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Commentary: Encouraging Clinicians to Incorporate Longitudinal Patient-Reported Symptoms in Routine Clinical Practice

By *Ethan Basch, MD, and Amy P. Abernethy, MD*

The previously ubiquitous clipboards that patients were once handed on entrance to physicians' waiting rooms are being replaced in many practices with web portals, with the expectation that patients will complete online questionnaires before visits. These questionnaires typically ask patients about their past medical history, current medications, allergies, risk factors, insurance information, and other baseline health or administrative data best obtained directly from patients. But it is far less common to use questionnaires for longitudinal tracking of patient health status, for example, to track symptoms, quality of life, functional status, satisfaction with care, or medication compliance.

Why wouldn't we routinely elicit such information from patients over time? After all, it is known that clinicians tend to underestimate the severity and prevalence of patients' symptoms and functional status problems¹; that patients are more likely to disclose "private" symptoms such as gynecologic or urinary problems via computer²; and that including self-reporting in routine practice leads to better symptom control, improved quality of life, enhanced patient-clinician communication, and higher patient satisfaction with care.³⁻⁷ Furthermore, the clinical "review of systems" is not only a standard part of the clinical exam that provides insight into evolving clinical problems and chemotherapy toxicity; its comprehensiveness directly contributes to the level for coding and billing of third-party payors. Longitudinal monitoring of patient health status forms the foundation of good care.

In oncology, longitudinal tracking of patient symptoms and health status has been found to be feasible even among patients with end-stage disease and heavy symptom burdens.^{2,3,8} Patients like longitudinal tracking and see it as an indication that their doctors care.² Moreover, oncologists feel that this is clinically actionable information that accurately reflects true patient status,⁹ and they will hold or reduce dosage of chemotherapy on the basis of patient-reported information.¹⁰

In clinical trials, it is common for serial assessments of patient-reported symptoms and health status to be collected to understand the patient subjective experience with treatment. Recently, the Food and Drug Administration issued a guidance document indicating that for subjective experiences such as symptoms, patient reporting, rather than clinician documentation, should be considered the standard approach for reporting information.¹¹

Given that patient self-reporting has demonstrated benefits, has been shown to be feasible, is common in trials, contributes to patient satisfaction, maximizes billing, and is increasingly affordable as technologies for self-reporting become cheaper, why wouldn't all patients in all practices self-report their own symptoms? Aside from benefits in symptom control and communication, clinicians would save time if patients self-reported information that otherwise would have to be elicited verbally by a doctor or nurse.

In fact, several oncology practices have been collecting patient-reported symptoms and health status information via elec-

tronic interfaces for some time. The West Clinic in Memphis, TN, has been handing out tablet computers to patients for many years, via which a review of symptoms is completed. This information is imported into patients' medical charts, including longitudinal, color-coded reports with symptom changes over time for oncologists and nurses to review at visits. Among academic centers, Duke Comprehensive Cancer Center, Memorial Sloan-Kettering Cancer Center, Johns Hopkins, and M.D. Anderson Cancer Center have similarly implemented systems to electronically track patient status over time, in some cases including between-visit reporting via the Internet or automated telephone systems. And now in-clinic online reporting is being used across oncology practices in Ontario, Canada.

But a perpetual concern in the development and use of such systems is clinician acceptance and adoption of this patient-reported information. It is essential that this information be integrated into existing workflows and not create new work for clinicians. It has consistently been found that nurses tend to review and use patient-reported information more commonly than physicians, as noted in the study reported by Bainbridge et al¹² in this issue of *Journal of Oncology Practice*. Nurses appear to be more attuned to patients' symptoms, are more engaged in day-to-day symptom control, and have more time to devote to supportive care. Although there is no lack of compassion among oncologists, they are more focused on overall disease trajectory, imaging and other test results, and treatment decisions. In other words, patient self-reporting of symptoms fits more logically into the existing workflow of nurses than that of physicians.

There also appears to be a cultural bias among nurses in favor of patient self-reporting, whereas the opposite holds true among physicians: only approximately half of the physicians interviewed in the Bainbridge et al¹² survey felt this approach would enhance patient care, help patients articulate symptom concerns, and facilitate clinical follow-up. The physicians often stated that they would rather assess symptoms on their own and were too busy to review patient self-reported information.

On the basis of these findings, to what extent should patient-reporting systems be designed to cater to existing workflows and cultural biases versus being used to overcome them? This is a rhetorical question. The reality is that these systems will likely increasingly be installed in large community practices and academic centers as components of patient portals or electronic health records. Consumers are becoming accustomed to communicating electronically in most areas of their lives, and providing such communication with patients will come to be an expected part of care delivery. As these systems are increasingly installed, it is likely that on the provider side they will be used most commonly by nurses. However, we suspect that as patient self-reports become better integrated into electronic health records and thus more able to support medical chart documentation, physicians will come to use and appreciate this information (as many have at the above-mentioned practices in which this approach has been in place for several years).

Notably, an older questionnaire and technology interface were used for the initial Ontario implementation described by Bainbridge et al.¹² We suspect that integration of a more cur-

rent symptom screening tool such as the PRO-CTCAE (Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events) and a newer technology interface for the next iteration of this project would improve acceptance and compliance rates among both patients and clinicians.

There are broader societal benefits to collecting longitudinal patient-reported information about symptoms and health status. Such data can be aggregated to provide information about the comparative effectiveness of treatments, to detect unexpected postmarket toxicities, to measure quality of care, to develop prediction models, and to support rapid learning health systems.^{1,2,13}

Rather than focus on the potential negative message of the Bainbridge et al¹² findings about physician acceptance, the overwhelming positive response of nurses and overall success of the Ontario program are perhaps more worthy of note. The vision and initiative of oncology practices across Ontario in simply implementing a patient reporting system represents a major advancement toward bringing the patient perspective into the longitudinal management of cancer. As technology, electronic record systems, and patient questionnaires become more sophisticated, we expect that the Ontario vision will transition to being considered "just good care."

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