v. 2, n. 33, 2022

International
Journal of
Health
Science

SENSITIVE INDICATORS TO NURSING CARE IN PALLIATIVE CARE: AN INTEGRATIVE LITERATURE REVIEW

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DOI 10.22533/at.ed.1592332230067

Abstract: Palliative care aims to improve the quality of life of patients and their families, following a process of chronic and/or advanced, severe and life-limiting disease. Nurses, through the therapeutic relationship with patients and their families, have a fundamental role in its implementation. Obtaining quality indicators sensitive to nursing care in palliative care is necessary to promote the quality and objectives of this care. The present study aimed to evaluate and synthesize empirical evidence on sensitive indicators for nursing care in palliative care through an integrative review with thematic synthesis, using the CINAHL, PubMed, MEDLINE, Nursing & Allied Health Collection: Comprehensive, Cochrane databases. Central Register of Controlled Trials and MedicLatina. Studies on sensitive indicators of nursing care in palliative care, written in English, Spanish or Portuguese, from May 2012 to April 2022 were considered. The articles were selected, evaluated and reviewed by two authors. Quality assessment was performed according to Hawker criteria. Found 1,528 records, 22 articles were included in the analysis. Fifty indicators were identified distributed in the dimensions of structure, process and result in 8 sensitive domains to nursing care in palliative care, namely structure and care process; physical aspects of care; psychological; cultural; spiritual, religious and existential; ethical and legal care and care for the patient in imminent death. The development of a set of indicators sensitive to nursing care is essential for the continuous improvement of care and visibility of nursing care in palliative care.

Keywords: palliative care; nursing; health indicators; revision

INTRODUCTION

Palliative Care (PC) is differentiated care that seeks to improve the quality of life of patients, families and caregivers, through the identification, diagnosis and treatment of physical, psychological, social or spiritual problems. They are applied early and in a timely manner in the course of chronic, complex or life-limiting diseases, in conjunction with disease-modifying or potentially curative therapies. They use ethical principles and advance care planning to identify patients' priorities and goals. They provide family care and bereavement support, personalized, for adults and children, as needed. They are provided by interdisciplinary teams: doctors, nurses, social workers, psychologists, spiritual/religious assistants with adequate training and experience; in the context of hospitalization or domicile. [27,35] Given their centrality and proximity to care recipients, nursing teams play a key role in identifying and meeting the needs of patients and families.

Health gains, sensitive to nursing care, demonstrate the variable and measurable state, behavior or perception of a person or family, which is largely influenced by nursing interventions that depend on the nurse's conception. [32] To monitor these gains, indicators are needed, defined as quantitative or qualitative factors or variables, which constitute a reliable and simple means of making a phenomenon measurable, fundamental to illustrating changes associated with a given intervention, since they describe and provide indications about this same phenomenon, in a given time and space. [26] The production of a set of care-sensitive indicators implies, however, that it is incorporated into the routine of the PC nursing teams and in the respective information systems. Ideally, they must be evidence-based with a theoretical foundation, such as Donabedian's theoretical model, where the conceptual framework is based on the concepts of structure, processes and outcomes. [7]

The objective of this study is to evaluate and synthesize empirical evidence on sensitive indicators for nursing care in PC.

METHODOLOGY

An integrative literature review was carried out in order to obtain a deeper understanding of the phenomenon, allowing the inclusion of several previous study methodologies. [25] The review presented followed the methodological procedures outlined by the Center for Reviews and Dissemination. [4] The *Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA)* methodology was used as a reporting guideline.

RESEARCH STRATEGY

The research strategy was defined in April 2022 by one of the authors with the help of an expert librarian. The phenomenon of interest was the sensitive indicators of nursing care in PC, in all PC contexts. [4] Systematic research work was carried out in May 2022.

DATABASE LOOKUPS

Systematic searches were performed in the CINAHL, PubMed, MEDLINE, Nursing & Allied Health Collection: Comprehensive, Cochrane Central Register of Controlled Trials and MedicLatina databases. Wereused the followingsearch phrases: " Palliative Care" AND "Delivery of Health Care" AND "Nurses"; "Palliative Care" AND "Quality Indicators, Health Care"; "Palliative Care/ standards" AND "Quality Indicators, Health Care" OR "Nursing"; "Clinical Competence/ standards" AND "Palliative Care" AND "Nursing"; Needs Assessment" AND "Palliative Care" AND "Nurses".

Studies written in English, Spanish and Portuguese, published in the last 10 years (from May 2012 to April 2022) were considered, in order to reflect the relevant and most recently published data, taking into account the development observed in the last decade. in terms of CP. In addition, all references and citations in the included articles were checked to ensure that no relevant research was missed.

ELIGIBILITY CRITERIA

Articles that presented empirical studies on sensitive indicators of nursing care in PC in various PC contexts were included. Table 1 provides detailed inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
1. Peer reviewed research; 2. Studies that integrate the provision of care to people aged ≥ 18 years; 3. Results with indicators associated with nursing care in the context of PC or end-of-life; 4. Full text available.	1. Results with indicators associated with other health or multidisciplinary professionals; 2. Studies carried out in contexts of care delivery outside the scope of PC.

Table 1. Inclusion and exclusion criteria.

SELECTION OF STUDIES

After rejecting duplicate and irrelevant articles, titles and abstracts were screened based on inclusion criteria. Screening was performed independently by two team members. 134 full-text articles were selected for eligibility, leaving 22 articles included in the initial quality assessment and analysis. Figure 1 presents the PRISMA flow diagram.

DATA EXTRACTION

Data extraction was also performed by two reviewers using a model that was developed and tested in 5 articles for the present study. [4] The model was based on the PICO structure, in which: P = participants/ population (nurses, patients and family members); I = intervention or phenomena of interest (sensitive indicators of nursing care in PC); C = context (different PC delivery contexts) and O = results (indicators). [4] Data from each study included information on author(s), country, research method(s), PC context, and main findings.

DATA ANALYSIS AND SYNTHESIS

The results of the included studies were summarized using a qualitative approach, given the diversity of objectives, methodology, participants, context and results. A synthesis was performed for the interpretation of the results.[4]

QUALITY ASSESSMENT

All studies included in the analysis were independently evaluated by two investigators. Taking into account the heterogeneity of the 22 studies included in this review, the Hawker and colleagues scale was used to assess methodological quality.[14] This 9-question scale has score limits between 9 and 36. The study scores ranged from 19 to 34 which reflects medium to high quality, so all studies were included.

RESULTS

The results of this review are presented, analyzing the characteristics of the articles included, followed by a presentation of the indicators sensitive to nursing care.

FEATURES OF THE INCLUDED ARTICLES

The articles included presented studies carried out with a frequency of 3 in Australia, [23,28,31] the United States of America (USA), [8,21,22] and Japan;[13,24,29] with 2 articles the Netherlands is presented;[17.33] with 1

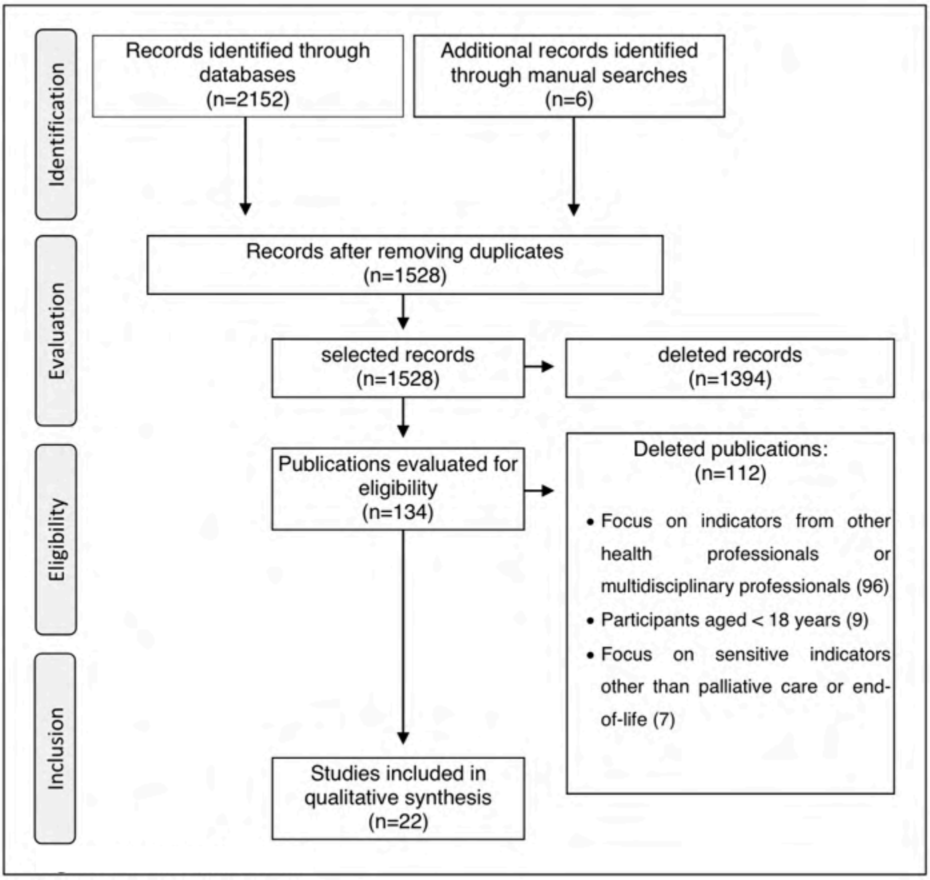

Figure 1. PRISMA flowchart.

article, Belgium, [20] Colombia, [37] South Korea, [36] Scotland, [15] Spain, [38] Italy, [30] Taiwan, [5] Norway, [12] New Zealand; [9] and 2 others in several countries [6.34] between 2012 and 2020. Regarding the design, the quantity stands out (n=9); [5,21-23,28-30,33,36] Delphi (n=6) [6,8,13,20,24,34] and with mixed methodologies (n=4). [12,36-38] The qualitative design was only used in 14% of the studies. [9,15,31] The participants were essentially nurses,[5,9,12,15,17,21-23,28,29,31,33,36-38] but patients were included, [17,21] family members [17,31] and others professionals.[6,8,13,20,23,24,30,33,34] The sample size in the included studies ranged from 1 to 2377 participants. The context of the studies focused on hospitals (PC services and acute services), home care services and *hospices.* The included studies investigated sensitive indicators for nursing care in PC from different perspectives and domains.

SENSITIVE INDICATORS FOR NURSING CARE IN PALLIATIVE CARE

From the thematic analysis, 50 indicators were synthesized in Table 2 and grouped into 8 domains: (i) structure and care process; (ii) physical aspects of caring; (iii) psychological aspects of caring; (iv) social aspects of caring; (v) spiritual, religious and existential aspects of caring; (vi) cultural aspects of caring; (vii) care for the patient in imminent death and (viii) ethical and legal aspects of care. The final set of indicators (reflecting the Donabedian model [7]) contains 11 structure, 32 process and 7 result indicators. The domain of the structure and care process was the only one that included indicators in the 3 dimensions of the model.

Process indicators are the ones that emerge most in the studies, in agreement with the literature, especially in the domains of (i) the structure and process of care and (ii) physical aspects of care. It seems to be more difficult to identify care indicators related to (iii) psychological, (iv) social, (v) spiritual and (vi) cultural aspects of care. However, some process indicators related to (vii) patient care in imminent death and (viii) ethical and legal aspects of care were identified.

The structure indicators identified are essentially included in the domain of (i) structure and care process, because they are usually related to material and human resources and other institutional or management aspects. A special preponderance of indicators related to the staffing and training of nurses was observed.

Few result indicators were identified, these being related to the domain (i) structure and process of care, emerging aspects related to the satisfaction of the patient and family with the care provided, the assessment of quality of life and the agreement between the preference of the place of death and its occurrence. The assessment of the grieving process was also identified. However, outcome indicators offer the opportunity to understand the experiences lived by patients and assess the effectiveness, effectiveness and efficiency of nursing care, so they have an important impact on the monitoring of care and their absence leads to a misunderstanding of the meaning. of the same.

In the context of PC provision, the results presented do not allow characterizing the theme in these contexts. However, it is necessary to reflect on this characterization for each context.

DISCUSSION

The synthesis of a set of sensitive indicators for nursing care in PC, using a recommended and evidence-based approach,[2,4] allows us to reflect on the need to assess the quality of care, taking into account the high multidimensional suffering of patients and their families in CP.

Domain	Structure	Process	Result
Structure and Process of Care	· Staffing of the nursing team per home team [30.31] · Total effective days of home care per year [30] · Service available 24 hours a day in the rural community [31] · Existence of a team self-care plan [23] · Presence of 1 nurse specialized in PC in the emergency department [22] · Existence of internal nursing consultation of PC [33] · Percentage of nurses with advanced training in PC [34] · Existence of an in-service training program on the main PC themes (communication, management and control of symptoms, ethical issues, teamwork, spiritual support) [5,9,17,36] · Percentage of nurses with knowledge and training in communication techniques and breaking bad news [29]	· Use of identification tools for patients with PC needs [17,21] · Percentage of patients in need of PC who receive specialized PC in an acute hospital setting [8] · Number of patients in follow-up [30] · Number of home visits per week per patient [30] · Percentage of all patients hospitalized for more than one day who had a comprehensive assessment (screening for physical symptoms and discussion of patient/family emotional or psychological needs) completed within 24 hours of admission [6.8] · Percentage of patients with a complete record of prognosis, psychosocial symptoms, functional status, symptom burden, and documentation of care wishes within 48 hours of admission [20] · Percentage of patients with assessment of their care preferences on admission [20,33] · Percentage of patients with a multidimensional and individualized care plan [29,34] · Percentage of patients with an advance care plan [6, 33] · Percentage of patients and family members with assessed needs and adequate treatment plans [33] · Coordination between hospital and community health care services [29] · Use of communication strategies in a multidisciplinary team [29] · Carrying out team self-care activities [23]	· Patient satisfaction index [21] · Family satisfaction index on the quality of care in the last month of the patient's life [8] · Caregiver Information Needs Satisfaction Index [37] · Percentage of patients scoring 5 or more on a scale of 0 to 10 for quality of life [20] · Quality assessment of nursing PCs by nurses [38]
Physical Aspects of Caring	· Percentage of nurses with knowledge and training on symptom relief per team [29]	· Percentage of patients who underwent a general symptom assessment (pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, well-being, shortness of breath, constipation) using a validated scale (e.g. ESAS scale) [6,20,21,24,34] · Percentage of patients with symptom assessment at least once day [13] · Percentage of patients reporting pain and/or other symptoms at admission that reduce intensity to a level of satisfaction within 24 hours of admission [34] · Percentage of patients/caregivers with teaching interventions on therapeutic regimen management [13] · Percentage of patients with regular oral care [29]	
Psychological Aspects of Caring		· Percentage of family members with a plan and support in the grieving process [13,20,24]	· Family grief assessment [24]

Social Aspects of Caring		· Percentage of caregivers with plans with assessment, discussion and planning of care according to their needs [15,20] · Percentage of caregivers who received all necessary assistance in the care process [20]	
Spiritual, Religious and Existential Aspects of Caring		· Percentage of patients/family with assessment, discussion and care planning plans based on spiritual/religious needs [8,28]	
Cultural Aspects of Caring		· Percentage of patients/family with assessment, discussion and care planning plans based on rituals and cultural habits [28,34]	
Care of the Patient in Imminent Death		· Percentage of patients who died in which the possibility of death in the last hours (UHV) or days of life (UDV) was identified [12,30,34] · Percentage of care plans adjusted to the needs of the patient/family in the UHV or UDV [29] · Percentage of family members informed about UHV or UDV [12] · Percentage of family members included in the care plan at the UHV or UDV [12]	· Percentage of patients who died at the desired location [30,31]
Ethical and Legal Aspects of Care	· Percentage of nurses with knowledge and training in palliative sedation [37]	· Percentage of patients with information on the name and contact details of the health care proxy or with information that there is no substitute, in the information system [8] · Percentage of patients with information on life support and treatment preferences in the information system [8] · Percentage of patients who were asked how they felt about end-of-life decisions [20] · Percentage of caregivers who received care plan goals and resuscitation status at admission [20] · Evidence in the information system of the ethical and legal aspects of care [34]	

Table 2. Sensitive indicators for nursing care in PC by domain.

In this review, there is a greater concern in evaluating the resources and processes necessary for the effectiveness of care, with special emphasis on training and human resources. Advanced training in PC is essential, recognized and applicable to different health contexts, in order to provide nurses and other professionals with the knowledge and training to provide the highest standard of care, in meeting the needs and challenges, regardless of diagnosis.[5,9,10,11,17,29,34,36] The staffing of specialized nurses, in turn, is essential for safe, quality care in all contexts, allowing quick access to the most appropriate type of PC for the their situation and relief from suffering.[30,31] Another important factor highlighted was the presence of indicators related to communication [29] and self-care [23] of the teams.

Regarding the physical aspects of care to the detriment of other aspects of care, there is a greater concern with identifying, evaluating and managing the most common and difficult-to-control symptoms (pain, dyspnea, fatigue, nausea, drowsiness, appetite and constipation) [6, 20,21,24,34] in advanced and terminal diseases such as oncological diseases and heart failure. This domain stands out in relation to the others, as it is the first line of suffering, of valorization and intervention due to the interference it has in the quality of life. However, the presence of other aspects of care are extremely important, and are interrelated with the physical aspects. The use of multidimensional assessment and intervention tools must be considered in the construction of indicators, such as the ESAS[16] scale or the IPOS,[1] which allows for this multidimensional assessment. The use of these tools will allow teams to better manage physical symptoms and improve intervention in non-physical needs. [1]

The psychological needs of the patient and family must be met throughout the disease process, from diagnosis to bereavement, the latter being the only evidence found in 3 articles.[13,20,24]

In consideration of the social aspects, the satisfaction of the patient's needs within the scope of their disease process requires an effective, physical and emotional response from the caregiver, which must be transposed into indicators, due to the high weighting of the results.[15.17]

Only 3 studies[8,28,34] showed 1 indicator on the spiritual needs and cultural habits of patients and families, revealing the absence of a culture of assessment of non-physical aspects of care. This aspect must be incorporated into PC activities allowing for best practices and evidence of results.[3]

The situation of the last hours or days of life implies communicating prognostic information with the patient and/or family in a clear but compassionate way that allows them to express their fears, hopes and goals for end-of-life care, ensuring that patients receive the care they would like.[19] Indicators must reflect the assessment of these specific objectives and family involvement.[12.29-31.34]

In PC, given the profile of aggravation, dependence and preferences for care, ethical and legal problems sometimes arise in care planning. Aspects related to palliative sedation, [18,37] the decision not to resuscitate[8] or other legally and ethically controversial issues, must be safeguarded in clinical decision-making, taking into account the protection of the well-being and quality of life of the patient and family.

It must be noted that the outcome indicators essentially focus on the assessment of satisfaction and the general quality of care by patients [20,21,] family members[8,37] and even nurses[38,] lacking evidence of indicators of all aspects of care, especially in the perspective of the patient and family. Patient-reported outcome measure feedback improves awareness of the unmet need and allows nurses to act to meet the needs of patients and families. Individual patient-reported data are essential to substantiate the clinically significant difference that PC makes.

Different models of care are needed in different countries and cultures, but all of them need to demonstrate improvements in care results, a fundamental aspect for the evidence of the characteristics of each context. The *European Association for Palliative Care,* through its Task Force,[2] recommends the introduction of results measurement in practice that allow national and international comparisons, from a perspective of quality improvement, benchmarking and comparability, requiring appropriate implementation strategies, such as education.

STRENGTHS AND LIMITATIONS

This review sought to systematically identify and synthesize the published evidence on sensitive indicators for nursing care in PC. The search strategy covered 6 databases. To reduce subjective selection bias, the inclusion process and the quality of the articles were carefully considered by the researchers.

However, this review has some limitations. The various descriptors used in the research made the search for studies based on the objective and established criteria challenging. Likewise, there is a risk that some research has been neglected due to the choice to only include articles published since 2012.

CONCLUSION

There are several indicators that are used in the evaluation of the impact of PC teams in the multiprofessional scope, however, specifically at the level of nursing care, the literature is residual. In the verified studies, there is little consensus and heterogeneity in the definition of these indicators, making it impossible to carry out meta-analyses of results to increase our knowledge base on the impact of nurses' intervention. With the objective of continuously improving the quality of PC provision and the evidence of nursing activity, empirical studies are needed to better characterize the sensitive indicators of nursing care in the different contexts and levels of PC.

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