

The Nurse's Relationship-Based Perceptions of Patient Quality of Life

Cynthia R. King, PhD, NP, RN, FAAN, Pamela Hinds, PhD, RN, CS,
Karen Hassey Dow, PhD, RN, FAAN, Lisa Schum, BA, and Catherine Lee

Purpose/Objectives: To explore patients' quality of life (QOL) as defined by RNs in adult and pediatric oncology settings and to examine, from the perspectives of clinical nurses, the knowledge that is needed to apply QOL research outcomes in clinical practice.

Design: Qualitative research design using a focus group technique to explore the research questions.

Setting: Three sites (i.e., a pediatric research center in western Tennessee and oncology nurses from a chapter of the Oncology Nursing Society (ONS) in Central Florida and another in upstate New York).

Sample: 24 oncology nurses working with adult or pediatric patients or both.

Methods: Oncology nurses were approached at work or through their local ONS chapters for a focus group discussion.

Findings: 47 unique themes were reported by all five focus groups in response to three questions. The most frequently reported themes were (a) Using the Patient's Standard, (b) Nursing Strategies, (c) Differences Decrease QOL Care, (d) Maintaining Social Interests, (e) Insightful Relations With Patient, and (f) Nurse-Patient Communication.

Conclusions: Nurses' assessments of QOL primarily are based on their established relationships with their patients. From these relationships, nurses derive perceptions of patients' QOL and clinical direction for interventions to positively influence QOL. Based on these findings, the investigators developed a conceptual model of the nurses' relationship-based perceptions of patients' QOL.

Implications for Nursing: The current QOL measures have minimal importance to nurse clinicians. Because nurse clinicians rely on their relationships with patients to assess QOL, available tools should be made more clinically useful. Further research should be conducted using the new conceptual model, specifically to learn more about how nurses complete a QOL assessment within the context of the nurse-patient relationship.

In 1995, the Oncology Nursing Society (ONS) convened a working group of nurses and psychologists to examine the state-of-the-knowledge concerning quality-of-life (QOL) issues for patients with cancer and their family members and healthcare providers; the results were published in 1997

Key Points . . .

- ▶ Nurses rely on their relationships with patients to assess quality of life (QOL).
- ▶ Tools that are available to assess QOL should be made more clinically relevant.
- ▶ A new conceptual model has been developed for future research.

(King et al., 1997). Working group members considered QOL issues from theoretical, research, and clinical perspectives and addressed a list of specific questions (see Figure 1). The group concluded that nursing had made unique contributions to QOL research, particularly in the areas of patients' spiritual needs and model development. Recommendations of the state-of-the-knowledge conference included the pressing need to evaluate the relevance of available information about QOL for nurses in clinical practice (King et al., 1997). The purpose of this article is to report the findings of a qualitative study designed to explore patients' QOL as defined and perceived by RNs in both adult and pediatric oncology settings and examine, from the perspectives of clinical nurses, the knowledge that is needed to apply QOL research outcomes in clinical practice.

QOL is a vital dimension of care provided by oncology nurses. Oncology nurses are important providers of cancer care,

Cynthia R. King, PhD, NP, RN, FAAN, is a nurse consultant for Special Care Consultants in Rochester, NY; Pamela Hinds, PhD, RN, CS, is the director of nursing research at St. Jude Children's Research Hospital in Memphis, TN; Karen Hassey Dow, PhD, RN, FAAN, is a professor in the School of Nursing at the University of Central Florida in Orlando; Lisa Schum, BA, is a pediatric oncology education student at St. Jude Children's Research Hospital; and Catherine Lee is a pediatric oncology education student at St. Jude Children's Research Hospital and a nursing student in the School of Nursing at Union University in Jackson, TN. (Submitted January 2002. Accepted for publication April 5, 2002.)

Digital Object Identifier: 10.1188/02.ONF.E118-E126

How do you define quality of life (QOL)?
What are the dimensions of QOL?
What are the common ways to measure QOL in patients with cancer?
What are reliable and valid predictors of QOL in patients with cancer?
Why is QOL important to nursing as a discipline?
What nursing interventions improve QOL?
What is oncology nursing's role in QOL research?
What are the clinical implications in QOL?
What prior research has been done in QOL in patients with cancer?
What should be the future research directions for oncology nurses related to QOL?

Figure 1. Questions Used to Guide Discussion of Quality of Life and the Cancer Experience

Note. From "Quality of Life and the Cancer Experience: The State-of-the-Knowledge" by C.R. King, M. Haberman, D.L. Berry, N. Bush, L. Butler, K.H. Dow, et al., 1997, *Oncology Nursing Forum*, 24, p. 28. Copyright 1997 by the Oncology Nursing Society. Reprinted by permission.

and their views about QOL are meaningful for patients and families (Fitch, 1998). Research has shown that QOL is subjective and unique for every person and that changes in QOL over time depend on individual responses to the cancer experience (Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995). Nurse clinicians are aware of the difference in perceptions of patient QOL among patients, nurses, and physicians (Aaronson, 1986; Carr & Higginson, 2001; Cella & Cherin, 1987; Dow, Ferrell, Haberman, & Eaton, 1999; Ferrell & Dow, 1996; King, Ferrell, Grant, & Sakurai, 1995; Lindley & Hirsch, 1994; Newell, Sanson-Fisher, Girgis, & Bonaventura, 1998; Schipper & Levitt, 1985; Slevin, Plant, Lynch, Drinkwater, & Gregory, 1988; Sprangers & Sneeuw, 2000; Varricchio, 1990; Wilson, Dowling, Abdoell, & Tannock, 2000). Healthcare providers' criteria for evaluating patients' QOL may differ from those of patients because the providers' criteria may be based on their own expectations of what is possible or optimal for patients.

At the core of oncology nursing practice is the value that human responses to illness are affected not only by the cancer but also by interpersonal, family, social, cultural, and work relationships. Therefore, one of the most significant goals of nursing practice is to assess human responses to illness. Consequently, the concept of QOL converges with this primary nursing goal throughout the entire cancer experience. QOL also is important to clinical practice because it provides a shared language across and significant to many health-related disciplines (King et al., 1997). Although the concept of QOL is an essential dimension of clinical care for oncology nurses, little is known about how nurse clinicians define and assess patients' QOL or how nurses apply QOL research outcomes in clinical practice.

Methods

This qualitative research design used the focus group technique to explore the main research questions (Krueger, 1994; Stewart & Shandasani, 1990). The focus group technique is ideally suited for this research study because it is designed to

obtain perceptions about a defined area of interest in a relaxed and nonthreatening environment. Focus groups help to provide a candid perspective of patients' QOL as defined and perceived by RNs in adult and pediatric oncology settings; focus groups also serve to expose the strengths and weaknesses of information and tactics aimed at improving patients' QOL in current clinical practice.

The focus groups were conducted in upstate New York, western Tennessee, and central Florida. After obtaining institutional review board approval from the University of Central Florida, three investigators contacted oncology nurses who worked with adult or pediatric patients with cancer or both and who were members of their local chapters of ONS to elicit interest in this study. The investigators provided detailed information to interested nurses, explained the intent of the focus group discussion, and answered any questions. Next, the participants gave written informed consent, and a mutually agreed upon time and place were selected for the focus group discussion. A copy of the article "Quality of Life and the Cancer Experience: The State-of-the-Knowledge" (King et al., 1997) was given to each participant to read prior to participation in the focus group to be a stimulus as well as a knowledge starting point. The article summarized QOL wisdom in nursing to that time. The investigators hoped that by reading the article, the nurse participants would be informed and therefore explain why this available wisdom was insufficient for their practice needs. The three investigators conducted five focus groups that were comprised of three to six nurses each from November 1998 to January 1999. Sessions lasted approximately 1.5 hours. At the end of each focus group session, participants received \$25 as compensation.

The focus groups were asked three questions to facilitate discussion.

- Quality of life—Could you say what the term means to you in terms of your nursing practice?
- What helps you to use quality-of-life information in your own nursing practice on any given day?
- Was there any particular content in the article that you found helpful about quality of life?

In addition, participants completed a brief sociodemographic questionnaire. The discussions were tape-recorded to ensure accuracy for analysis and later were transcribed by a trained medical transcriptionist who had considerable experience in transcription of focus group discussions.

Data Analysis

Each investigator independently reviewed the transcripts of the focus group discussions. Next, two investigators jointly created an initial coding dictionary containing a total of 47 unique codes. The third investigator and three other investigators used this dictionary to independently code each of the transcribed focus group discussions. The interrater reliability of coding a response from any of the groups of participants to any particular question was set at a minimum of 75%. The transcripts of the focus group interviews then were analyzed for the occurrence of the 47 specific codes. A final coding dictionary was constructed with all of the codes defined and their frequencies summarized.

Codes were the first level of labeling. The codes were grouped together for meaning (themes). After all data were coded and themes were defined, an inductive method of model development was used and certain themes were com-

bined according to similarity of meaning and relatedness in temporality (i.e., which code preceded another in time) and effect (i.e., mutual positive or negative influence).

Results

All but one of the focus group participants were women, and all but three were Caucasian (see Table 1). Most of the nurses had received baccalaureate degrees and provided direct patient care. In addition, the participants were experienced nurses who had worked an average of 15.9 years in nursing and an average of 9.2 years in oncology. Two focus groups were comprised of nurses who provided care to only pediatric patients with cancer, another two focus groups were comprised of nurses who cared for only adult patients with cancer, and the fifth focus group was comprised of nurses involved in the care of either adult or pediatric patients with cancer.

A total of 47 unique themes were developed from the coded segments reported by all focus groups in response to all questions. Responses of all focus groups to question one contained 90 coded segments, those to question two contained 181 coded segments, and those to question three contained 87 coded segments.

Question One: Quality of Life—Could You Say What the Term Means to You in Terms of Your Nursing Practice?

The most frequently reported themes in question one were Using the Patient's Standard (n = 22) and Nursing Strategies (n = 15) (see Table 2). Using the Patient's Standard represents nurses' belief that the most valid measure of QOL is what patients believe it to be. As one nurse noted,

I think that part of our job . . . is to find out what it is the patient needs to know and to do because they have their own perceptions . . . [QOL] would mean something different to me, [it] doesn't mean the same thing to [the patient].

The Nursing Strategies theme signifies the idea that specific tactics and procedures can be implemented to directly improve patients' QOL. For example, one nurse said,

I think quality of life in regards to the patient population I'm working with currently . . . is trying to understand the goals that they have set for their disease process and their treatments and trying to realistically help them meet those goals, and [I] often think of quality of life in terms of day-to-day [interaction] with patients.

Although other themes emerged, these two were the most frequently reported in all five focus groups.

Other frequently reported themes were Treating Souls (i.e., meeting patient care needs beyond those directly related to the illness) and Management of the Physical Self (i.e., attending to patients' physical changes can influence QOL). Although Treating Souls and Management of the Physical Self were not mentioned as frequently as Nursing Strategies and Using the Patient's Standard, nurses made significant statements describing these themes. One comment related to Treating Souls was

Yeah, you have to treat more than their sodium and their potassium . . . you got to treat their souls and give them that extra to fight.

Table 1. Demographics

Variable	n
Gender	
Female	23
Male	1
Ethnicity	
Caucasian	21
African American	1
Hispanic	1
Other	1
Highest nursing degree	
Associate	4
Diploma	5
Bachelor's	11
Nurse practitioner	3
Master's	1
Position	
Staff	14
Clinical nurse specialist	1
Retired	1
Disability	1
Administration	1
Education	1
Coordinator	1
Project RN	1
Nurse practitioner	3
Work setting	
Inpatient adult oncology	7
Inpatient pediatric	1
Outpatient medical oncology	7
Outpatient radiation oncology	1
Hospice care	2
Ambulatory care (oncology)	5
Bone marrow transplant outpatient	1
Age (years)	
\bar{X} = 43.5	–
Range = 30–81	–
Years in nursing	
\bar{X} = 15.9	–
Range = 6–34	–
Years in oncology nursing	
\bar{X} = 9.2	–
Range = 1–25	–

N = 24

Another believed the Treating Souls approach was important because it leads to treatment of the “whole person instead of just . . . an illness.” One nurse discussed Management of the Physical Self.

If you can treat the symptoms of the chemo and the pain from the cancer and all these things, then you're increasing the quality of life.

All of these themes represent specific parts of patients' environments, relationships, or physicality that oncology nurses found useful in improving or maintaining QOL.

Question Two: What Helps You to Use Quality-of-Life Information in Your Own Nursing Practice on Any Given Day?

Surprisingly, rather than responding to the question asked, respondents interpreted this question as application to

Table 2. Most Commonly Used Themes in Response to Question One

Theme	Definition	n	%
Using the Patient's Standard	Recognizing that the most valid measure of a person's quality of life (QOL) is what that person believes it to be and that this belief could be different from what others believe and could vary by situation.	22	24
Nursing Strategies	Staff recognizes that certain tactics and considerations can increase patients' QOL, including recognizing patients' need for control, family and friends, hope, and symptoms to be managed effectively and for making plans, meeting social needs, and maintaining a lifestyle somewhat similar to that before therapy.	15	17
Treating Souls	Staff speaks of meeting patients' care needs in all aspects as a way of assisting patients to successfully address the demands of the illness; in part, patients' success is attributed to the staff caring about patients.	5	6
Management of the Physical Self	Staff identifies that attention to the state of patients' bodies, such as managing side effects and adjusting role demands to cope with physical changes, can increase QOL.	4	4

clinical practice. The most frequently reported theme in response to question two was Maintaining Social Interests (n = 20), defined as helping patients remain appropriately involved in everyday life. One nurse spoke directly about Maintaining Social Interests.

I think most of the nurses . . . focus on getting patients to tell us how this year's going to be different. What about [patients'] holidays they're going to need to tone down, give away, get help with . . . and that's a big quality-of-life issue that we may not address at other times during the year, but just to make sure that people who are experiencing fatigue or other side effects . . . will be able to deal effectively with what's important to them over the holidays. . . . It's a good time of year for quality-of-life issues.

Another group of nurses described in detail the measures taken by one hospital to provide entertainment and activities to maintain social interests and thus foster patients' QOL. The Maintaining Social Interests theme was present in the responses of nurses in four focus groups. Another common response to this question was labeled as Insightful Relations With Patient (n = 19) in which nurses' close relationships with patients and their families permitted nurses to complete more accurate QOL assessments and interventions. In discussing Insightful Relations With Patient, one nurse said,

You establish a bond with them, and so then they do begin to trust you and they do begin to, you know, to look to you to help them when they have a problem.

Nurse-Patient Communication (n = 14) was the label assigned to the concept that being physically present for patients creates opportunities to assess and address QOL issues. For example, a participant said,

I think it's really important for nurses to be paying attention . . . [nurses] . . . really focus on what the patient really wants and needs and, and often [patients] are afraid to speak up to a physician.

This theme was assigned to responses of all questions by all focus groups, but more than 80% occurred in response to question two. Using the Patient's Standard occurred frequently

in response to question two in four of the five groups (n = 18). The Nursing Strategies theme also was reported frequently in reaction to question two.

Question Three: Was There Any Particular Content in the Article That You Found Helpful About Quality of Life?

Question three was not asked during one focus group in Florida because of time constraints. This inconsistency in procedure potentially affected both the number and, perhaps, the type of themes. However, this study is exploratory; therefore, the missing data probably detract minimally from the interpretability of the nurses' responses to the question.

The two most frequently reported themes generated in response to this question were Differences Decrease QOL Care (n = 11) (i.e., cultural, economic, and behavioral differences can be barriers in QOL assessment and intervention) and Sharing Information (n = 8) (i.e., reading and discussing QOL information leads to better QOL care). An example of Differences Decrease QOL Care is

I have no clue what my Hispanic families perceive their quality of life, what their quality of life would be, what they think quality of life is, I only have my perspective.

Another participant said,

Part of paying attention to quality of life when you could be ethnically or culturally different is to be willing to ask direct questions about what is important to them and to explain when I make a mistake . . . what [paying attention to what is important to them] conveys to them is . . . your willingness . . . to learn more about them, to pay attention to their quality of life.

In regard to Sharing Information, one respondent said,

Whatever your tools are, they have to be easily, readily usable in the clinical setting . . . they [the QOL tools] have to be that any nurse can pick up and use and say, "This is helpful."

The Nursing Strategies theme again was identified in responses from four focus groups to question three (n = 6). The themes of Management of the Physical Self and Using the Patient's Standard were reported frequently in response to

question three. All of these themes were represented in previous questions, indicating their importance to this sample.

Frequencies of Themes Among Responses to Any Questions

The frequencies reported here correspond to overall frequencies when coded segments from all five focus groups and across all three questions were combined (N = 358). The six themes that most commonly were found in focus group discussions were Using the Patient's Standard, Nursing Strategies, Differences Decrease QOL Care, Maintaining Social Interests, Insightful Relations With Patient, and Nurse-Patient Communication (see Tables 3–5).

Three themes (i.e., Using the Patient's Standard [13%], Nursing Strategies [11%], and Differences Decrease QOL Care [8%]) account for 32% of the reported coded segments in this study. Using the Patient's Standard was the theme that was reported most often, and 44% of the reports of this theme occurred in response to question one. Although Using the Patient's Standard was the predominant concern in most responses to question one, 45% of the reports of the Nursing Strategies theme were to question two. Maintaining Social Interests, Insightful Relations With Patient, and Nurse-Patient Communication had overall frequencies of 5.6%, 5.4%, and 4.6%, respectively.

The loosely structured format of the focus groups allowed participants to generate discussion about their individual experiences and practice sites. As a result, not all themes were represented equally among groups or in response to each question. For example, the type and frequency of question one responses of a focus group that was comprised of more experienced nurses who treated only pediatric patients with cancer differed distinctively from those of the other focus groups. Two of the most frequently reported themes for this group were Being Affected by Patient (i.e., being profoundly influenced by an experience or experiences with patients)

and Remembering the Patient (i.e., being aware of memories of particular patients and of the impact of those memories on families and survivors), with frequencies of 50% and 11%, respectively. This specific focus group identified aspects of QOL issues that affected them personally and professionally, whereas most other groups reported on the effect of QOL issues on patients only. Interestingly, this group highlighted the importance of considering oncology nurses' emotional adjustment to patients' increasing or decreasing QOL. Responses to question two resulted in another example of themes unique to one group's discussion. Sixty-two percent of responses by one group to question two (n = 26) were represented by the theme Maintaining Social Interests. This group, which met in December 1998, may have had specific or practice-specific reasons that would explain why they believed attention to social roles was essential to QOL. This theme was consistently reported by all but one of the groups.

Model Development

Using an inductive method of model development, certain themes were combined to form more abstract concepts that convey how nurses perceive patients' QOL (see Table 5). The model emphasizes the relational basis of the nurses' assessments (see Figure 2). Thus, nurses' QOL assessments primarily are based on the nurses' established relationships with their patients. From these relationships, nurses derive their perceptions of patients' QOL and clinical direction of the strategies that must be implemented to positively influence QOL. Nurses develop relationships with patients and implement nursing strategies that directly affect patients and attempt to influence the healthcare setting as an indirect way of influencing QOL. In turn, certain characteristics of patients' QOL concerns (e.g., coworker appreciation of patients' QOL concerns, availability of resources, time available to address QOL issues) influence nurses' efforts to implement

Table 3. Most Commonly Used Themes in Response to Question Two

Theme	Definition	n	%
Maintaining Social Interests	Staff recognizes that assisting patients in preserving the functional demands of particular roles and remaining involved in life events or some type of distraction contributes to quality of life (QOL).	20	11
Insightful Relations With Patient	Staff recognizes the need to establish a positive, trusting initial relationship with patients and families and that this relationship can be an important channel to observe behavior and ask revealing questions of patients and families to adjust the staff's mood and behavior in an appropriate manner and pace providing any treatment-related information so as not to overwhelm or alarm them.	19	10
Using the Patient's Standard	Recognizing that the most valid measure of a person's QOL is what that person believes it to be and that this belief could be different from what others believe and could vary by situation.	18	10
Nursing Strategies	Staff recognizes that certain tactics and considerations can increase patients' QOL, including recognizing patients' need for control, family and friends, hope, and symptoms to be managed effectively and for making plans, meeting social needs, and maintaining a lifestyle somewhat similar to that before therapy.	18	10
Nurse-Patient Communication	Staff recognizes that being physically present, especially when patients are not feeling well, is important to increasing QOL and can lead to opportunities in which staff can listen to patients and even share QOL- or treatment-related information with patients, thus decreasing patients' anxiety and providing a reassuring presence.	14	8

Table 4. Most Commonly Used Themes in Response to Question Three

Theme	Definition	n	%
Differences Decrease Quality-of-Life (QOL) Care	Staff recognizes that cultural, economic, and behavioral differences can cause barriers in QOL assessment and effectiveness, especially when other issues are of more immediate concern or if the staff feels inadequately prepared to appropriately manage these differences.	11	13
Sharing Information	Staff recognizes that reading an article about QOL or discussing QOL topics creates opportunities to change personal beliefs, alter practice, consider new uses of instruments, and become more aware of patient needs and experiences; all ultimately lead to formal inclusion of QOL assessment generating findings that staff can trust.	8	9
Nursing Strategies	Staff recognizes that certain tactics and considerations can increase patient QOL, including recognizing patients' need for control, family and friends, hope, and symptoms to be managed effectively and for making plans, meeting social needs, and maintaining a lifestyle somewhat similar to that before therapy.	6	7
Management of the Physical Self	Staff identifies that attention to the state of patients' bodies, such as managing side effects and adjusting role demands to cope with physical changes, can increase QOL.	5	6
Using the Patient's Standard	Recognizing that the most valid measure of a person's QOL is what that person believes it to be and that this belief could be different from what others believe and could vary by situation.	5	6

strategies to improve patients' QOL. In this study, clinically based nurses reported that currently available research-based information about QOL is not relevant to their particular patient populations because it does not guide them in completing an assessment of QOL or an appropriate intervention.

Discussion

This study is one of a very few that directly solicited nurses' perspectives regarding patients' QOL, specifically how nurses define patients' QOL and make use of available information (particularly research-based) about QOL. Findings are unique in their emphasis on nurses' relationship-based assessments of patients' QOL and on nurses' interventions (e.g., managing symptoms, providing hope, controlling for patient and family) designed to improve patients' QOL. In addition, the similarity of findings among groups from

three geographically distinct locations and from adult and pediatric oncology settings suggest that the findings will be valuable in other settings.

Although the focus of each interview question differed, nurses' responses had a similar theme: Patients' QOL is what patients say it is. This emphasis on the subjective, personal nature of patients' QOL was noted in only 5 of 15 definitions of QOL (Cella & Tulsy, 1990; Ferrans & Powers, 1985; Hinds, 1990; Keith & Schallock, 1994; Vivier, Bernier, & Starfield, 1994) included in a text about nurse and patient perspectives on QOL (King & Hinds, 1998). According to the nurse participants in the current study, their strong emphasis on patients' perceptions as the definition of patients' QOL occasionally resulted in tension between nurses and coworkers and between nurses and family members. This suggests that philosophic differences in the ways that staff and family define QOL affect interactions among healthcare team members and

Table 5. Model Concepts and Their Definitions

Concept	Definition
Nurse-Patient Relationship	Nurses rely on establishing strong rapport with patients and their family members, being physically present and technically competent to complete quality-of-life (QOL) assessments and adjusting their own behavior, mood, and pace of providing treatment-related information.
Nurses' Perceptions of Patients' QOL	Nurses recognize that their most valid measure of QOL is what the individual believes it to be; this belief could differ from what others (including healthcare professionals and family members) believe and could vary by situation.
Nursing Strategies	Actions can be initiated by nurses and directed toward improving patients' physical condition, functional abilities, and social interests and implemented in consideration of patients' values, preferences, definition of normalcy, and need for hope.
Clinically Obscure Research-Based QOL Information	Nurses' belief that the lack of a single or clear definition of QOL, clinical guidelines to assess patients' QOL, and population-specific strategies to influence QOL all contribute to nurses' conclusion that the findings from studies on QOL are not useful and contribute to the low likelihood of their use in practice.
Environmental Characteristics	Nurses describe how rules and procedures and the general atmosphere of a healthcare setting, as well as coworkers' views, can affect patient QOL and the nurses' ability to influence patient QOL.

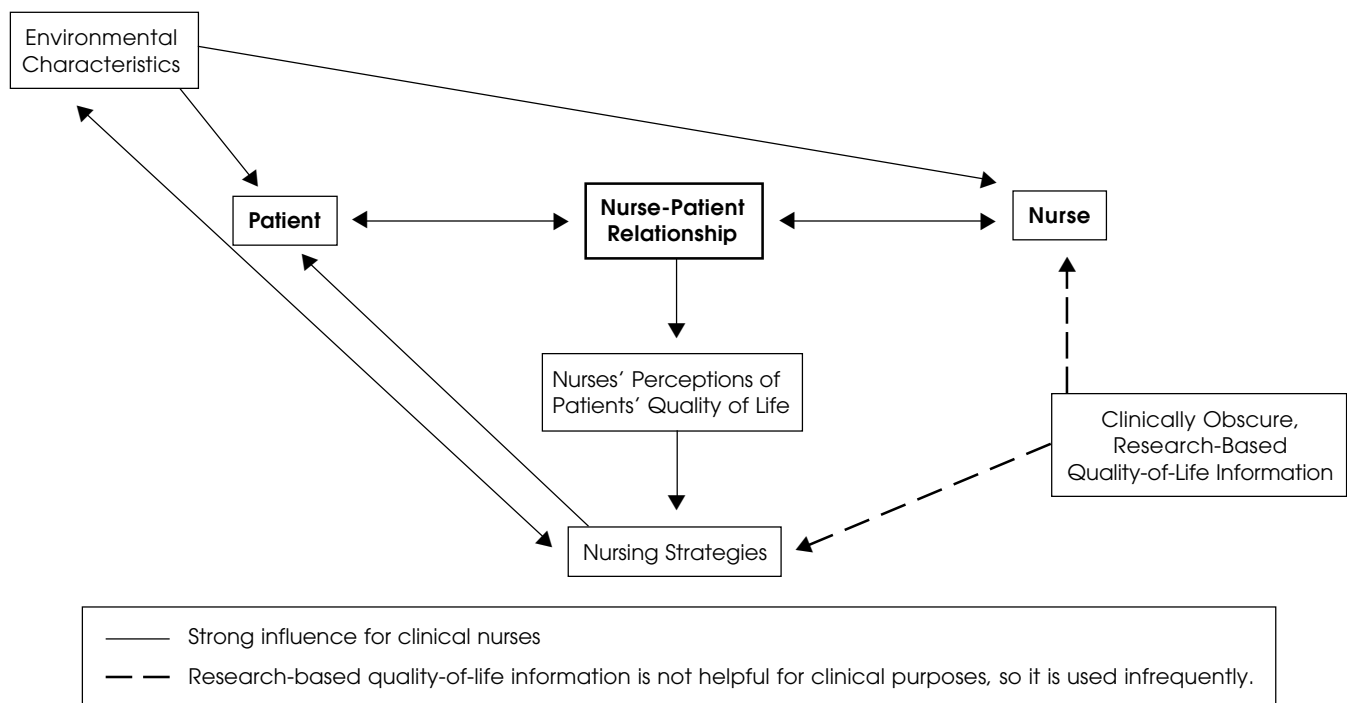


Figure 2. Nurses' Relationship-Based Perception of Patients' Quality of Life

among staff and family members. In addition, the nurses' comments indicated their belief that patients' QOL changes over time and situations and that QOL differs considerably among patients. This intra- and interpersonal variability suggests QOL assessments must be repeated so that key clinical junctures are included in the assessments and that the healthcare team is cautious when QOL assessments of different patients are compared. Because QOL can change over time with each patient and because patients differ from one another, interpreting just one data point is difficult. Therefore, repeated assessments would be more helpful. Change in assessments over time may help to further define patients' QOL.

Multiple coded segments and comments reflected nurses' personal efforts (e.g., being physically present, listening, asking certain questions) in assessing each patient's QOL and judging the validity of those assessments in large part on the basis of the nurse-patient relationship. The nurses' reliance on their relationship-based QOL assessments could raise concerns about the validity of such assessments, given the previously documented discrepancies between patient and proxy (e.g., physician, nurse, family member) QOL ratings in research measures (Churchill et al., 1987; Newell et al., 1998; Slevin et al., 1988). Certainly research is needed to determine whether differences in the size and frequency of QOL ratings obtained from relationship-based QOL assessments differ from those scores derived from QOL research measures. Despite the general acceptance that QOL is reported more accurately by patients and not by proxies (Ferrans, 2000; Osoba, 1994), proxies who have regular, close contact with patients and who complete QOL assessments multiple times and during different situations have a better chance of matching patients' QOL reports because proxies most likely become skilled at

making these assessments. In fact, Sprangers and Aaronson (1992) concluded that the most accurate proxy QOL ratings are given by those who are in regular contact with patients, including those who live in the same household or see patients most frequently in the healthcare system. Thus, a primary nurse who has regular contact with a patient can give a sensitive QOL assessment and accurately estimate a change in the patient's QOL.

Nurses' reliance on their relationships with patients as the basis for trusting QOL assessments may help to explain the participants expressed low enthusiasm for research-based measures of QOL and other forms of research-based information about QOL. Although 22 of 24 (97%) of the nurses conveyed how important patients' QOL is to them, they were reluctant to use nonrelationship-based research measures. In other words, nurses believe in the construct of QOL but not in the methods used in research to measure QOL. In their study about nurses' knowledge of patient QOL, Lindley and Hirsch (1994) found that nurses strongly valued the concept of measuring patient QOL, but they had little knowledge regarding its measurability; in particular, they knew little about the existence of reliable and valid tools for use in clinical practice. Participants in the current study indicated some familiarity with such tools but were reluctant to use them because the tools were too cumbersome for use in routine care.

Certain limitations exist in this study. The style of the facilitator for each focus group differed. Although the same or similar codes emerged from all five focus groups, the frequency and intensity of the responses differed; this difference could have resulted from the use of differing prompts by the facilitators. In addition, the nurses in each focus group energetically participated in the discussion of QOL of patients with cancer; therefore, the facilitators had difficulty in directing the discussion and clarifying all responses. Finally, nurses

volunteered for this study; as a result, they may represent a sample that has a unique interest in this concept and may not truly represent other adult and pediatric oncology nurses. However, innovation in practice frequently is initiated by nurses who have a special interest or existing knowledge in a specific area.

Nursing Implications

This study provides certain implications for research. Most importantly, the current array of available QOL measures has only limited clinical usefulness to nurses who provide direct patient care. Instead, these nurses rely on their relationships with patients as the basis for making patient-specific QOL assessments. This self-reliance indicates that the nurse-patient relationship itself needs to be the focus of study so that the method by which nurses complete assessments within the context of relationships can be documented and translated into practice guidelines. Studying purposefully altered contexts of relationships (e.g., patients have stable disease, are cured of disease, have recurrent disease, are at end of life, or differ culturally from nurses) also would yield valuable insights into clinically relevant patient- and disease-specific QOL assessments. Altering available measures to be more clinically useful while maintaining their psychometric strengths should be considered.

Additional research implications can be deduced from the nurses' relationship-based model. For example, the model contains a variable (i.e., environmental characteristics) that has been relatively unexplored in QOL research. The impact

of interventions designed to increase discussions among staff members about patient-specific QOL and the impact of sharing recent QOL information among staff members are intriguing new areas of study.


Summary

Assessment of patient QOL and altering care to improve QOL are important dimensions of care provided by nurse clinicians. The oncology nurses who participated in this research stated the importance of QOL in the clinical setting. They emphasized the significance of considering QOL as a subjective concept (i.e., based on the patient's perception), the importance of the nurses' relationship-based assessments of patient QOL (i.e., nurses rely on trusting relationships with patients to assess QOL), the presence of identifiable barriers that prevent nurses from providing effective QOL care, and the need for specific interventions to improve patients' QOL. The data from these focus group discussions provided new information and a conceptual model that may be critical to advancing QOL as a valuable concept and treatment outcome in the clinical setting. By exploring how nurses define and perceive patients' QOL and how nurses intervene to improve patients' QOL, QOL may be moved to the forefront of clinical practice, which ultimately may result in better patient care.

Author Contact: Cynthia R. King, PhD, NP, RN, FAAN, can be reached at crking@maknaus.com, with copy to editor at rose_mary@earthlink.net.

References

- Aaronson, N.K. (1986). Methodological issues in psychosocial oncology with special reference to clinical trials. In V. Ventafridda, F. van Dam, R. Yancik, & M. Tamburini (Eds.), *Assessment of quality of life and cancer treatment* (pp. 29–41). Amsterdam: Excerpta Medica.
- Carr, A.J., & Higginson, I.J. (2001). Are quality of life measures patient centered? *BMJ*, 322, 1357–1360.
- Cella, D.F., & Cherin, E.A. (1987). Measuring quality of life in patients with cancer. In *Proceedings of the American Cancer Society fifth national conference on human values and cancer* (pp. 23–31). Atlanta, GA: American Cancer Society.
- Cella, D.F., & Tulskey, D.S. (1990). Measuring quality of life today: Methodological aspects. *Oncology*, 4(5), 29–38.
- Churchill, D.N., Torrance, G.W., Taylor, D.W., Barnes, C.C., Ludwin, D., Shimizu, A., et al. (1987). Measurement of quality of life in end-stage renal disease: The time trade-off approach. *Clinical Investigative Medicine*, 10, 14–20.
- Dow, K.H., Ferrell, B.R., Haberman, M.R., & Eaton, L. (1999). The meaning of quality of life in cancer survivorship. *Oncology Nursing Forum*, 26, 519–528.
- Ferrans, C., & Powers, M. (1985). Quality of life index: Development and psychometric properties. *Advances in Nursing Science*, 8(1), 15–24.
- Ferrans, C.E. (2000). Quality of life as an outcome of cancer care. In C.H. Yarbrow, M. Goodman, M.H. Frogge, & S.L. Groenwald (Eds.), *Cancer nursing: Principles and practice* (5th ed., pp. 243–258). Boston: Jones and Bartlett.
- Ferrell, B.R., & Dow, K.H. (1996). Portraits of cancer survivorship: A glimpse through the lens of survivors' eyes. *Cancer Practice*, 4, 76–80.
- Ferrell, B.R., Dow, K.H., Leigh, S., Ly, J., & Gulasekaram, P. (1995). Quality of life in long-term cancer survivors. *Oncology Nursing Forum*, 22, 915–922.
- Fitch, M.I. (1998). Quality of life in oncology: Nurses' perceptions, values and behaviors. *Canadian Oncology Nursing*, 8(1), 24–39.
- Hinds, P.S. (1990). Quality of life in children and adolescents with cancer. *Seminars in Oncology Nursing*, 6, 285–291.
- Keith, K., & Schalock, R. (1994). The measurement of quality of life in adolescence: The quality of student life questionnaire. *American Journal of Family Therapy*, 22(1), 83–87.
- King, C.R., Ferrell, B.R., Grant, M., & Sakurai, C. (1995). Nurses' perceptions of the meaning of quality of life for bone marrow transplant survivors. *Cancer Nursing*, 18, 118–129.
- King, C.R., Haberman, M., Berry, D.L., Bush, N., Butler, L., Dow, K.H., et al. (1997). Quality of life and the cancer experience: The state-of-the-knowledge. *Oncology Nursing Forum*, 24, 27–41.
- King, C.R., & Hinds, P.S. (1998). *Quality of life: From nursing and patient perspectives: Theory, research, practice*. Boston: Jones and Bartlett.
- Krueger, R.A. (1994). *Focus groups: A practical guide for applied research* (2nd ed.). Thousand Oaks, CA: Sage.
- Lindley, C.M., & Hirsch, J.D. (1994). Oncology nurses' attitudes, perceptions, and knowledge of quality-of-life assessments in patients with cancer. *Oncology Nursing Forum*, 21, 103–108.
- Newell, S., Sanson-Fisher, R.W., Girgis, A., & Bonaventura, A. (1998). How well do medical oncologists' perceptions reflect their patients' reported physical and psychological problems? *Cancer*, 83, 1640–1651.
- Osoba, D. (1994). Lessons learned from measuring health-related quality of life in oncology. *Journal of Clinical Oncology*, 12, 608–616.
- Schipper, H., & Levitt, M. (1985). Measuring quality of life: Risks and benefits. *Cancer Treatment*, 69, 1115–1123.
- Slevin, M.L., Plant, H., Lynch, D., Drinkwater, J., & Gregory, W.M. (1988). Who should measure quality of life, the doctor or the patient? *British Journal of Cancer*, 57, 109–112.

- Sprangers, M.A., & Aaronson, N.K. (1992). The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: A review. *Journal of Clinical Epidemiology*, 45, 743–760.
- Sprangers, M.A.G., & Sneeuw, K.C.A. (2000). Are healthcare providers adequate raters of patients' quality of life perhaps more than we think? *Acta Oncologica*, 39(1), 5–8.
- Stewart, D., & Shandasani, P. (1990). *Focus groups: Theory and practice*. Beverly Hills, CA: Sage.
- Varricchio, C.G. (1990). Relevance of quality of life to clinical practice. *Seminars in Oncology Nursing*, 6, 255–259.
- Vivier, P.M., Bernier, J.A., & Starfield, B. (1994). Current approaches to measuring health outcomes in pediatric research. *Current Opinions in Pediatrics*, 6, 530–537.
- Wilson, K.A., Dowling, A.J., Abdoell, M., & Tannock, I.F. (2000). Perception of quality of life by patients, partners and treating physicians. *Quality of Life Research*, 9, 1041–1052. 

For more information . . .

- ▶ **CORDIS: Quality of Life Resources**
www.cordis.lu/life
- ▶ **International Society for Quality of Life Research**
www.isoqol.org
- ▶ **International Society for Quality of Life Studies**
www.cob.vt.edu/market/isqols

These Web sites are provided for information only. The hosts are responsible for their own content and availability. Links can be found using ONS Online at www.ons.org.
