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Improving Patient-Centered Medical-Surgical Nursing Practice with Quality of Life Assessment

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Abstract

Quality of life (QOL) measures have been evolving for almost three decades through oncology research, a major catalyst in the development and refinement of QOL instruments. Research in oncology has set a precedence for other disciplines to show results from the patient's perspective using QOL as an outcome. Health-related QOL assessment has been shown to enhance monitoring and provider-client communication, and results have been used to provide predictive/prognostic information and to guide treatment decisions. However, survey data on the administration of QOL instruments indicate that only 30–50% of clinicians routinely measure QOL in practice. This article will describe perceived barriers in assessment and application of QOL data, recent improvements in administration and analysis techniques, and an overview of the most widely used QOL instruments available. Nurses are in a prime position to both acquire and use QOL data in clinical practice to inform and monitor individuals and identify population characteristics and needs. The information in this article will inform nurses in oncology and other specialties of the advantages of measuring QOL in practice and to help identify an appropriate instrument for their population and setting.

Quality of life (QOL) research, which began in the field of oncology over 30 years ago, caused a paradigm shift in the evaluation of outcomes by placing more focus on the aspects of the patient's life affected by disease or the treatment of disease, instead of concentrating solely on clinical endpoints, such as length of stay, morbidity, and mortality (Velanovich, 2007). This transition improved the alignment between the objectives of research and the goals of practice. For medical-surgical nursing, this connection is especially relevant, as the application of nursing interventions is focused not simply on ensuring survival, but on the quality of survival throughout the disease process, surgical experience, and/or stages of recovery. Beyond preventing complications, decreasing costs, and getting the patient home sooner, our aims are directed toward facilitating adequate pain control, maximizing function and offering psychosocial support. However, the needs of the patient and superiority of one nursing intervention over another in meeting those needs are not always readily apparent. Moreover, due to the dynamic nature of the health-disease spectrum, the efficacy of specific nursing interventions may change throughout the disease course. It is in this regard that assessing quality of life can help to direct and improve nursing interventions for the medical-surgical patient and/or population.

Quality of life is a self-assessment, or subjective view, of the patient's health and well-being. Each quality of life instrument has different items, or questions, which focus on various aspects of quality of life, such as physical functioning, social interactions or psychological issues. As a standardized method of measuring the patient's status, quality of life assessment offers a patient-centered approach to study the various factors that affect patient-centered outcomes of the individual or population. These valuable tools can help monitor recovery or disease progression, identify factors that influence quality of life, and facilitate communication between the nurse and patient.

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Oncology nurses have led the way in QOL research, focusing on the interplay of disease, treatment, and QOL (Bailey, Wallace, & Mishel, 2007; Ding, Zhu & Zhang, 2007;Juarez, Ferrell, Uman, Podnos, & Wagman, 2008), as well as testing interventions to improve QOL (Davidson et al., 2003; Ward-smith, Wittkopp & Sheldon, 2004). This research has demonstrated that QOL assessment can provide new insight into the healthcare experience and is capable of improving the delivery and satisfaction with nursing care regardless of the specialty.

A recent meta-analysis of the QOL literature found that there has been a significant improvement in the ability to translate QOL research into practice (Efficace et al., 2007). Indeed, current publications show that QOL data can provide important information about outcomes between different types of treatment for the same disease (Conroy, Uwer, & Deblock, 2007; Zuydam, Lowe, Brown, Vaughan, & Rogers, 2005), variations in outcomes among diverse cultural populations (Ramsy, Zeliadt, Hall, Ekwueme, & Penson, 2007; Reeve et al., 2007), and the relationship between the risk of developing psychosocial morbidity and survival (Efficace, Bottomley, Coens et al., 2006; Efficace, Bottomley, Smit et al., 2006). Thus, QOL data can be used to provide patients with more meaningful information that they can use to make decisions, and can inform the clinician concerning how the patient is coping and the areas of life that require attention, in terms of support, interventions and/or resources (Detmar, Muller, Schornagel, Wever, & Aaronson, 2003; Velikova, Booth, Smith, & Selby, 2004). Since the factors that appear important to healthcare professionals may not be congruent with the priority issues for patients, assessment and analysis of QOL on an individual basis may help to better address patient needs (King, 2006; Snyder et al., 2007). Individualized assessment of QOL for the purpose of directing and prioritizing nursing care, and to evaluate and improve patient-centered practice, is consistent with the paradigm of medical-surgical nursing. The purpose of this article is to review the dimensions of QOL and commonly used conceptual frameworks, highlight some of the different types of QOL instruments available, and discuss relevant issues related to implementing a QOL practice-based approach to medical-surgical nursing care.

Definitions of Quality of Life and Conceptual Frameworks

There are a number of definitions of the term, ‘quality of life’ (Table 1). Although firm consensus in the nursing literature about the definition of QOL is lacking, there are five essential components that have been proposed: physical functioning or well-being, emotional and psychological well-being, social role well-being, spiritual well-being and disease/treatment-related symptoms (Haberman & Bush, 2003; Varricchio, 2006).

As a first step toward implementing QOL assessment as a tool to guide nursing practice, a conceptual framework that is aligned with the definition of QOL and goals of nursing care for the particular patient population and/or clinical setting should be chosen. The conceptual framework provides a theoretical linkage between the operational definition of QOL and the actual measurement of it and enables the clinician to view how nursing practice and other variables of interest affect the patient’s QOL (Vallerand, Breckenridge, & Hodgson, 2003). By linking the framework with the goals of nursing care, the nursing process can be applied to address the patient’s responses.

Both the City of Hope Model (Ferrell, Grant, Padilla, Vemuri & Rhiner, 1991) and Quality of Life Model (Ferrans, 1996) entail four elements of QOL; they are the most frequently used conceptual frameworks used to guide nursing practice. These models view QOL as a multidimensional construct that depends upon the subjective experience of the individual;, however, they differ in the application of QOL data to direct nursing care.

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The City of Hope Model includes the following dimensions: physical well-being and associated symptoms, psychological well-being, social concerns and spiritual well-being (Ferrell et al., 1991). Using this model, the influence of certain aspects or variables of the disease/illness experience, such as pain or fatigue, on the dimensions of QOL can be ascertained. Nursing interventions that have a direct influence on the dimensions of QOL, such as giving a specific medication for pain, or an indirect influence, such as providing teaching on self-management strategies for fatigue, can be evaluated. In this manner, nurses can use the QOL assessment to evaluate and improve interventions for specific symptoms or aspects of life, identify patterns of QOL status in the patient population, and compare interventions to determine which strategies are superior in improving outcomes.

In contrast, the Quality of Life Model includes the domains of health and functioning, socioeconomic, psychological/spiritual, and family (Ferrans, 1996). Unique to the QOL Model is the linkage between the importance of each QOL domain and the satisfaction of the individual with each domain. The Quality of Life Index, an instrument that was used to create the QOL Model, can promote patient-centered care by providing information to the nurse about aspects that are most highly valued by the client so that appropriate prioritization of nursing interventions can take place (Ferrans & Powers, 1992). Again, this model can be used to evaluate the effect of specific nursing interventions on QOL with the added feature of basing interventions in the context of what is most important to the individual.

Both models were developed through research and have been applied to numerous medical, surgical, and oncology populations to establish the conceptual basis. Ferrell and colleagues (1991) developed their model based on studies using the QOL survey. The QOL Model was based on extensive literature review and factor analysis from clients on hemodialysis (Ferrans, 1996). External and mutual validation of these two models has been tested in subsequent studies by the authors. A thorough review of other QOL conceptual frameworks applicable to nursing practice is described by King and Hinds (2003).

Choosing the Right Instrument

Once a conceptual model is chosen, the various instruments for measuring QOL can be reviewed to match the definition of QOL, population characteristics, and the goals of nursing care with the information that will be collected from the instrument. The measurement of some variables will be more or less important, depending upon the characteristics of the patient population. Examination of the dimensions of QOL and specific aspects that the instrument measures will assist in choosing one that best represents the patient experience and goals of nursing. The instrument must also be valid and reliable, be sensitive enough to identify changes, have translations that are linguistically equivalent, and be consistent with the timing of the measurement protocol in order to obtain trustworthy information that can be used to guide practice. Varricchio (2006) provides an excellent and thorough review of measurement issues that should be considered prior to choosing an instrument. Additionally, many web-based resources are available that provide access to descriptions and psychometric properties of QOL instruments (Table 2).

QOL instruments come in many forms; unidimensional, multidimensional, modular and global (Table 3). QOL assessments can also be generic, or applicable to a wide variety of chronic illnesses, or disease-specific, geared toward one specific condition or treatment. Generic instruments are commonly used in QOL research and lend themselves to comparisons between different patient populations; however, they may not be specific enough to identify the unique issues encountered in the medical-surgical experience, or

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sensitive enough to detect change (Haberman & Bush, 2003; Mehanna, 2007; Sloan et al., 2006).

Head-to-head comparisons of QOL instruments reveal that patients prefer the questionnaires that most closely reflect their disease and personal illness experience (Cooley et al., 2005). Thus, an instrument that has been created for the same population in which it will be used, and which has the conceptual focus desired, will impart more meaningful results. Using a unidimensional and multidimensional assessment together can provide comprehensive information regarding the patient's experience and areas of practice that need improvement; assessments that are of high value to patients (Snyder et al., 2007). However, responder burden, which refers to the amount of time and energy required to complete the forms, should be considered as well.

Comprehensive lists of QOL assessment questionnaires may be found in several sources (American Psychiatric Association/Taskforce for the Handbook of Psychiatric Measures, 2000; Frank-Stromborg & Olsen, 2003; King & Hinds, 2003). The following examples of modular and generic instruments are described to provide an overview of the many instruments that are well suited for practice. Again, the choice of instrument should be driven by the QOL framework in the context of the scope of nursing practice for the particular setting, the patient characteristics, and the objectives and psychometric properties of the instrument.

Examples of Modular Instruments

The Functional Assessment of Cancer Therapy (FACT) Measurement System, initiated in 1987, has evolved in its ability to measure multiple disease-related conditions and in 1997, it was renamed the Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System. Functional Assessment of Chronic Illness Therapy-General (FACIT-G), composed of the core QOL questions, has been well validated and used in many American and European clinical trials (Webster, Odom, Peterman, Lent, & Cella, 1999). It has been translated into 31 languages. FACIT-G contains 27 questions to which are added disease-, treatment-, symptoms-, or other-specific subscales (disease-specific scales include HIV, multiple sclerosis, arthritis, Parkinson's disease, stroke, many types of cancer and non-life-threatening conditions; treatment-specific scales include biological response modifiers, neurotoxicity, bone marrow transplant, and several chemotherapeutic agents; symptom-specific subscales include anorexia/cachexia, anemia/fatigue, diarrhea, endocrine symptoms, fatigue, fecal incontinence, urinary incontinence; and other subscales include palliative care, spiritual well-being and satisfaction with treatment). The questionnaire employs Likert type scoring to measure physical wellbeing, social/family well-being, emotional well-being, and functional well-being. Subscale reliabilities range between .82 and .88 with an overall scale reliability of .92 (Webster et al., 1999). Internal consistency assessed with Cronbach's alpha range between .65 and .82 for subscales with an overall alpha of .89. The average time to complete the FACIT-G is approximately five minutes (http://www.facit.org).

Another method of measuring quality of life is through the concept of life satisfaction. The Questions on Life Satisfaction Module (FLZ^{m}) has a 16-item general component that measures general life satisfaction and satisfaction with health (Henrich & Herschbach, 2000). The respondent is asked to rate each item twice, first for the degree of subjective importance and secondly for his/her present degree of satisfaction with the domain. The 8-item life satisfaction portion includes friends, leisure activities, occupation, living conditions, family life or partnership. Satisfaction with health, also 8-items, includes physical condition, ability to relax, and energy level or being free from anxiety. The scales range from 1 (not important) to 5 (extremely important) for the importance ratings and in the same format from 1 (dissatisfied) to 5 (very satisfied) for the satisfaction ratings. The two

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ratings are computed using a weighted satisfaction score: (*importance* - 1) × (2 × *satisfaction* - 5), yielding weighted satisfaction scores ranging from −12 to +20. With this transformation of raw scores to weighted satisfaction scores, negative scores indicate dissatisfaction and positive scores indicate satisfaction. Total scores for general life satisfaction and satisfaction with health are calculated by summing the weighted satisfaction scores in the eight or nine domains for each dimension. Good reliability and validity of the instrument have been reported (Henrich & Herschbach, 2000; Kuehler et al., 2003). Several additional modules are available to add on to the general measurement scores, including cystic fibrosis, growth hormone deficiency, movement disorders, and deep brain stimulation. The general form has also been studied in a variety of different conditions and treatments, including inflammatory bowel diseases, gender transformation surgery and to determine the effect of companion animals among lung transplant patients.

Examples of Generic Instruments

The Quality of Life Index (QLI) was originally developed for dialysis patients. Assessment of satisfaction and the importance of physical, functional, familial, sexual, social, and global aspects are measured. The questionnaire contains 68 questions based on a Likert scale. Developed in English, it has been translated into 18 other languages. Both satisfaction and importance are measured on a six-point Likert-like scale. Scores are calculated by weighting each item with its matched importance response. This weighting procedure results in the highest scores for combinations of high satisfaction/high importance and the lowest scores for high dissatisfaction/high importance. The range of possible scores is 0 to 30 for each subscale and for overall scores. In 1992, Ferrans and Powers performed a psychometric analysis of the original QOL tool and found a validity of 0.77 and an overall reliability of 0.93.

In contrast, the SF-36 Health Survey provides a general measure of health-related QOL. The SF-36 assesses eight health concepts (physical function, role limitations caused by physical problems, role limitations caused by emotional problems, social function, emotional well-being, vitality/fatigue, pain, and general health perceptions) and is among the most frequently used health-related QOL questionnaires worldwide (Ware, Kosinski, & Dewey, 2007). The 36-item self-report instrument takes ten minutes to complete. A shorter version (SF-12) is available. The SF-36 is a reliable and valid instrument and has been used extensively both inpatient and outpatient settings. Reliability of the SF-36 version 2 is reported to be high (0.85) and internal consistency (α=0.88 and 0.95) is good (Ware, Kosinski, & Dewey, 2007). The SF-36 results can be summarized into two components, a physical component summary (PCS) and a mental component summary (MCS) according to algorithms formulated by the developers.

A criticism of many of the modular and generic instruments is that they assume the importance of the different components of QOL to be the same for all individuals instead of allowing the patient to decide. Other generic, yet individualized QOL assessments have been developed to address this issue, such as the Schedule for the Evaluation of Individual QOL (SEIQOL) (McGee, O'Boyle, Hickey, O'Malley & Joyce, 1991) and the Patient-Generated Index (Annells, Koch, & Brown, 2001). Both instruments offer a way to obtain the patient's evaluation on matters that are most important to them. They are described in King's 2006 publication.

Quality of Life, Patient-Centered Nursing Practice

The goals of nursing practice for the particular setting will determine many factors in the implementation of QOL assessment; variables include how the assessment takes place, the frequency of assessment, analysis of the results, and discussion with the patient. Building

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upon the nurse-patient relationship, assessment results can be used by the nurse to begin dialogue about aspects of life that are not in concert with the patient's expectations. The nursing process can ensue by inquiring further into the QOL domains that the patient highly values but in which satisfaction, or the rating, is low. Together, the nurse and patient can begin planning ways to address these aspects of life, based upon the patient's experience and preferences. This method can enhance communication, allow more meaningful interactions between the nurse and patient, empower the patient through autonomous decision-making, and align interventions with the aspects of life that are highly valued by the patient.

The frequency of assessment will also depend on the goals of nursing and clinical setting. Ideally, QOL assessments should be done throughout the healthcare experience, as patient response and needs will vary depending on the individual's circumstances, stage of disease, the treatment regimen, and the response to treatment, both short and long-term. With the emergence of electronic medical records accessible across settings, interventions to address QOL could be documented and carried through on an ongoing basis to provide continuity in care.

Besides the paper-and-pencil format, portable computers with touch-screen technology are available, which might enhance the patient's ability to complete the assessment and provide quick access to the results by clinicians. This format has been shown to be acceptable and easy to use by patients in multiple settings (Bush et al., 2005; Millsopp, Frackleton, Lowe & Rogers, 2006). Such tools can be utilized to facilitate routine QOL assessment in the inpatient and outpatient setting, to provide clinicians with timely longitudinal QOL information about the patient and to overcome some of the resource restrictions preventing clinicians' participation.

The development of software that allows immediate analysis and results that can be discussed with the patient could accelerate the use of QOL data by clinicians and may prove to be extremely useful in being able to deliver patient-centered nursing care (see Quality-of-Life Recorder in Table 3). An automated program that links the patient's results to specific nursing interventions based on evidence-based practice may also be a valuable tool directing medical-surgical nursing interventions. Patient-teaching scripts, self-management information and local/national resources could be connected so that the nurse would be able to meet the immediate needs of the patient.

Conclusions

QOL assessment is a driving force behind our ability to address the multiple concerns of patients, in guiding treatment decisions throughout the course of illness and identifying areas that require further research. Medical-surgical nurses can play an instrumental role in obtaining and using QOL data to identify patient needs and direct interventions toward improving QOL. Identifying the most appropriate QOL framework and instrument for the specific patient population and setting in which it will be used is the first step. The goals of nursing care will dictate whether the measurement of QOL should be unidimensional, multidimensional, or limited to a symptom-severity scale. By matching the QOL conceptual framework and the instrument with the goals of the clinical setting, the nurse can gain valuable personalized knowledge about the patient's need for information and resources, how he/she is coping with illness, and the outcomes of applied strategies for managing symptoms. The time and resources spent on collecting and analyzing the data are becoming less of a barrier as computer-based systems are replacing the cumbersome use of paper-pencil assessments. In addition, as larger databases are compiled, QOL data will become another tool to help guide treatment decisions. QOL assessment has the potential to enhance clinical practice and improve the lives of patients. To that end, it is an outcome that is

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extremely valuable to medical-surgical nurses, however, it can only be realized if we take the time to implement QOL assessment as an approach to care.

References

American Psychiatric Association/Taskforce for the Manual of Psychiatric Measures. Handbook of psychiatric measures. Washington D.C: American Psychiatric Assoc; 2000.

Annells M, Koch T, Brown M. Client relevant care and quality of life: The trial of a client generated index (CGI) tool for community nursing. International Journal of Nursing Studies. 2001; 38:9–16. [PubMed: 11137718]

Bailey DE, Wallace M, Mishel MH. Watching, waiting and uncertainty in prostate cancer. Journal of Clinical Nursing. 2007; 16:734–741. [PubMed: 17402955]

Bush NE, Donaldson GW, Moinpour C, Haberman M, Milliken D, Markle V, Lauson J. Development, feasibility and compliance of a web-based system for very frequent QOL and symptom home self-assessment after hematopoietic stem cell transplantation. Quality of Life Research. 2005; 14:77–93. [PubMed: 15789943]

Conroy T, Uwer L, Deblock M. Health-related quality-of-life assessment in gastrointestinal cancer: are results relevant for clinical practice? Current Opinion in Oncology. 2007; 19:401–406. [PubMed: 17545808]

Cooley ME, McCorkle R, Knafl GJ, Rimar J, Barbieri MJ, Davies M, et al. Comparison of health-related quality of life questionnaires in ambulatory oncology. Quality of Life Research. 2005; 14:1239–1249. [PubMed: 16047500]

Davidson JR, Findlay L, Zetes-Zanatta L, Ram SS, Brundage MD, Smith A. Assessing the supportive care needs of patients who attend a cancer centre: development and feasibility of a questionnaire. Quality of Life Research. 2003; 2:814–820.

Detmar SB, Muller MJ, Schornagel JH, Wever LDV, Aaronson NK. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. JAMA. 2003; 288:3027–3034. [PubMed: 12479768]

Ding Y, Zhu Y, Zhang M. Quality of life of Chinese patients with ovarian malignancies during chemotherapy under condition of no recurrence. Cancer Nursing. 2007; 30:243–251. [PubMed: 17510589]

Efficace F, Bottomley A, Coens C, Van Steen T, Conroy P, Schöffski H, et al. Does a patient's self-reported health-related quality of life predict survival beyond key biomedical data in advanced colorectal cancer? European Journal of Cancer. 2006; 42:42–49. [PubMed: 16298522]

Efficace F, Bottomley A, Smit EF, Lianes P, Legrand C, Debruyne C, et al. Is a patient's self-reported health-related quality of life a prognostic factor for survival in non-small-cell lung cancer patients? A multivariate analysis of prognostic factors of EORTC study 08975. Annals of Oncology. 2006; 17:1698–1704. [PubMed: 16968876]

Efficace F, Osoba D, Gotay C, Sprangers M, Coens C, Bottomley A. Has the quality of health-related quality of life reporting in cancer clinical trials improved over time? Towards bridging the gap with clinical decision making. Annals of Oncology. 2007; 18:775–781. [PubMed: 17259641]

Ferrans CE. Development of a conceptual model of quality of life. Scholarly Inquiry for Nursing Practice: An International Journal. 1996; 10:293–304.

Ferrans CE, Powers MJ. Psychometic assessment of the Quality of Life Index. Research in Nursing and Health. 1992; 15:29–38. [PubMed: 1579648]

Ferrell B, Grant M, Padilla G, Vemuri S, Rhiner M. The experience of pain and perceptions of quality of life: Validation of a conceptual model. Hospice Journal. 1991; 7:9–24. [PubMed: 1820306]

Frank-Stromborg, M.; Olsen, SJ. Instruments for clinical healthcare research. Boston: Jones & Bartlett; 2003.

Haberman, M.; Bush, N. Quality of life: Methodological and measurement issues. In: King, CR.; Hinds, PS., editors. Quality of life from nursing and patient perspectives: Theory, research and practice. 2nd ed.. Boston: Jones & Bartlett; 2003. p. 117-139.

Henrich G, Herschbach P. Question on life satisfaction: A short questionnaire for measuring subjective quality of life. European Journal of Psychological Assessments. 2000; 16:150–159.

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Juarez G, Ferrell B, Uman G, Podnos Y, Wagman LD. Distress and quality of life concerns of family caregivers of patients undergoing palliative surgery. Cancer Nursing. 2008; 31:2–10. [PubMed: 18176125]

King CR. Advances in how clinical nurses can evaluate and improve quality of life for individuals with cancer. Oncology Nursing Forum. 2006; 33:5–12. [PubMed: 17202084]

King, CR.; Hinds, PS. Quality of Life from Nursing and Patient Perspectives: Theory, Research and Practice. 2nd ed.. Boston: Jones & Bartlett; 2003.

Kuehler A, Henrich G, Schroeder U, Conrad B, Herschbach P, Ceballos-Baumann A. A novel quality of life instrument for deep brain stimulation in movement disorders. Journal of Neurology, Neurosurgery, and Psychiatry. 2003; 74:1023–1030.

McGee HM, O'Boyle CA, Hickey A, O'Malley K, Joyce CR. Assessing the quality of life of the individual: The SEIQoL with a healthy and a gastroenterology unit population. Psychological Medicine. 1991; 21:749–759. [PubMed: 1946863]

Mehanna HM. Will measuring quality of life in head and neck cancer alter individuals' treatment? Current Opinion in Otolaryngology & Head & Neck Surgery. 2007; 15:57–62. [PubMed: 17413403]

Millsopp L, Frackleton S, Lowe D, Rogers SN. A feasibility study of computer-assisted health-related quality of life data collection in patients with oral and oropharyngeal cancer. International Journal of Oral and Maxillofacial Surgery. 2006; 35:761–764. [PubMed: 16697148]

Ramsey SD, Zeliadt SB, Hall IJ, Ekwueme DU, Penson DF. On the importance of race, socioeconomic status and comorbidity when evaluating quality of life in men with prostate cancer. Journal of Urology. 2007; 177:1992–1999. [PubMed: 17509278]

Reeve BB, Hays RD, Bjorner JB, Cook KF, Crane PK, Teresi JA, et al. Psychometric evaluation and calibration of health-related quality of life item banks: Plans for the patient-reported outcomes measurement information system (PROMIS). Medical Care. 2007; 45:S22–S31. [PubMed: 17443115]

Sloan JA, Frost MH, Berzon R, Dueck A, Guyatt G, Moinpour C, et al. The clinical significance of quality of life assessments in oncology: a summary for clinicians. Support Care Cancer. 2006; 14:988–998. [PubMed: 16794811]

Snyder CF, Dy SM, Hendricks DE, Brahmer JR, Carducci MA, Wolff AC, et al. Asking the right questions: investigating needs assessments and health-related quality-of-life questionnaires for use in oncology clinical practice. Support Care Cancer. 2007; 15:1075–1085. [PubMed: 17318591]

Vallerand, AH.; Breckenridge, DM.; Hodgson, NA. Theories and conceptual models to guide quality of life related research. In: King, CR.; Hinds, PS., editors. Quality of Life from Nursing and Patient Perspectives: Theory, Research and Practice. 2nd. Boston: Jones & Bartlett; 2003. p. 37-53.

Varricchio CG. Measurement issues in quality-of-life assessments. Oncology Nursing Forum. 2006; 33:13–21. [PubMed: 17202085]

Velanovich V. Using quality-of-life measurements in clinical practice. Surgery. 2007; 141:127–133. [PubMed: 17263966]

Velikova G, Booth L, Smith AB, Selby PJ. Measuring quality of life in routine oncology practice improves communication and patient well being: a randomized controlled trial. Journal of Clinical Oncology. 2004; 22:714–724. [PubMed: 14966096]

Ward-Smith P, Wittkopp D, Sheldon JM. Quality of life among men treated with brachytherapy for prostate cancer. Urologic Nursing. 2004; 24:95–99. [PubMed: 15131916]

Ware, JE.; Kosinski, M.; Dewey, JE. Users manual for the SF-36v2 Health Survey. Lincoln, RI: Medical Outcomes Trust and QualityMetric Incorporated; 2007.

Webster K, Odom L, Peterman A, Lent L, Cella D. The Functional Assessment of Chronic Illness Therapy (FACIT) measurement system: Validation of version 4 of the core questionnaire. Quality of Life Research. 1999; 8:604–611.

Zuydam AC, Lowe D, Brown JS, Vaughan ED, Rogers SN. Predictors of speech and swallowing function following primary surgery for oral and oropharyngeal cancer. Clinical Otolaryngology. 2005; 30:428–437. [PubMed: 16232247]

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Table 1

Commonly Identified Definitions of Quality of Life

Quality of life: a general measure of life satisfaction or well-being
Ferrans & Powers (1992): “a person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her” (p. 29).
Padilla & Grant (1985): “that which makes life worth living” (p. 45).
World Health Organization (1993): “the individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (p. 1).
Zhan (1992): “the degree to which a person’s life experiences are satisfying” (p. 796).
Health-related quality of life: the degree in which one’s usual or expected level of physical, emotional, and social well-being are affected by a medical condition or the treatment of the condition (Cella, 1998).

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Table 2

Web-based Resources for Quality of Life Assessments

The Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID) is easily accessible (http://www.qolid.com/), listing over 605 instruments, provides details on the objectives of the instrument, populations that is has been used in, the mode of administration, number of items, existence of a database, time recall, translations, and authors.
The Toolkit of Instruments to Measure End-of-Life Care (TIME) provides descriptions of many quality of life tools along with psychometric properties of some of the more established instruments (http://www.chcr.brown.edu/pcoc/Quality.htm).
The Australian Centre on Quality of Life offers many resources for identifying instruments, relevant publications and automated scoring systems (http://www.deakin.edu.au/research/acqol/instruments/index.htm).
The On-line Guide to Quality of Life Assessment (OLGA) provides instrument description, scoring, and measurement properties, including validity and responsiveness, of all major quality- of-life instruments. Each summary includes contact and copyright information, accumulated evidence of instrument validity, tables of reliability coefficients, review versions of instruments, and instrument-specific bibliographies (http://www.olga-qol.com/).
Mapi Research Institute is an international company with a special interest in advancing the worldwide use of patient-reported and clinical assessments through linguistic validation for appropriate cross-cultural use and interpretation (http://www.mapi-research.fr/index.htm).
The Hong Kong Society for Quality of Life (HKSoQOL) is a non-profit organization consisting of members who are interested in the study on quality of life. It promotes the application of informed knowledge of QOL to enhance services and policy development in public health, medical, rehabilitation and the social service sectors http://www.hksoqol.org/index.htm.
Quality-of-Life Recorder (http://www.ql-recorder.com/) offers software that enables patients to complete self-assessment questionnaires via a pen-computer, touch-screen. It supports a variety of QOL instruments in many languages and has an editor so that other questionnaires can be added. Patient results are tabulated immediately and can be printed, compared over time through the database, or downloaded to a statistical program.

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Table 3

Types of Quality of Life Instruments

Unidimensional instruments measure one variable, such as pain, fatigue or physical functioning.
Multidimensional instrument provides a comprehensive assessment of the essential dimensions of quality of life (as defined by the instrument developer).
Modular instrument is composed of two sections, a core set of general items applicable to many types of conditions, and a disease-or treatment-specific section.
Global instrument assess the general perception of QOL by asking one question directed at a single measure.
Generic instrument relates to people across the health-illness trajectory and can be used specifically to compare results across populations.
Cancer-specific instrument is designed to measure the dimensions of QOL in people with cancer; they can focus on a single type of cancer or be applicable to a variety of cancers and therapies.

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Table 4

Examples of Unidimensional, Multidimensional, and Global Instruments Commonly Used in Oncology

Unidimensional, Generic						
Instrument (Authors)	**Objective**	**Original language**	**Translations**	**Mode of administration**	**Number of items**	**Database**
Beck Depression Inventory – Second Edition (Beck, A. T.)	To measure the severity of depression in adults and adolescents	English	French for Belgium, Korean, Romanian, Spanish	Interviewer or Self	21	No
McGill Pain Questionnaire (MPQ) (Melzack, R.)	To provide quantitative measures of the sensory, affective and evaluative components of pain	English	Arabic Czech Danish, Dutch Finnish French German, Greek Hungarian Italian, Japanese, Norwegian, Polish, Potugueses, Slovak, Spanish, Swedish	Caregiver, Interviewer, Proxy, or Self	MPQ:20; MPQ Short Form:15	No

Unidimensional, Cancer-Specific						
Instrument (Authors)	**Objective**	**Original language**	**Translations**	**Mode of administration**	**Number of items**	**Database**
Karnofsky Performance Status Index (Karnofsky, D. A.)	To assess the functional status of cancer patients	English	Chinese, Turkish	Proxy	1	No
Structural-Functional Social Support Scale (Ulla-Sisko, L., Kellokumpu-Lehtinen, P.,	To obtain detailed information on the disease-specific social network and social	Finnish	English	Self	10	No

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Unidimensional, Cancer-Specific

Instrument (Authors)	Objective	Original language	Translations	Mode of administration	Number of items	Database
& Ojanen, M.)	support					
Supportive Care Needs Profile (Bonevski, B., Boyes, A., Burton, L., Cook, P., Girgis, A., Sanson-Fisher, R., & The Supportive Care Review Group)	To assess generic needs of patients with cancer	English	None	Self	SCNS-LF59: 59 needs items; SCNS-SF34: 34 needs items	No
Symptom Distress Scale (McCorkle, R.)	To facilitate control and management of cancer symptom distress	English	French Spanish Swedish	Self	13	No

Multidimensional, Generic

Instrument (Authors)	Objective	Original language	Translations	Mode of administration	Number of items	Database
McMaster Health Index Questionnaire (MHIQ) (Chambers, L. W.)	To supplement clinical ratings of health status, with QoL measures based on physical, social and emotional functions	English	None	Interviewer, Self or Telephone	59	No
Nottingham Health Profile (Hunt, S., McEwen, J., & McKenna, S. P.)	To provide a brief indication of a patient's perceived emotional social and physical health problems	English for U.K.	Over 21	Self	38	Yes

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Multidimensional, Generic

Instrument (Authors)	Objective	Original language	Translations	Mode of administration	Number of items	Database
Sickness Impact Profile (Bergner, M., & Gilson, B.)	To provide a descriptive profile of changes in a person's behavior due to sickness	English	Arabic Chinese Danish Finnish French Norwegian Potuguese Spanish Swedish Tamil Thai	Interviewer or Self	136	Yes
World Health Organization Quality of Life Assessment Instrument (WHOQOL)	To assess individuals' perceptions on the quality of their life	Croatian English French Hebrew Hindi Japanese Russian Spanish Thai	Over 39	Interviewer or Self	WHOQOL-100, 100 items. WHOQOL-BREF, 26 items.	Yes

Multidimensional, Cancer Specific

Instrument (Authors)	Objective	Original language	Translations	Mode of administration	Number of items	Database
Breast Cancer Chemotherapy Questionnaire (Levine, M. N.)	Developed for use as an outcome measure in clinical trials of adjuvant chemotherapy in women with stage II breast cancer	English for Canada	None	Interviewer	30	No
Linear Analog Self-Assessment (LASA) (Selby, P. J.)	Assessing the quality of life of cancer patients	English for U.K.	None	Self	31	No
Fox Simple QOL Scale (FSQOL) (Fox, S.)	To assess the quality of life in caner	English	None	Self	25	No
Quality of Life (QL) (Ferrell, B. R., & Grant, M.)	To assess quality of life in cancer	English	Spanish	Self	Patient version (QOL-CS): 41 /	No

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Multidimensional, Cancer Specific						
Instrument (Authors)	**Objective**	**Original language**	**Translations**	**Mode of administration**	**Number of items**	**Database**
					Family version: 37 / Bone Marrow Transplant version (QOL-BMT): 64 QoL items/ Breast Cancer version: 46 / Thyroid version (QOL-Thyroid): 30 / Ovarian Cancer version: 43	
Rotterdam Symptom Checklist (Cull, A., de Haes, J. C., Fayers, P., Hopwood, P., Olchewski, M., Sanderman, R., & Visser, M. R.)	To measure the quality of life in cancer patients	Dutch	Czech English Finnish French German Hungarian Italian Portuguese Serbian Spanish Turkish Zulu	Interviewer, Proxy or Self	38 + 1 global question	No

Global Single-item						
Instrument (Authors	**Objective**	**Original language**	**Translations**	**Mode of administration**	**Number of items**	**Database**
Perceived Adjustment to Chronic Illness Scale (PACIS) (Humy, C.)	To assess (with a single-item linear analogue self-assessment indicator) the adjustment process	English	Over 19 languages	Self	1	Yes

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Global Single-item						
Instrument (Authors	**Objective**	**Original language**	**Translations**	**Mode of administration**	**Number of items**	**Database**
Quality of Life Visual Life Analogue Scale (VAS) (Lorig, K.)	To assess perceived global quality of life	English	None	Self	1	No