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Review

Quality of life in hospitalized patients receiving palliative care: Do current tools cover all their needs?

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ABSTRACT

Introduction: Quality of life (QoL) is a central outcome in palliative care (PC), particularly in hospital settings, where patients often present with advanced illness, complex symptoms, and multidimensional needs. Accurate QoL assessment is essential to support patient-centered and family-centered decision-making; however, the diversity of available instruments and limited validation beyond oncology populations pose challenges for their clinical and research use.
Objectives: We aimed to identify tools measuring QoL in hospitalized PC patients, highlighting their domains and psychometric properties.
Methods: A scoping review was conducted following Joanna Briggs Institute guidelines and the PRISMA Extension for Scoping Reviews (PRISMA-ScR). We searched MEDLINE (PubMed), CINAHL, EMBASE, The Cochrane Library, Scopus, Web of Science, Google Scholar, and LILACS from inception until April 11, 2025. Independent reviewers assessed eligibility, extracted data, and evaluated risk of bias.
Results: Of 6026 studies retrieved, after removing duplicates ($n = 1680$) and full-text screening ($n = 17$), 12 met inclusion criteria, including 5 validation, 5 observational studies and 2 clinical trials. Eight tools were identified, most originally developed for advanced-stage conditions and applied in high-income countries. Main domains included physical comfort ($n = 7$), psychological well-being ($n = 7$), and spiritual well-being ($n = 7$). Quality of death was assessed in one instrument. Two instruments were validated for Brazilian Portuguese, primarily for cancer patients. Frequently reported psychometric properties were face validity ($n = 9$), content validity ($n = 6$), and construct validity ($n = 6$).
Conclusion: No gold-standard instrument exists for measuring QoL in PC. Selection should consider patient and family preferences, health status, prognosis, life expectancy, and intended use. Findings highlight the need for psychometrically robust instruments applicable across disease stages and conditions. Incorporation of death preparedness, quality of death, and patient- and family-centered outcomes remains limited but is important to guide individualized, safe, and equitable hospital-based PC.
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Calidad de vida en pacientes hospitalizados que reciben cuidados paliativos: ¿cubren las herramientas actuales todas sus necesidades?

Palabras clave:
Calidad de vida
Cuidados paliativos

RESUMEN

Introducción: La calidad de vida (CdV) es un resultado central en los cuidados paliativos (CP), particularmente en el ámbito hospitalario, donde los pacientes suelen presentar enfermedades avanzadas, síntomas complejos y necesidades multidimensionales. Una evaluación precisa de la CdV es esencial para apoyar la toma de decisiones

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Hospital
Instrumentos de medición

centrada en el paciente y la familia; sin embargo, la diversidad de instrumentos disponibles y la validación limitada más allá de las poblaciones oncológicas representan desafíos para su uso clínico y en investigación.
Objetivo: El objetivo de esta revisión fue identificar las herramientas utilizadas para medir la CdV en pacientes hospitalizados en CP, describiendo sus dominios y propiedades psicométricas.
Métodos: Se realizó una revisión de alcance siguiendo la metodología del Joanna Briggs Institute y la extensión PRISMA para revisiones de alcance (PRISMA-ScR). Se realizaron búsquedas en MEDLINE (PubMed), CINAHL, EMBASE, The Cochrane Library, Scopus, Web of Science, Google Scholar y LILACS desde su inicio hasta el 11 de abril de 2025. La selección de estudios, la extracción de datos y la evaluación del riesgo de sesgo fueron realizadas de forma independiente por los revisores.
Resultados: De los 6.026 registros identificados, 12 estudios cumplieron los criterios de inclusión tras la eliminación de duplicados ($n = 1.680$) y la evaluación de textos completos ($n = 17$). Se incluyeron cinco estudios de validación, cinco estudios observacionales y dos ensayos clínicos. Se identificaron ocho instrumentos de CdV, desarrollados principalmente para enfermedades en fases avanzadas y aplicados en países de altos ingresos. Los dominios más frecuentemente evaluados fueron el confort físico ($n = 7$), el bienestar psicológico ($n = 7$) y el bienestar espiritual ($n = 7$). La calidad de la muerte fue evaluada únicamente por un instrumento. Dos instrumentos fueron validados para el portugués brasileño, principalmente en poblaciones con cáncer. Las propiedades psicométricas más frecuentemente reportadas fueron la validez aparente ($n = 9$), la validez de contenido ($n = 6$) y la validez de constructo ($n = 6$).
Conclusiones: Actualmente no existe un instrumento de referencia para medir la CdV en pacientes hospitalizados en CP. La selección del instrumento debe considerar las preferencias del paciente y de la familia, el estado de salud, el pronóstico, la expectativa de vida y el propósito de uso. Los resultados evidencian la necesidad de instrumentos psicométricamente robustos y aplicables a diferentes etapas de la enfermedad y condiciones clínicas. La incorporación de dominios relacionados con la preparación para la muerte, la calidad de la muerte y los resultados centrados en el paciente y la familia sigue siendo limitada, pero resulta fundamental para orientar una atención paliativa hospitalaria individualizada, segura y equitativa.
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Introduction

The World Health Organization (WHO) defines QoL as an individual's perception of their position in life within the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns.[1] Despite this comprehensive conceptualization, there is no universally accepted definition of QoL, particularly in PC, where perceptions of well-being are influenced by the underlying disease, comorbidities, stage of illness, and limited life expectancy.[2,3]

Although palliative care (PC) is increasingly delivered in community and home-based settings, hospitalization remains common among patients with advanced disease. Acute symptom exacerbations, clinical instability, complex clinical decision-making, and transitions of care frequently require inpatient management, especially in the last months of life.[4,5] These circumstances may significantly influence patients' QoL and distinguish hospitalized PC patients from those receiving care in outpatient or home settings.

In hospital environments, patients often experience a high symptom burden, reduced functional capacity, and limited energy for lengthy assessments.[6] Consequently, QoL instruments used in this context must be feasible, sensitive to rapid clinical changes, and capable of capturing dimensions relevant to end of life care without imposing excessive burden on patients.[7]

Within the philosophy of PC, QoL is considered a central therapeutic objective, with the purpose of ensuring comfort, dignity, and comprehensive support for patients and their families.[1,8] In PC research, QoL has generally been assessed as a health-related construct, predominantly through multidimensional approaches,[2,3,9–11] or, less frequently, through global measures based on single-item assessments.[9]

Many studies conducted in hospital settings describe PC delivered in tertiary or specialized care environments, such as university hospitals, oncology centers, or dedicated inpatient PC units. These settings are characterized by high clinical complexity, access to advanced diagnostics, and multidisciplinary teams, which may influence both the content and applicability of QoL assessment tools.[12] Distinguishing between general hospital care and specialized or tertiary care is therefore essential when interpreting evidence related to QoL measurement.

Multiple instruments have been developed and applied to evaluate QoL in PC.[2,14]Albers et al.[14] proposed a framework identifying core domains relevant to patients with incurable illness, including physical comfort, physical functioning, cognitive functioning, psychological, social and spiritual well-being, as well as perceived quality of care.

Spirituality, as defined by the 2020 EAPC guidelines, refers to dynamic aspects of human life related to meaning, purpose, transcendence, and connectedness with oneself, others, nature, or the sacred, both within and beyond religious contexts.

Since QoL is a dynamic construct influenced by individual characteristics, disease-related factors, symptom burden, coping capacity, and prognosis, it has also been proposed that additional domains, such as meaning, purpose, spirituality, grief,[15] and quality of death,[16] particularly in the context of advanced disease and end of life care.However, not all domains considered important to patients are captured, such as financial and quality of death.[14–16]

The methodological quality of QoL instruments requires rigorous evaluation of psychometric properties, including validity (construct, content, and criterion), reliability (internal consistency and test–retest stability), and responsiveness.[2,3,13,14] Evidence from literature reviews indicates that many instruments present limited evaluation of these properties, especially responsiveness and construct validity, which may impair their applicability in both clinical practice and research.

Although previous reviews have summarized the instruments available for QoL assessment in PC,[3,14] a scoping review is needed to comprehensively map the tools currently applied in hospitalized patients receiving PC. This review aims to identify and describe QoL assessment instruments used in hospital-based pPC, examining their characteristics, psychometric evidence, and contextual relevance, including advances in validation methodologies and the incorporation of domains such as spirituality and quality of death, as well as instruments validated in Brazilian Portuguese. By synthesizing existing evidence, this scoping review seeks to inform clinicians and researchers about the strengths and limitations of available instruments and to highlight gaps for future research and instrument development.

Methods

Design

This study was conducted as a scoping review, following the methodological framework originally proposed by Arksey and O'Malley and further refined by Levac et al. and the Joanna Briggs Institute.[18–20] The review was reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist.[18] This methodology was applied to address the following guiding question: Which tools have been validated to assess quality of life in hospitalized patients receiving PC? The PRISMA-ScR checklist is presented in **Supplementary Appendix 1**.

In this review and the current methodology described, as well as in the article search strategy, the terms PC and QoL were considered. PC is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the QoL of patients, their families and their caregivers.[4] The WHO definition of QoL was adopted.[1]

Eligibility criteria

The inclusion criteria for the literature review were defined using the Participants, Concept, and Context (PCC) framework. Therefore, the criteria were as follows:

(a) Population: Studies involving adult or pediatric patients of any sex, diagnoses, or prognosis who were hospitalized and receiving PC for life-limiting or life-threatening conditions were eligible for inclusion.
(b) Concept: QoL assessment using structured instruments. Studies were included if they reported the development, validation, cultural adaptation, or application of QoL instruments in PC populations. This included evaluation of psychometric properties (e.g., validity, reliability, responsiveness), feasibility, or domain coverage.
(c) Context: Hospital-based PC delivered in tertiary or specialized healthcare settings, including university hospitals, oncology centers, and dedicated inpatient PC units. Tertiary care was defined as care provided in highly specialized hospital environments with access to advanced diagnostics, multidisciplinary teams, and complex therapeutic interventions.

Consistent with the exploratory aim of a scoping review, a broad range of study designs was considered eligible, including experimental, observational, qualitative, and validation studies, as well as randomized controlled trials. The search included studies published up to April 11, 2025, and was restricted to publications in English, Spanish, and Portuguese. Dissertations were also included. Reviews, study protocols, book chapters, conference abstracts, editorials, opinion pieces, commentaries, letters, interviews, and secondary analyses were excluded.

Search strategy

A comprehensive search strategy was developed using Medical Subject Headings (MeSH) and free-text terms related to PC, hospitalization, and QoL instruments, in consultation with an experienced librarian. The search was conducted in the following electronic databases: PubMed, LILACS, CINAHL, EMBASE, Cochrane, Scopus, Web of Science, and Google Scholar, according to a predefined strategy (**Supplementary Appendix 2**). No publication date restrictions were applied. The search strategy was validated by a librarian, and all identified references were uploaded to the online tool Rayyan QCRI for study selection.[21]

Selection of sources of evidence and data collection process

All retrieved records were imported into reference management software, and duplicates were removed. Two reviewers independently screened titles and abstracts, followed by full-text assessment of potentially eligible studies. Disagreements were resolved through discussion or consultation with a third reviewer. The study selection process is presented in a flow diagram adapted from the PRISMA-ScR framework.

A Microsoft Office Excel spreadsheet was used for data extraction. The following variables were extracted:

(i) Study characteristics: Country, year of publication, authors, objectives, study design, sample size, inclusion and exclusion criteria, and the QoL assessment instrument used.
(ii) Patient characteristics: Age, sex, comorbidities, inclusion and exclusion criteria, life expectancy, life-limiting illnesses, prognostic and performance indicators.
(iii) Instrument characteristics: Domains (content), validated psychometric properties, instrument type (e.g., questionnaire, scale, indicator), scoring method, number of items, administration time, need for specific training, and who administers the tool (e.g., professional, patient, or family/caregiver).

Bias risk assessment

Two reviewers independently appraised the methodological quality of the included studies using the Joanna Briggs Institute (JBI) critical appraisal tools appropriate to each study design.[17] In line with scoping review methodology, a formal risk of bias assessment was not undertaken; instead, this appraisal aimed to describe the rigor and credibility of the evidence base and to contextualize the findings rather than to exclude studies based on quality. The assessment focused on domains such as participant selection, the appropriateness of data collection methods, and the analysis and interpretation of results.[22]

For each evaluated domain, the tools allowed four possible responses: “Yes,” “No,” “Uncertain,” and “Not applicable.” Based on this analysis, studies were classified into three categories of risk of bias: low (score < 4), moderate (scores 5–6), and high (score ≥ 7), according to the final score assigned to each study.[23] Decisions regarding the scoring system and potential cut-off points were defined and agreed upon by all reviewers before the critical analysis began.

Synthesis of results

The systematization of the extracted data was accomplished by transcribing the data into tables and figures.

Results

Results of the search

The database search yielded a total of 6,026 records. After removing duplicates ($n = 1{,}680$), 4,346 records remained for title and abstract screening. During this phase, studies that did not meet the eligibility criteria related to population, context, or concept were excluded. A total of 17 articles were considered potentially relevant and were therefore assessed in full text. After full-text evaluation, 12 studies met all inclusion criteria and were included in the final analysis. The study selection process is presented in Fig. 1, adapted from the PRISMA-ScR flow diagram.

Studies identified through reference list screening and search updates were classified as additional records, rather than “new studies,” to avoid ambiguity regarding prior versions of the review.

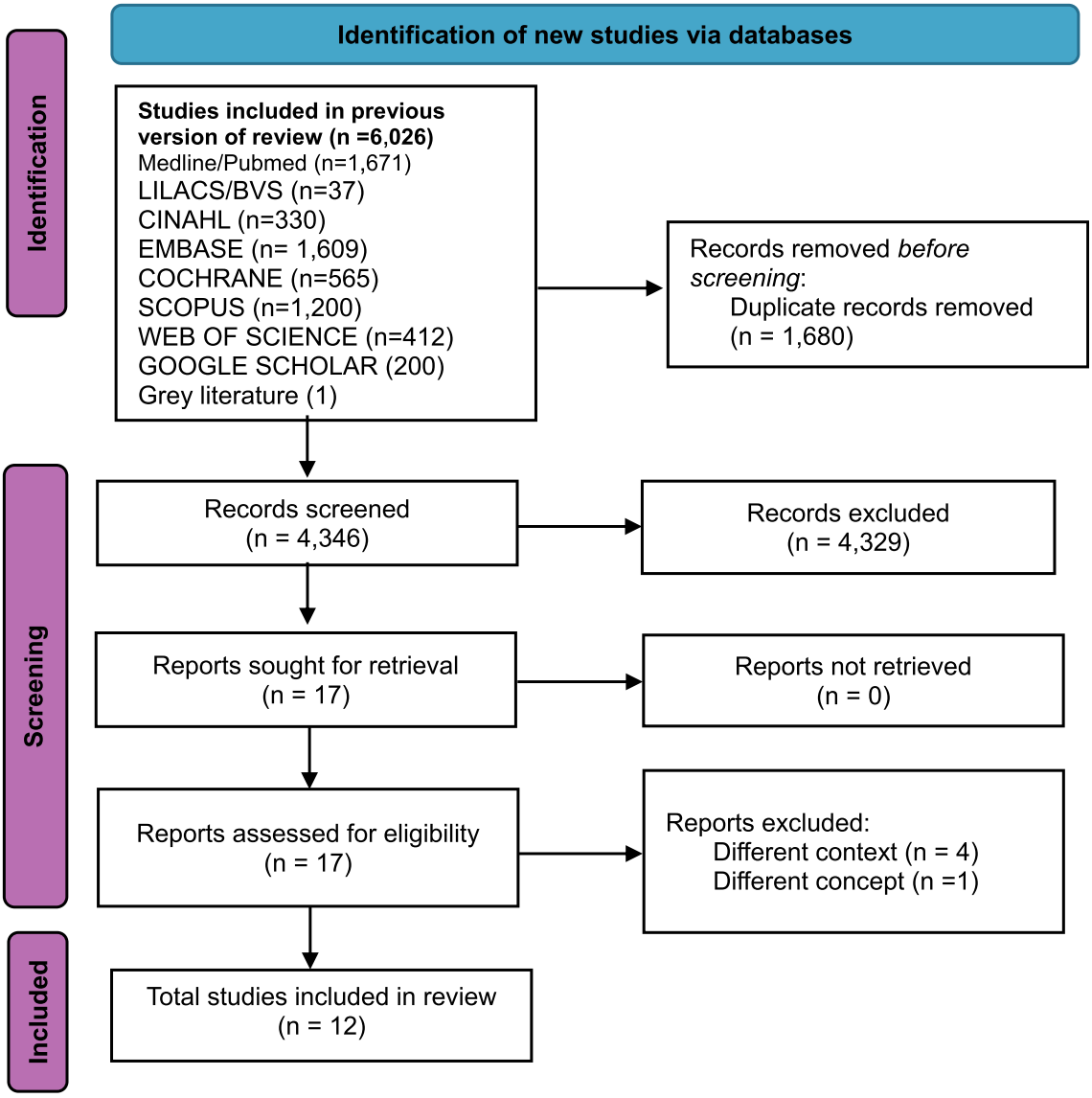

Fig. 1. Review flow diagram. *Source:* Author's own elaboration (2025).

Study characteristics

The included studies were published between 1997 and 2020 and were conducted predominantly in high-income countries (Table 1). Four studies were carried out in Europe, three in North America, two in Asia, two in Latin America, and one in Australia. Most studies were conducted in tertiary or specialized hospital settings, such as oncology centers and inpatient PC units. Adult patients with advanced cancer constituted the most frequently studied population, although some studies also included individuals with non-malignant life-limiting conditions. Regarding study design, observational studies ($n = 5$) and validation studies ($n = 5$) were the most common, followed by randomized clinical trials ($n = 2$) (Table 1).

Regarding study design, the review included observational studies, validation studies, randomized controlled trials, and qualitative studies. Randomized controlled trials were included when QoL instruments were used as outcome measures, providing indirect evidence of instrument feasibility and measurement performance in hospitalized PC populations.

Eight QoL instruments were identified across the included studies, including widely used and culturally adapted tools. The most frequently reported instruments were the Palliative Care Outcome Scale (POS) ($n = 3$) and the European Organization for Research and Treatment of Cancer QLQ-C15-PAL ($n = 3$). Additional tools included the McGill Quality of Life Questionnaire (MQOL) ($n = 1$) and its revised (MQOL-R) ($n = 1$) and Brazilian-adapted versions (BrP-MQOL-R) ($n = 1$), as well as QUAL-E ($n = 1$), FACIT-Pal ($n = 1$), and POS-Br ($n = 1$) (Table 1).

Qualitative studies contributed primarily to the evaluation of content validity, exploring patients' perceptions of relevance, clarity, and comprehensiveness of instrument items. These studies provided contextual insights into how well-existing instruments captured dimensions considered meaningful by hospitalized palliative care patients.

Patient characteristics

The studies enrolled 3046 participants, of whom 1,539 (50.8%) were women (Table 2). Three studies included patients with advanced chronic or end of life conditions regardless of diagnóstico, while eight studies focused specifically on patients with cancer. One study included mixed populations with different life-limiting

Table 1
Characteristics of studies enrolled ($n = 12$).

Authors (year)	Study design	Country	Objectives	Inclusion criteria	Exclusion criteria	Quality of life tool
Cohen et al. (1997)[24]	Validation study	Canada	To validate the McGill Quality of Life Questionnaire in eight Canadian hospitals.	All current patients and new referrals to each PC service during a three-month period. Patients had been followed by the PC service for periods varying from days to months.	Not fluent in English or French; impaired mental state, giving nonsensical consent; physical condition preventing completion of questionnaires.	MQOL
Hearn et al. (1999)[25]	Development and validation study	United Kingdom	To develop an outcome measure for patients with advanced cancer and their families, which would cover more than either physical symptoms or QoL-related questions. To validate the measure in various specialist and non-specialist PC settings throughout the UK (community, hospices, outclinics and hospitals).	Good command of English; no impaired mental state as previously assessed or judged by a team member; considered physically able to complete a questionnaire.	Not reported	POS
Lee et al. (2014)[26]	Retrospective cohort study	South Korea	To examine the predictability of survival based on patient-reported QoL using the EORTC QLQ-C15-PAL questionnaire in hospitalized patients with advanced cancer at the end of life.	Hospitalized patients over 18 years diagnosed with terminal stage by their physician; consent to participate in the study; ability to respond to the questionnaire.	Planned chemotherapy or radiotherapy for active cancer treatment; inability to participate due to cognitive dysfunction or altered consciousness.	EORTC QLQ-C15-PAL
Wilkinson et al. (2014)[27]	Validation study	Australia	Assess the acceptability and face validity of the instrument QUAL-E to measure the QoL of hospitalized patients.	Patients aged over 18; physically and emotionally able to participate; aware of terminal prognosis; diagnosed with cancer or multiple organ failure, but not dementia; currently hospitalized under PC; able to understand written and spoken English.	Diagnosis of dementia	QUAL-E
Warth et al. (2015)[28]	Randomized clinical trial	Germany	To evaluate the effects of music therapy on relaxation in hospitalized patients receiving PC.	Patients receiving palliative treatment according to OPS 8–892 or OPS 8–98e; sufficient understanding of German or English.	Advanced phase of disease approaching end of life cognitive; apathy syndrome; hearing loss; restlessness and agitation.	EORTC QLQ-C15-PAL
Hernández-Bello et al. (2016)[29]	Cross-sectional	Spain	To determine the perceived QoL of terminal cancer patients receiving PC, and the influence of health care satisfaction on the quality of life of these patients.	Patients aged over 18 years; diagnosed with terminal illness and receiving PC; willing to participate	Patients unable to respond to the interview due to being in the agonal phase of the disease or presenting cognitive impairments.	EORTC QLQ-C15-PAL
Rogers et al. (2017)[30]	Randomized clinical trial	United States of America	To investigate whether an interdisciplinary PC intervention, in addition to evidence-based chronic disease care, improves specific outcomes.	Patients who were at high risk of rehospitalization and mortality based on their ESCAPE risk score. Hospitalized patients could be enrolled if discharge was expected within 48 h. Recently discharged patients were eligible if discharged from the hospital within the past 2 weeks and met other study inclusion criteria.	Anticipated heart transplant or ventricular assist device placement within 6 months, non-cardiac terminal illness, or failure to meet disease severity criteria based on the ESCAPE risk score.	FACIT-Pal
Rugno (2017)[31]	Validation study	Brazil	To validate the self-report POS scale to Brazilian Portuguese	Participants had to be over 18 years old, able to complete the administered questionnaires, under regular clinical follow-up at their primary clinic, receiving PC, undergoing palliative chemotherapy, or being cared for by the hospital's PC team.	Patients who discontinued follow-up, had other conditions impairing cognition, or were expected to die within seven days of the start of data collection.	POS-Br
Cohen et al. (2017)[32]	Validation Study (secondary analysis of data)	Canada	To revise the McGill Quality of Life Questionnaire while maintaining or improving its psychometric properties and length.	Data from four different samples of people with life-limiting illnesses in Canadian healthcare settings were used and compared to data from four studies used for the original MQOL validation.	Not reported.	MQOL-R
Palat et al. (2018)[33]	Cohort study	India	To analyze the QoL of cancer patients admitted to the wards with a poor ECOG performance.	Hospitalized cancer patients aged 18 years or older with ECOG performance status 3–4.	Not reported	POS
Dawber et al. (2019)[34]	Prospective study	England	To ascertain the reliability and the nature of proxy symptom assessor (health professional versus informal caregiver) using a validated QoL measure.	Patients over 65 years old, terminally ill from any diagnosis, hospitalized for more than 7 days with regular visits from informal caregiver.	Patients without visitors, with impaired cognition (score ≤ 6 on the Abbreviated Mental Test), or who declined consent.	POS
Serrano et al. (2020)[35]	Cross-sectional	Brazil	To evaluate the psychometric Properties of the Reviewed McGill Quality of Life Questionnaire (MQOL-R) for Brazilian Portuguese (BrP) in a Teaching hospital.	Patients aged over 18 years from the Pain and PC Service (inpatients and outpatients).	Illiterate patients and those with cognitive impairment preventing them from responding to questions or communicating.	BrP-MQOL-R

BrP-MQOL-R = Reviewed McGill Quality of Life Questionnaire – Brazilian Portuguese; EORTC QLQ-C15-PAL = European Organization for Research and Treatment of Cancer; ESCAPE = Evaluation Study of Congestive Heart Failure and the Effectiveness of Pulmonary Artery Catheterization; ECOG = Eastern Cooperative Oncology Group; FACIT-Pal = Functional Assessment of Chronic Illness Therapy - Palliative Care scale; MQOL = McGill Quality of Life Questionnaire; PC = palliative care; PCAF = Palliative Care Assessment Form; POS = Palliative Care Outcome Scale; OPS = Classification of Operations and Procedures (the German modification of the International Classification of Procedures in Medicine; QUAL-E = Quality of Life at the End of Life. QoL: Quality of life.
Source: Developed by the authors (2025).

Table 2
Characteristics of patients ($n = 12$).

Authors (year)	Age (years)	Sample size *N*	Female sex *N*	Comorbidities	Life expectancy	Life-limiting illness	Prognostic and performance indicators
Cohen et al. (1997)[24]	26–92	143	87	Not reported	Not reported	Cancer (gastrointestinal, gynecologic, pancreatic, prostate, lung, breast, head and neck, bladder, and renal)	Not reported
Hearn et al. (1999)[25]	47 patients <65, 98 patients ≥65	148	82	Not reported	Not reported	Diagnoses (ICD-10 categories): Digestive organs, respiratory tract, genitourinary tract, breast, lymphatic/hematopoietic, other cancers, HIV/AIDS; cerebrovascular accident, ALS.	ECOG Performance Status: fully active (14), restricted (36), ambulatory (22), limited capacity (56), disabled (8)
Lee et al. (2014)[26]	5 patients <40, 75 patients = 40–65, 82 patients ≥65	162 (134 died during the study; 28 completed the study)	86	Hypertension ($n = 36$), Diabetes ($n = 25$), Others ($n = 15$)	Mean 24.5 days	Primary cancer type (lung, hepatobiliary, ovary/cervix, stomach, colorectal, pancreas, head and neck, renal/bladder, soft tissue, esophagus)	ECOG Performance Scale: ECOG 1 (19), ECOG 2 (27), ECOG 3 (58), ECOG 4 (59); PPS: ≥50% (65), 30–40% (69), ≤20% (27)
Wilkinson et al. (2014)[27]	Mean = 67.35	52	29 (56%)	Not reported	Not reported	Cancer (86%) and other conditions (cardiovascular diseases, liver failure, end-stage renal disease, and other non-malignant conditions)	Not reported
Warth et al. (2015)[28]	Mean = 63	68	48 (71.4%)	Not reported	Not reported	Most common primary diagnoses: breast cancer, pancreatic cancer, ovarian cancer, and prostate cancer. Except for two cases, all other patients had malignant tumors.	Not reported
Hernández-Bello et al. (2016)[29]	32–89 (mean 64)	47	20 (42.6%)	Not reported	Not reported	Cancer (lung, breast, colon, ovary, pancreas, prostate, esophagus, liver, kidney, uterus, mouth, brain, stomach, larynx, and melanoma)	Not reported
Rogers et al. (2017)[30]	Mean = 71	150	70 (47%)	Depression, alcohol and drug abuse, hypertension, coronary artery disease, diabetes mellitus, and stroke	Not reported	Advanced chronic disease	Not reported
Rugno (2017)[31]	Pre-test: Mean = 59.1 (min = 25; max = 82). Pilot study: Mean = 67.9 (min = 33; max = 89). Field research = Mean = 57.2 (min = 20; max = 85).	271	164	Not reported	Not reported; however, in the field research, all patients died within five years of cancer diagnosis.	Pre-test: Cancer (primary tumors located in the breast, cervix, and piriform sinus, with 28% presenting advanced disease). Pilot study: Neoplasm (liver, cervix, stomach, skin). Field research: different etiology of neoplasm.	Pre-test: KPS [Mean = 59.5 (DP = ±2); Median = 60 (min = 50; max = 90). Pilot study: KPS [Mean = 70.2 (DP = ±16.96); Median = 70 (min = 30; max = 90). Field research: KPS [Mean = 72.9 (DP = ±15.02); Median = 70 (min = 40; max = 100).
Cohen et al. (2017)[32]	Mean = 51–over 65	1,602*	832	Not reported	Not reported	End of life populations (cancer, HIV/AIDS before the existence of anti-retrovirals, various end-stage diseases)	Not reported
Palat et al. (2018)[33]	Mean = 49.9	38	19	Not reported	Not reported	Cancer (gastrointestinal, cervical, head and neck, lung, breast) and others	ECOG Status: ECOG 3 (22 patients – Group B), ECOG 4 (16 patients)
Dawber et al. (2019) [34]	>65	65	33	Not reported	Not reported	Any disease	Not reported
Serrano et al. (2020)[35]	25–75	146	68	Not reported	Not reported	Cancer (lung, stomach, breast, esophagus, intestine, colorectal, lymphoma, prostate, etc.) and others	KPS ≤30 ($n = 25$) and >30 ($n = 121$)

ALS = Amyotrophic Lateral Sclerosis) ECOG = Eastern Cooperative Oncology Group, ICD-10 = HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome) International Statistical Classification of Diseases and Related Health Problems 10th Revision, KPS = Karnofsky Performance Scale, PPS = Palliative Performance Scale Min = minimum Max = maximum.
Source: Developed by the authors (2025).
* The total sample reported in Table 1 (Data sets) of Cohen et al. (2017)[32] appears to be incorrect.

conditions (Table 2). Comorbidities were reported in two studies, with hypertension and diabetes often described. Only one reported the life expectancy of the patients; and five described the clinical characteristics of the participants, with the aid of KPS (Karnofsky Performance Scale), PPS (Palliative Performance Scale) and ECOG Performance Status (Eastern Cooperative Oncology Group Performance Status Scale) (Table 2).

Instrument characteristics

Palliative Care Outcome Scale (POS)

The POS,[25] developed in England, is an outcome measure designed for the multidimensional assessment of QoL in patients with advanced cancer receiving PC. It has two versions: a self-reported version for patients and a proxy version for healthcare professionals. The instrument

consists of 10 items covering physical, psychological, and spiritual domains, as well as an open space for listing main problems. Both patients and healthcare professionals completed the scale in an average of less than four minutes. The psychometric properties evaluated included content and consensus validity, face validity, construct validity, comparison of staff and patient ratings, internal consistency, test–retest reliability, and responsiveness to change. Healthcare professionals' perceptions of patients' conditions were generally close to, though not always identical with, patients' self-reports (Tables 3 and 4).

Brazilian Portuguese version – Palliative Care Outcome Scale (POS-BR)

The self-reported adapted version has been validated in Brazilian Portuguese for use with patients diagnosed with cancer (POS-Br).[31] It consists of 10 items covering the following domains: symptoms (PC assistance), psychological, emotional and social functioning, and global health. The validated psychometric properties were internal consistency, construct validity, and semantic validity. The mean administration time is 5–10 min (Tables 3 and 4).

McGill Quality of Life Questionnaire (MQOL)

The MQoL[24] is a multidimensional, self-reported instrument developed to assess QoL in individuals at the end of life. It comprises 16 items across four domains: physical (symptoms and general physical well-being), psychological, existential, and support. The instrument was validated in Canadian patients with life-limiting illnesses and includes the MQoL Single-Item Scale, a global QoL measure assessed through a single 0–10 numerical rating scale. Validated psychometric properties include construct validity (predicting QoL), as well as convergent and divergent validity (based on correlations between MQoL total scores and other questionnaires). The mean administration time is 15–20 min (Tables 3 and 4).

McGill Quality of Life Questionnaire–Revised

In the MQoL-R,[32] the support subscale was replaced with a social subscale that retained one support item; the physical subscale was restructured by combining physical symptoms and physical well-being; and the existential subscale was shortened. The MQoL-R comprises 14 items plus the global QoL item and demonstrated good internal consistency reliability. The mean administration time is 5–10 min (Tables 3 and 4).

Brazilian Portuguese version of the McGill Quality of Life Questionnaire (BrP-MQoL-R)

The BrP-MQoL-R[35] was validated for internal consistency, construct validity, criterion validity, known-group validity, and responsiveness. The authors also examined correlations between BrP-MQoL-R scores and the Karnofsky Performance Scale (KPS) and Numerical Pain Scale (NPS, 0–10). The mean administration time is 5–10 min (Tables 3 and 4).

European Organization for Research and Treatment of Cancer QLQ-C15-PAL

The EORTC QLQ-C15-PAL[38] is a 15-item abbreviated version of the EORTC QLQ-C30, developed for use in patients with advanced cancer receiving PC. The shortened tool excludes the social, cognitive, and role function scales, as well as the financial difficulties and diarrhea items. The retained domains include pain, emotional functioning, fatigue, nausea, loss of appetite, dyspnea, constipation, sleep disturbances, and overall QoL. Concentration and memory problems are not addressed in this version. The mean administration time is 5–10 min (Tables 3 and 4).

Quality of Life at the End of Life Questionnaire (QUAL-E)

The QUAL-E[36] was validated as a self-report measure among Australian patients receiving PC with a terminal prognosis, including those with cancer and multiple organ failure. The QUAL-E consists of 21 items covering four domains: symptom impact, relationship with healthcare providers, preparation for the end of life, and life completion. An additional open-ended question allows respondents to provide further comments. Psychometric evaluation included assessments of acceptability (the extent to which the instrument meets the needs of the target population and organizational context) and face validity (the extent to which the instrument measures the intended construct and how participants interpret and respond to the items), evaluated through questionnaire completion and researcher field notes. The mean administration time is 15–25 min (Tables 3 and 4).

Functional Assessment of Chronic Illness Therapy – Palliative Care (FACIT-PAL)

The FACIT-PAL[37] is a PC subscale derived from the Functional Assessment of Chronic Illness Therapy – General (FACT-G). It has been validated for patients with advanced or life-limiting illnesses and comprises 46 self-reported items assessing health-related quality of life (HRQoL). The FACIT-PAL incorporates the 27-item FACT-G, which measures four QoL domains: physical well-being (7 items), social/family well-being (7 items), emotional well-being (6 items), and functional well-being (7 items). Compared with the original instrument, the FACIT-PAL includes fewer items related to faith and spirituality. The mean administration time is 10–25 min (Tables 3 and 4).

The instruments identified were used to assess QoL in patients diagnosed with neoplasms ($n = 8$). Regarding the domains/content of the instruments, it was found that all included the physical ($n = 7$), psychological ($n = 7$), and spiritual well-being domains ($n = 7$). One instrument addressed preparation for death (QUAL-E), while spirituality

Table 3
Summary of palliative care quality of life assessment tools: domains covered and consideration of treatment-related symptoms.

Instruments	Physical domain	Psychological/emotional domain	Social domain	Spiritual/existential domain
MQOL[24]	Physical symptoms, physical well-being	Meaning of life, spiritual peace	Social support and relationships	Limited: symptoms may reflect treatment effects
POS[29]	Pain, discomfort, dyspnea, weakness	Anxiety, depression, fear	Family and social support	Meaning in life, inner peace
EORTC QLQ-C15-PAL[30]	Pain, fatigue, nausea, dyspnea	Anxiety, depression, and emotional well-being	Limited social relationships	Not directly assessed
QUAL-E[27]	General physical symptoms	Emotional well-being, satisfaction	Relationships and social support	Meaning of life, spirituality
FACIT-Pal[30]	Physical symptoms (fatigue, pain, dyspnea)	Mood, anxiety, well-being	Social function	Existential/spiritual concerns
POS-Br[31]	Pain, discomfort, dyspnea, weakness	Anxiety, depression, fear	Family and social support	Meaning in life, inner peace
MQOL-R[32]	Physical symptoms	Emotional/psychological	Social relationships	Existential/spiritual
MQOL-R BrP[35]	Physical symptoms	Emotional/psychological	Social relationships	Existential/spiritual

BrP-MQOL-R = Reviewed McGill Quality of Life Questionnaire – Brazilian Portuguese; EORTC QLQ-C15-PAL = European Organization for Research and Treatment of Cancer; FACIT-Pal = Functional Assessment of Chronic Illness Therapy - Palliative Care scale; MQOL = McGill Quality of Life Questionnaire; PC = palliative care; POS = Palliative Care Outcome Scale; QUAL-E = Quality of Life at the End of Life.
Source: Developed by the authors (2025).

Table 4
General characteristics of quality-of-life assessment tools in palliative care.

Instruments (reference)	Target population	Number of items	Number of response options	Scoring algorithm	Mean completion time	Self-report/proxy/ interview
EORTC QLQ-C15-PAL	Cancer patients	15	4/7	Subscale	5–10 min	Self-report
POS	Patients in advanced stages for a plethora of diseases	Patients: 12 Staff: 12	3/4/5	Total/Item-by-item analysis	10 min	Self-report/proxy
POS-BR	Cancer patients	Patients: 10	3/4/5	Total/Item-by-item Analysis	5–10 min	Self-report
QUAL-E	Seriously Ill patients	25	5	Subscale and total	15–25 min	Structured interview
FACIT-Pal	Patients with life-limiting illness	46	5	Total	10–15 min	Self-report
MQOL	People with life-threatening illness	16	11	Subscale and total	15–20 min	Self-report
MQOL-R	People with life-threatening illness	14	11	Subscale and total	5–10 min	Self-report
MQOL-R-BrP	People with life-threatening illness, in Brazil	14	11	Subscale and total	5–10 min	Self-report

BrP-MQOL-R = Reviewed McGill Quality of Life Questionnaire – Brazilian Portuguese; EORTC QLQ-C15-PAL = European Organization for Research and Treatment of Cancer; FACIT-Pal = Functional Assessment of Chronic Illness Therapy - Palliative Care scale; MQOL = McGill Quality of Life Questionnaire; PC = palliative care; POS = Palliative Care Outcome Scale; QUAL-E = Quality of Life at the End of Life.
Source: Adapted from Albers et al.[14] and developed by the authors.

was included in the POS, POS-BR, QUAL-E, FACIT-PAL, MQOL, MQOL-R, and MQOL-R-BrP (Table 3).

The number of items in the instruments ranged from 10 to 46. The average application time ranged from 4 to 25 min. Most instruments used a subscale scoring system, and the predominant method of administration was self-report by patients or health professionals (Table 4).

Only a subset of instruments explicitly incorporated spiritual or existential dimensions, and when present, these domains were often limited to items related to meaning, hope, or inner peace. No instrument comprehensively assessed spirituality using a multidimensional framework. Domains related to preparation for death, advance care planning, or end of life closure were largely absent from the identified instruments. Although some tools included items addressing emotional acceptance or peace, explicit assessment of preparedness for death was uncommon.

Risk of bias in the included studies

Overall, the evidence included demonstrated a moderate to high risk of bias. Cross-sectional studies predominantly showed a moderate risk ($n = 3$), while two cohort studies were classified as high risk. Among the qualitative studies, two were rated as high risk, two as low risk, and one as moderate risk. For randomized clinical trials, one study presented a high risk and another a moderate risk of bias (**Supplementary Appendix 3**).

Discussion

This review identified eight instruments used to assess QoL in hospitalized patients receiving PC, revealing substantial variability in their scope and applicability. Most tools were not specifically developed for hospital settings, which may limit their ability to capture the complex and rapidly changing needs of this population. Overall, the findings indicate that existing assessment tools predominantly focus on physical and psychological domains, while existential and end of life–related aspects are less consistently addressed. Furthermore, most tools were developed and validated in high-income countries and primarily applied to oncology populations, with limited cross-cultural adaptation.

Most instruments were developed for patients diagnosed with advanced-stage cancer. However, conditions such as heart failure, chronic obstructive pulmonary disease (COPD), HIV/AIDS, and neurological disorders also require specialized monitoring and tailored assessment tools.[39,40]

Consistent with previous literature, physical and psychological domains were prioritized across instruments, reflecting the high symptom burden and emotional distress commonly experienced by hospitalized PC patients.[10,7] In contrast, social, spiritual, and existential dimensions were less consistently assessed, despite their recognized importance in PC outcomes.[10]

The review also demonstrated that instrument feasibility varied according to patients' functional status and expected prognosis. Shorter instruments appeared more suitable for hospitalized patients with limited life expectancy, whereas longer and more comprehensive tools may be more appropriate earlier in the disease trajectory.[7,6] However, few studies explicitly evaluated QoL instruments across different stages of palliative care, limiting conclusions regarding their longitudinal applicability.

The scarcity of validated tools for diverse life-limiting conditions may hinder the delivery of individualized healthcare aligned with patients' and families' preferences and needs,[41] as signs and symptoms may vary depending on the clinical condition[42] and the emotional status of the patient. Therefore, instruments should be sensitive to patient differences and culturally adapted for vulnerable populations to promote equitable, effective, and safe care.

Instrument selection should also consider patients' life expectancy, as needs may differ with disease progression. Miyashita et al.[43] observed that dimensions related to physical and psychological comfort, maintenance of hope and independence, quality of family relationships and communication with healthcare teams, and spirituality are determinants for QoL. These findings reinforce the centrality of spiritual, psychological or emotional care, understood as a transversal axis of the palliative process.[16,44–46]

Physical and psychological/emotional domains were contemplated in the majority of instruments assessed. They can be significantly affected by adverse drug reactions (ADRs), leading to reduced QoL.[45] The availability of ADR-related QoL data depends on factors such as the medicines and health conditions considered.[46] Patients mainly perceive ADR burden in terms of effects on prescriptions, appearance, autonomy, daily life, psychological consequences, distressing experiences, and physical impacts.[47,48] Therefore, assessment instruments should explicitly capture patients' ADR experiences to support improved clinical care.

Tools have been developed to assess spirituality in clinical contexts, consistently showing that strong spiritual well-being contributes to better patient outcomes by reducing distress and anxiety, helping maintain a sense of dignity.[41,44,49,50] and facilitating patient decision-making in alignment with personal values and beliefs.[51] Furthermore, spiritual support may reduce aggressive treatment[49,52] and the use of sedatives and anxiolytics medicines,[50] while promoting patient-centered care.[53–55]

Three outcome measures were commonly used by professionals working in clinical care, clinical audit and research in PC across Europe

and Africa: the KPS, followed by the Edmonton Symptom Assessment Scale (ESAS) and the POS.[56] These instruments are mainly used for assessing patients' symptoms/needs, monitoring changes, evaluating care, and assessing family needs. Nevertheless, according to Selman,[57] the MQoL, the Measuring the QoL of Seriously Ill Patients Questionnaire, and the POS are the most appropriate multidimensional instruments containing spiritual items for use in culturally diverse palliative populations. Because of this, we did not include ESAS or other tools that were not specifically developed to assess QoL in PC.

"Good death" is an outcome or a process following a period of dying well. Needs and priorities vary among patients and their caregivers, across conditions, over time, and across communities and cultures.[16] Factors linked to a peaceful and dignified death impacting QoL, identified in a scoping review, include: not being a burden to the family, maintaining autonomy, having positive final days, protecting others from grief, and being able to make decisions about care until the final days[58].[59]In pediatric patients, recognizing childhood and related needs, such as the opportunity to play, is also essential. Death preparedness contributes to the autonomy and empowerment of patients and families.[59]

For patients, preparedness involves completing life tasks and unfinished business (e.g., financial, legal, and funeral arrangements), coordinating family affairs, and being treated as a whole person. For caregivers, it also includes affective and behavioral preparation, potentially easing the transition into bereavement. Both patients and caregivers prioritize the patient's desire not to be a burden and to have family presence at the time of death.[59] Patients and caregivers prepared for death demonstrated significantly higher QoL scores in the burden domain. This association remained robust in caregivers with low education, low social support, poor resilience, or dysfunctional families,[60] suggesting the necessity of including this domain in QoL instruments in PC.

The original QUAL-E was validated for measuring QoL at the end of life with patients with stage IV cancer, congestive heart failure, chronic obstructive pulmonary disease, or dialysis-dependent end-stage renal disease. The instrument included 25 items representing a four-domain structure: life completion, symptoms impact, relationship with health care provider, and preparation for the end of life. It offers additional constructs such as preparation, relationship with the health care provider, and completion. Preparation includes questions regarding patient concern over becoming a burden, reflection on life regrets, and perception of the extent of one's family's preparation for the patient's end of life.[36]

Measuring the quality of dying can guide care and support for dying individuals and their families, inform clinical decision-making, shape healthcare delivery, support policy development and evaluation, facilitate comparisons across institutions and countries, and track changes over time in settings where endoflife care is delivered.[16]

Among all quality of dying assessment instruments described in the literature, the Quality of Dying and Death Questionnaire (QoDD) is the most widely studied. The QoDD was translated and cross-culturally adapted into Brazilian Portuguese, demonstrating convergent and known-groups validity and internal consistency in assessing quality of death among cancer patients. It comprises 31 items divided into six domains: symptoms and personal control, preparation for death, family concerns, treatment preferences, whole-person concerns, and moment of death, reflecting experiences during the last seven days of life.[61] Consequently, the conceptual redefinition of death and the dying process has become a critical factor in safeguarding patient autonomy over bodily integrity and in optimizing QoL until the end of life.[62]

Conversely, domains related to functionality, autonomy in activities of daily living, cognitive and social aspects, and healthcare provision are fundamental for QoL assessment from the time of diagnosis.[63] Systematic reviews indicate that early PC for cancer patients improves QoL by reducing long-term psychological burden.[64]

Regarding the assessment of psychometric properties, it is important to underscore that, due to the intrinsic heterogeneity of patients receiving PC, instruments may not be interchangeable. This is attributable to multiple factors previously delineated in the literature, including cultural variables, disease type, disease stage, symptomatology, and other patient-specific characteristics. Consequently, the inherent complexity of this population constitutes a significant challenge for the development of robust instruments capable of accurately evaluating QoL.

In Brazil, two instruments identified in the present study have been validated in cancer patient populations. According to Rugno[31] the self-reported version of the POS-BR may serve as a practical tool for assessing QoL in patients with chronic and life-threatening conditions, as well as for evaluating care and screening for signs and symptoms, once its brevity and ease of completion allow for both self-administration and administration by healthcare professionals.

Although our search strategy did not retrieve the Brazilian versions of the Patient Dignity Inventory (PDI-Br) and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 15-Palliative Care (EORTC QLQ-C15-PAL),[65] it is important to emphasize that both have also been validated for Brazilian Portuguese as well. These validations were conducted in populations of patients with advanced diseases receiving PC (PDI-Br) and in patients with metastatic cancer in PC (EORTC QLQ-C15-PAL), respectively.

Understanding the relationship between dignity and psychosocial factors is important for the care of patients with advanced disease at the end of life, particularly in hospital settings, as it may be associated with perceived impairments in QoL and willingness to live. In Brazil, this issue is especially relevant, as the country ranked 79th out of 81 nations in the Quality of Death and Dying (2021)[58].[65] This ranking places Brazil among the least favorable locations for end of life care, only surpassing countries facing substantial developmental challenges or socio-political crises, such as Lebanon (80th) and Paraguay (81st).

No studies involving pediatric populations were identified. Pediatric PC represents a distinct field in which QoL assessment typically requires age-appropriate instruments and the inclusion of caregiver-reported outcomes. This gap highlights the need for future research focused on the development and validation of QoL measures specifically tailored to children with life-limiting conditions.[66] The predominance of evidence from high-income countries, where PC policies are more established and methodological approaches are more mature, may partly explain the scarcity of validated instruments applicable to broader contexts.[67]

Furthermore, the limited number of studies conducted in low- and middle-income countries may underscore the inequality of PC access for mixed populations.

Study limitations

This scoping review may have been constrained by limitations inherent to the search strategy, particularly regarding the identification of instruments specifically tailored for hospital-based PC and the inclusion of gray literature, as conference abstracts were excluded. Besides, we focused on hospital settings, since hospitals often remain the primary setting for patients with advanced illness, particularly in the last year of life, to manage their symptoms, due to the low coverage of PC in healthcare systems, mainly in low- and middle-income countries. Prioritizing QoL assessment tools for these patients may support individualized care and optimize the therapeutic plan.

Nevertheless, the present review highlights important advances and persisting challenges in the development of QoL instruments for PC. While most available instruments include physical, psychological, and spiritual domains, their heterogeneity limits comparability and may overlook critical aspects of end of life care. Cultural validation remains scarce, particularly in low- and middle-income countries, and balancing comprehensiveness with feasibility is still a challenge. In addition, ADR,

which intensifies physical symptoms and psychological distress, can indirectly undermine social, psychological and spiritual well-being, yet is rarely addressed in current tools. Future instruments should integrate these dimensions more explicitly to better capture the holistic experience of patients in PC.

Use of artificial intelligence

Artificial intelligence tools were used exclusively for language translation, language editing, and preparation of the graphical abstract. Google Gemini and ChatGPT were used following detailed instructions provided by the authors, without any influence on the scientific content, data analysis, or interpretation of results.

Previous presentation at conferences

This manuscript has not been previously presented at scientific meetings or conferences.

Data access statement

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Data availability statement

The materials supporting the findings are available in the supplementary materials.

CRediT authorship contribution statement

Ivis Vinicius de Oliveira Martins: Writing – review & editing, Writing – original draft, Validation, Methodology, Investigation, Formal analysis, Conceptualization. **Igor Massocatto Marques:** Validation, Investigation. **Felipe Augusto Trinca Alves da Silva:** Investigation. **Maria Eduarda Marques Trinca:** Investigation. **Lais Beanucci Coelho:** Validation, Investigation. **Ana Maria Rosa Freato Gonçalves:** Validation. **Albert Figueras:** Writing – original draft. **Maria Olívia Barboza Zanetti:** Writing – original draft. **Leonardo Regis Leira Pereira:** Writing – original draft. **Maria Teresa Herdeiro:** Writing – original draft. **Fabiana Rossi Varallo:** Writing – original draft, Validation.

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Declaration of interest statement

The authors declare that there are no conflicts of interest.

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Appendix A. Supplementary data

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