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Review Article

Capture, Transfer, and Feedback of Patient-Centered Outcomes Data in Palliative Care Populations: Does It Make a Difference? A Systematic Review

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Abstract

Context. Patient-centered outcome measures (PCOMs) are an important way of promoting patient-professional communication. However, evidence regarding their implementation in palliative care is limited, as is evidence of the impact on care quality and outcomes.

Objectives. The aim was to systematically review evidence on capture and feedback of PCOMs in palliative care populations and determine the effects on processes and outcomes of care.

Methods. We searched Medline, Embase, CINAHL, BNI, PsycINFO, and gray literature from 1985 to October 2013 for peer-reviewed articles focusing on collection, transfer, and feedback of PCOMs in palliative care populations. Two researchers independently reviewed all included articles. Review articles, feasibility studies, and those not measuring PCOMs in clinical practice were excluded. We quality assessed articles using modified Edwards criteria and undertook narrative synthesis.

Results. One hundred eighty-four articles used 122 different PCOMs in 70,466 patients. Of these, 16 articles corresponding to 13 studies met the full inclusion criteria. Most evidence was from outpatient oncology. There was strong evidence for an impact of PCOMs feedback on processes of care including better symptom recognition, more discussion of quality of life, and increased referrals based on PCOMs reporting. There was evidence of improved emotional and psychological patient outcomes but no effect on overall quality of life or symptom burden.

Conclusion. In palliative care populations, PCOMs feedback improves awareness of unmet need and allows professionals to act to address patients' needs. It consequently benefits patients' emotional and psychological quality of life. However, more high-quality evidence is needed in noncancer populations and across a wider range of settings. *J Pain Symptom Manage* 2015;49:611–624. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc.

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Key Words

Outcome assessment (health care), palliative care, review, data collection, quality of life, hospice care

Introduction

By measuring the change in a patient's health status over time, health-related outcome measures¹ allow us to assess the effectiveness and cost-effectiveness of health care. Internationally, there is a growing emphasis on outcome measurement rather than process management in health care. This shift to outcome measurement

enables the effectiveness of health care interventions to be assessed at individual and population levels.² Patient-reported outcome measures (PROMs) are a form of outcome measure and comprise standardized validated questionnaires that are completed by patients to measure their perceptions of their own health status and well-being.³ These improve emphasis on person-centered care.

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Because of their patient-centered nature, PROMs are increasingly used in palliative care.⁴ However, one of the important challenges to their use in palliative care is that a proportion of palliative care patients have impaired cognition and/or are too unwell to complete outcome measures themselves. This varies by setting: In a hospice study, 57% of patients required help in completing outcome measures,⁵ and in some conditions, such as end-of-life care in patients with advanced dementia or those otherwise unable to communicate, self-reporting is virtually impossible.^{6,7} Focusing on patient-reported measures alone runs the risk of excluding these less well patients; proxy outcome measures completed by families and professionals have been shown to be useful and need to be considered in this context.⁸ Patient-centeredness has been highlighted by previous authors as key to outcome measurement in palliative care.^{9,10} To reflect this reality, we adopt the term “patient-centered outcome measures” (PCOMs) to encompass both patient-reported and proxy-reported measures, which nevertheless have a prime focus on the concerns important to patients. We use the term PCOMs throughout this article to refer to patient- and proxy-reported outcome measures.

The case for patient-centered outcome measurement is strong, but integration of outcome measurement into routine practice has proved challenging. In a recent systematic review, Antunes et al.¹¹ noted barriers and facilitators in the implementation of PCOMs in palliative care and suggested that these need to be addressed in future implementation projects. A key factor in the implementation of PCOMs into routine practice is the way in which PCOMs information is used. This is because PCOMs information must be successfully collected and transferred between patient and clinician in a form that is easy to integrate into shared decision making.^{12,13} This can only occur after data have been captured successfully.

In some settings, notably oncology, there is growing evidence on the use and usefulness of PCOMs,^{14–17} but in palliative care, the effectiveness of PCOMs by themselves in improving patient outcomes is as yet unclear in two ways: First, as Antunes et al. recognized in their systematic review, there is limited consensus on which method of data collection is most amenable to successful information transfer and feedback.¹¹ Many different methods of data capture have been used, from pencil-and-paper surveys and paper forms with optical readers to electronic pens with wireless links and tablet- or internet-based rapid learning questionnaires with visual reports. Many electronic methods have been shown to be equivalent to paper in terms of completion rate and acceptability,¹⁸ but the range used in palliative care populations and the effect that modality might have on data capture, transfer, and feedback in palliative care are less well documented.

Second, although several reviews of the general literature address this question,^{12,19,20} evidence for how PCOMs impact on processes and outcomes of care in palliative care is limited. It could be argued that completion of these measures facilitates patient reporting and clinician recognition of health care need and that consequently clinicians would be better equipped to address patients’ needs. If needs are more comprehensively addressed, then health outcomes should improve. However, this hypothesis requires further testing. What is needed is a review of the evidence on PCOMs implementation in palliative care populations, including the effect of feeding back PCOMs information.

Therefore, in this review, we aimed to understand the methods by which PCOMs data are captured, transferred, and fed back in palliative care populations and to determine the effect of PCOMs feedback on processes and outcomes of care.

Methods

As detailed in the following sections, we performed a systematic search of the literature and quality assessment of articles in line with standard systematic review protocols.²¹

Search Strategy

Our search strategy (reported in [Figure 1](#) in accordance with the PRISMA guidelines²¹) included a systematic search of databases, hand searching of reference and citation lists of relevant articles, searching databases of gray literature, and contact with researchers where required.

Database Search. We used a combination of previously used search strategies to identify PCOMs^{22–24} and modified these based on scoping searches to increase sensitivity to articles that focused primarily on information transfer and feedback of these measures. To identify articles relevant to palliative care populations, we incorporated a search strategy adapted from that used by Sladek et al.²⁵ As outcome measurement was defined in 1980¹ and PCOMs began to be used in the late 1980s, we excluded articles published before 1985, as previous work has done.¹¹ Databases searched were Medline (Ovid), Embase, PsycINFO, CINAHL, and British Nursing Index from 1985 to October 2013. The searches were conducted between October 6 and 8, 2013.

Hand Searching Reference and Citation Lists. Evidence-based search strategies for palliative care articles have been shown to have a relatively low sensitivity.²⁵ Therefore, we hand searched both reference and citation lists of relevant articles to identify further articles

1. score*.tw
2. questionnaire*.tw
3. scale*.tw
4. measure*.tw
5. instrument*.tw
6. tool*.tw
7. 1 OR 2 OR 3 OR 4 OR 5 OR 6
8. performance status
9. disability scale
10. functional status
11. quality of life
12. health status
13. Outcome assessment, healthcare /
14. outcome assessment.tw
15. outcome measure*.tw
16. 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15
17. 7 OR 16
18. Feedback.tw
19. 'Feed back'.tw
20. Audit.tw
21. Interpersonal communication/
22. Professional patient relations/
23. Handover
24. 'Hand over'
25. 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24
26. Data collection/
27. Information processing.tw
28. Information transfer
29. Information storage and retrieval/
30. 26 OR 27 OR 28 OR 29
31. 25 OR 30
32. patient care planning/
33. exp attitude to death/
34. exp bereavement/
35. death/
36. hospices/
37. long term care/
38. palliative care/
39. exp terminal care/
40. terminally ill/
41. palliat\$.tw.
42. hospice\$.tw.
43. "terminal care".tw.
44. 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43
45. 17 AND 31 AND 44

Fig. 1. Search strategy for Medline (Ovid).

for inclusion. Reference and citation list searching was done for relevant review articles found in our database searches ($n = 29$), all included articles ($n = 16$), and selected relevant articles known to the research team ($n = 13$). Reference and citation list searching was completed between November 1 and December 18, 2013. Our reference and citation list search did not include "related citations" lists in databases such as PubMed, and so on.

Unpublished Literature. We searched dissertations and theses via the British Library database and the DART European thesis database (all dates) to capture unpublished literature in this area. Beyond this, gray literature searching has been shown to provide poor returns in palliative care.²⁶

Personal Contact. Using departmental contacts, we contacted experts in the field of outcome measurement in palliative care. We also contacted authors of

promising conference abstracts identified in our search to identify further articles.

Inclusion/Exclusion Criteria

A pilot test was conducted with five multiprofessional researchers to refine our inclusion/exclusion criteria. The pilot showed that a two-tier review structure was required to answer our review questions. At Level 1 of the review, we identified publications that commented on the method of data capture of PCOMs in palliative care. A subset of these publications described in detail the process of capture, transfer, and feedback of PCOMs data and the effects on processes and outcomes of care—the Level 2 articles. Therefore, we had two levels of inclusion and exclusion criteria.

For Level 1 of the review, inclusion criteria were the use of PCOMs, description of the methods of data capture, and applicability to a palliative care population. We reviewed a number of existing definitions of PROMs^{3,19,27} and used these to produce our own definition of a PCOM as a "standardized, validated questionnaire that is completed by a patient or their proxy to measure their perceptions of the patient's functional status and well-being and with a prime focus on the concerns important to patients." A palliative care population was defined as patients receiving specialist or generalist palliative care input in any health care setting or patients with advanced life-limiting or terminal illness (including studies recruiting >50% of patients with advanced/metastatic cancer). We used a very broad definition of palliative care to assess evidence on generalist and specialist palliative care in a wide range of advanced illnesses.

Level 1 exclusion criteria were articles without any detail on methods of data capture, those not applicable to palliative care, articles in languages other than English, and review articles. Level 1 articles were briefly reviewed with the main aim being to report the range of methods that are currently used to collect PCOMs data in palliative care populations.

All Level 2 articles needed to fulfill the Level 1 criteria. Additionally, inclusion criteria were 1) serial measurement of PCOMs in a clinical setting, 2) the main focus of the article was on capture and information transfer of PCOMs, and 3) the article addressed at least two of the following points: How information on PCOMs data was transferred from/fed back to patients, the impact of this transfer of information on clinician practice, the attitudes of both parties toward the measurement/information transfer, and/or the effect on outcomes.

Exclusion criteria for Level 2 articles were insufficient information on any of the aforementioned criteria or a pilot study that was focused purely on feasibility or validity of a measurement system.²⁸ We did not limit our inclusion to randomized trials, as

we expected a proportion of the evidence to be from studies of other design. Level 2 articles underwent full data extraction and quality assessment before synthesis of evidence.

Screening of Results

Search results were imported into Endnote X6 (Thomson Reuters, UK) and deduplicated. Remaining articles were screened by title and abstract by two reviewers (S. N. E. and W. K.). Reviewers screened different articles with 10% cross-checking at each level to ensure agreement. Disagreement was resolved by discussion within the research team and consensus opinion. Articles selected for full-text review were assessed for eligibility by a single reviewer (S. N. E.); 10% were checked with a second reviewer (W. K.). Articles included at Level 1 were reassessed against Level 2 criteria (S. N. E.), with a further 10% cross-checking (W. K.).

Data Extraction

Data extraction was undertaken by two reviewers (S. N. E. and W. K.) for all Level 1 articles, with 25% cross-checking to ensure consistency. Data regarding outcome measures used, method of data capture, sample size, disease group, setting, and where available, completion rate were extracted.

At Level 2, detailed data were extracted by two reviewers based on an agreed and piloted proforma (J. W. extracted data for five articles and S. N. E. for 11 articles). A third reviewer (W. K.) cross-checked data extraction across all articles to ensure consistency. Data regarding primary and secondary outcomes, information transfer and feedback, randomization methods, impacts on process and outcomes of care, acceptability, and feasibility were extracted.

Quality Assessment

All articles selected for inclusion into the review at Level 2 were assessed for quality. There are no universally accepted guidelines or criteria against which to measure study quality, especially when included articles are not all expected to be randomized controlled trials (RCTs). Factors assessed as important in this review were a clear study design and background, details of population and inclusion to the study including the level of participation, and appropriateness and generalizability of conclusions. We were also interested in the inclusion and completion rates of studies, as in some cases this can be a proxy indicator for the acceptability of the intervention (although care must be taken when interpreting loss to follow-up and missing data in palliative care trials²⁹). We decided that the modified Edwards et al. criteria were well suited for this review because they take much of this information into account, and this is also the only scale that allows

assessment of both interventional and observational studies.^{30,31} Based on their percentage Edwards score, we classified articles as low (<60%), medium (60%–80%), or high (>80%) quality.

Analysis

Narrative synthesis was planned as results were expected to be heterogeneous in terms of outcomes addressed.³² Therefore, data from included studies were initially tabulated and common themes identified. After this, conceptual mapping allowed us to map and further investigate common themes between articles. This method has been recommended for reviews containing complex data.³³ Tabulation and conceptual mapping led to a synthesis of the data. The strength of evidence for each synthesized theme was assessed on a three-point scale. This was based on the quality of articles contributing to the finding, agreement between contributing articles, and quantity of evidence, as used by a previous systematic review in palliative care.³⁴

Results

Our database search produced 6580 results after deduplication, from which we identified 367 articles for full-text review (Figure 2). We identified a further 65 articles from other sources for full-text review. One hundred eighty-four of these articles fulfilled our Level 1 inclusion criteria.

Level 1: Methods of Data Capture

The 184 Level 1 articles comprised 79 (43%) observational studies (including 53 [29%] cross-sectional and 26 [14%] longitudinal), 43 (23%) intervention studies (including 28 [15%] RCTs and 15 (8%) non-RCTs), 39 (21%) pilot studies, 19 (10%) validation studies, and four (2%) other designs including methodological studies. The articles referred to work with 70,466 patients. A total of 38.84% of patients ($n = 27,374$) were recruited from specialist palliative care settings (i.e., hospices, specialist palliative care in community) and 38.35% of patients ($n = 27,024$) from oncology settings (i.e., oncology inpatients, outpatients, or community oncology); 19.53% of patients ($n = 13,763$) were from two major studies of hospital inpatients with serious advanced illness and 3.27% of patients ($n = 2305$) were recruited to studies of other specific advanced illnesses including renal, cardiac, neurologic diseases, and AIDS.

One hundred twenty-two different PCOMs were used in these articles; the three most frequently used measures were the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30, $n = 38$ studies),³⁵ the Edmonton Symptom Assessment System (ESAS, $n = 27$),³⁶ and the Palliative care Outcome Scale

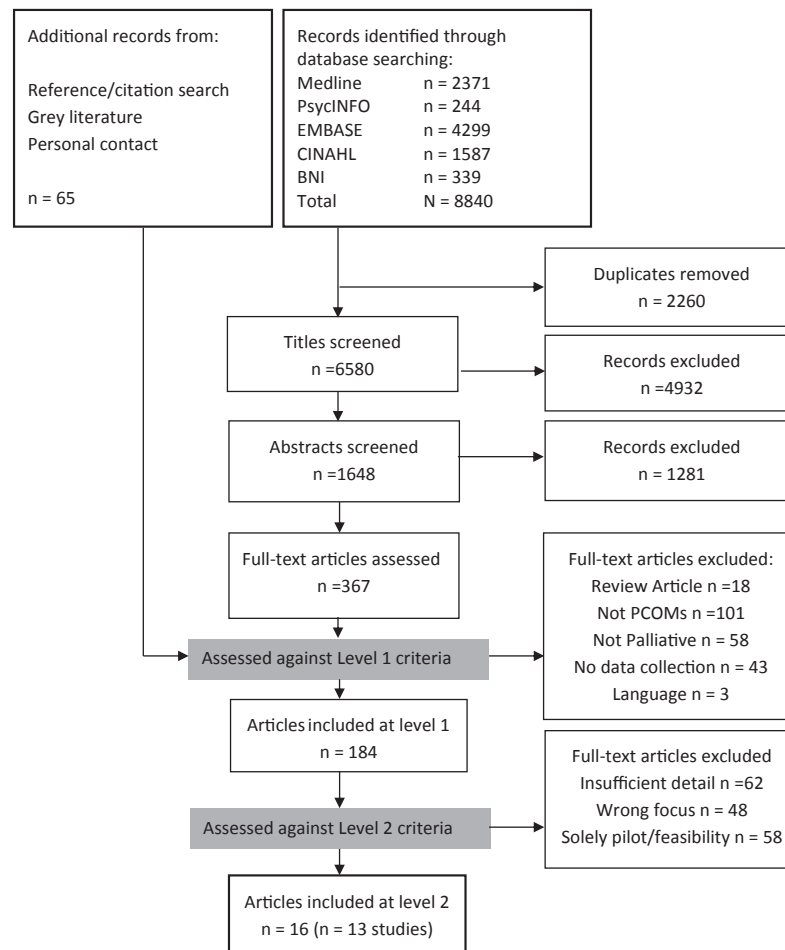


Fig. 2. Systematic review flow chart (adapted from PRISMA²¹). PCOM = patient-centered outcome measure.

(POS, $n = 14$).³⁷ Eighty-nine studies (49%) used a paper format for collection of PCOMs data, 44 (24%) used electronic formats, 44 (24%) used interviews, 16 (9%) used telephones, and three (2%) solely used proxy completion of PCOMs (some studies used multiple formats). Several electronic formats were used, most frequently tablet computers ($n = 21$), internet platforms ($n = 9$), electronic pens ($n = 6$), and desktop computers ($n = 6$).

Level 2: Capture, Transfer, and Feedback of PCOMs Data

Of the 184 Level 1 articles, 16 articles, corresponding to 13 studies, fulfilled Level 2 criteria for inclusion and, therefore, were reviewed in detail (Table 1).^{5,7,38–51} These studies included 11 RCTs, one quasi-experimental study,⁵ one large-scale implementation project,⁵⁰ and one preliminary study (included alongside the subsequent RCT).³⁹ A total of 2839 patients were included, the large majority (93%) of whom had advanced cancer; 1638 patients (58%) were recruited from oncology clinics, 930 (33%) from palliative home care services, 72 (2.5%) from hospices, and 181 (6.5%) from nursing homes. Article quality assessment

found seven articles of high quality (>80% using modified Edwards et al. criteria); these were predominantly clinical trials in an oncology setting. There were five medium-quality and four low-quality articles.

Figure 3 summarizes the scope of the review evidence, indicating the populations studied, the outcome measures used, the methods of completion and feedback of PCOMs, and the outcomes that were measured.

Effect on Processes and Outcomes of Care

All studies addressed at least one process or outcome of care (Table 1). Processes assessed included patient-professional communication, the understanding by professionals of patient's quality of life (QOL; assessed by congruence between patient and professional health-related quality of life [HRQOL] scores), reporting and recognition of symptoms, and actions taken in response to identified health care need. We found that PCOMs data capture and feedback led to increased reporting/recognition of symptoms (strong evidence), greater congruence between patient and professional HRQOL scores (moderate

Table 1
Summary of Articles Included at Level 2

First Author (Country)	Patient Population	Research Question	Study Design and Quality	Primary Outcome and Main Result
Detmar (The Netherlands) ³⁸	Outpatient oncology	Do standardized HRQOL assessments facilitate patient-physician communication and increase physicians' awareness of their patients' problems?	A crossover RCT to assess the impact on patient-physician communication of incorporating a standardized HRQOL assessment and feedback into clinic visits. High quality	Primary outcome: a composite communication score of whether HRQOL topics were discussed in the clinic. Result: improved communication score in the intervention group.
Davis (U.S.) ^{39,a}	Outpatient oncology	Is an innovative symptom monitoring system developed for patients with advanced lung cancer starting chemotherapy feasible to implement and acceptable to use?	A feasibility study to assess the implementation of an automated PCOM reporting system with a focus on feeding back information to providers in advanced lung cancer. Low quality	Primary outcome: qualitative patient and physician views on use of this system. Result: positive feedback regarding usability and feasibility.
Yount (U.S.) ^{41,a}	Outpatient oncology	Does technology-based symptom monitoring and reporting reduce symptom burden in patients with advanced lung cancer?	A prospective, multisite, randomized controlled trial that implemented weekly patient reporting of symptoms and routine feedback and discussion with physicians in an advanced lung cancer group. Symptom reporting was compared with reporting and systematic feedback to clinicians. High quality	Primary outcome: overall symptom burden using the symptom distress score. Result: more symptoms reported, but no effect on symptom burden.
Hill (New Zealand) ⁵	Hospice inpatient unit	Does using patient-reported QOL data to make a joint management plan improve QOL outcomes in hospice patients?	A pretest/post-test quasi-experimental study that looked at QOL in patients receiving conventional hospice care, compared with patients where admission QOL data were discussed with their nurse to make a joint management plan. Low quality	Primary outcome: improvement in HRQOL. Result: no between-group differences in HRQOL. Within-group improvement in HRQOL.
Kornblith (U.S.) ⁴²	Community oncology	Will distress in older patients with advanced cancer be reduced with educational materials (EM) and monthly telephone monitoring (TM) because of quicker referrals?	A randomized trial comparing the use of educational materials alone with the combination of educational materials with monthly telephone calls + self-reported symptoms. High quality	Primary outcome: the level of anxiety/depression on the HADS at six months. Result: reduced distress in the intervention group.
McMillan (U.S.) ⁴⁸	Home hospice patients	Does the feedback of patient/caregiver-reported HRQOL information to a hospice multidisciplinary team (IDT) improve HRQOL compared with standard hospice care?	A randomized trial in two home hospice teams where all patient/caregiver dyads completed standardized QOL assessments on admission and seven days later. In the intervention group, this information was fed back to the IDT. Medium quality	Primary outcome: four patient outcomes (depression, distress, spiritual needs, and QOL) and three caregiver outcomes (depression, received support, and spiritual needs). Result: improved depression in the intervention group.

Nicklasson (Sweden) ⁴⁴	Outpatient oncology	Does individual health-related quality of life (HRQOL) evaluation increase attention toward symptom control and psychosocial function in advanced cancer?	Randomized study comparing HRQOL measurement alone with measurement and feedback to physicians at an oncology clinic. High quality	Primary outcome: analysis of recorded consultations for attention to symptom/psychosocial issues. Result: greater discussion of emotional issues in the intervention group.
Velikova (U.K.) ^{46,b}	Outpatient oncology	Does routine use of HRQOL screening and feedback to clinicians improve patient well-being and communication?	Randomized study in which patients completed HRQOL measures electronically. Summary reports were given to clinicians. An attention control group completed the same measures but without feedback. Control group received standard care. High quality	Primary outcome: HRQOL scores Result: intervention and attention control groups had improved HRQOL scores.
Takeuchi (U.K.) ^{40,b}	Outpatient oncology	How does the feedback of patient-reported outcomes affect the content of consultations in outpatient oncology?	Exploratory analysis of data from Velikova (2004) looking at the content of consultations and whether the intervention affected the frequency of discussion of HRQOL.	Primary outcome: content of consultations, especially discussion of symptom burden and functional status. Result: more discussion of symptoms.
Velikova (U.K.) ^{47,b}	Outpatient oncology	How are patients affected by the use of routine HRQOL screening and feedback to clinicians—what are their views?	Medium quality Secondary analysis of Velikova (2004) investigating the acceptability of the intervention to patients. Using patient satisfaction measures to assess this in the same patients and looking for a difference by trial arm.	Primary outcome: patient satisfaction scores. Result: high satisfaction scores in the intervention group.
Chih (U.S.) ⁴⁹	Outpatient oncology	Are caregivers with access to a clinician report better prepared and experience less physical burden and less negative mood than those without access?	Medium quality Pooled analysis of two randomized trials (one for breast/prostate cancer patients; one for lung cancer patients) to explore the effect of a clinician report and alert system on caregiver outcomes at six- and 12-month follow-up.	Primary outcome: comparison of caregiver preparedness, physical burden, and negative mood at six and 12 months between intervention and control. Result: improved caregiver outcomes at six months.
Mills (U.K.) ⁴⁵	Outpatient oncology	Does regular recording of HRQOL data by patients have beneficial outcomes for those with inoperable lung cancer?	Medium quality A pragmatic RCT of the effects of patient-held symptom diary on HRQOL, communication, and satisfaction with care. Patients completed the diary on a weekly basis and chose whether to share the diary with professionals. High quality	Primary outcome: mean change in HRQOL measure. Result: no improvement in HRQOL, possible worsening.

(Continued)

Table 1
Continued

First Author (Country)	Patient Population	Research Question	Study Design and Quality	Primary Outcome and Main Result
Rosebloom (U.S.) ⁴³	Outpatient oncology	Does structured, detailed feedback about patients' HRQOL to treating nurses facilitate clinical management changes and, ultimately, impact patients' self-reported HRQOL and satisfaction over time?	A RCT of the effect of detailed structured feedback about patients' HRQOL on patient management and HRQOL. Three groups included usual care, HRQOL assessment only, and HRQOL assessment plus nurse interview. For the two latter groups, HRQOL information was fed back to treating nurses.	Primary outcome: a comparison of patients' HRQOL and satisfaction between intervention and control groups at three and six months. Result: no improvement in HRQOL.
Gilbert (Canada) ⁵⁰	Outpatient oncology in cancer centers	What is the impact of the PPCIP on improvement aims and care processes?	High quality Report on the implementation of the provincial palliative care integration project (PPCIP), which included 1) implementation of the Edmonton Symptom Assessment System (ESAS), 2) use of "rapid-cycle change" processes to improve screening and symptom management, and 3) focus on integration and access.	Primary outcome: improvements in 1) symptom screening and assessment, 2) percentage of the population with assessment/referral for high symptom scores, and 3) use of best practices in the provision of collaborative care planning. Result: some improvement in all outcomes—project ongoing.
Fuchs-Lacelle (Canada) ⁷	Long-term care units	Does systematic pain assessment in older dementia patients lead to improved pain management practices and decreased nurse stress?	Low quality Three-month comparative longitudinal study to assess the impact of regular pain assessment on nursing practice, stress, and pain scores, comparing an intervention group (regular use of pain assessment tool) vs. a control group (regular use of activity log).	Primary outcomes: pain assessment scores, nursing stress. Result: improved pain scores, indications of improved nursing stress.
Lind (Sweden) ⁵¹	Palliative home care	Does symptom reporting via an electronic pen system reduce time to noticing of symptoms compared with paper-based symptom recording?	Low quality RCT to determine if symptom reporting via electronic pens using scales similar to ESAS reduces the time to symptom recognition compared with a control group who recorded symptoms on paper and reported at their next consultation. Open-label RCT.	Primary outcome: time until clinician noticed symptom report. Result: reduced time to symptom recognition.

HRQOL = health-related quality of life; RCT = randomized controlled trial; PCOM = patient-centered outcome measure; QOL = quality of life.

^{a,b}Articles with the same superscript letters relate to the same research study.

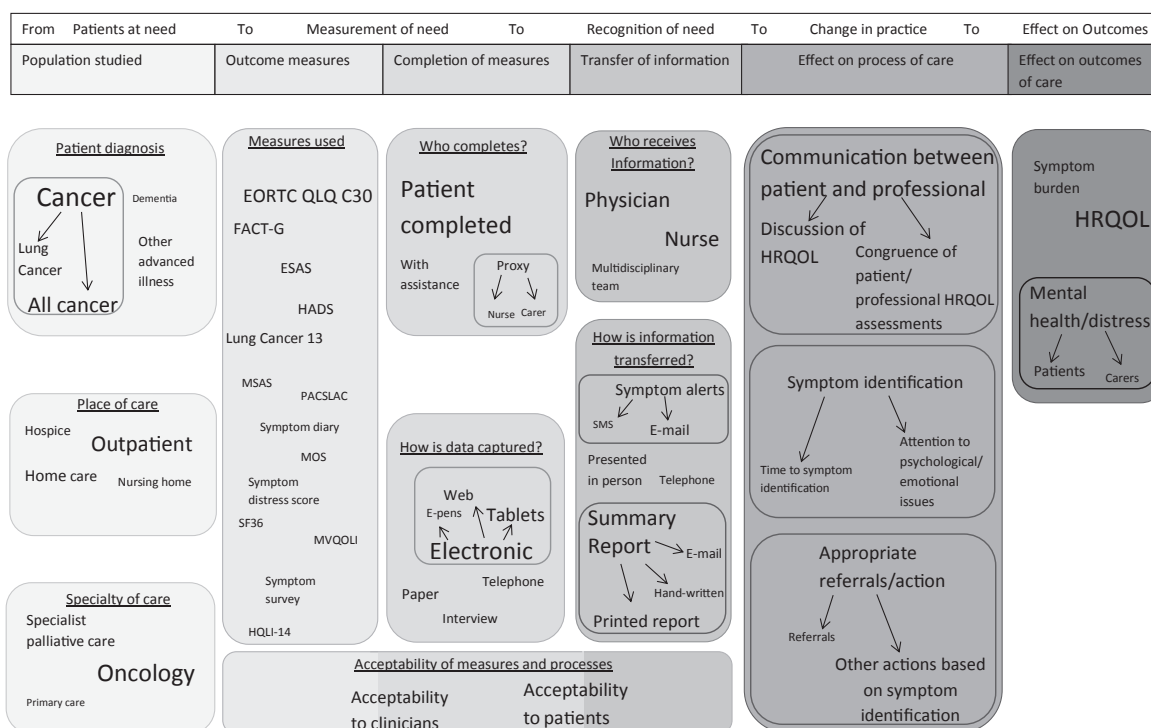


Fig. 3. Visual map summarizing the scope of the Level 2 review evidence in terms of the process of PCOMs implementation. Note: the font size indicates the frequency with which each area is reported in the review evidence. EORTC QLQ C30 = European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30; HRQOL = health-related quality of life; ESAS = Edmonton Symptom Assessment System; FACT-G = Functional Assessment of Cancer Therapy - General; HADS = Hospital Anxiety and Depression Scale; MSAS = Memorial Symptom Assessment Scale; PACSLAC = Pain Assessment Checklist for Seniors with Limited Ability to Communicate; MOS = Medical Outcomes Study core questionnaire; SF36 = Short Form health survey 36; MVQOLI = Missoula-Vitas Quality of Life Index; HQLI 14 = Hospice Quality of Life Index 14.

evidence), and a larger number of actions taken based on HRQOL data (strong evidence; Figure 4).

Outcomes assessed were overall HRQOL, symptom burden, and emotional/psychological QOL. We found that PCOMs data capture and feedback improved psychological and emotional HRQOL for patients (moderate evidence) and carers (weak evidence) but found no improvement in symptom burden (moderate evidence), and no change in overall HRQOL was demonstrated (strong evidence; Figure 5).

Acceptability and Feasibility

The included articles contained limited evidence on the acceptability and feasibility of completing and feeding back PCOMs. Five articles^{38,39,41,42,47} reported on acceptability to patients. The main findings were that patients found the intervention “helpful in discussing important issues/telling professionals how they were feeling” (weighted mean 69%) and that patients “would use PCOMs feedback as part of standard care” (weighted mean 88%). Six articles^{5,39,46–48} reported on acceptability to professionals with mixed results. In two articles,^{38,46} a weighted mean of 51% stated that HRQOL summaries facilitated communication and 77% said that an HRQOL summary provided a useful overall

impression of patients’ experience. Another reported a “generally favourable impression of PCOMs feedback”³⁹ and a fourth that “Teams were generally receptive to the intervention.”⁴⁸ There was some negative feedback: In one article, 19% stated that the intervention “interfered with their daily practice.”⁴⁷ Another article found that nurses had “difficulty completing [the] intervention protocol due to time constraints.”⁵ Other articles exist that comment solely on the acceptability and feasibility of PCOMs implementation.^{52,53} However, these did not meet the inclusion criteria, and comprehensive synthesis of this evidence is outside the scope of this review.

Discussion

This review systematically identifies and synthesizes evidence on the implementation of PCOMs in palliative care populations. To our knowledge, our findings describe for the first time current capture and feedback of PCOMs data in palliative care, including the range of settings in which PCOMs are implemented and the methods of data capture and feedback that are used in palliative care.

We demonstrate strong evidence for an effect of PCOMs feedback on processes of health care that

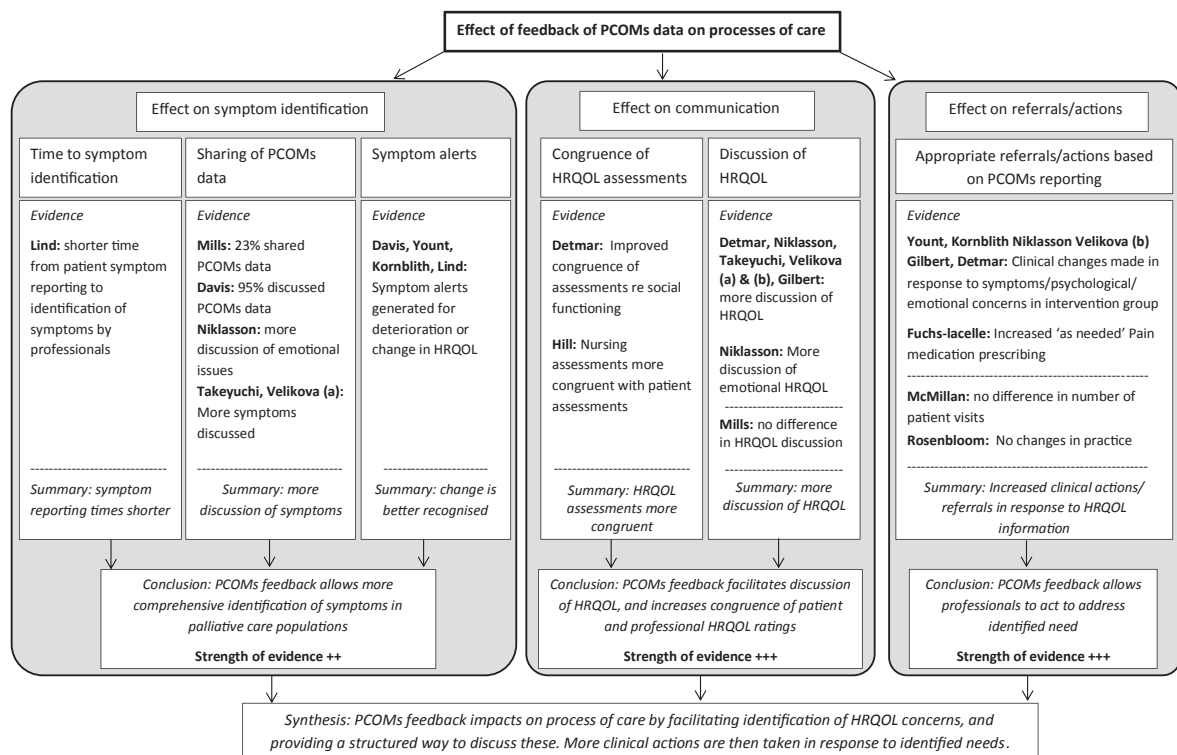


Fig. 4. Summary of evidence from review regarding how capture, transfer, and feedback of PCOMs data impact on processes of care. PCOM = patient-centered outcome measure; HRQOL = health-related quality of life.

allows more responsive and holistic care. Specifically, the data show that 1) there is more comprehensive recognition of symptoms, 2) there is greater communication regarding HRQOL, and 3) clinicians take more actions (as evidenced by referral activity) in response to HRQOL information, if this is routinely fed back to them.

We present moderate evidence that feedback of PCOMs data has a beneficial effect on patients' emotional and psychological HRQOL. However, there is evidence from several publications that PCOMs feedback does not affect overall HRQOL and moderate evidence that there is no effect on overall symptom burden.

We also present evidence regarding the acceptability of PCOMs data capture and transfer to patients and clinicians. This is not comprehensive; however, data demonstrate that the intervention is largely acceptable in palliative care populations.

An important consideration is that this high-quality evidence related to PCOMs measurement in palliative care populations is predominantly from oncology patients in outpatient settings. This finding resulted despite the use of a wide definition of palliative care in this research. This limits the generalizability to other populations. In addition, there is no guaranteed level of palliative care support that oncology outpatients will receive.

There is also limited evidence on the effects of feedback of PCOMs data to multidisciplinary teams, rather than single physicians or nurses.

Our findings support those of systematic reviews from other settings, which also have shown that PCOMs data capture and feedback result in improved processes of care.^{14,19,20,23} In their review of PCOMs in oncology, Chen et al. demonstrated that well-implemented PCOMs improved patient-provider communication and detection of unrecognized problems.¹⁴ In reviews of the general literature, Espallargues et al.²⁰ and Marshall et al.¹⁹ noted some process of care benefits attributed to PCOMs use. The mechanism for how PCOMs feedback affects processes of care has been considered.¹³ In one sense, PCOMs can act as a reminder to clinicians to address particular areas and appear to work well in this regard. This "reminder effect" is particularly evident in symptom alerts, which notify clinicians if a patient's symptom either crosses a threshold of severity or worsens significantly.

We also demonstrate evidence that PCOMs feedback does impact on health care outcomes in palliative care. This is in contrast to systematic reviews in more general populations in which Boyce and Browne²³ and Greenhalgh and Meadows¹² reported a weak evidence base for effect of PCOMs on patient health care outcomes in studies that addressed this issue. The evidence we have collated shows some

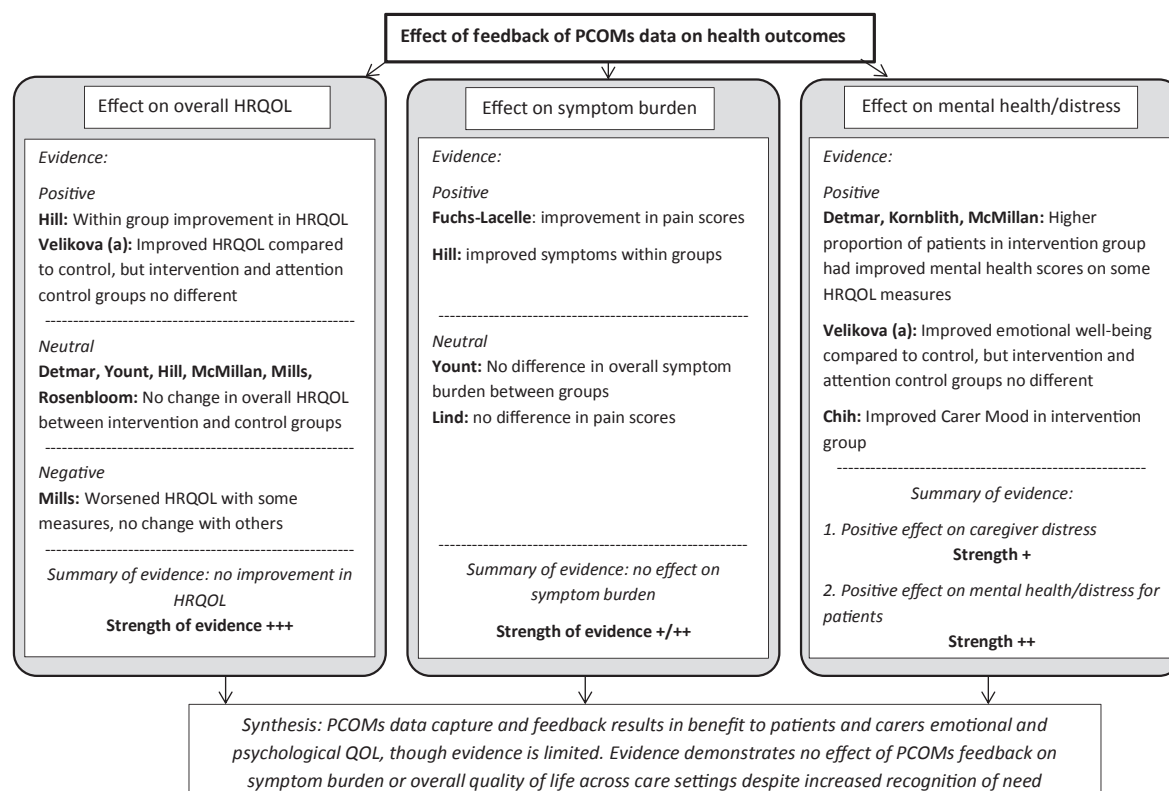


Fig. 5. Summary of evidence from review regarding how capture, transfer, and feedback of PCOMs data impact on health care outcomes. PCOM = patient-centered outcome measure; HRQOL = health-related quality of life.

beneficial effect of PCOMs feedback on emotional and psychological HRQOL in five of 16 articles. This novel finding has many possible explanations and requires further investigation. Possible explanations include that PCOMs use resulted in increased attention to emotional/psychological QOL. This is supported by the finding that some studies saw increased discussion of emotional/psychological issues when PCOMs data were fed back.⁴⁴ However, there was also more physical symptom reporting with no similar effect on outcomes.^{45,48} One article⁴² found that regular monitoring of distress alone (without other intervention) reduced distress, and another possible explanation is that the process of feeding back PCOMs may allow patients to feel better supported and reduces distress and anxiety in this way.

We found evidence of no effect of PCOMs feedback on overall HRQOL, and this is consistent with the conclusions of previous reviews in other health care settings.^{20,23} Existing reviews have also concluded that there is insufficient evidence to definitively address this issue.^{19,23} Two articles included in this review argue that the explanation for this absence of effect is that the intervention of PCOMs data capture and feedback is insufficient to change physical HRQOL.^{43,45} However, there are many other possible theories behind the lack of impact of PCOMs, and these have been discussed elsewhere.¹³

Our review has a number of strengths. Our search strategy was systematic, including searches of multiple databases and several other sources, and was informed by previously tested strategies. This was supplemented with extensive reference and citation searching, which allowed inclusion of articles published very recently.⁴¹ The review team comprised a multiprofessional team of expert clinicians and researchers, and this aided the development of the review question, protocol, analysis, and synthesis of findings. Furthermore, our two-level review strategy allowed us to appraise the evidence from a general as well as specific perspective.

Some limitations to this study should be noted. First, our methods were limited by the fact that only a subset of articles was independently reviewed by two reviewers during the screening process. Although we made efforts to ensure agreement between reviewers by cross-checking a subset of articles at each stage, it is possible that reviewers differed slightly in their interpretation of the inclusion and exclusion criteria.

In addition, the main focus of our search strategy was on identifying articles that provided detailed information about the data capture and feedback of PCOMs information and the impact of this. This means that although we are confident that we have accessed articles relevant to Level 2 of the review systematically and comprehensively, some evidence relevant to the more basic Level 1 of the review may not have

been included. Efforts were made to search unpublished literature; however, it is possible that some studies with negative results were unpublished because of publication bias and thus not included in this review.⁵⁴ The focused search strategy also meant that our Level 2 inclusion criteria were narrow, including only articles that provided information relevant to very specific questions about the transfer and feedback of PCOMs data. This limits the generalizability of our findings, and we cannot comment on the more general topic of PCOMs implementation.

In terms of assessment of study quality, we used a scale suitable for assessing both intervention and observational studies as we had been expecting to capture a variety of study designs. However, in the final sample, the large majority of articles included at Level 2 were experimental or quasi-experimental in design. It could be argued that quality assessment criteria specific to experimental designs may have been more useful. Despite this, we consider that the modified Edwards et al. criteria do contain enough items relevant to experimental designs to remain appropriate for this review.

Several of the included articles addressed the acceptability of PCOMs as an intervention. In general, there seemed to be high levels of acceptability; however, because our search strategy was not specifically directed at acceptability, we did not capture all the evidence regarding acceptability of PCOMs use. A number of articles that addressed this issue did not meet the inclusion criteria in other ways.

As the distribution of evidence from Level 1 of this review shows, PCOMs implementation in palliative care is widespread, and many measures have been and are being developed for palliative care patients. Although we have shown in Level 1 that PCOMs are widely used in many different health settings and disease groups, the evidence for the impact on processes and outcomes of care comes from a less widely distributed population. The Level 2 articles are dominated by clinical trials in patients with cancer (11 of 13 studies), and most patients were recruited from outpatient oncology settings. There is very little evidence from patients with nonmalignant disease or multimorbidity at Level 2.

As well as deriving from a limited, mainly oncology, population, the Level 2 evidence also maps poorly onto the global population in need of palliative care, which comprises 34% cancer, 38% cardiovascular disease, and 10% chronic obstructive pulmonary disease as its three largest disease groups.⁵⁵ More evidence is required in noncancer patients and nonoutpatient settings to truly measure the effect of PCOMs implementation on palliative care.

Furthermore, many of the frequently used PCOMs at both Levels 1 and 2 of the review, such as the

EORTC QLQ-C30, are research based. These are well suited for RCTs but may not be as useful for clinical implementation projects; the use of research-based measures may limit the clinical applicability of our results. More evidence using clinical PCOMs such as the ESAS and POS is needed.

There is also limited information about feedback of PCOMs data to groups of people, such as multidisciplinary teams, rather than to individual doctors or nurses. The one study that investigated the feedback of PCOMs to multidisciplinary teams found a positive effect on patient depression.⁴⁸ The multidisciplinary team is an integral part of palliative care provision, and evidence of the effect of feedback to teams, rather than individuals, is, therefore, of particular interest in this setting; hence, more work is needed in this area.

In this review, the main effect of capture and feedback of PCOMs data is a beneficial effect on patient and possibly caregiver emotional and psychological HRQOL. The evidence supporting this is predominantly from high-quality articles; however, it is not extensive, and the mechanism behind this requires further exploration. More qualitative or mixed-methods research investigating the link between PCOMs feedback and emotional/psychological HRQOL is warranted.

The evidence from this review demonstrates that feedback of PCOMs provides no improvement in symptom burden or overall HRQOL in palliative care. Further research should investigate the reasons behind this to allow more effective future implementation of patient-centered outcome measurement. Implementation projects should embed research to understand how and why the implementation works or fails to work. The ongoing Outcomes Assessment and Complexity Collaborative project⁵⁶ aims to implement outcome measurement in palliative care in South London and will take into account the findings of this review.

Conclusion

We have presented evidence that implementation of PCOMs in palliative care improves processes of care and psychological and emotional HRQOL. To date, the evidence for impact on psychological outcomes is only moderate, but it does indicate that PCOMs data capture and feedback can positively impact patients' health status. However, there is evidence that PCOMs feedback does not appear to improve overall HRQOL in palliative care. The evidence for these conclusions predominantly stems from oncology settings. To aid implementation projects, future work should investigate other disease areas and particularly other settings of care relevant to palliative care patients.

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References

- Donabedian A. The definition of quality and approaches to its assessment. Vol 1. Explorations in quality assessment and monitoring., Capítulos del 1 al 3. Ann Arbor, MI: Health Administration Press, 1980.
- Putting Patients First The NHS England business plan for 2013/14 – 2015/16. NHS, 2012.
- Dawson J, Doll H, Fitzpatrick R, et al. The routine use of patient reported outcome measures in healthcare settings. *BMJ* 2010;340:c186.
- Simon S, Higginson I, Harding R, et al. Enhancing patient-reported outcome measurement in research and practice of palliative and end-of-life care. *Support Care Cancer* 2012;20:1573–1578.
- Hill N. Use of quality-of-life scores in care planning in a hospice setting: a comparative study. *Int J Palliat Nurs* 2002;8:540–547.
- McGuire DB, Reifsnnyder J, Soeken K, et al. Assessing pain in nonresponsive hospice patients: development and preliminary testing of the multidimensional objective pain assessment tool (MOPAT). *J Palliat Med* 2011;14:287–292.
- Fuchs-Lacelle S, Hadjistavropoulos T, Lix L. Pain assessment as intervention: a study of older adults with severe dementia. *Clin J Pain* 2008;24:697–707.
- Kutner JS, Bryant LL, Beaty BL, et al. Symptom distress and quality-of-life assessment at the end of life: the role of proxy response. *J Pain Symptom Manage* 2006;32:300–310.
- Carr AJ, Higginson IJ. Measuring quality of life: are quality of life measures patient centred? *BMJ* 2001;322:1357.
- O'Connor R. Measuring quality of life in health. London: Churchill Livingstone, 2004.
- Antunes B, Harding R, Higginson IJ, et al. Implementing patient-reported outcome measures in palliative care clinical practice: a systematic review of facilitators and barriers. *Palliat Med* 2014;28:158–175.
- Greenhalgh J, Meadows K. The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: a literature review. *J Eval Clin Pract* 1999;5:401–416.
- Greenhalgh J, Long AF, Flynn R. The use of patient reported outcome measures in routine clinical practice: lack of impact or lack of theory? *Soc Sci Med* 2005;60:833–843.
- Chen J, Ou L, Hollis SJ. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. *BMC Health Serv Res* 2013;13:211.
- Hjermstad MJ, Lie HC, Caraceni A, et al. Computer-based symptom assessment is feasible in patients with advanced cancer: results from an international multicenter study, the EPCRC-CSA. *J Pain Symptom Manage* 2012;44:639–654.
- Abernethy AP, Zafar SY, Uronis H, et al. Validation of the Patient Care Monitor (version 2.0): a review of system assessment instrument for cancer patients. *J Pain Symptom Manage* 2010;40:545–558.
- Abernethy AP, Etheredge LM, Ganz PA, et al. Rapid-learning system for cancer care. *J Clin Oncol* 2010;28:4268–4274.
- Gwaltney CJ, Shields AL, Shiffman S. Equivalence of electronic and paper-and-pencil administration of patient-reported outcome measures: a meta-analytic review. *Value Health* 2008;11:322–333.
- Marshall S, Haywood K, Fitzpatrick R. Impact of patient-reported outcome measures on routine practice: a structured review. *J Eval Clin Pract* 2006;12:559–568.
- Espallargues M, Valderas JM, Alonso J. Provision of feedback on perceived health status to health care professionals: a systematic review of its impact. *Med Care* 2000;38:175–186.
- Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ* 2009;339:b2535.
- Smith SC, Cano S, Lamping DL, et al. Patient-reported outcome measures (PROMs) for routine use in treatment centres: recommendations based on a review of the scientific evidence. Final report to the Department of Health. 2005. Available at: <https://www.lshtm.ac.uk/php/hsrp/research/promsnickblack2005.pdf>. Accessed December 2013.
- Boyce MB, Browne JP. Does providing feedback on patient-reported outcomes to healthcare professionals result in better outcomes for patients? A systematic review. *Qual Life Res* 2013;22:2265–2278.
- Terwee C, Jansma E, Riphagen I, et al. Development of a methodological PubMed search filter for finding studies on measurement properties of measurement instruments. *Qual Life Res* 2009;18:1115–1123.
- Sladek R, Tieman J, Fazekas BS, et al. Development of a subject search filter to find information relevant to palliative care in the general medical literature. *J Med Libr Assoc* 2006;94:394–401.
- Cook AM, Finlay IG, Edwards AGK, et al. Efficiency of searching the grey literature in palliative care. *J Pain Symptom Manage* 2001;22:797–801.

27. Patrick DL, Burke LB, Powers JH, et al. Patient-reported outcomes to support medical product labeling claims: FDA perspective. *Value Health* 2007;10(Suppl 2):S125–S137.
28. Arain M, Campbell MJ, Cooper CL, et al. What is a pilot or feasibility study? A review of current practice and editorial policy. *BMC Med Res Methodol* 2010;10:67.
29. Preston NJ, Fayers P, Walters SJ, et al. Recommendations for managing missing data, attrition and response shift in palliative and end-of-life care research: part of the MOR-ECare research method guidance on statistical issues. *Palliat Med* 2013;27:899–907.
30. Edwards A, Elwyn G, Hood K, et al. Judging the ‘weight of evidence’ in systematic reviews: introducing rigour into the qualitative overview stage by assessing signal and noise. *J Eval Clin Pract* 2000;6:177–184.
31. Higginson IJ, Finlay I, Goodwin DM, et al. Do hospital-based palliative teams improve care for patients or families at the end of life? *J Pain Symptom Manage* 2002;23:96–106.
32. Rodgers M, Sowden A, Petticrew M, et al. Testing methodological guidance on the conduct of narrative synthesis in systematic reviews: effectiveness of interventions to promote smoke alarm ownership and function. *Evaluation* 2009;15:49–73.
33. Kastner M, Makarski J, Hayden L, et al. Making sense of complex data: a mapping process for analyzing findings of a realist review on guideline implementability. *BMC Med Res Methodol* 2013;13:112.
34. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006;332:515–521.
35. Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993;85:365–376.
36. Bruera E, Kuehn N, Miller MJ, et al. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991;7:6–9.
37. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. *Palliative Care Core Audit Project Advisory Group. Qual Health Care* 1999;8:219–227.
38. Detmar SB, Muller MJ, Schornagel JH, et al. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. *JAMA* 2002;288:3027–3034. [Erratum appears in *JAMA* 2003;289:987].
39. Davis K, Yount S, Del Ciello K, et al. An innovative symptom monitoring tool for people with advanced lung cancer: a pilot demonstration. *J Support Oncol* 2007;5:381–387.
40. Takeuchi EE, Keding A, Awad N, et al. Impact of patient-reported outcomes in oncology: a longitudinal analysis of patient-physician communication. *J Clin Oncol* 2011;29:2910–2917.
41. Yount SE, Rothrock N, Bass M, et al. A randomized trial of weekly symptom telemonitoring in advanced lung cancer. *J Pain Symptom Manage* 2014;47:973–989.
42. Kornblith AB, Dowell JM, Herndon JE, et al. Telephone monitoring of distress in patients aged 65 years or older with advanced stage cancer: a Cancer and Leukemia Group B study. *Cancer* 2006;107:2706–2714.
43. Rosenbloom SK, Victorson DE, Hahn EA, et al. Assessment is not enough: a randomized controlled trial of the effects of HRQL assessment on quality of life and satisfaction in oncology clinical practice. *Psychooncology* 2007;16:1069–1079.
44. Nicklasson M, Elfström ML, Olofson J, et al. The impact of individual quality of life assessment on psychosocial attention in patients with chest malignancies: a randomized study. *Support Care Cancer* 2013;21:87–95.
45. Mills ME, Murray LJ, Johnston BT, et al. Does a patient-held quality-of-life diary benefit patients with inoperable lung cancer? *J Clin Oncol* 2009;27:70–77.
46. Velikova G, Booth L, Smith AB, et al. Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. *J Clin Oncol* 2004;22:714–724.
47. Velikova G, Keding A, Harley C, et al. Patients report improvements in continuity of care when quality of life assessments are used routinely in oncology practice: secondary outcomes of a randomised controlled trial. *Eur J Cancer* 2010;46:2381–2388.
48. McMillan SC, Small BJ, Haley WE. Improving hospice outcomes through systematic assessment. *Cancer Nurs* 2011;34:89–97.
49. Chih MY, DuBenske LL, Hawkins RP, et al. Communicating advanced cancer patients’ symptoms via the Internet: a pooled analysis of two randomized trials examining caregiver preparedness, physical burden, and negative mood. *Palliat Med* 2013;27:533–543.
50. Gilbert JE, Howell D, King S, et al. Quality improvement in cancer symptom assessment and control: the Provincial Palliative Care Integration Project (PPCIP). *J Pain Symptom Manage* 2012;43:663–678.
51. Lind L, Karlsson D. Electronic patient-reported symptom assessment in palliative end-of-life home care. *Health Syst* 2013;2:171–180.
52. Chang CH, Cella D, Masters GA, et al. Real-time clinical application of quality-of-life assessment in advanced lung cancer. *Clin Lung Cancer* 2002;4:104–109.
53. Abernethy AP, Herndon JE, Wheeler JL, et al. Feasibility and acceptability to patients of a longitudinal system for evaluating cancer-related symptoms and quality of life: pilot study of an e-/Tablet data-collection system in academic oncology. *J Pain Symptom Manage* 2009;37:1027–1038.
54. Dubben HH, Beck-Bornholdt HP. Systematic review of publication bias in studies on publication bias. *BMJ* 2005;331:433–434.
55. Connor S, Bermedo M, eds. *Global Atlas of Palliative Care at the End of Life*. London: Worldwide Palliative Care Alliance, 2014. Available at: http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf. Accessed June 2014.
56. Cicely Saunders Institute. *The Outcome Assessment and Complexity Collaborative (OACC)*. 2013. Available at: <http://www.csi.kcl.ac.uk/oacc.html>. Accessed June 2014.