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Author manuscript

J Oncol Pract. Author manuscript; available in PMC 2017 October 01.

Published in final edited form as:

J Oncol Pract. 2016 October ; 12(10): 859–862. doi:10.1200/JOP.2016.015610.

Implementation of Symptom Questionnaires Into Oncology Workflow

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Treatment-related symptoms are common among patients with metastatic cancer and can result in distress, decrements in physical function, and unplanned hospitalizations.^{1,2} Symptom management is a cornerstone of clinical practice, and both symptom management and quality of life are consistently among the highest priorities to patients with cancer and their caregivers.^{3,4} Typically, clinicians elicit symptom information at clinic visits through unstructured discussions. However, with this approach, care teams do not detect burdensome symptoms up to one half of the time, and clinicians' symptom ratings have low reliability.^{5–7} Under detection of symptoms occurs for several reasons. Visits with clinicians may be too infrequent or too short to adequately capture symptom burden. Patients may have trouble recalling how frequent or burdensome their symptoms have been in between visits due to recall bias.^{8,9} Communication between clinicians and patients may be hampered by status and educational differences, language barriers, expectations about clinical encounters, lack of trust, not feeling well, and more.^{10,11}

One solution is to systematically screen for symptoms between visits by asking patients to complete weekly patient-reported outcome (PRO) measures about their pain, nausea, and other symptoms. PRO measures are the preferred approach for assessing symptoms across health care contexts because patients are in the best position to report on their own experiences and because PROs provide a more comprehensive understanding of those experiences.¹² Routine use of PROs has been identified as a priority area by the President's Cancer Panel and national oncology societies such as ASCO.^{13,14} However, health care systems lack roadmaps for how to change multiple system levels and infrastructures to integrate PRO measures into clinical workflow, which is an implementation problem. Thus, a critical need exists for comprehensive implementation strategies that address barriers and strengthen facilitators unique to each health care system.

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Authors' Disclosures of Potential Conflicts of InterestDisclosures provided by the authors are available with this article at jop.ascopubs.org.**Implementation of Symptom Questionnaires Into Oncology Workflow**

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No relationship to disclose

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A growing body of evidence shows that the collection of PRO measures from patients and their review during visits yield better clinical outcomes. For example, use of symptom questionnaires increases communication between clinicians and patients, detection of problematic symptoms, and satisfaction with care.^{15–18} In a single-site randomized trial in the United States, > 700 patients who underwent chemotherapy were randomly assigned to complete weekly Web-based symptom questionnaires versus usual care. Patients in the intervention group who systematically completed symptom questionnaires were more likely to be alive at 1 year, were able to continue with treatment longer, and had fewer emergency department visits.¹⁹ Treating physicians received symptom reports at visits, and nurses received e-mail alerts when patients reported a worsening of 12 common symptoms (ie, predetermined clinical criteria were met). The PRO intervention showed the greatest benefits for patients with lower education and less computer experience,¹⁹ which suggests that health disparities could be reduced with PRO integration into clinical workflow.

A second phase III randomized trial in Europe was closed early for clear survival benefit for the intervention group, which completed weekly symptom questionnaires. At multiple sites, patients with metastatic lung cancer randomly assigned to complete weekly symptom questionnaires had a mean survival time of 19 months versus 12 months in usual care patients.²⁰ Similar benefits have been shown in other randomized trials.^{21–24} The probable mechanism at work is that clinicians were made aware of symptom increases sooner and could then intervene earlier to avoid adverse and costly outcomes.

As more trials demonstrate efficacy and the idea of patient-centered care matures,^{25,26} incorporation of symptom questionnaires into routine clinical workflow will become increasingly important for health care systems. Every US health care system faces this issue as the Centers for Medicare & Medicaid Services Electronic Health Record Incentive Program's meaningful use requirements continue to increase annually.²⁷ National (and international) oncology societies, federal agencies, and individual health care systems have a major opportunity to plan and implement a rollout of system-level changes over the next 5 years to ensure that PROs are integrated into routine clinical workflow. This may require an evolution of organizational culture to emphasize the importance of PROs and adaption of electronic health record systems.

National oncology and PRO methodology societies and federal agencies have published recommendations for questionnaire implementation, but no comprehensive plans have been put forward. For instance, the International Society of Quality of Life Research²⁸ and Snyder et al²⁹ outlined a series of starter questions that health care systems can use to self-assess their unique needs for PRO implementation planning. Similarly, the Department of Veterans Affairs has several recommendations for designing applications to capture patient-generated data to enhance patient-clinician partnerships, including health system culture, data value, architecture, policy, data standards, clinical workflow, data visualization, and analytics and population reach.³⁰

The National Cancer Institute recommends that the following 12 common symptoms be assessed across cancer types during clinical trials: fatigue, insomnia, pain, anxiety (includes worry), depression (includes sadness), anorexia (appetite loss), nausea, constipation,

diarrhea, dyspnea, cognitive problems, and sensory neuropathy.³¹ The idea is that practices can assess common symptoms and decide on additional PRO areas relevant for each cancer type.^{32,33} For instance, bladder and bowel issues are relevant in prostate and colorectal cancer but less relevant in breast cancer. At least one systematic review is needed that identifies all PRO and quality-of-life measures (general and disease specific) and then provides a menu of the best-performing scales in oncology practice. Oncology societies and federal agencies then can provide guidance on how to choose PRO measures so that results are comparable across health care systems.

This collection of recommendations is an excellent start to implementation planning, but more work that focuses on systems-level changes is needed. A newer field, implementation science, can guide societies, agencies, and health care systems to start to think through solutions to the system barriers they will face.^{34–36} Implementation strategies typically encompass six key stages: planning, educating, financing, restructuring, managing quality, and attending to the policy context.³⁷ For the planning and educating stages, the involvement of all potential stakeholders, including patients, clinicians, practice staff, decision makers, quality officers, financial officers, informaticians, PRO methodologists, health services and researchers, will be critical. Health care innovation changes typically take 2 to 4 years for full implementation³⁸; thus, planning should start early. Research on multidisciplinary teams with skill sets in clinical care, informatics, PRO methodology, and implementation science is needed to develop and evaluate comprehensive implementation plans that are sustainable.

Broad-level guidance is needed from societies and federal agencies, but each health care system and practice will need tailored implementation strategies that fit their unique needs. Implementation measures for health care have advanced significantly over the past 20 years.^{39–42} Interdisciplinary research teams will be able to map implementation process and outcome measures to the challenges specific to PRO integration. More useful results will be obtained if research teams evaluate implementation strategies simultaneously at multiple levels (eg, patient, provider, care team workflow, medical record system) rather than treat them as separate interventions.⁴² In 6 to 8 years, this new field should be ready to develop cluster randomized trials with head-to-head comparisons of various implementation strategies to examine what works best in which context and for whom.

Three final issues that health care systems and research teams will need to consider are flexible workflows that allow for future change, the training of care team members on how to use PRO measures, and reduction of clinician burden. The idea of learning health care systems is that they continually improve processes as more data emerge from within the health care system itself and as national guidelines are updated for high-quality cancer care.⁴³ In other words, health care systems need to not only learn implementation strategies but also be flexible enough to de-adopt low-value clinical procedures that are no longer recommended or do not perform well in some contexts.⁴⁴ A key piece to flexible workflows is the training of clinicians and staff on how to interpret PRO results for the specific questionnaires chosen and the best ways to discuss results with patients. PRO training could be incorporated into existing training needs, such as the Commission on Cancer's training recommendation for interpreting psychosocial distress measures.⁴⁵ This is one area where

oncology societies could make a big difference in ensuring high-quality training in PRO measures for clinical practice.

The redesign of clinical workflow also allows the opportunity to consider pieces that are no longer relevant in favor of adding PRO implementation. For example, clinicians spend a considerable amount of time in documenting quality performance measures.⁴⁶ A lesser known benefit of integrating PRO measures into clinical workflow is that PRO results could be quality metrics in and of themselves.^{47,48} For example, similar practices could be compared on the percentage of patients who receive chemotherapy who report moderate to high pain.⁴⁶⁻⁴⁸ In this case, clinicians may be able to reduce performance metric documentation because PRO results would be available for practice comparisons. An emerging research issue in this area is which variables to adjust for to ensure fair comparisons (case-mix and risk adjustment).⁴⁸

In summary, five key areas should be considered for comprehensive implementation planning of PRO integration into health care systems:

- A menu of implementation strategies that overcomes not only barriers that most systems face but also barriers and facilitators unique to each system;
- Multidisciplinary teams with all potential stakeholders represented during the planning and educating stages to ensure sustainability;
- Flexible workflows that allow for future implementation and de-adoption of low-quality care;
- Careful consideration about the best ways to reduce burden on clinicians when changing workflow; and
- Training for clinicians and staff on PRO interpretation and how to discuss results with patients.

Acknowledgments

The production of this manuscript was funded by the Conquer Cancer Foundation Mission Endowment. Supported by Grant No. R25-CA116339 from the Cancer Care Quality Training Program and Grant No. R25-CA171994 from the Mentored Training in Dissemination and Implementation in Cancer project. We thank Leah Zullig, David Chambers, and Ramzi Salloum for reading a prior draft.

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