Ethical challenges of outcome measurement in palliative care clinical practice: a systematic review of systematic reviews

Sandra Martins Pereira¹,²,³*, Pablo Hernández-Marrero¹,²,³*

¹Instituto de Bioética, Universidade Católica Portuguesa, Porto, Portugal; ²UNESCO Chair in Bioethics, Instituto de Bioética, Universidade Católica Portuguesa, Porto, Portugal; ³CEGE: Research Centre in Management and Economics (Centro de Estudos em Gestão e Economia), Católica Porto Business School, Universidade Católica Portuguesa, Porto, Portugal

Contributions: (I) Conception and design: All authors; (II) Administrative support: All authors; (III) Provision of study materials or patients: All authors; (IV) Collection and assembly of data: All authors; (V) Data analysis and interpretation: All authors; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

*These authors contributed equally to this work.

Correspondence to: Sandra Martins Pereira. Instituto de Bioética, Universidade Católica Portuguesa, Rua Diogo Botelho, 1327, 4169-005 Porto, Portugal. Email: smpereira@porto.ucp.pt.

Abstract: Several outcome measures have been systematically implemented to be used in palliative care. However, routine use in clinical practice is not without ethical challenges, which are not commonly addressed. The objectives of this study are therefore (I) to identify the ethical challenges/issues of outcome measurement in palliative care and (II) to understand how these ethical challenges/issues are addressed in palliative care clinical practice. The study consisted of a systematic review of systematic reviews, which is a type of review that brings together a summary of reviews in one place. We searched PubMed, Web of Science, EBSCOhost searching CINAHL Complete, MEDLINE Complete, Nursing & Allied Health Collection: Comprehensive, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Cochrane Methodology Register, Library, Information Science & Technology Abstracts, MedicLatina, from inception to January 2018. Out of 159 articles screened, only two [2] articles were included for analysis. The main ethical challenge/issue identified in these two reviews was cognitive impairment, particularly in patients with dementia. This challenge was addressed via proxy (family carers or health professionals) reporting outcome measurement. Ethical challenges/issues are poorly addressed in the existing systematic reviews about outcome measurement in palliative care clinical practice. Only two systematic reviews addressed ethical challenges/issues, namely cognitive impairment, particularly in persons with dementia. Further research is needed on this subject and to foster the use of outcome measurement among this vulnerable group of patients.

Keywords: Ethical issue; outcome measure; patient reported outcome measurement; palliative care; systematic review

Submitted Feb 21, 2018. Accepted for publication Jun 14, 2018.
doi: 10.21037/apm.2018.06.05

View this article at: http://dx.doi.org/10.21037/apm.2018.06.05

Introduction

Measurement is a fundamental component of evidence-based medicine and provides the information needed for clinicians to make decisions in patient care and management (1). It is therefore not surprising that several outcome measures have been systematically implemented to be used in palliative care, as they play an increasing role in improving the quality, effectiveness, efficiency and availability of this type of care (1-3).

A person (or patient)-centred approach is being promoted
in this field, as the person (or patient)’s perspective should inform clinical practice and inherent decision-making processes (1,2,4-6). Patient-reported outcome measures (PROMs), which can be also called patient-centred outcome measures (PCOMs), are an important and standardised way of measuring and interpreting the outcomes of health care interventions. The use of these measures is increasingly being promoted to inform patient-professional communication, by asking patients to complete validated questionnaires that measure their perceptions of their own status and wellbeing (1,2,4-6).

Person (or patient)-centred outcome measures are considered to be the gold standard for outcome measurement of subjective experiences (1,4,7). In palliative care, this is of foremost relevance as it may (I) facilitate the identification and screening of physical, psychological, spiritual and social needs, (II) provide information about the experience of the disease trajectory and process, (III) enable patient-family-clinician communication and promote, simultaneously, a person-centred care approach, a shared decision-making process and advance care planning, and (IV) give relevant information to monitor the quality of care provided and its costs (1). These mechanisms are aligned with several ethical principles, namely, the ethical principles of integrity [an ethical principle that focuses on enhancing the holistic perspective of care, the coherence of life, which is remembered from experiences and can be told in a narrative (8,9)], dignity [ethical principle that highlights the intrinsic quality of personhood (8-10)], autonomy [in the sense of self-determination and meeting the person-patient’s wishes and preferences for care (8,10-13)], beneficence and non-maleficence [defined as the dual obligation healthcare professionals have to seek to maximize the benefit and to prevent as much as possible any potential harm (8,10-13)], and even justice [as equitable access to care and fairness in the allocation of health resources (8,10-14)].

Nevertheless, routine use of person (patient)-centred outcome measures in palliative care clinical practice is not without ethical challenges. While several international studies report on the validation, implementation, and use of this type of measures in clinical practice, referring to its barriers and facilitators (1,4,15-17), ethical challenges/issues are not commonly or specifically addressed.

The objectives of this study are therefore (I) to identify the ethical challenges/issues of outcome measurement in palliative care and (II) to understand how these ethical challenges/issues are addressed in palliative care clinical practice.

Methods

This study consists of a systematic review of systematic reviews. This is a type of review that brings together a summary of reviews in one place (18).

Systematic review of systematic reviews: methodological considerations

A systematic review of systematic reviews is a logical and appropriate approach that allows the findings of separate reviews to be compared and contrasted, providing relevant information on the topic of interest (18). It is suitable for describing the quality, discerning the heterogeneity, and identifying lacunas in the current evidence, since it synthesizes evidence from relevant previous systematic reviews (19).

Since several systematic reviews have already been published about outcome measurement in palliative and end of life care clinical practice, we found it appropriate to analyse and synthesize the evidence from these existing reviews with respect to our objectives. The methodological steps recommended by Whitlock et al. (20) were followed and adapted in our systematic review of systematic reviews (Figure 1).

Sources and searching

We searched PubMed, Web of Science, EBSCOhost searching CINAHL Complete, MEDLINE Complete, Nursing & Allied Health Collection: Comprehensive, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Cochrane Methodology Register, Library, Information Science & Technology Abstracts, MedicLatina, from inception to January 2018. This search was complemented with the manual search of journals from the field of palliative care. Reference lists of the retrieved articles were screened for additional studies.

Systematic reviews were identified, screened and assessed for inclusion based on the inclusion and exclusion criteria presented in Table 1. The following search terms were used: “outcome” AND “palliative care” AND “systematic review”. The general search strategy is presented in Table 2 and further details are provided in Table S1.

Review selection

Systematic reviews identified through the search were examined for inclusion in a three-step process. First, we performed an initial screening of titles and removed any duplicates and review protocols. Second, the abstracts of the remaining studies were assessed, with eligible systematic
Figure 1 Methodological steps used in this systematic review of systematic reviews. PROMs, Patient Reported Outcome Measures; PC, Palliative Care; SRs, Systematic Reviews; PICO, Participants/Population/People/Patient/Problem, Intervention(s), Comparison/Control, Outcome.
reviews being further subjected to full-text screening. Third, we screened full-text systematic reviews against the inclusion criteria to identify relevant studies to be included in our systematic review of systematic reviews.

**Data extraction, analysis and synthesis**

The search strategy was designed by S Martins Pereira and P Hernández-Marrero. Studies were independently identified and assessed by S Martins Pereira and P Hernández-Marrero. Doubts about the inclusion of papers were discussed and decided by consensus between the two researchers. Data from the studies were extracted into a table by S Martins Pereira. P Hernández-Marrero complemented data extraction independently. All systematic reviews and data were thoroughly analysed by S Martins Pereira and P Hernández-Marrero independently, based on the objectives of the study. If there was any uncertainty about inclusion, eligibility or analysis of data, these were further discussed by the two researchers until reaching consensus. Systematic reviews and data were thematically analysed by S Martins Pereira and P Hernández-Marrero. Data were extracted from the identified articles and tabulated according to PICO’s methodology: P—Participants/Population/People/Patient/Problem, I—Intervention(s), C—Comparison/Control, O—Outcome (21-25). A thematic analysis was performed to extract the main themes aligned with our research objectives.

**Results**

**Characteristics of the systematic reviews**

Out of 159 articles screened, only two articles were included for analysis. Figure 2 illustrates our PRISMA (26) flowchart.

Out of the two systematic reviews included for analysis, one focused on the use of the Palliative Outcome Scale and of the Support Team Assessment Schedule in palliative care (27) and the other focused on existing PROMs of quality end of life care (28). Table 3 summarizes the main characteristics of these two systematic reviews using the PICO methodology (21-25) as a framework.

**Quality assessment of the systematic reviews included for analysis**

After review selection, the methodological quality of the systematic reviews was assessed using the AMSTAR tool (29-31). This is an empirically developed instrument for

---

**Table 1 Inclusion and exclusion criteria**

| Inclusion criteria                                                                 
<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Systematic reviews</td>
</tr>
<tr>
<td>English, Portuguese, Spanish, French, and German</td>
</tr>
<tr>
<td>Relevant findings for the identification of ethical challenges/</td>
</tr>
<tr>
<td>issues in outcome measurement in palliative care clinical practice</td>
</tr>
<tr>
<td>Exclusion criteria</td>
</tr>
<tr>
<td>Other types of reviews and studies</td>
</tr>
<tr>
<td>Any other language</td>
</tr>
<tr>
<td>Findings or content not related to the objectives of the review,</td>
</tr>
<tr>
<td>or insufficiently informative results</td>
</tr>
</tbody>
</table>

**Table 2 Search strategy**

<table>
<thead>
<tr>
<th>Database</th>
<th>Search terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>PubMed</td>
<td>(outcome[Title/Abstract] AND palliative care[Title/Abstract]) AND systematic review[Title/Abstract]</td>
</tr>
<tr>
<td>EBSCO Host Searching</td>
<td>SU outcome AND SU palliative care or end of life care AND SU systematic review</td>
</tr>
<tr>
<td>CINAHL Complete, MEDLINE Complete, Nursing &amp; Allied Health Collection: Comprehensive, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Cochrane Methodology Register, Library, Information Science &amp; Technology Abstracts, MedicLatina</td>
<td>TITLE: (outcome) AND TITLE: (palliative care) AND TITLE: (systematic review)</td>
</tr>
<tr>
<td>Web of Science</td>
<td>Indexes: SCI-EXPANDED, SSCI, A&amp;HCI, CPCI-S, CPCI-SSH, ESCI, CCR-EXPANDED, IC</td>
</tr>
</tbody>
</table>
documenting the quality of systematic reviews and it was found to have good agreement, reliability and construct validity (29-31). The AMSTAR tool refines and enhances previous published instruments used to assess the quality of systematic reviews (29,32,33). It is considered to be a successful tool, and it is widely used in the quality assessment of systematic reviews in healthcare and palliative care research (34-38). Based on the use of this tool, the two systematic reviews included in our systematic review can be considered of good quality as they met, respectively, 8 and 7 out of the 11 AMSTAR items/criteria (Table 4).

Figure 2 PRISMA flowchart [based on Moher et al. (26)]. *, manual searches were performed in the following journals: Palliat Med, Palliative Medicine; JPM, Journal of Palliative Medicine; Ann Palliat Med, Annals of Palliative Medicine; Am J Hosp Palliat Care, American Journal of Hospice and Palliative Care; J Pain Symptom Manage, Journal of Pain and Symptom Management; Int J Palliat Nurs, International Journal of Palliative Nursing; J Hosp Palliat Nurs, Journal of Hospice and Palliative Nursing; BMJ Support Palliat Care, British Medical Journal of Supportive and Palliative Care; Eur J Palliat Care, European Journal of Palliative Care; Indian J Palliat Care, Indian Journal of Palliative Care; Palliat & Support Care, Palliative and Supportive Care; BMC Palliat Care, Biomed Central Palliative Care; Current Opinion Supp Palliat Care, Current Opinion in Supportive and Palliative Care.
Table 3 Characteristics of the systematic reviews included for analysis

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>P: participants</th>
<th>I: intervention(s)</th>
<th>C: comparison(s)</th>
<th>O: outcome(s) related to our research objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collins et al.</td>
<td>2015</td>
<td>Patients with a variety of diagnoses (cancer, HIV/AIDS, COPD, neurological diseases, chronic heart failure, chronic kidney disease)</td>
<td>To appraise the use of the Palliative Outcome Scale (POS) and the Support Team Assessment Schedule (STAS) in palliative care</td>
<td>Comparison of the use of the POS and the STAS in palliative care</td>
<td>Both the POS and the STAS can be applied for a variety of diagnoses. The POS has been applied for diagnoses, including dementia, multiples sclerosis, and Parkinson disease. The POS was completed by healthcare professionals and informal caregivers as a retrospective analysis of decedents with dementia. Barriers for the use of both the POS and the STAS are reported as well as patient-specific issues (27).</td>
</tr>
<tr>
<td>Kearns et al.</td>
<td>2017</td>
<td>Adults (18 years of age and above) with any chroming condition and in any type of healthcare setting using assessment measure(s) with described psychometric properties</td>
<td>To identify, describe and critically evaluate existing patient reported outcome measures of quality of end of life care for patients with chronic disease in various healthcare settings</td>
<td>A total of 15 measures were identified and assessed</td>
<td>None of the measures identified included patients with cognitive impairment in their validation samples. No cognitive impairment/dementia-specific patient reported outcomes measures were identified, and no adaptations were identified for use with patients with cognitive impairment were reported (28).</td>
</tr>
</tbody>
</table>

**Ethical challenges/issues of outcome measurement in palliative care**

Ethical challenges/issues are poorly addressed in the existing systematic reviews about outcome measurement in palliative care clinical practice. In fact, only two systematic reviews addressed ethical challenges/issues as part of their findings. The main ethical challenge/issue mentioned in these two systematic reviews was cognitive impairment, particularly in patients with dementia. One study (Collins et al.) mentioned that the Palliative Outcome Scale had been applied for different types of diagnoses, including dementia. In the case of patients with dementia, completion had been made by healthcare professionals and informal caregivers (27). The other study (Kearns et al.) highlighted that none of the measures identified included patients with cognitive impairment in their validation samples. According to the authors of this second study, neither cognitive impairment/dementia-specific patient reported outcome measures were identified nor adaptations of these type of measures for use with patients with cognitive impairment (28).

**Addressing ethical challenges/issues of outcome measurement in palliative care**

The main way of addressing the lack of capacity in completing an outcome measure due to cognitive impairment was using proxy measures. This was particularly highlighted by Collins et al. (27) who referred to the use of specific outcome measures, such as the Palliative Outcome Scale, that can be completed by a proxy (family member or healthcare professional).

*Table 5* illustrates these findings with quotations from the included systematic reviews.

**Discussion**

**Summary of main findings**

Ethical challenges/issues are poorly addressed in the existing systematic reviews about outcome measurement in palliative care clinical practice. Only two systematic reviews addressed ethical challenges/issues as part of their findings. The main ethical challenge/issue mentioned in these two
systematic reviews was cognitive impairment, particularly in patients with dementia. This ethical challenge/issue was addressed via proxy measurement.

The ethical challenge/issue of outcome measurement in patients with cognitive impairment, particularly dementia

Our findings show that the main ethical challenge/issue of outcome measurement in palliative care clinical practice is cognitive impairment, particularly in patients with dementia. Considering the trend of the ageing population in developed countries worldwide, this is of foremost relevance and constitutes a major concern as most of the people living and dying in old ages will face some type of dementia (39-43).

From an ethical perspective, by either excluding patients with dementia or cognitive impairment from their study samples or by performing a proxy-assessment of needs and outcomes, it seems that some vulnerable patients are at risk of developing further vulnerabilities. According to Kipnis (44,45), there are seven categories of vulnerabilities: incapacitacional or cognitive (when the person lacks the capacity to deliberate and make a decision), juridical (when the person is declared to be legally incompetent to make decisions), situational (when the person is in a situation in which medical exigency prevents the time, education and deliberation needed to make a decision), medical (when the person has a medical, serious health-related condition that may increase vulnerability), allocational (when the person lacks in subjectively important social goods), social (when the person belongs to a group whose rights and interests are socially disvalued), and deferential (when the person may be at risk of having a deferential behaviour and agrees on something regardless of his/her willingness to actually do so). Considering our findings, cognitive impairment (which may be linked to cognitive vulnerability) may be increased by other categories of vulnerability (medical, allocational and social, for instance) if patients with dementia are systematically being left out of relevant research that may assess and improve the outcomes of the care they are receiving. According to Harrison et al. (46), the field of dementia and cognitive impairment has fewer evidence-based interventions when compared to many other common diseases. Nevertheless, it is known that providing high-quality medical treatment or healthcare requires high-quality research and evidence. In other words, assessing medical interventions or care provision requires some measure of treatment or care effect (46). This situation becomes even more complex, as evidence shows that patients with dementia, particularly older patients, are

<table>
<thead>
<tr>
<th>AMSTAR item</th>
<th>Author and publication year</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Was an ‘a priori’ design provided?</td>
<td>Yes</td>
</tr>
<tr>
<td>2. Was there duplicate study selection and data extraction?</td>
<td>Yes</td>
</tr>
<tr>
<td>3. Was a comprehensive literature search performed?</td>
<td>Yes</td>
</tr>
<tr>
<td>4. Was the status of publication (i.e., grey literature) used as an inclusion criterion?</td>
<td>Can’t answer</td>
</tr>
<tr>
<td>5. Was a list of studies (included and excluded) provided?</td>
<td>No</td>
</tr>
<tr>
<td>6. Were the characteristics of the included studies provided?</td>
<td>Yes</td>
</tr>
<tr>
<td>7. Was the scientific quality of the included studies assessed and documented?</td>
<td>Can’t answer</td>
</tr>
<tr>
<td>8. Was the scientific quality of the included studies used appropriately in formulating conclusions?</td>
<td>Yes</td>
</tr>
<tr>
<td>9. Were the methods used to combine the findings of studies appropriate?</td>
<td>Yes</td>
</tr>
<tr>
<td>10. Was the likelihood of publication bias assessed?</td>
<td>Yes</td>
</tr>
<tr>
<td>11. Was the conflict of interest included?</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Legend: yes (i.e., systematic review fulfilling the criteria); no (i.e., systematic review does not fulfil the criteria); can’t answer (i.e., cannot answer as, although relevant, it is not reported); not applicable (i.e., not relevant item).

Table 4 Quality assessment of the systematic reviews included for analysis using the AMSTAR (29)

© Annals of Palliative Medicine. All rights reserved.  
apm.amegroups.com  
less likely to be referred to palliative care services (47-50). Furthermore, it is known that most of the evidence sustaining palliative care provision is built on research in other diseases/medical conditions (51-54). From an ethical perspective, the ethical principle of justice in the access to both research and palliative care services seems to be compromised.

The main challenges posed to outcome measurement in patients with dementia and/cognitive impairment occur at the end of life (2). At this stage, increasing cognitive impairment and physical dependence may indicate that palliative care is the appropriate approach. Decision-making capacity remains as an ethical issue to consider, which needs to be balanced in light of the patient’s vulnerability and of other ethical principles and values (e.g., beneficence, non-maleficence, integrity, dignity, respect, empathy, trust) that should be taken into consideration in clinical practice and research.

Questions can also be raised about whether or not the measurement of psychological, social and spiritual concerns, problems, needs and care outcomes at this level is reliable at all in advanced dementia patients (2). As for other interventions requiring consent and decision-making capacity, proxy assessment can indeed be an alternative source of information that can be particularly useful at the end of life (2,3). The validity of such ratings has however been discussed, with suggestions that proxies tend to overestimate the patient’s experiences and that healthcare professionals tend to underestimate them (55,56).

Evidence shows that the continuing use of proxies rather than direct self-report for quality of life measures can be problematic, particularly considering the growing reports

<table>
<thead>
<tr>
<th>Main themes</th>
<th>Main findings</th>
<th>Authors</th>
<th>Quotation illustrating findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethical challenges/issues of outcome measurement in palliative care</td>
<td>The main ethical challenge/issue of outcome measurement in palliative care clinical practice is cognitive impairment, particularly in patients with dementia.</td>
<td>Collins et al. (27)</td>
<td>“One of the main challenges to the use of PROMs in palliative care is the high proportion of palliative care patients with impaired cognition or those who are otherwise too unwell to complete them” (p. 843)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“Both POS and STAS measures can be applied for a variety of diagnoses. (…) the POS has been applied (…) for a range of additional diagnoses (…) dementia (…)” (p. 844)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“(…) several barriers still exist that might limit the implementation of outcome measures into routine clinical practice” (p. 849)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Kearns et al. (28)</td>
<td>“(…) various inclusion criteria used, such as the ability to remember and report, and to be mentally well enough act as de facto barriers to participation from patients with cognitive impairment. No cognitive impairment/dementia-specific PROMs were identified, and no adaptations of the PROMs identified for use with patients with cognitive impairment were reported” (pp. 20, 23)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“The POS was the only measure reviewed that was used in a research study that included patients with cognitive impairment in the study sample, although the number of such participants was not reported” (p. 23)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“The findings of this review underline the lack of PROMs of EoL care for patients with chronic disease outside the cancer care model, and the absence of any PROMs of EoL care developed or validated for use with patients with cognitive impairment” (p. 24)</td>
</tr>
<tr>
<td>Addressing ethical challenges/issues of outcome measurement in palliative care</td>
<td>The main way of addressing the lack of capacity in completing an outcome measure due to cognitive impairment was using proxy measures.</td>
<td>Collins et al. (27)</td>
<td>“The POS was completed by health care professionals and informal caregivers as a retrospective analysis of decedents with dementia” (p. 844)</td>
</tr>
</tbody>
</table>

Table 5 Quotations from the systematic reviews illustrating the main findings of this systematic review of systematic reviews
that show discrepant ratings between self-reports and proxy reports (55-61).

Implications of this systematic review of systematic reviews

This systematic review of systematic reviews shows that the ethical challenges/issues are poorly addressed in the existing systematic reviews about outcome measurement in palliative care clinical practice. A few possible explanations can be hypothesized on why this occurs. On the one hand, there might be the case that once the research studies on outcome measures are approved by ethical boards, clinicians and researchers might consider that all ethics procedures are safeguarded when using those measures in clinical practice. On the other hand, as scientific journals commonly only ask whether or not the study complies with required ethics procedures, authors may not feel obliged to provide further details on this matter. A third possible reason could be that clinicians and researchers might consider ethics procedures in clinical dementia research as a barrier to conduct research studies that include patients with dementia as participants. In our opinion, further research is needed to allow a better understanding of the reasons behind this finding.

Nevertheless, and taking into account the overall findings of our systematic review of systematic reviews, a set of recommendations can be driven. First, more research is needed specifically focusing on the ethical challenges/issues that outcome measurement raises in palliative and end of life care clinical practice. Second, there is also the need to foster and improve the use of tailored outcome measures, designed to meet the specific needs and conditions of patients with cognitive impairment and/or dementia. As an example, decision aids (e.g., videos, visual images or other non-conventional informed consent forms) for people with dementia and/or impaired decision-making capacity have been described to improve informed consent and decision-making capacity about considering taking part in clinical trials (62-66). While findings are not consensual, they show the increasing use of these aids. Similar studies could be conducted to tailor the use of person (or patient)-centred approaches for outcome measurement in people with cognitive impairment and/or dementia. While some initiatives have been done to validate and implement the use of PROMs in persons with dementia (67), very little is known on the use of aid tools when measuring outcomes in this group of patients. Third, it is known that patients with dementia often have multiple problems, frailties and vulnerabilities. Disease-oriented structures and models of research funding are not applicable for this type of patients, as they do not easily fit into existing disease-oriented research designs (68). Due to these vulnerabilities and to cognitive impairment that may compromise their decision-making capacity, persons with dementia are more at risk of being left out of some relevant research projects. More research and funding are needed for palliative care research, especially including older people and people with dementia or cognitive impairment, and not necessarily for disease-orientated projects. In fact, international and national funding policies are urged to provide more funding in order to support quality research focusing on the needs and problems of all people, regardless of their age or disease (68).

Strengths and limitations

This study tackles the paucity of research on the ethical issues/challenges that may occur in outcome measurement in palliative care clinical practice. This is of foremost relevance as high quality care and high quality research cannot be without high ethical standards. Moreover, sensitive search strategies with few limitations and in a range of literature databases were performed, and methodological frameworks (20) and reporting guidelines (26) were followed to ensure the trustworthiness and reliability of our findings. Nevertheless, this systematic review of systematic reviews is not without limitations. Since we could not find any primary evidence about ethical issues/challenges in outcome measurement in palliative care, but we believed that there were already many systematic reviews on outcome measurement in this field, we decided to perform a systematic review of systematic reviews. While this assumption was correct, none of these systematic reviews was specifically focused on ethical issues/challenges and we could only find two systematic reviews addressing ethical issues/challenges in their findings/discussion. Therefore, caution is needed in the interpretation of our findings. Finally, as recommended by Whitlock et al. (20), a more robust dialogue and methodological research are needed to better assist with the specification of methods and development of reporting standards when performing and conducting systematic reviews of systematic reviews.

Conclusions

Ethical challenges/issues are poorly addressed in the existing systematic reviews about outcome measurement in palliative care clinical practice. Only two systematic reviews addressed
ethical challenges/issues as part of their findings. The main ethical challenge/issue mentioned in these two systematic reviews was cognitive impairment, particularly in patients with dementia. Further research is needed on this subject and to foster the use of outcome measurement among this vulnerable group of patients. Recommendations are driven to tackle the paucity of research on ethical challenges/issues in outcome measurement in palliative care clinical practice and on how to improve person-centred outcome measurement for people with dementia/cognitive impairment.

Acknowledgements
This manuscript was written during the duration of Projects InPalIn “Integrating Palliative Care in Intensive Care” and Subproject ETHICS II of Project ENSURE “Enhancing the Informed Consent Process: Supported Decision-Making and Capacity Assessment in Clinical Dementia Research”. Therefore, SMP and PHM would like to thank Fundação Merck, Sharp & Dohme and Fundação Grünenthal for their financial support to Project InPalIn and ERA-NET NEURON II, ELSA 2015, European Comission, and Fundação para a Ciência e a Tecnologia (FCT), Ministério da Ciência, Tecnologia e Ensino Superior, Portugal, for their financial support to the Subproject ETHICS II of Project ENSURE NEURON-II/0001/2015. The funders had no role in the design of the study, collection, analysis, and interpretation of data, and in writing the manuscript.

Footnote
Conflicts of Interest: The authors have no conflicts of interest to declare.

References


Martins Pereira and Hernández-Marrero. Ethical challenges of outcome measurement in palliative care

2016;8:48.


Table S1 Detailed search strategies

<table>
<thead>
<tr>
<th>Database</th>
<th>Search terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>EBSCO Host Searching:</td>
<td>CINAHL Complete, MEDLINE Complete, Nursing &amp; Allied Health Collection: Comprehensive, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Cochrane Methodology Register, Library, Information Science &amp; Technology Abstracts, MedicLatina ethical challenges AND outcome measurement AND palliative care or end of life care [SU Subject Terms] ethical challenges AND outcome measures or outcome assessment AND palliative care or end of life care [SU Subject Terms] ethical issues AND outcome measures or outcome assessment AND palliative care or end of life care [SU Subject Terms]</td>
</tr>
<tr>
<td>Web of Science</td>
<td>Indexes: SCI-EXPANDED, SSCI, A&amp;HCI, CPCI-S, CPCI-SSH, ESCI, CCR-EXPANDED, IC TITLE: (outcome) AND TITLE: (palliative care) AND TITLE: (systematic review) TOPIC: (ethic*) AND TOPIC: (outcome meas*) AND TOPIC: (palliative*) TOPIC: (ethic*) AND TOPIC: (outcome meas*) AND TOPIC: (palliative*) AND TOPIC: (systematic review) TOPIC: (outcome meas*) AND TOPIC: (palliative*) AND TOPIC: (systematic review)</td>
</tr>
</tbody>
</table>