Instruments for the identification of patients in need of palliative care: a systematic review protocol of measurement properties

Abstract

Objective: to provide a comprehensive overview of the psychometric properties of available clinician-reported instruments developed to identify patients in need of general and specialized palliative care in acute care settings.

Introduction: Identification of patients in need of palliative care has been recognized as an area where many healthcare 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. To our knowledge, no instrument are available to date to assist healthcare professionals to make this identification.

Inclusion criteria: Will be included studies reporting : i) instruments aiming to identify patients in need of PC, ii) sample of adult patients in need of PC in acute care settings, iii) Clinician-reported outcome measures (ClinROMs), iv) the development process or one or more of its measurement properties. Will be excluded studies conducted intensive care units, emergency departments, and nursing homes.

Methods: We will search studies published in English and French in: Embase.com, Medline Ovid SP, Pubmed, and CINAHL EBSCO and other sources, such as Google Scholar, government websites, and hospice websites. All citations will be screened and selected by two independent reviewers. Data extraction, quality assessment, and syntheses of included studies will be performed according to the COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) criteria.

PROSPERO systematic review registration number: CDR42020150074.

Keywords: Identification; palliative care; measurement properties; instruments.

Introduction

Patients in need of palliative care (PC) are present in all different care settings. Prevalence varies from 9% to 73% in acute care settings depending on pathologies, co-morbidities or frailty.[1-5] An international prevalence study revealed that the proportion of individuals who died from diseases indicating a need for palliative care ranged from 38% to 74%.[6] According to Murtagh et al.,[7] 63% to 82% of the population will need palliative care at some point of their disease trajectory. With the increase of the ageing population and the number of patients suffering from chronic diseases and polymorbidity, the number of patients in need of PC is likely to increase further.

When patients do not receive appropriate PC, there is strong evidence of (i) excess hospital mortality - 80% - while the majority of people wish to die at home;[8-11] (ii) suboptimal symptom management;[12-14] (iii) unplanned hospitalizations with longer hospital stays;[15-16] (iv) prescription of inappropriate treatments due to a lack of anticipative care plans,[17-18] and (v) insufficient support for the patient and their relatives.[15, 19-20] Out of all patients in need of PC, about 75% to 80% of them can be cared by non-specialist teams (general PC) and the remaining 20%-25%, may need specialized PC provided by PC specialists due to the complexity of their conditions.[21-23] There is an internationally recognized distinction between patients requiring "general" versus "specialized" palliative care. General PC are provided by non-specialized professionals for situations without any element of complexity. Specialized PC are for patients whose illness is characterized by great clinical instability and/or a high level of psycho-socio-existential suffering, making their situation complex to the point, where non-specialist in PC do not have the necessary competences to care for them.[8, 12]

Identification of patients in need of general or specialized PC is a pre-requisite for appropriate management.[24] However, adequate identification is challenging as it relies on an unclear World Health Organization (WHO) definition which defines PC as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.[25[para.1]] This definition does not allow differentiating between general and specialized PC.[26-29] Despite this, experts agree with PC not being exclusively associated with terminal care and not depending only on patient diagnosis or prognosis, but also on patients’ needs. They confirm that PC should be initiated early in a patient disease trajectory.[30] The identification of patients in need of PC without a valid tool is sub-optimal because it occurs mostly at the end of life or only for highly complex situations.

A growing number of instruments exists to help professionals identifying patients in need of PC. These instruments include criteria concerning the severity of illness, the progression of the disease, and its associated frailty. Some instruments were designed only for a specific setting, such as the emergency department or intensive care.[31] Although, it is recommended to integrate palliative care early in the stage of a life-threatening event, treatment goal of patients who require intensive care, is primarily to sustain vital functions. Instruments designed for PC patients may therefore not be appropriate for this

population. Other instruments were designed for a specific pathology, for example interstitial lung disease;[32] or for a specific age group such as older people.[33] Others were designed for general use.[34-36]

To implement such an instrument into daily practice it is necessary to select the most suitable one based on its psychometric properties, particularly validity (measure what it is supposed to measure), reliability (consistency), and responsiveness (ability to detect change over time).

In palliative care, many patients are not able to fill in a patient-reported outcome to evaluate their own palliative care needs. For example patients with dementia, any cognitive impairment or delirium, and those who are not well informed about the stage of their disease, or who have some cultural barriers to discuss this topic. In this context, it seems important that healthcare professionals carry out this first screening, which will assist them to engage in discussion with the patient and her/his relatives about the disease trajectory and their needs, and to give them the most appropriate care. The focus of this review is therefore on clinician-reported outcome measures (ClinROMs) for the identification of patients in need of PC.

A preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews, the COSMIN database, and the JBI Database of Systematic Reviews and Implementation Reports was conducted and two systematic reviews on the topic were identified.[37-38] Both reviews are focused on the inventory and the description of the available instruments.

Maas et al. completed their systematic review by a survey conducted with European general practitioners (GPs) to identify non published instruments.[37] They carried out their review in only two databases (PubMed/MEDLINE and Embase) and they focused their searching on articles describing identification instruments suitable for use in primary care. A narrative approach was used to synthesize data. Then they compared the content of the different instruments and the identification criteria. Few or no information are available about the data collection process, the quality assessment of the studies, the studies' characteristics and whether authors have been contacted to obtain complementary data. They found five articles, which described four different instruments. These instruments are: the RADbout indicators for Palliative Care needs (RADPAC),[39] the Residential home palliative care tool,[40] the Supportive and Palliative Care Indicators Tool (SPICT) [35] and the Early identification tool for palliative care patients.[41] The complementary survey allowed finding three instruments which had not been identified in the literature although two of them are widely known, which raises questions about the quality of the review. These three instruments are: the Prognostic Indicator Guide of the UK-based Gold Standard Framework (PIG-GSF),[34] the NECPAL-CCOMS-ICO[36] and the Quick guide.[42] Then instruments were compared. When sensitivity and specificity were reported in the original studies, the authors of this review mentioned them, but without mentioning any psychometric assessment. None of the presented instruments distinguishes patients in need of general vs. specialized PC.

Walsh et al. realized their systematic review following the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA).[38,43] Most of the PRISMA criteria are presented but they did not perform any systematic evaluation of the psychometric properties and risks of bias. They used a deductive approach to analyze the content of four instruments to determine the usability and acceptability in clinical practice. These four instruments are: the Prognostic Indicator Guide of the UK-based Gold Standard Framework (PIG-GSF),[34] the NECPAL-CCOMS-ICO;[36] the SPICT[35] and the RADPAC.[39] They concluded that there is limited evidence these instruments appropriately identify patients in need of PC early in their illness trajectory. None of the presented instruments distinguishes patients in need of general vs. specialized PC.

In conclusion, neither of these two reviews included a systematic appraisal of the psychometric properties of the selected instruments. This justifies the necessity to perform a new systematic review with the following aim: to provide a comprehensive overview of the psychometric properties of available clinician-reported instruments developed to identify patients in need of palliative care regardless of the care setting – except for intensive care units and emergency departments.

Review Question

The question of this review is: what are the measurement properties of instruments that allow the identification of adult patients in need of palliative care and that can be used in all acute care settings except for emergency and intensive care units?

Inclusion Criteria

The COSMIN (COnsensus-based Standards for the selection of health Measurement INstruments) guidelines for systematic reviews of measurement properties recommend the following criteria of inclusion:[44] 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), iii) the study should concern the type of measurement instrument of interest (ClinROMs), 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.

Population

This review will consider studies including adult patients with life limiting cancer or non-cancer illness (e.g. chronic, progressive, incurable illness likely to cause death), in palliative care or in end of life care situation. Patients will need to be hospitalized in any acute care settings, except intensive care units, emergency departments and nursing home.

Instrument and construct

This review will consider studies presenting any measurement property of clinician-reported outcome measurement (ClinROMs), allowing the identification of patients in need of generalized or specialized palliative care (construct of interest). As those instruments have to be used by others professionals than physicians, we will include instruments comprising general indicators of decline and frailty (e.g. , but exclude biological markers that require specific investigation or exam (e.g. serum albumin). Due to the necessity to identify patients in need of PC as early as possible, prognostic instrument will be excluded.

Inclusion criteria: palliative care, adult patient (>18yrs), all pathologies (cancer/non-cancer), acute care settings, instruments/tools for identification, studies reporting the development of instruments or one or more measurement properties of instruments: content validity, reliability, responsiveness.

Exclusion criteria: disabled persons, intensive care, emergency, nursing homes, caregivers, pediatric patients, neonates, prognosis instrument, surprise question only, biomarkers, instrument used as an outcome measurement with no measurement properties reported.

Outcomes

The outcomes will include the measurement properties of the assessed instruments. They refer to the psychometric properties of the identification instruments.

The COnsensus-based Standards for the selection of health status Measurement INstruments (COSMIN) propose a guideline for systematic reviews of measurement properties for patient-reported outcome measures (PROMs).[44] As this guideline designed for PROMs include criteria that are not relevant for ClinROMs (e.g. box 2a-2c content validity), only the relevant criteria will be used in this review. The following 10 steps recommendations and instruments will be used. Steps 1 to 4 are standard procedures when performing systematic reviews. Steps 5 to 7 concern the evaluation of the measurement properties of the included instrument. Steps 8 to 10 concern the evaluation of the interpretability and feasibility of the instruments and the reporting of the instruments included in the systematic review. The COSMIN Risk of bias checklist will be followed.[45] This review will focus on the development of instruments and mainly on their measures of validity and reliability.

The development of instruments is evaluated through questions about the construct, the target population, the context of use, the item generation, the data analyses, the comprehensibility and comprehensiveness, as well as how the instrument was tested.[46.]

Psychometric properties of the instruments are assessed through several types of validity. For this review, the COSMIN group taxonomy measurement will be used.

Measures of validity refer to the degree to which an instrument measures the construct it has to measure. They include:

- content validity: the degree to which the content of an instrument is an adequate reflection of the construct to be measured, including face validity. Content validity is evaluated by relevant items for the construct, the target population, the comprehensiveness of the instrument and by the Content Validity Index (CVI).
- construct validity: the degree to which the scores of an instrument are consistent with hypotheses based on the assumption that the instrument measures the construct to be measured. It also includes the structural validity, in other words the degree to which an instrument adequately captures the dimensionality of the construct that must be measured. Construct validity is evaluated by factor analysis.
- criterion validity: the degree to which the scores of an instrument are an adequate reflection of a 'gold standard' criterion.[45] Criterion validity is evaluated by the correlation with the gold standard and will only be considered if the gold-standard is in accordance with COSMIN guidelines.[44]

Measures of reliability refer to the extent to which scores for patients who have not changed are the same for repeated measurement under several conditions. They include:

- internal consistency: the degree of the interrelatedness among the items. It is measured by Cronbach's alpha or KR-20.
- reliability: the proportion of the total variance in the measurements which is due to 'true' differences between patients. It is assessed by intra-class correlation coefficients (ICC), weighted or un-weighted Kappa statistics and standard error of measurement (SEM).
- measurement error: the systematic and random error of a patient's score that is not attributable to true changes. It is measured by the Standard Error of Measurement (SEM), Smallest Detectable Change (SDC), Limits of Agreement (LoA) or a percentage of agreement.[45]

When applicable, responsiveness – the ability to detect change over time in the construct to be measured - will be assessed using the following criteria: absolute or relative correlations or differences of the change scores, area under the Receiver Operating Curve (ROC), or sensitivity and specificity.

Types of studies

Any quantitative study design will be considered for inclusion in this systematic review of measurement properties; however, the included studies will be those that report on the development and/or validation of measurement instruments as described above. Studies published in English and French – authors' commonly spoken languages - will be included.

Methods

The proposed systematic review will be conducted in accordance with the COSMIN methodology for systematic reviews of measurement properties for PROMs.[47] The title has been registered on the JBI

registry. All the documents that will be used for this review are on the COSMIN website: https://www.cosmin.nl/cosmin-tools/.

Search strategy

The search strategy will aim to locate published and unpublished studies. It will be based on the COSMIN recommendations and using the precise search filter for measurement properties to capture relevant measurement properties.[48] The systematic literature search will be performed in collaboration with a librarian. An initial limited search of MEDLINE and CINAHL will be conducted, followed by an analysis of text words contained in the title and abstract, and of the index terms used to describe the article. The search strategies will be adapted to the syntax and subject headings of each database. An example for a draft strategy in Medline Ovid SP is provided in Appendix I. The search will be conducted in four electronic bibliographic databases without date restrictions.

Information sources

The bibliographic databases to be searched will include Embase.com, Medline Ovid SP, Pubmed (NOT medline[sb]) and CINAHL EBSCO. The search for unpublished studies will include Google Scholar, government websites (i.e., National Institute of Nursing Research), hospice websites, the Library Network of Western Switzerland and WorldCat. We will also contact researchers who have recently published a paper on this topic, to make sure we are not missing on some unpublished work that could be included in this review. Finally, the reference list of all studies selected for critical appraisal will be screened for additional studies.

Study selection

As recommended by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)[43], following the search, all identified citations will be collated and uploaded into EndNote X8 /2016 (Clarivate Analytics, PA, USA) and duplicates removed. Titles and abstracts will then be screened by two independent reviewers (FTL & ASR) for assessment against the inclusion criteria for the review with the free software Rayyan QCRI that allows blinded assessment.[49] The full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers (FTL & ASR). Reasons for exclusion of full text studies that do not meet the inclusion criteria will be recorded and reported in the systematic review. Any disagreements that arise between the reviewers at each stage of the study selection process will be resolved with a third reviewer (CMA) and through discussion. The results of the search will be reported in full in the final systematic review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram.[50]

Assessment of Methodological Quality

Selected studies will be critically appraised by two independent reviewers for methodological quality using the standardized critical appraisal instrument from COSMIN methodology and instruments

(https://www.cosmin.nl/wp-content/uploads/COSMIN-RoB-checklist-V2-0-v17_rev3.pdf). “The result of each study on a measurement property should be rated against the updated criteria for good measurement properties. Each result is rated as either sufficient (+), insufficient (–), or indeterminate (?)”.[47 [p.28]] Any disagreements that arise will be resolved with a third reviewer and through discussion. Following critical appraisal, the decision to exclude or not studies will be based on the COSMIN recommendations.

Data Extraction

Data will be extracted from included studies, using the modified pilot tested data extraction form (Appendix II) by two independent reviewers (FTL & ASR). The data extracted will include specific details about the tests, populations, study methods and outcomes of significance to the review question and specific objectives. Any disagreements that arise between the reviewers will be solved through discussion, and if no consensus can be found a third reviewer (CMA) will be involved. Authors of papers will be contacted to request missing or additional data where required.

Data Synthesis

The results will be quantitatively pooled or qualitatively summarized. They will be reported in a table with the rating of the pooled or summarized results and the grading of the quality of evidence (high, moderate, low, very low). “If possible, the results from different studies on one measurement property should be statistically pooled in a meta-analysis. Pooled estimates of measurement properties can be obtained by calculating weighted means (based on the number of participants included per study) and 95% confidence intervals”.[47[p.31]] This meta-analysis will be performed by a statistician. The strategy for meta-analysis will be based on the COSMIN guide. Where statistical pooling is not possible the findings will be presented in narrative form including tables and figures to aid in data presentation where appropriate.

Assessing Confidence

Grading of the quality will be based on a modified GRADE approach, where the quality of the evidence is graded as high, moderate, low, or very low evidence.[45] “For evaluating measurement properties of systematic reviews of PROMs, the following four factors should be taken into account: (1) risk of bias (i.e. the methodological quality of the studies), (2) inconsistency (i.e. unexplained inconsistency of results across studies), (3) imprecision (i.e. total sample size of the available studies), and (4) indirectness (i.e. evidence from different populations than the population of interest in the review)”.[47[p.32]] A 'summary of findings' table will be created using GRADEPro GDT software.

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Conflicts of interest

There is no conflict of interest in this project.

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393 Appendices

394 Appendix I: Search Strategy

395 Overview of the Medline Ovid SP search strategy

396 (exp palliative care/ OR terminal care/ OR exp terminally ill/ OR exp palliative medicine/ OR exp hospice
397 and palliative care nursing/ OR (palliative OR "terminally ill" OR (terminal ADJ1 (care OR disease* OR
398 patient*))).ab,ti,kf.) AND (exp patient selection/ OR exp transitional care/ OR referral and consultation/
399 OR needs assessment/ OR (identification OR identify OR identifying OR referral OR (patient* ADJ3
400 selection*) OR (transition* ADJ3 care) OR (assessment* ADJ6 (need OR needs))).ab,ti,kf.) AND
401 (surveys and questionnaires/ OR (tool OR tools OR questionnaire* OR instrument OR instruments OR
402 scale OR scales OR (surprise* ADJ3 question*) OR "gold standards framework" OR "gold standard
403 framework" OR NECPAL OR SPICT OR RADPAC OR HR-PRO OR NAT OR PC-NAT OR GSF OR
404 CriSTAL OR SPICT OR DanPaCT OR P-caREs).ab,ti,kf.)

Appendix II: Data Extraction Instrument

Data extraction form for studies of measurement properties
Citation Details
Authors:
Title:
Journal:
Year:
Issue:
Volume:
Pages:
Study details
Study design:
Instrument(s) assessed (sub-scales if applicable):
Construct assessed:
Country (language) in which instrument assessed:
Mode of administration (e.g. online, paper-based, etc.):
Setting/Context:
Participant Characteristics (study inclusion/exclusion information):
Description of main results (measurement properties) for each instrument:
Reviewer comments: