

Assessing Quality of Life in Oncology Clinical Practice: A Review of Barriers and Critical Success Factors

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Formal assessment of patients' health-related quality of life (QOL) is now an important component of many clinical trials. Data from these trials have improved our understanding of the effects of disease and its treatment. QOL studies historically have been conducted with the expectation that, in time, health care providers would routinely incorporate measurement of QOL into clinical practice. However, despite the utility of health status measures, QOL assessment is not widely used in the clinical practice setting [1-7]. QOL assessment, as a clinical tool, has potential to guide treatment planning and decision making. However, this potential will never be realized unless QOL assessment is integrated into practice and embraced as an integral component of care. This article reviews the literature on clinical application of QOL assessment in the oncology setting. We discuss some of the barriers to assessing QOL in oncology practice and identify critical success factors for overcoming these barriers.

Brief Review of the Literature

In the late 1980s, several investigators noticed that the advent of brief, valid health status assessments introduced the opportunity to formally and routinely evaluate patient QOL in the clinical practice setting. Although most of this work was done outside oncology, there is a great deal of overlap in the perceived barriers and necessary factors to incorporating routine assessments into clinical practice [8-16]. Identified barriers include provider perceptions about the utility and availability of instruments, methodologic concerns (eg, validity and reliability of measures), and logistic/practical considerations (eg, ease of administration, scoring, and interpretation). Similarly, factors necessary for routine inclusion in clinical practice include buy-in from health care professionals and the availability of a variety of well-developed measures and instruments that are easy to use and provide clinically meaningful scores.

Use of QOL Information by Physicians

In the oncology setting, Morris et al [5] found that less than 50% of physicians reported using a formal instrument to

assess QOL in clinical practice. Interestingly, more than 80% of physicians endorsed the importance of QOL outcome data. In a survey of 146 oncologists and medical students, Tanaka and Gotay [4] reported that health-related QOL was believed to be as important as survival in making decisions regarding treatment. Similarly, Bezjak et al [6] reported that 84% of the oncologists they surveyed stated that they felt their knowledge about QOL literature was limited, yet 82% reported the belief that QOL data was beneficial for patient care and that they would increase their use of data in the future. This pattern seems to parallel the limited findings/results from randomized clinical trials in clinical practice [17].

Sample Lessons from Clinical Trials

Some controlled clinical trials have helped inform daily management of patients. For example, 2 early studies demonstrated ways that QOL can be used to inform clinical practice. Coates et al [18] compared women with advanced metastatic breast cancer receiving intermittent therapy with women receiving continuous chemotherapy. The former had a significantly worse response rate, a shorter time to disease progression, and a trend toward shorter survival. They also reported decreased physical well being, mood, appetite, and overall QOL. Another main finding was the apparent value of including QOL assessments in the evaluation of treatment for cancer. Physicians could use the results from this study to share with patients in similar situations who were evaluating and planning for a similar treatment course.

In a second study, Ganz et al [19] compared the QOL of women with early-stage breast cancer who were given a choice between breast conservation therapy and mastectomy as a primary treatment. Results showed that women receiving a mastectomy reported more difficulty with issues concerning clothing and body image, while patients who chose breast conservation may have had an increased need

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for more intensive psychosocial interventions. The overall conclusion of the study was that women receiving breast conservation did not experience significantly better QOL or mood compared with women who chose to have a mastectomy. The importance of sharing the results from this and other studies with women trying to evaluate treatment options and decide what is best for them [20–22] is indisputable. Both studies demonstrate the utility of QOL assessment for patients, physicians, and the interactions between the two by providing useful information for developing a treatment plan. Additionally, when this type of information is given to patients, it encourages them to take an active role in the decision-making process. Psychologically, this increases the limited amount of control that a person with a cancer diagnosis feels [23], particularly at the outset of treatment or at a time when new treatment options are being explored.

Incorporating QOL Assessment into Clinical Practice

To date, there is sparse documentation of the use of QOL research in the clinical setting. The results from one such study were recently published by Carlson et al [24]. Cancer patients were recruited from the pain and symptom control clinic of an ambulatory outpatient clinic within a comprehensive cancer center. Forty-six patients completed the computerized EORTC-QLQ-C30, a 30-item cancer-specific questionnaire [25], and an attitudinal questionnaire. A research assistant approached patients in the waiting area of the pain clinic. After the patients completed the computerized questionnaire, they received a 1-page computer generated report of their responses. Patients completed a post-survey questionnaire after their appointment. The staff member who conducted the interview also completed a staff evaluation form. Staff received no training in QOL issues but were told that they might use the questionnaire results to identify specific QOL issues and to guide discussions with patients about their concerns. Patients reported that the computerized version of the questionnaire was easy to use, understandable, enjoyable, and a good use of waiting room time. Approximately 39% of patients stated that the report was “very helpful” in guiding their interaction with staff, and another 39% ranked the usefulness of the report as a 4 (5 being most useful). The clinic staff also found the instrument useful, with 70% to 78% stating that the report was “helpful” or “very helpful” in promoting patient-provider communication and in identifying areas of patient concern. These results confirmed early findings of Buxton, White, and Osoba [26], who evaluated the ease and acceptability of using a touch-sensitive video monitor by cancer patients to assess health-related QOL with a computerized version of the EORTC-QLQ-C30.

In a recent study of patients with advanced non-small cell lung cancer (NSCLC) [27], physicians used QOL data collected

at 4 different visits (baseline, 6 weeks, 12 weeks, and 6 months) to guide treatment decisions. At baseline (start of chemotherapy), patients completed demographic and health history questionnaires and a handheld computer-based version of the Functional Assessment of Cancer Therapy-Lung (FACT-L) [28]. This was followed by a patient evaluation of the experience using the computerized FACT-L. Following each assessment and before the oncologist met with the patient, a graph of the patient’s QOL scores was presented across several subscales including physical, social/family, emotional, functional well-being, lung cancer symptoms, total QOL, and the Trial Outcome Index. The oncologists reviewed the results prior to meeting with the patient and could discuss the overall QOL score as well as any particular areas of concern. The oncologists also completed a brief evaluation of the study after every 10 patients to provide continual feedback of how “real-time” QOL data could be used in clinical practice. This study led to the development of an ongoing, weekly monitoring program for patients with advanced NSCLC.

In a similar study, Taenzer et al [29] attempted to assess whether the provision of QOL data to clinic staff resulted in improved patient satisfaction, increased identification of QOL issues, and increased documentation of QOL concerns. They determined that computer technology was an easy and effective means of detecting QOL concerns and resulted in greater chart documentation of such concerns. Ultimately, computers were viewed as a welcome addition to health care practice because of the many potential benefits that they can provide in the outpatient setting. Velikova et al [30] found similar benefits and acceptance of computer-based QOL assessment by patients and physicians. While there is increasing evidence demonstrating the beneficial uses of computer-based QOL assessment, efforts need to be directed toward making the information easy to use and understand in clinical practice.

Barriers to Assessing QOL Data in the Clinical Setting

Our review of the literature revealed 3 broad categories of current barriers to routine assessment of QOL in clinical settings. These are (1) provider inexperience with formal QOL assessment, (2) methodologic concerns about reliability and validity, and (3) logistic barriers that inhibit feasibility of clinical implementation and integration. Nine specific barriers falling under these 3 categories are summarized in [Table 1](#) and discussed below.

Provider Inexperience with QOL Assessment

Lack of provider experience conducting formal QOL assessments is one of the most important barriers to routine use in clinical practice [5,6]. Because providers are the information gatekeepers in the health care setting, their support in the use

of QOL data to inform and guide clinical practice is essential. Currently, there is a large discrepancy between the number of providers who report that QOL assessment is useful and those who actually use an instrument to assess QOL [5,6,31]; the lack of a standardized systematic approach to QOL assessment may account for the discrepancy. Surveys of providers reveal that the knowledge base about assessment is limited but that with greater experience and exposure to available instruments, providers may be willing to use them on a routine basis [6,31]. Understanding the role that provider inexperience with QOL assessment plays and determining ways to increase health care professional's exposure is critical for any attempt at integrating this data into routine clinical practice.

An implication of provider inexperience with QOL assessment is the potential for limited patient-provider communication. Although some physicians have expressed concerns that QOL data will be used as a substitute for direct communication rather than as an adjunct to care [34], the opposite appears to be true. Recent studies have reported that patients and staff found QOL assessments helpful for identifying patient concerns and improving communication [6,7,24,30,32].

Methodologic Barriers

A second category of barriers refers to methodologic problems. Historically, physicians have been skeptical about the sensitivity and specificity of QOL instruments [5,31]. In spite of significant efforts to define QOL and improve measures, doubts about the methodologic development of instruments persist. At present, some clinicians doubt the ability of available instruments to measure subtle individual changes. This is of particular concern for cancer patients who may present from one week to the next with slight clinical changes that represent significant quality of life changes according to themselves and/or family members. More studies are needed to help determine whether a given change in QOL score has clinical meaning or significance to the individual. Experience with an instrument improves its usefulness, so increased use will itself improve the utility of an instrument as clinicians develop their own practice-based "norms." A final methodologic concern is the limited ability to compare scores across different instruments. There is some hope that modern psychometric analysis techniques, such as item-response theory (IRT), will allow more direct comparison of scores across commonly used assessment tools. In addition, techniques such as computerized adaptive testing, which involves selective asking of only the most informative questions, can address this and other methodologic concerns [2,3].

Feasibility and Logistic Barriers

A third category of barriers pertains to feasibility and logistic problems associated with data collection and recording. These

Table 1. Barriers to Assessing QOL in Clinical Practice

	Reference
Provider inexperience	
Lack of provider familiarity with formal QOL assessment instruments	5,6,30,31,32
Lack of knowledge about usefulness of results for patients and providers (eg, usefulness of assessment in improving patient-provider communication and physician awareness)	6,24,30,32
Methodologic barriers	
History of methodologically flawed measures (sensitivity and specificity)	5,31
Limited ability of instruments to detect clinically meaningful changes	27
Limited ability of instruments to compare scores across instruments	33
Feasibility/logistic barriers	
Administrative burdens (staff, patients, clarity, length, user-friendliness, scoring, interpretation)	6,26,30
Delayed presentation of results limits clinical relevance for treatment planning	27
Perceived time constraints (longer visits and longer wait times)	7
No universally accepted instruments	6

barriers apply to both providers and patients. Assessments that are long, complex, and not user-friendly are not likely to be used by health care professionals [6]. Additionally, results must be ready in real-time, at the visit when the data are gathered. Concern about the timing of the presentation of results was the most common problem cited by oncologists in the study with advanced NSCLC patients [27]. Oncologists also stated that more frequent assessments were necessary to help guide treatment planning and decision making. Another barrier is the scoring and interpretation of data for clinical usefulness. Scores must be clinically meaningful to both providers and patients. Results must be presented in a format that is easy to read, provides useful information, and facilitates direct discussion about topics such as treatment options and general and specific aspects of QOL [6,24,26,29,30]. Routine assessment of QOL will require a major commitment of resources from both clinical and administrative areas that are not currently standard components of the outpatient setting.

Critical Success Factors

There are several critical factors that are likely to increase the use of QOL assessment in routine clinical practice. As with the barriers, these can be grouped into 3 broad categories embracing 9 specific factors. The categories are (1) an acceptable set of

Table 2. Critical Success Factors for Assessing QOL in Clinical Practice

	Reference
An acceptable set of core measures	
Clear set of measures from which to choose	6,7
Streamline assessments, such as those allowed by IRT models (eg, CAT)	33,35
Clinical relevance and ease of use	
Clear demonstration of how QOL results can be used to discuss treatment options with patients	6,7,27,30,36
Administration platform that minimizes staff burden	7,26,27,29,30
Test platform that provides clinically meaningful feedback in "real-time" and allows comparison over time	6,7,26,27,30,37,38
Routine assessment	7,27
Buy-in from staff and patients	
Staff knowledge and positive attitude about usefulness of formal QOL assessments	3-6,29,30,32,36,39-41
Staff buy-in based on clinical relevance of assessment	4-7,16,24,29,30,32-34,42-45
Patient buy-in regarding usefulness in guiding communication about specific concerns	6,7,24,26,29,30,36,45

CAT = computerized adaptive tests; IRT = item-response theory.

core measures, (2) ease of use and clinical relevance, and (3) buy-in from staff and patients. Each of the 3 categories and their associated factors are summarized below and in **Table 2**.

An Acceptable Set of Core Measures

A core set of QOL measures needs to be accepted and endorsed by health care providers. Having several standardized instruments from which clinicians can choose may increase the use of routine assessment by addressing barriers related to provider knowledge and instrument quality. These would include a list of tools with adequate validity and reliability and that accurately predict scores on longer instruments. The establishment of a core set of measures would allow clinicians to tailor the use of assessments to meet their needs and those of their patients. Broader use of more modern IRT models in the development of instruments should be considered. IRT measurement models may allow ways to compare different instruments or estimates of how a person may score on a given instrument based on their responses to another instrument [33]. Computerized adaptive testing is one way these types of measurements could be developed and used while preserving other critical factors. This could result in more precise assessment of an individual's ability while simultaneously decreasing the number of questions that need to be administered.

Ease of Use and Clinical Relevance

Ease of assessment is one of the most important factors necessary for assessing QOL because it often can set the stage for the consideration of an assessment as clinically meaningful. Addressing this success factor can diminish barriers in all 3 categories: provider inexperience, clinical significance and interpretability, and administrative burden (Table 1). Detmar and Aaronson [7] demonstrated the feasibility of routine administrations of QOL assessment. Computer-based testing (CBT) is one way that more frequent assessments can be conducted with minimal burden on patients and providers. CBT eliminates the need for a test administrator, such as in traditional paper and pencil formats; rather, patients administer the instrument to themselves. This gives patients a sense of control that is particularly important for cancer patients, who often feel that the cancer diagnosis severely limits their control in life. CBT also decreases the burden on clinic staff while providing immediate real-time feedback. Information from assessments can be displayed in graphic reports as visual aids that help guide discussions about treatment options and care planning. Patients have reported that these types of discussions improve communication with health care providers [30]. Additionally, discussions help patients feel understood both physically and emotionally [7]. The positive feelings of patients can impact buy-in by encouraging clinicians to use QOL assessments on a regular basis.

Buy-in from Staff and Patients

The more providers are educated about QOL and the benefits for clinical practice, the stronger the likelihood that they will use this data. This addresses the "provider inexperience" barrier and is supported by the previously mentioned study by Bezzak et al [6], who reported that the majority of oncologists surveyed felt their knowledge about QOL literature was limited but believed in the benefit of QOL for patient care and would likely increase their use of QOL information in the future. This buy-in from key staff is indeed critical to the successful use of QOL information [4-7,17,32,35,42-44]. If QOL data were to be incorporated into general medical education, it may eventually become a routine component of patient care [4,33]. Education needs to focus on information about QOL conceptually, interpretation of specific measures, and uses of QOL data in clinical practice. Finally, organizational requirements for QOL endpoints in clinical trials, as have been mandated by the National Cancer Institute of Canada [46], may also increase exposure, knowledge, and use of QOL assessment by clinicians.

Buy-in from patients, including the desire for and willingness to take routine assessments, is equally important. Support can be attained by presenting QOL assessments as a regular part of patient care to highlight unstated patient concerns typically indirectly assessed by health care professionals.

Providers can explain that assessments at regular intervals are a way to facilitate patient-provider communication [30]. Detmar and Aaronson [7] reported that most patients felt that after multiple assessments, physicians were more informed and aware of the physical and psychosocial impact of treatment on their daily activities.

Conclusion

This review reveals known categories of barriers and critical success factors associated with the application of QOL research findings in clinical oncology practice. While there is increasing interest in QOL, it is evident that providers must be committed to conducting formal QOL assessments as a routine part of clinical practice. The lack of systematic or standardized documentation of successful uses of QOL data has resulted in limited use of this information in the clinical setting. Because self-report is the best way to assess QOL, it is incumbent upon the provider to establish a routine system for obtaining reliable assessment. Improvements in technology, such as CBT and computerized adaptive testing, can address concerns ranging from length of assessment to defining a meaningful change within and across measures. Given this information, clinical application of research findings should increase, providing benefits for patients and health care providers.

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