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Instruments for the identification of patients in need of palliative care in hospital

settings: a systematic review of measurement properties

Objective: The objective of this review was to provide a comprehensive overview of the measurement

properties of the available instruments used by clinicians for identifying adults in need of general or

specialized palliative care in hospital settings.

Introduction: Identification of patients in need of palliative care has been recognized as an area where

many health care professionals need guidance. Differentiating between patients who require general

palliative care and patients with more complex conditions who need specialized palliative care is

particularly challenging.

Inclusion criteria: We included development and validation studies that reported on measurement

properties (eg. content validity, reliability, or responsiveness) of instruments used by clinicians for

identifying adult patients (>18 years and older) in need of palliative care in hospital settings.

Methods: Studies published until March 2020 were searched in four databases: Embase.com, Medline

Ovid, PubMed, and CINAHL EBSCO. Unpublished studies were searched in Google Scholar,

government websites, hospice websites, the Library Network of Western Switzerland, and WorldCat.

The search was not restricted by language; however, only studies published in English or French were

eligible for inclusion. The title and abstracts of the studies were screened by two independent reviewers

against the inclusion criteria. Full-text studies were reviewed for inclusion by two independent reviewers.

The quality of the measurement properties of all included studies were assessed independently by two

reviewers according to the COnsensus-based Standards for the selection of health Measurement

INstruments (COSMIN) methodology.

Results: Out of the 23 instruments identified, four instruments were included, as reported in six studies:

the Center to Advance Palliative Care (CAPC) criteria, the Necesidades Paliativas (NECPAL), the

Palliative Care Screening Tool (PCST), and the Supportive and Palliative Care Indicators Tool (SPICT).

The overall psychometric quality of all four instruments was insufficient according to the COSMIN

criteria, with the main deficit being poor construct description during development.

Conclusions: For the early identification of patients needing palliative care in hospital settings, there

is poor quality and incomplete evidence according to the COSMIN criteria for the four available

instruments. This review highlights the need for further development of the construct being measured.

This may be done by developing additional studies on these instruments or by conducting a new

instrument for the identification of patients in need of palliative care that addresses the current gaps in

construct and structural validity.

Systematic review registration number: PROSPERO CRD42020150074.

**Keywords:** identification; instrument; measurement properties; screening; palliative care.

## **Summary of Findings**

## Instruments for the identification of patients in need of palliative care

Bibliography: Teike Lüthi F, MacDonald I, Rosselet Amoussou J, Bernard M, Borasio GD, Ramelet AS. Instruments for the identification of patients in need of palliative care in hospital settings: a systematic review of measurement properties. JBI Evid Synth. 2021;19(0):000-000.

Psychometric property	Summary or pooled results	Overall rating	Factors determining the quality of evidence	Quality of evidence
Content validity (CAPC, <sup>80</sup> NECPAL, <sup>49,86</sup> PCST, <sup>82,84</sup> SPICT <sup>50</sup> )	Six studies with doubtful content validity. None of the studies described details of the development of items and methods used to establish the final version, including relevance, comprehensiveness and comprehensibility.	± inconsistent	-1 risk of bias -1 inconsistency	Low
Reliability (CAPC <sup>80</sup> )	One study evaluated inter-rater reliability.	– insufficient	-1 risk of bias -1 imprecision	Low

CAPC, Center to Advance Palliative Care; NEPCAL, Necesidades Paliativas; PCST, Palliative Care Screening Tool; SPICT, Supportive and Palliative Indicators Tool

### **Definition of quality levels**

**High**: we are very confident that the true measurement property lies close to that of the estimate of the measurement property

**Moderate:** we are moderately confident in the measurement property estimate: the true measurement property is likely to be close to the estimate of the measurement property, but there is a possibility that is substantially different

Low: our confidence in the measurement property estimate is limited: the true measurement property may be substantially different from the estimate of the measurement property Very low: we have very little confidence in the measurement property estimate: the true measurement property is likely to be substantially different from the estimate of the measurement property

The Summary of Findings follows a modified GRADE approach proposed in the 2018 COSMIN methodology for systematic reviews of patient-reported outcome measures.<sup>77</sup>

## Introduction

Patients in need of palliative care (PC) come from all settings, including hospital. The prevalence of inpatients receiving PC varies considerably, from 7% to 75%, depending on illness/diagnostic grouping and care setting.<sup>1-9</sup> A population-based estimate calculation found that 63% to 82% of deceased persons required PC.<sup>10</sup> The demand for PC services will grow as the population ages and as chronic diseases and polymorbidities increase.<sup>11</sup>

Palliative care has evolved over the past decade, shifting from a focus on terminal cancer to include all chronic and life-limiting conditions. <sup>12,13</sup> The World Health Organization defines PC as "an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual." <sup>14[para.1]</sup> However, this definition has two shortcomings. First, it implies early identification of patients needing PC but does not clearly state the health care professional (HCP) responsible, in which setting, or the timing of this identification. Second, it does not distinguish between the type of PC provided (general vs. specialized).<sup>5,15-17</sup>

The ability to distinguish between patients in need of general or specialized PC is a prerequisite to respond to specific needs of patients and families. <sup>18,19</sup> The terms "general palliative care" or "specialized palliative care" are often used without clearly differentiating between them or mentioning when specialized PC should begin. <sup>(20-22)</sup> For the purpose of this review, general PC refers to patients with a life-threatening prognosis of a chronic, progressive, incurable, and life-threatening disease, or patients who have reached the end of their life who do not have complex health problems. <sup>21,22</sup> It has been estimated that 75% to 80% of all patients in need of PC do not have complex care needs and thus do not require PC specialists. <sup>23</sup> Thus, general PC can be provided by all HCPs in all care settings. General PC should be initiated not only in the early stages of an incurable disease, but also in cases of significant age-related frailty. <sup>24</sup> Specialized PC is intended for patients with complex conditions, including unstable clinical conditions or high levels of psycho-socio-existential suffering (accounting for approximately 20% to 25% of all PC patients). <sup>20,24-26</sup> The complexity of the situation, characterized by several interrelated issues, requires specific treatment or care provided by PC specialists in a specialized unit or by professionals from mobile PC teams. <sup>20</sup>

Identifying patients in need of PC, including physical, psychosocial, and spiritual needs, is challenging for HCPs who do not specialize in PC due to the unpredictability of illness courses, the uncertainty about who is responsible for identification, difficulties in communication with the patient about PC, and difficulties in collaboration between specialized and non-specialized HCPs.<sup>27-29</sup> As a result, patients are often not identified or identified too late, leading to high rates of hospital mortality, with up to 80% of deaths occurring in hospital while most patients wish to die at home<sup>11,30-32</sup>; suboptimal symptom management<sup>33-35</sup>; unplanned hospitalizations with longer hospital stays<sup>36,37</sup>; prescription of inappropriate treatments<sup>38,39</sup>; and insufficient support for patients and their relatives.<sup>36,40,41</sup> These adverse events decrease the quality of life for patients and their families and increase hospital

expenditures. Because hospitalizations are frequent along the disease trajectory, they present opportunities for identifying patients in need of PC. This would better manage distressing transitions between the hospital and the community, promote discussions about the evolution of the disease, and allow for advance care planning.<sup>42-44</sup>

There is a growing number of available instruments to identify patients in need of PC that include criteria for illness severity, progression, and associated frailty. Decisions made during instrument development concerning the context for the instruments has resulted in major differences that affect usability of current PC instruments. Some instruments were designed for specific settings, such as emergency departments or intensive care units, where patients are acutely unstable, making the identification of PC needs difficult.<sup>45</sup> Other instruments were designed for specific diseases (eg, cancer or interstitial lung disease) or specific populations (eg, older people).<sup>46,47</sup> A few instruments were designed for general use.<sup>48-50</sup> Finally, all instruments were initially developed by physicians with an emphasis on diagnostic information, which limits their use by others HCPs.

Palliative care is a philosophy based on an interprofessional approach that provides holistic, patient-centered, and family-centered care throughout the disease trajectory until death.<sup>51-53</sup> Thus, it is necessary that nurses who care for patients and relatives are empowered to autonomously employ instruments for the early identification of PC needs.<sup>54</sup>

Self-identification of PC needs by patients is often impossible or unreasonable. Some conditions, such as severe cognitive impairment or delirium, make it impossible for patients to complete an instrument. Furthermore, patients, families, and HCPs are often reluctant to discuss PC due to the sensitive and difficult nature of the topic of death and dying.<sup>55,56</sup> In such conditions, it would be unethical to ask patients, or relatives, to complete, unassisted, an instrument for identifying PC needs that could confront them with this sensitive issue. Support, collaboration, and discussion between HCPs, patients, and families are necessary to provide information so they can make informed decisions and express their choices about their care.<sup>57-59</sup> Thus, it is important that nurses and physicians carry out PC assessment using a clinician-reported outcome (ClinRO) measurement instrument, allowing HCPs to engage in discussions with the patient and their family.

Two systematic reviews on PC instruments were identified in a preliminary search conducted in PubMed in February 2017.<sup>60,61</sup> Maas et al.<sup>60</sup> steered a review with an accompanying survey of European general practitioners to discover instruments for the identification of patients in need of PC in the primary care setting. This review found four instruments: the RADboud Indicators for Palliative Care Needs (RADPAC),<sup>62</sup> the residential home palliative care tool,<sup>63</sup> the Supportive and Palliative Care Indicators Tool (SPICT),<sup>50</sup> and the early identification tool for palliative care patients.<sup>64</sup> The survey<sup>60</sup> identified an additional three instruments: the Gold Standards Framework Prognostic Identification Guidance (GSF PIG),<sup>48</sup> the NECPAL CCOMS-ICO,<sup>49</sup> and the Quick Guide.<sup>65</sup> One limitation of this review was the lack of systematic appraisal of the instruments' psychometric properties, with sensitivity and specificity being the only criteria reported.

The second systematic review, conducted by Walsh et al.<sup>61</sup> aimed to identify diagnostic tools for the early identification of PC patients in general practice. They identified four instruments: the GSF PIG,<sup>48</sup> the NECPAL CCOMS-ICO,<sup>49</sup> the SPICT,<sup>50</sup> and the RADPAC.<sup>62</sup> They analyzed the content of the four instruments to determine their usability and acceptability, but did not evaluate measurement properties.

Both reviews concluded that there is limited evidence showing the ability of the included instruments to support HCPs in the identification of patients in need of PC early in their illness trajectory. The lack of a comprehensive evaluation on the psychometric properties of ClinRO instruments for PC, and the inability of current instruments to distinguish between general and specialized care, are two gaps in the literature and in clinical practice, respectively. This review evaluated the available evidence on the instruments for the identification of PC needs according to the a priori published protocol.<sup>66</sup> The objectives of this systematic review were as follows: i) to critically appraise, compare, and summarize the measurement properties and quality of evidence of the available ClinRO measurement instruments for identifying adult patients in need of general or specialized PC in hospital settings, and ii) to ascertain the existence of an instrument differentiating between general and specialized PC, independently of its quality of evidence.

### Review questions

- What are the measurement properties of instruments for identifying adult patients in need of general or specialized PC in hospital settings (excluding emergency departments and intensive care units)?
- Is there an instrument for identifying adult patients in need of PC that differentiates between general and specialized PC needs?

### Inclusion criteria

To the authors' knowledge, there are no specific guidelines to assess measurement properties of ClinROs. The inclusion criteria for this review were developed following the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidelines for systematic reviews of measurement properties of patient-reported outcomes (PROs) version 1.0 dated February 2018 (version 1.0 dated January 2021 was not available at the time of commencement of this review).<sup>67, 68</sup> COSMIN guidelines recommend the following inclusion criteria: i) the instrument should aim to measure the construct of interest (identification of patients in need of PC), ii) the study sample should concern the target population of interest (adult patients in need of PC independently of their pathology in hospital settings), iii) the study should concern the type of measurement instrument of interest (ClinROs), and iv) the aim of the study should be the development of a measurement instrument or the evaluation of one or more of its measurement properties.

### **Participants**

This review considered studies that included adult patients (> 18 years of age) with life-limiting cancer or non-cancer illness (ie. chronic, progressive, incurable illness likely to cause death), in need of PC in hospital. Studies involving persons with a disability or pediatric populations were excluded. Intensive care units and emergency departments were excluded due to the instability and acute nature of patient conditions in these settings. Studies of persons in long-term care facilities, home setting, or community care setting were also excluded.

#### Instrument/construct

This review considered studies presenting measurement instruments for identification of patients in need of PC (based on the World Health Organization's definition).<sup>14</sup> Studies must have reported on the development of the instrument or one or more of its measurement properties: validity, reliability, or responsiveness.

Health research outcomes are divided into two types: i) biomarkers, which are biochemical measurements (eg, blood pressure, serum albumin) and require no clinical judgment, and ii) clinical outcome assessments used to measure a patient's symptoms or psychological state, and/or the effect of a disease or a specific condition on patient function.<sup>69</sup> Clinical outcome assessments are divided into four categories based on the type of rater: PRO measures, ClinRO measures, observer-reported outcome measures, and performance outcome measures. 70 This review focused only on ClinROs. Clinician-reported outcomes are useful when a patient is unable to self-report on their own status, and reflect patients' feelings or functions or predict survival. 69,70 To be defined as a ClinRO, the rating must come from a trained HCP after observing a patient's health condition. This involves clinical judgment based on observable signs, behaviors, or other physical manifestations related to a disease or a specific condition, but cannot directly assess symptom intensity, which is known only to the patient.<sup>69,70</sup> Three types of ClinROs exist: readings with dichotomous responses, ratings with a categorical or continuous score including at least three possible levels, and global assessments (ie, a clinician's overall judgment on an aspect of patient health status for which variables are not consistently defined).<sup>70</sup> Palliative care is a broader construct than end of life; for this reason, this review included ClinRO instruments comprising general indicators of decline and frailty (eg, weight loss, falls, pressure ulcers).

The following types of instruments were excluded: biological markers of decline that require a specific investigation or examination (eg, serum albumin), and instruments centered on prognosis. This includes the well-known surprise question, "Would you be surprised if this patient were to die in the next 12 months?" which is based on a prognostic estimation.<sup>71,72</sup> However, if the surprise question were incorporated into a ClinRO together with other criteria, the instrument was included. Instruments were also excluded if they referred to one specific pathology only, were developed for use in intensive care or emergency care, were addressed to caregivers, or were instruments used as an outcome measurement with no measurement properties reported.

#### **Outcomes**

The outcomes were stipulated in the *a priori* published protocol.<sup>66</sup> In order to improve the description of the selected instruments, we added the following information: i) original language and existing translation(s); ii) first target population of users; iii) number of items and dimensions; iv) response options and scoring; and v) administration burden (time for completion, HCPs training).

### Types of studies

This review considered any quantitative study reporting on the development and/or validation of measurement instruments as previously described.

## **Methods**

This review was conducted in accordance with the JBI methodology for systematic reviews of measurement properties and according to the *a priori* published protocol registered in PROSPERO (CRD42020150074).<sup>66</sup> All appraisal documents used for this review are available on the COSMIN website: https://www.cosmin.nl/cosmin-tools/.

## Search strategy

The search strategy aimed to identify published and unpublished studies. A comprehensive literature search was performed in collaboration with a medical librarian (JRA). Following an initial limited search of MEDLINE and CINAHL, the search strategy was updated. Databases searched included Embase, MEDLINE (Ovid), PubMed (NOT medline[sb]), and CINAHL (EBSCO), with no date or language restrictions, although only articles published in English or French were eligible for inclusion. The search was conducted in August 2018 and was updated in March 2020. The precise filter for measurement properties of Terwee was used to identify measurement properties. We have adapted the original PubMed filter to the subject headings and to the syntax of the other databases. The full search strategies are provided in Appendix I. Additional records were identified through backward citation searching. The search for unpublished studies included Google Scholar, government websites (ie, National Institute of Nursing Research), hospice websites, the Library Network of Western Switzerland, and WorldCat. The search strategy included the surprise question because it could have been a keyword for some instruments.

In an effort to not miss any unpublished work, 10 authors of published papers with missing measurement properties were contacted for further information. Three responded, but no additional details were provided. Finally, the reference lists of all studies selected for critical appraisal were screened for additional studies.

## Study selection

As recommended by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA),<sup>74</sup> following the search, all identified articles were collated and uploaded into EndNote X9<sup>75</sup> and duplicates were removed. Two reviewers (FTL & IMD or FTL & ASR) independently screened titles and abstracts against the inclusion criteria. This stage was completed using the free software Rayyan (Qatar Computing Research Institute, Doha, Qatar) that allows blinded assessment.<sup>76</sup>

The full texts of the selected articles were assessed in detail against the inclusion criteria by the same independent reviewers (FTL & IMD or FTL & ASR). Reasons for exclusion of full-text studies that did not meet the inclusion criteria were recorded and collected in the review report. Any disagreement between reviewers at each stage of the study selection and assessment process was resolved through discussions between the three reviewers (FTL, IMD, ASR).

## Assessment of methodological quality

Different articles describing the same instrument were treated as one study for the assessment of the methodological quality, as they contained complementary information. Selected studies were critically appraised by two independent reviewers (FTL & IMD or FTL & ASR) for methodological quality, using the COSMIN methodology and instruments as described in the 2018 COSMIN guideline for performing systematic reviews of PRO instrument.<sup>67,77,78</sup> The first step of this methodology is to establish content validity. This is the most important measurement property because it is a prerequisite for the assessment of the other measurement properties. The evaluation of measurement properties consists of three sub-steps: i) assessing the methodological quality of each included study; ii) rating of each study against the updated criteria for good measurement properties as either "sufficient (+)," "insufficient (-)," "inconsistent (±)," or "indeterminate (?)"; and iii) summarizing the evidence and applying the Grading of Recommendations, Assessment, Development and Evaluations (GRADE) approach to each measurement property.<sup>(67)</sup>

The COSMIN checklist consists of 10 boxes.<sup>77</sup> Each box includes quality standards for evaluating PROs development (box 1), content validity studies (box 2), structural validity (box 3), internal consistency (box 4), cross-cultural validity (box 5), reliability (box 6), measurement error (box 7), criterion validity (box 8), hypothesis testing for construct validity (box 9), and responsiveness (box 10). Content validity refers to the degree to which the content of the instrument adequately reflects the construct measured. Structural validity is assessed through the unidimensionality of the instrument using factor analysis, but it is only relevant for instruments based on a reflective model. Internal consistency is measured using Cronbach's alpha (continuous scores) or the Kuder-Richardson Formula 20 (KR-20; dichotomous scores). Cross-cultural validity is evaluated by assessing whether differential item functioning occurs (eg, using logistic regression analysis), or if the structure factors are equivalent across groups (eg, using multi-group confirmatory factor analysis). Reliability is assessed by test-retest or inter-rater agreement. Measurement error is assessed with information about the smallest detectable change as well as the minimally important change. Criterion validity is the degree by which the scores from the instrument

correspond to those obtained using a gold standard assessment. Criterion validity is assessed through sensitivity and specificity for dichotomous scores and through the area under the curve for continuous scores. Hypothesis testing for construct validity and responsiveness include expected relationships between the instrument under review and the comparison instrument.

Each box of the COSMIN checklist contains a different number of items. Response options vary per box, but in general, each item is rated as "very good," "adequate," "doubtful," "inadequate," or "not applicable. Scores are based on the "worse-score-counts" among all items within each box. Therefore, in order to obtain a rating of strong evidence, all items in each box must meet the established COSMIN criteria. Studies with an insufficient quality score in the content validity criteria cannot continue with the assessment of other measurement properties and are excluded due to inadequate development.<sup>67</sup> The same exclusion criteria is applied to structural validity; an instrument is excluded from further measurement property review if the quality score is determined to be insufficient.<sup>67</sup>However, as none of the studies assessed had good content validity (due to the construct of PC being poorly defined), we did not exclude studies with poor content validity in this review. Due to the nature of the construct under study ("palliative care"), and as recommended in the COSMIN user manual, <sup>77</sup>we skipped the evaluation of criterion validity and criterion approach for responsiveness in studies that used mortality rate as the gold standard. Construct validity and responsiveness were not assessed because these were not reported in any of the studies.

The COSMIN guideline was developed for PROs<sup>67</sup> but can be adapted for ClinRO measures (Terwee C, 2019, unpublished data). We changed all items that required patient involvement as part of the development or validation processes into HCP involvement. For example, we modified item 5 of the general design requirements (COSMIN box 1) as follows: "Was the PROM development study performed in a sample representing the target population for which the PROM was developed?" into "Was the PROM development study performed with input of HCPs for which the PROM was developed?" To assess the standards for the quality of content validity studies (COSMIN box 2), we evaluated if HCPs were asked about the relevance, comprehensibility, and comprehensiveness. To comprehensively assess content validity of the instruments, we included all translated versions.

## Data extraction

Data were extracted by FTL using a modified COSMIN risk of bias checklist manual for systematic reviews of PROs.<sup>77</sup>The data extracted included specific details about the tests, populations, study methods, and outcomes of significance to the review question, as well as specific objectives. A double check of this database was completed by IMD.

### Data synthesis/assessing certainty in the findings

Data on instrument characteristics, validity, and reliability were described narratively. To facilitate the compressibility of the data, a summary of the main features of included instruments was added. The rating of the summarized results and the grading of the quality of evidence ("high," "moderate," "low,"

"very low") are presented in tables. Grading of the study quality was based on a modified GRADE approach, where the quality of the evidence is graded as high, moderate, low, or very low.<sup>79</sup> Four GRADE factors are taken into account: risk of bias, inconsistency, imprecision, and indirectness.<sup>77</sup>

### Results

## Study inclusion

The search of the four databases yielded 5693 articles (Figure 1). Searches for unpublished records identified 11 additional articles. After removing the duplicates, 2121 articles remained. Another 2060 articles were excluded after screening titles and abstracts, resulting in 61 full-text articles assessed for eligibility. After reading the full texts, a total of 52 articles were excluded due to ineligible construct of interest, ineligible population, no measurements used to assess PC, or not on development or psychometric properties (Appendix II). Nine articles reporting data on four instruments met inclusion criteria for quality assessment. 49,50,80-86 Three publications were excluded following assessment of methodological quality (Appendix III).81,83,85 Finally, six studies reporting on four instruments were included, namely the Center to Advance Palliative Care (CAPC) criteria, the Necesidades Paliativas (NECPAL), the Palliative Care Screening Tool (PCST), and the Supportive and Palliative Care Indicators Tool (SPICT) (Table 1). 49,50,80,82,84,86 Due to incomplete reporting on content validity, additional sources consulted: **NECPAL** user guide,87 the **SPICT** the (https://www.spict.org.uk/developing-the-spict-2/), and another conceptual article about the CAPC criteria.88

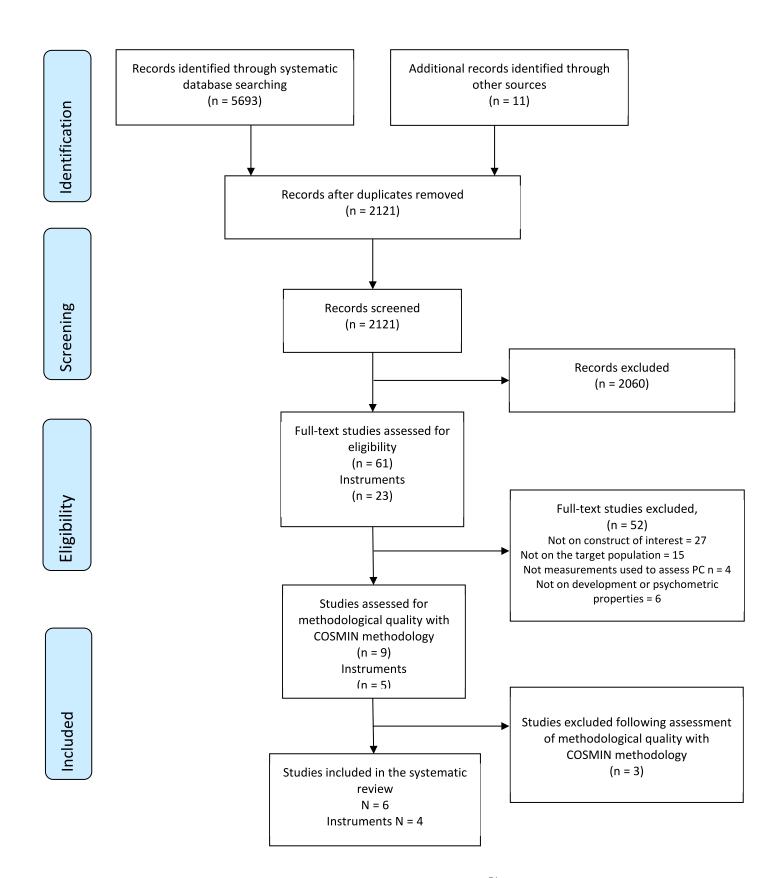


Figure 1: PRISMA flow diagram of search and study selection process<sup>74</sup>

#### Characteristics of included studies

The six included studies focused on instrument development and/or the assessment of measurement properties of instruments that allow the identification of adult patients in need of PC. Publication dates ranged from 2012 to 2018.

As the evaluated instruments were ClinROs, only HCPs were involved in instrument development and content validity studies. Several methods were used in the development of the instruments, including interviews, focus groups with experts, Delphi processes, and website utilization.<sup>49,50,84</sup> Patient study samples were congruent with the definition of PC, including cancer and non-cancer patients<sup>49,50,80,86</sup> from hospital settings<sup>50,80,82,84</sup> and sometimes from both hospital and community settings.<sup>49,86</sup> The mean age of the patients ranged from 63 to 81 years (Table 1). Health care professional samples varied depending on the instrument and on the measurement properties assessed. Development of the instrument was always initiated and led by physicians. Physicians accounted for the largest proportion of participants in all development and content validity studies.<sup>49,50,84</sup> Nurses and psychologists participated in the development and the pre-test of the NECPAL and in the prevalence study.<sup>49,86</sup> Nurses contributed to the pre-test of the SPICT,<sup>50</sup> and three research nurses were involved in the administration of the CAPC.<sup>80</sup> For the PCST, while it is not clear which professionals were involved in the development, nurses did contribute to the content validity.<sup>82,84</sup> Description of the HCP samples was generally succinct, and the participants' professions were not always clearly presented.<sup>50,84</sup>

## **Review findings**

## Description of instruments

The four included instruments (CAPC, NECPAL, PCST, SPICT) were developed for clinical practice. They can be considered as ClinROs because they were designed for use by HCPs and not by the patients themselves or their families, although some of the data come from patient assessment. For example, the PCST includes a symptom assessment scale to assess symptom intensity directly with the patient. Two instruments (SPICT, NECPAL) were developed for all care settings, including hospital, long-term care facilities, and primary care. The CAPC was developed specifically for hospitalized patients with two different versions: one for admission and another for the hospital length of stay. The PCST was also developed for hospital settings.

The NECPAL and the SPICT are included in national PC programs. The SPICT is based on criteria developed by the Gold Standard Framework.<sup>89</sup> The NECPAL is based on criteria developed by the Gold Standard Framework and on the SPICT. The target patient population for the SPICT, the NECPAL, and the CAPC are patients with advanced, chronic, life-threatening illness. The CAPC<sup>88</sup> and the PCST<sup>84</sup> were developed in the USA, the NECPAL in Spain,<sup>49</sup> and the SPICT in Scotland.<sup>50</sup>

The four included instruments are at varying levels of development. The SPICT is continually being revised and there are multiple versions available. The NECPAL is in its third revision, and the CAPC is finalized. Three slightly different versions of the PCST were identified, including the revised PCST.

According to the COSMIN criteria, one aspect of content validity is to define the recall period, but none of the included studies reported a clear time frame for assessment.

The CAPC has primary and secondary criteria. Primary criteria are minimum indicators that HCPs should use to screen patients in need of PC (eg, frequent admissions, complex care requirements, decline in function), while secondary criteria are more specific indicators of a higher likelihood of unmet PC needs (eg, cognitive impairment, chronic home oxygen use, limited social support). The NECPAL and the SPICT have indicators that are general (eg, nutritional decline, unplanned hospital admissions, persistent symptoms) and clinical/disease-related (eg, metastatic or advanced loco-regional cancer in progression; extensive, untreatable coronary artery disease; persistent dysphagia). The PCST consists of two disease-related scores (basic and concomitant disease process), a score for the functional status of the patient, and other criteria to consider (eg. help needed with complex decision-making and determination of goals of care; uncontrolled psychosocial and spiritual issues). Only the NECPAL and the PCST include an exploration of psychosocial/spiritual suffering. The NECPAL and the CAPC include the surprise question as an item. None of the four instruments differentiate between general and specialized PC needs.

The SPICT contains 27 items, the PCST 20, the NECPAL 14, and the CAPC 10 (admission version) and 19 (hospital length of stay version). For the CAPC, the NECPAL, and the SPICT, each item is rated based on a structured "yes/no" response format. For the PCST, a score is given depending on the number of items selected. The original version of SPICT had no cut-off value, while other versions defined a cut-off value (ie, in the 2015 version  $\geq$  2 general indicators and/or  $\geq$  1 clinical indicator). For the NECPAL, the surprise question must be positive and  $\geq$  1 general indicator or  $\geq$  1 specific indicator must be present. For the CAPC, the cut-off value is when  $\geq$  1 criteria is present. For the PCST, different cut-offs were identified depending on the version of the instrument; in the first version, a cut-off  $\geq$  12 is required for a referral to a PC team consultation, whereas the latest version requires a cut-off  $\geq$  4.

With regard to translations of the instruments included in this review, the SPICT, which was developed in English, has been translated into French, Spanish, German, Portuguese, Brazilian, Danish, Italian, Japanese, Dutch, and Swedish, but only data on the Spanish, German, and Italian translations were published. 90-92 The NECPAL was developed in Spanish but translated into English for publications; the translation process was not detailed. The CAPC and the PCST are available only in English. There are two English versions of the SPICT, the standard one and one termed "for all."

The SPICT has a one-page instruction document to aid in its use. For the CAPC, the PCST, and the SPICT, instructions are directly on the questionnaire. For the SPICT, complementary information is on the website. A detailed user guide was developed for the NECPAL. Neither information about necessary training for the use of these instruments nor the time for completion were found. A summary of the main features of the included instruments is presented in Appendix IV.

## Content and structure of dimensions

Instruments included in this review are checklist-type screening instruments<sup>93</sup> and not diagnostic instruments.<sup>94</sup> Their use helps HCPs to identify patients' PC needs. In each of the instruments, the concept of PC was divided into two domains: i) diagnosis and disease progression (disease-related),

and ii) suffering and symptom management (addressing physical, psychological, and practical issues). All of the included instruments contained at least one item in each domain. Although none of the development studies specified unidimensionality or multidimensionality of the instrument structure, multidimensionality was assumed due to the breadth of the PC concept. However, none of the studies described distinct dimensions of the respective instrument. Two of the four instruments (NECPAL, CAPC) included the surprise question as an initial question. The surprise question was originally included in the first SPICT version and removed in a subsequent revision. The SPICT and the NECPAL offer some recommendations for practice, yet provide no reference to available evidence.

## Methodological quality

The quality of the content validity and the other measurement properties are presented in Table 2 and Table 3. No results could be statistically pooled in a meta-analysis due to heterogeneity of the studies and the lack of measurement properties assessed. Globally, the available psychometric evidence appears to favor the NECPAL over the other instruments.

Content validity. All studies reported on some aspect of content validity. However, the measurement quality was doubtful in all studies due to a lack of methodological data reported on the development process of the instrument or poor reporting on the comprehensibility, comprehensiveness, or relevance assessment of the instruments. The cognitive interview or pilot test were poorly rated in three studies due to questionable methodologies and/or insufficient data (CAPC, PSCT, SPICT). The PCST assessed a content validity ratio<sup>82</sup> with a range between –.58 to .88, with an average of .29. None of the instruments calculated a scale content validity score. In conclusion, the quality of evidence related to content validity was heterogeneous and poor in all six studies.

Structural validity. None of the studies reported on factor analysis or item response theory/Rasch analysis for the unidimensionality testing. Therefore, there is no evidence regarding the structural validity.

*Internal consistency.* None of the studies reported internal consistency measurements.

Cross-cultural validity. None of the studies reported on cross-cultural validity assessments.

Reliability. One study reported on reliability. The CAPC $^{80}$  considered inter-rater agreement and reported it as being between k = .31 and k = 1.00, depending on the items and ward on which the patient was hospitalized. $^{80}$  The assessment was completed by nurses through a retrospective review of the electronic medical record, which does not conform to ClinRO assessment criteria. The quality of the methodology was insufficient due to a lack of information about patients' demographics and methodological bias.

*Measurement error.* None of the studies reported on measurement error.

#### **Discussion**

To the best of our knowledge, this systematic review is the first to provide a comprehensive overview of the measurement properties of available ClinRO measurement instruments for the identification of patients in need of PC for the hospital settings, using the COSMIN criteria. The most striking finding of

this review is the low quality of reporting of PC instruments. It is worth noting that out of the 23 instruments identified, nine could not be appraised due to lack of reporting on the development process, and only four instruments (CAPC, NECPAL, PCST and SPICT) progressed through the screening process for inclusion in the final analysis. Evaluation of these four instruments highlighted overall poor psychometric testing, resulting in the failure to demonstrate good measurement properties.

The content validity appeared doubtful in all four instruments. The COSMIN methodology considers content validity the most important measurement property of a PRO, but also the most challenging to assess. This review confirms the numerous challenges in evaluating content validity, which involves considering if items are relevant, comprehensive, and comprehensible, and reflect the construct to be measured. Hence, the origin of the construct has to be clear, well described, and based on a well-established conceptual framework. According to the COSMIN criteria, the two options can only be "very good" or "inadequate." However, the construct of "palliative care" is still in development, and has evolved with time and cultural influences. The PC construct is multidimensional, encompassing physical, psychosocial, and existential dimensions as well as multiprofessional aspects, making it difficult to clearly delineate. According to the COSMIN criteria, the two options can only be "very good" or "inadequate." However, the construct of "palliative care" is still in development, and has evolved with time and cultural influences. The PC construct is multidimensional, encompassing physical, psychosocial, and existential dimensions as well as multiprofessional aspects, making it difficult to clearly delineate.

Another challenge in evaluating the content validity was related to the distinction between general versus specialized PC that is essential for the definition of the construct, but for the moment not well recognized. PC that is essential for the definition of the construct, but for the moment not well recognized. The absence of solid theoretical foundations contribute to the lack of conceptual clarity for the identification of PC needs. Moreover, cultural influences regarding PC, death, and dying have to be included in the construct elicitation because they could affect the content validity of the instruments. As all instruments were developed before the COSMIN criteria used for this review, 67,77,78 we decided nevertheless to give a "very good" rating for the construct definition even if it was not clearly specified. On several occasions, we would have preferred to assign an "adequate" or "doubtful" rating, but these options are not available. This choice had consequences on the remaining quality assessment, as all included instruments lacked a clear definition of the construct.

None of the four instruments demonstrated the multidimensionality of PC, because structural validity was not tested (no factor analysis or item response theory/Rasch analysis were performed). These four checklists are presumably based on a formative model where the different items are heterogeneous with respect to the construct. This is different than a reflective model in which all items are a manifestation of the same underlying construct and are highly correlated.<sup>68</sup> In such conditions, factor analysis is not relevant. The underlying conceptual framework must be specified at the outset to determine the measurement theory to be used in the development of the instrument and to better assess instruments' measurement properties.<sup>68</sup>

Criterion validity assessments in the NECPAL, SPICT, and other studies used mortality as the gold standard, which is not consistent with the construct of PC, the concept of PC needs, or with the intention to develop an instrument to assess PC needs and not based on prognosis.<sup>98</sup> It is important to note that in the process of further refinement of the SPICT, prognosis has been added as one of its outcomes.<sup>85</sup> In our view, it will be necessary to operationalize a shift from estimation of prognosis (which does not

conform to the basic concept of PC, and is also unreliable in non-cancer patients) to a proactive identification of patients who would benefit from PC.<sup>99</sup> At this stage and in the absence of more objective measures, we can only recommend expert clinical assessment by specialists in PC as a gold-like standard to assess criterion validity. This has been done in other studies where a gold standard was not available.<sup>100,101</sup>

The distinction between general and specialized PC is crucial for breaking down barriers to initiate PC and provide appropriate care to patients in need of PC, including non-cancer patients.<sup>19,29</sup> None of the instruments included in this review differentiate between general and specialized PC.

Instruments for the identification of patients in need of PC were mainly developed by specialists based on their clinical judgment and experiences. This was an important step in the development of PC and in the recognition of the requirement to identify patients in need of PC earlier in the disease course. The GSF PIG<sup>48</sup> is the first instrument commonly used as a basis for the development of other instruments and is widely used in the United Kingdom. Unfortunately, the GSF PIG could not be included in this review because it was designed for primary care and its development was based on clinical expertise without any reported data on the development process.

One systematic review on instruments for the identification of PC needs was published since the publication of our protocol and the commencement of our review. It aimed to identify instruments for primary care settings and assessing their accuracy. The authors identified 10 instruments, two of which were also designed for the hospital setting (NECPAL and SPICT). They observed that most of the instruments are used for prediction of death and/or deterioration, which does not align with early identification of PC needs. Their results showed low precision of the instrument in detecting PC needs, with sensitivity ranging from 3% to 94%, and specificity from 26% to 99%. The authors recommend a shift from identification of mortality prediction to a standardized screening process to assess early PC needs. This is congruent with the assumptions on which our review was based.

## Strengths and limitations

The use of the COSMIN criteria as a structured process for evaluating psychometric properties is the main strength of this review. COSMIN has the merit of being a well-acknowledged and rigorous method used in health care research. The drawback is that this method is stringent because it takes into account only the worst rating per domain. As a result, the global confidence in each instrument decreases rapidly, giving the impression of a relatively poor level of evidence quality. In addition, since the revised COSMIN criteria were published in 2018, it is possible that some previously published instruments may have been excluded due to reporting shortcomings as opposed to poor psychometric quality.

Using criteria developed to assess PROs for ClinROs could be considered as another limitation. However, in the absence of criteria for ClinROs, it has been recommended by the primary author of the COSMIN methodology to modify the PROMs criteria to accommodate ClinROs. Therefore, this review was conducted with the most robust methods available. The COSMIN group is currently developing criteria for ClinROs, and when available, these criteria would be preferable for use in future reviews of

PC instruments. This review focused on hospital settings only. While this clearly excluded instruments developed for patients in the community or in long-term care settings, we were able to clearly state the review questions and focus our search strategy, which retrieved more than 5000 articles.

### Conclusion

For the early identification of patients in need of PC in hospital settings, there is poor quality and incomplete evidence according to the COSMIN criteria for the four available instruments. This review highlights the need for further studies to reinforce measurement properties of these instruments or the need for new instruments for the identification of patients in need of PC that address the current gaps in construct and structural validity. In addition, no current instruments differentiate between patients who would benefit from general vs. specialized PC.

## Recommendations for practice

This review assessed the measurement properties of four instruments used by HCPs for the identification of patients in need of PC in hospital settings, namely CAPC, NECPAL, PCST, and SPICT. According to the COSMIN criteria, the overall quality of the results is poor. Thus, none of the reviewed instruments can be recommended for clinical practice in the hospital setting based on these criteria.

#### Recommendations for research

This review highlights the need for further development in the understanding of the construct of patients in need of PC and to reinforce construct and structural validity. A more robust theoretical foundation about the concept of PC needs and about the distinction between general and specialized PC needs is needed, specifically when developing instruments. We recommend that future instrument developers use the COSMIN methodology, especially in the conceptualization phase. Special attention must be paid to the preliminary phases of development and to content validity in order to have a clear definition of the concept and a transparent process of item generation. Finally, we encourage the use of a gold standard other than mortality in future criterion validity studies and hypothesis testing for construct validity studies.

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## **Conflict of interest**

The authors declare no conflict of interest.

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## Appendix I: Search strategies

Note: for finding studies on measurement properties, we used the search filter 2 "Precise search filter for measurement properties" in combination with the "Exclusion filter." (73) We adapted the original PubMed filter to the subject headings and syntax of each bibliographic database.

Query on March 4, 2020 Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily 1946 to March 04, 2020 (palliative care/ OR terminal care/ OR terminally ill/ OR palliative medicine/ OR "hospice and palliative care nursing"/ OR (palliative OR "terminally ill/ OR (terminal ADJ1 (care OR disease* OR patient*))).ab,ti,kf.) AND (patient selection/ OR transitional care/ OR referral or (patient* ADJ3 selection*) OR (identification OR identify OR identifying OR referral OR (patient* ADJ3 selection*) OR (transition* ADJ3 care) OR (assessment* ADJ6 (need OR needs))).ab,ti,kf.) AND (surveys and questionnaires/ OR (tool OR tools OR questionnaire* OR instrument OR instruments OR scale OR scales OR (surprise* ADJ3 question*) OR "gold standards framework" OR NECPAL OR SPICT OR RADPAC OR HR-PRO OR NAT OR PC-NAT OR GSF OR CriSTAL OR SPICT OR DanPaCT OR P-caREs).ab,ti,kf.) AND (instrumentation.fs. OR Validation Study,pt. OR exp reproducibility of results/ OR reproducib*.ab,ti,kf. OR exp psychometrics/ OR (psychometr* OR clinimetr* OR clinometr*).ab,ti,kf. OR exp observer variation/ OR "observer variation" ab,ti,kf. OR exp discriminant analysis/ OR (reliab* OR valid* OR coefficient OR "internal consistency" OR (cronbach* AND (alpha OR alphas)) OR "item correlation*" OR "item selection*" OR greement OR precision OR imprecision OR "precise values" OR test-retest OR (test AND retest) OR (reliab* AND (test OR retest)) OR stability OR interrater OR inter-caster OR interacter OR intra-tester OR intra-tester OR intra-tester OR intra-tester OR intra-tester OR intra-examiner OR intra-participant OR intra-participant OR intra-participant OR intra-participant OR intra-participant OR inter-individual OR intra-individual OR intra	MEDLINE Ovid SP	
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AND ('patient selection'/de OR 'transitional care'/de OR 'patient referral'/de OR 'needs assessment'/de OR (identification OR identify OR identifying OR referral OR (patient\* NEXT/3 selection\*) OR (transition\* NEXT/3 care) OR (assessment\* NEAR/6 (need OR needs))):ab,ti,kw) AND ('questionnaire'/de OR (tool OR tools OR questionnaire\* OR instrument OR instruments OR scale OR scales OR (surprise\* NEXT/3 question\*) OR "gold standards framework" OR "gold standard framework" OR NECPAL OR SPICT OR RADPAC OR HR-PRO OR NAT OR PC-NAT OR GSF OR CriSTAL OR SPICT OR DanPaCT OR P-caREs):ab,ti,kw) AND ('reproducibility'/exp OR 'validation study'/de OR reproducib\*:ab,ti,kw OR 'psychometry'/exp OR (psychometr\* OR clinimetr\* OR clinometr\*):ab,ti,kw OR 'observer variation'/exp OR "observer variation":ab,ti,kw OR 'discriminant analysis'/exp OR (reliab\* OR valid\* OR coefficient OR "internal consistency" OR (cronbach\* AND (alpha OR alphas)) OR "item correlation\*" OR "item selection\*" OR "item reduction\*" OR agreement OR precision OR imprecision OR "precise values" OR test-retest OR (test AND retest) OR (reliab\* AND (test OR retest)) OR stability OR interrater OR inter-rater OR intrarater OR intra-rater OR intertester OR inter-tester OR intratester OR intra-tester OR inter-observer OR inter-observer OR intraobserver OR intra-observer OR intertechnician OR intertechnician OR intratechnician OR intratechnician OR interexaminer OR inter-examiner OR intraexaminer OR intra-examiner OR interassay OR inter-assay OR intra-assay OR inter-individual OR inter-individual OR intraindividual OR intra-individual OR interparticipant OR inter-participant OR intraparticipant OR intra-participant OR kappa OR kappa-s OR kappas OR "coefficient of variation" OR repeatab\* OR ((replicab\* OR repeated) AND (measure OR measures OR findings OR result OR results OR test OR tests)) OR generaliza\* OR generalisa\* OR concordance OR (intraclass AND correlation\*) OR discriminative OR "known group" OR "factor analysis" OR "factor analyses" OR "factor structure\*" OR dimensionality OR subscale\* OR "multitrait scaling analys\*" OR "item discriminant" OR "interscale correlation\*" OR ((error OR errors) AND (measure\* OR correlat\* OR evaluat\* OR accuracy OR accurate OR precision OR mean)) OR "individual variability" OR "interval variability" OR "rate variability" OR "variability analysis" OR (uncertainty AND (measurement OR measuring)) OR "standard error of measurement" OR sensitiv\* OR responsive\* OR (limit AND detection) OR "minimal detectable concentration" OR interpretab\* OR (small\* AND (real OR detectable) AND (change OR difference)) OR "meaningful change" OR "minimal important change" OR "minimal important difference" OR "minimally important change" OR "minimally important difference" OR "minimal detectable change" OR "minimal detectable difference" OR "minimally detectable change" OR "minimally detectable difference" OR "minimal real difference" OR "ceiling effect" OR "floor effect" OR "Item response model" OR IRT OR Rasch OR "Differential item functioning" OR DIF OR "computer adaptive testing" OR "item bank" OR "cross-cultural equivalence" OR "discriminant analys\*");ab,ti,kw) NOT (editorial:it OR letter:it OR "conference abstract":it) NOT ('juvenile'/exp NOT ('adult child'/de OR 'adult'/exp))

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care"[tiab] OR (assessment*[tiab] AND (need[tiab] OR needs[tiab]))) AND (tool[tiab] OR tools[tiab] OR questionnaire*[tiab] OR instrument[tiab] OR instruments[tiab] OR scales[tiab] OR	

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## 12 Appendix II: Studies ineligible following full-text review

Reference	First reason for exclusion
Abernethy AP, Wheeler JL, Currow DC. Utility and use of palliative care screening tools in routine oncology practice. Cancer J. 2010;16(5):444-60.	Criterion 2
Afshar K, Feichtner A, Boyd K, Murray S, Junger S, Wiese B, et al. Systematic development and adjustment of the German version of the Supportive and Palliative Care Indicators Tool (SPICT-DE). BMC Palliat Care. 2018;17(1):27.	Criterion 2
Ahmed N, Bestall JC, Payne SA, Noble B, Ahmedzai SH. The use of cognitive interviewing methodology in the design and testing of a screening tool for supportive and palliative care needs. Support Care Cancer. 2009;17(6):665-73.	Criterion 1
Allgar VL, Chen H, Richfield E, Currow D, Macleod U, Johnson MJ. Psychometric Properties of the Needs Assessment Tool-Progressive Disease Cancer in U.K. Primary Care. J Pain Symptom Manage. 2018;56(4):602-12.	Criterion 2
Asadi-Lari M, Gray D. Health needs assessment tools: progress and potential. Int J Technol Assess Health Care. 2005;21(3):288-97.	Criterion 1
Boland JW, Reigada C, Yorke J, Hart SP, Bajwah S, Ross J, et al. The adaptation, face, and content validation of a needs assessment tool: progressive disease for people with interstitial lung disease. Journal of Palliative Medicine. 2016;19(5):549-55.	Criterion 2
Boyd K, Murray SA. Recognizing and managing key transitions in end of life care. BMJ. 2010;341:c4863.	Criterion 4
Buzgova R, Kozakova R, Sikorova L, Zelenikova R, Jarosova D. Development and psychometric evaluation of patient needs assessment in palliative care (PNAP) instrument. Palliat Support Care. 2016;14(2):129-37.	Criterion 3
Cardona-Morrell M, Hillman K. Development of a tool for defining and identifying the dying patient in hospital: Criteria for Screening and Triaging to Appropriate aLternative care (CriSTAL). BMJ Support Palliat Care. 2015;5(1):78-90	Criterion 1
Carvalho JR, Vasconcelos M, Marques da Costa P, Marinho RT, Fatela N, Raimundo M, et al. Identifying palliative care needs in a Portuguese liver unit. Liver Int. 2018;38(11):1982-7.	Criterion 4
Casale G, Magnani C, Fanelli R, Surdo L, Goletti M, Boyd K, et al. Supportive and palliative care indicators tool (SPICT): content validity, feasibility and pre-test of the Italian version. BMC Palliat Care. 2020;19(1):79.	Criterion 2
Chang CH, Boni-Saenz AA, Durazo-Arvizu RA, DesHarnais S, Lau DT, Emanuel LL. A system for interactive assessment and management in palliative care. J Pain Symptom Manage. 2007;33(6):745-55.	Criterion 1
Costantini M, Rabitti E, Beccaro M, Fusco F, Peruselli C, La Ciura P, et al. Validity, reliability and responsiveness to change of the Italian palliative care outcome scale: a multicenter study of advanced cancer patients. BMC Palliative Care. 2016;15:23.	Criterion 1
Currow DC, Tieman JJ, Greene A, Zafar SY, Wheeler JL, Abernethy AP. Refining a checklist for reporting patient populations and service characteristics in hospice and palliative care research. J Pain Symptom Manage. 2012;43(5):902-10.	Criterion 1
Duenk RG, Verhagen C, Bronkhorst EM, Djamin RS, Bosman GJ, Lammers E, et al. Development of the ProPal-COPD tool to identify patients with COPD for proactive palliative care. Int J Chron Obstruct Pulmon Dis. 2017;12:2121-8.	Criterion 2
Fachado AA, Martinez NS, Rosello MM, Rial JJV, Oliver EB, Garcia RG, et al. Spanish adaptation and validation of the supportive & palliative care indicators tool - SPICT-ESTM. Rev Saude Publica. 2018;52:3.	Criterion 2
Feder SL, Redeker NS, Jeon S, Schulman-Green D, Womack JA, Tate JP, et al. Validation of the ICD-9 Diagnostic Code for Palliative Care in Patients Hospitalized with Heart Failure Within the Veterans Health Administration. Am J Hosp Palliat Care. 2018;35(7):959-65.	Criterion 1
Fergus CJ, Nicol JS, Russell PB. Is a STAS-based tool valid to triage patients at a specialist palliative care inpatient unit? Int J Palliat Nurs. 2008;14(1):24-9.	Criterion 1
Fischer SM, Gozansky WS, Sauaia A, Min SJ, Kutner JS, Kramer A. A practical tool to identify patients who may benefit from a palliative approach: the CARING criteria. J Pain Symptom Manage. 2006;31(4):285-92.	Criterion 1
Froggatt KA, Wilson D, Justice C, Macadam M, Leibovici K, Kinch J, et al. End-of-life care in long-term care settings for older people: a literature review. Int J Older People Nurs. 2006;1(1):45-50.	Criterion 4

Ghesquiere A, Gardner DS, McAfee C, Kenien C, Capezuti E, Kozlov E, et al. Development of a community-based palliative care screening tool for underserved older adults with chronic illnesses.	Criterion 3
Am J Hosp Palliat Care. 2018;35(7):929-37.  Glare PA, Chow K. Validation of a simple screening tool for identifying unmet palliative care needs in patients with cancer. J Oncol Pract. 2015;11(1):e81-6.	Criterion 2
Grbich C, Maddocks I, Parker D, Brown M, Willis E, Piller N, et al. Identification of patients with non-cancer diseases for palliative care services. Palliat Support Care. 2005;3(1):5-14.	Criterion 1
Hermans K, Spruytte N, Cohen J, Van Audenhove C, Declercq A. Usefulness, feasibility and face validity of the interRAI Palliative Care instrument according to care professionals in nursing homes: a qualitative study. Int J Nurs Stud. 2016;62:90-9.	Criterion 1
Hua M, Li G, Clancy C, Morrison RS, Wunsch H. Validation of the V66.7 code for palliative care consultation in a single academic medical center. J Palliat Med. 2017;20(4):372-7.	Criterion 1
Hughes P, Ahmed N, Winslow M, Walters SJ, Collins K, Noble B. Consumer views on a new holistic screening tool for supportive and palliative-care needs: Sheffield Profile for Assessment and Referral for Care (SPARC): a survey of self-help support groups in health care. Health Expect. 2015;18(4):562-77.	Criterion 1
Hui D, Mori M, Meng YC, Watanabe SM, Caraceni A, Strasser F, et al. Automatic referral to standardize palliative care access: an international Delphi survey. Support Care Cancer. 2018;26(1):175-80.	Criterion 1
Imhof SL, Kaskie B, Wyatt MG. Finding the way to a better death: an evaluation of palliative care referral tools. J Gerontol Nurs. 2007;33(6):40-9.	Criterion 1
Janssen DJA, Johnson MJ, Spruit MA. Palliative care needs assessment in chronic heart failure. Curr Opin Support Palliat Care. 2018;12(1):25-31.	Criterion 4
Johnsen AT, Petersen MA, Pedersen L, Groenvold M. Development and initial validation of the Three-Levels-of-Needs Questionnaire for self-assessment of palliative needs in patients with cancer. J Pain Symptom Manage. 2011;41(6):1025-39.	Criterion 3
Johnson MJ, Jamali A, Ross J, Fairhurst C, Boland J, Reigada C, et al. Psychometric validation of the needs assessment tool: progressive disease in interstitial lung disease. Thorax. 2018;73(9):880-3.	Criterion 2
Kelley AS, Bollens-Lund E. Identifying the population with serious illness: the "denominator" challenge. J Palliat Med. 2018;21(S2):S7-S16.	Criterion 1
Kishi Y, Matsuki M, Mizushima H, Matsuki H, Ohmura Y, Horikawa N. The INTERMED Japanese version: inter-rater reliability and internal consistency. J Psychosom Res. 2010;69(6):583-6.	Criterion 1
Leppert W, Majkowicz M, Ahmedzai SH. The adaptation of the Sheffield Profile for Assessment and Referral for Care (SPARC) to the Polish clinical setting for needs assessment of advanced cancer patients. J Pain Symptom Manage. 2012;44(6):916-22.	Criterion 3
Liyanage T, Mitchell G, Senior H. Identifying palliative care needs in residential care. Aust J Prim Health. 2018;24(6):524-9.	Criterion 1
Maamoun J, Fitch MI, Di Prospero L. The evaluation of a new supportive care screening tool for radiation therapy patients. J Med Imaging Radiat Sci. 2013;44(3):141-9.	Criterion 1
Maas EA, Murray SA, Engels Y, Campbell C. What tools are available to identify patients with palliative care needs in primary care: a systematic literature review and survey of European practice. BMJ Support Palliat Care. 2013;3(4):444-51.	Criterion 4
McDaid P. A quick guide to identifying patients for supportive and palliative care. NHS; 2011.	Criterion 4
Meffert C, Rucker G, Hatami I, Becker G. Identification of hospital patients in need of palliative careapredictive score. BMC Palliat Care. 2016;15:21.	Criterion 1
Osse BH, Vernooij-Dassen MJ, de Vree BP, Schade E, Grol RP. Assessment of the need for palliative care as perceived by individual cancer patients and their families: a review of instruments for improving patient participation in palliative care. Cancer. 2000;88(4):900-11.	Criterion 1
Osse BH, Vernooij-Dassen MJ, Schade E, Grol RP. A practical instrument to explore patients' needs in palliative care: the Problems and Needs in Palliative Care questionnaire short version. Palliat Med. 2007;21(5):391-9.	Criterion 1
Rainone F, Blank A, Selwyn PA et al. The early identification of palliative care patients: preliminary processes and estimates from urban, family medicine practices. Am J Hosp Palliat Care. 2007;24(2):137-40.	Criterion 2
Rhodes RL, Kazi S, Xuan L, Amarasingham R, Halm EA. Initial development of a computer algorithm to identify patients with breast and lung cancer having poor prognosis in a safety net hospital. Am J Hosp Palliat Care. 2016;33(7):678-83.	Criterion 1

Richardson P, Greenslade J, Shanmugathasan S, Doucet K, Widdicombe N, Chu K, et al. PREDICT: a diagnostic accuracy study of a tool for predicting mortality within one year: who should have an advance healthcare directive? Palliat Med. 2015;29(1):31-7.	Criterion 1
Slaven M, Wylie N, Fitzgerald B, Henderson N, Taylor S. Who needs a palliative care consult?: the Hamilton Chart Audit tool. J Palliat Med. 2007;10(2):304-7.	Criterion 1
Sleeman KE, Higginson IJ. A psychometric validation of two brief measures to assess palliative need in patients severely affected by multiple sclerosis. J Pain Symptom Manage. 2013;46(3):406-12.	Criterion 1
Thomas K, Noble B. Improving the delivery of palliative care in general practice: an evaluation of the first phase of the Gold Standards Framework. Palliat Med. 2007;21(1):49-53.	Criterion 2
Thoonsen B, Engels Y, van Rijswijk E, Verhagen S, van Weel C, Groot M, et al. Early identification of palliative care patients in general practice: development of RADboud indicators for PAlliative Care Needs (RADPAC). Br J Gen Pract. 2012;62(602):e625-31.	Criterion 2
Tuca A, Gomez-Martinez M, Prat A. Predictive model of complexity in early palliative care: a cohort of advanced cancer patients (PALCOM study). Support Care Cancer. 2018;26(1):241-9.	Criterion 2
Waller A, Girgis A, Currow D, Lecathelinais C; Palliative Care Research Program team.  Development of the palliative care needs assessment tool (PC-NAT) for use by multi-disciplinary health professionals. Palliat Med. 2008;22(8):956-64.	Criterion 2
Waller A, Girgis A, Lecathelinais C, Scott W, Foot L, Sibbritt D, et al. Validity, reliability and clinical feasibility of a Needs Assessment Tool for people with progressive cancer. Psychooncology. 2010;19(7):726-33.	Criterion 2
Youngwerth J, Min SJ, Statland B, Allyn R, Fischer S. Caring about prognosis: a validation study of the CARING criteria to identify hospitalized patients at high risk for death at 1 year. J Hosp Med. 2013;8(12):696-701.	Criterion 1

- 13 Inclusion criteria recommended by the COSMIN guidelines for systematic reviews of measurement properties:67
- 14 1. The instrument should aim to measure the construct of interest (identification of patients in need of palliative care).
- 15 16 17 2. The study sample should concern the target population of interest (adult patients in need of palliative care without specific pathology in hospital setting).
- 3. The study should concern the type of measurement instrument of interest (clinician-reported outcomes).
- 18 19 4. The aim of the study should be the development of a measurement instrument or the evaluation of one or more of its measurement properties.

## 21 Appendix III: Studies excluded on methodological quality

Reference	Reason for exclusion
De Bock R, Van Den Noortgate N, Piers R. Validation of the Supportive and Palliative Care Indicators Tool in a geriatric population. J Palliat Med. 2018;21(2):220-4.	Retrospective prognosis assessment
O'Callaghan A, Laking G, Frey R, Robinson J, Gott M. Can we predict which hospitalised patients are in their last year of life? A prospective cross-sectional study of the Gold Standards Framework Prognostic Indicator Guidance as a screening tool in the acute hospital setting. Palliat Med. 2014;28(8):1046-52.	Lack of data about initial content validity
Wang SS, Huang CM, Feng RC, Wu YL, Huang SJ. Validation of a concise screening tool for the identification of palliative care needs among inpatients: a prospective study in hospital setting. J Formos Med Assoc. 2019;118:883-890.	Criterion validity against death

Appendix IV: Characteristics of included instruments

Instrument Author (year)	Country and original language	Other languages	Setting	Target patient population	Dimensions and number of items	Format and response option	Scoring
CAPC criteria Center to Advance Palliative Care Andersen et al., (2013)80	USA, English	1	Hospital	All pathologies	Primary criteria: Life-limiting illness Secondary criteria: Surprise question Admission Problems with symptoms (physical or psychological) Complex care requirements Decline in functioning, feeding intolerance, weight loss 19 items	Checklist Yes/No	One criterion triggers the need for further primary palliative care assessment.
NECPAL NECesidas NECesidas PALiativas Centro Colaboado de la Organizacion Mundial de la Salud - Institut Catala d'Oncologia Gomez-Baptiste et al., (2013) <sup>49,86</sup>	Spain, Spanish	English	Primary care, hospital	All pathologies	Surprise question Need/demand of palliative care General indicators Severe dependence Geriatric syndromes Persistent symptoms Psychosocial aspects Multimorbidity Use of resources Disease-specific indicators 14 items	Checklist Yes/No	Surprise question = no AND One other question = yes trigger the need for palliative care
PCST Palliative Care Screening Tool Trout et al. (2012) <sup>82,84</sup>	USA, English	I	Hospital	All pathologies	Basic disease process Concomitant disease process Functional status No curative or life-sustaining treatment Persistent symptoms Psychosocial and spiritual issues Use of resources 22 items (16 items in the revised version)	Checklist Different number of points per item	Cut-off ≥ 12 points trigger the need of a palliative care consultation
SPICT	Scotland, English	French Spanish	Primary care, hospital	All pathologies	General indicators Unplanned hospitalization	Checklist Yes/No	At least two indicators of general health

Weight loss
Persistent symptoms
Asking for palliative care
Disease specific indicators
22 items Performance status Care dependence German Portuguese Brazilian Danish Italian Indicators Tool Highet et al., (2014)<sup>50</sup> Supportive and Palliative Care

Japanese Dutch Swedish

indicator of advanced disease trigger the need for palliative care. deterioration AND one

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Table 1: Summary of the of measurement properties of instruments for the identification of patients in need of palliative care in hospital settings

Instrument	Study design and authors	Measurement properties reported Study population, N	Age mean (SD, range)	Gender % women	Results of measurement properties	Proportion of patients in need of palliative care
CAPC criteria	Retrospective, exploratory study (Andersen et al., 2013)80	Inter-rater reliability: Participants: cancer patients in oncology or progressive care units receiving palliative care services, N = 87	K.	38% in oncology unit 40% in progress care unit	Inter-rater reliability:  Oncology:  Overall k value 0.39 (95% CI, 0.09-0.69), P = .003  k = 1.00 for 8 of the 19 criteria (42%)  k = 0.99-0.81 for 4 of the 19 criteria (21%)  k = 0.80-0.61 for 4 of the 19 criteria (21%)  k values for all other criteria were lower  Progressive care:  Overall k value: 0.25 (95% CI, 0.08-0.43), P < .0001  k = 1.00 for 8 of the 19 criteria (42%)	NR
					k = 0.99-0.81 for 5 of the 19 criteria (26%) k = 0.80-0.61 for 3 of the 19 criteria (16%)	
NECPAL	Development and prevalence study (Gomez- Baptiste et al., 2013) <sup>49,86</sup>	Development and content validity: Participants: physicians, nurses, and psychologists experts in palliative care, N = 18	N N	K K	Development and content validity:  Translation and cultural adaptation of the most relevant items of the GSF PIG and the SPICT were realized through three rounds of expert consultation. Appropriateness, comprehensiveness, and feasibility were assessed through interviews. Main differences between the NECPAL and the GSF PIG/SPICT are explained.	NA
		Face validity: Primary care setting physicians and nurses, N = 18	NR	NR	Face validity: Comprehensibility was assessed through interviews.	NA
		Prevalence and feasibility: Patients with chronic condition from nine different care services (home, nursing homes, hospitals, and social-health center), N = 1064	81 years (SD 12) for the SQ+ patients	61.5% for the SQ+ patients	Feasibility: Feasibility assessed with health care professionals thorough focus group.	Prevalence: NECPAL and SQ+ = 64.3% (1.33% general population and 7% population over 65 years)

PCST	Development and pre-test	Development	NR	NR	Development:	AN
	study (Trout et al., 2012) <sup>84</sup>	Experts working in palliative care			Development with experts involved in palliative care. Input asked on what would constitute an appropriate signal that might indicate the need for a palliative care consultation. Not clear how comprehensibility, comprehensiveness or relevance were assessed.	
		Pre-test	63.4 years (SD	55.4%	Pre-test:	35.7% of referral to
		Hospitalized patients at	13.8)		Palliative care consultation increased. No other	specialized palliative
		admission, N = 56			information on data about comprehensibility, comprehensiveness, or relevance.	care
	Transversal online survey	Content validity:			Content validity:	
	and retrospective study (DiLello et al., 2018) <sup>82</sup>	Convenience sample of 248 health care professionals from cardiology, primary care, oncology, pulmonology, nephrology, emergency, internal medicine: 93 physicians and 27 nurses, N = 120	N N	K K	Item CVR ranged from –.58 to .88, with an average CVR of .29.	NA
SPICT	Development and case- finding study (Highet et al., 2014) <sup>50</sup>	Development and content validity: Participants: interested clinician and policy-makers from around the world, and primary and secondary care leads for palliative care from UK in a participatory online process supervised by a research team (18 months), N = NR	<u>~</u>	<u> </u>	Development and content validity: 15 major revisions were made through an online participative process. No clear data about assessment of relevance, comprehensiveness, or comprehensibility.	<b>V</b>
CAPC Center	to Advance Palliative Care. Cl. co.	infidence interval: CVR content val.	lidity ratio: GSF PIG	Gold Standards F	CAPC, Center to Advance Palliative Gare: Cl. confidence interval: CVR, content validity ratio: GSE PIG. Gold Standards Framework Promostic Identification Guidance: NA, not applicable: NEPCAL. Necesidades	ole: NEPCAL Necesidades

CAPC, Center to Advance Palliative Care; CI, confidence interval; CVR, content validity ratio; GSF PIG, Gold Standards Framework Prognostic Identification Guidance; NA, not applicable; NEPCAL, Necesidades Palliative Indicators Tool; SQ, surprise question

Palliativas; NR, not reported; PCST, Palliative Care Screening Tool; SD, standard deviation; SPICT, Supportive and Palliative Indicators Tool; SQ, surprise question

Table 2: Summary of findings: development and content validity

ClinRo	Develo study	Development Content validity study	Conte	nt validity								
			Relevance	ance		Compre	Comprehensive- ness		Compr	Comprehensibility		Content validity evidence
Instrument MQ QC MQ	MQ	OC	MQ	သွ	Quality of MQ evidence	MQ	OC	Quality of MQ evidence	MQ	OC	Quality of evidence	
CAPC <sup>80</sup>	_		٥	+1	Low	٥		Very low	٥	+1	Low	Very low
NECPAL <sup>49.86</sup>	Ω	+	۵	+	Moderate	۵	+	Moderate	۵	+	Moderate	Moderate
PCST82,84	_		۵		Very low	۵		Very low	۵	1	Very low	Very low
SPICT <sup>50</sup>	_			+1	Moderate			Very low	Ω		Very low	Very low

ClinRO: clinician reported outcome; MQ: measurement quality; QC: quality criteria; V: very good; A: adequate; D: doubtful; I: inadequate; 0: not tested; CAPC: Center to Advance Palliative Care; NECPAL: Necesidades Paliativas; PCST: Palliative Care Screening Tool; SPICT: Supportive and Palliative Care Indicator Tool.

Table 3: Summary of findings: other measurement properties

Other measurement properties

ClinRo

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igi ti	Structural validity		Internal consiste	Internal consistency		Cross- cultural validity			Reliability	bility		Measurement error	əment	
ζ	gc	MQ QC Quality of evidence	MQ	OC	MQ QC Quality of evidence	MQ	) ၁୯	Quality of evidence	MQ	OC	MQ QC Quality of MQ QC Quality of evidence	MQ	OC	MQ QC Quality of evidence
			0			0			>	+	Low	0		
			0			0			0			0		
			0			0			0			0		
			0			0			0			0		

ClinRO: clinician reported outcome; MQ: measurement quality; QC: quality criteria; V: very good; A: adequate; D: doubtful; I: inadequate; 0: not tested; CAPC: Center to Advance Palliative Care; NECPAL: Necesidades Paliativas; PCST: Palliative Care Screening Tool; SPICT: Supportive and Palliative Care Indicator Tool