

## 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. All rights reserved.

## 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 measures<sup>1</sup> 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.<sup>2</sup> 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.<sup>3</sup> These improve emphasis on person-centered care.

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Because of their patient-centered nature, PROMs are increasingly used in palliative care.<sup>4</sup> 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,<sup>5</sup> 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.<sup>6,7</sup> 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.<sup>8</sup> Patient-centeredness has been highlighted by previous authors as key to outcome measurement in palliative care.<sup>9,10</sup> 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.<sup>11</sup> 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.<sup>12,13</sup> 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,<sup>14–17</sup> 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.<sup>11</sup> 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,<sup>18</sup> 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,<sup>12,19,20</sup> 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.<sup>21</sup>

### Search Strategy

Our search strategy (reported in [Figure 1](#) in accordance with the PRISMA guidelines<sup>21</sup>) 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<sup>22–24</sup> 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.<sup>25</sup> As outcome measurement was defined in 1980<sup>1</sup> and PCOMs began to be used in the late 1980s, we excluded articles published before 1985, as previous work has done.<sup>11</sup> 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.<sup>25</sup> Therefore, we hand searched both reference and citation lists of relevant articles to identify further articles

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