

ARTICLES

Approaching Death: A Phenomenologic Study of Five Older Adults With Advanced Cancer

Patricia Y. Ryan, PhD, RN, AOCN®

Purpose/Objectives: To explore the lived experience and the associated meaning of approaching death among older adults with advanced cancer.

Research Approach: A phenomenologic inquiry.

Setting: Urban cancer center.

Participants: 5 individuals diagnosed with advanced cancer who were 65 years or older.

Methodologic Approach: A series of semistructured interviews were tape-recorded, transcribed verbatim, analyzed, and developed into narrative summations.

Findings: The study elucidated the experience of approaching death from advanced cancer. The insightful and compelling narratives of five individuals' experiences suggest that genuine caring, compassionate honesty from trusted healthcare professionals, cautious hopefulness maintained by patients and their loved ones, unquestioned faith, an involvement in desired life activities, and positive interactions within the healthcare system and in personal relationships were meaningful to participants.

Conclusions: Knowledge developed from dying patients allows for an awareness that moves beyond assumption toward an in-depth understanding that can enable healthcare professionals to design meaningful care for these individuals.

Interpretation: Knowledge gained directly from patients' experiences of what is meaningful and helpful as death approaches can guide effective interventions to improve palliative care practices and enhance overall quality of life while living with an incurable illness. Nurses have the ability to contribute meaningfully to patients facing death by relating to them with genuine care that acknowledges their humanity, conveying information with a compassionate honesty that recognizes the impact it will hold for patients and their loved ones, supporting patients' faith and cautious hopes, assisting patients in enjoying an active involvement in life within their limitations, and providing a safe and trusting environment in which to receive care.

Information, from patients' perspective, about the lived experience of approaching death as a result of advanced cancer is limited. Healthcare professionals often make assumptions regarding the care they believe people want as they approach death. However, much more is assumed than is known regarding the desires of dying individuals (Field & Cassel, 1997). A great deal of the knowledge in this area is based on primary caregiver reports and healthcare professionals' perceptions. Unfortunately, caregiver reports sometimes are unreliable and healthcare professionals' perceptions often differ from patients' and families' perceptions (Payne, Langley-Evans, & Hillier, 1996; Ryan, 1992; Teno & Coppola, 1999). These assumptions lack real understanding and lead to less-than-opti-

Key Points . . .

- Nurses have the capacity to establish a rapport that fosters an authentic professional relationship and respects the human lives they are treating.
- Educating patients and family members about treatment options, anticipated side effects, symptom management, and what to expect as death approaches is invaluable.
- Professional boundaries do not have to be dehumanizing.
- Caring communication delivered sincerely and with a confirmation of the humanity of a patient renders a sense of security and is an essential component to the meaningful care of patients facing death.

mal end-of-life care. Knowledge acquired directly from patient experiences is needed to design care that will improve the dying trajectory in ways that are meaningful to patients.

The purpose of this study was to explore the lived experience and associated meaning of approaching death among older adults with advanced cancer using a phenomenologic design.

Literature Review

Deficiencies in the care of the dying have been well documented (Field & Cassel, 1997; Last Acts, 2002; SUPPORT Principal Investigators, 1995). The prevailing approach to inquiry concerning end-of-life issues has been problem based. Most of the previous research efforts have focused on symptom management that, although useful, tend to isolate symptoms from the overall cancer experience. Palliative care principles encourage healthcare professionals to depart from

Patricia Y. Ryan, PhD, RN, AOCN®, is a postdoctoral fellow in the Behavioral Sciences Department in the College of Medicine at the University of Kentucky in Lexington. This study was funded by an American Cancer Society Doctoral Scholarship, a University of Kentucky Donovan Scholars Scholarship, and the Kentucky Association for Gerontology. (Submitted November 2004. Accepted for publication March 8, 2005.)

Digital Object Identifier: 10.1188/05.ONF.1101-1108

the strictly problem-based model. According to Byock (1999), "Within palliative care, the experience of dying—that is, the experience of living with progressive, incurable illness and significant disability—can be viewed as a natural and normal part of life. A patient-centered perspective can acknowledge the difficult medical issues involved, and the often arduous and distressing nature of the patient's experience, while not dismissing the potential value of this time in the life of the person and family" (p. 87).

A Good Death

The notion of a good death has been expressed in a variety of ways: appropriate death (Weisman, 1988), healthy death (Smith & Maher, 1993), happy death (Corless, 1994), peaceful death (Callahan, 1993), and dying well (Byock, 1997). The literature reflects the perspectives of healthcare providers (Davis & Slater, 1989; McNamara, Waddell, & Colvin, 1995; Taylor, 1993) and comparisons between patients and staff (Payne et al., 1996) wherein patients identified a sudden death or dying in one's sleep as a good death and the staff members' responses were focused on pain and symptom management. Singer, Martin, and Kelner (1999) performed a secondary data analysis on three studies (N = 126) originally focused on advance directive preferences and control at the end of life among patients on dialysis, with HIV, or in long-term care. The analyses identified five domains of quality end-of-life care: (a) receiving adequate pain and symptom management, (b) avoiding inappropriate prolongation of dying, (c) achieving a sense of control, (d) relieving the burden on loved ones, and (e) strengthening relationships with loved ones. Steinhäuser et al. (2000) used focus groups to gather descriptions of the components of a good death from patients, families, and healthcare providers. Physicians' discussions primarily were related to biomedical topics and differed greatly from patients and families who identified psychosocial and spiritual issues as being as important physiologic concerns. In a follow-up study, Steinhäuser et al. (2001) asked respondents (i.e., physicians, nonphysician healthcare professionals, seriously ill patients, and bereaved family members) to rate the importance of 44 attributes of the experience at the end of life. The data revealed a broad consensus from all participants regarding a desire to prepare for the end of life; however, physicians were less likely than patients to note the importance of feeling as though life was complete. Findings from these studies highlight the discrepancies among patients', caregivers', and healthcare professionals' perceptions of a good death; in addition, none of the studies engaged dying individuals directly in discussions concerning their own death.

Patients' Perspectives on Anticipated Death

In a three-part study, researchers attempted to develop a quality-of-life scale that was sensitive to the changes in clinical status among patients with cancer who had a life expectancy of six months or less (Greisinger, Lorimor, Aday, Winn, & Baile, 1997). Patients rated existential concerns (hope, meaning, and purpose) highest and reported that although their disease was assessed repeatedly, their spiritual, existential, familial, and emotional concerns rarely were addressed. The study provided insight into the importance of acknowledging the concerns of patients with advanced cancer directly.

Yedidia and MacGregor (2001) used an ethnographic approach to identify dominant themes characterizing patients'

perspectives on death during their last months of life. The inquiry was focused on the awareness, prospect, and process of dying. The researchers concluded that the outlooks on dying among the patients interviewed were thoroughly grounded in the frames of references that gave meaning to other major events in their lives and that an awareness of relevant features of a person's biography assists in planning care.

Recently, various researchers used a phenomenologic approach among patients with advanced cancer to explore the meaning of an expressed desire to hasten death (Coyle & Sculco, 2004), to describe hope-fostering strategies (Duggleby & Wright, 2004), and to examine fatigue (Potter, 2004). To date, no published studies have used a phenomenologic approach to explore the experience of approaching death from patients' perspectives; therefore, the current study's researcher used the phenomenologic approach to provide insight into the lived experience of individuals with advanced cancer who were approaching death. The goal was to develop a better understanding of what older adults with advanced cancer experience and the meaning associated with their experiences. Care should be based on understanding, not merely assumption or retrospective reports, and a more holistic approach rather than a solely problem-based approach should be used. Only by knowing about the experience of living with advanced cancer can meaningful care be developed for patients and those who love and support them.

Methods

Qualitative inquiry is the appropriate methodology for uncovering or understanding a phenomenon about which little is known (Strauss & Corbin, 1990). Phenomenology, a type of qualitative inquiry, has its base in philosophy (Anderson, 1989; Cohen, 1987; Crabtree & Miller, 1992; Creswell, 1998; Munhall, 2001; van Manen, 1984, 1990). Generalizability of findings is not a goal of phenomenologic research; instead, its goal is to accurately describe the experience of the phenomenon under study (Morse & Field, 1995). Many challenges can be encountered when conducting a phenomenologic study; in addition, the inquiry requires a commitment of time, energy, and self to be acutely attentive and authentic to the search for meaning in the experience of the phenomenon. Presentation of a phenomenologic study must include a faithful description with cautious objectification (Spiegelberg, 1975), documentation that is true to the lives of the people described (Anderson), and the ability to avoid homogenizing differences in favor of presenting a heterogeneity of meaning (Munhall) that will lead to the enhancement of knowledge about the phenomenon under study.

Phenomenologic methodology based on Munhall's (2001) approach was used for this study because Munhall offered a precise method for phenomenologic inquiry in nursing. The approach is circular rather than a set of linearly prescribed steps and was designed as an elaboration of van Manen's (1984, 1990) method. Munhall called for immersion as an essential critical beginning for phenomenologic inquiry and asserted that this process leads to "becoming phenomenologically present to the world" (p. 134), which, in turn, leads to the pursuit of greater understanding. People express themselves in language, not themes, and Munhall supported adhering as much as possible to the language of the participants to remain authentic to the meaning of their expression. In addition, the

typical collapsing or categorizing of themes was avoided so that the end narrative does not homogenize participants but reflects many stories of meaning for individuals. Therefore, the end narrative shows the similarities among participants about a particular question. This result is accomplished by consciously withdrawing from the usual stereotypes, assumptions, and predispositions about the phenomenon under study. The withdrawal encourages a deeper understanding—understanding as opposed to identifying—that allows for a focus on the uniqueness of human experience.

Sample

The sample consisted of five purposively selected older adults with advanced cancer, defined as cancer that had metastasized from the original site and was associated with a prognosis of less than one year. The sample number was determined by the number of participants needed to reach saturation of information. Saturation was determined by informational redundancy. A physician on the oncology and hematology service at an urban cancer center agreed to identify potential participants according to the following inclusion criteria: (a) age 65 or older with a diagnosis of advanced cancer, (b) willingness to participate in the study, (c) ability to speak English, (d) lucidity, and (e) the physical capacity, as determined by the participant, to complete interviews. An invitation to participate in the study was offered at scheduled clinic visits to eligible individuals. The researcher explained the study in detail to interested participants, obtained written informed consent, and scheduled a subsequent interview to take place in participants' homes. Conducting the interviews in a participant's natural setting was conducive to relaxed and productive sessions in a nonthreatening environment. Only one individual declined the invitation to participate in the study citing privacy issues. Six participants were enrolled to participate; however, one man's condition deteriorated dramatically the day following enrollment and rendered him unable to participate. Five participants completed the study: three men and two women aged 65–83 years. The diagnoses included liver cancer with pancreatic metastasis ($n = 1$), colon cancer with liver metastasis ($n = 1$), metastatic pancreatic cancer ($n = 2$), and metastatic renal cancer ($n = 1$).

Protection of Participants

The study was approved by the University of Kentucky's institutional review board. Interviews were tape-recorded, but they were coded so that only the researcher had knowledge of the participants' identities. To protect confidentiality, pseudonyms were used and identifying information was removed in the report of findings.

Data Collection

In qualitative research, the investigator is the instrument of data collection. Because the understanding of a phenomenon or experience was sought, in-depth interviews (aided by an open-ended question guide) were conducted instead of using a precise, preworded questionnaire. Interviews were based on the overarching question: "What is the lived experience and the meaning of approaching death as a result of advanced cancer for older individuals?" Multiple interview sessions were conducted with each participant to gain knowledge about the experience. The initial interview session was directed by the open-ended question guide. Subsequent interviews involved

bringing reflections, descriptions, and interpretations of the interviews to participants for verification and clarification as well as expanding on the information shared in previous interviews. The following requests and open-ended questions designed by the researcher were used as a general guide.

- Please tell me about yourself.
- Please tell me about this time in your life.
- How has your life changed since your diagnosis of cancer?
- How are you feeling about these changes?
- What is important at this time in your life?
- What would you like healthcare professionals to know about this time in your life?

In response to participants' answers, other questions were added as appropriate to each interview. Several steps were taken to support trustworthiness. Specifically, the researcher participated in peer-debriefing sessions throughout the investigation. A second reviewer, a doctorally prepared nurse with oncology and research experience, also read the transcriptions for description, interpretation, and meaning. Prolonged engagement was promoted by multiple interview sessions. The participants were asked to verify the descriptions and interpretations. Interviews were tape-recorded to ensure accuracy in recording data, and field notes were kept. All interviews, verbatim transcription, and analyses of the data were performed by the researcher. Exploration, contemplation, summation, clarification, and confirmation of material according to Munhall's (2001) approach were ongoing. Three to six interview sessions were conducted with each participant, and each session ranged from 40–120 minutes in duration. Interviews spanned one to six months and were discontinued because of a decline in participants' condition, death, or saturation of information on the topic. Three of the participants died during the course of the study.

Data Analysis

Data analysis began following the first interview. Each taped interview was reviewed following its completion and transcribed verbatim by the researcher. The material was subjected to a process of contextual processing (Munhall, 2001) wherein the researcher writes the situated context of each participant, a concept based on Heidegger's "being in the world." The situated context refers to four existential life worlds: spatiality, corporeality, temporality, and relationality. This process provided a departure from generating themes and categories and allowed for the composition of a narrative that reflected each participant's description of the experience within his or her situated context. Narrative summations were composed for each participant and adhered to the original language as much as possible. Recognizing that verification of the final narrative may not be possible, the researcher incorporated verification in the cycle of inquiry as much as possible in the taped interviews. The goal of the narratives was to communicate not only a rich understanding of the meaning of the experience for each participant but also to present a reverent representation of the incredible contribution each participant offered to this study at such a critical time in his or her life.

Findings

Five courageous individuals shared their lived experience of advanced cancer with the hope that their involvement would

enlighten many and improve the experience for others. They provided a more complete picture of the experience of approaching death as a result of advanced cancer than available in previous research studies. The resulting narratives reflected stories of their lived experience of approaching death—five individual stories of life with advanced cancer, diverse in detail, yet similar in context.

Joe: Changing Planes

Joe was no stranger to cancer; he had been fighting it since 1997. A hard-working man all of his life, he approached his disease with the same energy. He was tireless in his effort to survive. Having endured multiple cancers and various treatments, Joe developed an impressive resilience. His past experiences influenced the perspective that he and his family had toward his present condition. Joe learned to adjust to the limitations imposed by his disease. He had an admirable ability to accept what life presented and adjust and endure.

With this cancer, uh, I've got it. I've had it. I've been there. I've done that, and, like I say, whatever level you fall to or jump to, whichever the case is, why, there you adjust. You know, some people you could put out here in the wilderness and they'd die within, you know, a couple or three days, but there's other people you'd put out there in the same wilderness and the first thing they would do is look for a way to survive. . . . I mean, just as we sit here and talk and stuff, I wish it could be better, but then you realize, you know, hey, wishes might come true, they might not. You just got to take what comes and go with it. I guess it is sorta like poker playin'. You play the cards that you are dealt and go from there. Try to make the best of the hand that you've got [laughing].

Joe traveled 90 miles one way to receive medical care at a cancer center. He lived in a rural community and jokingly referred to the healthcare providers there as "horse doctors." Plainspoken and straightforward, he shared his experience with cancer. He worked most of his life as a heavy machine operator and loved his work. After his initial cancer diagnosis, surgery, and radiation and chemotherapy treatment, he returned to manual labor. At the advanced stage in his illness when he could no longer work, Joe said, "Not being able to work centers on my mind a lot. It's just hard to withdraw. If I was going strong at 70, why, and they wanted me, why, I'd still be there."

Joe spoke highly of his healthcare providers and expressed an appreciation for their contribution to his care. He was impressed with their ability to care for so many people suffering with cancer. He held the cautious hope that he might be "the lucky one" to beat the cancer. Never fond of doctors, Joe developed a trust in the professionals treating him and tried to comply with all of their instructions. He had developed a friendship with his oncologist through a shared interest in growing tomatoes. Throughout his journey with cancer, Joe had managed to adjust to adversity and find meaning in the experience.

Oh, I've learned more in the past five years than I learned in the previous 60. . . . I wouldn't ring my own bell or anything, but I think it has made me a better person. . . . You appreciate little things you might have run by before. You are a lot more dedicated, and I really feel like faith has pulled us through to this point.

Joe had a solid faith and a loving and supportive family. When he experienced a medical episode that limited his quality of life even further, his family realized that his life would soon end. After becoming a grandfather, Joe became a storyteller, inventing tales that incorporated lessons about fear of water, respecting elders, and kindness to others. Joe's wife wanted him to write the stories out, but his hands were too unsteady, so the researcher tape-recorded Joe telling his stories. In a single attempt, *Papaw Joe's Bedtime Stories* was recorded as a timeless and treasured legacy for his family.

I look at those trees out there sometime, and I say, hey, you guys are gonna be here long after I'm gone. I don't know, I mean, it all comes back to the realization that to begin with you are not going to live forever. . . . To accept the fact that you are subject to growing older and you are subject to dying. . . . Once you accept that fact, and I guess put it in perspective, then you can live.

Rose: Not Afraid

Rose had no fear of death. She calmly accepted her situation. Sweet and loving, she was a pleasure to know. She had not lived an easy life, but at 83, her life had been long. She had enjoyed many years with a loving family, and then her life was altered abruptly by pancreatic cancer. Appreciative of the knowledge that her disease was beyond curative treatment, Rose lived her final days with the realization that death was imminent. She was able to share her story and say good-bye to her family. As she rapidly approached death, Rose's strong faith provided her with a sense of comfort and reassurance.

Well, I think more about God and I pray a lot more, which would be natural, I guess. But I'm not afraid. He saved my soul when I was about 30 years old, and I trust Him to the end. He says I'll never leave you or forsake you, I'll go with you all the way. And I believe He will.

Rose had survived two previous diagnoses of cancer. She could have been bitter after being cancer free for 10 years only to be diagnosed a third time, but instead, Rose faced this diagnosis with assured faith and a peaceful resolve. She appreciated the honest way the oncologist had discussed the prognosis with her.

When I went in, well, I asked him some questions, you know, and, uh, when he got through answering my questions, I, uh, asked him what he thought [about the prognosis], and that's when he told me I would have probably to my birthday and he wasn't sure about Christmas. And . . . we talked about, you know, the possibilities of chemotherapy and radiation and . . . I asked him about, you know, what it would be like and stuff and he said it could *not* do *any* good. And I said, "Well, you answered my question right there [chuckles]. I don't want it."

Rose did not live to her next birthday; she died within 10 days of that conversation. Despite her condition, ascites, inability to eat, reflux, and fatigue, she did not complain. She frequently said, "It's not so bad; it could be worse" and "God gives us what we can stand, and what we can't stand, He don't give us." Her family arranged for hospice services. Lying in bed with oxygen to ease her increased shortness of breath, her words came softer and slower.

I just didn't expect this to be so quick. Here I was up and going Monday and then whammo. I expected to bounce back just quick and didn't. . . . Funny thing about death, you don't expect it regardless and you expect to get better all the time. . . . I don't know whether it is because it hit me so quick or what it was. I still sort of expected to get better.

Rose held the cautious hope that she would improve. She had bragged to friends that she thought she would live to be 100. "I guess I started bragging too soon." When she realized that her life was ending, her hope changed to that of a peaceful death.

I know I'm not going to get any better, so I pray for a quick death and as painless as possible. And I'd like to go in my sleep if I could. I've known a few people that have, and it seems to be easier on the family as well as yourself, you know.

Rose voiced an appreciation for the healthcare professionals who had been so honest with her about her condition. She admired people who could tell her what to expect during this ordeal. In response to what she would like healthcare professionals to know about this experience, she stated,

I think you have to help me out a lot by being just plain truthful. You should tell people what they want to know. . . . I like an honest man. . . . I tell the truth too [grinning].

Rose required liquid morphine to ease the discomfort of her expanding abdomen. As she became more somnolent, her family kept a vigil at her bedside and shared stories of her life. They remarked that she had touched many with her faith.

I feel I'm going to a better place than where I am. There won't be any pain. He said man cannot even imagine the good things that He has in store for them. . . . I'm not afraid to die.

Frank: Making Peace

Frank loved life. A self-made man, he was respected and highly regarded. He had worked diligently to craft a successful business and enjoyed a fulfilling life. Direct and goal oriented, he faced his cancer with purpose. When the treatments failed, he realized his situation, accepted it with a peaceful resolve, and prepared his family for his death.

It's just the realization that you have to face somewhere in life, you know . . . but I appreciate the honesty. . . . I don't want to go on like this if I can't get better. I mean, I am no fun to them, the family. There is no sense in getting in that car and working a few hours, coming home, laying down, and going to sleep, exchanging three of four words. There is no quality there. . . . I want them to be truthful with me. Just tell me up front . . . I have complete confidence in him [my oncologist].

Frank valued education and appreciated knowledge. Gratitude and admiration were emotions he shared easily. Always direct and honest, Frank desired the same from his oncologist. He had built a happy life and a notable career based on integrity, trust, faith, kindness, respect, and a strong work ethic. He had a clear concept of an acceptable quality of life.

Frank believed that hope was helpful and that strength would improve the remaining time in his life. Typically direct and exacting, Frank offered his most loquacious response to a question about what he would want healthcare professionals to know about this experience.

The waiting is almost unbearable, and I think sometimes we've been getting preferential treatment. I know if we just walked in off the street what could happen to me. And I said, "God forbid I should go without Nancy and Kevin or somebody to flag for me or to get up and go." Sometimes it is just not worth the hassle. Both of those [issues] are pretty concerning. It is an awesome aspect to be turned loose into that system. I think they expect us [pause], they think we know more than we know. But, we are almost completely ignorant of the procedure or what to expect or how to do. You know if you do it every day, it becomes second nature to you. I would say the time aspect of it and to keep you a little more informed.

As Frank's abilities diminished, his life became a series of struggles: shaving left him exhausted, solid uninterrupted sleep evaded him, and his desire to work, read the paper, or watch sports dissipated. Frank recognized that these changes signaled his death was near and he wanted confirmation that his suspicion about his condition was accurate: "I can tell you there is not much left of me. I just feel like I am at the limit and I want to go out the best way I can . . . as painlessly as possible."

When Frank saw no possibility of improvement, he welcomed death. He said, "You realize and you make your peace." Once he had reached that point, he set about preparing his family. Although the conversation was not unexpected, his practicality could not balance their sorrow. They listened as he explained that getting into a comfortable position was the highlight of his day and that the exhaustion got to him as much as anything. They tearfully accepted Frank's acknowledgment of his situation and supported him through his remaining days of life. Frank remained alert until the last few hours before his death and was able to say good-bye to those he loved so dearly.

Jesse: The Work of Dying

Jesse was fighting to live. His life had involved many struggles. He was not proud that he had been married three times and was not the father he wanted to be. Eventually, he found the love of his life only to lose her to cancer. He had difficulty adjusting to this loss, and it colored his own battle with liver cancer. Jesse was devastated by the limitations imposed by his illness. Although he found solace in prayer and the kindness of others, he suffered physically and emotionally: "I always said I wouldn't ever give up, but it is hard not to. I said I would fight it as long as I could. I said I was going to hope and be cheerful."

Jesse had been fighting cancer for about a year when he became a participant in the study. He was experiencing painful ascites, fatigue, and some depression. Jesse was still grieving the loss of his wife to cancer six years earlier. His personal battle with cancer brought back many memories of his wife's experience. He said, "I thought I knew what my wife went through, but I didn't." He described how dying involved suffering, being so weak you cannot walk, and taking 30

minutes to get to a chair. He explained how he had given up things little by little: driving, walking around a lake, attending church, visiting with friends, and even talking on the phone.

Well, it's been terrible, like a horror movie, when you can't do nothing for yourself. I can get to the bathroom. I can get to the kitchen table and the bed. Other than that, I stay right here or in that bed. Don't shave because I'm too nervous. That's something I never did miss, and I feel like I been let down or something. A person that's always been well and all of the sudden, you can't do nothing for yourself. I can't even . . . I can barely open a can of Ensure® [Abbott Laboratories, Abbott Park, IL]. I used to be known to be strong with my hands. People would ask me to open things for them, bring them to me. I could open the tightest jar, bottle, or anything there was and now . . . it's a big letdown. I feel like I've gone from being a king to being a pauper. I didn't even want to carry a cane up there for a long time. It would have helped me but, and a wheelchair was clear out of the notion. I just felt like I was too good to ride in a wheelchair. I know that is not right. It [cancer] just knocks you down to where you feel like you could crawl underneath the door. You lose all your self-respect [tearful]. I never did take nothing off nobody. I wanted something done, I done it or had it done. That is just not my style of living.

Jesse valued kindness and common courtesy. He quietly noted all expressions of kindness and concern. Prayer, cards, phone calls, and visitors all benefited Jesse on a personal level. His encounters with healthcare professionals were viewed much through the same lens of intent as his personal encounters. He recounted the kindness of healthcare professionals and expressed his awareness and appreciation when they called him by name, gave him warm blankets, or adjusted his head on an examination table.

Well, I've already told him [the oncologist] I didn't want to die, but I know for some people it is inevitable. Whether they catch it early or what all the reasons are . . . I've agreed to everything he has mentioned, and I haven't had any [regrets]. . . . I haven't been sorry about nothing I've told him to do and he's always asked me in a nice way and I think he [tearful] . . . he's got you at heart when he makes his decisions, and I trust him with my life whether it works or not. And I went into it knowing that it might not work and I still feel that way. . . . I feel safe there and I'm not afraid there, but when you leave, it's gone.

This trust, not freely given by Jesse, was earned through respectful interactions and authentic listening. When Jesse was first diagnosed with cancer by a local gastroenterologist, he found the experience was very unpleasant because of how he perceived he was treated.

He [the gastroenterologist] was about halfway a smart aleck. He didn't have no bedside manners or nothing. He just broadsided me—get out of my way, I'm running this place. I was sitting up on the table, and he said, "*You got cancer!*" Well, if he had shot me right then, you couldn't of done nothing worse. I just fell to pieces, and he told me where it was, about the size of a peach seed at the end of that tube that comes down to your small intestine. Pancreas . . . I said I wanted to get a second opinion.

Because Jesse was offended by the manner in which he was informed of his cancer diagnosis, he revisited this issue close to the end of his life. Fortunately, his experience at the cancer center was much more positive and helpful for him and his family.

If I could go back and do it over again [life], I'd do things differently. I think of all the times I've wasted in my life. Keep up with your age. Think young and act young because one day you won't be able to do the things you want to do. Dying is no easy thing; there's a lot to it.

Ann: One Day at a Time

Ann had a positive attitude. Since the time of diagnosis, she approached her cancer with assured faith. She placed her trust in God and refrained from useless worry. She lived by the belief that all anyone can do is face life one day at a time.

I never doubt, and that is faith when you don't doubt. And I mean, I feel like I'm at the place where I can accept a lot of things. Cause there is gonna be good and there is gonna be bad. You know a lot of people just get so upset. But I mean, I do not get upset with it 'cause I feel like I am not alone. In nothing I go through, I am not alone.

Ann had been a caregiver to many ill family members and worked in the medical field with trauma patients. She had faced personal adversity in her life and found faith to be her stronghold. Three generations lived in her home, and her family viewed her as a strong person: "Anything come up, I was always there. Sickness or whatever, death or whatever, I was there. I never backed away from nobody who was sick. I was always there to help my family." Because of her background, she was comfortable in the medical setting and familiar with procedures. She was impressed with the approach of her oncologist.

He usually sits down and talks to you, and he takes the time to listen to what I am saying. I asked him some questions, and he said, "Did you want to see your chart?" Which, I mean, nobody else had did that. . . . I was free to look through anything I wanted to. . . . I never had been able to do that. Any question I had to ask, he was gonna try to answer. He sits down with you. He tells me what I need to know. But, I mean, I want you to be truthful with me. I don't want no ifs, ands, or buts. Give me what's the facts.

Ann's first words at the time of her original diagnosis were "I trust in God." She described feeling calm and believed that she was not alone. She was realistic about her condition but did not dwell on what might be coming in the future. She believed that worry led to increased suffering.

I want to live as long as I can, but, I mean, this is not going to keep me from livin'. You know I'm not gonna worry myself about it, which I don't. I don't worry myself about it. . . . It is not going to get me down. I take one day at a time. You have to take one day at a time. You can't jump too far ahead. I've been one day at a time 'cause if I live for tomorrow, I can't live for today.

Discussion

The lived experience of approaching death as a result of advanced cancer for older adults was explored in this phenomenologic study. This approach allowed for a departure from the

familiar problem-based approach. Five individuals' narratives provided valuable insight into the overall experience. The narratives presented the participants' personal experiences on their paths toward death. They offered an opportunity for a more complete consideration of the complexities of cancer's final months, days, and hours. In this departure from a purely medical model and problem-based approach, the impact of disease and death on older adults can be recognized and acknowledged.

By looking beyond the diagnosis and considering the lived experience, a more vivid picture of the whole person and the meaning of the experience become evident. Many losses precede the loss of life itself. These losses, as well as death, affect everyone connected to an ill person in a ripple effect.

Cancer affects more than the physical body; it affects the life of an individual, a life that is bound tightly by context—an entire life world. When considering the four life worlds through which human experience is lived, the connectedness of human beings becomes evident. Connections are formed by commonalities shared simply by living during a certain period in time (temporality). Relationships with others connect people in important and valued ways (relationality). The communities (spatiality) and the roles inherent in them connect people to the environment. Lastly, the physical body (corporeality) generally is the most familiar area for healthcare professionals. Often, healthcare professionals attend solely to the corporeal aspect of patients because providers are comfortable acknowledging the effects of disease on the body. Interventions and treatments address corporeal changes, but too often, consideration of the whole person—body, mind, and spirit as they are incorporated with the world—is lacking in interventions.

Joe, Rose, Frank, Jesse, and Ann were approaching death as a result of advanced cancer. Certainly, they shared some similarities in their experiences (e.g., symptomatology, suffering, adaptation). However, the similarities are not as challenging as the differences (Munhall, 2001). Understanding the differences particularly in the meaning of the experience among individuals allows healthcare providers to approach care in individualized and meaningful ways. Recognizing that each person brings a unique perspective and contextual meaning to this experience is the first step to improving the care that healthcare professionals provide. Accessing that perspective through authentic listening and genuine concern requires a commitment to caring for the whole person instead of merely the physical body plagued by disease.

Acknowledging that each person brings a unique perspective to dying, the researcher found that major concepts existed that represented the meaning of the experience for the study participants. These concepts were genuine caring, compassionate honesty, cautious hopefulness, unquestioned faith, active involvement in life, and a trusting participation in the healthcare system. In this in-depth approach to the human experience of approaching death, the concepts presented prominently and were intertwined intricately. The reductionistic tendency to homogenize individuals into groups and clusters has led to an oversimplification of the concepts as they relate to the care of dying individuals. Awareness and acknowledgment of the concepts described herein can enhance the lives of individuals facing death.

Limitations

The small number of participants and recruitment from one urban cancer center were limitations to the study. However,

generalizability is not a goal of phenomenology. The goal of phenomenology is to provide knowledge of an experience about which little is known.

Nursing Implications

Practice

By allowing patients an opportunity to share their stories, nurses can discover that which is meaningful for individuals at a vulnerable time in life. In this study, communications that were delivered sincerely by healthcare providers with a confirmation of people's humanity instilled a sense of security and were essential to the meaningful care of individuals facing death. Such a relationship supports a rewarding reciprocity that is reflective of the affinity of the human spirit. Caring gestures such as adjusting a pillow or providing a warm blanket or a place to recline while waiting for a procedure or treatment convey concern. Acknowledging patients by name and remembering to inquire about family members or special interests indicate a sense of genuine interest. Listening also is perceived as a form of caring. Patients appreciate authentic listening, "listening to the losses," both emotional and physical. Patients with advanced cancer are acutely aware and appreciative of simple yet sensitive expressions of caring. The demonstration of such care by healthcare professionals can positively affect patients' comfort and quality of life. Providing support for an individual's faith and hopes is also meaningful at this time.

Identification of a common interest with a patient provides an opportunity for a healthcare professional to personalize that patient's experience. In a healthcare system that has dehumanized care, oncology nurses have the potential to create an atmosphere of warmth and an attitude of openness to each person's unique cancer experience. The perception of a professional and reciprocal relationship based on trust and respect is invaluable to an individual's involvement in the healthcare system. Assurance that assistance is available from proficiently skilled and genuinely concerned professionals provides a sense of solace. Authentic professional interactions can prevent the allure of arrogant assumption that seemingly pervades so much of health care. Professional boundaries do not have to be dehumanizing. Knowledge of what is meaningful and useful as death approaches can guide effective interventions to improve current palliative care practice. This knowledge can provide the basis for model development of comprehensive palliative care programs, improve patients' overall quality of life while living with an incurable illness, and enable healthcare professionals to act more thoughtfully in the care of dying patients. Knowledge in this area can provide the rationale needed to recognize different paths toward death and allow for the development of programs that are flexible enough to adapt to individual and cultural differences.

Education

Among healthcare professionals, oncology nurses spend the greatest amount of time with patients with cancer. Nurses have the capacity to establish a rapport that fosters an authentic professional relationship and respects the human life they are treating. Educating patients and family members about treatment options, anticipated side effects, symptom management, and what to expect as death approaches is invaluable. Patients with advanced cancer are distinctive in that they are acutely aware of the delicate balance of life. The awareness that they

are approaching death is a reality and not just a possibility. The consciousness that each day is a gift affects the way they interact in their life world. They frequently begin to appreciate the little things. Valued relationships and small pleasures become more meaningful. Faith often gets stronger. Knowledge of this experience allows healthcare professionals to honor the remaining moments of their patients' lives by respecting their humanity, preserving their dignity, ensuring their comfort, and advocating for the highest quality of palliative care.

Research

This study provided knowledge of the experience of approaching death as a result of advanced cancer from an individual's perspective. Elucidating the meaning of this experience enhances an awareness that can allow healthcare providers to move beyond assumption toward understanding. A deeper understanding of this experience can contribute to improved care and the possibility of more positive contributions to quality palliative care and meaningful end-of-life care for individuals

with advanced cancer. Such knowledge can enable healthcare professionals and others providing care to assist individuals approaching death and their families to do so in ways that are meaningful rather than merely tolerable. Future research could focus on determining the importance of the concepts identified in this study as helpful and meaningful to oncology nurses and other healthcare providers. Similar research with individuals facing the end of life as a result of other advanced incurable illnesses (e.g., congestive heart failure, chronic renal disease, chronic obstructive pulmonary disease) also would be helpful. Improvements in care and research advancements in this area have the potential to ease societal concerns about suffering as a result of incurable illness.

The author gratefully acknowledges all of the participants and their families who contributed so meaningfully to this research.

Author Contact: Patricia Y. Ryan, PhD, RN, AOCN®, can be reached at patty.ryan@insightbb.com, with copy to editor at ONFEditor@ons.org.

References

- Anderson, J.M. (1989). The phenomenological perspective. In J.M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 15–26). Rockville, MD: Aspen.
- Byock, I.R. (1997). *Dying well: The prospect of growth at the end of life*. New York: Riverhead Books.
- Byock, I.R. (1999). Conceptual models and the outcomes of caring. *Journal of Pain and Symptom Management*, 17, 83–92.
- Callahan, D. (1993). Pursuing a peaceful death. *Hastings Center Report*, 23, 33–38.
- Cohen, M.Z. (1987). A historical overview of the phenomenologic movement. *Image—Journal of Nursing Scholarship*, 19, 31–34.
- Corless, I.B. (1994). Dying well: Symptom control within hospice care. *Annual Review of Nursing Research*, 12, 125–146.
- Coyle, N., & Sculco, L. (2004). Expressed desire to hasten death in seven patients living with advanced cancer: A phenomenologic inquiry. *Oncology Nursing Forum*, 31, 699–706.
- Crabtree, B.F., & Miller, W.L. (Eds.). (1992). *Doing qualitative research*. Newbury Park: Sage.
- Creswell, J.W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.
- Davis, A.J., & Slater, P.V. (1989). U.S. and Australian nurses' attitudes and beliefs about the good death. *Image—Journal of Nursing Scholarship*, 21, 34–39.
- Duggleby, W., & Wright, K. (2004). Elderly palliative care cancer patients' descriptions of hope-fostering strategies. *International Journal of Palliative Nursing*, 10, 352–359.
- Field, M.J., & Cassel, C.K. (Eds.). (1997). *Approaching death: Improving care at the end of life*. Washington, DC: National Academy Press.
- Greisinger, A.J., Lorimor, R.J., Aday, L.A., Winn, R.J., & Baile, W.F. (1997). Terminally ill cancer patients. Their most important concerns. *Cancer Practice*, 5, 147–154.
- Last Acts. (2002). *Means to a better end: A report on dying in America today*. Washington, DC: Last Acts National Program Office.
- McNamara, B., Waddell, C., & Colvin, M. (1995). Threats to the good death: The cultural context of stress and coping among hospice nurses. *Sociology of Health and Illness*, 17, 222–244.
- Morse, J.M., & Field, P.A. (1995). Principles of doing research. In J.M. Morse & P.A. Field (Eds.), *Qualitative research methods for health professionals* (2nd ed., pp. 69–88). Thousand Oaks: Sage.
- Munhall, P.L. (2001). Phenomenology: A method. In P.L. Munhall (Ed.), *Nursing research a qualitative perspective* (3rd ed., pp. 123–184). Sudbury, MA: Jones and Bartlett.
- Payne, S.A., Langley-Evans, A., & Hillier, R. (1996). Perceptions of a "good death": A comparative study of the views of hospice staff and patients. *Palliative Medicine*, 10, 307–312.
- Potter, J. (2004). Fatigue experience in advanced cancer: A phenomenological approach. *International Journal of Palliative Nursing*, 10, 15–23.
- Ryan, P.Y. (1992). Perceptions of the most helpful nursing behaviors in a home-care hospice setting: Caregivers and nurses. *Journal of Hospice and Palliative Care*, 9, 22–31.
- Singer, P.A., Martin, D.K., & Kelner, M. (1999). Quality end-of-life care: Patients' perspectives. *JAMA*, 281, 163–168.
- Smith, D.C., & Maher, M.F. (1993). Achieving a healthy death: The dying persons' attitudinal contributions. *Hospice Journal*, 9, 21–32.
- Spiegelberg, H. (1975). *Doing phenomenology: Essays on and in phenomenology*. The Hague, Netherlands: Nijhoff.
- 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, 727–737.
- Steinhauser, K.E., Clipp, E.C., McNeilly, M., Christakis, N.A., McIntyre, L.M., & Tulsky, J.A. (2000). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine*, 132, 825–832.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. London: Sage.
- SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA*, 274, 1591–1598.
- Taylor, B. (1993). Hospice nurses tell their stories about a good death: The value of storytelling as a qualitative health research method. *Annual Review of Health Social Sciences*, 3, 97–108.
- Teno, J.M., & Coppola, K.M. (1999). For every numerator, you need a denominator: A simple statement but the key to measuring the quality of care of the "dying." *Journal of Pain and Symptom Management*, 17, 109–113.
- van Manen, M. (1984). *"Doing" phenomenological research and writing. An introduction*. Alberta, Canada: University of Alberta Press.
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany, NY: State University of New York Press.
- Weisman, A.D. (1988). Appropriate death and the hospice program. *Hospice Journal*, 4, 65–77.
- Yedidia, M.J., & MacGregor, B. (2001). Confronting the prospect of dying: Reports of terminally ill patients. *Journal of Pain and Symptom Management*, 22, 807–819.