

# Measuring Patient-Oriented Outcomes in Palliative Care: Functionality and Quality of Life

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Outcomes measurement is necessary to evaluate quality of care, increase knowledge about experiences with cancer and therapies, and determine the effectiveness of interventions directed toward improving symptoms and quality of life (QOL) in research and clinical care. Recent attention on outcomes measurement and research in palliative care settings has emphasized the need to incorporate patient-reported outcomes. Unlike other areas of research in oncology, palliative care research is comprised largely of descriptive studies elucidating the process involved with palliative care, with a notable void in well-designed patient-oriented studies employing standard instruments for measuring functional status, QOL, symptoms, and psychosocial well-being. Outcomes programs in practice settings where palliative care is an integral part of clinical services can offer important information about patient experiences across the continuum of care and help to identify patients most likely to benefit from palliative care interventions. Therefore, oncology nurses must be informed about outcome-measurement issues, including ways to select reliable and valid instruments and determine which ones are appropriate for palliative care populations. Content related to the measurement of patient-oriented outcomes is presented to assist nurses in developing outcomes programs in palliative care settings.

**A**n outpatient palliative care service, the Pain and Supportive Care Program, has been established at the Joan Karnell Cancer Center (JKCC) at Pennsylvania Hospital in Philadelphia. The three-year-old program serves patients with cancer at the nation's first hospital with an enrollment average of 400 patients in various phases of disease from newly diagnosed to end stage. As part of the program, an interdisciplinary team comprised of oncology nurses, advanced practice nurses, physicians, social workers, physical therapists, a psychologist, music therapists, and other health professionals is designing an outcomes research program to measure the effectiveness of targeted palliative care interventions (e.g., symptom management strategies, structured counseling, music therapy sessions). The team has been challenged to find ways to document how a palliative care program achieves optimal outcomes for patients and families. Recognizing the importance of outcomes measurement, advanced practice nurses at JKCC partnered with two nurse researchers in the School of Nursing at the University of Pennsylvania to review standard instruments to capture patient outcomes throughout the cancer experience. A detailed summary of the team's work, focused on the measurement of functionality and quality of life (QOL) in palliative care, is presented, and a thorough appraisal of standard instruments and their application in palliative care practice settings is provided.

## At a Glance

- ◆ Measurement of patient outcomes with palliative care is important to understand patient experiences and evaluate the effectiveness of interventions.
- ◆ Numerous reliable and valid patient-reported instruments can be used in palliative care settings.
- ◆ Knowledge of measurement and instruments can assist nurses in selecting the most appropriate outcome measures for clinical care and research.

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Digital Object Identifier:10.1188/08.CJON.65-77

Oncology nurses in inpatient, outpatient, and homecare settings play an important role in patient-oriented outcomes measurement and research. First, oncology nurses can determine the feasibility of collecting patient-oriented outcomes in clinical practice. Is there enough time to obtain patient-reported outcomes? Is there a place where patients can complete questionnaires or instruments? Who is available to assist patients? Second, nurses have unique knowledge of their patients and can help to select the appropriate tools for specific patient populations. Third, nurses appreciate how outcomes can be used to direct clinical care. For example, nurses routinely assess pain and symptoms and use responses from patients to intervene and ensure the appropriate level of care. Last, nurses always are searching for ways to document that their care truly makes a difference in the lives of patients.

To participate in outcomes programs, oncology nurses must (1) understand the underlying concepts of outcomes measurement, (2) have knowledge of indicators of quality of care, (3) be familiar with criteria used to evaluate the strengths and weaknesses of instruments, and (4) be able to determine measures that are best suited for their patient populations and practice settings. After all, issues related to measuring patient perceptions and experiences are not new to many nurses because undergraduate and graduate courses in clinical practice, research, and statistics emphasize the reliability and validity of outcomes measures. In fact, many nurses participate in journal clubs, are involved in critiquing research when developing evidence-based practice protocols and guidelines, and are responsible for conducting performance-improvement projects linking care with outcomes. Such activities require an understanding of methods and outcomes of research studies, in addition to how conclusions are formed from measurement indicators. Oncology nurses who work in settings that conduct clinical trials are exposed to a variety of standard patient-reported instruments for functionality and QOL, and some even explain and administer the questionnaires to patients.

Oncology nurses continually are challenged to identify ways to measure patient responses to treatments and supportive care interventions such as palliative care. Although considerable progress has been made in developing and testing patient-specific instruments for outcomes research and performance improvement, the instruments seldom are used in clinical practice to build outcomes programs (Clancy & Lawrence, 2002). Outcomes measurement is essential to assess quality of care, increase knowledge about patient experiences with cancer, and evaluate the effectiveness of interventions directed toward improving QOL and symptoms. Demands for greater accountability for quality performance imposed by administrators and national accreditation agencies and organizations have warranted more formalized approaches to gathering data from patients. Outcomes research in oncology is an emerging area of investigation that encompasses the study of quality of adjustment, QOL, satisfaction with care, and the societal impact of cancer. From the National Cancer Institute's perspective, "Outcomes research describes, interprets, and predicts the impact of various influences, especially (but not exclusively) interventions on 'final' endpoints that matter to decision makers, patients, providers, private payers, government agencies, accrediting organizations, or society at large" (Lipscomb & Snyder, 2002,

p. 3). Recent attention has focused on outcomes in palliative care settings, emphasizing the need to design comprehensive outcomes programs. Oncology nurses can use patient outcomes to understand individual experiences, direct care, and gauge the success of palliative or supportive care interventions. As such, oncology nurses need to know how to obtain reliable and valid patient-reported data and how to do so in clinical practice and with research. This article informs nurses about the psychometric properties of standard instruments for measuring functionality and QOL, criteria for selecting appropriate instruments for various populations, and strategies for building outcomes programs based on patient-reported measures. Supporting evidence on the utility of the tools in palliative care settings forms the basis for making decisions regarding the most appropriate tools to employ in routine clinical practice and for the purposes of research.

## Outcomes Measurement in Palliative Care: A Call for Action

In the United States, palliative care has expanded beyond just caring for people at the end of life to improving QOL for all people living with serious, complex, and eventually terminal illnesses; it is offered simultaneously with life-prolonging and curative therapies (National Palliative Care Research Center, 2007). According to the World Health Organization (2002), "Palliative care is an interdisciplinary team approach that improves the quality of life of patients and families living with a life-threatening illness through early identification, assessment, and treatment of pain and other physical, psychological, and spiritual problems." From 2001–2003, the number of hospital-based palliative care programs grew from 632 to 1,027, a 60% increase (Morrison, Maroney-Galin, Kralovec, & Meier, 2005). Despite the proliferation, limited research demonstrates the benefits of interventions by palliative care teams on patient and care outcomes (Francke, 2000; Higginson et al., 2002; Jack, Hillier, Williams, & Oldham, 2003). Unlike other areas of oncology research, palliative care research is comprised largely of descriptive studies elucidating the process involved in delivering care. An earlier review of 16 studies investigating the effectiveness of palliative care teams showed encouraging results for physical symptoms but no clear and somewhat contradictory findings for other areas such as psychosocial and spiritual outcomes, costs of care, and resource consumption (Francke).

Two nationally publicized documents call for greater emphasis on practice-based models that incorporate outcomes measurement in routine clinical care. At the December 2004 National Institute of Health (NIH) State-of-the-Science Consensus Conference on Improving End-of-Life Care, consensus was reached about the significant gaps in science and knowledge related to patient-reported outcomes with palliative care ("NIH State-of-the-Science Conference Statement," 2004). Similarly, recommendations put forth by experts at the July 2002 NIH State-of-the-Science Conference on Symptom Management in Cancer Pain, Depression and Fatigue drew attention to the lack of focused approaches to assess and treat symptom clusters, specifically pain, fatigue, and depression (Patrick et al., 2003).

The message from the National Palliative Care Research Center (2007) is that “without research, palliative care is an art, not a science.” Well-designed studies are needed to determine the effectiveness of palliative care and to identify patient populations likely to benefit most from interventions. Moreover, outcomes research programs in practice settings where palliative care is an integral part of clinical services can provide valuable information about patient experiences across the continuum of care. Because of more broadly defined palliative care, standardized instruments originally designed to measure outcomes with treatment protocols have been adapted and tested specifically for palliative care populations. With so many of the questionnaires and tools, clinicians struggle with when, how, and what to measure in palliative care programs.

## Considerations in Outcomes Measurement

### Instrument Selection

Before selecting outcomes measurement tools for use in palliative care settings, oncology nurses must consider the following. First, the intent or purpose for outcomes measurement in palliative care has important implications for selecting measurement tools. In research, outcome measures must be capable of generating data to answer questions and test hypotheses. Performance-improvement projects often involve careful attention to measuring outcome(s) related to indicators that monitor quality of care. Outcomes measurement in routine clinical practice may use various approaches, from capturing multiple patient outcomes to a more focused effort of measuring the effectiveness of specific treatments and supportive care approaches. Patient outcomes studies or projects that are conducted to generate information or data for internal institutional use (e.g., performance or quality improvement) in the course of routine clinical practice may not require prior approval from an institutional review board (IRB). On the other hand, when the intent of a study or project is to disseminate findings externally through professional venues (e.g., presentations, publications), researchers must check with the institution's office for human subjects protection or IRB to determine whether IRB approval may be required. For outcomes research that is an integral part of routine clinical practice, nurses may seek authorization for waiver of informed consent with imposed stipulations on access to protected health information and de-identification of results. Regardless of how data are used or the scope of data collection, appropriate instruments are selected based on their measurement domains, psychometric properties, applicability to patient populations, and feasibility of use.

Second, careful attention must be paid to the conceptual basis and domains of an instrument and whether the instrument reflects the outcomes that are of greatest importance to measure. Theory-derived instruments are guided by theoretical constructs and concepts from theories in the construction of items or groups of items. The theoretical constructs or conceptual underpinnings of an instrument generally are cited in the original work describing how the instrument was developed. Conceptual domains, part of a theory or conceptual framework, often are

represented by an instrument's subscales or item groupings measuring a similar concept. Multidimensional measures such as QOL instruments typically have several measurement domains, such as functional status and ability, physical symptoms (e.g., pain, fatigue, nausea, anorexia), psychosocial issues (e.g., psychological distress, occupational concerns, social relationships, sexuality and intimacy, financial concerns), and spirituality.

Third, outcomes measures must be used for the appropriate group of respondents, especially for patient-reported instruments. For example, instruments centered on treatment side effects, occupational-related functioning, or rehabilitation may not be appropriate for patients nearing the end of life who have exhausted all treatment options. Disease- and treatment-specific instruments may address unique experiences or aspects of care that are relevant to a given population and, therefore, may be applicable only to certain patients. Last and importantly, outcome measures must be reliable and valid in palliative care. Instruments are selected for their ease of use, number of items, time for completion, readability and interpretability of items or questions by responders, timing and sequencing of administration, and scoring methods. When evaluating culturally diverse populations, nurses must take into account availability of instruments in multiple languages and cultural variations.

### Psychometric Properties of Patient-Reported Instruments

Psychometric properties of instruments are defined by measures of reliability and validity. Estimates of reliability and validity are obtained from results of either homogeneous (similar) or heterogeneous (diverse) study samples and are interpreted in relation to the samples. Psychometric properties of an instrument may not hold up across various groups of patients; therefore, clinicians should select tools that have demonstrated reliability and validity in populations similar to the ones they wish to study.

Reliability refers to consistency in measurement, consistency over time, and an instrument's reproducibility in results. The reliability coefficient is an index of stability and is represented by a value assigned using a particular method, usually a correlation coefficient between 0 and 1; the higher the correlation coefficient, the higher the reliability. The threshold for acceptable reliability is generally 0.8; however, slightly lower values are tolerated depending on the numbers of items assessed and methods used (Nunnally & Bernstein, 1994). Reliability may be higher for the overall items of an instrument compared to item groups and subscales. Table 1 describes several forms of reliability; meeting the requirements for reliability using only one method is sufficient.

Validity indicates how well an instrument measures what it is supposed to measure. Judgments are based on evidence and statistical procedures to ascertain the appropriateness of inferences drawn from the results of scores obtained from a group of respondents and can be “acceptable” or “weak.” An instrument that is not reliable is not considered valid and consequently would not meet the rigor required for acceptable psychometric properties (Polit & Beck, 2007). The types of validity and the ways in which validity can be determined are detailed in Table 1.

**Table 1. Types of Reliability and Validity**

TYPE OF RELIABILITY	DEFINITION AND METHODS
Internal consistency reliability	Refers to the extent to which items in a test are related to one another; estimated based on one administration of a questionnaire or survey. The most common measure of internal consistency reliability is Cronbach's alpha.
Test-retest reliability	Extent to which the test yields similar results or is consistent over time and is stable. The same instrument is administered to the same group on two separate occasions, and the scores are correlated. The shorter the retest interval, the better, and situational factors and conditions under which the instrument is administered must be controlled. This type of reliability may not be appropriate for unstable attributes or variables that fluctuate considerably over time (e.g., pain, other symptoms).
Alternate forms reliability	Also referred to as parallel or equivalent forms, reliability assesses the consistency of the results of two instruments constructed in the same way, from the same content domain, and standardized on the same population. A new measure may be compared to an existing one with established reliability. The results from both instruments are correlated, and the higher the correlation, the better the reliability.
TYPE OF VALIDITY	DEFINITION AND METHODS
Face validity	Extent to which a measurement tool makes intuitive sense. Generally face validity is obtained by looking at the item or items and making an uncalculated judgment.
Content validity	Extent to which an instrument makes intuitive sense to a group of experts in the area and the extent to which the content of an instrument sufficiently covers the area it purports to measure. A content validity index can be calculated between judgments by experts.
Construct validity	The degree to which an instrument relates to the underlying theoretical construct of the tool or scale. It is important to demonstrate what the test purports to measure as it is to demonstrate what the test does not measure. Methods of conducting construct validity include a factor analysis (which is a technique to group similar items in constructing subscales of an instrument or confirming the domains) and contrasted groups approach (detecting significant differences between respondents possessing a high level of the attribute or variable measured to those with a low level). The following other forms of validity are used to support construct validity.
Concurrent validity	Also called criterion-related validity, determines the extent to which an instrument yields the same results with a population compared with another well-established instrument. Levels of 0.80 or greater are typically considered to be adequate for concurrent validity.
Predictive validity	Extent to which the results of a test are predictive of the future performance of a population. To determine the predictive value of an instrument, statistical tests such as regression analyses are used and these techniques can estimate just how good an instrument is predicting future outcomes for patients.
Convergent validity	Demonstrates that an instrument correlates with other measures in ways that are consistent with theoretical underpinnings of the instrument and relates to how well an instrument correlates with other measures of the same construct (correlation should be 0.4–0.69), but can only be meaningfully established within the context of discriminant validity. One is not meaningful without considering the other.
Discriminate validity	Demonstrates little relationship between the results of instruments and other variables with which the test scores theoretically should not correlate. A test should not correlate highly with tests unrelated to the construct being evaluated (0.0–0.39).

*Note.* Based on information from DeVellis, 1991; Frank-Stromborg & Olsen, 2004; Nunnally & Bernstein, 1994; Polit & Beck, 2007; Waltz et al., 2003.

Unlike reliability, no single validity coefficient or indicator exists for an instrument; rather, techniques are based on estimates and judgments of what scores on a measure really mean.

### Item Burden

Attention to respondent item burden is an important consideration in selecting an instrument or combining instruments or tools, especially when studying patients who must contend with complex treatment regimens, progressive disease, and the end of life. Little research has been done to address item burden, but some factors that contribute are: (a) relevance of measurement domains and items to respondents, (b) length of a questionnaire

and time for completion, (c) sequence and timing of administration, and (d) overall impact on the respondent, such as time commitment, physical exhaustion, and emotional distress from answering questions that may be upsetting. Equally important is determining the optimal point during the course of the disease trajectory, the individual readiness of patients, and their cognitive capacity for completing questionnaires. Figure 1 outlines strategies to help researchers overcome item burden.

### Palliative Care Outcome Measurement Tools

The Center to Advance Palliative Care ([CAPC], n.d.) and National Council for Palliative Care Web sites are excellent places to

find outcome measures that are suitable for use in palliative care settings. Many of the tools can be downloaded as PDF files so that clinicians and researchers can view the items that are included in the measure. However, practicing clinicians also must evaluate the measurement domains and consider the relative contributions that the instruments offer in capturing the outcomes of greatest interest. This article presents several instruments for measuring functionality and QOL, with relevant research supporting their psychometric properties and suitability for palliative care populations. A list of the instruments and practical information about their structures, measurement formats, and time required for completion appear in Table 2.

## Functional Status Instruments

### Karnofsky Performance Scale

The Karnofsky Performance Scale (KPS) is a single-item, unidimensional functional status scale used to obtain a global measure of level of activity, especially for patients undergoing cancer treatment (Hwang et al., 2004). Level of functionality is rated by a healthcare provider as a percentage ranging from 100% (normal, no complaints, no evidence of disease) down to 0% (dead). Acceptable reliability and validity have been established in research and clinical practice, especially when standardized scoring guidelines are used and opportunities to interview patients are possible (Mor, Laliberte, Morris, & Wiemann, 1984; Schag, Heinrich, & Ganz, 1984). A low KPS score is associated with high symptom distress (Hwang, Chang,

Fairclough, Cogswell, & Kasimis, 2003). Because it correlates closely with levels of symptom distress, the KPS often is used as a proxy measure for a global evaluation of a patient's status and most appropriately as a prognostication tool to predict life expectancy (Maltoni & Amadori, 2002; Stanley, 1980). A clear disadvantage of the KPS is its lack of specificity for defining aspects of function from the patient's perspective.

### Palliative Performance Scale

The Palliative Performance Scale (PPS) is based on a similar premise as the KPS and is completed by a healthcare provider. The original version, consisting of a unidimensional scale (Anderson, Downing, Hill, Casorso, & Lerch, 1996), has been expanded to include dimensions of ambulation, activity, evidence of disease, self-care, intake, and consciousness level. A healthcare professional scores each dimension by assigning a value from 100% to 0% (death), with 10% denoting the lowest level of functioning (PPS version 2) (Victoria Hospice, 2001). Ratings of ambulation and activity and evidence of disease are dominant over the latter variables. For example, a patient who mainly sits or lies down all day (50% ambulation score) but has normal intake and normal consciousness level (100% intake and conscious level scores) has an overall PPS score of 50%. Therefore, researchers and clinicians who plan to use the PPS version 2 should consider whether the hierarchy reflects the priorities for assessing patients.

Acceptable reliability and validity have been established for the PPS version 2, and studies have shown strong agreement with the KPS (Bradley, Davis, & Chow, 2005; Hwang et al., 2004). Studies differ in the value of PPS version 2 scores as prognostic indicators. PPS version 2 scores on admission have been shown to be significant predictors of survival among patients receiving palliative care and hospice care, but studies differ in measuring the impact of diagnosis on survival. Harrold et al. (2005) found the PPS to be a stronger prognostic tool for nursing home residents with noncancer diagnoses than for those with cancer, whereas Lau, Downing, Lesperance, Shaw, and Kuziemy (2006) reported no appreciable impact of diagnosis on survival of patients admitted to a palliative care unit. Such differences likely are related to sample size and characteristics and study settings. The scale has successfully predicted length of stay in hospice; declining scores are associated with worsening condition and death, whereas stable scores are associated with discharge from hospice care (Head, Ritchie, & Smoot, 2005). However, the PPS version 2 demonstrates insufficient sensitivity to distinguish outcomes between patients in the 30% category from those at 40% or between those in the 50% category from those in at 60% (Head et al.). Variations in performance of the scale may be attributed to discrepancies among users in interpreting and applying criteria from the scale, rather than an inherent problem with the scale itself.

### Short-Form Health Survey

The Short-Form Health Survey (SF-36) is one of the most widely used health outcomes survey. It consists of eight subscales measuring limitations in physical activities, social activities, and role activities caused by physical health and emotional problems, in addition to physical pain, general mental health, vitality, and general health perceptions (Stewart, Hays, & Ware,

- Be cautious about generic instruments, especially quality of life and other health outcome measures as some may have little relevance to the measurement domains or experiences of the target population and may lack specificity and sensitivity.
- Consider instruments tested on a similar target population to provide some assurance of its utility.
- Pay attention to overlap of measurement domains and redundancy of items among multiple instruments that can place additional item burden on respondents.
- Use specific screening questions, which can be a strategy to eliminate additional burden in completing questionnaires.
- Take into account ease of administration, number of items, and time for completion.
- Pilot test instrument(s) to evaluate patient acceptance and estimated time for completion.
- Select short-form versions of instruments, if available, reliable and valid.
- Examine relevant research on the instrument to determine response rates and frequency of missing data, which can be an indication of the relevancy of items, patient acceptance and ability of respondents to complete the questionnaire.
- Determine the appropriate intervals to administer questionnaires and avoid asking respondents to complete instruments more often than necessary.
- When using multiple instruments, sequence administration to reduce burden at any given time point.
- Think about the overall impact on respondents completing the questionnaire, weighing the risks and benefits.

**Figure 1. Strategies to Reduce Instrument Item Burden**

**Table 2. Instruments for Assessing Functional Status and Quality of Life (QOL)**

INSTRUMENT	NUMBER OF ITEMS; MEASUREMENT SCALE	TIME TO COMPLETE	MEASUREMENT CATEGORIES OR SUBSCALES	TIME FRAME; RESPONDENT	PATIENT POPULATION	DEVELOPMENT
<b>Functional status</b>						
Karnofsky Performance Scale (KPS)	One category; range = 100% (normal) to 0% (dead)	Observer, short	Health status	Present; healthcare provider	Adults in multiple cancer populations in all phases of illness	Expert
Palliative Performance Scale (PPS version 2) <sup>a</sup>	Five categories; range = 100% (full level) to 0% (death)	Observer, short	Ambulation, activity and evidence of disease, self-care, intake, consciousness level	Present; healthcare provider	Palliative care, hospice, and end-of-life patients	Expert adaptation from the KPS
36-Item Short-Form Health Survey (SF-36 version 2) <sup>a</sup>	36 items; scales vary, with a higher score indicating better health	5–10 minutes	Eight health concepts: limitations physical, social, and role activities; body pain; role emotions; general mental health; vitality; and general health	Variable: present and over the past month; patient or interviewer	Multiple cancer populations in all phases of illness; 14 years and older	Adapted from the Medical Outcomes Study (MOS) survey without respondent input
<b>Quality of life</b>						
European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30 version 3) <sup>a</sup>	30 items: 28 items four-point scale and two items seven-point scale	11–12 minutes	Five functional status scales, three symptom scales, one overall QOL and health status scale, six individual items	During the past week; patient	Adult patients with cancer	Expert design with respondent input
European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Palliative Care (EORTC QLQ-PAL-C15) <sup>a</sup>	15 items: 14 items four-point scale and one item seven-point scale	5–10 minutes	Derived from the original EORTC QLQ-C30 subscales; includes item for global QOL	During the past week; patient	Adult patients with cancer with poor prognoses	Expert design with respondent input
Functional Assessment of Cancer Therapy–General (FACT-G version 4) <sup>a</sup>	27 items; range = 0 (not at all) to 4 (very much); higher scores indicate better QOL.	5–10 minutes	Physical, functional, social and family, and emotional well-being subscales	During the past week; patient	Adult patients with cancer	Expert design with respondent input
Functional Assessment of Cancer Therapy–Bone Marrow Transplant (FACT-BMT version 3) <sup>a</sup>	47 items; FACT-G plus 20 BMT items; higher scores indicate better QOL.	15 minutes	FACT-G subscales plus 18 areas of concern specific to hematopoietic stem cell transplantation	During the past week; patient	Adult recipients of bone marrow transplants	Expert design with respondent input
Functional Assessment of Cancer Therapy–Fatigue (FACT-F version 3) <sup>a</sup>	41 items: FACT-G plus 14 fatigue items; higher scores indicate better QOL.	10–15 minutes	FACT-G subscales plus a subscale specific to fatigue issues	During the past week; patient	Adult patients with cancer	Expert design with respondent input
Functional Assessment of Cancer Therapy–Anemia (FACT-An) <sup>a</sup>	47 items: FACT-G plus 13 fatigue items plus seven additional items; higher scores indicate better QOL.	15 minutes	All FACT-F subscales and a subscale specific to anemia issues not included on the FACT-F	During the past week; patient	Adult patients with cancer	Expert design with respondent input
Cancer Rehabilitation Evaluation System–Short Form (CARES-SF) <sup>a</sup>	59 items; range = 0 (not at all) to 4 (very much)	30 minutes	Physical, psychosocial, medical interaction, marital and sexual functioning	Over the past month; patient	Adult patients with cancer	Adapted from the CARES by expert review

<sup>a</sup> Licensing agreement for use is required.

*(Continued on next page)*

**Table 2. Instruments for Assessing Functional Status and Quality of Life (QOL) (Continued)**

INSTRUMENT	NUMBER OF ITEMS; MEASUREMENT SCALE	TIME TO COMPLETE	MEASUREMENT CATEGORIES OR SUBSCALES	TIME FRAME; RESPONDENT	PATIENT POPULATION	DEVELOPMENT
McGill Quality of Life Questionnaire (MQOL) <sup>a</sup>	17 items; range = 0 to 10 points	10–30 minutes	Physical well-being and symptoms, psychological symptoms, existential well-being and support, and global QOL item	During the past two days; patient	Adult patients with cancer	Expert design with respondent input
Spitzer Quality of Life Index (QLI)	Five items; range = 0 (best QOL) to 2 (worst QOL)	Brief	Activity, daily life, health perceptions, social support, behavior	During the past week; healthcare provider or patient	Terminally ill patients	Adult patients with chronic illness
Schedule of Evaluation Individual Quality of Life Questionnaire (SEIQoL) <sup>a</sup>	46 items; visual analog scale; 100 mm scale; 0 (worst possible) to 100 (best possible)	40 minutes	Five respondent-nominated QOL domains, their relative importance, QOL with respect to each domain	Not applicable; patient with aid of interviewer	Relatively healthy patients	Expert design
Schedule of Evaluation Individual Quality of Life Questionnaire—Direct Weighting (SEIQoL-DW) <sup>a</sup>	15 items; visual analog scale; 100 mm scale; 0 (worst possible) to 100 (best possible)	5–10 minutes	Five respondent-nominated QOL domains, their relative importance, QOL with respect to each domain	Not applicable; patient in a structured interview	General population (including those with advanced disease)	Expert design
Therapy Impact Questionnaire (TIQ) <sup>a</sup>	36 items; four-point scale = 0 (not at all) to 4 (awful)	Not reported	Physical, functional, emotional, social, and cognitive status	During the past week; patient or healthcare provider	Terminally ill patients with cancer	Expert design
Functional Living Index—Cancer (FLIC)	22 items; seven-point scale; higher score indicates better quality of life.	Less than 10 minutes	Five domains: physical well-being and ability, emotional state, sociability, family situation, and nausea	Variable; patient	Adult patients with cancer	Expert design with respondent input

<sup>a</sup> Licensing agreement for use is required.

1988). Although it commonly is touted as a functional status and QOL instrument, it sometimes is described as a measurement of global health status. The SF-36 evolved from the 20-item Medical Outcomes Study (MOS) short form, which was inadequate in representing its domains and had less measurement sensitivity (Ware & Sherbourne, 1992). The survey can be completed by the patient or an interviewer. The SF-36 is capable of detecting outcomes related to QOL independent of mood, as measured by the Profile of Mood States (POMS), among patients with neuropathic pain (Deshpande, Holden, & Gilron, 2006). When compared to the Functional Assessment of Cancer Therapy-General (FACT-G), a QOL instrument, and Symptom Distress Scale (SDS), the SF-36 ranked first in achieving a 100% completion rate, and patients with lymphoma, early-stage cancer, or recent treatment had a higher preference for the SF-36 (Cooley et al., 2005). However, most patients favored the FACT-G and the SDS over the SF-36. Nevertheless, the SF-36 is a valid and reliable instrument that has been used extensively with patients with cancer (Golden-Kreutz et al., 2005; Ware, Kosinski, & Keller, 1994; Ware, Snow, & Kosinski, 2000). Shorter versions of the SF-36, such as the

SF-12, are available, but they have not been adequately studied in palliative care settings (Radbruch et al., 2000).

## Quality-of-Life Instruments

### European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30

The European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire Core 30 (QLQ-C30) consists of five multi-item scales measuring functionality in physical, role, social, emotional, and cognitive dimensions; three symptom scales measuring fatigue, pain, and nausea and vomiting; six single-item symptom measures; and a global health and QOL scale. Bruley (1999) raised concern about the appropriateness of the EORTC QLQ-C30 for patients in palliative care settings because it conceptualizes QOL in terms of normal life for a healthy individual. Researchers have concerns that the length of the instrument may be too demanding for respondents and that the items are not well suited for palliative care (Groenvold et al.,

## Case Study 1

Mrs. B is 35 years old and was recently diagnosed with metastatic breast cancer after a 3-year disease-free interval following lumpectomy with radiation therapy and aggressive chemotherapy. Upon a follow-up bone scan, two metastatic lesions are found in her pelvis and lumbar vertebrae, which are associated with significant pain and impaired mobility. For the past three weeks, she has been unable to work as an elementary teacher, care for her two young children, or manage her household. She and her husband are devastated by the news and the prospect of needing more chemotherapy. A pain regimen is started in the outpatient oncology clinic and she returns in two weeks for her first course of treatment. She reports being depressed, anxious, unable to sleep because she is worrying about dying, and has not left her house or spoken to her friends since news of her recurrence. Her oncology nurse coordinates palliative care interventions with counseling and social support by a social worker and psychologist and music therapy sessions by a music therapist. A symptom management plan is implemented.

### Opportunities for Outcomes Measurement

What patient-reported outcome measures could be used to gauge the effectiveness of outpatient palliative care on function and quality of life (QOL)? Given her treatment status, symptoms, psychological status, and the interference that her disease imposes on her social role in the family, a QOL measure that is robust in measuring aspects of emotional and social well-being is preferred. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30 v3) or the Functional Assessment of Cancer Therapy-General (FACT-G v4) administered monthly would provide important information about how she is responding to cancer treatment and palliative care interventions.

2006a). The EORTC QLQ-C30 is most appropriate for use during and directly after cancer treatment because of its emphasis on physical and functional aspects of QOL, which are most relevant at that time (Kopp et al., 2000). Several studies have demonstrated reliability and validity for the EORTC QLQ-C30 and its sensitivity to changes in QOL over time (Bjorner et al., 2004; Groenvold, Klee, Sprangers, & Aaronson, 1997; Hjermstad, Fossa, Bjordal, & Kaasa, 1995; Kaasa et al., 1995; Niezgodna & Pater, 1993). The EORTC QLQ-C30 has been translated and validated in 81 languages, and several disease-specific supplements exist, including breast, lung, head and neck, esophagus, ovary, gastric, and cervical cancers and multiple myeloma (EORTC Quality of Life Questionnaires, 2006).

### European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Palliative Care

To reduce respondent burden in multi-instrument studies, researchers and clinicians should consider using the shorter version of the EORTC QLQ-C30, the EORTC Quality of Life Questionnaire for Palliative Care (QLQ-C15-PAL), which has 15 items specifically designed for palliative care (Groenvold et al., 2006b). The elimination of items from the EORTC QLQ-C30 such as “Were you limited in pursuing your hobbies or other leisure time activities?” may have modified the original version in such a way to be better suited for end-of-life populations, limiting its utility with patients across the continuum of care. Because items were not respondent generated, the EORTC QLQ-C15-PAL fails to address existential and spiritual issues (Echteld, Deliens, Onwuteaka-Philipsen,

Klein, & van der Wal, 2006). Similar to the EORTC QLQ-C30, the EORTC QLQ-C15-PAL captures the physical domains of QOL, favoring its use for measuring functionality. Although the EORTC QLQ-C15-PAL is relatively new, it has considerable potential for use with patients with progressive disease.

### Functional Assessment of Cancer Therapy-General and Other Versions

The Functional Assessment of Cancer Therapy-General (FACT-G) is a 27-item QOL assessment tool with a five-point rating scale and measured well-being in physical, social, emotional, and functional dimensions. Its reliability, validity, and sensitivity to changes over time have been documented consistently (Cella et al., 1993). The development of the instrument was guided by respondent-generated information prioritizing the content of greatest importance to patients. Another major strength of the FACT-G is its minimal variability, which requires fewer respondents than instruments with large variability. In comparison to the EORTC QLQ-C30, smaller sample sizes may be required for FACT-G versions because it has greater ability to detect treatment differences in differentiating patient groups based on performance status (Cheung, Goh, Thumboo, Khoo, & Wee, 2005). Disease-specific and treatment-specific versions of the FACT tools differ from the EORTC QLQ modules in their QOL evaluation strategies. Whereas FACT tools seem to address the multitude of facets of QOL equally, the EORTC QLQ modules focus more on the physical aspects of patients' lives that are likely to influence QOL (Kopp et al., 2000). The FACT-G is part of an entire collection of questionnaires, the Functional Assessment of Chronic Illness Therapy (FACIT), which include several validated disease-specific, symptom-specific, and treatment-specific versions, available at [www.facit.org](http://www.facit.org) (Cella, 1997, n.d.).

### Spitzer Quality of Life Index

The Quality of Life index (QLI) measures health-related QOL with only five items rated on a scale from 0 (indicating best QOL) to 2 (indicating worst QOL) (Perez, McGee, Campbell, Christensen, & Williams, 1997; Spitzer et al., 1981). The instrument measures activity, daily life, health perceptions, social support, and behavior. Along with the FACT-G and the Spitzer Uniscale (not reviewed here), the QLI was one of the most frequently used QOL assessments in the late 1990s (Buchanan, O'Mara, Kelaghan, & Minasian, 2005). A low QLI score has been associated with a greater likelihood of death within six months compared with higher scores; however, scores from the limited item set have not been able to predict the type or length of treatment required for terminally ill patients (Addington-Hall, MacDonald, & Anderson, 1990). Its brevity and ease of administration and scoring certainly are desirable for use in clinical practice, but the QLI is a global measure and thus not recommended as a comprehensive measure to evaluate QOL.

### Cancer Rehabilitation Evaluation System and Its Short Form

The Cancer Rehabilitation Evaluation System (CARES) is designed to evaluate the rehabilitation status of patients with cancer. The scale has five domains: physical, psychosocial,



## Case Study 2

Mr. M is 56 years old and presents to the outpatient oncology clinic after a lengthy course of chemotherapy for diffuse B-cell lymphoma followed by an autologous hematopoietic stem cell transplant, which was unsuccessful. He has evidence of disease, is extremely fatigued and weak, and gets periodic blood transfusions to maintain his hemoglobin above 10 gm/dl. He is quite debilitated, has not worked for six months, and continues to experience physical symptoms (e.g., nausea, anorexia, pain). He receives supportive care by a physical therapist who has designed a structured exercise program and occupational therapist who sees him weekly to help restore strength in performing activities of daily living. He remains optimistic that he will have some quality of life and agrees to more chemotherapy in hopes of prolonging his life. His oncology nurse and a social worker provide ongoing emotional support and counseling for decision making regarding advanced directives and uncertainty of his prognosis at each visit including and regularly by phone. This oncology outpatient setting has designed an outcomes research program to evaluate patients' progress following transplants. His oncology nurse is responsible for obtaining regular patient-reported measures and coordinates these assessments with the patient's home health nurse.

### Opportunities for Outcomes Measurement

Which outcome measure(s) would best capture this patient's response to palliative care interventions? The Palliative Performance Scale (PPS) can be a useful measure to assess overall function and disposition. Mr. M is assigned a level of 50% across all dimensions of the scale: ambulation—mainly sit/lie; activity and evidence of disease—unable to do any work/extensive disease; self-care—considerable assistance required; intake—normal; and consciousness level—full. The PPS provides a global rating of performance status that can easily be obtained on a frequent basis (e.g., weekly) by both the oncology and home health care nurse. Monthly assessments with the Functional Assessment of Cancer Therapy—Anemia (FACT-An) is an appropriate instrument for measuring treatment outcomes, fatigue and anemia-specific indicators. Because he has opted for chemotherapy and is engaged in physical and occupational therapy to improve function and strategies to promote emotional and social well-being (e.g., counseling), it will be possible to measure the benefits of these interventions. Because he has no cognitive deficits and the instrument is easy to complete in a brief time period, this tool may not be burdensome. Patient acceptance is an important consideration and the FACT-An is specifically designed for patients who have undergone stem cell transplantations, therefore the items are relevant to his disease and treatment circumstances. Although it is possible to compare scores on different items from time to time, a researcher or data analyst may be needed to calculate and interpret overall and subscale results.

medical interaction, marital, and sexual (Schag, Heinrich, & Ganz, 1983). Every patient answers the first 88 of 139 questions, but only certain patients answer the remaining 51 items, which relate to population-specific concerns. Respondents rate the extent to which each statement applies to them during the past month on a five-point scale. Internal consistency reliability and test-retest reliability are excellent for the CARES, and validity has been established (Schag et al., 1983; Schag, Heinrich, Aadland, & Ganz, 1990). The one-month time frame may be difficult for patients with fluctuating symptoms and dramatic changes in status. The CARES may not be ideal for use in routine clinical practice because of the number of items, may not have sufficient ability to determine how a patient's life is affected by treatment interventions, and may not be appropriate for patients nearing the end-of-life.

A short-form, 59-item version of the CARES has been created, the CARES-SF (Schag, Ganz, & Heinrich, 1991). The CARES and CARES-SF have a unique set of subscales, which generally are not emphasized in other QOL instruments, namely medical interactions, marital, and sexual. Concurrent validity has been demonstrated for the CARES-SF. In a study of patients newly diagnosed with breast cancer, rehabilitation scores correlated with results from the FLIC (Schag et al., 1991). Another study of 130 patients after stem cell transplantation showed a strong and statistically significant correlation between the physical subscales of the CARES-SF and the EORTC QLQ-C30 (Hjermstad et al., 2003). With 80 patients with metastatic breast cancer, a significant correlation was found between mood disturbance, as measured by the Hospital Anxiety and Depression Scale, and physical rehabilitation status, as measured by the CARES-SF (Fulton, 1999). The CARES and CARES-SF may be appropriate for patients with cancer receiving palliative care rehabilitation interventions and when specific aspects of physical and psychosocial functioning are important to measure.

### McGill Quality of Life Questionnaire

The 17-item McGill Quality of Life Questionnaire (MQOL) incorporates a unique dimension: the existential domain defined as a patient's subjective well-being as affected by imminent death, loss of freedom, isolation, and meaning or purpose in life. Additional domains include physical, psychological, and support along with a global QOL item. Reliability and validity have been established in patients with cancer at all stages of disease and with individuals with varying prognoses. The MQOL has been used and tested in hospice and palliative care settings. Because of its brevity, the MQOL may not be the best measure to monitor QOL for any single patient over time. However, it is sufficiently sensitive to detect differences among groups receiving various treatments and services (Cohen & Mount, 2000). When compared to the Patient Evaluated Problem Scores (PEPS) (an individualized questionnaire requiring patients to identify and rate major problems affecting their QOL), using a small sample of 36 patients, the MQOL was acceptable to 95% of respondents and favored by 60% because they believed that it was comprehensive (Pratheepawanit, Salek, & Finlay, 1999). However, it did not detect some of the problems noted in the PEPS, such as isolation.

### Schedule for Evaluation of Individual Quality of Life

Some instruments, such as the Schedule for Evaluation of Individual Quality of Life (SEIQoL), are considered respondent generated because they are constructed to allow respondents to define the domains of QOL from their own perspectives (Macduff, 2000). The instrument's underlying measurement framework focuses on the areas of life that are important to respondents, how they currently are doing in each of area, and the perceived importance of the areas to overall QOL (O'Boyle & Waldron, 1997). A trained interviewer must conduct semistructured interviews to elicit responses on 46 items, first by asking respondents to draw a bar from bottom to top indicating how good or bad life is with respect to each domain (bottom being worst, top being best). Next, respondents rate their overall QOL on a visual analog scale, placing a mark on 100 mm line from

### Case Study 3

Mrs. L, a 75 year-old inpatient with advanced colon cancer, is referred to the Palliative Care Service for management of symptoms and psychological and social support around decision making at the end of life. Prior to hospitalization, she was living independently and reported an acceptable quality of life (QOL). Her primary concern is that she not be a significant burden to her family. Her daughter will be caring for at home and plans for discharge include a referral to a home hospice program and several symptom management interventions to alleviate nausea, pain and constipation. She is looking forward to being with her grandchildren but requests that she be placed in a predetermined long-term care facility when she is no longer able to participate in her care and interact with her family. She has planned for this possibility and has private insurance to cover long-term care.

### Opportunities for Outcomes Measurement

What functional status and QOL measures are appropriate for patients are nearing the end of life? The Palliative Performance Scale (PPS) can be used to obtain a pre-discharge baseline measure of performance status and weekly assessments by home hospice nurses provide important data for the Palliative Care Service who will remain involved in the patients care. Her current performance level is 40% for all dimensions of the scale: ambulation—mainly in bed; activity and evidence of disease—unable to do any activity/extensive disease; self-care—mainly assistance; intake—reduced; and, conscious level—drowsy with or without confusion. Home health hospice professionals will honor her request and consider placement when her PPS level reaches 10%. Weekly assessments using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Palliative Care also provides useful information about her QOL. This instrument is brief, easy to comprehend, and has relevant items addressing issues with progressive illnesses. It can be promptly scored, and the results can be used to gauge the effectiveness of symptom management interventions and hospice care.

poorest QOL to best QOL. Finally, they complete a “judgment analysis procedure,” in which 30 hypothetical scenarios are presented and expected QOL is rated.

The original SEIQoL is valid and reliable in relatively healthy patient populations. However, it may be too burdensome for repetitive clinical use and takes about 40 minutes to complete. In one study, 22% of patients failed to finish the SEIQoL because of fatigue (Waldron, O’Boyle, Kearney, Moriarty, & Carney, 1999). The SEIQoL-Direct Weighting (SEIQoL-DW) is a shortened version, also validated, that requires about 15 minutes and thus may be more acceptable for patients with progressive cancer (Campbell & Whyte, 1999; Kaasa & Loge, 2003; Willener & Hantikainen, 2005). With the SEIQoL-DW, the “judgment analysis procedure” is replaced with interlocking discs representing the weight given to each nominated domain of QOL. A patient stacks them in such a way that the weight of each domain can be calculated and analyzed in combination with the other sections of the assessment (Lhussier, Watson, Reed, & Clarke, 2005). Insignificant correlation exists among the SEIQoL-DW, KPS, and EORTC QLQ-C30 for patients with leukemia undergoing autologous stem cell transplantation, which may illustrate its conceptual departure from traditional health-related QOL assessments (Frick, Borasio, Zehentner, Fischer, & Bumered, 2004). Researchers warn that an interviewer’s behavior and wording of instructions, as well as an optional list of prompts for patients who fail to think of five domains on their own, may

introduce bias in the SEIQoL and SEIQoL-DW. The long and short versions of the SEIQoL can yield valuable information about a patient’s QOL; however, the facts that interviewers must be trained carefully, administration is complex, and specific software is needed to analyze responses preclude its feasibility in routine clinical practice.

### Functional Living Index–Cancer

The Functional Living Index–Cancer (FLIC) is a 22-item, seven-point rating QOL measure. Construct validity for the sub-scale structure of measurement domains (physical well-being and ability, emotional state, sociability, family situation, and nausea) has been supported in three cancer populations (King, Dobson, & Harnett, 1996; Schipper, Clinch, McMurray, & Levitt, 1984). A unique feature of the FLIC is the phrasing of items. For example, social functioning is measured in terms of a patient’s “willingness to see and spend time with relatives and friends,” as opposed to the extent to which disease and treatment interfere with social interactions (Kuenstner et al., 2002). Responses to items for the FLIC are framed in the context of how patients feel the day of completing the questionnaire. As a result, responses on the FLIC may differ from answers to items from QOL measures that ask patients how they feel in general, recently, or within the past two weeks. This may explain the problem of construct divergence or differences in results noted between the FLIC and SF-36 (Wilson, Hutson, & VanStry, 2005).

## Putting Outcomes Measurement Into Practice

To illustrate how oncology nurses can use standardized measurement tools in practice, a few case-based examples are provided throughout the text of this article. Selecting the most suitable instrument to capture the most critical information about patients’ status and experiences is paramount. The case scenarios make clear just how valuable patient-assessment criteria and patient-reported information can be in clinical practice. Moreover, the use of outcomes measures provides a useful way to quantify, communicate, and track relevant data about patients.

## Conclusions

The viability and expansion of palliative care programs no doubt will rely on healthcare professionals’ ability to demonstrate the programs’ unique contributions to high-quality patient care. Therefore, a system that tracks patient outcomes over time is critical. Nurse leaders in palliative care should be accountable for developing a comprehensive plan for measuring and monitoring the impact of services and interventions that are part of palliative care programs. However, that is not easy and may require additional time and resources to accomplish data collection, analysis of findings, and reporting mechanisms. A major challenge can be identifying the most appropriate indicators to quantify the benefits that palliative care interdisciplinary teams bring to patient care. Nurses who are knowledgeable about outcomes measurement are in a better position to plan and make decisions

regarding the best options for measuring the effectiveness of interventions and the overall well-being of their patients. Collaborations between clinicians and researchers greatly enhance the feasibility and capacity for implementing outcomes programs in routine clinical practice and for research.

*The authors gratefully acknowledge Theresa Alcorn, BSA, assistant to the Palliative Care Program in the Joan Karnell Cancer Center at Pennsylvania Hospital in Philadelphia, for her dedication and enthusiasm in the development of this article.*

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