

Understanding the Meaning of Social Well-Being at the End of Life

Maryjo Prince-Paul, PhD, APRN BC-PCM

Purpose/Objectives: To advance understanding of the social well-being domain, a dimension of quality of life, from the perspective of dying individuals.

Research Approach: Qualitative, hermeneutic, and phenomenologic.

Setting: Private residences in a community setting.

Participants: 8 terminally ill adult patients with cancer, aged 35–75, enrolled in hospice care.

Methodologic Approach: In-depth, semistructured, tape-recorded, and transcribed interviews were analyzed using the Giorgi method.

Main Research Variables: Social well-being and quality of life at the end of life.

Findings: Six themes emerged that described the meaning of close personal relationships at the end of life: meaning of relationships with family, friends, and coworkers; meaning of relationships with God or a higher power; loss and gains of role function; love; gratitude; and lessons on living.

Conclusions: Patients who were terminally ill with advanced cancer expressed the importance of close personal relationships at the end of life and the need to communicate their importance through love and gratitude. All participants believed that personal relationships were strengthened by the end-of-life experience.

Interpretation: Nurses can support terminally ill patients by understanding the importance of social relationships at the end of life. The relationships may be enhanced when nurses raise patients' conscious awareness of the relationships and encourage them to express their importance.

Key Points . . .

- ▶ Close, personal relationships are an important component of social well-being at the end of life that may be defined as having a relationship with God or a higher power.
- ▶ Relational communication of love and gratitude support close personal relationships.
- ▶ Nurses can increase dialogue and conversation with patients at the end of life by having a list of themes targeting the importance of the social well-being domain of quality of life.

(Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997). However, within the context of end-of-life (EOL) care, the social domain of QOL has been largely untapped. If knowledge about the meaning of social well-being at EOL from the perspective of the terminally ill patient with cancer is gained, it will broaden the understanding of QOL at EOL, specifically contributing to understanding of the importance and meaning of close personal relationships. This study aimed to advance the understanding of the social well-being domain, as a dimension of QOL, from the perspective of dying patients within the context of terminal illness.

Literature Review

According to Bowlby (1979), adults have a need to form enduring, emotional attachments with other adults. Close personal relationships take on a variety of forms and have been found to be of paramount importance for the well-being of individuals experiencing stressors such as those associated with life transitions (Berschied & Peplau, 1983).

Maryjo Prince-Paul, PhD, APRN BC-PCM, is an assistant professor in the Frances Payne Bolton School of Nursing at Case Western Reserve University, a research associate at the Hospice of the Western Reserve, and a postdoctoral fellow at Case Comprehensive Cancer Center, all in Cleveland, OH. This research study was supported by a doctoral scholarship from the American Cancer Society (DSCN—05-188-01). (Submitted July 2007. Accepted for publication October 24, 2007.)

Digital Object Identifier: 10.1188/08.ONF.365-371

The dying experience affects all dimensions of an individual. Dying evokes many changes and reactions in the patient as well as the family. Only people with a terminal illness understand the experience of living with such an illness. The need to belong, to have close personal connections and relationships with others, is the very essence of human existence (Baumeister & Leary, 1995). According to the National Consensus Project for Quality Palliative Care (2004), a comprehensive interdisciplinary social assessment, including relationships, lines of communication, and existing social networks, should be completed and documented. Most quality-of-life (QOL) models, within the context of patients with cancer, have concentrated on physical, psychological, and spiritual domains (Steinhauser et al., 2001). One QOL conceptual framework focuses primarily on patients with cancer and lends support to the concept of close personal relationships in the context of the social well-being domain

In addition, relationships entail a variety of interpersonal changes, undergo myriad complex crises and challenges, vary in terms of their importance at different times of the life cycle, and can be examined in many different ways (Berschied & Peplau; Hendrick & Hendrick, 2002). Very little empiric testing has investigated the relationship among close personal relationships, terminal illness, and the social well-being domain. That which is known relies on the seminal work reported some time ago in sociologic, psychological, and family theory literature.

Close personal relationships are defined as the interdependence between two people, involving a great degree of emotion and thought (Kelley et al., 1983), extending a considerable duration, and evolving through a negotiated set of disclosures (Altman & Taylor, 1973). When the emotional interconnectedness between two people is broken by a multifaceted or extended series of psychological events, Duck (1988) suggested that the relationship becomes fractured. People at the EOL seem to have an increased desire to understand their relationships with parents, family members, and significant others; those with fractured relationships need resolution before death (Kuhl, 2002).

According to Sulmasy (2006), humans are beings in relationships; in other words, the very essence of human existence is to have close personal connections and relationships with others. The author suggested that the appropriate care of the dying person requires restoration of all the interpersonal and extrapersonal relationships that can be addressed. Sulmasy (2001) further asserted that illness disrupts families, dismantles former patterns of coping, and raises questions about relationships with the transcendent, including purpose and meaning. Transcendence is a term that conveys a sense of being part of a greater whole, going beyond the self, the body, and the physical world. It aims to connect with something outside of the self or become open to a greater reality that “may be in the depths of one’s being, with another person, with the world or with God” (Cobb, 2001, p. 22).

In psychology, close relationships have been associated with a fundamental motivation of belongingness (Baumeister & Leary, 1995). Some of the most well-respected personality theorists have emphasized that people are motivated to form and maintain close relationships with others. For example, Sullivan (1953), Fromm (1956), Horney (1945), and Bowlby (1979) all made similar suggestions and noted the need to form and maintain close relationships as a basic human motivation as well as an important component of psychological growth and development and emotional peacefulness. Furthermore, Maslow (1970) ranked “love and belongingness needs” as a basic human motivation that supercedes esteem and self-actualization needs.

Mikulincer, Florian, and Hirschberger (2003) suggested that close relationships may serve as a fundamental means in coping with impending death. First, close relationships promote self-preservation (Mikulincer et al.). Second, close personal relationships may help people with death concerns. Some data suggest that an imminent threat (e.g., terminal disease) motivates people to seek physical proximity to other people. Third, the formation and maintenance of close relationships (however defined by the dying individual) may be important components of the social paradigm, providing order and assigning meaning and value. In support of that notion, Mikulincer et al. posited that the meanings of close personal relationships that transcend

physical death may provide a protection that enables one to better cope with the reality of death.

Methods

Phenomenology focuses on universal experience and relies on narratives that aim to understand the lived experience of human beings. Through narratives, the researcher attempts to explicate the richest descriptions of the phenomenon of interest through interpretation. Phenomenology investigates subjective phenomenon in the belief that essential components are grounded in the lived experience. According to Churchill, Lowery, McNally, and Rao (1998), investigation is done through empathetic dwelling, intense focusing, thematized meanings, and motivational context of the experience. The hermeneutic approach to phenomenology involves the description and meaning of the phenomenon within the context of the participant’s daily activities. This interpretative approach allows the essence of the experience to be captured in the words of the person who is living the experience and interpreted by the researcher (Van Manen, 1990).

Participants and Setting

Eight adult terminally ill patients with cancer who resided in their private homes in a community setting were purposively selected from a large, nonprofit hospice program in the midwestern United States. Participants needed to demonstrate satisfactory cognitive status on the Short Portable Mental Status Questionnaire (i.e., fewer than two errors) (Steinhauser et al., 2002) and be able to state that their physical pain was at an acceptable level for the interview to be conducted.

Procedure

After approval from the institutional review board of University Hospitals of Cleveland, OH, the study was explained to members of the interdisciplinary hospice team. The various hospice nurses introduced the research study to all participants who met eligibility criteria to obtain consent for the researcher to make phone contact. The primary nurse designated to the hospice patient called the investigator after the patient was admitted to the hospice program. The nurse provided the researcher, who validated eligibility criteria, with the patient’s name, diagnosis, and telephone number. The researcher then called the patient within 24 hours to determine a mutually agreed upon time to meet. All participants received an explanation of the study from the investigator, and informed consent was obtained to conduct tape-recorded interviews.

Interview Process

The principal researcher conducted all of the interviews. Because the understanding of the phenomenon or experience was sought, in-depth, tape-recorded, semistructured interviews were conducted. Prior to beginning the interview, the researcher explained to each participant that the focus of the questions was on the experiences of relationships with others who are important to the participant. An interview guide, developed by the researcher (see Figure 1), was used to aid in the facilitation of the interview. This guide was not used to limit the content of the interview but ensured that important questions were asked. At completion of the interview, participants were asked whether they would be willing to be interviewed within a week. The purpose of an additional

I am here to talk to you about close people in your life; specifically, I would like to learn about relationships in your life. First, I would like to learn a little more about you. How old are you? How long have you been diagnosed with _____?

- Tell me about people in your life—your relationships.
- Tell me about the most important people in your life.
- How are these persons you have mentioned related to you?
- How do you communicate the importance of the relationship? Tell me how this communication has changed or not changed over the course of your illness.
- Tell me about your physical symptoms. Now, you have told me that you have _____ [symptom], how does this symptom affect your relationships with others?
- Many people have told us that they have fears and are afraid of what the future may bring. What is happening with you psychologically/emotionally? How does this affect your relationships with others?
- For some people, spiritual issues are important, and for others, it takes less importance. Can you tell me a little bit about that? How has this affected your relationships with others?
- Is there anything more you would like to tell me that would help me understand personal relationships?
- How has your illness affected your family?
- What are your thoughts about how your illness has affected the person/people you have mentioned in this interview?

Figure 1. Interview Guide

interview was twofold: It would allow an opportunity for the investigator to clarify and validate the previous conversation, and the time between the interviews might allow for additional insight into the phenomenon of close personal relationships and increased desire to share that information. The average time of the interviews was one hour. New patients continued to be recruited during the interview process until no further themes emerged, which is known as theoretical saturation. A field note was tape recorded by the researcher prior to and following the interview. To ensure confidentiality, no names were included in the transcripts.

Data Analysis

Data collection and analysis were conducted simultaneously to ensure that findings from initial interviews were followed and explored in greater depth in later interviews. All interviews were transcribed verbatim by the researcher using the Tedlock (1983, 1990) method of transcription, which allows the pacing of the dialogue to be incorporated into the text. The eight interviews and two follow-up interviews yielded more than 300 pages of data. Analysis was guided by the Giorgi (1971) method as outlined by Omery (1983). The Giorgi method of analysis consists of five steps. Each transcript and field note was read to get a sense of the whole; individual constituents or units of the experience were identified; each interview was coded based on emerged categories and identification of essential meanings; and new data were compared and contrasted until themes emerged. The last step of the analysis involved the synthesis and integration of the various themes into a description of the phenomena that was enriched with illuminating parts of the text.

Rigor

Prior to conducting this study and throughout the process, the researcher recognized and put aside subjective views and personal thoughts and feelings about the phenomenon of in-

terest so that reduction could be facilitated—a process called “bracketing.” Bracketing involves “suspending one’s various beliefs in the reality of the natural world in order to study the essential structures of the world” (Van Manen, 1990, p. 175). Credibility was achieved by several means, including coding that was performed jointly by the principal investigator and a doctorally prepared nurse scientist, who was an expert qualitative researcher and grounded in phenomenology. Periodic debriefing sessions were conducted by the researcher, the nurse scientist, and a doctorally prepared faculty member in the school of nursing who had no direct involvement in the study. Consensus resolved any differing interpretations. Realities, as interpreted by the researcher, were clarified through member checking, an important technique that Lincoln and Guba (1985) suggested as most important for establishing validity of findings. Formal member checking was carried out with the first and seventh participants through an additional interview to ensure that the analysis of the initial transcript was valid. To achieve auditability, the researcher kept an audit trail in the form of raw data, analysis, synthesis, and member-checking transcripts, as well as bracketing. A reflective journal that recorded logistics and methodologic notes, including memos written during the project, served as the criterion to establish confirmability.

Findings

Three males and five females with a mean age of 61.1 years (range = 44–74) agreed to participate. Demographic data are presented in Table 1.

Meaning of Relationships With Family, Friends, and Coworkers

All participants not only revealed the heightened importance of maintaining close personal relationships but also the need to express the importance of those relationships through the communicative acts of love and gratitude. Most of the participants were gravely ill; however, all of them identified with the need to be surrounded by family and participate in social activities. This, in turn, provided them with a reason to live—a purpose to stay involved and live while they were dying. In addition, many of the respondents focused on relationships with others that had been difficult and described them as closer as a result of the cancer experience. Although not all relationships were intact and without challenge, most of the participants talked about attempted healing and conversations that embodied the meaning of the relationship.

Participant 3: I used to yell at my mom all of the time. . . . In fact, I hated her when I was younger and I gravitated to my dad. Now, I thank her a million times a day; I tell her how much I love her. It’s weird because neither one of us would have expected it to turn out this way.

Participant 5: I have had a little difficulty with my daughter over the years. . . . My son and daughter are just different. . . . We don’t agree on a lot of things . . . but my relationships with them today, you know, I’d rather be with them than anybody else, other than my wife.

Participant 1: I love those moments when we take the time, I mean, I don’t feel fantastic but we, we drive.

Table 1. Demographic Characteristics

Subject	Gender	Age (Years)	Karnofsky Performance Scale	Ethnicity	Religious Affiliation	Days From Hospice Admission to Interview	Days From Interview to Death
1	Male	59.0	45	Caucasian	Protestant	9.0	159.0
2	Female	61.0	40	Caucasian	Catholic	18.0	12.0
3	Female	44.0	20	Caucasian	Methodist	11.0	18.0
4	Male	74.0	60	Caucasian	Protestant	82.0	137.0
5	Male	74.0	40	Black	Catholic	10.0	123.0
6	Female	48.0	30	Caucasian	Lutheran	36.0	60.0
7	Female	73.0	40	Caucasian	Lutheran	128.0	Alive at study end
8	Female	56.0	60	Black	Baptist	15.0	60.0
Sample \bar{X}	—	61.1	42	—	—	38.6	81.2 ^a

N = 8

^a Subject 7 was not included in this calculation.

[My wife] helps drive and motivates me to get up and do things . . . rather than withdraw into a cave or the bedroom and stay hidden away. We, we still have things, we can still do little things, and be places . . . this gives me a reason to live.

Relationships from the past began to resurface and many participants spoke of how those reconnections renewed their sense of understanding of the values and importance of relationships with others on whom they had made impressions or who had imprinted in their lives in some way. Relationships with friends and coworkers often were connected with a sense of gratitude. Many participants discussed the type of support that friends and coworkers provided through caregiving or the contribution of time, money, energy, and resources, including manual labor. Although the following quotation represents the feelings of a man with liposarcoma, the essence of its meaning was shared by all participants.

Participant 1: It is amazing how people come out of the walls. Those I haven't talked to or seen for years, somehow they find out . . . and just then, here they come . . . doing things . . . fixing meals, helping with care, praying. It surely does show you how much you are loved and how much you may have touched someone's life.

Meaning of Relationship With God or a Higher Power

All participants discussed a relationship, defined as human or existential, that was strengthened by the cancer experience. A relationship with God or a higher power had not always taken a central role in participants' lives before their cancer diagnosis; however, at the time of the interviews, all participants spoke of a change in thinking and meaning about God or a higher power. Those relationships were viewed as personal, positive, and directive. The participants also described the relationships as having a greater power, a larger presence in their lives, as compared to human relationships. The use of prayer was described as central in the relationships.

Participant 5: A person without God has no relationship—there's just nothing left. Without God's presence and input, my life would be a mess. I'm being led and if I follow the way I'm being led, things will turn out right. He carries me through.

Participant 4: I count it a privilege to be able to share my life, my [wife], our life, and that is what we said to God when we got married that we would glorify Him, our relationship would glorify Him, not us. He is comfort to us. He's faithful. He's a bigger picture than what we picture and I never pictured my life to be this way [with the cancer] . . . in this part of my life . . . but I am thankful for each day we have together and I am not angry or bitter.

Participant 7: I put [God] on a shelf for awhile during my life—like when I was married and then going through a divorce . . . but it took me awhile to understand and when I came back to Him I learned that it's very important. . . . He's very important to bring in my life every day. If not, I don't have my full life . . . I can't lead it or I miss something in the day.

Loss and Gains of Role Function

The cancer experience and subsequent terminal illness shared by all of the participants brought along threats to social identity, performance of roles, and hopes for the future. Roles that were once performed were redefined, and relationships and their corresponding activity were transformed. Most respondents acknowledged how their roles had changed within the context of their illness and their relationships with others. Many participants shared how their physical appearance was altered and how they had to take on a dependent role regarding self—one that increased caregiver burden and stress. Even though each role's definition and function differed, all participants expressed the desire to maintain current roles with some sense of normalcy.

Participant 1: It was no problem for me physically before and now I have to depend on my wife for the physical part. . . . It's brought us closer together though. Instead of being the one doing the cooking, I help out with the cooking. I know that she's here; I tell her all the time how much I love her, how much I appreciate what she's doing. It's still hard though.

Participant 6: We've talked about dying and what's gonna happen. But, she's my mom and she shouldn't have to be burying her baby. I'm not really the baby—I'm really the oldest of her children. I would just love to get up and walk instead of saying, "Can I have this

or that?" I don't like being babied and being babied is what I have to be. I'm not being me anymore . . . it's like I'm not free. She gets everything for me though because I can't. She gets me dressed, gets me undressed, puts each leg in my underwear because of the catheter and everything. She even holds me. But, she's the greatest—she helps me through everything; she's been a great help to me here at home.

Love

Participants described the meaning of their relationships through love. Love seemed to be a core element that connected them with others and dwelled in each of them. Participants were able to describe love as a need to comfort and provide trust. They were not only able to reveal the love they felt from others and through prayer but were able to communicate the words "I love you." All participants elucidated the need to communicate the importance and meaning of their relationships through the expression of love. Love was based on a participant's need to be completed by another. In addition, participants seemed to have a powerful desire to help others, to be in another's presence, and to be cared for by that person.

Participant 7: I tell [my son] all the time how much I love him, oh how much I love him. It seems like ever since I've gotten sicker, he's constantly here at night—even if he's got to take his son to hockey practice.

Participant 5: You know, we'll be sitting here on the couch watching TV and she says, "Would you rub my neck?" . . . so I do. She's hurting. I'm hurting. I care; we empathize. I still try and give her relief in her shoulder and neck. . . . She has worked all day . . . and I do it lovingly and caringly.

Participant 1: I would tell my mother I loved her, call to tell her just that, see how she was doing. I tell my wife that I love her and that she's important too and that she's helped me through a lot. I tell my daughter that I love her; we tell each other that a lot. You do things that shows that you love them . . . I give them gifts. I think about them when I go on trips. I want them to constantly know that they're important by talking to them and letting them know I love them.

Gratitude

The concept of gratitude permeated all conversations. For most of the participants, it represented a core element of important relationships. Experiences of profound gratitude were reported by all participants and encompassed the meaning, act, and expression of gratitude. In this context, they described a connection to others—both human and existential. Reverent wonder toward an acknowledgment of a higher power and its force was clearly expressed. They were able to voice a capacity to appreciate the basics of life and thankfulness for one more day. Each participant expressed gratitude toward others, as well as toward nature and nonhuman sources.

Participant 2: I am amazed at the power of nature, its glory. I view things differently now—a snowflake, a flower, a drop of rain . . . all of it just seems to mean something different now. Maybe it's because I have fi-

nally stopped and taken note of what is powerful around me—what I don't have control of . . . what I need to be thankful for.

Participant 3: When it's time for you to go, it's time for you to go. And one of the things that I have come to accept is the fact that I'm thankful for the years that I've been on earth.

Participant 1: I'm so thankful . . . God has been good. My wife is a wonderful, beautiful person . . . she's been through every dark hour with me.

Participant 8: My [friend] . . . she will just sit with me for hours. She will rub my feet and tries to warm them up and keep them moving. She, like so many people, have just given up major portions of their lives to be here and just make sure that I am never alone. . . . I am just so thankful for everyone.

Lessons on Living

All participants wanted to tell others about the importance of looking at the "big picture" of life. Most stated how they felt blessed to wake up one more day and be able to have time to reflect, talk, and participate in "living activities." One man profoundly stated the need to tell others around him how important it was to live each day, not yesterday or tomorrow, as it comes. All of the participants seemed to take an inventory of their relationships and their lives in an effort to teach others how to go on living life as it comes.

Participant 1: We may have seven years, or seven days, or seven hours, and it's important with family that you embrace what you have. Life is precious. We must live each day to its fullest. Each day is special, and there are no guarantees.

Participant 4: Each day is precious and special. . . . Each day that we wake up is one more day that we have cause we don't know . . . what life has for us each day. . . . We're not promised tomorrow so we must live each day as if it is our last . . . that we must live as an open book ready to die.

Participant 8: It's like my days are numbered and I'm gonna lose them, so I just treasure every minute that I get.

Discussion

Phenomenology focuses on the universal experience and relies on narratives that aim to understand the lived experiences of human beings. All of the study participants graciously accepted the investigator into their homes and were eager to share their perspectives. Interviews lasted one to two hours, and most commented on how quickly the time passed, how cleansed they felt after talking about things that "really mattered," and how much better they felt after the interview. The centrality of close personal relationships and their importance emerged in the first 10 minutes of the interview for all participants. In addition, the references to God or a higher power as a close personal relationship emerged spontaneously in the first 30 minutes of the interview and, in some cases, was identified and described before subjects

spoke of their human relationships. In fact, in any interview, the interview guide was not needed as a probe beyond its introductory statement.

This study not only demonstrated the importance of social relationships at EOL but also revealed that merely thinking about them was not enough. Each participant expressed the need to verbally communicate love and gratitude. Contrary to other literature (Block, 2001; Byock, 1996, 1997; Greisinger, Lorimor, Aday, Winn, & Baile, 1997; Kearney, 1996; Kuhl, 2002), the need to express farewell or say goodbye was not raised by any of the participants. Most recently, Keeley and Yingling (2007) published results of more than 80 bereaved family members who told stories about their loved ones who died and their final conversations. Those results confirmed the themes and importance of love, God, and difficult relationship talk found with role changes within close personal relationships at EOL. Although those results represented the narratives of the surviving loved ones, the authors concluded that relational communication between the dying person and the survivors is an important component of the surviving partner's grief and healing.

The narratives in the present study clearly described the meaning of close personal relationships and shed some additional light on specific constituents of the social well-being domain at EOL. Although the four domains of physical, psychological, social, and spiritual well-being have been widely accepted, the content domains, specifically relating to the social and spiritual domains, continue to remain unclear. Close personal relationships have primarily been discussed as a constituent of the social well-being domain (Byock & Merriman, 1998; Cohen, Mount, Strobel, & Bui, 1995; Ferrell et al., 1997). Based on the stories told by the current study's participants, close personal relationships also may be defined as having a relationship with God or a higher power—a constituent often found only within the spiritual well-being domain of most QOL models (Byock & Merriman; Cohen et al.; Ferrell et al.). Several themes in the participants' descriptions seemed to suggest that the social and spiritual well-being domains are interrelated and connected through relationships—relationships with self, others, and God or a higher power. In a secondary analysis of 231 homecare hospice patients, McMillan and Weitzner (2000) investigated the QOL of patients with advanced cancer. Patients reported the greatest level of well-being in the social and spiritual domain, and "relationship with God" received the highest mean score among all of the items. Consistent with the current study's results, patients appeared to be able to maintain social relationships and relationships with God or a higher power, even when their social roles changed and their physical status declined. Further investigation is needed, however, to determine whether the spiritual and social domains are empirically distinct or conceptually connected.

Not only has this investigation broadened the understanding of the QOL domains within the context of the terminally ill patients, but it also has made unique contributions to theory, concept development, and definitions. Research regarding relationship functioning and illness is in its infancy (Coyle, 2006). Future research should examine what factors influence the affirmation of social relationships and their maintenance at life's end using a mixed-methods approach.

Limitations

This study was conducted with patients from one large hospice who were primarily Caucasian and of Protestant denomination and Christian faith. Although the sample size does not allow for generalizability, that is not the goal of phenomenologic inquiry. Rather, it is to elucidate the presence of multiple realities and attempt to represent those multiple realities adequately. A more heterogeneous sample representing different religious and nonreligious backgrounds, ethnicities, and race may have provided an even richer description of the meaning of social well-being at life's end.

Implications for Nursing

In the current environment in which the U.S. median length of stay in hospice care is 20.6 days (National Hospice and Palliative Care Organization, 2007), nurses must act swiftly, proficiently, and effectively. At the point of the initial hospice visit, when a greater length of time is spent with the patient and family, nurses have an opportunity to lay the groundwork for addressing the meaning of close personal relationships, their importance, and how the importance of the relationship is communicated. This initial investment of time can establish trust among the patient, family, and nurse, and potentially catalyze the opportunity for increased dialogue and conversation. Time may be used more effectively if healthcare providers have a priori list of themes or tasks targeting the importance of social and spiritual well-being. This may be facilitated through the expressions of gratitude and love.

Most importantly, EOL care providers must begin to use and build the evidence base for practice (George, 2002). In 2001, a consortium of four key national palliative care organizations formed the National Consensus Project to create a set of voluntary clinical practice guidelines to direct the growth and expansion of palliative care in the United States. These included, but were not limited to, physical, psychological, social, spiritual, and existential aspects of care. In 2004, the guidelines were published and a request was made to the National Quality Forum (NQF) to review and adopt the guidelines. In 2006, the NQF Board of Directors endorsed the guidelines with the intent of establishing best practice, including evidence-based research, that would apply to hospice and palliative care patients and families. Of importance to the current study are two of the NQF consensus standards—social aspects of care and spiritual, religious, and existential aspects of care. The findings from this study have the potential to contribute to the evidence base needed to ensure standards of care in patients with advanced cancer at EOL.

The author gratefully acknowledges Barbara J. Daly, PhD, RN, FAAN, and Terry Standing, PhD, RN, in the Frances Payne Bolton School of Nursing at Case Western Reserve University for their guidance and mentorship, the Hospice of the Western Reserve for its continued support, and the study participants for opening their homes and lives and sharing their stories of the cancer experience.

Author Contact: Maryjo Prince-Paul, PhD, APRN BC-PCM, can be reached at mxp42@case.edu, with copy to editor at ONFEditor@ons.org.

References

- Altman, I., & Taylor, D. (1973). *Social penetration: The development of interpersonal relationships*. New York: Holt, Rinehart, and Winston.
- Baumeister, R.F., & Leary, M.R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin*, 117(3), 497–529.
- Berschied, E., & Peplau, L. (1983). The emerging science of relationships. In H. Kelley, E. Berschied, A. Christensen, J. Harvey, T. Hustun, G. Levinger, et al. (Eds.), *Close relationships* (pp. 1–20). New York: Freeman.
- Block, S. (2001). Psychological considerations, growth, and transcendence at the end of life: The art of the possible. *JAMA*, 285(22), 2898–2905.
- Bowlby, J. (1979). *The making and breaking of affectional bonds*. London: Tavistock.
- Byock, I. (1996). The nature of suffering and the nature of opportunity at the end of life. *Clinics in Geriatric Medicine*, 12(2), 237–252.
- Byock, I. (1997). *Dying well: The prospect for growth at the end of life*. New York: Riverhead Books.
- Byock, I., & Merriman, M. (1998). Measuring quality of life for patients with terminal illness: The Missoula-VITAS Quality-of-Life Index. *Palliative Medicine*, 12(4), 231–244.
- Churchill, S., Lowery, J., McNally, O., & Rao, A. (1998). The question of reliability in interpretive psychological research: A comparison of three phenomenologically based protocol analyses. In R. Valle (Ed.), *Phenomenological inquiry in psychology: Existential and transpersonal dimensions* (pp. 63–86). New York: Plenum Press.
- Cobb, M. (2001). *The dying soul: Spiritual care at the end of life*. Buckingham, England: Open University Press.
- Cohen, S.R., Mount, B., Strobel, M., & Bui, F. (1995). The McGill Quality-of-Life Questionnaire: A measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability. *Palliative Medicine*, 9(3), 207–219.
- Coyle, N. (2006). The hard work of living in the face of death. *Journal of Pain and Symptom Management*, 32(3), 266–274.
- Duck, S. (1988). *Relating to others*. Milton Keynes, England: Open University Press.
- Ferrell, B.R., Grant, M., Funk, B., Otis-Green, S., & Garcia, N. (1997). Quality of life in breast cancer. Part I: Physical and social well-being. *Cancer Nursing*, 20(6), 398–408.
- Fromm, E. (1956). *The art of loving*. New York: Harper Collins.
- George, L. (2002). Research design in end-of-life research: State of the science. *Gerontologist*, 42(3), 86–98.
- Giorgi, A. (1971). Phenomenology and experimental psychology. In A. Giorgi, W. Fischer, & V. Eckartsberg (Eds.), *Duquesne studies in phenomenological psychology: Volume I* (pp. 66–79). Pittsburgh, PA: Duquesne University Press.
- Greisinger, A., Lorimor, R., Aday, L., Winn, R., & Baile, W. (1997). Terminally ill cancer patients: Their most important concerns. *Cancer Practice*, 5(3), 147–154.
- Hendrick, S., & Hendrick, C. (2002). Love. In C. Snyder & S. Lopez (Eds.), *Handbook of positive psychology* (pp. 472–485). Oxford, England: Oxford University Press.
- Horney, K. (1945). *Our inner conflicts: A constructive theory of neurosis*. New York: Norton.
- Kearney, M. (1996). *Mortally wounded: Stories of soul pain, death, and healing*. New York: Scribner.
- Keeley, M., & Yingling, J. (2007). *Final conversations: Helping the living and the dying talk to each other*. Acton, MA: VanderWyk and Burham.
- Kelley, H., Berschied, E., Christensen, A., Harvey, J., Hustun, T., Levinger, G., et al. (Eds.). (1983). *Close relationships*. New York: Freeman.
- Kuhl, D. (2002). *What dying people want. Practical wisdom for the end of life*. New York: Public Affairs.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Thousand Oaks, CA: Sage.
- Maslow, A. (1970). *Motivation and personality*. New York: Harper.
- McMillan, S., & Weitzner, M. (2000). How problematic are various aspects of quality of life in patients with cancer at the end of life? *Oncology Nursing Forum*, 27(5), 817–823.
- Mikulincer, M., Florian, V., & Hirschberger, G. (2003). The existential function of close relationships: Introducing death into the science of love. *Personality and Social Psychology Review*, 7(1), 20–40.
- National Consensus Project for Quality Palliative Care. (2004). Clinical practice guidelines for quality palliative care. Retrieved October 11, 2007, from <http://www.nationalconsensusproject.org>
- National Hospice and Palliative Care Organization. (2007). NHPCO facts and figures: Hospice care in America. Retrieved October 17, 2007, from http://www.nhpco.org/files/public/Statistics_Research/NHPCO_facts-and-figures_Nov2007.pdf
- National Quality Forum. (2006). National framework and preferred practices for palliative and hospice care. Retrieved October 17, 2007, from <http://www.qualityforum.org>
- Omery, A. (1983). Phenomenology: A method for nursing research. *Advances in Nursing Science*, 5(2), 49–63.
- Steinhauser, K.E., Bosworth, H.B., Clipp, E.C., McNeilly, M., Christakis, N.A., Parker, J., et al. (2002). Initial assessment of a new instrument to measure quality of life at the end of life. *Journal of Palliative Medicine*, 5(6), 829–841.
- Steinhauser, K.E., Christakis, N.A., Clipp, E.C., McNeilly, M., Grambow, S., Parker, J., et al. (2001). Preparing for the end of life: Preferences of patients, families, physicians, and other care providers. *Journal of Pain and Symptom Management*, 22(3), 727–737.
- Sullivan, H. (1953). *The interpersonal theory of psychiatry*. New York: Norton.
- Sulmasy, D.P. (2001). At wit's end: Forgiveness, dignity, and the care of the dying. *Journal of General Internal Medicine*, 16(5), 335–338.
- Sulmasy, D.P. (2006). *The rebirth of the clinic: An introduction to spirituality in healthcare*. Washington, DC: Georgetown University Press.
- Tedlock, D. (1983). *The spoken word and work of interpretation*. Philadelphia: University of Pennsylvania Press.
- Tedlock, D. (1990). From voice and ear to hand and eye. *Journal of American Folklore*, 103(408), 133–156.
- Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany, NY: State University of New York Press.