

DOI: <https://doi.org/10.36489/saudecoletiva.2021v11i69p7000>

The daily life of the family caregiver of the person in palliation at home: integrative review

O cotidiano do cuidador familiar da pessoa em palição no domicílio: revisão integrativa

La vida cotidiana del cuidador familiar de la persona en paliación en el hogar: revisión integradora

RESUMO

Objetivo: analisar as produções científicas sobre as mudanças no cotidiano do cuidador familiar da pessoa em palição no ambiente domiciliar na realidade brasileira. Método: revisão integrativa da literatura, realizada nos meses de setembro e outubro de 2020, na qual definiu-se como questão de pesquisa: Quais mudanças ocorrem no cotidiano do cuidador familiar da pessoa em palição no ambiente domiciliar no contexto brasileiro? Foram acessadas as bases de dados, utilizando os descritores “cuidadores” and “cuidados paliativos”. Resultados: foram selecionados 10 artigos, publicados de 2010 a 2020. A análise dos estudos primários revelou que o cotidiano do cuidador familiar sofre várias mudanças com repercussões laborais, sociais, econômicas e emocionais. Ao cuidar do ente querido que vivencia os cuidados paliativos muitos sentimentos afloram, dentre eles, o medo. Conclusão: mudanças drásticas acontecem no cotidiano do cuidado familiar, contribuindo para o seu desgaste psíquico e físico. Cabe aos profissionais de saúde oferecer apoio à família e minimizar o sofrimento da pessoa adoecida.

DESCRIPTORES: Cuidadores; Família; Cuidados Paliativos; Enfermagem.

ABSTRACT

Objective: to analyze scientific productions on changes in the daily life of family caregivers of people undergoing palliation in the home environment in the Brazilian reality. Method: an integrative literature review, carried out in September and October 2020, in which the research question was defined: What changes occur in the daily life of the family caregiver of the person in palliative care in the home environment in the Brazilian context? Databases were accessed using the descriptors “caregivers” and “palliative care” were used. Results: 10 articles were selected, published from 2010 to 2020. The analysis of primary studies revealed that the daily life of family caregivers undergoes several changes with labor, social, economic and emotional repercussions. When caring for a loved one who experiences palliative care, many feelings arise, including fear. Conclusion: drastic changes happen in the daily life of family care, contributing to their psychological and physical wear. It is up to health professionals to offer support to the family and minimize the suffering of the sick person.

DESCRIPTORS: Caregivers; Family; Palliative care; Nursing.

RESUMEN

Objetivo: analizar producciones científicas sobre cambios en la vida cotidiana de los cuidadores familiares de personas sometidas a paliaciones en el ámbito del hogar en la realidad brasileña. Método: revisión integradora de la literatura, realizada en septiembre y octubre de 2020, en la que se definió la pregunta de investigación: Qué cambios ocurren en la vida diaria del cuidador familiar de la persona en cuidados paliativos en el ámbito del hogar en el contexto brasileño? Se accedió a las bases de datos utilizando los descriptores “cuidadores” y “cuidados paliativos”. Resultados: Se seleccionaron 10 artículos, publicados de 2010 a 2020. El análisis de estudios primarios reveló que la vida diaria de los cuidadores familiares sufre varios cambios con repercusiones laborales, sociales, económicas y emocionales. Al cuidar a un ser querido que experimenta cuidados paliativos, surgen muchos sentimientos, incluido el miedo. Conclusión: ocurren cambios drásticos en el cuidado diario de la familia, contribuyendo a su desgaste psicológico y físico. Corresponde a los profesionales sanitarios ofrecer apoyo a la familia y minimizar el sufrimiento del enfermo.

DESCRIPTORES: Cuidadores; Família; Cuidados paliativos; Enfermería.

RECEIVED: 09/09/2021 APPROVED: 10/11/2021

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INTRODUCTION

Palliative care (PC) represents an approach that promotes the quality of life of individuals and their families who face diseases that threaten the continuity of life, through early identification, correct assessment and treatment of pain and other problems, whether physical, spiritual or psychosocial.¹

It is estimated that around 40 million people worldwide will need PC at some point in their lives, with chronic degenerative conditions being the most eligible.² In Brazil, PCs are offered in the health care network, making up the list of continuous integrated care, within the scope of the Unified Health System (SUS), according to resolution No. 41, of October 31st, 2018.³

Caring for the family becomes essential when considering that they experience the process of illness of their loved one and are often overloaded in their routine of life.⁴ The family member who is completely at the disposal of the sick person is called family caregiver. He plays an important role in all stages of illness, experiencing the challenges and burden of care, always aiming to provide better conditions for the sick person.⁵ Thus, the family caregiver requi-

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res from health professionals an active and qualified listening, and must be recognized and glimpsed in its uniqueness, being the target of interventions by the team.⁴

In this context, the role of the nurse with the caregiver stands out, who, through listening, aims at accepting the diagnosis and seeking to reduce the family's anxiety, always being attentive to problems in order to manage them in the best way. For this communication to become effective, it is important to seek an authentic approach and the establishment of a bond, providing a climate of trust so that the person can show their weaknesses and potential.⁶

A closer relationship with the family caregiver allows nurses to assess and recognize the needs that emerge in daily life, enabling the implementation of care aimed at contributing to the adaptation and improvement of quality of life. Therefore, this professional will be able to intervene, seeking to promote physical, social, spiritual and emotional well-being for the family, reduce the burden of care and implement effective strategies such as training the caregiver in providing care to the person in palliative care, health education, promoting moments of rest, and directing formal support services.⁷

Taking on comprehensive care leaves family members emotionally drained, physically exhausted and completely overwhelmed. Thus, support from within or outside the family circle becomes essential. As stated, the family caregiver also needs to be glimpsed in their singularities. Thus, the present aims to analyze the scientific productions on the changes in the daily life of the family caregiver of the person in palliation in the home environment in the Brazilian reality.

METHOD

This is an integrative review, with data collection carried out from secondary sources, through a bibliographic survey based on the daily life of the family caregiver of the person undergoing palliative care in the home environment.⁹

The integrative review was developed in six distinct stages: theme identification and formulation of a research question with relevance to health and nursing; and definition of databases and inclusion and exclusion criteria; categorization of selected studies and information collected; analysis of included studies; evaluation and discussion of results; presentation of the main results evidenced in the analysis of the articles included.⁹

The survey of scientific productions took place in September and October 2020, based on the guiding question: "What changes occur in the daily life of the family caregiver of the person undergoing palliation in the home environment in the Brazilian context?". The construction of the question involved the PICO acronym

¹⁰, where P stands for "population" (family caregiver of the person undergoing palliation); the I for "intervention" (not applicable); the C for "comparison" (not applicable, as it is not a comparative study) and O for "outcome" (changes in the daily lives of family caregivers).

The databases accessed were: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Online Medical Literature Analysis and Retrieval System (MEDLINE/PubMed), Latin American and Caribbean Health Science Literature (LILACS) and Scientific Electronic Library Online (SCIELO).

The descriptors, contained in the Health Sciences Descriptors - DeCS, "cuidadores" (caregivers) and "cuidados paliativos" (palliative care) were combined using the Boolean "AND" connector. In the LILACS and SciELO databases, descriptors were used in Portuguese and in CINAHL and MEDLINE/PubMed, in English.

The sample inclusion criteria were: national and international publication, including theses, dissertations and articles from online journals, with the text available for free access, whose focus has been the daily life of family caregivers, aged between 19 and 80 years, in the palliative care of the person in the home environment; in Portuguese, Spanish and English; and published in the last 10 years (2010-2020). Reviews, editorials, review articles and duplicate productions in the databases were excluded.

After reading the titles and abstracts of the 2105 publications found, scientific productions that were not in line with the proposed theme were excluded, as well as duplications, choosing 25 studies for full

reading. After a thorough analysis, 10 articles were selected to compose this review, being the research by two researchers. The process of identification, selection and inclusion of studies followed the recommendations of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).¹¹

To extract and organize the data, as well as to facilitate the characterization, analysis and discussion of the publications, a data collection instrument was used with the description of the following information: title; authors; year of publication; periodical; study population and setting; study design and method; purpose of the study; results; level of evidence.

The categorization of the level of evidence was based on the Agency for Health Care Research and Quality (AHRQ), in seven classification levels.¹²

RESULTS

The primary studies selected for this review were published between 2011 and 2019. As for the methodological design, only one publication falls under level 5 of evidence, as it is a systematic review of qualitative and descriptive studies, the others are level 6, that is, descriptive or qualitative studies.

Table 1 presents the characterization of the analysis of the articles referring to the title, year of publication, main results and level of evidence (LE).

DISCUSSION

The preservation of social life and leisure

Table 1. Primary studies selected for integrative review. Juiz de Fora/Minas Gerais, Brazil. 2021

TITLE	Year	MAIN RESULTS	LE
Support and support network of family caregivers of patients undergoing palliative care at home ¹³ .	2019	It was observed that some caregivers gave up their jobs and others stopped practicing leisure activities. Religion was a point of balance and support.	6
Together we resist, apart we fall: experiences of family caregivers of cancer patients in palliative care ¹⁴ .	2019	Changes such as social isolation, deprivation of leisure and disconnection from employment activities were noted. Religiosity and spirituality improve the general state of well-being and the caregiver's confidence, reducing the incidence of anxiety and depression.	6

Circumstances and consequences of care: characterization of the family caregiver in palliative care ¹⁵	2018	Professional disconnection was observed as a change; reduced working hours and lack of support. Depression and caregiver burden increase as patients' functional status declines. As for grief, anxiety, depression and somatization in the first months were unanimous.	6
Comfort level of caregivers of cancer patients receiving Palliative Care ¹⁶	2018	It was observed that caregivers who work outside the home experience a "second shift" in caring for the family. Receiving help is a positive condition for the caregivers' general comfort.	6
Corporeality of oncological patients in home palliative care: the experience of family ¹⁷	2018	A daily routine permeated by the caregiver's stress and impatience was evidenced when they needed to take care of a (usually) bedridden body, with a self-care deficit and that requires constant surveillance.	6
Meaning of being a caregiver of a family member with cancer and dependent: contributions to palliation ¹⁸	2016	It was observed that the caregiver experiences fear in their daily lives when receiving confirmation of the diagnosis, when facing the treatment, fears due to uncertainties regarding the indicated therapies.	6
Burden in care and its repercussions on caregivers of end-of-life patients: systematic literature review ¹⁹	2015	It was noted that the burden exposes caregivers to developing complicated, prolonged or traumatic grief.	5
Factors that influence the experience of the terminal and mourning phase: perspective of the main caregiver ²⁰	2014	It was observed that the caregiver is unable to ensure other socio-professional responsibilities and needs professional intervention. The communication established by nurses with the patient and family facilitates the caregiver's role.	6
Discussion of protocol for caregivers of cancer patients in palliative care ²¹	2012	It was noted that concerns about family and financial issues are recurrent and compromise well-being. Belief in spiritual help positively affects.	6
Family caregiver of the elderly in palliative care: the process of dying at home ²²	2011	It was noted that negative feelings are intensified with the proximity of death. Caregivers revealed emotional changes, physical strain and financial difficulties. Life has changed, highlighting: job loss, change of address and reduction of social life, in addition to neglecting your life or part of it, generating feelings of sadness, isolation, loss of freedom and carelessness.	6

Source: author.

re, even if partially, gives the caregiver strength to face the challenges that are placed in their life, however, in most cases, they do not feel motivated to reestablish a social life. This is because total dedication to care entails a lack of autonomy for the caregiver to lead their own life, as they are unable and insecure to leave the house and leave the family member alone or with another person, in addition to feelings of loneliness and loss of freedom.²³

An American study reveals that almost 40% of the interviewed caregivers who are not yet of retirement age decided to leave their jobs due to the demands of care and service. On the other hand, those who cho-

se to remain in work activity declared the existence of complications at work, resulting in low productivity and, consequently, emotional stress and doubled overload.²⁴

The amount of hours dedicated to caring for the family member is not always directly related to the level of overload presented, that is, even those caregivers who dedicate more than 18 hours of their day to care may have a low level of overload, showing the influence of other personal factors in their well-being.²⁵

The psychological wear of caregivers during the various stages of the illness process is inevitable, and it is necessary to develop multidisciplinary strategies to alle-

viate and/or face this situation.²⁶ However, many family caregivers may not feel entitled to seek psychological support, after all, they are not the carriers of the disease, emphasizing the importance of the healthcare team's attentive look.²⁷

The link between the nurse and the caregiver allows the professional to include actions in the patient's therapeutic plan in an integrated manner, positively affecting the experience of both and reiterating family-centered care. This interaction directly contributes to the caregiver's self-confidence, giving him the certainty that he is performing home care in a competent and safe manner.²⁸

Family support has positive effects on the caregiver's overall quality of life, as well as on the physical and mental domains.²⁹ However, a study reveals that 60% of participants do not have help to carry out care.¹⁶ The lack of recognition and help from family members can generate emotional exhaustion for the caregiver, which can lead to isolation and even to adopt attitudes of emotional contempt towards that recipient of care.³⁰

Family dysfunction worsens the caregiver's somatic symptoms, which stems from a constant need for readaptation to ensure care for the person undergoing palliation, as well as living in a conflictual environment, directly reflecting on their well-being.³⁰

The support from friends, neighbors and

colleagues will impact the general quality of life and the physical domain, but some negative effects in the mental domain; while the support of health professionals has positive effects in the physical and mental domains and in alleviating the burden. At this juncture, it can be said that social support reduces the emotional burden and prevents future health implications for the family caregiver.²⁹

The role of religiosity/spirituality is also highlighted, which gives meaning and logic to that condition of illness and death, which results in teachings and personal growth, minimizing suffering.³¹ It is up to health professionals, including the Nurse, to wake up to the religious and spiritual dimensions, aiming to reduce stress and anxiety and im-

prove the quality of life of family members at a time of so many uncertainties.³²

CONCLUSION

Drastic changes happen in the daily life of the family caregiver, especially if the level of dependence of the sick family member is high, generating a greater demand and a consequent increase in the level of burden. This continuous care contributes to the caregiver's psychological and physical strain, exacerbated by the lack of rotation, the impossibility of keeping a job or social relationships, and by the feelings experienced daily.

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