

PALLIATIVE CARE IN RHEUMATOLOGY: AN INTEGRATIVE REVIEW OF THE LITERATURE

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Abstract: Introduction: Systemic rheumatic diseases have seen great progress in their treatment over the last few decades, however some patients face limitations in their quality of life. Palliative care seeks to improve quality of life in advanced stages of these diseases, with rheumatologists playing a crucial role. The incorporation of this care into rheumatology practice is limited, highlighting the need to understand doctors' knowledge to improve care. **Objective:** Analyze scientific articles disseminated in online journals in the international and national scenario on the subject of palliative care and rheumatology. **Methods:** Integrative literature review, with data collection in the months of December 2023 and January 2024 in the LILACS, SCIELO and PubMed databases. 11 publications were identified that corresponded to the inclusion and exclusion criteria of the work. **Results:** Palliative care in rheumatology is crucial due to the complexity and impact of chronic diseases, which can result in great physical and emotional suffering for patients. Individualized treatment, focused on the specific needs of each person, is essential to improve quality of life and provide a more dignified end to life. **Conclusion:** Palliative care in rheumatology is essential to alleviate suffering and improve patients' quality of life, highlighting the importance of investing in research and training to offer more comprehensive and effective care. **Keywords:** Rheumatology, Palliative Care, Autoimmune diseases.

INTRODUCTION

Systemic rheumatic diseases have seen great progress in their treatment over the last few decades. Despite this, a specific population of patients persists (systemic vasculitis, scleroderma, inflammatory myopathies, severe forms of systemic lupus erythematosus and rheumatoid arthritis) who

still deal with illnesses that limit their quality of life (SALTMAN et al., 2020).

The most recent definition of palliative care is "active holistic care, offered to people of all ages who are in intense suffering related to their health, resulting from serious illnesses, especially those at the end of life. The objective of Palliative Care is, therefore, to improve the quality of life of patients, their families and their caregivers" (IAHPC, 2018).

In the final stage of systemic rheumatic diseases, patients face intense pain, multiple comorbidities, hospitalizations and recurrent infections. Palliative care is essential in this context, with crucial support from a multidisciplinary team dedicated to such care, aligned with the rheumatologist who, as an attending physician, must be prepared to offer comprehensive support, facilitating the early establishment of advance care planning (CHO et al, 2019).

The therapeutic arsenal is constantly evolving, giving patients longevity, although this does not always translate into quality of life. Despite this, as evidenced in the work of Crosby and Wilcock in 2015, the inclusion of palliative care in the theme of rheumatology has been unusual. As a consequence, there is a scarcity of publications on the topic.

Given this demand, it is important to know the most recent evidence on palliative care in rheumatology to promote better patient care.

OBJECTIVES

PRIMARY OBJECTIVE

Present an integrative review of the scientific literature on palliative care in rheumatology.

METHODOLOGY

This study constitutes an integrative review of the literature, whose purpose is to identify, capture and synthesize the bibliographic production on a specific topic (Mendes, et al., 2008). It covers the period from December 2023 to January 2024, following the following methodological procedures: formulation of a central question; selection of articles (considering inclusion and exclusion criteria); evaluation of pre-selected studies; analysis of results and preparation of a bibliographic review.

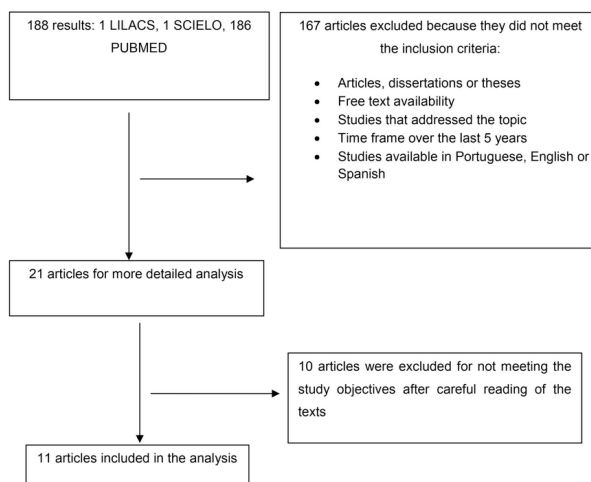
The theme of this study was established based on the guiding question: “What is the most recent evidence on palliative care in the context of rheumatology?”.

Subsequently, the search keywords were selected on the Health Sciences Descriptors (DeCS) platform, namely: “Palliative care”; “Rheumatology”; “Autoimmune diseases”. To carry out the search, the keywords were used in association with the Boolean operator “AND”. Therefore, the search for articles was carried out in electronic databases: Portal Regional VHL (LILACS), Scientific Electronic Library Online (SciELO) and National Library of Medicine (PUBMED).

The eligibility criteria used were applied as follows: full articles available electronically for free were included; written in English, Portuguese or Spanish; published between 2019 and 2023, and that were in line with the study theme. Abstracts of annals, dissertations, duplicate articles, ongoing projects, pilot studies or those presenting a conflict of interest were excluded.

The inclusion criteria were applied, leaving 21 articles to be analyzed. After the first selection, a more detailed evaluation of the articles was carried out, read in full, examining whether the topic in question was being addressed and whether there were duplicate articles in more than one database, ending

the search with 11 studies to be evaluated, as shown flowchart 1.



Flowchart 1 – Search strategy with the descriptors: “Palliative Care”, “Rheumatology” and “Autoimmune diseases”

Source: The author.

RESULTS AND DISCUSSION

Currently, medicine is witnessing major technological and scientific advances, which has led to the development of new therapies, increasing life expectancy and reducing mortality rates. On the other hand, the increase in the prevalence of neoplasms and chronic degenerative diseases requires medicine that, even without a guarantee of cure, improves the quality of life and guarantees a dignified death for the population (CONCEAÇÃO et al., 2019).

By the year 2050, it is estimated that life expectancy in Brazil will be eighty years. Therefore, the number of elderly people who will need palliative services will grow exponentially. Despite this, current data show that Brazil offers only 0.48 palliative care services per 1 million inhabitants (PASTRANA et al., 2012).

Faced with this challenge, an approach aimed at improving the quality of life of patients and their families in the face of a disease that puts the continuity of life at

risk becomes necessary. This care occurs through prevention and relief of suffering, which involves early identification, rigorous assessment and treatment of pain and other biopsychosocial and spiritual problems (SILVA; NIETSCHE; COGO, 2022).

The principles of palliative care include: seeking to understand the importance of life and death as a natural process; the establishment of care that does not accelerate the arrival of death, nor prolong it with disproportionate measures; providing relief from pain and other distressing symptoms; the integration of psychological and spiritual aspects in the care strategy and the offering of a support system to the family so that they can face the patient's illness and survive the period of mourning (HERMES; LAMARCA, 2013).

As the needs of patients and the disease evolve, there is a progressive transition between curative and palliative care. It is therefore assumed that the beginning of the palliative approach can occur from diagnosis, in a flexible, non-exclusive intervention model, leading to the provision of continuous, shared and preventive care (VASCONCELOS; CRUZ; BRAGANÇA, 2015).

All countries must implement palliative care programs with the aim of improving the quality of life of individuals with terminal and/or incurable illnesses and their families and interest in this approach has been growing in recent decades. However, most research and initiatives on the subject have occurred in economically developed countries (SILVA; NIETSCHE; COGO, 2022).

A WHO estimate shows that, in Brazil, between 521 thousand and 536 thousand people need palliative care, however, this tends to be indicated only in the final phase of life. Therefore, most people do not have access to this essential area of medicine, which restricts the work of specialized teams in this aspect. Furthermore, in their daily work,

health professionals encounter obstacles when applying palliative care, especially in decision-making, communication with family members and pain control (COSTA, 2021).

In recent decades, considerable progress has been seen in the treatment of rheumatic diseases, with a significant decrease in morbidity and mortality and physical limitations, in addition to an increase in survival. Despite these improvements, it is still common to find patients dealing with illnesses that progress rapidly or result in major physical deterioration, such as recurrent infections, damage to vital organs, loss of muscle mass, and treatment side effects, with a limited therapeutic response and prognosis. restricted lifestyle. In advanced stages, associated diseases, such as heart failure, pulmonary fibrosis, chronic kidney disease and dementia, negatively impact functionality, burden caregivers and increase healthcare costs (SIMON; SCHWARZEYWILL; BAUSEWEIN, 2008).

A study carried out by CHO et al. (2019) between 2006 and 2016 examined medical records of adult patients with rheumatic diseases who died in a Singapore hospital. The results showed that around half of the patients (50.9%) had disease activity in the last year of life. The most common symptoms included pain (81.4%), loss of appetite (80.1%), dyspnea (77%), and reduced functional capacity (64.6%). At the time of terminal hospitalization, common symptoms were dyspnea (83.9%), mental confusion (74.5%), loss of appetite (70.2%) and pain (68.3%). About 56.5% of patients received resuscitation attempts, while 11.2% underwent aggressive immunosuppressive treatments during terminal hospitalization.

Rheumatologists, doctors responsible for the long-term follow-up of patients with chronic diseases, play a fundamental role in providing supportive and psychosocial care

at the end of life, as highlighted by many treatment guidelines for rheumatological diseases, consistently mentioning quality of life measures (VAN VOLLENHOVEN et al., 2014) (FRAENKEN et al., 2021).

Palliative care, including management of depression and discussion of prognosis, is most appropriately provided by the primary treating physician. The common occurrence of premature deaths in rheumatic diseases highlights challenges in the natural course of these diseases. Despite therapeutic limitations and the potentially “fatal” nature of intense and systemic manifestations, palliative care has not yet received a comprehensive approach in the area of rheumatology (CROSBY; WILCOCK, 2011).

The care planning process involves discussions between the patient, family members and the healthcare team to make decisions about treatment goals, which can be adjusted as necessary. Carried out in advance, it helps to identify the patient’s concerns, values, personal goals, understanding of the disease and prognosis, as well as specific preferences for future assistance or treatments, according to availability and need (RIETJENS et al., 2017).

Identifying the end-of-life stage in patients with deteriorating chronic illnesses is challenging, even for familiar clinical teams. Prognostic assessment, based on the natural history of the disease and indicators of clinical decline, such as deterioration in functional status, is crucial. A pragmatic approach suggests asking the question “Would it be surprising if the patient died in the next twelve months?” as a signal to offer advance care planning. This approach requires sensitive communication skills to explore the patient’s wishes regarding end-of-life care in a voluntary, patient-centered manner. (THOMAS; STOBART-ROWLANDS, 2011)

Advances in palliative medicine, especially in non-oncological specialties such as neurology, cardiology and nephrology, have been made in recent years, reinforcing the importance of also developing palliative care in rheumatology, especially for patients with severe conditions or a poor prognosis (KAVALIERATOS et al, 2016) (TEMEL et al., 2010).

It is crucial to consider not only the specific symptoms of the rheumatic disease being treated, but also to recognize that rheumatic patients face symptoms other than physical ones that can cause distress. Therefore, individualized treatment, aimed at meeting the specific demands of each patient, is beneficial to improve quality of life and general well-being.

Therefore, it is essential to expand research into palliative care in rheumatology and the training of professionals to deal with the various forms of patient suffering, improving clinical practice and the quality of life of those seeking care.

CONCLUSION

Palliative care plays a significant role in rheumatology, especially for patients with chronic diseases with a poor prognosis. This approach not only alleviates the physical, emotional and spiritual suffering of rheumatic patients, but also improves their quality of life and overall well-being.

Therefore, it is essential to expand research and training in palliative care in the area of rheumatology, ensuring that healthcare professionals are trained to provide more comprehensive and effective care to patients.

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