population, Concept, and Context (PCC):

- **Population**: Studies were considered eligible if they addressed informal caregivers of adult individuals (aged 18 years or older) in end-of-life situations.

- **Concept**: Studies could focus on any caregiver needs, including emotional support, stress management, palliative care, and anticipatory grief.
- **Context**: No restrictions were imposed regarding the context (home settings, community, hospital, institutional, or outpatient environments).
- **Type of Sources**: Quantitative, qualitative, and mixed-methods research designs, as well as systematic reviews published in electronic databases, were included. Grey literature, such as dissertations, theses, and organizational reports, was excluded. This decision was made to ensure the inclusion of studies subjected to rigorous peer-review processes, thereby guaranteeing higher quality and validity of evidence. Additionally, excluding grey literature allows for greater consistency in data evaluation and facilitates the replicability of the review, focusing solely on published sources accessible in major scientific databases.

ii. Search Strategy

The search was conducted in electronic databases relevant to health and palliative care, including: CINAHL Complete (via EBSCOHost), Medline Complete (via EBSCOHost), PubMed, Cochrane Library, and Scopus.

To develop the search strategy, a preliminary search was performed to identify the most appropriate terms and Medical Subject Headings (MeSH), such as *"Caregivers"*, *"Terminal Care"*, *"Terminally Ill"*, and *"Needs Assessment"*. The complete search strategy was then adapted for each database.

No time restrictions were applied regarding the publication date. All studies published up to January 12, 2024, the date of the final search, were considered. Publications in Portuguese, English, or Spanish were included, as these are the languages mastered by the research team.

iii. Selection process

The search strategy resulted in the identification of 822 publications. The search results from the databases were initially exported to the reference management software Rayyan (Ouzzani et al., 2016), where duplicate records were identified and removed (306 publications). The screening of studies was conducted in two stages.

First, two independent reviewers evaluated the titles and abstracts of the studies. Any discrepancies between reviewers were resolved by a third reviewer. A total of 427 records were excluded based on the title and abstract screening, and the remaining records proceeded to the full-text review stage.

In the full-text analysis, conducted by two independent reviewers, publications that did not meet the inclusion criteria were excluded, and the reasons for exclusion were documented. Specifically, 33 publications were excluded for not addressing the population relevant to this review, 23 for not addressing the concept, and 3 for being written in languages that did not meet the inclusion criteria. Ultimately, 30 publications were included in the review.

The identification and selection of studies were conducted following the flow recommended by the PRISMA-ScR guidelines (*Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews*) (Tricco et al., 2018) and are presented below in the PRISMA flow diagram (Figure 1).

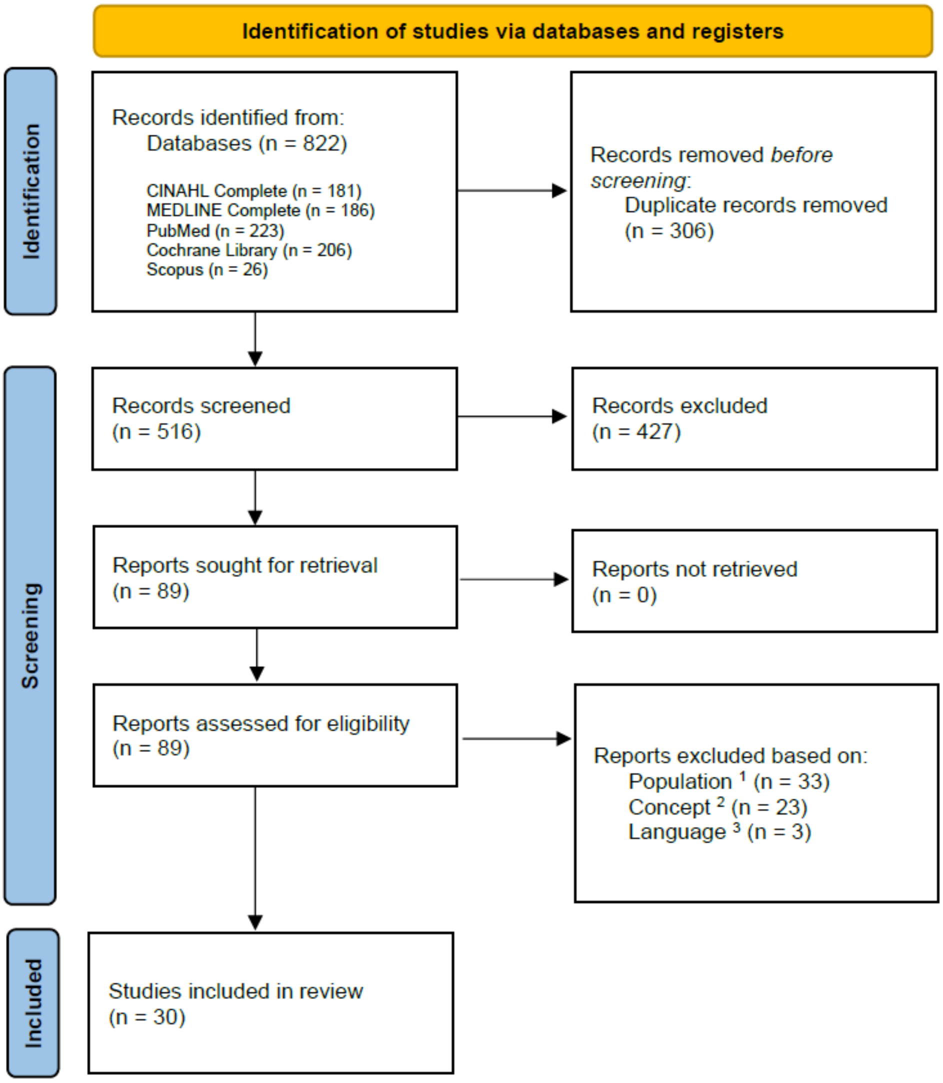

Figure 1

PRISMA Flow Diagram for Literature Reviews

Note: Reasons for exclusion: 1 – Articles focused on professional teams or related to caregivers of children/adolescents. 2 – Articles with a focus other than the needs of caregivers of individuals at the end of life. 3 – Articles written in a language not mastered by the researchers. Adapted from Page et al. (2021).

iv. Data extraction

Data were extracted from each included study using a predefined data extraction tool, as recommended by the Joanna Briggs Institute (Peters et al., 2020a). This tool was pretested on a pilot set of five studies to ensure consistency and clarity in the extraction process.

The extracted data included information on the authors, year of publication, study design, population characteristics, identified caregiver needs, and key findings. Two independent reviewers conducted the data extraction, and a third reviewer was consulted in case of discrepancies.

v. Data synthesis and presentation

The results were synthesized and organized into tables to present the main characteristics of the included studies. A narrative analysis was conducted to describe and interpret the key themes, such as the emotional

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and physical needs of informal caregivers, and how these needs vary according to the context (e.g., home, hospital, etc.).

RESULTS

This review included 30 studies published between 1997 and 2023. Of these, five studies originated from Australia, corresponding to approximately 16.67% of the total, while Europe (24.1%) and North America (24.1%) accounted for the largest continental percentages.

Regarding the study samples, approximately 10% were obtained in hospital settings, and 80% in home-based contexts. The synthesis of results is presented in Table 3.

Table 3

Summary of Results / Included Studies

No. Art. Authors / Year Country	Title	Study Type / Objective(s)	Sample	Needs of Informal Caregivers of Individuals at End of Life
A1 Zhang et al 2023 China	Exploring the needs and coping strategies of family caregivers taking care of dying patients at home: a field study.	Qualitative observational study / Identify the needs and coping strategies of family caregivers providing care to individuals with terminal illness at home.	25 caregivers of individuals receiving palliative care at home.	Acquisition of skills for providing care. Maintenance of the well-being of the person being cared for while preserving normality in their own lives. Access to knowledge to facilitate decision-making. Ability to interpret signs and symptoms in the final hours of life. Improvement in the quality of life of the person being cared for. Acceptance of the inevitable outcome, facing death, and providing emotional support. Access to resources for caregiving and preparation for funeral arrangements. Balancing caregiving responsibilities with their own needs.
A2 Poppe et al 2022 Switzerland	Supportive needs of informal caregivers of people with amyotrophic lateral sclerosis in Switzerland: a qualitative study.	Qualitative observational study / Explore the support needs of informal caregivers of individuals with amyotrophic lateral sclerosis (ALS).	36 participants, including 9 caregivers, 14 bereaved caregivers, and 13 healthcare professionals.	Specialized home support, particularly during the terminal phase, to ensure the comfort and well-being of the person being cared for. Increased contact with healthcare providers, ensuring continuity and quality of care delivered. Support in identifying and accessing social assistance, preventing the burden caused by difficulties in accessing available resources and services.
A3 Kim et al, 2020 Korea	Comparison of spiritual needs between patients with progressive terminal kidney disease and their family caregivers.	Cross-sectional observational study / Compare differences in spiritual needs and influencing factors between individuals with progressive end-stage renal disease and their caregivers.	102 individuals with progressive end-stage renal disease and 88 family caregivers.	Maintaining a positive mindset despite the inherent challenges of the caregiving process. Receiving affection and psychological support, which are fundamental in managing the emotional impact of the caregiving role. Spiritual support, essential for providing comfort and guidance during the end-of-life journey. Preserving a sense of purpose in life, crucial for the caregiver's well-being and resilience.
A4 Park et al., 2010 South Korea	Impact of caregivers' unmet needs for supportive care on quality of terminal cancer care delivered and caregiver's workforce performance.	Cross-sectional observational study / Understand the unmet needs of caregivers in the quality of end-of-life care they provide.	1,662 family caregivers of individuals with cancer who passed away in any of the 17 hospitals in South Korea.	Support in symptom management to ensure the comfort and quality of life of the person being cared for. Psychosocial support, essential to address the emotional and social impact inherent to the caregiver role. Religious support, vital for providing spiritual comfort to both the person being cared for and the caregiver. Financial and community support, crucial for securing adequate resources and the backing of social and community networks.
A5 Becqué et al 2021 Netherlands	How nurses support family caregivers in the complex context of end-of-life	Qualitative observational study / Explore how nurses currently approach and support family caregivers in end-of-life home care and	14 nurses from nine home care organizations in the southwestern	Practical support and training to enhance the quality of care provided. Decision-making support regarding treatment options, ensuring informed and appropriate choices aligned with the needs of the person being cared for. Emotional support, crucial for managing the psychological impact

	home care: a qualitative study.	identify the factors influencing their support to family caregivers.	region of the Netherlands.	associated with the caregiving role. Organization of temporary care, such as night care, aimed at alleviating the caregiver's burden.
A6 Bee et al., 2009 Manchester, UK	A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer.	Systematic review / Analyze the practical information needs of informal caregivers providing end-of-life care to individuals with advanced cancer.	26 primary studies addressing practical aspects of home-based palliative care.	Lack of practical support, often due to inadequate information exchange. Need for increased access to practical information. Enhanced confidence in their ability to provide care.
A7 Close et al., 202 United Kingdom	Qualitative investigation of patient and carer experiences of everyday legal needs towards end of life.	Qualitative study / Analyze the impact and management of legal needs in the context of end-of-life care.	27 participants, including 14 individuals receiving care and 13 caregivers.	Practical support and training aimed at optimizing care delivery and ensuring greater effectiveness. Support on social and legal matters, including areas such as employment, finances, and housing, to ensure stability and security. Support in managing distress arising from life-limiting health conditions of the person being cared for, with the goal of alleviating emotional suffering.
A8 Fitzsimons et al 2019 United Kingdom	Inadequate communication exacerbates the support needs of current and bereaved caregivers in advanced heart failure and impedes shared decision-making.	Mixed-methods study / Explore the experience of caregivers providing care for a loved one with advanced heart failure at the end of life and identify any unmet psychosocial needs.	30 interviews, including 10 caregivers from the United Kingdom, 10 caregivers from Ireland, and 10 bereaved caregivers from the United Kingdom.	Improved communication with service providers. Adequate provision of services to reduce the ongoing physical burden (24/7 care). Assistance in ensuring continuity of care. Support in coping with uncertainty. Support in managing emotional exhaustion. Assistance in the ability to plan for the future.
A9 Conley & Burman, 1997 Florida	Informational needs of caregivers of terminal patients in a rural state.	Qualitative study / Determine the information needs of caregivers of individuals in the terminal phase.	Rural caregivers.	Receiving information tailored to their level of literacy to ensure proper understanding and application of the care provided. Access to clear and accurate information about the health status of the person being cared for, enabling informed decision-making. Support in interpreting complex medical information, ensuring that the caregiver fully understands clinical and therapeutic aspects.
A10 Ülgüt et al., 202 Germany	Experiences and support needs of informal long-distance caregivers at the end of life: a scoping review	Scoping review / Map the international literature on the experiences and needs of long-distance informal caregivers at the end of life.	21 articles for review.	Overcoming the geographical barrier in caregiving, which complicates in-person assistance. Improvement of long-distance communication methods, effectively utilizing video calls and phone calls to monitor the condition of the person being cared for. Balanced management of the burdens and benefits associated with long-distance caregiving, aiming to minimize challenges and optimize the advantages of this type of support. Promotion of harmonious interaction and conflict resolution with local caregivers, ensuring effective and continuous collaboration. Addressing the desires and support needs of distant caregivers, ensuring they receive the necessary resources to perform their role effectively.
A11 North et al. 2021 Newcastle Upo Tyne, UK	The unmet needs of patients with advanced incurable head and neck cancer and their carers: a systematic review and meta-ethnography of qualitative data.	Systematic review / Synthesize qualitative data from individuals with advanced illness and caregivers to inform improvements in services and care.	51 articles on unmet needs of individuals with head and neck cancer and their caregivers.	Overcoming challenges in meeting the needs of the person being cared for to ensure appropriate and effective assistance. Support in managing distress arising from the emotional and psychological demands inherent to the caregiving role. Minimization of isolation associated with caregiving, promoting social inclusion and essential emotional support.
A12 Shanmugasund ram, 2015 Australia	Unmet needs of the indian family members of terminally ill patients receiving palliative care services.	Grounded theory / Explore the needs of caregivers of individuals with terminal illnesses.	Six family caregivers in hospital and home care settings.	Adequate access to home care services. Provision of detailed information about the clinical condition of the person being cared for. Specialized psychological support and assistance in stress management. Financial support to address the costs associated with caregiving.

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A13 Aoun et al, 201 Australia	Caregivers of people with neurodegenerative diseases: profile and unmet needs from a population-based survey in south australia.	Qualitative study / Determine the profile and unmet care needs of individuals who identify as having provided care to a person who experienced an expected death.	230 respondents who had a close person pass away from a neurodegenerative disease in the past five years.	Adequate emotional support, particularly in the context of the grieving process, to help manage the distress associated with the loss of the person cared for. Meeting spiritual needs through religious and/or spiritual guidance and support, aimed at providing comfort and solace during this challenging time.
A14 Shanley et al 2011 Australia	Living through end-stage dementia: the experiences and expressed needs of family carers.	Qualitative study / Understand the experiences and needs of family caregivers during the terminal stage of dementia.	15 participants who are caregivers of individuals with terminal-stage dementia.	Adequate support for instrumental needs related to performing daily caregiving tasks. Specialized technical assistance to enhance the quality of care provided. Effective management of the loneliness inherent in the caregiving role. Emotional support to cope with the difficulty of witnessing the dying process of a family member. Empowerment to anticipate and experience the dying process consciously and with preparedness. Support in reestablishing and reintegrating life after funeral ceremonies. Meeting psychosocial needs, essential for balancing caregiving responsibilities with personal well-being.
A15 Mohammed e al., 2016 China	Family caregivers' experience of providing end of life homecare in advanced cancer: a grounded theory study.	Grounded theory / Examine the experience of family caregivers providing home care to individuals with advanced cancer.	61 family caregivers of individuals with advanced cancer who passed away between 6 months and 5 years prior to the study.	Ensure the delivery of high-quality care to the person being cared for. Provide adequate preparation for the terminal stages of life, focusing on acquiring knowledge to play a more meaningful role during this period. Foster a sense of security and emotional comfort throughout the caregiving process. Support in effectively managing multiple administrative responsibilities following the family member's passing.
A16 Mohammed e al., 2018 Canada	"I didn't want to be in charge and yet i was": bereaved caregivers' accounts of providing home care for family members with advanced cancer.	Systematic review / Describe the experiences of bereaved caregivers in providing home care to individuals with advanced cancer.	A total of 26 studies were included, refined to 37 findings, and integrated into 9 categories and 5 synthesized findings.	Strengthening formal support, deemed insufficient for their demands. Ensuring consistency and quality in the care provided. Receiving detailed and accurate information on what to expect during the final stages of life. Provision of appropriate resources and support to facilitate effective caregiving.
A17 Lipnick et al 2019 Canada	Caregiver stress in advance care planning (acp) conversations: a qualitative analysis of data from a randomized controlled trial.	Qualitative analysis of data from a randomized controlled trial / Understand how caregivers of individuals with advanced illness perceive the stress associated with care planning and identify the factors contributing to this level of stress.	130 semi-structured interviews: caregivers who completed advance care planning conversations.	Appropriately and sensitively addressing end-of-life discussions and issues. Acceptance of the reality of the family member's illness as part of the adaptation and preparation process. Managing the fear of diminishing the family member's hope as the illness progresses. Support in overcoming the fear of disagreeing with the family member's end-of-life wishes. Access to appropriate social support to alleviate isolation and the emotional pressures inherent in the caregiving role.
A18 Pepin & Hébert 2020 Canada	Needs of caregivers of patients receiving in-home palliative and end-of-life care.	Descriptive qualitative study / Describe needs throughout the caregiving trajectory.	20 caregivers who participated in semi-structured interviews.	Continuous and guaranteed access to support services, essential for ensuring the quality of care provided. Specialized and continuous support from nursing professionals, regarded as crucial. Informational, emotional, and psychosocial needs arising from changes in the relationship with the family member during the caregiving process. Spiritual needs, reflected in the meaning attributed to the experience of providing home care.
A19 Joad et al., 2011 Jaipur, India	What does the informal caregiver of a terminally ill cancer patient need? A study	Qualitative study / Evaluate the needs of informal caregivers of individuals with terminal cancer.	54 informal caregivers of individuals registered in the palliative care service.	Adequate home support, ensuring the continuous provision of care at home. Specialized technical support, aimed at improving the effectiveness and quality of the care provided. Psychological support, essential for coping with the emotional strain associated with the caregiving role.

	from a cancer centre.			Financial support, to address the costs associated with providing prolonged care.
A20 Butow et al. 2014 Australia	Caring for women with ovarian cancer in the last year of life: a longitudinal study of caregiver quality of life, distress and unmet needs.	Descriptive study / Understand caregiver burden, quality of life, and unmet needs at the end of life.	99 caregivers who completed at least one assessment within the last year of life of the woman they were caring for.	Balancing personal and professional needs, such as reconciling work responsibilities with the caregiving role. Support in decision-making during uncertain situations, ensuring informed and context-appropriate choices. Specialized psychological support, necessary to manage emotions and cope with clinical prognoses.
A21 Hasson et al. 2009 Northern Irelan	Experiences and needs of bereaved carers during palliative and end-of-life care for people with chronic obstructive pulmonary disease.	Qualitative study / Explore the experiences of caregivers who provided care to a loved one at the end of life due to COPD (Chronic Obstructive Pulmonary Disease).	9 bereaved caregivers.	Relief from physical and emotional burden, exacerbated by insufficient availability of support services. Improvement in quality of life, significantly affected by the demands associated with the caregiving role. More appropriate support and provision of information from healthcare professionals, ensuring informed decisions and more effective care. Psychological and spiritual support during the grieving period, crucial for coping with the loss and its emotional repercussions.
A22 Thompson & Roger, 2014 Canada	Understanding the needs of family caregivers of older adults dying with dementia	Literature review / Describe the domains of the needs of family caregivers of individuals with terminal dementia and their impact on the provision of palliative care services.	Articles on the needs of family caregivers of individuals with dementia and the impact on the provision of palliative care services.	Assistance with physical needs related to the daily caregiving tasks. The need for clear information and support in decision-making to ensure informed and appropriate choices. Instrumental support, essential for facilitating the execution of caregiving tasks. Support with psychological, emotional, and spiritual needs, crucial for ensuring the emotional and mental well-being of the caregiver.
A23 Cui et al., 2014 China	Needs of family caregivers of advanced cancer patients: a survey in shanghai of China.	Cross-sectional study / Explore the needs of family caregivers of individuals with advanced cancer.	649 participants from 15 hospitals in Shanghai.	Ensuring the maintenance of the health and well-being of the person being cared for through continuous and appropriate care. Support from healthcare professionals, ensuring the quality and continuity of the care provided. Acquisition of detailed knowledge about the illness and treatments to enable informed decision-making. Assistance in symptom management, aiming to promote the comfort of the person being cared for. Psychological support, essential for managing the emotional impact associated with the caregiving process. Financial support to address the costs associated with the care of the person being cared for. Support in organizing funeral arrangements, to facilitate the management of this particularly delicate moment.
A24 Goy et al., 2008 Oregon, USA.	Needs and experiences of caregivers for family members dying with parkinson disease.	Exploratory descriptive quantitative study / Analyze the needs and experiences of caregivers of family members who pass away from Parkinson's disease.	Surveyed 47 family caregivers of Parkinson's disease patients a median of 18 months after death.	Support with tasks that involve physical effort, in order to minimize the physical strain on the caregiver. Enhancement of education and training in caregiving, to ensure more effective and informed assistance. Support in managing stress and physical and emotional tension arising from the demands associated with the caregiving role. Support in social and legal areas, to ensure the protection of the caregiver's rights and adequate access to necessary services.
A25 Perreault et al. 2013 Canada	The experience of family members caring for a dying loved one.	Qualitative phenomenological approach / Explore the experience of family members caring for a loved one in the terminal phase.	10 participants (families of patients in palliative care units).	Support in managing feelings of helplessness associated with the progression of the illness and the inability to alleviate the pain and discomfort of the person being cared for. Support in decision-making during difficult and emotionally demanding situations. Support from healthcare professionals to help the caregiver confront their personal limits.
A26 Hudson, 2004. Australia	Positive aspects and challenges associated with caring for a dying relative at home.	Qualitative (semi-structured interviews) / Identify the positive aspects and challenges associated with caring for	47 family caregivers of individuals who have recently	Support in managing their own compromised health, resulting from the physical and emotional demands of the caregiving role. More time for themselves, essential for preserving their physical and psychological well-being. Support in controlling the symptoms of the person being cared for, to ensure their comfort and quality of life.

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		a family member at the end of life at home.	started home palliative care.	Greater support from healthcare professionals to ensure the continuity and quality of care provided. Support in managing family circumstances, often complex in the context of end-of-life care.
A27 Grande et al. 1997 Cambridge	Support needs in the last year of life: patient and carer dilemmas.	Semi-structured interviews / Identify support needs and challenges in introducing support for terminal patients and their caregivers.	43 terminal patients, 30 caregivers, 93 doctors.	Support with transportation to facilitate the mobility of the person being cared for. Assistance with personal care and household tasks, relieving the daily responsibilities of the caregiver. Specialized technical support from healthcare professionals to ensure the quality and effectiveness of care provided. Overcoming reluctance to seek help, stemming from the perception of a lack of resources and time from healthcare professionals. Preservation of the independence of both the caregiver and the person being cared for, ensuring autonomy and respect for self-determination. Maintenance of dignity and familial aspects of life, ensuring respect and quality of life throughout the caregiving process.
A28 Saavedra et al. 2021 Cuba	Care needs of the elderly's family caregiver at the end of life based on comfort theory.	Observational, descriptive, cross-sectional study / Identify the caregiving needs of family caregivers of elderly individuals at the end of life, based on the Comfort Theory.	44 family caregivers of elderly individuals at the end of life.	Support in managing physical demands, with an emphasis on relieving muscle pain and fatigue associated with prolonged caregiving. Support in psychological and spiritual dimensions, addressing feelings of loneliness and isolation often experienced in the context of caregiving.
A29 Cruz & Mcghee 2021 California	Case study method to design and evaluate person-centred integrated palliative and end-of-life care.	Case study / Understand the caregiving experience from the perspective of both the patient and the caregiver, and describe how the method can be replicated to address gaps in evidence related to person-centered integrated care.	35 caregivers from the public, private, and tertiary sectors.	Better coordination between formal and informal caregivers. Support in communication and collaboration among different caregivers to ensure continuity and effectiveness of care. Increased integration of informal caregivers into the care plan, benefiting the person being cared for.
A30 García et al. 2005 Spain	Experiences, expectations and perceived needs of informal caregivers of patients with longstanding diseases.	Qualitative study, interviews, and focus groups / Examine the experiences and needs of long-distance (LD) caregivers at the end of life.	Female caregivers of terminal cancer patients, elderly individuals with dementia, and terminal AIDS patients.	Support in managing the physical demands of tasks, which often overwhelm caregivers. Support in developing appropriate technical skills, suggesting additional training and more frequent visits from healthcare professionals to improve the quality of care provided. Support in managing the emotional demands inherent in caregiving tasks, given the significant emotional burden associated with end-of-life care.

The direct search in databases formed the foundation for an in-depth analysis to identify the needs of informal caregivers of individuals at the end of life, a growing area of concern given their central role in providing care to terminally ill individuals. Informal caregivers take on the responsibility of delivering physical, emotional, and psychological care, which can significantly impact their own well-being. Thus, it is essential to comprehensively understand their needs to inform nursing practices and develop appropriate interventions. In this context, the use of a robust theoretical framework is crucial. Virginia Henderson's Model of Basic Human Needs (Henderson, 1966) and Madeleine Leininger's Transcultural Care Theory (Leininger & McFarland, 2006) provide a solid theoretical basis to support these findings.

Virginia Henderson's theory, centered on basic human needs, offers a comprehensive structure for assessing human needs in various contexts, including that of informal caregivers (Henderson, 1966). This model emphasizes that, regardless of health status, individuals have needs that must be met to promote their physical and emotional well-being. For informal caregivers of individuals at the end of life, these needs become even more critical, as they often neglect their self-care while attending to the demands of caregiving. The application of this theory is justified by its ability to identify the different dimensions of caregivers' needs. Studies suggest that neglecting these needs can lead to exhaustion and burnout, compromising the quality of care provided (Salvage & White, 2019).

On the other hand, Madeleine Leininger's Transcultural Care Theory (2006) introduces a crucial cultural dimension for understanding the needs of informal caregivers, particularly in multicultural contexts. This theory argues that care must be culturally congruent, meaning it should align with the beliefs, values, and practices of each individual and family within their environment. This perspective is particularly relevant in palliative care, where cultural beliefs deeply influence perceptions of death and the dying process (Leininger & McFarland, 2006). This theory complements Henderson's Model of Human Needs by emphasizing the importance of understanding cultural differences in the caregiving role. In many cultural contexts, caring for a family member at the end of life is seen as a familial or religious obligation, which can increase the emotional and psychological burden on the caregiver (Cohen et al., 2020). Integrating Leininger's theory into this study allows for exploration of how caregivers' needs vary across cultural contexts, offering a richer and more complex perspective on the factors influencing their well-being.

Thus, combining these two theories provides a robust and comprehensive foundation for constructing the theoretical framework for this study. Henderson's theory offers a clear structure for evaluating the physical and emotional needs of caregivers, while Leininger's theory introduces a crucial cultural perspective for understanding the diverse experiences of caregivers in different contexts.

The complementarity of these two theories enables a holistic and multidimensional analysis of the needs of informal caregivers, identifying not only practical needs but also cultural aspects that influence the caregiving role.

This approach lays a solid foundation for future research and interventions in palliative care, aiming to develop interventions that are more suitable and tailored to caregivers' individual needs. It promotes a deeper and more sensitive analysis of the various dimensions of informal caregiving.

1. Physiological and physical health needs

This category focuses on the necessary support to ensure the comfort of the cared-for individual and to minimize the physical and emotional burden on the caregiver. These measures aim to provide comprehensive support to caregivers, promoting both the well-being of the cared-for individual and the sustainability of the caregiving role. It includes:

- Symptom control: support in managing symptoms to ensure the comfort and quality of life of the cared-for individual (A1, A4, A5, A12, A19, A23).
- Physical needs: assistance in providing daily care related to the physical needs of the cared-for individual (A1, A14, A24, A26, A28).
- Reduction of physical burden: support in tasks requiring physical effort, helping to reduce caregiver fatigue, particularly in continuous care settings (24 hours in day / 7 days in week) (A2, A5, A6, A8, A23, A24, A27).
- Specialized support: intervention by healthcare professionals to ensure the quality and effectiveness of the care provided (A2, A5, A7, A12, A19, A24, A27).

2. Information and decision-making needs

This category focuses on empowering caregivers by ensuring access to essential information and knowledge for making informed decisions and providing effective care. It includes:

- Training and skills development: building practical competencies to provide care and interpret signs and symptoms, particularly in the final hours of life (A1, A5, A6, A15, A19, A22).
- Health literacy and tailored information: providing clear information adjusted to the caregiver’s literacy level, promoting accurate understanding and application of care and clinical processes (A6, A9, A12, A23).
- Decision-making support: access to detailed information about the health status of the cared-for individual and guidance for making informed decisions regarding treatments and care (A3, A5, A7, A8, A16).
- Practical information: availability of specific, situation-adjusted information to facilitate care management (A6, A9, A13, A22).
- Support in complementary areas: guidance on social and legal matters, such as employment, finances, and housing, to ensure the caregiver's security and stability (A7, A10, A12, A24, A27).

3. Emotional and psychological needs

This category addresses the emotional and psychological impact associated with the caregiver's role, ensuring the necessary support to face the demands of caring for an individual at the end of life. It includes:

- Emotional support: assistance in managing the emotional impact associated with the caregiving role and its demands (A3, A4, A8, A14, A21, A25).
- Psychosocial support: interventions aimed at addressing the emotional and social challenges inherent to caregiving (A4, A8, A13, A14).
- Stress management: specialized psychological support to help manage stress related to caregiving responsibilities (A12, A17, A18, A24, A26).
- Bereavement support: emotional guidance during the grieving process, helping caregivers cope with the loss of the cared-for individual (A12, A17, A18, A24, A26)
- Managing uncertainty and emotional exhaustion: support to deal with uncertainty and emotional fatigue, often linked to end-of-life caregiving (A8, A17, A26).
- Preparation for the dying process: training and support to help caregivers anticipate and navigate the dying process consciously and preparedly (A14, A15, A18).

4. Cultural, spiritual, and religious needs

This set of needs focuses on the cultural, religious, and spiritual aspects of the caregiver's role, ensuring they receive appropriate support aligned with their beliefs and values, enabling them to provide similar support to the cared-for individual. Key elements include:

- Spiritual support: essential for providing comfort and guidance throughout the end-of-life journey (A3, A4, A7, A13, A14).
- Religious support: necessary to offer spiritual solace to both the caregiver and the cared-for individual (A4, A13, A14).
- Fulfilling spiritual needs: ensuring access to religious and/or spiritual guidance, offering comfort during the end-of-life process (A7, A13, A14).
- Spiritual support during bereavement: helping caregivers cope with loss and the associated emotional and spiritual repercussions (A13, A21).

5. Social and support needs

This category focuses on the support required to ensure that caregivers have access to resources and services that facilitate caregiving while maintaining the continuity and quality of care. These measures aim to

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reduce caregiver burden, promote efficient resource management, and enhance the quality of care provided. It includes:

- Resources for care and funeral arrangements: support in obtaining essential resources for caregiving and organizing funeral procedures (A1, A13, A23).
- Specialized home care: provision of specialized care at home, particularly during the terminal phase, to ensure the comfort of the cared-for individual (A2, A5, A12, A19).
- Continuity of care: increased contact with healthcare providers to maintain the quality and consistency of care (A2, A5, A8, A27).
- Access to social support: assistance in identifying and obtaining social resources to mitigate the burden associated with difficulties in accessing available services (A2, A7, A23, A27).
- Financial and community support: help to ensure access to adequate financial resources and support from the social network (A4, A7, A12, A19, A23).
- Management of complex family situations: support in addressing familial challenges often associated with end-of-life caregiving (A26, A27).
- Temporary care arrangements: facilitation of alternatives such as nighttime care to alleviate caregiver burden (A5, A26).
- Improved communication with service providers: promotion of better interaction and increased contact with care providers to ensure the continuity and effectiveness of services (A8, A10, A27).

6. Self-care and quality of life needs

This category highlights the importance of maintaining a balance between the caregiving role and self-care, ensuring that caregivers preserve their health and well-being while providing continuous care. These measures aim to enable caregivers to perform their role sustainably, preserving their quality of life and promoting the well-being of the cared-for individual. It includes:

- Balance between caregiving and personal life: ensuring that caregivers can maintain normality in their own lives while attending to the cared-for individual (A1, A18, A20, A26).
- Managing responsibilities and personal needs: providing support to balance caregiving responsibilities with the caregiver's individual needs (A1, A18, A20, A26).
- Positive attitude: promoting a resilient and positive approach to the inherent challenges of caregiving (A3, A20).
- Confidence in caregiving: enhancing the caregiver's confidence in their ability to provide effective and appropriate care (A6, A23).
- Sense of purpose: preserving a clear purpose, essential for emotional well-being and caregiver resilience (A3, A15).
- Quality of life: support to improve the quality of life for both the cared-for individual and the caregiver (A1, A24, A26).
- Stress management: assistance in managing stress and the physical and emotional demands of the caregiving role (A12, A24, A26).

Summary and key findings:

1. Physiological and physical health needs

Symptom control: support in managing symptoms to ensure the comfort and quality of life of the cared-for individual.

Physical assistance: help with daily care related to the physical needs of the cared-for individual.

Reducing physical burden: support for physically demanding tasks to alleviate caregiver fatigue, especially in continuous care settings.

Specialized support: intervention from healthcare professionals to ensure the quality and effectiveness of care provided.

2. Information and decision-making needs

Skill acquisition: developing capabilities for effective caregiving.

Access to knowledge: facilitating informed decision-making.

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Symptom interpretation: understanding symptoms in the final stages of life.

Practical guidance: access to practical and actionable caregiving advice.

Adjusted information: receiving information tailored to the caregiver's literacy level.

Health status of the cared-for individual: access to clear and detailed information about the cared-for individual's condition.

Medical information interpretation: support in understanding complex clinical data.

Practical training: equipping caregivers to provide higher-quality care.

End-of-life guidance: helping caregivers understand and anticipate the final stages of life.

Informed decision-making: ensuring caregivers can make appropriate treatment decisions.

Social and legal matters: support with issues like employment, finances, and housing for stability.

3. Emotional and psychological needs

Emotional and psychological support: managing the emotional and psychological impact of the caregiving role.

Psychosocial support: assistance in addressing the emotional and social challenges of caregiving.

Grief support: helping caregivers cope with the (imminent) loss of the cared-for individual.

Stress management: assistance in handling the emotional demands of caregiving.

Living with uncertainty: helping caregivers deal with uncertainty about the future.

Managing emotional exhaustion: preventing emotional burnout caused by caregiving.

Emotional preparation for death: helping caregivers face and accept the dying process.

4. Cultural, spiritual, and religious needs

Spiritual support: providing spiritual comfort to the caregiver and cared-for individual.

Religious support: ensuring religious support during the end-of-life process.

Spiritual needs: offering spiritual solace during the end-of-life phase.

Grief support with spirituality: helping caregivers cope with loss through spiritual support.

5. Social and support needs

Essential resources: access to resources for caregiving and funeral preparation.

Home care support: ensuring comfort and specialized care at home.

Healthcare professional contact: reinforcing connections with healthcare professionals to maintain care quality and continuity.

Social support: assistance in obtaining social resources and services to reduce caregiver burden.

Financial and community support: ensuring access to financial resources and social network assistance.

Family situation management: help in resolving familial challenges associated with end-of-life care.

Temporary care solutions: organizing alternatives like nighttime care to relieve caregiver burden.

6. Self-care and quality of life needs

Maintaining well-being: balancing caregiver well-being with the care provided.

Responsibility management: balancing caregiving responsibilities with personal needs.

Positive attitude: facing caregiving challenges with optimism.

Confidence in abilities: enhancing self-confidence in providing effective care.

Sense of purpose: preserving a clear purpose essential for emotional well-being and caregiver resilience.

Stress management: assistance in handling the physical and emotional demands of caregiving.

DISCUSSION

The formalized grouping reflects the integrated approach proposed by Henderson's and Leininger's theories, addressing the various dimensions of the informal caregiver's role within the context of palliative care. The caregiver is viewed as an agent with multidimensional needs, ranging from physical support to emotional, cultural, and spiritual dimensions, which are crucial for performing their role effectively and in balance.

1. Physiological and physical health needs

Informal caregivers' needs include support in symptom management, physical burden reduction, and specialized technical assistance, aiming to ensure the well-being of both the cared-for individual and the caregiver. Caregivers often face significant physical demands, frequently without adequate support to alleviate this burden.

Roth et al. (2015) document the substantial physical impact of prolonged caregiving, including fatigue and physical strain, especially when technical assistance is unavailable. Physical burden is exacerbated by demanding tasks such as lifting or mobilizing the patient, placing additional strain on caregivers. Adelman et al. (2014) emphasize that physical burden is a primary cause of burnout among caregivers, severely affecting their health and well-being. Furthermore, Schulz & Beach (1999) report that caregivers exposed to high levels of physical and emotional stress are at greater risk of mortality due to the prolonged impact of caregiving demands on their health.

These studies underscore the importance of providing specialized support to informal caregivers to reduce the physical demands of their role. The provision of technical assistance and appropriate resources can safeguard caregivers' physical health, preventing exhaustion and improving their quality of life.

2. Information and decision-making needs

The needs of informal caregivers of individuals at the end of life include access to clear and precise information, practical training to improve care provision, and support in making informed decisions regarding necessary treatments and care. However, many caregivers, according to Funk et al. (2010), often feel unprepared to make informed decisions, particularly regarding symptom management and understanding the deterioration of the cared-for individual's health.

Van Ryn et al. (2011) highlight that improving caregivers' health literacy is crucial. A lack of clinical knowledge may limit their ability to make appropriate decisions, increasing anxiety and stress. This lack of preparation directly impacts the quality of care provided and the caregivers' well-being.

To address this challenge, Parker Oliver et al. (2017) emphasize the importance of providing caregivers with access to technological and informational resources to overcome these difficulties. These tools can enhance caregivers' confidence and enable them to make well-informed decisions more effectively. These studies reinforce the need for educational interventions that offer clear and practical information to improve informal caregivers' decision-making abilities, ensuring care quality and caregivers' emotional well-being.

3. Emotional and psychological needs

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In this context, caregivers' needs include emotional and psychological support, stress and emotional exhaustion management, and preparation for facing the processes of death and grief. Caring for an individual at the end of life imposes a significant emotional burden, with caregivers often experiencing high levels of stress and anxiety.

Hudson & Payne (2011) note that this emotional strain is exacerbated by the uncertainty and complexity of the end-of-life process. Prolonged caregiving can lead to emotional exhaustion, increasing the risk of depression. Schulz et al. (2016) emphasize that the strong emotional bond between the caregiver and the cared-for individual makes caregivers particularly vulnerable to high levels of psychological distress, especially when lacking adequate support. Williams et al. (2017) suggest that psychosocial interventions, such as counseling or therapy, are crucial in helping caregivers manage the emotional impact of their role. These interventions can provide tools to address stress and emotional exhaustion, fostering resilience. The analyzed studies highlight the importance of continuous emotional support for caregivers, not only to improve their quality of life but also to prevent the development of severe mental health issues.

4. Cultural, spiritual, and religious needs

Identified needs in this category include spiritual and religious support, offering comfort and guidance both during the end-of-life journey and the grieving period. The cultural and spiritual needs of informal caregivers are particularly significant in the context of palliative care, as they play a central role in their emotional well-being. McCaffrey & McConnell (2015) emphasize that spirituality is essential for emotionally supporting caregivers, helping them cope with loss and suffering. Including spiritual care as an integral part of care for both the patient and caregiver can enhance resilience and provide a greater sense of peace. According to Puchalski et al. (2014), integrating spiritual support in end-of-life care is critical for caregivers and patients, contributing to better acceptance of death and relief from emotional suffering.

Balboni et al. (2013) add that respecting religious and cultural beliefs is vital for providing humanized care. This respect allows for a more dignified and meaningful experience for both caregivers and their loved ones, fostering a more holistic and compassionate approach throughout the end-of-life process.

5. Social and support needs

This category includes access to financial resources, social and community support, and improved communication with healthcare providers to ensure continuity and quality of care. The absence of social support can significantly intensify the burden on informal caregivers, making their task even more challenging.

Schulz et al. (2012) indicate that caregivers without access to strong social support networks experience higher levels of stress, isolation, and burden. Bastawrous (2013) corroborates this view, showing that community support and financial resources are critical factors in alleviating caregivers' burden, enabling more effective caregiving. Reblin et al. (2016) emphasize the importance of regular contact with healthcare professionals, noting that frequent communication between caregivers and healthcare teams contributes to the continuity and quality of care. This contact helps ensure that caregivers do not feel abandoned or isolated in the caregiving process.

These studies underscore the need to create effective social and community support networks to assist caregivers in their daily lives, providing them with the resources and support necessary to perform their role sustainably and with less burden.

6. Self-care and quality of life needs

This topic addresses the balance between caregiving responsibilities and caregivers' personal well-being, the preservation of a sense of purpose, and the improvement of quality of life for both the cared-for individual and the caregiver. The burden associated with caregiving often compromises the quality of life of informal caregivers. Gaugler et al. (2014) demonstrate that caregivers' self-care is often neglected as they prioritize the cared-for individual's needs over their own, leading to deterioration in their physical and emotional health. Pearlin et al. (1990) stress the importance of teaching caregivers effective stress management strategies to prevent burnout and preserve their personal well-being. Similarly, Rabow et al. (2004) emphasize that caregivers must balance their caregiving responsibilities with personal needs to ensure resilience and long-term quality of life. These studies highlight that self-care support should be a priority to prevent caregivers from experiencing significant health deterioration while providing care.

CONCLUSION

This study successfully met its objective of mapping the existing literature on the needs of informal caregivers of individuals at the end of life. The detailed analysis of different categories—physiological, informational, emotional, cultural, social, and self-care needs—revealed that the role of informal caregivers is characterized by a significant physical, emotional, and psychological burden.

The findings emphasize the urgent need for a rigorous scientific approach to guide future interventions and policies supporting informal caregivers. The reviewed literature underscores the importance of developing structured and personalized programs that address caregivers' multifaceted needs, focusing on continuous training, emotional and psychological support, social assistance, and care integration that considers cultural and spiritual dimensions.

However, several limitations of this study should be noted. First, the review was based on existing literature, which may not reflect all geographical and cultural realities, potentially restricting the generalization of results. Moreover, while numerous needs were identified, the variability in caregivers' experiences—particularly regarding emotional, social, and cultural burdens—may not have been fully addressed, suggesting the need for more detailed empirical investigations in specific contexts. Finally, the heterogeneity of the included studies may have complicated a uniform analysis of the most effective interventions for each category of identified needs.

Another significant limitation is the exclusion of grey literature, which could have provided valuable insights into unpublished studies, enriching the understanding of informal caregivers' realities. Future studies are encouraged to include grey literature to ensure a more comprehensive and representative analysis.

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