

# End-of-life care in rheumatological diseases: current perspectives

## Introduction

Palliative care (PC), recognized as a rapidly expanding field, has become crucial in the treatment of patients with serious illnesses. The World Health Organization defines PC as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering”.<sup>1</sup> Its primary objective is to enhance the quality of life for patients and reduce burnout among caregivers, including both family members and health workers, in order to ensure a dignified life journey, regardless of the diagnosis.

Currently, PC is undeniably vital in cancer patient management. Its relevance is also growing in rheumatic diseases, particularly in handling complications and symptoms in patients with severe, treatment-resistant chronic conditions. This includes issues like malnutrition, anorexia-cachexia, metabolic alterations, and immunosuppression.<sup>2</sup> The primary focus in rheumatic research is attaining remission, even during highly active disease stages. Despite treatment limitations and the often severe and systemic nature of rheumatic diseases, PC remains relatively underexplored in rheumatology. This is particularly true where immunosuppressive therapy alone falls short.

## The need of palliative care in rheumatological diseases

As life expectancy increases and healthcare access expands, the need for adaptable PC grows. Although new treatments have improved outcomes and reduced morbidity and mortality in rheumatological diseases, some advanced cases still severely impact daily activities. This is particularly relevant for “fatal diseases,” known for their rapid, progressive, or complex courses. It has been reported that in hospice services, about 50% of patients experience symptoms of depression, while 70% encounter clinically significant anxiety, hindering a favourable evolution of the underlying disease.<sup>3</sup> Consequently, there’s a distinct role for PC in improving patients’ quality of life. This is particularly important given the current gaps in knowledge and skills in managing patients with rheumatological conditions, alongside standard curative treatments.

This need arises not only from the natural progression of certain rheumatological conditions like systemic sclerosis, which eventually become fatal regardless of advancements in treatments and eventually necessitate palliative management. It is also due to its association with various comorbidities and the long-term side effects of treatments.

In a recent paper, Cho,<sup>4</sup> reported a high prevalence of end-of-life symptoms in patients with systemic rheumatic diseases who passed away between 2006 and 2016, which was on par with that in other end-stage medical conditions, including cancer. Among these symptoms, pain—encompassing physical, mental, social, and spiritual aspects—was the most commonly reported by critically ill rheumatology patients, regardless of the diagnosis. Its multifactorial nature (inflammatory, central amplification of nociception, hyperalgesia) means that this symptom often resists conventional strategies, which calls for a holistic

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approach encompassing the assessment of factors associated with the disease, including gender, age, weight, ethnicity, and psychosocial status (anxiety, addiction), and the exploration of various methods for management, such as opioids, radiotherapy, spiritual practices, or supportive social interactions. Providing PC can take various forms: specialized hospitals and infirmaries, outpatient clinics, home care, etc. There’s no one-size-fits-all model for care delivery as it should be adapted to local needs and resources.

This will not only ensure a more dignified end-of-life experience for patients but also enhances their satisfaction with care. It can reduce symptom burden and, in some cases, improve survival rates, especially when introduced early in the patient’s journey.<sup>5</sup> This has prompted several guidelines to incorporate quality-of-life measures, such as fatigue management, depression, and pain assessment, in addition to the treat-to-target recommendations for conditions like SLE, Gougerot-Sjogren’s syndrome, and rheumatoid arthritis. The aim is to not only control disease activity and prevent damage but also to regularly assess the quality of life of these patients.

## Limitations of palliative care in rheumatological diseases

While the concept of integrating PC into rheumatoid conditions appears promising in theory, the reality presents a different picture. There is limited literature available regarding the prevalence of PC use in rheumatological diseases. For instance, one study focused on SLE patients, drawing data from the National Inpatient Sample database, which included a vast cohort of 1,467,126 SLE patients. The findings revealed that the utilization of hospital-based PC in these patients was quite low, at just 0.6% over a span of 10 years.<sup>6</sup> In the same study conducted by Cho and all, only a small fraction of these patients, specifically five individuals (3.1%), received the benefits of PC.<sup>4</sup> This raises the important question of why such a small number of patients with rheumatic diseases receive PC. One possible explanation is that, unlike in other neoplastic conditions where there is a consensus on staging that guides treatment decisions, there is no consensus on what

defines an “advanced rheumatological disease” that would warrant a shift towards PC rather than pursuing intensive treatment.

In contrast to advanced cancer, there can be a substantial time gap between the diagnosis of a rheumatic disease and the eventual passing of the patient. For example, in the case of patients with SLE, a significant majority (89%) experienced their deaths after a median duration of 10.2 years from diagnosis. The trajectory of rheumatic diseases can be intricate, characterized by fluctuating cycles of flares [ref], making it challenging to establish a clear “temporal proximity to death.” Additionally, there is often a considerable amount of time that elapses between the initial diagnosis of the condition and the eventual demise of the patient.<sup>7</sup>

Another significant limitation is the financial burden of PC, which often necessitates specialized facilities. This leaves many patients with unmet needs, especially in underdeveloped countries, where resources are scarce. This is further exacerbated by the fact that these patients often have multiple comorbidities, such as infections, cardiovascular diseases, and cumulative organ damage, requiring continuous monitoring. Another hindrance to the widespread adoption of PC is the lack of training for residents and appropriate assessment tools in clinical management, end-of-life education, and emotional support for patients. This results in a lack of confidence in their skills and delays in referring patients to PC, especially among younger patients.<sup>8</sup>

## Conclusion

Palliative care is a branch of medicine that utilizes an interdisciplinary approach to enhance the quality of life for patients facing serious illnesses and their families. When it comes to rheumatological diseases, PC still encounters numerous obstacles, whether due to the unpredictability of the courses of these conditions, the lack of training for the residents, or the limited resources (i.e., personnel, specialized facilities, and patients’ financial resources) necessary to meet their needs. Recent and comprehensive PC research could offer guidelines to physicians to develop better patient categorizations, enhance communication with patients,

prepare professionals for the job market with the essential tools to evaluate these illnesses, and ultimately provide a more optimal and personalized approach to end-of-life care, aiming to maintain the highest possible quality of life.

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## Conflicts of interest

The authors declare that there are no conflicts of interest.

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