Prognostication in Advanced Cancer: Nurses' Perceptions of the Dying Process

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Purpose/Objectives: To determine how experienced nurses describe the dying process of patients with advanced cancer.

Sample/Setting: Fifteen nurses, experienced in the care of patients with advanced cancer, employed by a midsize midwestern hospice or academic inpatient oncology unit.

Methods: Individual interviews using structured and semi-structured questions. Responses were content-analyzed using Krippendorff's techniques.

Main Research Variable: Dying process in cancer.

Findings: Nurses view the dying process as a weeks-to-months-long, multidimensional process that encompasses physical, psychosocial, and spiritual/existential domains. Impending death is recognized and monitored. Common clinical signs include declining interest in life, increased weakness, somnolence, and changes in respiratory, circulatory, and cognitive status.

Conclusions: Active (or acute) dying processes are recognized and monitored by nurses; the complexities and patterns of the phenomenon remain unarticulated.

Implications for Nursing: Future research could explore both empirical and contextual aspects of acute dying processes. Nurses are in a position to develop useful knowledge about acute dying processes in cancer.

Key Points . . .

- Nurses generally recognize impending death in patients with advanced cancer.
- Nurses cite psychosocial factors as a key influence in the length of survival of patients with advanced cancer.
- Nurses are in a key position to study the dying processes of patients with advanced cancer.

When cancer is diagnosed as advanced (i.e., metastatic and uncontrollable), estimating length of survival becomes important to many patients and families. "How much time?," they ask. Clinicians would like to answer such questions, make good therapeutic decisions, and use support services appropriately. Studies repeatedly have shown, however, that clinicians are unable to accurately predict how long individual patients will survive (Forster & Lynn, 1988; Heyse-Moore & Johnson-Bell, 1987; Parkes, 1972). The inability to prognosticate is thought to be related to the complexities of advanced disease (i.e., the various clinical manifestations and psychosocial dynamics that influence treatment and survival).

Although clinicians may not be able to predict the overall course and nature of any one individual's illness, experienced clinicians recognize the impending death of patients with advanced cancer. In many cases, a dying process, lasting hours, days, or occasionally weeks, precedes death. Nurses have used the term "terminal syndrome" for the dying process seen in multiple end-stage diseases (Adams & Nichols, 1996). The frequently symptomatic dying process that concludes a cancer illness often is heralded by a sudden, significant change in functional status, symptom profile, or disease status. Nurses routinely monitor the dying process of patients and alert family members of impending death. Nurses' perceptions about the dying process have not been explored; their insights about the process could enhance prognostication for the final phase of terminal cancer. The purpose of this study was to ascertain how experienced oncology nurses describe the dying process of patients with advanced cancer. Do they describe dying as a brief, recognizable process? Is the dying process recognized and monitored? What, if any, clinical signs are associated with its onset, progression, and culmination?

Prognostication in Advanced Cancer

Patients with advanced cancer and their families commonly ask clinicians for estimates of survival, initially when advanced disease is diagnosed and again when death is imminent. Knowledge of the projected length of an advanced cancer illness enables patients to make appropriate plans. The need for clear, reliable information increases during this phase

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of illness (Hull, 1989; Leonard, Enzle, McTavish, Cumming, & Cumming, 1995; Lewandowski & Jones, 1988; Wright & Dyck, 1984). Studies have shown that families want to be physically near the patient at time of death (Hampe, 1975; Irwin & Meier, 1973; Molter, 1979).

Multiple studies have demonstrated that clinicians are unable to accurately predict how long individual patients will survive. In 1980, researchers noted a relationship between functional status and length of survival as an ancillary finding in a study designed to evaluate the reliability and validity of the Karnofsky Performance Status (KPS) scale (Yates, Chalmer, & McKegney, 1980). Subsequent studies showed a modest-to-moderate association between functional status and length of survival (Evans & McCarthy, 1985; McCusker, 1984; Mor, Laliberte, Morris, & Wiemann, 1984). Researchers also have examined whether clinical symptoms combined with functional status affect length of survival. In a large, retrospective study using data from the National Hospice Study, a number of clinical symptoms, including problems with eating, shortness of breath, dry mouth, swallowing difficulties, and weight loss, were found to be associated with shorter survival times (Reuben, Mor, & Hiris, 1988). The researchers speculated whether the presence of one or more of the symptoms might represent a "terminal cancer syndrome" that theoretically develops in large numbers of patients. The syndrome is thought to develop regardless of primary site, treatment history, or site of metastases (Schonwetter, Teasdale, & Storey, 1989).

Other studies have examined the relationship between functional status, length of survival, and a wide variety of clinical and nonclinical variables, including demographics, medical history, primary site of cancer, availability of funds, knowledge of prognosis, number of preadmission medications, presence of "unendurable" symptoms, presence of cognitive failure, laboratory findings, and quality of life (Addington-Hall, MacDonald, & Anderson, 1990; Bruera, Miller, Kuehn, MacEachern, & Hanson, 1992; Forster & Lynn, 1989; Maltoni et al., 1999; Rosenthal, Gebski, Kefford, & Stuart-Harris, 1993; Schonwetter, Teasdale, Storey, & Lucchi, 1990; Ventafridda, Ripamonti, Tamburini, Cassileth, & DeConno, 1990).

Both methodologic and conceptual problems are present in these studies, including small sample sizes; differing definitions of terminal illness, which then affect sample characteristics; and an absence of any sort of conceptual or theoretical framework to explain the choice of variables or the findings. The symptoms most often associated with progressive advanced cancer illness include deteriorating functional, nutritional, cognitive, and respiratory status (den Daas, 1995).

Additionally, although clinicians may not be able to predict length of survival when advanced disease first is diagnosed, recent work has shown that the prognostic ability of experienced clinicians improves as patients move closer toward death. Highly experienced, expert-level physicians estimate more accurately short-term survival (days to weeks) than less experienced physicians or when predicting based on functional status scores (Maltoni et al., 1994). Oxenham and Cornbleet (1998) found that clinicians predicted length of survival more accurately when patients were within one week of death compared to predictions made at time of admission. Healthcare workers with closer and more prolonged contact with dying patients estimate length of survival more accurately than those less involved with patients (Buchan, 1995). Such findings support a theory that a relatively brief, recognizable, and somewhat predictable dying process precedes the death of many patients with advanced cancer.

Nurses typically spend more time with dying patients and their families than other members of the healthcare team. Their observations and insights about the dying process have not been explored and might lead to improved prognostication for the final phase of advanced cancer illness.

Methods

Design, Sample, and Setting

An exploratory/descriptive design was used. Fifteen nurses experienced in the care of patients with advanced cancer were recruited from the University of Wisconsin (UW) inpatient oncology unit, a local hospice (Hospice Care, Inc.), and the local chapter of the Hospice and Palliative Nurses Association. Eligible nurses were required to have cared for at least six patients with advanced cancer (who died while under their care) during the previous two years. Of 64 nurses screened (18 hospice, 46 inpatient), 22 met the eligibility criteria. Of the 22 eligible nurses (18 hospice, 4 inpatient), 21 agreed to participate (94% response rate). The investigator was unable to reach four eligible, interested participants despite multiple phone calls. Seventeen interviews were conducted to obtain 15 usable transcripts (one interview was not recorded because of equipment malfunction; another was discarded because of the participant's knowledge of the specific study aims).

Instrument

Participants completed a brief demographic and professional background questionnaire prior to the interview. The investigator developed a brief interview instrument that consisted of a series of open and closed questions. The questions were presented to a group of oncology nurses who worked on a cancer research team. The questionnaire then was pretested with three nurses who worked in a hospice that was not used as a recruitment site. Following analysis and review of transcripts prepared from the interviews, a revised instrument (see Figure 1) was resubmitted and reapproved by the institutional review board (IRB).

Procedures

Prior to study initiation, the investigators obtained IRB approval and computer and office support from cancer center administrators. Recruitment opportunities were secured through the cooperation of the nursing management at UW Hospital and Clinics and Hospice Care, Inc.

The investigator presented the study to potential participants during a regularly scheduled staff meeting. Response slips, on which the nurse indicated his or her willingness and eligibility to participate, were distributed and collected. Eligible, interested nurses were contacted by telephone and scheduled for an interview. Prior to interview, participants signed a consent form and completed the demographic/professional background questionnaire. The investigator conducted the interviews in convenient, private areas; all interviews were audiotaped and ranged from 4–20 minutes in length. Unfortunately, the investigator did not ask not all participants all 10 interview questions.

1. How would you describe the dying process to someone who has never seen it?
2. Are you able to sense when death is imminent?
3. How do you sense when death is imminent?
4. Have there been times when a patient's death has caught you by surprise?
5. Describe those situations (when death occurred unexpectedly).
6. Is dying a short, long, or highly variable process?
7. Do you think anything influences the dying process?
8. Describe these influences.
9. Are there common clinical signs that appear as death draws near?
10. Describe these signs.

Figure 1. Interview Questions

Data Analysis

Following completion of the interviews, a secretary in the research mentor's department transcribed the tapes. The investigator then reviewed the transcripts for accuracy. Minor corrections in language and formatting were made. Structured (yes/no) questions were analyzed by generating the percentage of yes and no responses and noting the number of interviews in which the questions were asked. The investigator analyzed the open-ended questions individually in sequential order, using content analysis techniques described by Krippendorff (1980). In the first open-ended question, for example, the 15 responses were separated from their respective interviews and listed together on a single page. The investigator and research mentor carefully read the responses and made summary-like notes and comments in the margins. The notations then were listed, analyzed, and grouped together into common themes, generating a theme list for the question.

The theme list, together with the question and responses (listed individually on separate pages), then were routed to two expert-level hospice nurses. The nurses independently read the responses and coded each response with the number (or numbers) of the listed theme(s). The coded interviews then were returned to the primary investigator and an interrater reliability score was computed. The number of times a theme was reported and the percentage of interviews demonstrating the theme was calculated. The remaining open-ended questions were analyzed similarly, in sequential order.

Results

Fourteen female and one male nurse participated. The average age was 40.94 years (SD = 10.80), with a range of 26–58 years. The sample was 93% Caucasian (n = 14). Most participants worked at least 20 hours a week (93%); a majority worked in a hospice setting (73%). Sixty percent reported caring for more than 48 patients with advanced cancer in the previous two years; 40% reported caring for 6–48 patients. Eleven of the 15 (73%) were staff nurses. The nurses' ranges of experience were from less than 3 years (33%) to more than 15 years (7%); 60% had 4–15 years of experience. All participants reported working with predominantly adult or geriatric populations. Level of nursing education ranged from diploma (13%) to associate (33%) to baccalaureate degree (53%). Forty percent had national certification in a nursing specialty.

Describing the Dying Process

The first question, whether nurses describe dying as a distinct, recognizable, and fairly brief process, was addressed by interview questions 2 and 6. Most nurses (93%) said the process was variable in length; only one nurse (7%) described it as a short process. Nurses recognized and monitored dying; 93% said they recognized imminent death by the onset and development of clinical indicators. The process most frequently was described as a time of physical deterioration: ". . . the whole body just kind of slows down or shuts down" (see Table 1).

Dying also was viewed as a time of intensive nursing care, with patients and families needing information and support.

> Most of [these patients] want to know what's going to happen as far as how they will deteriorate, how the cancer will affect them as it gets closer to the end. . . . I think that's a lot of what they fear as much as anything . . . they don't know what's coming . . . they don't know how it's going to be.

> I usually tell people that it's not as graphic, it's much simpler than they imagine . . . they often think it's traumatic, whether they lose control of their bowels or bladder or cough up blood or gasp for air . . . I try to down-play that because those are the exceptions rather than the rule . . . I usually tell them . . . that things just slow down and [that] they quit breathing.

> There's a mechanical part of dying, during the last stage, that families need to be advised of . . . as to what's normal . . . breathing changes, for example. Also, some people have a hard time dealing with every twitch and wiggle that [the dying] person has . . . they can be watching somebody so closely . . . [they] see normal irregularities [of movement, breathing] and yet they get very concerned about it. . . . There seem to be unmet issues when a family member becomes so focused on those things . . . and then you need to bring those out and talk more about them. . . .

Table 1. Describing the Dying Process

Theme	Interrater Reliability (%)	Number With Theme (%)
A time of		
Physical deterioration	60	10 (67)
Intensive nursing care	66	7 (47)
Multiple patient/family concerns	87	4 (27)
Emergence of spiritual issues	87	4 (27)
A part of life	87	4 (27)
A societal taboo	87	3 (20)

N = 15 interviews

Dying was seen as a highly emotional time, when patients and families address important relationship and spiritual issues.

> There's the emotional side of dying that I think we, as nurses, think is a huge, huge area . . . we see a lot of things in our practice . . . but we lack research in these areas . . . to know how to improve care. . . .

> I guess if someone asked me, I'd emphasize how often I've seen [dying people] sort of spark up toward the end of life and actually spend some time articulating things to people, identifying things they want to accomplish in the very near future . . . expressing feelings to family members or whoever . . . sort of a moment or two of clarity before they really start to make a fade away. . . .

> There's the spiritual component that people don't want to discuss, because if we do, that gets into religion . . . and we shouldn't do that because then you're talking something controversial . . . but it's a very, very big part of dying and it doesn't get addressed as much as it needs to. . . .

Other themes that emerged included dying as societal taboo and dying as a natural part of life.

> In this country we don't talk about dying . . . people try to avoid the whole subject of dying, even though we all know that someday we're going to die . . . people don't want to talk about it.

Another nurse reflected on dying's connection to life.

> I often liken it to being along the continuum of birth and death and how it's very precious and wonderful . . . and that no two deaths are alike . . . people say, tell me what it's like and first off, I don't know what it's going to be like, and secondly, it's going to be very different for everybody . . . it's whatever it is for that person . . . it's their journey and nobody else's.

Sensing Impending Death

Most nurses commented that changes in physical, emotional, and activity status generally served as signs of an impending death (see Table 2).

> [You see] a lot of things . . . a change in behavior, a kind of separation from the world I guess . . . family . . . friends . . . not so much an isolation . . . [it's] more a preparation to go away.

One nurse noted that patients' completion of personal goals often seemed to be associated with a significant change in status.

> I don't think it's the way they look, I think it's more their attitude. I think it's, I don't know, I hate this cliché, but it's that they've come to peace with themselves. If they've done the things they know they have to do, they have this closure, and then sometimes you can actually see someone deteriorate from day to day.

The use of symbolic language also was noted. "[There is] . . . talking about leaving . . . and bags being packed . . .," and "[patients] have vision-like experiences [and] talk about people who've died before them. . . ."

> Symbolic language is pretty common . . . [they talk about] going on a trip. They may sound like they are really confused to the family members, but it's a metaphor for leaving this world . . . that kind of stuff. Or they say they've got to get going . . . or they've got to get ready.

Table 2. Sensing Impending Death

Theme	Interrater Reliability (%)	Number of Interviews	Number With Theme (%)
Changes in			
Psychosocial status	71	14	13 (93)
Physical status	66	15	7 (47)
Habits and routines	93	14	3 (21)

Changes in physical status were noted to signal imminent death.

> We generally see the blood pressure begin to decline and the heart rate increase . . . [and] their orientation status changes. . . . We also notice a change in the respiratory rate . . . they have periods of apnea.

Clinical signs associated with the dying process included weight loss, anorexia, declining interest in daily life, increased weakness and somnolence, a decreased level of consciousness, skin mottling, chest and upper airway congestion, a "glazed" look in the eyes, changes in vital signs, and anuria. One nurse reported that she sometimes witnessed changes in a patient's pain status. "Sometimes the pain is increased and sometimes the pain is just gone. . . ." Finally, changes in a patient's habits and routines also were noted to occur shortly before death.

> Being able to see them in their own homes, you get a feel of what their usual pattern of things are, and when their pattern changes, that's the biggest indicator for me . . . I had one man . . . he didn't really want to talk about his disease, but he had an incredible history and memories of all sorts of things that had happened during his life. . . . And I said to him, "Stanley, when you quit telling me your stories, I will know that things are changing. . . ." And that's exactly what happened . . . he died within a week or so after that change.

Unexpected Death

Nurses reported that unexpected deaths occurred when a dying process went much faster or slower than expected (see Table 3). Although most nurses recognized impending death, a significant majority (84%) also noted that patient deaths occasionally "caught them by surprise."

> One [patient] in particular, a leukemia patient who I remember, when I left on vacation, [I had] a moment of thinking, "Will she be here when I get back?" . . . and feeling like, "yeah, she will be," and then I came back and she had died . . . on the other end, expecting that they're going to die in a couple days and they live for a week or a month . . . that too has taken me by surprise.

Participants attributed unexpected deaths to sudden, acute events or disease complications.

> The ones I can think of that were totally unexpected, the person died of a heart attack or maybe a rupture, you know, bled out, or something like that . . . the disease [process] didn't go as expected.

Table 3. Unexpected Death

Theme	Interrater Reliability (%)	Number With Theme (%)
Faster or slower than expected	75	11 (83)
The patient experienced an acute event.	75	9 (75)

N = 12 interviews

Influences on the Dying Process

All of the nurses said the dying process is influenced by multiple factors, including the patient's attitude about life, death, and the illness (see Table 4). One nurse commented about a woman in her 40s with pancreatic cancer.

> This woman wouldn't quit. She looked like she should quit, but she wouldn't. She would go out and visit others instead of letting others come to visit her. An amazing woman . . . I really think their will for life and their zest for life really make a difference.

Another nurse told a story about a particular patient.

> I had a patient a number of years ago . . . and I still can't explain this . . . a young man who, while he was in Vietnam, had gotten a dog tag with the date he was going to die written on it . . . this was way before he got cancer . . . the date was July 4, 1994. I had him as a patient, and he kept telling me this was the day he was going to die. And he did. I can't explain it . . . but I think . . . prognosis is affected by people, events, and circumstances.

Nurses also noted that the dying process is influenced by the goals patients set out to achieve.

> I had a patient who was Catholic. . . . She had a saint that was her saint and there was a religious article that was a picture of this saint that she was waiting for . . . she was nonresponsive . . . but her family had sent off to have this thing sent to her and she knew this . . . and it arrived in the mail three hours or so before she died . . . once she knew it was there . . . [she died].

Other nurses related stories of patients celebrating final holidays or birthdays shortly before their deaths.

> I had a lady with cancer . . . she was declining, but not significantly . . . I thought she'd probably go through Christmas, just because of the wonderful day she'd had at Thanksgiving . . . the plan had been for her to go down to her daughter's house in Indianapolis over the holiday and then come back. . . . She managed to do that. She walked into the door the Saturday after Thanksgiving and became unresponsive that night. She died the next Tuesday. That was very amazing how she did that. But I feel very strongly that she hung on to make sure she was there for the family . . . all her daughters gathered around for the holiday time . . . and then she waited until she got home so she could die. . . . That was very clear to me.

Finally, nurses noted that type of cancer, type and efficacy of therapy, and presence of preexisting conditions can affect the dying process. "Some of the treatments seem to be more helpful with specific types of cancer. . . ." Another nurse observed, ". . . the type of cancer . . . what part of the body it's affecting . . . [can affect] whether or not it's a slower dying process."

Additional Comments

At the end of the interview, when nurses were given the opportunity to make final comments, most reinforced responses to one or more of the previous questions. Two previously undocumented themes emerged (see Table 5).

Several nurses commented that the multidisciplinary and coordinated hospice model of care helps dying patients and families. Three of the nurses suggested that patients frequently sensed their imminent demise.

> [A patient] called me into the room and said, "You need to call my daughters. . . ." My first reaction to that was that she had been a little confused . . . not talking much . . . not taking anything to eat or drink, not taking any of her medications. . . . So when she said that my initial thought was that she might be confused about what was going on. It was about 10 o'clock at night and I hesitated to call her daughter, who I knew had just had a baby. About a half hour later her daughter called me and I said, "Y'know, Grace asked about you earlier . . . I'm not sure what she meant so maybe you should come in." And she wanted to come in [so she did]. They had the most wonderful conversation and time together . . . if I hadn't paid [any] attention to that . . . or if the daughter hadn't called me, I may have potentially let that go. . . . She died that next morning, about six in the morning. Three years later, that daughter still finds that time with her mother so valuable.

Table 4. Influences on the Dying Process

Theme	Interrater Reliability (%)	Number With Theme (%)
Patient's attitude toward life, death, and disease	57	6 (86)
Patient's goals	75	5 (71)
Patient's response to disease and therapy	92	4 (57)

N = 7 interviews

Table 5. Additional Comments

Theme	Interrater Reliability (%)	Number With Theme (%)
Hospice philosophy of care is helpful.	100	4 (29)
Patients have some control over time of death.	100	3 (21)

N = 14 interviews

Discussion

The nurses in this study described the dying process associated with advanced cancer as highly variable and multidimensional, encompassing physical, psychological, emotional, spiritual, and existential domains. The process was not described as a fairly brief, hours-to-days-long process. Rather, it most often was described as weeks to months in length, what the investigator would conceptualize as the longer advanced cancer illness. Only one of the study participants conceptualized dying as a short process. Two of the nurses used the term "active dying process," a term that surfaced in the literature (Furman & McNabb, 1997). Another way of conceptualizing the phenomenon may be to conceptualize it as an acute dying process.

The lack of clear, conceptual definitions when studying nursing phenomena is noted to be problematic (Rodgers & Knafl, 1983). The varying definitions for terms such as "dying process" and "terminal illness" have been noted to be an impediment to knowledge development in end-of-life care (MacDonald, 1993). In recent cancer prognostication studies, patient samples have included individuals with fairly high functional status levels (KPS scores of 70) as well as individuals with lower functional levels (bedbound and moribund). Synthesizing findings under such conditions becomes difficult.

Current prognostication research assumes that disease status is the dominant factor affecting the length and nature of advanced cancer illness. The United States Government, through its SEER (Surveillance, Epidemiology, and End Results) program, assesses factors such as primary site when reporting survival statistics in aggregate level populations, but such macro level data is not useful for predicting outcomes in individual patients. Additionally, the treatment of common complications, such as pleural effusion, severe pain, spinal cord compression, and others, have an impact on the nature and duration of an advanced cancer illness. The influence of psychosocial issues on the development and course of cancer remains controversial (Angell, 1985).

The majority of nurses in this study, however, cited psychosocial factors as having an impact on length of survival and the nature of the terminal illness experience. The interview responses would seem to indicate that nurses conceptualize patients as dying within contexts that encompass life philosophies, personal characteristics, family dynamics, and personal goals that must be achieved before dying. Odd coincidences and noteworthy times of deaths are remembered and contribute to a hospice culture that traditionally has been non-research-oriented.

The notion that nurses routinely recognize and monitor impending death was supported, however, and this strengthens the argument that a brief, recognizable clinical phenomenon occurs at the conclusion of terminal illness. Clinical signs of impending death cited by the participants included anorexia, somnolence, weakness, decreased responsiveness, and deteriorating respiratory and circulatory status. These signs have been noted in previous prognostication research. Although almost all of the participants said they recognized impending death, they also acknowledged that some dying processes went much faster or slower than expected. Deaths that occurred unexpectedly often were precipitated by an acute complication (e.g., hemorrhage in a patient with advanced head and neck cancer). Slower, more prolonged dying processes are less easily explainable, and the frequency and significance of such dying processes remain unknown.

Implications for Practice and Research

To consider practice implications from the present research is premature. Additional studies should be conducted along multiple lines of inquiry, including validation or exploration of the issues raised by the current study. Future interview research might be restricted to highly experienced, expert-level nurses and focus groups. Clearly defining the phenomenon of interest would be mandatory in any future research in this area.

Future inquiry also should attempt to determine what event or events trigger or herald the onset of the acute dying process. The frequency or pattern of clinical signs should be studied. Prospective observational studies of acutely dying patients should be conducted to assess for the emergence and development of recognizable and measurable clinical signs. The contextual influences on the active dying process should be explored via participant observation research with hospitalized and home-dying patients. Other questions of interest include factors associated with clinical perceptions of "good" and "bad" deaths.

Death from advanced cancer illness and the dying process that immediately precedes it are sources of both significant turmoil and growth for patients and families. A better understanding of the dying process in cancer may be possible through research. Nurses who care for patients acutely dying from advanced cancer and their families are in an ideal position to develop useful knowledge to ultimately improve care.

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For more information . . .

- The National Hospice and Palliative Care Organization
  www.nhpco.org
- The Center to Advance Palliative Care
  www.capcmssm.org
- International Association for Hospice and Palliative Care
  www.hospicecare.com

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