Physician Perspective on Incorporation of Oncology Patient Quality-of-Life, Fatigue, and Pain Assessment Into Clinical Practice

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Abstract

Purpose: Patient-reported outcomes (PROs) such as pain, fatigue, and quality of life (QOL) are important for morbidity and mortality in patients with cancer. Systematic approaches to collect and incorporate PROs into clinical practice are still evolving. We set out to determine the impact of PRO assessment on routine clinical practice.

Methods: Beginning in July 2010, the symptom assessment questionnaire (SAQ) was administered to every patient in a solid tumor oncology practice at an academic center. The SAQ measures pain, fatigue, and QOL, each on a scale of 0 to 10 points. Results were available to providers before each visit in the electronic medical record. Eighteen months after the SAQ was implemented, an online survey was sent to 83 oncology care providers regarding the use of the SAQ and how it affected their

clinical practice, including discussion with patients, duration of visits, and work burden.

Results: A total of 53% of care providers completed the online survey, producing 44 evaluable surveys. Of these, 86% of care providers reported using information from the SAQ; > 90% of care providers indicated the SAQ did not change the length of clinic visits or contribute to increased work burden. A majority of care providers felt that the SAQ had helped or enhanced their practice. Providers endorsed the SAQ for facilitating communication with their patients.

Conclusion: This study indicates that simple single-item measures of pain, fatigue, and QOL can be incorporated into oncology clinical practice with positive implications for both patients and physicians without increasing duration of visits or work burden.

Introduction

Patient-reported outcome (PRO) instruments capture the impact of disease and/or treatment on patients' perspectives concerning their daily function.¹ PRO data elements not only facilitate communication between patients and clinicians but also convey proven prognostic information.²⁻⁴ Specifically, patient-reported pain, fatigue, and overall quality of life (QOL) have been demonstrated to be important regarding morbidity and mortality in patients with cancer.⁵⁻⁹ However, the ideal methods to capture these subjective measures and incorporate them into clinical practice are not universally established.¹⁰ Most importantly, the clinical significance of the information that PROs impart in ongoing clinical management is still largely unknown.

The best example of PRO utility in clinical practice is demonstrated by the usefulness of patient-reported pain for physicians' management decisions.¹¹ Charles S. Cleeland pioneered the item that came to be known as the Brief Pain Inventory 25 years ago, assessing pain on a numeric analog scale from 0 to 10. Collection of pain scores has had a profound impact on clinical care outcomes.^{12,13} Pain scores from 0 to 4 can be considered as mild pain, not needing clinical intervention. A score of 5 to 6 is moderate, whereas scores ≥ 7 are indicative of a clinically urgent situation.^{14,15} Pain assessments have demonstrated that effective cancer pain management can have a profound impact on clinical

care^{16,17} and are required for accreditation by agencies such as the Joint Commission.

Fatigue is universally recognized as the most prevalent symptom in patients with cancer and may be reflective of the underlying malignant biologic process of malignancy and/or a result of treatment adverse effects.¹⁸ Fatigue can profoundly affect treatment compliance and outcomes.^{19,20} Similar to pain, fatigue has been demonstrated to be measurable by single-item assessments.²¹ Recent work has indicated that a score ≤ 5 on a scale of 0 to 10 points is prognostic for survival.⁹

The assessment of QOL in a clinical setting is an attempt to detect physical or psychosocial issues that might affect a patient's life and may be overlooked during routine appointments.²² QOL is a more abstract, multidimensional concept than pain or fatigue. QOL includes key aspects such as physical, psychological, intellectual/cognitive, social, and spiritual domains.^{23,24} Multiple studies have suggested that QOL is a powerful prognostic predictor of survival in hematologic and oncologic malignancies.^{6,25-27} A score ≤ 5 on a scale of 0 to 10 points has been previously validated to indicate clinically deficient QOL.²⁸⁻³⁰

Although there has been a significant increase in the collection of patient-based measures of health such as QOL and fatigue data in clinical trials, incorporating standardized PRO assessments into daily oncology practice in a way that adds value to the patient remains a challenge.³¹⁻³⁵ One of the barriers to

using PROs in clinical practice is the perception of increased work burden for the patient and clinician.³⁶ Indeed, prior studies evaluating effectiveness of QOL patient-based measures in routine oncology practice used several lengthy QOL instruments that limited their practical application in an actual practice setting.^{37,38} Another barrier to using PROs is a lack of clear guidelines on interventions for patients with poor QOL and/or increased fatigue and a lack of data showing that these interventions improve outcomes.^{39,40}

Linear Analog Self Assessment (LASA) items to measure overall QOL, fatigue, and pain on a scale of 0 to 10 have been validated as general measures of global QOL multidimensional constructs in numerous settings,^{32,33,37,38} including > 40 different clinical research studies at Mayo Clinic. These studies have indicated that the LASA measures of fatigue, pain, and QOL have prognostic implications for patients with cancer. As a result, in July 2010, the Division of Medical Oncology Clinical Practice Committee at Mayo Clinic initiated the implementation of routine QOL, fatigue, and pain data collection using three LASA items before each patient visit. Approximately 18 months after implementation of the questionnaire, a survey was sent to oncology providers in an attempt to summarize and explore the impact of the questionnaire on physician time and patient management.

Methods

Administration of the Symptom Assessment Questionnaire

The Symptom Assessment Questionnaire (SAQ) consists of three LASA items; patients rate their pain and fatigue on a scale of 0 to 10, with 10 being the worst, and rate their overall QOL on a scale of 0 to 10, with 0 being the worst (Appendix Fig A1, online only). The three questions were given to patients at the time they checked in for their appointment. They were instructed by the front desk personnel to answer the questions in relation to how they had been feeling over the past week. The patients completed the LASA items in paper-and-pencil format as they were waiting to be roomed for their appointment. When they were roomed, the clinical assistant entered the information into the electronic medical record, identical to the method for recording vital signs.

The completed questionnaire was then provided to the oncology provider (staff oncologist, oncology fellow, physician assistant, or nurse practitioner). No specific instructions on how to use the information provided on the form were given to the providers before implementing the questionnaire into clinical practice. Providers could choose to act on the information on the questionnaire at their discretion. Desk personnel were asked to bring scores > 6 to the attention of providers when patients were roomed.

Evaluation of SAQ Implementation

A brief questionnaire was given to medical oncology staff using an online survey. A standard e-mail script was sent to the 53 physicians and allied health staff in the Division of Medical

Oncology requesting their participation in the study. Results were collected anonymously. The goals of the study were as follows:

- Assess the impact on clinical practice of including real-time PRO data collection, including changing care plans, consult time, and other aspects of the patient encounter.
- Synthesize the ways in which physicians and allied health staff individually incorporate PRO data into clinical practice.

Approval for this analysis was granted by the Mayo Clinic Investigational Review Board. Statistical analysis was primarily descriptive, using percentages and means where appropriate to summarize the scores obtained and the endorsement and implementation of questions. Qualitative analysis of the qualitative data was undertaken independently by the two principal investigators to identify themes and then cross referenced.

Results

The online survey was completed by 44 (53%) of 83 oncology care providers. More than half of respondents were staff physicians (55%); 25% were fellows, and 20% were nurse practitioners or physician assistants.

Usage

The majority of responding providers (86%) reported using the information provided by the SAQ in their practice; 90% of responding providers indicated that they did typically talk to the patient about ratings of pain, fatigue, or QOL, although more than half said they did so only if an abnormal score was observed. Of those who reported not looking at the SAQ, the main reason given was that they did not think it would add to their practice style.

Cut Points

We asked the care providers what cutoff would prompt them to take action (Fig 1). More than 80% of respondents indicated that a score ≥ 4 would cause them to ask about fatigue. However, one of every three respondents indicated that the fatigue score would have to be at least 6 for them to inquire. Pain cut points were substantially lower than those for fatigue. Even a mild score for pain (ie, 0 to 4) would cause 75% of care providers to ask patients about their pain. Results for QOL were similar to those for pain scores. More than 93% of care providers indicated that a QOL score < 8 would cause them to inquire about patient QOL.

Practice Implications

More than 90% of the responding care providers indicated that the SAQ did not change the length of clinic visits, nor did it add more work. More than 56% of care providers indicated that the SAQ had helped or enhanced their practice; a further 22% were unsure. Similar levels of endorsement were given regarding the care provider's opinion that the SAQ benefited patients.

Figure 1. Cut points for (A) fatigue, (B) quality of life, and (C) pain: numbers that trigger clinicians to inquire about each patient-reported outcome.

The survey included an opportunity for clinicians to provide actions that they took when patients had decreased QOL or increased pain or fatigue. Responses are summarized in Table 1. As expected, adjustments in pain medication, referral to pain clinic, and expansion of history/examination to evaluate the source of increased pain were common actions for poorly controlled pain.

Among patients with low QOL, providers assessed the impact of treatment on patient QOL by considering dose reductions or delays in the current treatment regimen, changing the regimen, or discontinuing treatment altogether. Poor QOL also led clinicians to broaden their questioning to assess what psychosocial issues may be contributing. Use of other services including complementary/alternative medicine clinic, palliative care, or hospice was also a response to QOL deficits.

A broad range of action items were given in response to elevated levels of fatigue. These included exercise and relaxation recommendations, nutrition evaluations, pharmacologic interventions, and laboratory evaluations. For some providers, high fatigue led to re-evaluation of the current treatment regimen. Providers also considered dose reductions, treatment delays, and cessation of treatment in response to elevated fatigue.

Qualitative Data Summary

Roughly one third of the care providers added qualitative commentary. Common threads raised were as follows:

The SAQ facilitated communication between them and their patients. “I think they are helpful, and often stimulate important discussions on how the patients are really doing. I think it’s a good springboard to discuss bigger problems.” “Many patients seem to be more ‘open’ and more ready to admit to poor pain control, quality of life or fatigue.”

The SAQ identified problems that otherwise would have likely gone unnoticed. “Knowing these scores before entering the room allows me to prepare myself mentally for the encounter and to establish goals for the encounter that I may not have had without this information.”

The actual score on each item was sometimes not as important as the change in the score over time. “I typically don’t base decisions on the actual number, but how the number has changed for them over time.”

The study also highlighted that the clinical pathways care providers should take were not always clear. “I am still struggling with exactly how to use the scores; they seem most helpful when an unexpected score comes up, or when one comes up that seems discordant with patient appearance.”

Clinical Examples

Since initiating the SAQ, we have received multiple reports of how a simple LASA item can identify issues that may not otherwise have been recognized. The following are examples of case reports from clinicians:

An 8-year lymphoma survivor was seen at his annual visit and rated his QOL as 2 on a 10-point scale. When questioned about his score, he admitted to insomnia and suicidal ideations. He was referred to psychiatry, and an antidepressant medication was initiated. One month later, he rated his QOL as 7.

A 60-year-old patient with a history of colorectal cancer returned for an office visit 3 months after completing adjuvant therapy. Laboratory studies, imaging, and examination suggested no evidence of recurrent disease. However, the patient reported his QOL to be 0. When questioned about his poor QOL, the patient admitted to erectile dysfunction. Treatment for erectile dysfunction was initiated, and his QOL improved to 8.

A 57-year-old patient with colorectal cancer returned to clinic for a toxicity check before the next cycle of combination fluorouracil and irinotecan. Although laboratory studies and examination were normal, the patient reported a fatigue score of 8. Dose modifications were made to the patient’s chemotherapy regimen, and the fatigue score improved to 2 (on a 10-point scale).

Discussion

This study demonstrates that simple, single-item measures of pain, fatigue, and QOL can be incorporated into oncology clinical practice with positive implications for improving the patient-physician encounter. Oncology physicians and allied health staff strongly endorsed the use of these simple QOL measures, indicating that clinician acceptance and use of PRO measures are not necessarily barriers to PRO data collection in routine clinical practice, as they have been perceived.⁴¹ Clinicians reported that these items allowed them to go into the clinical interaction with the patient more prepared, facilitated

Table 1. Interventions for Abnormalities in PRO Scores for Fatigue, QOL, and Pain

Reported Action or Intervention
Elevated fatigue (33 responses, 11 skipped)
Recommend exercise
Evaluate patient's nutrition status
Re-evaluate chemotherapy regimen
Consider dose reduction
Consider delay in treatment
Consider stopping treatment
Pharmacologic intervention
Antidepressants
Dexamethasone
Methylphenidate
Review medications
Expand history to assess for causes of fatigue
Assess sleep hygiene (or sleep apnea)
Assess for depression
Review laboratory results
Hemoglobin to assess need for RBC transfusion
Relaxation techniques
QOL deficits (32 responses, 12 skipped)
Re-evaluate chemotherapy regimen
Consider dose reduction
Consider delay in treatment
Consider new regimen
Consider stopping treatment
Expand history to assess for causes of decreased QOL
Assess for depression
Assess for anxiety
Assess how patient is coping with diagnosis
Review social support
Assess for social stressors
Assess level of pain
Assess level of fatigue
Re-evaluate goals of care
Life goals assessment
Referral to complementary/alternative medicine clinic
Referral to palliative care service
Discuss hospice care
High pain levels (35 responses, nine skipped)
Adjust/increase pain medications
Referral to pain clinic
Expand history to assess for causes
Assess for depression
Assess for anxiety
Assess/image for new areas of pain

Abbreviations: PRO, patient-reported outcome; QOL, quality of life.

decision making, and established additional patient care goals. Although the actual lengths of the clinic visits were not timed in this study, most clinicians did not perceive that these items made the visits longer or created more work.

Our study is consistent with other studies demonstrating that adding QOL-related PROs into oncology clinical practice raises awareness of patient functioning and facilitates communication without prolonging encounters.^{11,42-44} In 2004, Velikova et al⁴³ reported the results of a randomized clinical trial involving the collection of health-related QOL (HRQOL) information using touch-screen technology. (This study used the European Organisation for Research and Treatment of Cancer–Core Quality of Life Questionnaire [version 3.0] and the Hospital Anxiety and Depression Scale.) A total of 286 patients with cancer were randomly assigned to: (1) an intervention group, in which HRQOL data were collected and feedback provided to clinicians; (2) an attention-control group, in which HRQOL data were collected but no feedback given to physicians; or (3), a control group, in which no HRQOL data were collected. Patients in the intervention and attention-control groups had significantly better HRQOL, and patients in the intervention group had significantly better emotional well-being. Patients in the intervention group had more frequent discussions of symptoms, which did not prolong visits.

Our study was limited by a small sample size of 44 clinicians comprising various levels of training, including staff oncologists, oncology nurse practitioners, physician assistants, and fellows. Although results from this single-institution study do not guarantee generalizability to other institutions or community practices, the LASA items have been successfully used in a broad spectrum of patient settings for clinical research, including community-based practices.^{45,46} Measures such as the MD Anderson Symptom Inventory and the Edmonton Symptom Assessment Scale have also been used in clinical practices.⁴⁷⁻⁴⁹ Encouraging results from research by Velikova et al,⁴⁴ for example, indicate the potential broad acceptability of PRO assessment in clinical practice.

We recognize that the LASA items addressing fatigue and QOL do not address the specific domains that contribute to the overall measures. For example, fatigue may be a result of disturbed sleep, pain, lack of appetite, nausea, or insomnia, which could be elucidated by a more detailed questionnaire. However, it should also be recognized that a number of studies have indicated a comprehensive review of systems via multiple PRO domains is impractical in a modern oncology practice.⁵⁰ Our intention with the SAQ was to keep it simple: use the SAQ as a triage measure, and if a problem is identified, the clinician can probe further with questioning to determine the appropriate intervention.

Regardless of the specific PRO data collection tool used, there is clear evidence that assessing PROs provides benefits to patients in terms of patient-clinician communication, detection of psychological concerns, and overall well-being.^{42,43} Assessment of PROs provides a window of opportunity for patients to express functional issues, such as emotional distress, or family or sexuality issues that they may not otherwise feel comfortable raising with their provider.³⁶ Addressing PRO concerns acknowledges concern for issues important to patients beyond the status of their cancer and treatment toxicities.

The next logical step is to develop and institute specific clinical pathways to guide clinicians in the management of patients with increased pain, poor QOL, and elevated fatigue. The feedback from clinicians in this study provided a number of potential interventions to address problems identified during PRO screening. These interventions could be incorporated into a tool such as an electronic automated decision tree incorporating more situation-specific questionnaires, which may enhance the assessment of the individual patient.^{33,36} Web-based guidelines may serve as a basis, but our clinical trials experience has indicated that these need to be supplemented with more specific clinical pathways.⁴⁰

In conclusion, within the scope limitations of our study, it seems that the collection of PRO data can be incorporated into clinical practice without a perceived increased work burden for providers. PRO questionnaires have the potential to increase communication regarding how patients are functioning in their daily lives, beyond the specifics of disease and treatment. Future research will establish specific pathways to probe further into issues raised by PRO screening. Until then, simple questioning may identify underlying issues for which there are useful interventions to be considered in patient management.

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