**Quality-of-Life Assessment in Palliative Care**

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**Background:** Understanding the effects of cancer on the quality of life of affected patients is critical to clinical research as well as to optimal management and care.

**Methods:** Nine instruments for assessing quality of life in patients with cancer are identified, and their effectiveness during palliative care is analyzed.

**Results:** Most of the instruments included physical, functional, and symptom control, as well as psychologic and social aspects. Financial and spiritual aspects were included less often. While all but two of the instruments had adequate validity and reliability data published, only two - the Spitzer Quality-of-Life Index and the Hospice Quality-of-Life Index - were designed and validated for palliative care populations.

**Conclusions:** Although a variety of instruments is currently available, none is ideal for all palliative care settings. Further development and refinement of instruments are needed.

**Introduction**

Patients with cancer enter therapy with the recognition that therapy aimed at cure is often accompanied by side effects that have a negative impact on their quality of life. In recent years, many clinical cancer treatment research protocols have included a quality-of-life feature to evaluate the balance between side effects and quality of life during sometimes highly toxic treatment regimens.[1]

When cure is impossible, goals change from an intent to cure to the prolongation of life and palliation of symptoms. Palliative care is concerned primarily with managing side effects, controlling symptoms, and supporting overall quality of life when cure or control of the cancer is no longer believed to be possible.[2] During this stage of disease, quality-of-life issues are particularly important.

Initial approaches to the study of quality of life were based on the concept that a balance between cytotoxic therapy and quality of life was warranted. However, recent studies have found that when more aggressive therapy regimens were compared with less aggressive regimens designed to maintain quality of life, patients who received more aggressive regimens reported better quality of life, thus implying better palliation of the disease.[3-6] The availability of valid and reliable quality-of-life instruments was critical in evaluating these clinical outcomes.

Several instruments to measure quality of life have been developed and refined in the past two decades. This report describes the ability of these instruments to assess quality of life in palliative care.

**Background**

Early studies equated quality of life with functional status as measured by the Karnofsky Performance Status Scale,[7] the Zubrod Scale,[8] or the ECOG Scale. These measures of functional status have been used extensively because of the correlation between functional ability and tumor response.[9] However, studies of functional status and overall quality of life have shown weak correlations and suggest that while quality of life and functional status are related, more is involved in the perception of quality of life than functional abilities. Indications of quality of life continue to be evaluated by the Karnofsky Performance Status Scale,[10] although more specific tools have been developed and validated for use with cancer populations. Overall quality of life addresses not only functional abilities, but also symptoms, side effects, and social, psychologic, spiritual, family, and financial aspects.[2-9-14]

**Characteristics of Instruments**

The assessment of quality of life is becoming a standard component in the overall care of patients with cancer. Therefore, any tool designed to measure quality of life should be multidimensional, subjective, useful in the setting, valid, and reliable.[2,9]

1. The instruments must be multidimensional (ie, they must measure all aspects of quality of life that may be affected by a life-limiting illness). Most researchers accept that quality of life is multidimensional. The investigator can use either several one-dimensional instruments or one multidimensional instrument that measures all aspects of quality of life.

Taken together, the resulting scores of a group of one-dimensional tools that individually measure selected aspects of quality of life may shed light on the overall quality of life of the person with cancer.[9] These instruments may include individual measures of physical health, socioeconomic status, affect, social support, family, achievement of life goals, and depression. Disadvantages associated with the use of multiple instruments are their cost to administer, the demands placed on the time and energy of the patient, and the specific problems presented in palliative care settings where patients are likely to be debilitated.[9,15,16] The second option is the use of one multidimensional instrument that captures all aspects of quality of life.[9] Several multidimensional instruments have evolved that incorporate domains such as physical and functional status and include measures of symptoms, psychosocial aspects of well-being, and economic status.

2. Instruments should provide subjective data obtained via self-report of patients. Early studies of quality of life of persons who received palliative care were
3. *Instruments must be useful in the settings in which they will be used.* Readability and length of the instrument are important considerations in the measurement of quality of life. Patients unable to read above the fifth- or sixth-grade level may provide unreliable scores to instruments written at a higher level. In addition, patients undergoing palliative care are likely to be fatigued or in pain so that their concentration on a long instrument may be compromised. The usefulness of the tool must be evaluated in light of its readability and length.[21]

4. *Instruments must be valid and reliable.* Validity is an important psychometric characteristic because it helps to define the degree of confidence that a researcher can have in the scores derived from the instrument. The quality-of-life instrument for the patient with advanced cancer should have been developed or studied in palliative care situations. An assessment of quality of life that was developed for the general population may not address aspects of quality of life that are most relevant to persons with incurable disease. If the meaning of the scores is unreliable, then researchers can have little confidence in the research outcomes.

Like the clinician cannot be confident about patient assessments.[21] Reliability is related to accuracy or consistency of measurement. An instrument may measure what it was intended to measure, but it may do so in a less dependable way so that the scores vary randomly. When scores are unreliable, the researcher or clinician cannot depend on the accuracy of the scores in representing the phenomenon of interest—in this case, quality of life. Thus, both validity and reliability are critical in instruments that measure quality of life.[21]

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Palliative Care Use</th>
<th>Year Published</th>
<th>Dimensions</th>
<th>Self Report</th>
<th>Length</th>
<th>Validity Data</th>
<th>Reliability Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality-of-Life Index (Spitzer et al)</td>
<td>Yes</td>
<td>1981</td>
<td>Activity, living, health, support, outlook on life</td>
<td>No</td>
<td>Interview focusing on these issues</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Hospice Quality-of-Life Index</td>
<td>Yes</td>
<td>1986</td>
<td>Physical, functional, psychologic, social, spiritual, financial</td>
<td>Yes</td>
<td>25 items in a standardized rating scale</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Linear Analog Self-Assessment</td>
<td>Unknown</td>
<td>1976</td>
<td>Physical, social, psychological effects of disease, personal relationships</td>
<td>Yes</td>
<td>25 visual analog scale items</td>
<td>Limited</td>
<td>No</td>
</tr>
<tr>
<td>Functional Living Index-Cancer</td>
<td>For use in clinical trials</td>
<td>1984</td>
<td>Physical well-being, psychosocial, family, spiritual, social, spiritual, somatic, sexual</td>
<td>Yes</td>
<td>22 Likert-like items</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Quality of Life Index (HQLI)</td>
<td>For cancer patients</td>
<td>1990</td>
<td>Symptom control: physical, psychological, psychological well-being</td>
<td>Yes</td>
<td>14 visual analog scale items</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Quality-of-Life Index (HQLI)</td>
<td>For cancer patients</td>
<td>1990</td>
<td>Satisfaction and importance of health/functioning, physical, emotional, spiritual well-being, family</td>
<td>Yes</td>
<td>26 questions in a standardized rating scale</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Symptom Modulation Evaluation System-Short Form</td>
<td>For cancer patients</td>
<td>1991</td>
<td>Physical, psychosocial, medical, emotional, social, functional</td>
<td>Yes</td>
<td>64 Likert-like items</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Functional Assessment of Cancer Therapy QOL</td>
<td>For cancer patients</td>
<td>1993</td>
<td>Physical, emotional, social, functional, relationship with doctor</td>
<td>Yes</td>
<td>28 Likert-like items</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Quality-of-Life Questionnaire-Cancer</td>
<td>For use in clinical trials</td>
<td>1993</td>
<td>Functional (physical, role, social, emotional, financial)</td>
<td>Yes</td>
<td>30 items on a 0-100 scale</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

### Quality-of-Life Instruments for Palliative Care

The Quality-of-Life Index (QL Index) developed by Spitzer et al.[22] and the Hospice Quality-of-Life Index (HQLI)[14] were designed specifically for palliative care and were validated within palliative care populations (Table). Other quality-of-life instruments, such as the Cancer Rehabilitation Evaluation System and the Functional Assessment of Cancer Therapy, were designed for use in oncology populations. They include some aspects of quality of life that are relevant in palliative care and thus, with careful evaluation, may be deemed useful in some situations.

#### QL Index

The Spitzer QL Index.[22] was designed as an objective quality-of-life index for use by physicians to enhance quality of life in patients with terminal cancer. An interview with the physician includes topics such as activity, living, health, support, and outlook on life. Each is rated on a three-point scale (0 to 2), with a range of scores from 0 to 10. Evidence of content validity of the QL Index was gathered during its development. Three panels (n=129) were used to identify the overall domain encompassing quality of life. The original QL Index was pilot-tested, the dimensions of the final tool were developed, and the final form was reviewed by a panel of experts. The QL Index has been piloted by 150 physicians with 879 patients at varying stages of cancer. Discriminant construct validity was supported by the ability of the QL Index to differentiate among patients with varying levels of health. Among these groups were terminally ill patients who reported the lowest item and mean scores. It is reported to have adequate internal consistency (alpha=.775) and interrater reliability (r=.81).[22]

Data from the National Hospice Study[18] indicated that as patients approached death, their QL Index scores decreased. This finding was supported by a British study in 1990.[23] If quality of life decreases as death nears, then findings from these studies support the validity of the QL Index for use in terminal illness.

### Hospice Quality-of-Life Index
The 25-item Hospice Quality-of-Life Index (HQLI) is a self-report questionnaire that was developed to assess the overall quality of life of hospice patients.[13] Each item is rated on a scale of 1 to 10, with total scale scores ranging from 25 to 250 (lowest to highest quality of life). Patients indicate their satisfaction with each item by circling the appropriate number. The HQLI includes four major categories: physical/functional, psychologic, social/spiritual, and financial.[14] The social/spiritual subscale includes items about relationships with the health care team. Validity of the original version of the HQLI was assessed by a panel of experts. Items with low content validity indexes were refined.[13] The HQLI was administered to patients with cancer on admission to hospice and after three weeks of hospice care. Factor analysis with varimax rotation was applied to the final form and confirmed the four factors. Reliability of the HQLI was acceptably high with subscale alphas ranging from .66 to .87 and an overall alpha of .88.[14] Although the HQLI was designed for palliative care patients, it has been studied only in a home-based hospice. Further study is needed to validate this instrument for other palliative care settings.

**Linear Analog Self-Assessment**

The Linear Analog Self-Assessment,[24] is a self-report questionnaire consisting of 25 visual analog scales to assess the continuum of selected emotional, physical, or social experiences. Items are scored in centimeters from 0 to 10. Physical condition is assessed in 10 items, while social interactions, psychologic effects of disease, and personal relationships are examined in five items per category. McGowan et al.[25] found a moderately strong correlation between the Linear Analog Self-Assessment and the Spitzer QL Index in 54 patients who received palliative laser therapy for inoperable rectal cancer.

**Functional Living Index-Cancer**

The Functional Living Index-Cancer (FLIC)[26,27] is a subjective tool developed for use in clinical trials. This 22-item self-report questionnaire is designed for ease of administration. Items are presented in a Likert-like format on a scale of 1 to 7. Subscales assess physical well-being, psychologic state, family situational interaction, social ability, and somatic sensation. Patients can complete the questionnaire in less than 10 minutes.

Evidence of convergent and discriminant validity was provided by correlation of FLIC subscales with the Karnofsky Performance Status Scale, the Beck Depression Index, the State-Trait Anxiety Inventory, the Katz Activities of Daily Living Index, the McGill/Melzack Pain Index, and the General Health Questionnaire. Validity was assessed using factor analysis that confirmed the five subscales. Reliability was not addressed by the authors.[26,27]

**Quality-of-Life Index**

The Quality-of-Life Index developed by Padilla et al.[28,29] is a self-report instrument designed to measure the quality of life of patients with cancer. This index consists of 14 visual analog scale items that measure symptom control (pain, nausea, vomiting), physical well-being (strength, appetite, work, eating, sex), and psychologic well-being (general quality of life, fun, satisfaction, usefulness, sleep). Item scores range from 0 to 100, and total scores are averaged to range between 0 and 100. The instrument can be completed in five to 10 minutes.

Validity was studied in four groups: healthy nonpatient volunteers (n=43), oncology outpatients receiving chemotherapy (n=43), oncology outpatients receiving radiation therapy (n=39), and oncology inpatients receiving chemotherapy (n=48). Significant differences among the groups supported construct validity, with the nonpatient group scoring highest and the inpatient group scoring lowest.[29] Test-retest reliability coefficients were greater than r=.60 for all samples; patient samples had the highest coefficients. Internal consistency was high.[29] Subsequently, Ryan[30] used this quality-of-life index in a study of 422 veterans with lung or colon cancer and reported similarly high internal consistency (r=.93).

**Quality-of-Life Index-Cancer Version**

The Quality-of-Life Index developed by Ferrans et al.[11] measures satisfaction with areas of life that are important to the individual. The authors suggested that the individual's values may have a varying impact on his or her overall quality of life. This approach led to a weighting of traditional satisfaction items with its importance graded by the individual. The resulting 35-item tool assesses four domains of the global construct of quality of life: health and functioning, socioeconomic, psychologic/spiritual, and family. Individuals indicate their satisfaction with each item and then the importance of that item. 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.

The Quality-of-Life Index-Cancer Version (QLI-CV), a modification of the original index that is used for the general population, also includes physical discomfort or pain, control over one's own life, and influence of government.[31] Validity of the QLI-CV was assessed in two ways. First, the correlation between the QLI-CV and the assessment of life satisfaction (r=.80) supported validity. Second, patients were divided into groups on the basis of self-reported levels of pain, depression, and success in coping with stress. Patients who reported less depression (P=.0001), less pain (P=.002), and better coping with stress (P=.0001) had significantly higher QLI-CV scores if they reported less depression (P=.0001), less pain (P=.002), and better coping with stress (P=.0001). The internal consistency generally was high.

**Cancer Rehabilitation Evaluation System-Short Form**

The Cancer Rehabilitation Evaluation System-Short Form (CARES-SF) is a multidimensional self-report questionnaire designed to gather clinically relevant research information about the day-to-day problems and rehabilitation needs of persons with cancer.[32] Based on the 139-item CARES, the CARES-SF has 59 items rated on a scale from 0 (not at all) to 4 (very much). In addition to a total score (0 to 236), the CARES-SF provides subscale scores representing physical, psychosocial, medical interaction, marital, and sexual problems.

Validity was evaluated in several cancer samples by correlating the CARES-SF with the original CARES. Interscale correlations were moderate to low, indicating that the CARES-SF subscales measure different dimensions of quality of life. Factor analysis with varimax rotation confirmed six subscales.[32] Reliability was estimated by using Cronbach's alpha. Resulting alphas were lower than those of the longer CARES (alpha=.60-.85).[32]

**Functional Assessment of Cancer Therapy Scale-General**

The 28-item Functional Assessment of Cancer Therapy-General (FACT-G) scale is a multidimensional self-report instrument that measures health-related quality of life in cancer patients who are receiving therapy.[33] This core or general measure can be supplemented with site-specific and treatment-specific measures. A five-point (0-4) Likert-type format is used with scale scores ranging from 0 to 112. Five subscales are reported that address physical, functional, social, and emotional well-being as well as the patient-physician relationship.

Validity of the FACT-G was assessed (n=545) using factor analysis that confirmed the five subscales. Evidence of convergent and discriminant validity was generated...
Test-retest with brief delay was assessed with 60 outpatients. Subscale reliabilities ranged between .82 and .88 with an overall scale reliability of .92. Internal consistency assessed with Cronbach's alpha ranged between .65 and .82 for subscales with an overall alpha of .89.[33]

Quality-of-Life Questionnaire-Cancer

The 30-item Quality-of-Life Questionnaire-Cancer (QLQ-C30) is a multidimensional self-report measure of quality of life designed for use with clinical trials.[34] It addresses functional (physical, role, social, cognitive, and emotional) and financial aspects of quality of life as well as symptoms, global health, and global quality of life. Items are scaled from 0 (lowest on functional and symptom items) to 100 (best functioning but most symptoms). The QLQ-C30 was translated into other languages using a forward-backward translation procedure.

Validity was evaluated with 305 patients in 13 countries. An average of 11 minutes was needed to complete the questionnaire. Moderate interscale correlations support the distinct components of the quality-of-life construct. The functional and symptom measures discriminated among patients according to clinical status. In addition, significant differences were found in QLQ-C30 scores over time for patients whose clinical status changed with treatment. Reliability estimates for the subscales were similar across cultural subgroups (alpha = .52-.89).

Conclusions

Although several tools are available to study quality of life in persons with cancer, only two were designed specifically for and studied in palliative care settings. The Spitzer QL Index was designed for palliative care and validated in palliative care patients, but it provides a caregiver assessment rather than a self-assessment, and its interview format makes it expensive to use. Although the HQLI was developed and studied specifically for palliative care, it is a relatively new tool designed for hospice settings, and its use in other settings needs study. The remaining tools were designed for patients undergoing cancer treatment and not specifically for patients who are receiving palliative care. They may be useful in palliative care situations, but further validity and reliability data are needed to ascertain their appropriateness and accuracy with patients who are receiving palliative care.

Although quality-of-life instruments have been used primarily in clinical trials, their use is not limited to research. Clinicians may choose to evaluate quality of life of patients on a case-by-case basis to help in monitoring the effects of the disease and its treatment. In light of the current emphasis on evaluating health care outcomes, assessments of quality of life may become essential elements of care. While ongoing assessment of quality of life in clinical settings is plausible with the current availability of instruments, continued development and refinement of these instruments are needed.

References


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