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## The Potential Role of Symptom Questionnaires in Palliative and Supportive Cancer Care Delivery

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### Abstract

**Purpose of Review**—The American Society of Clinical Oncology (ASCO) palliative care recommendations have been updated into a full guideline. Symptom questionnaires—completed and reviewed with patients during care delivery—are poised to play a large role in this guideline because they provide a more comprehensive understanding of symptoms. This article provides an overview of the guideline and describes how symptom questionnaires can be used to satisfy the guideline.

**Recent Findings**—Standardized symptom questionnaires can be used for three purposes in care delivery: symptom management, referral to specialty palliative and supportive care, and to assess high-quality care. Challenges include necessary changes to clinic workflow to collect patient responses and respond to electronic alerts for worsening symptoms.

**Summary**—Symptom questionnaires administered as part of routine care delivery are highly informative and worth the time to enhance symptom management in routine care, to increase referrals, and to standardize performance metrics.

### Keywords

Quality of healthcare; Patient-centered outcomes research; Patient-centered care; Patient outcome assessment; Clinical oncology; Healthcare delivery; Quality of life

### Introduction

There is an international interest in integrating symptom questionnaires into routine cancer care delivery. This interest is particularly timely for palliative and supportive care in the USA because the American Society of Clinical Oncology (ASCO) palliative care

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#### Compliance with Ethical Standards

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recommendations were recently updated into a full guideline [1••]. The guideline is intended to enhance assessment and ongoing management of symptom burden in routine care. Clinicians will also have a clearer understanding of when cancer patients need to be referred to specialty palliative or supportive care. A third benefit is standardized metrics for assessing high-quality care for both routine and specialty palliative care. Symptom questionnaires are poised to play a large role in ASCO's palliative care guideline because they can serve as a conduit to achieving all three of these goals.

ASCO's palliative care guideline was developed by an expert steering committee of over 30 multidisciplinary panelists, including medical oncologists from different geographic regions and practice types and sizes, medical oncology societies, cancer patient advocate groups, and representatives from ASCO and the American Academy of Hospice and Palliative Medicine (AAHPM) [1••]. Literature searches were conducted and published frameworks were reviewed, such as the National Consensus Project for Quality Palliative Care [2]. Panelists rated over 900 palliative care service items on their importance for high-quality palliative care, feasibility, and scope within medical oncology practice [1••]. The committee selected nine domains including:

- Appropriate Specialty Palliative Care and Hospice Referral
- Coordination and Continuity of Care
- Communication and Shared Decision-Making\*
- Symptom Assessment and Management
- Psychosocial Assessment and Management
- Spiritual and Cultural Assessment and Management
- Advance Care Planning\*
- Carer Support (Distress)
- End-of-Life Care\*

ASCO's steering committee also recommended general metrics within each domain for assessing whether high-quality palliative care was provided. For instance, in the "Appropriate Palliative Care and Hospice Referral" domain, one performance metric is that oncology clinicians should describe the difference between palliative care and hospice to patients and caregivers and benefits and drawbacks [1••].

The largest domain is the foundation of palliative and support care, Symptom Assessment and Management. It includes 22 different symptoms, physical function, and chemotherapy-related toxicities reported by Patient-Reported Outcome measures (PROMs). "PROMs" is an umbrella term encompassing questionnaires completed by patients about their symptoms, quality of life, or experiences with care. PROMs are directly reported by patients without interpretation by a clinician or anyone else [3]. In this article, we focus specifically on

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\*The domains with the highest consensus included end-of-life care, communication and shared decision-making, and advanced care planning.

symptom questionnaires reported by oncology patients during routine care delivery for the purpose of review by their clinician.

In the next sections, we show how symptom questionnaires could be used to satisfy three parts of ASCO's guideline: ongoing symptom assessment and management in routine care, appropriate referral to specialty palliative care through the use of questionnaire cutoff scores, and performance metrics for both routine and specialty palliative and supportive care.

## How Symptom Questionnaires Can Be Used for Symptom Assessment and Management in Routine Care

In the case of symptom assessment and management in routine care, the ASCO steering committee recommends that all symptoms be assessed (including a basic psychosocial and distress assessment), with increased attention to common symptoms such as nausea. Clinicians are also advised to (1) educate patients and caregivers about the cause and management of their symptoms and (2) assess the patient's response to adjusted medication or other treatments by the next clinical encounter [1••].

Symptom questionnaires are a natural fit for communication with patients and other providers and for assessing treatment response. Clinicians [4, 5] and cancer patients [4, 6] generally find symptom questionnaires to be useful and valuable during care delivery. They have been shown to enhance communication between patients and clinicians and increase patient engagement in decision-making [7–9, 10••, 11]. Costly hospital readmissions also decrease when standardized symptom questionnaires are completed systematically [12••], perhaps because clinicians are alerted to worsening symptoms sooner and can change treatment plans. Finally, cancer patients report better quality of life [7–11, 12••] and higher satisfaction with care [13] when they complete symptom questionnaires, and clinicians review the answers with them during visits.

Notably, ASCO's panel was not asked to endorse specific standardized questionnaires to use during routine palliative and supportive care. This is likely because there is no consensus about which symptom questionnaires to use [14]. There are at least 85 symptom questionnaires available in the palliative medicine and PROMs literatures [14, 15]. This points to a need for a systematic review (with expert and patient input) to identify and rate existing symptom questionnaires. For example, symptom questionnaires could be rated on their validity, reliability, psychometric performance, brevity, whether the symptom questionnaire was developed with patient input, and whether patients find the questions to be meaningful and comprehensible. ASCO and the AAHPM may also be able to provide guidance on using a limited number of symptom questionnaires with good psychometric properties to promote consistency and equivalence across practices.

It will also be important for ASCO and AAHPM to educate practices and clinicians that different symptom questionnaires may be needed for the purposes of symptom assessment and management, referral to specialty care, and performance metrics. For instance, a patient's initial questionnaire would ideally cover a broad range of symptoms, including the 12 common symptoms recommended by the National Cancer Institute [16]. The National

Institute of Health's Patient-Reported Outcomes Measurement Information System (PROMIS) measures are standardized, general questionnaires assessing physical, mental, and global health across a variety of health conditions [17]. PROMIS measures are being tested for clinical use [17]. For symptom management, a cancer-specific symptom questionnaire may be more informative, such as the National Cancer Institute's PRO-CTCAE [18, 19] or the European Organization for Research and Treatment of Cancer QLQ-C30 quality-of-life instrument [20]. Research is also needed to determine which symptom questionnaires (general and/or cancer-specific) are better suited as performance metrics.

General and cancer-specific symptom questionnaires have both pros and cons that practices and healthcare systems will need to carefully consider before implementation [21–23]. Practices should also anticipate necessary changes to clinic workflow and EHR systems to collect and store patient responses and to respond to alerts for worsening symptoms [21–23].

## How Symptom Questionnaires Can Be Used for Referrals to Specialty Palliative Care

Symptom questionnaires can provide a standardized approach to specialty palliative and supportive care referral through the use of cutoff thresholds. For instance, a current guideline for referral to psycho-oncology services for depression is a cutoff score of 8 on the 9-item Patient Health Questionnaire (PHQ-9) [24, 25]. For example, a cancer patient completes the PHQ-9 in the waiting room and scores a 20, which exceeds the cutoff of 8 necessary for a psycho-oncology referral. Her PHQ-9 answers trigger an alert in the EHR for the nurse (and potentially the physician) who further assess the patient's depressive symptoms during the encounter. She is referred to a specialty palliative care clinician in the same healthcare system either through an automated referral or a direct referral from the nurse and/or physician. Depending on the resources of the healthcare system, the patient sees the psycho-oncology care specialist in a timely manner and has an in-depth assessment for a depressive disorder. She is prescribed an antidepressant that is concordant with her chemotherapy regimen and a note is added to the EHR that is fed back to the original nurse and physician. The patient is reevaluated for depression during every clinic visit with the goal of remitting symptoms by 3 months (score of <8 on the PHQ-9). All of these steps toward better quality and more personalized care for the patient started with a symptom questionnaire and standardized cutoff scores.

However, the ASCO committee did not recommend specific symptoms questionnaires to use for specialty palliative and supportive care referrals. A second systematic review is needed to determine which high-performing symptom questionnaires can validly and reliably predict which cancer patients need to be referred to specialty palliative and supportive care versus those that can be managed in routine care. Additionally, a systematic review could identify typical cutoff scores for common symptom questionnaires to use as thresholds for referrals.

## Shifting Toward a Palliative Care Model Where Symptoms Are Assessed in Between Visits

The typical model where patients complete symptom questionnaires in the waiting room at visits may need to be adapted to improve palliative and supportive care delivery. Instead of asking patients to report on their symptoms at clinic visits, a better model for high-quality palliative care may be to ask cancer patients to report on their symptoms at home *in between visits*. We know that recall biases start as soon as a few days [26, 27], and thus symptom reporting at visits may mean that symptoms are missed or underreported. Additionally, clinicians and healthcare teams generally underestimate patients' symptoms [28–30], suggesting that a more standardized approach to symptom assessment is warranted. For example, when cancer patients and clinicians rate the patient's frequency and intensity of symptoms, the correlation is very low [28–30].

Data from a randomized trial suggests that weekly symptom reporting from home (via the web or through interactive voice response using their telephone) leads to better patient quality of life, avoids emergency department and hospital readmissions, and may lengthen survival for patients with advanced cancers who are receiving chemotherapy for palliative intent [12••]. Notably, the intervention benefit for weekly symptom reporting was more pronounced for patients without prior computer experience [12••], perhaps because the symptom questionnaire helped the patient and clinician to communicate better.

A large RCT funded by the Patient-Centered Outcomes Research Institute (PCORI) is examining whether these positive results obtained in an academic medical center generalize to community practices [31].

Fifty community oncology practices are being randomized to determine whether patient outcomes improve when advanced cancer patients complete weekly symptom questionnaires at home (online or interactive voice response) [31]. In the trial's intervention arm, patients receiving chemotherapy self-report weekly on 12 common symptoms [16] from the National Cancer Institute's validated PRO-CTCAE symptom measure [18, 19]. Weekly symptom reporting continues up to 12 months. Email alerts are triggered to nurses when patients report severe or worsening symptoms. Nurses in the intervention arm are also provided with evidence-based symptom management recommendations tailored to the burdensome symptom(s) that patients report. Patients in the intervention arm are also provided with self-management strategies tailored to the symptoms they are experiencing [31]. The control arm is usual care enhanced with nurses and patients receiving general symptom management recommendations and self-management strategies (but there is no self-reporting of symptoms) [31]. Key outcomes include physical function, quality of life, survival, ER/hospital visits, and perspectives about relative benefits and burdens from patients, clinicians, and national organizations [31]. The trial is in the start-up phase with recruitment opening anticipated for the fall of 2017.

## How Symptom Questionnaires Can Be Used as Performance Metrics in Palliative Care

Symptom questionnaires could also be used as a performance metric in and of themselves. This idea of evaluating the quality of care delivery with symptom questionnaires is a shift in ideology from typical performance metrics such as mortality and hospital readmissions [32, 33]. Symptom questionnaires are a more patient-centered approach to assessing quality of care that captures what is important to patients and other stakeholders. In the future, this may mean that adults with cancer and caregivers who are making treatment decisions will have access to public reports describing how well clinicians and healthcare teams controlled their prior patients' symptoms and maintained quality of life. For instance, adults making treatment decisions could compare practices on the percentage of prior patients who reported burdensome nausea. High-quality care would be defined as a low percentage of chemotherapy patients reporting burdensome nausea.

However, before performance metrics based on symptom questionnaires can be implemented in practice, research is needed to develop the methodology for fair reporting. For instance, a multisite study is underway to determine whether scores from symptom questionnaires can be meaningfully and fairly compared across similar cancer practices as a performance metric [34]. The "Patient-Reported Outcomes-Based Performance Measures" (PRO-PM) study grew out of work conducted by ASCO's PRO Workgroup that developed a framework for creating and testing patient-reported performance metrics [35]. One goal of the PRO-PM study is to determine adjustment variables at the patient, clinician, and healthcare system levels to fairly compare practices. Adjustment variables will be selected based on empirical data and input from stakeholders such as patient investigators, clinicians, state and national stakeholders [36], healthcare administrators and quality officers, and researchers with expertise in health services research and PROMs.

The PRO-PM study feasibility testing will be occurring in six healthcare systems [34], with an eye toward national dissemination. Anticipated uptake is expected to be high, as national organizations are interested in using symptom questionnaires as performance metrics [35] and patients increasingly seek information about how they will "feel and function" as part of decision-making. One symptom important to patients is nausea during chemotherapy, and thus it is being tested as a performance metric in the PRO-PM study. Nausea is a common symptom reported during chemotherapy [37, 38] and is actionable in that clinicians can prevent and treat it with treatment modifications. Additionally, there are explicit guidelines for how to prevent nausea [39]. These characteristics make it likely that a patient-reported nausea score will be a performance metric in future oncology practice.

In the past, performance metrics were developed without consideration of how quality of care is perceived by patients themselves due to time pressures and lack of input from patient stakeholders. The PRO-PM study included a variety of stakeholders (including patient investigators) to assure that the developed methodology is meaningful and captures what is important to patients and clinicians and other stakeholders, scientifically rigorous, and widely applicable. Testing is ongoing and results are expected in 2–3 years.

## Summary

In summary, benefits of using symptom questionnaires during care delivery include a better understanding of a patient's symptoms (e.g., nausea), including the frequency, intensity, and extent of interference with everyday activities. Standardized symptom questionnaires can be used for three purposes in palliative and supportive care: symptom assessment and management in routine care, referral to specialty palliative and supportive care clinicians, and as a performance metric for assessing high-quality care. Challenges for palliative care include identifying the best PROMs to use for symptom assessment, management, and palliative care referral and implementing symptom questionnaires into routine workflow and EHR systems.

## Conclusion

Symptom questionnaires administered as part of routine care delivery are highly informative and worth the time to enhance symptom management in routine care, to increase specialty palliative and supportive care referrals, and to standardize performance metrics.

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