

CONTINUING EDUCATION

Expressed Desire for Hastened Death in Seven Patients Living With Advanced Cancer: A Phenomenologic Inquiry

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Purpose/Objectives: To explore the meanings and uses of an expressed desire for hastened death in seven patients living with advanced cancer.

Design: A phenomenologic inquiry.

Setting: Urban cancer research center.

Sample: Terminally ill patients with cancer who had expressed a desire for hastened death.

Methods: A series of in-depth semistructured interviews were audio-taped, transcribed, coded, and organized into themes.

Findings: The expression of desire for hastened death had many meanings and uses and communicated the following: (a) a manifestation of the will to live, (b) a dying process so difficult that an early death was preferred, (c) an intolerable immediate situation, even if not specifically identified by a patient, required immediate action, (d) a hastened death could extract a patient from an unendurable and specific situation, (e) manifestation of the last control the dying can exert, (f) a way of drawing attention to "me as a unique individual," (g) a gesture of altruism, (h) an attempt at manipulation of the family to avoid abandonment, and (i) a despairing cry depicting the misery of the current situation.

Conclusions: Expression of desire for hastened death has many meanings and uses and is a tool of communication.

Implications for Nursing: Listening to the patient's story will help nurses understand what is being asked for through the expression of a desire for hastened death.

Key Points . . .

- Expression of desire for hastened death is a communication tool used by patients.
- Expression of desire for hastened death is not necessarily a literal request and can have many meanings and uses.
- Expression of desire for hastened death can best be understood within the context of a patient's current situation, life history, and experiences.

Goal for CE Enrollees:

To explore the meanings and uses of an expressed desire for hastened death in seven patients living with advanced cancer.

Objectives for CE Enrollees:

On completion of this CE, the participant will be able to

1. Explore the meanings and the uses of expressed desire for hastened death in seven patients living with advanced cancer.
2. Recognize that a patient's expression of desire for hastened death is a communication tool.

Individuals living with advanced cancer sometimes express desire for hastened death (Breitbart et al., 2000; Brown, Henteleff, Barakat, & Rowe, 1986; Chochinov et al., 1995; Coyle, Adelhardt, Foley, & Portenoy, 1990; Emanuel, Fairclough, & Emanuel, 2000; Rosenfeld et al., 2000; Seale & Addington-Hall, 1994). The need to have a clear understanding of what such an expression means and what the individual is asking for is present at clinical and societal levels. Clinically, nurses and physicians need to understand such an expression so that they can respond appropriately to the individual's needs. At a societal level, understanding also is needed so that rational social policies can be formulated

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regarding how to respond as a society when a terminally ill patient with cancer expresses desire for hastened death. For this study, the researcher postulated that gaining insight into the lived experience of a cohort of patients with advanced cancer who had expressed, at least once, desire for hastened death would provide insight into the meanings and uses of such an expression. This is one in a series of articles arising from that study (Coyle, 2002).

Literature Review

Research to explore why terminally ill patients with cancer express desire for hastened death has focused in large part on the relationship between depression or psychologic distress and the desire for death (Breitbart & Rosenfeld, 1999; Breitbart et al., 2000; Chochinov, 2002; Chochinov et al., 1995; Ganzini et al., 2002). Psychological and social factors typically have appeared to have more influence than physical symptoms such as pain. Overall, the studies have attempted to understand patients' experiences through preselected domains of study. Little in-depth research could be found that examined individual meanings and uses of an expressed desire for hastened death derived directly from narratives of terminally ill patients with cancer (Mak & Elwyn, 2003).

A body of literature does exist on euthanasia, clinician-assisted suicide, and suicide in the terminally ill, all of which are potential outcomes of an expressed desire for hastened death, and therefore was appropriate to review for the study. This literature reflects various perspectives, including caregivers' perspectives of dying patients' desire for death (Emanuel et al., 2000; Jacobson et al., 1995; Matzo & Schwarz, 2001; Seale & Addington-Hall, 1994), dying patients who acknowledge desire for death (Breitbart et al., 2000; Brown et al., 1986; Chochinov et al., 1995; Mak & Elwyn, 2003; Suarez-Almazor, Belzile, & Bruera, 1997), and patients whose behavior suggests that they might be considering hastening death sometime in the future (Emanuel, Fairclough, Daniels, & Clarridge, 1996; Owen, Tennant, & Jones, 1992), as well as suicide, one outcome of desire for death (Breitbart, 1987; Ferrell, Virani, Grant, Coyne, & Uman, 2000; Filiberti et al., 2001; Ganzini et al., 2002; Grzybowska & Finlay, 1997; Matzo & Schwarz; Quill, 1991). The current study was designed using a different methodologic approach than those used in the previously described studies. The design was selected as one that would provide added insight into the lived experience of a patient with advanced cancer who had expressed, at least once, desire for hastened death. Through this insight, the researcher hoped that a clearer understanding of the meanings and uses of an expressed desire for hastened death in this population could be gained. No assumptions were made in the current study as to whether an expressed desire for hastened death was or was not a literal request.

Methods

Phenomenology (from the Greek work, phenomenon, which means to show itself) was the methodologic basis for this qualitative study. This approach is one of discovery and description and emphasizes meaning and understanding in the study of the lived experience of individuals (Creswell, 1998; van Manen, 1990). Phenomenologic research requires active

involvement from the researcher, study participants, and audience who eventually will read and evaluate the research report. Reinharz (1983) described this process as one of "transformation" of private experience into public knowledge and has outlined specific steps to explain it. These steps include self-revelation by the study participant; listening, interpreting, and producing a coherent and meaningful written account of the phenomenon by the researcher; and creation of a personal understanding by the reader of the final report. A good phenomenologic description is "something that we can nod to, recognizing it as an experience that we have had or could have had" (van Manen, p. 27). Van Manen also wrote that "a phenomenologic description is always one interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially richer or deeper transcription" (p. 31). The study findings report one interpretation of the meanings and uses of an expressed desire for hastened death in a select group of patients living with advanced cancer.

Setting and Sample

The sample was limited to English-speaking adults with advanced cancer who were followed by the Pain and Palliative Care Service at an urban cancer research center either as inpatients or outpatients who were not known to the researcher from her clinical practice and who had expressed, at least once, a desire for hastened death. This expression could be either verbal or nonverbal, that is, expressed by an action that was interpreted by the physician as reflecting such a desire. Patients who fulfilled these criteria were eligible for the study.

Attending palliative care physicians were asked to approach patients who met the study criteria to determine whether they were interested in participating in the study. Patients who expressed interest in participating were given the option either to contact the researcher directly or have their attending physicians ask the researcher to initiate the contact. Once the researcher had been informed about an interested potential study participant, she contacted that individual either that day or the following day in person or by telephone. After a brief explanation of the purpose of the study, if the individual remained interested, the researcher set up a convenient time to explain the study protocol in full, to ask whether the individual would like the researcher to speak with a family member, and to leave a copy of the study protocol and informed consent for the individual to review. The rationale for these steps was that, in the researcher's experience, terminally ill individuals often like to include family members or friends in the decision-making process. The researcher recontacted the individual within two days to see whether he or she was interested in participating in the study. If interested, a time was set for the researcher to obtain a signed consent and conduct the first interview. In addition to the signed informed consent, process consent was used throughout the study, that is, the researcher obtained consent verbally prior to each interview. New participants continued to be recruited until no further themes of the lived experience of advanced cancer emerged (known as reaching "theoretical saturation"). No more than two interview series were ongoing at any one time.

Protection of Participants

The study was approved by the Memorial Sloan-Kettering Cancer Center and New York University institutional review

boards. Pseudonyms were used for all identifying information about the participants to protect confidentiality.

Interview Process

One researcher conducted all of the interviews. A series of two to six in-depth interviews was conducted with each participant for a duration of 30–60 minutes each at intervals ranging from one day to six months apart. The basis for deciding on the number of interviews per participant was that each interview series would continue until no new information was forthcoming from the participant (saturation) or until circumstances intervened that prevented further interviews from being conducted with the participant. The initial study protocol specified a time interval of three to four weeks between interviews. However, when the interview process began, the researcher noted that some participants were very eager to continue the interview process within a much shorter time frame and, on occasion, to extend the interval between interviews to a longer period. The protocol was amended with institutional review board approval to accommodate the participants' wishes. These flexible time frames and interview lengths reflecting individual patients' needs are consistent with the research method.

The interviews were held at a place that was convenient to each patient, either at home or in the hospital, outpatient clinic, or long-term care facility. Each interview was audiotaped, transcribed, and reviewed before the next interview. At the beginning of each interview series, the researcher explained to participants that she was there to learn from them about their experience of living with a serious illness and how that experience had affected their attitudes toward life and death. The follow-up question asked participants to describe their lives before they were sick and their lives at the present time. Follow-up probe questions were flexible and dependent on an individual's responses. Each patient's interview series continued until no new information was forthcoming, the patient developed cognitive impairment, the patient became too weak or fatigued to continue, or death intervened.

Data Analysis

During the interview series with each participant, the researcher conducted ongoing initial content analysis of the data. Each line of text was the unit of analysis. The researcher coded for meaning, clustered codes into conceptual categories, and identified the need for further data collection for clarification or expansion of categories. Consistent with the philosophical underpinnings of the study, data analysis was an interactive process with the researcher reading and rereading the transcripts and interacting with and interpreting the data (Creswell, 1998; van Manen, 1990). This ongoing analysis between interviews allowed the researcher to explore and verify with the participant themes that had been uncovered and to "member check" that her interpretation of what had been said was valid. Data were analyzed at the completion of all of the interviews according to the steps in Figure 1.

A solid data trail, documenting each step of the research process and open to scrutiny, was maintained. Two master's-of-art-prepared individuals (one in philosophy and one in anthropology) provided an external check that the coding and themes were grounded in the narratives. In addition, an auditor ensured that the researcher adhered to the planned process and that the coding and derivation of themes adequately repre-

- The entire set of interviews was examined as a whole to get an overall understanding of the text.
- The text of each interview and then all interviews for each participant were summarized (into narrative summaries and individual portraits).
- Themes were identified from the codes. Excerpts from the interviews were organized to support interpretations resulting in thematic consensus.
- A second person reviewed the coding and themes. Where necessary, clarification was achieved through data review and discussion.
- Themes that cut across all participants were identified as supported from the data.
- Finally, an interpretive narrative using the identified themes was written. Sufficient data were organized to support the interpretive analysis and allow for validation of the findings by the reader.

Figure 1. Steps in Data Analysis

sented the raw data (Ely, 1991; Lincoln & Guba, 1985; van Manen, 1990).

Findings and Interpretative Analysis

Sample

Eight patients were approached for the study. Seven agreed to participate, and one patient declined because of deep fatigue. Participant demographics can be found in Table 1. The number of interviews per participant ranged from two to six, and time period for the interviews varied from two days to six months. The reasons for terminating an interview series were cognitive impairment ($n = 2$), information saturation ($n = 2$), and death ($n = 2$), and a participant believed that she had completed her contribution to this research ($n = 1$) (see Table 2). Although information saturation was reached in only two participants, theoretical saturation across all participants was reached after recruitment of the seven participants. That is, no new themes were forthcoming across participants. Six of the seven participants had died by the time the study was completed.

Antecedents and Trigger Events Preceding Expression of Desire for Hastened Death

Chronic antecedents or triggers that preceded expression of desire for hastened death in these participants included debilitating progression of disease; perception of chronic and progressive loss of social supports, dignity, autonomy, and sense of worth; loss of sense of purpose (place) in the world; and perception of being a burden on self or others in the present or future. Acute events included uncontrolled pain, shortness of breath, and medical information that produced fear, hopelessness, and a sense of dread. Antecedents and trigger events for the expressed desire for hastened death in these participants were chronic, acute, or acute superimposed on chronic.

Forms of Expression of Desire for Hastened Death

Although most of the expressions of desire for hastened death by these participants were in verbal form, two were expressed by action. One participant refused surgery that had the potential to lengthen her life by several years without significant morbidity, and a second acquiesced to transfer from an acute care cancer hospital to a terminal care facility, an action perceived by him as helping to realize his goal of a hastened death. Examples of circumstances under which each participant expressed a desire for hastened death and forms this expression took are seen in Table 3.

Table 1. Participant Demographics

Characteristic	n
Age (years)	
40–49	1
50–59	2
60–69	2
70–79	2
Gender	
Male	4
Female	3
Cancer diagnosis	
Endometrial	1
Lymphoma/HIV	1
Lymphoma	1
Lung	1
Prostate	1
Rectal	1
Sarcoma	1
Ethnicity	
White	6
Hispanic/Latino	1
Religion	
Jewish	3
Catholic	2
Protestant	2
Occupation	
Professional	5
White collar	1
Blue collar	1

N = 7

Meaning and Uses of an Expression of Desire for Hastened Death

The seven participants illustrated the complexity of the meanings and uses of an expressed desire for hastened death. Sometimes the meanings and uses were explicit and directly stated, and other times they were more indirect and inferred or interpreted by the researcher within the context of what each participant described. The expression of a desire for hastened

death was, in all instances, a tool of communication, and the examples evidenced in the individual narratives are explicated in the following paragraphs. The researcher found that the meanings and uses of this expression of desire for hastened death could be different from patient to patient and from intent to intent. For example, one patient might wish to call attention to him- or herself and also to signal an urgent need for help. In another instance, the expression might be used to affect a participant’s support systems and/or to express despair. The meanings and uses often were intertwined and overlapping—the same and yet different for each expression and each patient. Nine distinct and yet sometimes intertwined and overlapping meanings and uses of an expressed desire for hastened death were extrapolated from the narratives.

1. A manifestation of the will to live: The researcher named this the “primary paradox,” that is, the participant’s behavior evidenced the will to live despite having expressed at least once a desire for hastened death. “The goal is now to die. . . . I’m using my flexibility not to devote my time toward how I am going to die and praying, etc. . . . I’m using my flexibility in time management to do things that the living do, not the dying.” The paradox and struggle also were evidenced in the following statement: “See, there’s a problem while planning or pursuing your death. . . . On the one hand, I am saying all these things, and, on the other hand, I am going down for radiation.”

The ability to live a full and normal life shrunk with the progression of the disease and sometimes led to the expression of desire for hastened death. Yet the participants frequently found a way to value aspects of their life that remained, such as being with their family, and to affirm the urge for continued existence.

I think passively sitting in my own garden, sitting on my own deck, would still be preferable to, to, to death. Quality of life, the concept of quality of life is shifted. I can live with an inactive life . . . and I’d still fight a bit to gain incrementally.

This response shift was a sign of the will to live despite having expressed desire for hastened death.

Table 2. Interview Characteristics

Participant	Number of Interviews	Time Period for Interviews	Location of Interviews	Reason Interview Series Halted	Patient Status
1	6	3 weeks	Cancer center (4) Terminal care hospital (2)	Cognitive impairment	Died seven days after last interview
2	3	3 months	Participant’s home (1) Cancer center (1) Outpatient clinic (1)	Information saturation	Alive at time of study completion
3	2	2 days	Terminal care hospital (2)	Cognitive impairment	Died one month after last interview
4	3	4 weeks	Participant’s home (1) Cancer center (2)	Death	Died seven days after last interview
5	4	2 months	Cancer center (1) Rehabilitation center (2) Student residence (1)	Participant believed that she had completed her contribution to this research	Died four months after last interview
6	3	4 weeks	Participant’s home (3)	Death	Died one month after last interview
7	6	6 months	Researcher’s office (5) Cancer center (1)	Information saturation	Died one year after last interview

Table 3. Participants' Desire for Hastened Death

Participant	Circumstances	Forms of Expression
1	When first diagnosed with cancer to prevent his family having to "go through" his terminal illness Later in response to an increasingly debilitated state and loss of bowel and bladder control Later still in the setting of severe pain	In written form, in a personal diary and shared with no one until shown to researcher; no plan outlined In verbal form, shared with his wife; various plans such as blowing air into his central line discussed In verbal form, shared with his wife and palliative care physician; no plan outlined
2	In response to decreased ability to walk, chronic pain, and loss of sense of self-worth	In verbal form, a constant rumination to staff; no plan outlined
3	In response to feeling a burden on his family and not wanting them to remember him as a debilitated and dependent person	In form of action, accepting transfer to a terminal care hospital that he stated was an act that would hasten his death because he would no longer be in a mode of life-prolonged care
4	In response to fear of a suffocating death after experiencing an acute episode of dyspnea	In verbal form to palliative care physician and nurse, discussed various plans: taking an overdose of morphine available to him for pain, jumping in front of a train, selecting an institution for terminal care that would not interfere with self-administration of medication
5	As the only way to get staff to "really hear" her	In verbal form to the inpatient staff which triggered a palliative care referral; later in thoughts of the future if she became "sicker" or pain increased; no plan outlined
6	In response to lack of mobility, chronic neuropathic pain, and inability to live in a personally meaningful way	In verbal form to her palliative care physician; no plan outlined. "How does one do it? I don't know."
7	In response to fear of living for a prolonged time in a dependent state and using her financial resources to the detriment of her family	In form of action, refusing treatment that might have prolonged her life for several years without significant morbidity

2. The dying process itself was so difficult that an early death was preferred: This was named by the researcher as the "secondary paradox." In these situations, the expression of desire for hastened death reflected that the dying process itself was so difficult that death was better than going through it. The secondary paradox also could be characterized as, "I can't bear the dying process so I'll short circuit it by dying," or "I don't want to go through the dying process so I'll kill myself." Thus, expressed desire for hastened death could reflect a desire to end a dying process that had become too overwhelming and burdensome for a participant. "I don't want to undergo that [explicative] feeling of helplessness, that there's not a [explicative] thing that I or anyone else can do," or "Sometimes I start yell-

ing at my shrink that this is horrible, that why don't I die right now? . . . Why do I have to live through this?"

In these situations, the reasons triggering the expression of a desire for hastened death were multiple and often overlapping, including uncontrolled symptoms, perceived loss of dignity, a feeling of having no place in the world, and the fear of leaving a damaged legacy. "After a while, your family, who you love so dearly, will remember you as a washed-out role model. . . . It will remind them of what they have to go through, the lack of strength, the weakness, and so forth." The desire was to end the process before further destruction of self occurred. These participants did not wish to cease existing, but they saw no point in going through the process and wanted it to end.

3. The immediate situation was unendurable and required instant action: An expressed desire for hastened death in these situations was an urgent request for help that the immediate situation was unendurable and required instant action. "There were many times when I was in such pain and such misery. I said, let me go . . . finished . . . no more of this torture." This called attention to any variety of problems arising from the lived experience of advanced cancer: physical, psychological, social, spiritual, and existential. The message sent was, "You don't know how much I am suffering. Come and deal with me; I need your attention and help." One participant gave this signal through nonverbal communication by refusing surgery that could have prolonged her life for several years without significant morbidity. Others expressed their suffering verbally. "I feel, deep inside, I don't want to feel hurtin [sic] . . . that I want to end this. . . . I ask God why he don't take me, why I suffer so much." The urgent need for help was indicative of a layer of suffering experienced by a participant that was so confusing and overwhelming that he or she was unable to specifically indicate what was causing the suffering and what was required. On the other hand, when a participant was focused on a specific experience or event that he or she knew would be intolerable, the expression of desire for hastened death took another form, the "if-then" proposition.

4. A hastened death was an option to extract oneself from an unendurable situation: The option to extract oneself from an untenable situation through a hastened death sometimes was expressed as an "if-then" proposition; for example, "If the pain gets worse, then I want to be dead." "Pain is my biggest fear. It puts me in a darkness and a lack of will to go forward and a desire to die. . . . The pain wants me to have a vehicle to just, just stop my life." Severe pain or acute, severe shortness of breath were the two symptoms that overwhelmed the participants and were identified as being incompatible with life. "If I had to go through [an acute episode of shortness of breath] again, I would throw myself in front of a subway train. I am not going through that again."

5. A manifestation of the last control the dying person can exert: The expression of desire for hastened death was sometimes an assertion of ultimate control over an untenable situation as reflected in many of the previously described situations. Loss of control so frequently was a source of suffering for these participants that it warranted a category in and of itself. An example was the participant who said that he would throw himself under a train if he was in a situation of uncontrolled shortness of breath again. "If I had to go through [an episode of acute shortness of breath] again, I would throw myself in front of a subway train. I am not going through that again." The "if-then" situation and a manifestation of the last

control a dying person can exert are intertwined concepts, but separating them conveys a broader understanding of the human struggles and thoughts behind the expression of desire for hastened death.

6. A way of drawing attention to “me as a unique individual”: The demand from the participants that they be understood and heard as individuals with a life and valued outside of their role as patients was another use of the expression of desire for hastened death. Patients sometimes have difficulty making themselves visible as persons in the hospital environment. Attention is focused on the disease process, disease management pathways, and protocols. One participant reported using an expressed desire for hastened death specifically as a tool to draw attention to self and be heard, listened to, and understood in the depth of her experiences, her losses, and her suffering. No other form of communication had worked for her.

7. A gesture of altruism: In some cases, the desire for hastened death was to relieve the family of the burden of care and of witnessing the participant’s progressive deterioration. In some instances, this use of expressed desire for hastened death occurred early in the disease process when disease progression was anticipated: “There have been times I’ve felt so much a burden on my family that maybe it is best for me to die just to relieve them of going through the terminal phase of my disease.” Another participant stated that he did not want his family to witness what “they would have to go through themselves” at some point (their own dying). He accepted transfer to a terminal care facility to spare his family the burden and responsibility of his physical care and the daily witnessing of his physical deterioration. In another instance, when a participant acknowledged that no tumor-directed therapy options were possible for him,

All of a sudden, it dawned on me that there was no solution, and if there was no solution to my cancer, then why was I hanging around? I got thinking about death as a practical matter. Why hang around and cause a lot of people a lot of grief?

8. An attempt at manipulation of the family to avoid abandonment: The expressed desire for hastened death can be a message to those around an individual as to how dependent he or she is upon them. One participant described involving his family in every decision that was made regarding his care, including his thoughts about a hastened death.

I shared that I wouldn’t do it until we discussed it together. . . . She didn’t have to worry about me taking the pills. . . . It wasn’t fair to them. . . . It would leave them wondering, did they do, you know, contribute to it, did they do all they could. . . . And I want them to feel comfortable that they’ve done everything.

Could any family really say, “Yes, we are burdened by your care, and yes, both you and I would be better off if you were dead”? Involving the family in this way almost certainly reinforced to his family how vulnerable he was to their presence, their care, and his desperate need for them. Shifting the responsibility for decision making onto the family might be interpreted as a way of ensuring that they stayed by his side. This appeared to be the case with this participant: He was never left alone, and his family constantly reinforced to him the benefit they were deriving from his care and his presence.

9. A despairing cry depicting the misery of the current situation: Finally, the expression of desire for hastened death sometimes took on the form of a lament—a despairing cry to the universe about the misery of the current situation. Sometimes the cry was directed to the ear of a compassionate and trusted healthcare professional; at other times, the lament was voiced to heaven. A sense of abandonment by God was expressed by two of the participants. This lament, which was given voice from time to time, was the visible part of a deep-seated well of grief. “Why do I have to go through this? Why can’t I just die right now?” and, “When I pray, I use [sic] to feel the power of God on me. . . . Now I sometimes feel as though I am talking to the air.”

Discussion

The topic explored in this study was the expression of desire for hastened death by individuals living with advanced cancer. The researcher postulated that an exploration of the lived experience of these individuals through a series of face-to-face interviews would shed light on the meanings and uses of this expression. The intent of this qualitative study was to explore the human dimensions of living with advanced cancer, the impact of that experience on the individual, and how that impact led to an expression of a desire for hastened death. A paradox was seen: On one side, the expressed desire for hastened death represents the desire for cessation of life; on the other side, the evidence for the desire for life and continued existence is strong.

Parse (1981, 1992), a nursing theorist, has recognized the paradoxical nature of people’s experiences as living human beings. Parse’s (1992) theory of Human Becoming (formerly Man-Living-Health [Parse, 1981]) is what “is embedded in meanings, patterns in relationships, and in hopes and dreams” (p. 37). She described paradox as “apparent opposites” but emphasized that these are not opposites but rather two sides of the same coin.

The expression of a desire for hastened death seems consistent with the paradoxical pattern of Human Becoming described by Parse (1992). In this conceptual model, the present participle is used to express continuous process. Parse suggested that development (becoming) is a combination of affirmation and negation: a paradoxical process. The expression of a desire for hastened death—a movement from being to non-being—is consistent with Parse’s definition of “powering,” which is the continuous affirming of self in the light of non-being. As demonstrated in the current study and other studies (e.g., Chochinov et al., 1995), an expressed desire for hastened death is not always continuous. It can be understood as a transformation or the struggle toward what is not yet. According to Parse (1998), “These rhythmical patterns are not opposites, they are both sides of the same rhythm that coexist as a whole, and both sides of the rhythm are present simultaneously” (p. 42). Through the expression of a desire for hastened death, the transformation that is sought—the regaining of dignity, autonomy, and wholeness—may occur.

When a patient with advanced cancer expresses a desire for hastened death, the process described by Parse (1992) is very apparent. The reality of “becoming” pushes and pulls patients with advanced cancer in a quest to guide and control the becoming. “Revealing-concealing” in the expressed desire for hastened death is illustrative of how little we know about the lives of the patients for whom we care. The person we see, the present revealed, conceals the past and the be-

coming. “Enabling-limiting” in the expression of desire for hastened death attempts to control the future and, through that control, may cut off the future. Ambivalence is common. “Connecting-separating” in the expression of desire for hastened death often draws the individual closer to the family as they plan to separate. The individual’s sense of the imminence of nonexistence can intensify the separating and connecting. Parse (1992) saw paradox as a model for human experience and identifies opposing forces in human behavior and understanding. The findings from the current study support this view. The particular applicability of this insight to the understanding of the end-of-life experience of the patient with advanced cancer is striking. The parallels between palliative nursing and Parse’s (1992) theory of Human Becoming have been described previously (Hutchings, 2002). Leaving aside the complexities of her theory, the insight that Parse (1992) described in the paradoxical nature of human experiences and human feelings elicits the “phenomenologic nod” (van Manen, 1990) from the researcher.

For the person living with advanced cancer, the paradox is poignantly present in the urge to live and the inevitability of death. The experience of belonging to both the world of the living and the world of the dying can be bewildering and confusing. Similar findings were shown by Benzein, Norberg, and Saveman (2001), when exploring the experience of hope in 11 patients followed in palliative home care. The participants were described as being torn between a will to live and the awareness of a final capitulation to death. The prominence of one domain over the other varied with the individual’s changing physical and emotional circumstances.

The findings from the current study suggest that the expression of a desire for hastened death is a complex language and may not be generated by suicidal ideation but rather by the lived experience of the individual with advanced cancer. Although some of the expressions of desire for hastened death may be associated with depression and hopelessness, this study has illuminated several factors pervading the experience of the dying patient that may underlie or trigger the expression of desire for hastened death, providing a broader basis to understand this language.

Limitations

The number of participants was small, and the participant pool was limited by recruiting them only from the Pain and Palliative Care Service of an urban cancer research center. Most were white professionals older than 50. The implication of these small numbers and the limited participant pool is that the study findings are not traditionally generalizable. However, the aim of qualitative research is not to find significant numbers but rather themes that emerge from the narratives that are indicative of common human experiences.

Nursing Implications

Practice

Listening to patients’ stories through the narrative interview and giving them an opportunity to describe their lived experience of advanced cancer may help nurses and others to understand what actually is being asked for when a patient expresses desire for hastened death. This is extraordinarily important because many patients living with advanced cancer are not able to identify or articulate the particulars of what is causing them

such overwhelming distress and may indicate their distress globally through the expression of desire for hastened death. This expression is a communication tool in all instances and has many meanings and uses that appear to be common to patients with advanced cancer and unique to individual patients. Their uniqueness to the particular person can be understood best within the context of that person’s current situation, life history, and experiences. The findings of the current study help to provide a framework or matrix of categories for nurses to listen to and address the needs of a patient with advanced cancer who expresses a desire for hastened death. Time for the narrative interview needs to be built into palliative nursing practice.

Education

The research findings suggest that the vulnerability of patients with advanced cancer cared for in an urban research cancer center is profound. They also suggest that nurses can educate patients to reduce that vulnerability. The research suggests that patients can be empowered by learning how to communicate with their doctors and nurses, to address their pain issues, and to understand their treatment options. The research findings also underscore the importance of nurses being prepared to provide patients with answers to questions about how they might die and what their options are for care at the end of life. Empowerment through education can help to provide those living in the face of death with a systematic way of dealing with their sense of vulnerability.

Research

This is a small exploratory study that raises many questions and areas for future research. The methodology used in the study included an interpretive analysis in determining the uses and meanings conveyed by each participant when expressing desire for hastened death. The researcher did not in all instances ask the participants if that interpretation was the one that was intended. Future research on the uses and meanings of an expressed desire for hastened death could use the categories delineated through the research as a guide to see if they hold true in other populations in a similar environment or in a different environment such as a hospice setting. Only patients were included in the current study. Research is needed on how staff interpret and respond to the expression of desire for hastened death by patients and the impact of that expression on their attitudes and behavior toward patients following such an expression. Research also is needed regarding how families interpret and respond to the expression of desire for hastened death and the impact of that expression on their attitudes and behavior toward the patient following such an expression. Finally, researchers should ask the following questions. Can “vulnerability markers” be identified in patients who express desire for hastened death? What are these markers? If identified early would interventions decrease future suffering?

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The continuing education examination and test form for the preceding article appear on the following pages.