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# PALLIATIVE CARE PATIENT COMPLEXITY CRITERIA: SCOPING REVIEW

Critérios de complexidade do doente em situação paliativa: *scoping review*

Criterios de complejidad para pacientes en situación paliativa: *scoping review*

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## ABSTRACT

**Background**: the multifaceted nature of palliative care requires continuous monitoring by a specialised team to ensure appropriate referral. **Objective**: to map existing evidence on the concept of complexity in palliative care and establish a consensus on classification processes for patients with palliative care needs. **Methodology**: a scoping review was conducted following the Joanna Briggs Institute methodology, using predefined eligibility criteria based on the mnemonic Population, Concept and Context. The search strategy included the CINAHL Complete, MEDLINE Complete and Science Direct databases. The inclusion criteria encompassed studies focused on adult populations in need of palliative care, studies reflecting the complexity of palliative care needs, and describing systems that characterise the complexity levels of patients. **Results**: of the five studies included, there was no consensus on the concept of complexity in Palliative Care. However, several common criteria emerged, including the presence of physical symptoms requiring management, functional decline, issues related to socio-family support, and ethical considerations. **Conclusion**: considering the limited number of available studies, further research is needed to establish a universally accepted concept. In Portugal, developing clear and unequivocal referral criteria aligned with patient complexity is essential to ensure appropriate levels of care.

**Keywords**: palliative care; complexity; classification

## RESUMO

**Enquadramento**: a complexidade em Cuidados Paliativos exige acompanhamento por uma equipa especializada, sendo fundamental para uma referenciação adequada. **Objetivo**: mapear a evidência acerca do conceito de complexidade em Cuidados Paliativos, procurando um consenso sobre a caracterização dos processos de classificação dos doentes com necessidades paliativas. **Metodologia**: *scoping review*, fundamentada no método preconizado pelo Joanna Briggs Institute; definidos critérios de elegibilidade relacionados com a mnemónica População, Conceito e Contexto. A pesquisa foi conduzida nas bases de dados CINAHL Complete, MEDLINE Complete e Science Direct. Os critérios de inclusão foram: população adulta com necessidade de Cuidados Paliativos, estudos que traduzam a complexidade das necessidades em Cuidados Paliativos e que descrevam sistemas que caraterizem os doentes de acordo com o nível de complexidade. **Resultados**: dos cinco estudos incluídos, não houve consenso sobre o conceito de complexidade em Cuidados Paliativos, surgindo, no entanto, alguns critérios comuns: sintomatologia física com necessidade de gestão, deterioração funcional, questões relacionadas com suporte sociofamiliar e questões éticas. **Conclusão**: são necessários mais estudos para definir universalmente o conceito, considerando o número limitado de trabalhos disponíveis. Em Portugal, devem ser estabelecidos critérios claros e inequívocos de referenciação, ajustados à complexidade dos doentes, para garantir a adequação do nível de cuidados.

**Palavras-chave**: cuidados paliativos; complexidade; classificação

## RESUMEN

**Marco contextual**: la complejidad de los cuidados paliativos requiere el seguimiento de un equipo especializado, lo que es esencial para una derivación adecuada. **Objetivo**: mapear la evidencia sobre el concepto de complejidad en cuidados paliativos, buscando un consenso sobre la caracterización de los procesos de clasificación de pacientes con necesidades paliativas. **Metodología**: *scoping review*, basada en el método recomendado por el Instituto Joanna Briggs; criterios de elegibilidad relacionados con la mnemotecnia Población, Concepto y Contexto. La búsqueda se realizó en las bases de datos CINAHL Complete, MEDLINE Complete y Science Direct. Los criterios de inclusión fueron: una población adulta con necesidad de cuidados paliativos, estudios que reflejen la complejidad de las necesidades de cuidados paliativos y que describan sistemas que caractericen a los pacientes según su nivel de complejidad. **Resultados**: de los cinco estudios incluidos, no hubo consenso sobre el concepto de complejidad en Cuidados Paliativos, aunque surgieron algunos criterios comunes: síntomas físicos que necesitan tratamiento, deterioro funcional, cuestiones relacionadas con el apoyo sociofamiliar y cuestiones éticas. **Conclusión**: son necesarios más estudios para definir universalmente el concepto, teniendo en cuenta el limitado número de estudios disponibles. En Portugal, deben establecerse criterios de derivación claros e inequívocos, ajustados a la complejidad de los pacientes, para garantizar la adecuación del nivel asistencial.

**Palabras clave**: cuidados paliativos; complejidad; clasificación

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## INTRODUCTION

The lack of standardised criteria for assessing complexity in palliative care (PC) presents a significant challenge in ensuring the appropriateness of the level of care.

The World Health Organization (WHO, 2020) defines PC as an approach that aims to enhance the quality of life of patients with life-threatening health conditions and their families. Its primary objective is to prevent and alleviate suffering through the early detection and treatment of physical, psychological and social problems. The Palliative Care Framework Law (Lei n. º 52/2012, p. 5119) defines palliative care as “active, coordinated and global care, provided by specialised units and teams, either in hospital settings or at home”.

In turn, the Strategic Plan for the Development of Palliative Care 2021-2022 (PEDCP), developed by the Comissão Nacional de Cuidados Paliativos (2021), highlights the organisation of the National Palliative Care Network. This network integrates PC within the community, hospital, and integrated long-term care settings by establishing specialised PC teams responsible for direct care and advisory functions. In 2020, it is estimated that only around 14% of individuals worldwide in need of PC received it (WHO, 2020), with approximately 9,000 individuals in Portugal requiring such care (Comissão Nacional de Cuidados Paliativos, 2021).

This same document highlights the existing gaps in the provision of PC, particularly the disparity between identified needs and the actual delivery of care by specialists in the field. Consequently, the complexity and high demands of end-of-life care require a broader scope and quality of interventions, which should be guided by well-defined and up-to-date protocols (Soares et al., 2023).

Therefore, given the documented lack of resources for the provision of PC in Portugal, and to ensure their appropriate allocation - prioritising patients with the most urgent care needs - it is important to define the concept of complexity in PC.

Currently, there is no standard definition for the concept of complexity associated with PC. However, the National Health Service (2010) understands it as a multidimensional construct involving the number, severity, and interaction of various domains within a holistic patient assessment. Similarly, Hodiamont et al. (2019) define it as arising from the patient’s condition and the extent of their resulting needs. They characterize it as a multifaceted concept influenced by patient-specific factors influencing the surrounding environment, encompassing the intensity of the symptoms experienced that often necessitates the intervention of PC specialists.

From the perspective of Carduff et al. (2018), complexity in PC serves as a distinguishing factor between patients with terminal illnesses who benefit from a specialised approach and those whose needs can be met by a team of undifferentiated professionals. They further argue that exploring the determinants of complexity within palliative contexts is essential for ensuring appropriate patient referral to different care contexts.

Therefore, this scoping review aimed to map the recommendations in the scientific literature on the criteria for assessing the complexity of patients in palliative care. The objective was to identify a consensus on the characterisation of the processes for classifying patients with palliative needs.

## METHODOLOGICAL REVIEW PROCEDURES

The selected methodology - scoping review - is designed to explore the existing literature on a given topic, mapping and synthesising factual evidence while identifying gaps in current knowledge (Peters et al., 2020).

To carry out this type of review, five stages were outlined: formulating the research question, identifying relevant scientific evidence, selecting articles for inclusion, structuring the collected data and synthesising and presenting the findings (Arksey & O'Malley, 2005). It is important to note that this methodological approach does not require ethical approval and is not intended to assess the potential systematic errors in the included scientific publications that could lead to biased results (Peters et al., 2020).

This review followed The Joanna Briggs Institute (2015) framework, using the PCC mnemonic (Population, Concept, Context).

In this study, the population under study comprised patients with advanced and progressive incurable diseases in the context of PC. The concept under investigation focused on the complexity of PC needs, namely the classification processes to categorize these patients.

Based on the use of PCC, it was possible to formulate the research question: "What are the criteria for assessing the complexity of a patient in a palliative situation?".

To ensure unequivocal interpretation, the formulation of the research question needed to incorporate the elements defined within the PCC framework. These elements established the inclusion criteria to guide the research, providing a robust foundation for conducting this methodological approach (Peters et al., 2020).

This review included primary studies involving adult populations requiring PC, addressing the complexity of their PC needs and describing classification systems that characterise patients based on their level of complexity. Studies on populations under 18, lacking explicit classification of PC needs, were excluded from the review.

The selection process was guided by the PRISMA Extension for Scoping (Tricco et al., 2018) and the entire process is explained in the following sections.

This research began with an enquiry into the available evidence across various electronic databases, using broad terms related to the topic. Titles, abstracts, and indexing terms were screened to refine the selection of relevant search terms. Following this step, controlled vocabulary terms from MeSH, CINAHL headings, and a free-text term were defined (Table 1).

The literature search was conducted across three databases - CINAHL Complete, MEDLINE Complete, and Science Direct, accessed via the EBSCOhost content aggregator provided by the Escola Superior de Enfermagem do Porto. The Boolean search strategy applied was ('PALLIATIVE CARE')AND('COMPLEX*') AND('CLASS*').

Table 1

Search terms

| **DeCs** | **Mesh** | **Cinahl Headings** | **Free Terms** |
|---|---|---|---|
| *Palliative Care* | *Palliative Care* | *Palliative Care* | |
| *Classification* | *Classification* | *Classification* | |
| | | | *Complexity* |

This review included all studies published up to 29 April 2022 in the specified databases. Regarding search limitations, studies were restricted to three languages - Portuguese, English and Spanish - and only studies published in peer-reviewed scientific journals were considered. This criterion ensured all included studies had undergone expert scrutiny within the same academic field. However, as a result, grey literature was excluded, which may be considered a limitation of this study.

The relevance of the selected articles was assessed by two independent reviewers (DS and AC) by reading the titles and abstracts. In the next phase, the full texts of the studies that met the predefined criteria were also analysed by two independent reviewers.

Subsequently, two independent reviewers (CF and AS) synthesised the extracted data using a standardised data extraction table (Table 2).

The issues emerging during the described phases were resolved through discussions between those involved and the other authors not included in the specific phase under consideration.

## RESULTS

The selection process for studies included in this research is shown in Figure 1, using a flowchart. This process was conducted in accordance with the PRISMA Extension for Scoping Reviews, providing a schematic representation of the initially identified publications, those ultimately incorporated into this research, and the excluded publications, along with the reasons for their exclusion (Tricco et al., 2018).

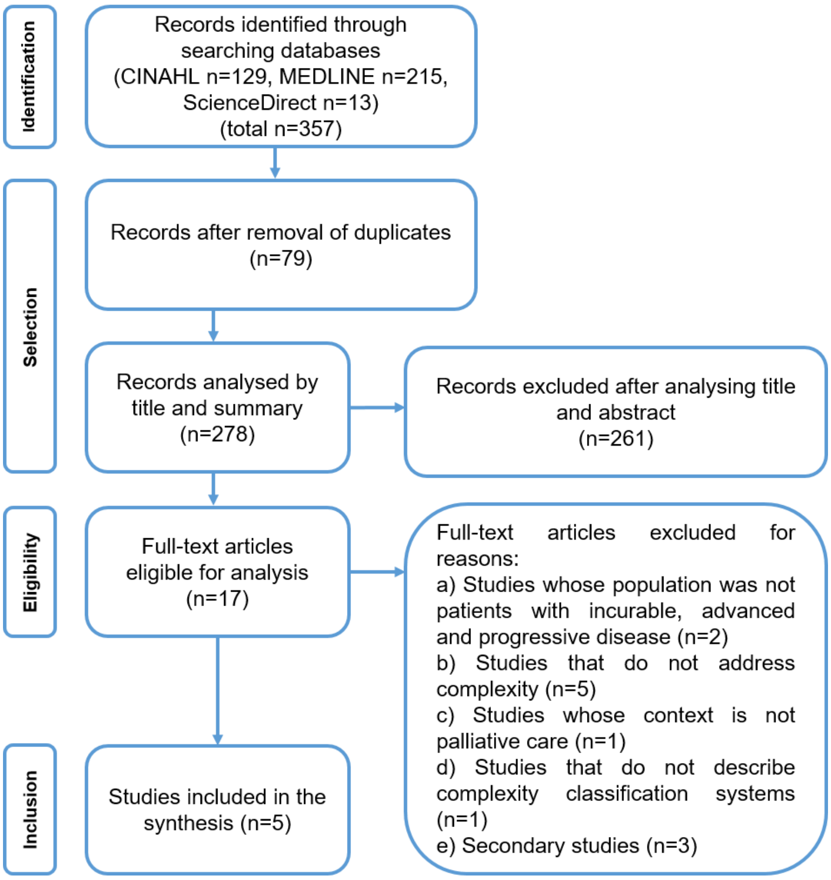

Figure 1

PRISMA flowchart of the study selection process (adapted from Tricco et al., 2018)

The search identified 357 studies in the selected databases. Following the removal of duplicates, 278 studies were retained for analysis. After reading their titles and abstracts, 261 studies were excluded. A full-text reading of the remaining 17 studies led to the exclusion of 12 papers because they did not meet the predefined inclusion criteria. Consequently, a total of five studies were incorporated into this review.

A complete analysis of the five eligible studies enabled the extraction of data relevant to addressing the research question and the objective of this scoping review. Table 2 summarises the extracted data, including details on the authors, year and country of origin, objective, study design, interventions and key findings.

Table 2

Answers to the research questions addressed in the study

| Author(s), date and country of origin | Participants | Objective | Study design | Assessment Interventions/ Instruments | Results |
|---|---|---|---|---|---|
| Comino et al., 2017<br>Spain | 74 patients in need of PC. | To describe the complexity of patients registered as recipients of PC in health centres and PC teams in the Seville health area. | Cross-sectional descriptive observational study. | Application of the PC Complexity Diagnostic Instrument (IDC-Pal©), which identifies 36 elements of complexity grouped into three categories (patient, family and social environment, care organisation). | The most prevalent element of complexity was a sudden change in the level of functional autonomy, followed by symptoms that were difficult to control.<br>The element most used to activate the advanced PC team is the oncological nature of the disease.<br>General care and advanced care PC teams treat patients regardless of complexity.<br>IDC-Pal© could be the solution for deciding on referral. Need to homogenise the term complexity in PC. |
| Tuca et al., 2017<br>Spain | 24 care centres (16 primary centres, three hospitals, three home PC teams and two medium-long term care centres).<br>324 patients in need of PC. | To identify factors related to the definition of complexity in PC in patients with advanced cancer, to explore previous models and to propose a scale for assessing levels of complexity. | Prospective observational study multicentre. | Questionnaire filled in by patients. | The variables that define complexity in PC are symptom burden, refractory pain, deterioration in general or functional status, socio-family risk and ethical/existential problems.<br>Creation of two scales to assess complexity in PC: PALCOM 1 and PALCOM 2.<br>Difficulty in defining homogeneous complexity criteria. |
| Esteban-Pérez et al., 2018<br>Spain | 500 patients (248 in the prospective phase and 252 in the retrospective phase). | Validate the application of a care model in the management and referral of complex cases by three healthcare | Cross-sectional and observational study in two phases: prospective | A model based on patient/family needs, with six areas of complexity: clinical, psycho-emotional, socio-family, spiritual, death-related and ethical. | The area of complexity most observed by the teams was clinical complexity, followed by psycho-emotional, socio-familial and ethical complexity. |

| | | | | | |
|---|---|---|---|---|---|
| | | teams (primary healthcare, community team and hospital). | and retrospective. | | The tool is useful for assessing levels of complexity regardless of the type and prognosis of the illness. |
| Pask et al., 2018<br>United Kingdom | 65 participants (10 patients and carers, 38 health professionals and 17 managers). | Explore what makes a PC patient more or less complex, develop a concept of complexity. | Qualitative study, using interviews. | Face-to-face interviews were held to discuss complexity in PC and how it can be characterised. | The elements of complexity identified were related to the person; the illness and needs; interactions between the family, professionals and the environment; PC services and social influences.<br>The complexity of the patient implies a holistic view. |
| Carrasco-Zafra et al., 2020<br>Spain | 501 patients. | To describe the levels of complexity in patients admitted to a PC centre, to determine which elements are most prevalent and to identify factors that may be related to complexity in patients with advanced cancer. | Observational retrospective study. | Collection of the patient's clinical data<br>Use of the Barthel Index and the Palliative Performance Scale;<br>Analysis of the data according to the IDC-Pal©. | The most commonly observed dimension of complexity is the clinical dimension, through reduced autonomy and symptoms that are difficult to control.<br>The absence of a carer or insufficient family support is a frequently observed item.<br>Significant prevalence of levels of complexity in patients with advanced cancer. |

## DISCUSSION

This study aims to map the available scientific evidence regarding the complexity of patients undergoing PC. To achieve the research objective, five primary studies published in 2017, 2018 and 2020 were included. The contemporaneity of these studies suggests that the topic has gained recognition in recent years. All selected studies examined the European context, particularly in Spain and the United Kingdom. In terms of study design, four of the studies employed quantitative methodologies, while one adopted a qualitative approach.

Three of these studies, Tuca et al. (2017), Carrasco-Zafra et al. (2020) and Pask et al. (2018), concur that there is currently no standardised definition of the concept of complexity. Comino et al. (2017) further emphasise that defining and classifying this concept is essential to ensuring patient access to specialised services. Meanwhile, Esteban-Pérez et al. (2018) acknowledge the challenges in reaching a consensus on a definition, highlighting the importance of clarifying complexity assessment models. They specifically refer to the model described in their study as a tool for improving management and facilitating referrals across different levels of palliative care.

Tuca et al. (2017) are the only authors to propose a definition of complexity, formulated based on their research findings. They define complexity as a multidimensional construct influenced not only by variables stemming from the patient's life experiences but also by the expertise and training of the healthcare team responsible for their care. The authors conclude that analysing the interaction between these variables provides a more significant representation of patient complexity than examining each variable in isolation (Tuca et al., 2017).

All the studies reviewed propose models for classifying patients based on their complexity. Comino et al.

(2017) and Carrasco-Zafra et al. (2020) focused their research on the use of the IDC-Pal©, aiming to describe the complexity of patients receiving PC and determine the prevalence of factors contributing to this complexity. Comino et al. (2017) concluded that the most prevalent element of complexity in their study was the sudden decline in the level of functional autonomy, independent of the patient's relationship with the healthcare team, followed by symptoms that were difficult to manage. The authors concluded that both general and advanced PC teams provide treatment irrespective of patient complexity and, consequently, recommended the IDC-Pal© as a tool to facilitate the referral process of PC patients.

Similarly, Carrasco-Zafra et al. (2020) identified the clinical dimension, loss of autonomy, and challenging symptom management as the most complex descriptors, adding the recurrent aspect of the lack of family support. The authors emphasised that using a structured instrument to define patient complexity is valuable for helping healthcare professionals anticipate patient needs, adjust levels of care accordingly, and facilitate appropriate referrals (Carrasco-Zafra et al., 2020).

Given the similarities in the conclusions drawn from both studies, the IDC-Pal© can be regarded as a valid and reliable tool for assessing patient complexity. Its application in two different contexts yielded highly consistent results, demonstrating its robustness in defining criteria that determine complexity in PC. Furthermore, since the IDC-Pal© has already been validated for use in the Portuguese population, it is the instrument recommended by PEDCP 2021-2022 to support an adequate assessment of complexity. This tool aims to facilitate the early referral of patients with complex palliative care needs.

The remaining three studies on developing models that diverge from existing ones. In the study by Tuca et al. (2017), the authors describe the creation of two instruments: PALCOM 1, which aims to assess the influence of five previously identified variables on the definition of complexity in PC, and PALCOM 2, which aims to estimate the probability of the level of complexity in PC based on the data collected from an initial questionnaire and subsequent data gathered through the application of PALCOM 1. The authors concluded that the most statistically significant variables were symptom burden, refractory pain, deterioration in general or functional status, socio-familial risk and ethical/existential problems.

Esteban-Pérez et al. (2018) proposed a model based on six domains: clinical, psycho-emotional, socio-familial, spiritual, aspects related to death and the dying process, and ethical considerations. These factors were assessed at the time of patient admission to PC and upon discharge to correlate these factors with the observed level of complexity. The authors concluded that the most prominent domains among patients identified as complex, were clinical, followed by psycho-emotional, socio-familial and ethical. The instrument was applied by various teams with different levels of training and professional experience across different care contexts. Despite this variability, consensus was reached in identifying and differentiating levels of complexity, thus ensuring the instrument's viability and reliability.

In the study by Pask et al. (2018), the authors describe a model based on Bronfenbrenner's ecological systems theory and its applicability to PC. This model outlines elements associated with the individual, dynamic aspects related to the illness and care needs, interactions between the family, healthcare professionals and the environment, PC services, and social influences. The components of this model were derived from data obtained through semi-structured interviews, exploring the definition of complexity as perceived by health professionals, carers and patients themselves. Given the qualitative design of the study, it is important to note that the interpretation of the collected data may always be influenced by subjective factors, which constitutes a limitation of the study.

Although the last three studies employ different instruments, an analysis of their results reveals that the criteria for complexity most frequently mentioned align in several key areas: the presence of physical symptoms requirement management, deterioration in functional status, issues related to socio-family support, and ethical concerns. Compared to the first two studies analysed in this chapter, it can be concluded that the presented models also share areas of convergence. For example, the IDC-Pal© focuses its evaluation points on issues related to clinical and psycho-emotional factors, elements influenced by the family and the environment, and those related to the organisation of care. Consequently, it can be inferred that all the studies analysed exhibit common conclusions.

Due to the specificities of the research strategy employed, this scoping review includes data derived exclusively from five studies. This limitation, coupled with the constraints previously discussed throughout the text, may restrict the generalisability of the results. Furthermore, as noted, the studies were published between 2017 and 2020, indicating that the topic is still in its early stages of investigation. This limited timeframe suggests that the subject remains a recent area of inquiry, underscoring the need for further research to enable the development of more robust conclusions.

## CONCLUSION

In light of the preceding discussion and alignment with the objectives of this review, it can be concluded that, based on the scientific evidence presented, all the models used are based on the needs of patients and their families. These models are essential for defining the concept of complexity in PC and adequately guiding the necessary care.

The five studies analysed converge on the importance of assessing patients with palliative needs in a holistic manner, recognising the significance of the patient, their interpersonal relationships and the surrounding environment.

Upon reviewing and comparing the studies included in this research, it can be concluded that a clear and unambiguous definition of the complexity of PC, as well as the criteria that underpin it, has broad implications for the clinical practice of the multidisciplinary team. Such a definition allows for accurately determining of the appropriate level of care based on the patient's care needs, facilitating timely referrals and enabling more effective management of available resources. In turn, this enhances the quality of the care provided and improves clinical outcomes. In sum, it ensures that patients are allocated to the appropriate care setting, where a multidisciplinary team with the requisite expertise can deliver the necessary care.

The development of this scoping review indicates that, given the contemporary nature of the subject, further quantitative and qualitative studies should be carried out in the future to establish a universally accepted definition for the concept of complexity in PC. Specifically, within the Portuguese context, it is crucial to validate additional instruments for assessing complexity, such as PALCOM, and to define clear unequivocal criteria for patient referral to the different levels of PC according to the complexity of the patients.

## CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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