

Advances in How Clinical Nurses Can Evaluate and Improve Quality of Life for Individuals With Cancer

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Purpose/Objectives: To describe advances in the ways that clinical nurses understand, assess, and work to improve quality of life (QOL) for individuals with cancer since the 1995 Oncology Nursing Society's State-of-the-Knowledge Conference on QOL.

Data Sources: Published research and clinical articles.

Data Synthesis: The number of QOL assessment tools and methods for understanding QOL results has increased. However, scant literature has focused on how clinical oncology nurses evaluate QOL and the methods they use to affect QOL for individuals with cancer.

Conclusions: Based on the nurse-patient relationship, clinical nurses are able to assess QOL in individuals with cancer and intervene appropriately to improve QOL.

Implications for Nursing: Clinical nurses can involve individuals with cancer in rating their QOL to assist in providing high-quality care that is directed at positively affecting QOL.

Quality of life (QOL) for individuals with cancer should be a concern for all nurses, whether caring for patients in the hospital, clinic, private office, homecare, or hospice setting. In addition, QOL is a central issue for oncology nurses whether they care for individuals undergoing radiation, surgery, chemotherapy, biotherapy, hematopoietic stem cell transplantation, palliative care, or end-of-life care. QOL is an essential aspect of nursing practice. Thus, it is critical to understand how clinical nurses are dealing with QOL issues while caring for individuals with cancer and their families. Until recently, little was known about clinical nurses' values, conceptualizations, and practices regarding QOL, even though this lack of knowledge was identified as a pressing issue by King et al. in 1997 and all three of these elements are important to the development of a therapeutic nurse-patient relationship (Hinds & Varricchio, 1996; King et al., 1997). Furthermore, as we learn more about patterns of clinical practice regarding QOL and how nurses assess and make decisions about QOL, then we will be able to develop and implement appropriate interventions to help individuals with cancer and their families to improve QOL. This article will discuss advances in ways that clinical nurses understand, assess, and have worked to improve QOL for individuals with cancer since the mid-1990s.

Cancer and Quality of Life

Although there continues to be numerous controversies related to QOL (e.g., how to define, what dimensions are included, how to assess, how to measure), there is adequate

Key Points . . .

- ▶ Clinical oncology nurses must understand the term "quality of life" (QOL).
- ▶ Oncology nurses in the clinical setting need to assess QOL.
- ▶ Oncology nurses should learn methods to positively affect the QOL of individuals with cancer.

support for the fact that cancer can affect various dimensions of QOL for individuals who have suffered from any type of cancer (Fitch, 1998; Kaasa & Loge, 2003; King, 2003a; King et al., 1997; Matza, Swensen, Flood, Secnik, & Leidy, 2004; Sneeuw et al., 1999). Additionally, QOL is mentioned frequently in the nursing literature. However, no consensus has been reached regarding a definition of QOL or the exact dimensions or domains of QOL. Generally, QOL is used as a broad term encompassing the question, "How is your life with everything taken into consideration?" Ferrans and Powers (1985) believed that QOL is a subjective perception of well-being that stems from either satisfaction or dissatisfaction with domains of life that are important to an individual. In a review of 68 studies that included QOL assessment, QOL frequently was described as being subjective, multidimensional, and recognized as a significant outcome (Buchanan, O'Mara, Kelaghan, & Minasian, 2005). Some researchers and QOL experts use the term "health-related QOL"; however, the term is more focused than overall QOL and refers to the aspects of QOL that are affected by healthcare interventions. This article will use the overall term of QOL.

Some of the commonly discussed dimensions of QOL include physical health, psychological well-being, social or socioeconomic resources, functional ability, spiritual well-being, and satisfaction with life. The focus of the various dimensions includes the aspects of QOL that are affected by disease or its treatment. Components of the dimensions may include symptoms; physical

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functioning; emotional, cognitive, and social issues; and sexual functioning. The cancer experience can cause uncertainty, fear, anxiety, and disruption in every aspect of life for patients and families. One of the most frequently cited models in the nursing literature was developed at the City of Hope National Medical Center (see Figure 1). The model highlights the four key dimensions of physical well-being, psychological well-being, social well-being, and spiritual well-being.

According to the literature, clinical nurses can have a significant effect on various aspects of QOL for individuals with cancer. Nurses can help patients adjust to challenges of cancer and treatment because of their relationships with their patients. For example, Maughan and Clarke (2001) found that by implementing specific clinical nurse specialist interventions for women with gynecologic cancers (e.g., providing emotional support, supporting individual coping strategies, promoting social support networks, providing information on resumption of sexual activity), they positively influenced QOL and sexual functioning. The oncology nursing literature also reflects research in other patient populations, such as bone marrow transplantation (BMT) recipients, patients with breast cancer, and men with prostate cancer, that has demonstrated that nurses have improved QOL for patients (Bush, Haberman, Donaldson, & Sullivan, 1995; Crowe & Costello, 2003; Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996; Galbraith, Ramirez, & Pedro, 2001; Wallace, 2003; Ward-Smith, Wittkopp, & Sheldon, 2004).

Nurses' Perceptions of Quality of Life

Oncology nurses have been interested in QOL because they are eager to gain knowledge about patients throughout their

cancer experience and, in turn, use that knowledge to help individuals throughout their journey. Oncology nurses also have direct and prolonged contact with individuals with cancer and recognize that QOL is an outcome indicator that is sensitive to nursing interventions. The attitudes, knowledge, and perceptions of nurses regarding QOL are crucial to advancing QOL as an accepted treatment outcome, but clinical nurses should not assume they know how QOL is affected when individuals are living with cancer or undergoing treatment.

A number of studies have been performed to assess nurses' perceptions of QOL. In 1995, King, Ferrell, Grant, and Sakurai explored nurses' perceptions of the effect of BMT on the QOL of survivors. The researchers compared nurses' responses on a QOL questionnaire with the responses of BMT recipients; significant differences were found between the nurses' and patients' perceptions of the effect of BMT on QOL. The nurse respondents identified positive and negative consequences of BMT and believed that patients had poorer QOL than the patients actually reported (King et al., 1995). Other researchers have discovered similar differences in perceptions of patients' QOL among patients, nurses, and physicians (Aronson, 1986; Carr & Higginson, 2001; Cochran & Ganong, 1989; Dow, Ferrell, Haberman, & Eaton, 1999; Ferrell & Dow, 1996; Johnston, 1982; Larson, 1984, 1986; Mayer, 1987; Schipper & Levitt, 1985; von Essen & Sjoden, 1991; Wilson, Dowling, Abdolell, & Tannock, 2000).

Lindley and Hirsch (1994) conducted an exploratory survey of oncology nurses' attitudes, perceptions, and knowledge regarding the relevance and measurability of QOL in individuals with cancer. At a conference exhibit booth, nurses completed two questionnaires that displayed 11 QOL tools (i.e., general and disease-specific examples). One survey addressed nurses' opinions of (a) the impact of cancer treatments and side effects on QOL, (b) the importance of QOL as an outcome measure for patients with cancer, (c) the current status of QOL assessment in oncology practice, and (d) barriers to measuring QOL in clinical settings. Participants marked an "X" on a 100 mm visual analog scale ranging from 0–10 (0 = not at all to 10 = a great deal) to indicate their assessment of the impact of cancer treatments and side effects on QOL. A five-point Likert scale (ranging from 1 = strongly agree to 5 = strongly disagree) was used for responses to statements regarding the importance of and methods for measuring QOL in a clinical setting. The remaining questions were multiple choice. The second survey involved a brief test of knowledge related to QOL measurement issues (specifically reliability and validity, the multidimensional nature of QOL, and aspects of instrument design). QOL issues were discussed only after participants completed the questionnaires.

Six hundred twenty-one nurses completed both surveys. Overall, nurses perceived chemotherapy, surgery, and radiation treatment as negatively affecting QOL, with chemotherapy having the greatest negative impact. The participants indicated that nausea and vomiting had negatively affected QOL more than fatigue, hair loss, and sleep disturbance. Moreover, the respondents demonstrated knowledge of a number of key QOL measurement issues. Unfortunately, a third of the nurses indicated that they believed no reliable and valid instruments existed for measuring QOL in individuals with cancer (Lindley & Hirsch, 1994).

Although it is critical that oncology nurses not assume that they understand what the cancer experience is like for

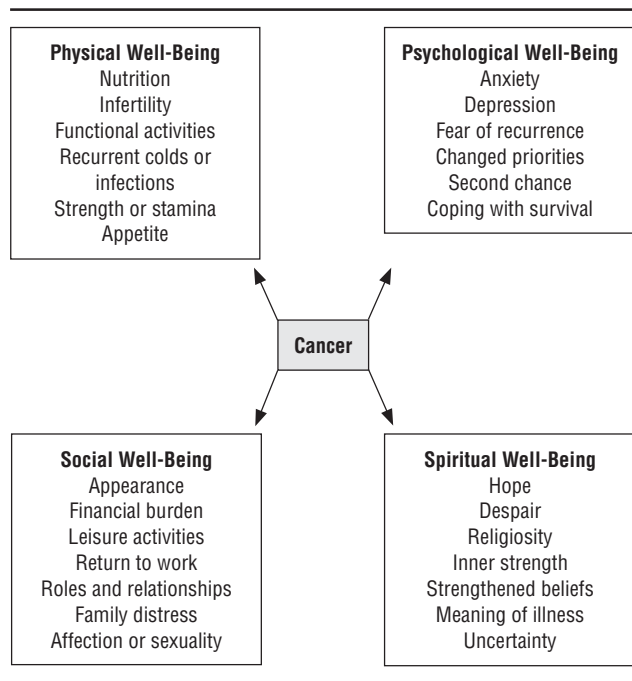


Figure 1. Quality-of-Life Model

Note. From "Quality of Life in Long-Term Cancer Survivors," by B.R. Ferrell, K.H. Dow, S. Leigh, J. Ly, & P. Gulasekaram, 1995, *Oncology Nursing Forum*, 22, p. 916. Copyright 1995 by the Oncology Nursing Society. Adapted with permission.

individuals, nurses (as instructors) still need to lead or guide patients along the journey. Nurses should help patients to understand their strengths, areas of need, and the physical, psychological, social, and spiritual aspects that will affect their performance or ability to cope with cancer. To assist patients with the aspects, nurses need to have competence, commitment, and compassion and patients need motivation, focus, support, and a positive attitude (King, 2001).

Importance of the Nurse-Patient Relationship

The relationship between oncology nurses and individuals with cancer involves dynamic caring. King (2001) used the analogy of a newly diagnosed individual with cancer to a novice dancer and the oncology nurse as the dance instructor. The analogy is helpful because the relationship between the nurse and patient is fluid and dynamic as is the relationship between the dancer and instructor. As King (2001) stated,

At times, the dance may be a duet (nurse and patient together), a solo composition (patient dancing and nurse supporting from the side), or a company of dancers (nurse, other team members, patient, family, and caregivers all together). . . . Dance like life is a process, including rhythmic bodily movements, rather than a product. Dance is about not only doing the steps but also the attitude and motivation (and physical, psychological, social, and spiritual influences). This is similar to living with cancer, which is not about dying but about living life to its fullest with a positive attitude (p. 29).

QOL can be viewed as being similar to dance. Both are based on key relationships (see Figure 2). As a result of a study to explore patients' QOL as defined and perceived by adult and pediatric clinical nurses, King, Hinds, Dow, Schum, and Lee (2002) discovered that clinical nurses both derive their perceptions of patients' QOL and decide on interventions to improve QOL based on their relationship with patients. A model was developed to depict the significance of the nurse-patient relationship (see Figure 3). From the study, the

researchers determined that oncology nurses develop relationships with patients and implement interventions that directly affect patients and the environment (healthcare setting) as an indirect method of influencing QOL. However, certain environmental characteristics (e.g., availability of resources, time available for nurses to address QOL issues) can negatively affect nurses' efforts to instigate specific interventions. In the King et al. (2002) study, oncology nurse researchers and clinicians needed to work to bridge the gap and make tools more clinically relevant.

Patients' Perceptions of Quality of Life

One unique program that has been developed in Canada is Interlink Community Cancer Nurses (ICCN). A nonprofit, community-based oncology program, ICCN was designed to provide individuals with cancer and their families access to oncology nurses' expertise, information, education, and psychosocial support and, ultimately, to help individuals meet the challenges of cancer and improve QOL. Howell, Fitch, and Caldwell (2002) conducted a qualitative study to evaluate the effect of ICCN nurses on patients' experiences with cancer. The core themes revealed in the study included (a) nurses sharing the journey with patients because of the strong nurse-patient relationship, (b) the patients' ability to unburden thoughts and fears to nurses because the nurses listened compassionately, (c) the nurses taking the time necessary to address all of the patients' needs, (d) the nurses' ability to help patients understand the illness and guide them through the experience of cancer because of their knowledge and experience, (e) the nurses' abilities to provide a link to information and resources, (f) patients' perceptions of nurses as a stabilizing force in their experience with cancer, and (g) the nurses' ability to uncover the strengths of individuals with cancer and to foster hope and courage, which ultimately helped them to survive.

Assessment of Quality of Life in the Clinical Setting

Some of the previous problems or methodologic issues that have been associated with assessing and measuring QOL include the variety of tools used, timing of QOL assessments, attrition of patients and data, lack of predefined end points, response shift in patients' perception of QOL, difficulty in interpreting QOL findings, and lack of patients' view of the importance of different symptoms and functions related to QOL (Lindblad, Ring, Glimelius, & Hansson, 2002).

The clinical interpretation of the meaning of QOL scores has not been publicized or taught in clinical training. Routine use of QOL tools in the clinical setting rarely has been reported in the United States (Berry et al., 2004; Detmar, Muller, Schornagel, Wever, & Aaronson, 2002; Levine & Ganz, 2002; Velikova, Brown, Smith, & Selby, 2002). Nurses may have difficulty learning to make QOL assessments in daily clinical practice, yet individualized care planning and follow-up based on QOL information may lead to better outcomes of treatment and informed autonomous decision making by patients.

Self-Report Versus Proxies

One continuing issue related to assessing QOL is whether individuals with cancer should complete self-administered

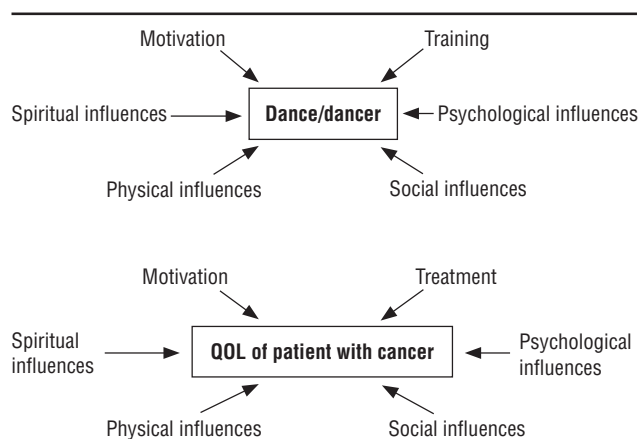


Figure 2. Similarity of Dance and Quality of Life (QOL)

Note. From "The Dance of Life," by C. King, 2001, *Clinical Journal of Oncology Nursing*, 5, p. 31. Copyright 2001 by the Oncology Nursing Society. Reprinted with permission.

stoic, men may minimize or deny the occurrence or severity of their experience (Ferrell, Dow, & Grant, 1995). Therefore, Ferrell, Dow, and Grant suggested that healthcare providers be aware of how questions are worded and asked of patients so that accurate and rich information is gained.

Individualized Quality-of-Life Assessments

The most recent approach to QOL is evaluation by individualized measures that assess QOL as defined by patients with cancer. This recent approach is seen by the increase of QOL assessments in clinical research. The increase may be caused partly by the pressure to evaluate outcomes of patient care because of limited resources and an increased focus on evidence-based practice. As Gunnars, Nygren, and Glimelius (2001) and other experts have noted, many methodologic issues are related to current measurements in QOL. Some of these issues include the number and variety of QOL questionnaires, the timing of measurements, patient and data attrition, and a response shift in patient perceptions of QOL. Another important issue is that most of the current tools do not collect the perceptions of individuals with cancer. Healthcare providers are just beginning to conduct studies with outpatients with cancer to learn about the influence of QOL considerations on clinical decision making and outcomes. The findings from collecting patient-specific QOL information have demonstrated that routine assessments of QOL in clinical practice are useful (Annells, Koch, & Brown, 2001; Detmar, Aaronson, Wever, Muller, & Schor-nagel, 2000; Taenzer et al., 2000).

The Schedule for the Evaluation of Individual QOL (SEIQOL) (McGee, O'Boyle, Hickey, O'Malley, & Joyce, 1991) and the Patient-Generated Index (Annells et al., 2001) are appealing QOL instruments because they incorporate topics that are of the greatest concern to patients. Both instruments were designed to overcome the problem of imposing an external value system on individuals rather than allowing them to describe their lives and experiences in terms of factors that they consider important. Certain goals or behaviors (e.g., religious services or practices, hunting or fishing, being with family) may be important to one individual and not another. Additionally, similar goals or behaviors do not have the same significance for all individuals experiencing them, and the significance of a goal or behavior can change for one individual over the course of an illness (Lindblad et al., 2002; McGee et al.). Using individualized QOL measures can be advantageous for care planning and follow-up, attaining better outcomes of treatment, aiding in informed and autonomous decision making, and enhancing the standard clinical interview that generally focuses on physical aspects.

Previously, some QOL instruments were developed based on patient-generated items (e.g., patient interviews, focus groups). The Functional Assessment of Cancer Therapy-General and its disease-, treatment-, and condition-specific subscales were developed this way (Cella et al., 1993). The European Organisation for Research and Treatment of Cancer QOL Questionnaire also includes patient interview information (Fayers & Bottomley, 2002). Unfortunately, both instruments assume the weightings for different components of QOL and are the same for all individuals rather than allowing patients to vary the weight they assign to different aspects of QOL (Campbell & Whyte, 1999; McGee et al., 1991).

The three-step SEIQOL is one example of a truly individualized QOL assessment. In the first step, a semistructured interview, the patient identifies five areas that are of greatest importance in terms of QOL. Next, the individual rates his or her current status in each of the five areas. Lastly, the individual quantifies the relative contributions of each of the five areas to his or her overall QOL (McGee et al., 1991). Because the assessment is cumbersome and burdensome for some individuals, a shortened form, the SEIQOL-Direct Weight, has been developed that uses a less-demanding weighting procedure using pie charts (Hickey et al., 1996). The SEIQOL and SEIQOL-Direct Weight have shown reliability and validity in terminally ill individuals with cancer (Waldron, O'Boyle, Kearney, Moriarty, & Carney, 1999).

The Patient-Generated Index is another tool designed to assess individualized QOL. Individuals are given a list of areas of life that most frequently are mentioned by patients with cancer (or another disease) and are asked to freely describe the most important areas for their QOL. After they select the five most important areas, the individuals then rate how badly each of the areas has been affected. Lastly, individuals are asked to prioritize the areas that they would most like to improve (Macduff & Russell, 1998; Ruta, Garratt, Leng, Russell, & MacDonald, 1994). The Patient-Generated Index is reliable and responsive to change when used with group comparisons and has been used in various patient populations (Herd, Tidman, Ruta, & Hunter, 1997; Jenkinson, Stradling, & Petersen, 1998; Ruta, Garratt, & Russell, 1999).

Barriers to Assessing Quality of Life in the Clinical Setting

Barriers continue to exist when assessing QOL in daily clinical practice. Barriers most frequently cited include time, lack of resources, lack of appropriate instruments, the belief that QOL assessments are unnecessary, healthcare professionals' unwillingness to administer questionnaires, and healthcare professionals believing QOL measurement is an invasion of a patient's privacy. However, most oncology clinicians believe that if an appropriate tool existed, QOL data could be collected on a routine basis (Lindblad et al., 2002; Lindley & Hirsch, 1994). Figure 4 lists criteria required for QOL instruments to be practical and useful in clinical practice.

Computerized Assessments of Quality of Life

Patients' symptoms and QOL experiences must be taken into account when planning complete clinical assessments, disease, and treatments. Thus, patients' symptoms and QOL experiences must be reported in a reliable and efficient way. Electronic technology now is being developed and used to capture patients' self-reports of symptoms and QOL data (Berry et al., 2004; Mullen, Berry, & Zierler, 2004). This method allows for confidential and private responses to questions and eliminates many of the steps in retrieving patient interview data. Numerous resources in the oncology literature indicate instances in which electronic assessments have been used. Mullen et al. developed and tested software for evaluating patients' symptoms and QOL in a radiation oncology setting. The researchers found that 70% of the participants liked computers, 79% reported the computers were easy to use, 91% reported the computers were easy to understand, and 71% enjoyed the computers.

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- Short
 - Easy to use
 - Multidimensional
 - Prospective design
 - Not burdensome
 - Easy to score and interpret
 - Clearly defined endpoints
 - Sensitive to changes in a patient's health status
 - Capable of international and cross-cultural standardization
 - Contains global questions regarding the cancer experience
 - Captures cancer-specific morbidity
 - Captures cancer treatment-specific morbidity
 - Self-administered
 - Standardized, reliable, and valid
 - Measures distress in addition to frequency and degree
 - Captures baseline status and can be administered longitudinally
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Figure 4. Characteristics of Instruments Needed to Measure Quality of Life in Cancer

Ways for Clinical Nurses to Affect Quality of Life for Patients With Cancer

Despite potential barriers for formal assessment of QOL, oncology nurses can positively affect QOL for individuals with cancer (see Figure 5). This is an important role for oncology nurses because they are present throughout the cancer journey and develop a relationship with patients and families just as the dance instructor develops a relationship with the dancer. However, the ever-increasing number of tasks, both physical and technologic, being performed and practiced within a restrictive environment may cause nurses to avoid being present with patients. Everyday tasks, lack of time, and mounting paperwork have begun to prevent nurses from having the important therapeutic relationships they need with patients (Bishop & Scudder, 1990; Melnechenko, 2003). Being present with patients—giving of oneself in an intersubjective reciprocal relationship (Liehr, 1989; Pettigrew, 1990)—is an important way to improve QOL. The relationship involves mutual openness, unconditional love, and a sense of comfort. When “being present,” a nurse enters a patient’s world to see it from the patient’s perspective. Nurses also have to let go of their own personal concerns while sharing of themselves (Melnechenko).

Another essential way to improve QOL is to ensure that patient-centered communication is a basic component of care. This is crucial to facilitate the development and maintenance of an effective and positive nurse-patient relationship and results in the delivery of high-quality nursing care. Patient-centered communication is very different than task-centered patient care (McCabe, 2004).

Currently, few clinical courses and only one textbook (King & Hinds, 2003) are available for nurses on the subject of QOL. However, the scarcity of information should not stop clinical nurses from learning about QOL issues, developing skills to assess QOL for individuals with cancer, and creating ways to help positively affect QOL for patients and families.

Nursing Implications

It is essential that oncology nurses in clinical settings understand the term QOL, bring together the perspectives of nurses

and patients related to QOL, and emphasize their commonalities. The views are linked because nurses have knowledge of the disease, health, and human development and respect for patients and their perceptions, values, and preferences. Nurses can be compared to dance instructors who share their learning and experience with dancers; however, students will interpret the dance according to their individual personalities. The basics of QOL can be taught, but individuals with cancer must discover what improves their QOL because they are the experts. The relationship between the dance instructor and dancer influences the dance just as the relationship between nurses and patients influences the cancer journey. Consequently, clinical oncology nurses must assess QOL, whether formally or informally, and learn ways to positively affect the QOL of individuals with cancer. Not every nurse will be comfortable with all the techniques outlined in Figure 5, but all nurses can use or develop various skills for improving QOL for individuals with cancer.

Conclusion

Although oncology nurses cannot know exactly what individuals with cancer experience on the cancer journey, nurses

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- Be creative like dancers and dance instructors.
 - Increase knowledge and skills related to quality of life (QOL).
 - Attend presentations and seminars.
 - Read articles and books.
 - Use the Internet.
 - Start a journal club.
 - Network with colleagues.
 - Assess QOL, including physical, psychological, social, and spiritual well-being.
 - Understand that QOL is what the individual with cancer says it is.
 - Help individuals with cancer and their families identify what makes QOL better or worse.
 - Use QOL information to individualize care planning and follow-up.
 - Be accessible to individuals with cancer and their families.
 - Be present with patients and families (i.e., giving of oneself in a reciprocal relationship).
 - Be sensitive to individual situations.
 - Be respectful and honest.
 - Help patients to derive hope.
 - Use effective nurse-patient communication techniques to explore patients’ QOL.
 - Use distraction and keep interests up.
 - Help patients to achieve goals.
 - Provide support groups for men with prostate cancer and their partners.
 - Assist with religious or spiritual issues.
 - Care for families as well as individuals with cancer.
 - Provide information and/or education for individuals with cancer and their families.
 - Concentrate on concrete objective information.
 - Provide information on symptoms and symptom management.
 - Provide information on potential long-term effects of treatment on QOL.
 - Encourage individuals with cancer to participate in activities that improve QOL.
 - Address the negative effects of cancer treatments on QOL.
 - Help individuals with cancer learn new coping strategies (e.g., guided imagery, meditation, music).
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Figure 5. Ways for Oncology Nurses to Positively Affect the Quality of Life of Individuals With Cancer

do develop a close relationship with each patient and family and thus are in an optimal position to assess and positively affect QOL. Whether informally or formally, nurses must learn the physical, psychological, social, and spiritual aspects that increase or decrease the QOL of each individual with cancer. Oncology nurse clinicians and researchers must learn to work

more closely to make QOL tools easier to use in the clinical setting and to translate research findings into practice.

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