Quality of Life Assessment in Culturally Diverse Populations

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CHICAGO—While the main objective in caring for cancer patients has been to prolong life and to focus on short-term and long-term survival, more recent efforts include considerations of health-related quality of life (QOL).[1,2] The World Health Organization defines QOL as “not merely the absence of disease but a state of physical, emotional, and social well being.”[3]

Evaluation of QOL involves assessments of a wide spectrum of human functioning, including emotional response to cancer and treatment, physical activity, and the impact of the specific cancer on physical and psychological capacities. QOL now constitutes an important part of study for epidemiology, clinical trials, and health services research.

From a cancer surveillance perspective, information about health-related QOL is important because it provides indicators for trends in cancer treatments and their impact on patients’ lives. From a clinical trialist’s perspective, QOL outcomes are increasingly included as endpoints in oncology clinical trials.[2] Finally, from the perspective of health services research, health-related QOL is considered a major part of medical outcomes research, since a cancer patient’s life is a highly dynamic experience.[4]

Since many oncology treatments do not cure cancer but can extend life for long periods of time, it is wise to examine all aspects of disease burden to allow accurate assessment of therapeutic progress. Although many clinical trials, outcomes studies, and epidemiology studies now include health-related QOL assessments for persons with many different types of cancer, efforts that include large numbers of racial/ethnic minorities are rare.

Most of the questionnaires used to assess QOL in clinical settings are written in English and are tailored for relatively highly educated, white populations. The content and format of the questionnaires can act as a barrier that immediately precludes numerous cancer patients from socioeconomically and ethnically diverse populations, or whose first language is not English.

In recent years, this problematic situation has gained attention and motivated researchers to begin drafting instruments that allow for accurate evaluation of populations that speak languages other than English and who have different daily life circumstances.

In addition, QOL measurement in cancer patients can present further challenges when the disease has markedly affected physical, role, social, and emotional functioning, making adherence to self-administered questionnaires difficult.

In this article, we focus on the work of three researchers who presented papers at the 1999 Robert H. Lurie Comprehensive Cancer Center Health Policy Symposium: Frank Baker, MD, of the American Cancer Society; David Cella, PhD, of the Evanston/Northwestern Healthcare System and Northwestern University; and Sara J. Knight, PhD, of the VA Chicago Healthcare System/Lakeside Division and Northwestern University.

All three have been actively involved in developing appropriate methods for evaluating the QOL of patients with cancer in culturally diverse populations.

Cultural Equivalence
Dr. Frank Baker’s research is based on the practical observation that QOL measurement in cancer patients from lower socioeconomic and minority backgrounds presents numerous challenges.[5] His work has focused on delivering information regarding the cultural equivalence of QOL instruments so that they may be used across culturally diverse populations.

In one study he described, only a minority of the different QOL measures demonstrated adequate reliability and validity for black and Hispanic populations. It was further shown that the family functioning dimension was particularly difficult to address across the different cultural backgrounds, because of widely variant attitudes toward this domain.
Dr. Baker’s research is novel, since most QOL instruments include predominantly middle-class white cohorts and since normative QOL data on specific populations, categorized by socioeconomic status, cultural identity, and literacy level, generally are not available.

In response to this issue, the appropriateness of several existing QOL instruments has been evaluated and new methods developed for assessing QOL in minority populations. Dr. Baker and his colleagues have identified five main areas of QOL testing that make up the core elements required to evaluate a person’s physical and psychological health state.

The first is cultural equivalence, which refers to whether the items in the questionnaires are relevant to the specific lifestyle background of the population. Another important aspect of determining instrument validity is semantic equivalence, referring to the way questions are worded. Questions should be presented in Spanish to a Spanish-speaking group of patients. It is also critical that the phrases be written in the everyday language of the cohort, because people may use different dialects and have different Spanish literacy levels.

Technical equivalence determines whether the different QOL instruments are actually measuring the same aspects of health. Finally, criteria equivalence and conceptual equivalence, as ascertained by statistical method analyses, ensure that the same ideas are being examined across cultures.

Developing Better QOL Measures

Dr. David Cella’s research is dedicated to developing better, more relevant, and more culturally appropriate QOL measures,[6,7] including the Functional Assessment of Cancer Therapy-General Scale (FACT-G) (the fourth version is currently used), a 27-item questionnaire written at the third-grade level.

Dr. Cella and his colleagues have shown that there are no significant differences in the validity of the FACT-G between high-literacy and low-literacy populations or between interview-assisted or self-administration assessment methods.

In another 3-year National Cancer Institute funded study, the Bilingual Intercultural QOL project, Dr. Cella’s team translated the English FACT into Spanish and tested its reliability. Translation from one language to another, however, does not always guarantee that meaning is preserved. As a result, QOL assessments for cohorts made up of Hispanics using the Spanish version of a test cannot be compared with those obtained from cohorts of whites.

Furthermore, Dr. Cella has pointed out that the conception of QOL is embedded within any given culture, and, therefore, it is impossible to expect any measure of QOL to be void of cultural influence.[8] Nonetheless, the research indicates that we can expect a good QOL instrument to be “culture equivalent.”

Dr. Cella’s presentation stemmed from his previous work on these issues and focused on cultural differences that affect the validity of QOL questionnaires as well as the low-literacy issues surrounding quality of health care.

Low Literacy Underappreciated

Illiteracy affects many people in the United States, yet it is an underappreciated factor in understanding variations in the quality of medical care and specific outcomes. It is estimated that 48% of the adult population in the United States have insufficient literacy skills, and 23 million are functionally illiterate.[9]

In clinical situations patients are routinely expected to read and understand consent forms, medication instructions, educational materials, and scheduled appointment notices. However, Dr. Cella pointed out, studies have demonstrated that medical information given to patients often exceeds their reading ability.[10-12] Therefore, many patients do not comprehend medical information that is pertinent to their health care experience. This lack of adequate literacy skills is a significant barrier to receiving optimal health care.

Although most QOL instruments require reading levels as high as seventh and eighth grades, most of
the patients tested with these instruments are elderly, and many have very low literacy skills, Dr. Cella said. Thus, instruments need to be tailored for lower reading levels so that they can yield accurate information about patients.

On the other hand, it is important not to lower the items' literacy level below a certain point, since the desired nuances of meaning can be lost. Dr. Cella recommended that questionnaires should not be worded below the third-grade reading level when used in a cohort of patients with diverse reading skills, since higher literacy patients can be adversely affected by an instrument that is significantly below their literacy level.

Another problem with many current QOL instruments is that they are administered in English or require a person to understand written English, a language that not all patients speak, read, or write fluently.

Most QOL instruments have also been primarily tested in white, middle-class populations. Dr. Cella commented that it is critical not to generalize the use of these instruments from one majority population (mainly whites) to other populations such as blacks or Hispanics.

**Low Literacy & Cultural Sensitivity**

Dr. Sara J. Knight focused on the quality of life of ethnic minorities, low-income people, and the elderly population. These groups are extremely disadvantaged when confronted with health care decisions and evaluations of their health care experience. Health care providers and researchers have the large responsibility of investigating the ways in which people's lives are affected by various treatments and routine visits to the health care setting.

Dr. Knight believes that it is critical that QOL be examined in all people who live with cancer, since there are a large number of factors that affect health states. Low literacy interferes with the understanding of instruments designed to measure QOL preferences and outcomes, especially when the questionnaires are self-administered.

One 1998 study found that in men with prostate cancer, stage of disease and race were significant predictors of the literacy level of the majority of patients.[13] Men with metastatic progression were more likely to have lower literacy levels than men with localized disease. In addition, black men were more likely to have lower literacy levels and to present with advanced disease than were white men. These findings contribute to numerous other studies that have obtained similar results, which all warrant more research into factors such as low literacy that affect a person's cancer experience. Health education materials and QOL instruments not only need to be tailored for low-literacy populations, they also need to be culturally sensitive, Dr. Knight said. For example, many of the available patient education pamphlets target populations that are mostly from white backgrounds, while many patients live in culturally diverse settings.

The dispersal of information and the use of questionnaires must sufficiently focus on a specific lifestyle in order to be valid within a particular patient population.

Dr. Knight has reported that low-acculturated Hispanic women and low-income black women prefer to have health education materials that are appropriate for their level of understanding, rather than many of the available materials currently distributed. Hispanic women prefer to have materials that have a minimal amount of written information and instead contain pictures that depict specific subject matter. Similarly, black women in low-income postpartum clinics favor materials with graphics, but they also find the information easier to understand if written text is included.

These two findings indicate how important it is to evaluate patients' preferences when assessing QOL instrument reliability and validity, since the preferences are potentially shaped by a person's cultural background.

**Prostate Cancer Study**

Dr. Knight also presented data from one of her research projects focusing on QOL of veterans with prostate cancer. Her work was a collaborative effort between Dr. Charles L. Bennett and the VA Cancer of the Prostate Outcomes Studies group.

The study utilized the EORTC-QLQ-30, the QLI, and the FACT-G in an attempt to validate interviewer-assisted administration of these instruments in low-literacy populations. The interviews were conducted face-to-face by a research assistant, while the patient was able to follow along with his own copy of the questionnaire.

More than half of the patients in the cohort were black, while most of the other participants were white. Treatment modalities included radical prostatectomy, orchiectomy, radiation therapy, and hormonal therapy.

As measured by the EORTC instrument, the men who had progressive disease exhibited worse emotional, physical, social, and role functioning, compared to those with stable disease. Similarly,
the men with progressive disease fared worse in the domains of physical and emotional functioning as measured by the FACT.

**Study Limitations**

Dr. Knight noted several limitations of her study and also others that validate QOL instruments. A primary concern is that health literacy is often not measured in these types of studies. Clearly, it is essential to know the literacy level of the patient population in order to be certain that the cohort understands the questions posed.

There is also considerable variability in the methods of instrument administration. Different results can be obtained depending on the way that the questionnaire is presented, such as self-administration, interviewer assistance, and whether the interview is conducted face-to-face or via the telephone. Furthermore, sensitivity to interviewer sex, ethnicity, and age is often not evaluated.

Although these limitations exist in Dr. Knight’s study and similar studies, her results nonetheless support the reliability and feasibility of interviewer-assisted administration of QOL instruments among veterans with low literacy. Minority and low-literacy populations face several serious barriers in the health care setting. With the recent consideration of QOL factors in both clinical trials and independent investigations, critical weaknesses in the measurement of patients’ experiences have surfaced.

Based on the aforementioned researchers’ work, the outlook on accurate QOL assessment in ethnic minorities, low-literacy populations, and the medically underserved is promising. As the instruments become approved for their validity and reliability, implementation in the appropriate health care setting is warranted. ONI

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