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Cancer Patients' Preferences for Control at the End of Life

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Abstract

The achievement of a death consistent with personal preferences is an elusive outcome for most people with cancer. Maintaining a sense of control is a core component of a dignified death; however, control might be a Western bioethical notion with questionable relevance to culturally diverse groups. Thus, the purpose of our study was to explore the meaning of control and control preferences in a group of racially and ethnically diverse patients with an advanced cancer diagnosis. Using a hermeneutic, phenomenological approach, we interviewed 20 patients with advanced cancer and uncovered two themes: (a) preferences for everyday control over treatment decisions, family issues, final days of life, and arrangements after death, versus (b) awareness that cancer and death are controlled by a higher power. Although the sample included non-Hispanic Whites, African Americans, and Hispanics, participants shared common views that are characteristic of American cultural norms regarding the value of autonomy.

Keywords

cancer; death and dying; end-of-life issues; ethics/moral perspectives; race; ethnicity; hermeneutics; illness and disease, life-threatening/terminal; palliative care; phenomenology; race

End-of-life care is a key component of essential services for people with advanced cancer. Unfortunately, most terminally ill cancer patients in the United States (U.S.) do not die according to their personal preferences (Foley & Gelband, 2001). Not unlike other U.S. initiatives to improve health care, legislative and practice activities to enhance the quality of end-of-life care services resemble a patchwork quilt of programs that benefit some individuals while excluding others. For example, the Medicare program hospice benefit covers supportive care for terminally ill persons 65 years or older, while millions of uninsured or underinsured Americans might do without such services. Given that the overall incidence of cancer is expected to increase by 45% over the next 20 years and that the number of cancer deaths will grow dramatically (Smith, Smith, Hurria, Hortobagyi, & Buchholz, 2009), efforts to improve end-of-life care are imperative.

Good end-of-life care includes assisting patients to maintain a sense of control over appropriate aspects of their care. The psychological drive to control one's life might be important; however, a desire for control can have varying impacts on personal health.

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Typically, a higher perception of control over health and illness is a positive attribute associated with improved outcomes such as decreased stress, better emotional well-being, and better adaptation (Báñez, Blasco, Fernández-Castro, & Viladrich, 2009; Fang et al., 2006). Perceptions of control within the context of a cancer diagnosis can be associated with poor adjustment, distress, depression, and anxiety (Neipp, López-Roig, & Pastor, 2007). Nonetheless, maintaining a sense of control is considered an important component of end-of-life care for people with cancer (National Comprehensive Cancer Network, 2009; Peters & Sellick, 2006). The specific nature of what advanced cancer patients want control over, however, is not well understood, nor is the relevance of the concept to patients who might have values and perspectives that are contrary to the Western bioethical ideal of controlling one's own healthcare decisions. Therefore, the purpose of our study was to explore the meaning of control and control preferences in a group of racially and ethnically diverse patients with an advanced cancer diagnosis. Because cancer in the United States is most prevalent in non-Hispanic Whites, African Americans, and Hispanic people (American Cancer Society, 2010), we recruited study participants from these groups.

Background

Conceptual Orientation

The desire to control one's health is a core construct codified by the bioethical principles of autonomy and the right to self-determination. Control over one's health outcomes is a multi-dimensional psychological construct that affects physical and mental well-being. Hence, the relationship between control and health-related outcomes can be described by a variety of concepts and theories. For example, in a systematic literature review of control beliefs in cancer, Neipp, López-Roig, and Pastor (2007) found that the most frequent control constructs used in studies of cancer patients included locus of control (Rotter, 1966), causal attribution (Weiner, 1985), self-efficacy (Bandura, 1977), and perceived control (Thompson, 1981). In addition, many studies focus on decisional control of treatment in early stage disease as exemplified by Degner and colleagues (Degner et al. 1997; Singh et al., 2010).

Because of its applicability to people with an advanced cancer diagnosis, we selected Lewis's (1987) conceptual typology of control to guide our work. Her theoretical framework includes five types of control that constitute responses to aversive events, stimuli, or stressors: processual control, contingency control, cognitive control, behavioral control, and existential control. Processual control refers to an individual's participation in decisions that affect an aversive event, including interactions between patients and health care providers, to influence the aversive event. Contingency control includes an individual's perception of the connection between her/his response to the event and outcomes. Cognitive control refers to an individual's cognitive management of an event, such that the event's perceived threat is reduced and reframed as controllable. Behavioral control is the actual behavior that alters the qualities or outcome of an event. Existential control is the attribution of meaning and purpose to an event such that the potential threat is lessened. Lewis and her colleagues used this conceptual orientation to frame a number of studies of people with advanced cancer diagnoses (1982, 1986, 1989). More recently, Volker, Kahn and Penticuff (2004a, 2004b) used Lewis's typology to frame a study of patient control and end-of-life care from the perspectives of advanced practice nurses and advanced cancer patients. In sum, cancer patients who want to control aspects of their end-of-life experience might use the types of control described in Lewis's typology.

Control and Cancer

Newly diagnosed cancer patients and those undergoing initial treatment are the focus of numerous studies of control preferences and treatment-related decision making. For

example, in a study of information needs and decision-making preferences in gynecological, breast, and colorectal cancer patients, Beaver and Booth (2007) found that patients preferred to either share or delegate control over treatment decisions to their physicians instead of making their own decisions. Similarly, Stacey, Paquet, and Samant (2010) investigated cancer treatment decision-making in a group of ambulatory patients. Results revealed that patients who perceived that they were offered treatment choices were more likely to be actively involved in decision making and prefer a shared model of decision making than those patients who felt that they were not offered choices. Not surprisingly, the group who perceived that they were involved in treatment decision making was likely to be less passive and more satisfied with the process. Such studies indicate that cancer patients have varying preferences for control over decision making and provide guidance for the development of individualized decision support strategies.

Both physical and psychological outcomes can be linked to perceptions of control over disease and treatment. For example, some studies of newly diagnosed patients indicate that higher levels of perceived personal control can buffer stress and promote better adjustment to the disease and treatment (Bárez, Blasco, Fernández-Castro, & Viladrich, 2007, 2009; Henselmans et al., 2010; Heppner, Armer, & Mallinckrodt, 2009; Ranchor et al., 2010). Perceived control also was investigated as a coping strategy for controlling cancer treatment outcomes. In a study of patients diagnosed within 24 months of study participation, Link, Robbins, Mancuso, and Charlson (2004) concluded that patients who tried to control their disease were “younger, lived with others, had less depressive symptoms, and greater fighting spirit” than patients who did not attempt such control efforts (p.223). Similarly, studies based on locus of control theories indicate that breast cancer patients with a stronger internal locus of control beliefs had less depression and anxiety than those who believed that their health outcomes were controlled by external, powerful others (Bettencourt, Talley, Molix, Schlegel, & Westgate, 2008; Naus, Price, & Peter, 2005). Of note, most of the reported studies of health outcomes and control did not report race/ethnicity of their participants. Of those that did, samples were predominantly White (Bettencourt et al.; Naus et al.)

Patients with advanced cancer diagnosis might have unique needs and issues associated with their disease. Accordingly, control preferences were studied in this population. In a systematic review of information giving and decision-making intervention studies, Gaston and Mitchell (2005) concluded that most patients with advanced cancer wanted complete information about their disease and treatment. Although this mirrors the same desire voiced by newly diagnosed patients, only two thirds of patients wanted to be actively involved in controlling palliative care decisions. Likewise, Pardon et al. (2009) studied advanced lung cancer patients’ preferences for decision making about treatment and end-of-life issues. They found that almost all of the participants wanted information about diagnosis and treatment, but only half wanted control over end-of-life decisions. In a phenomenological study of patient control and advanced cancer patients, participants indicated that they preferred to control a wide variety of aspects of daily life including management of pain and symptoms, cancer treatments, personal time and priorities, impact on family, and the dying process (Volker et al., 2004b). Applicability of these study findings to a diverse population is unknown; Gaston and Mitchell, and Pardon et al. did not report race and ethnicity data, and the Volker study sample was 86% White.

Whether strong control preferences are beneficial for advanced cancer patients remains unclear. In a longitudinal study of self-esteem, optimism, control, and quality of life in women with breast cancer, Tomich and Helgeson (2006) found that women who had high baseline perceptions of control over their disease and subsequently experienced a recurrence of disease reported a decline in physical and mental functioning. Conversely, control beliefs were not related to physical and mental functioning in women who remained disease-free.

Given that the study sample was 90% White, potential applicability to other racial/ethnic groups is unknown.

Control and End of Life

Search for control within end-of-life care can manifest in a variety of ways, including completion of advance directives, participation in treatment-related decision making, selection of hospice for care, and choosing place of death. An advance directive is a mechanism for exerting control over health care decisions when a person is unable to speak for him or herself. Directives can include a living will, medical power of attorney for health care decisions, and out-of-hospital do not resuscitate orders. Since the passage of the Federal Patient Self-determination Act in 1991, considerable energy was expended to improve the completion of these tools. Presumably, a person who has an advance directive will be more likely to have care preferences honored during a life-limiting illness. However, few Americans have completed these tools, advance directives often are not shared with medical staff, and end-of-life care might be inconsistent with specified preferences (Collins, Parks, & Winter, 2006). Indeed, some proxy decision makers named in advance directives have difficulty honoring a loved one's wishes for palliative care instead of life-prolonging treatments (Winter & Parks, 2008). Advance directives are also criticized for being static tools that do not reflect changing care preferences over time. Although some evidence suggests that preferences for control over end-of-life treatment decisions can be stable over time (Sulmasy et al., 2007), other studies indicate that choices evolve during the course of illness and should be addressed in an iterative process that is revisited periodically (Fried & O'Leary, 2008; Garrett, Tuokko, Stajduhar, Lindsay, & Buehler, 2008).

Although advance care planning is an important component of quality end-of-life care, advance directives, and other similar tools might not be relevant across all racial/ethnic groups. In a multi-institutional study of racial/ethnic disparities in advance care planning and end-of-life care in patients with advanced cancer, Smith and colleagues (2008) determined that Black and Hispanic patients were 40% less likely than Whites to have an advance care plan. Additionally, the Black and Hispanic patients were less likely to consider themselves terminally ill and more likely to want life-prolonging treatment. These findings are consistent with other studies that documented racial/ethnic disparities in the completion of advance directives (Degenholtz, Arnold, Meisel, & Lave, 2002; Welch, Teno, & Mor, 2005). Possible explanations for lower completion rates include mistrust of health care providers, preference for family decision-making and verbal communication, a lack of culturally sensitive education about advance directives, and fear of losing control over decision making (Volker, 2005).

Patients and families can express a desire for control over treatment-related decisions at the end of life that might not be codified in an advance directive. For example, in a survey of family proxies, Bakitas and colleagues (2008) determined that involvement in decision making was a key quality-of-care indicator. This finding is supported by other studies (Byock, Corbeil, & Goodrich, 2009; Sulmasy et al., 2007); however, these studies included White participants only. Of note, ideas regarding a desire for autonomy and control over decision making were absent in a study about the perceptions of a good death in persons with lung cancer (Hughes, Schumacher, Jacobs-Lawson, & Arnold, 2008). Instead, participants characterized a good death as occurring during sleep, pain free, peaceful, and quick. The racial and ethnic characteristics of the sample were not reported. Therefore, the link between desire for control over treatment-related decisions and quality end-of-life care is unclear. Barnato and colleagues (2007) investigated whether regional variations in end-of-life treatment intensity in the United States were associated with patient preferences for end-of-life care. Although their sample of Medicare beneficiaries preferred a focus on palliative treatments, the investigators concluded that regional variations in expenditures likely did not

reflect patients' treatment preferences. More investigation of the linkage between preferences and outcomes is needed.

The provision of end-of-life care within hospice settings is considered the gold standard for care. The philosophy of hospice care includes the concept of enhancing patient and family control. However, hospice remains an underutilized resource in the United States, even in those patients eligible for hospice care. The average length of stay for Medicare beneficiaries dying of cancer is about 46 days (Iglehart, 2009). To achieve maximum benefit from hospice, a patient and family should be under care for 3 months (Teno et al., 2007). Barriers to accessing hospice care include patient and family misunderstandings about hospice services, assumptions that a hospice referral means death is near, fear of losing control over their care, worry about losing contact with primary oncologists and nurses, desire for life-extending treatment, and conflicting spiritual beliefs (Jennings, Ryndes, D'Onofrio, & Baily, 2003; Johnson, Kuchibhatla, & Tulskey, 2008). Given that African Americans and Hispanics are less likely to use hospice services than are Whites (O'Mahony et al., 2008), race/ethnicity can affect hospice utilization. Whether this represents varying preferences for control is unclear; reluctance to use hospice services might be influenced by language barriers, mistrust of the system, prohibitive costs, and a lack of diversity in hospice personnel.

Voicing a preference for place of death can represent another manifestation of desire for control. Although most Americans prefer to die at home, the majority die in hospital settings (Gruneir et al., 2007). Studies reveal that the likelihood of dying at home is associated with being White, married, and of a higher socioeconomic status (Gallo, Baker, & Bradley, 2001; Weitzen, Teno, Fennell, & Mor, 2003). For example, in a qualitative study of 180 terminally ill patients with cancer, Tang (2003) found that almost 90% of participants wanted to die at home. Most of these individuals lived with another person, which might have influenced their notion of the feasibility of a death at home. In a retrospective study of place of death and its predictors in cancer patients in a large metropolitan city, Bruera and colleagues (2003) determined that most participants died in the hospital and that the odds of a hospital death were significantly increased in African Americans. These types of studies provide insight into where cancer patients actually died versus where they preferred to die. However, it is not clear that the desired and actual places of death result from an explicit desire for control over the dying process versus other variables. Moreover, when disease evolves, personal preference for control over the place of death might evolve and change in priority when other needs become apparent.

In summary, how life unfolds in our final days might or might not be a result of an explicit plan for control. The nature of desired control is not well understood and neither is the influence of race or ethnic background on control preferences at the end of life. Our literature search revealed no studies that focused on the exploration of the concept of, and desire for, control of end-of-life care in diverse sample of people with advanced cancer. Hence, the purpose of our study was to explore the meaning of control and control preferences in a group of racially and ethnically diverse patients with an advanced cancer diagnosis.

Methods

Given the existential, contextual nature of the study's purpose, we designed the study using a hermeneutic phenomenological approach according to Cohen, Kahn and Steeves (2000). Hermeneutic phenomenology is a qualitative, naturalistic approach used to seek a deeper understanding of human, lived experience. This approach is used to answer questions of meaning and is appropriate for studies that focus on understanding experience from the

perspective of the person who is living that experience. Human nature drives us to make sense of or to interpret our experiences; these experiences can be shared through dialogue with each other (Cohen et al.). Hence, the goal of a phenomenological study is to uncover the essence of an experience so that others can better understand the significance of that experience in a richer, more in depth way (van Manen, 1990). The complex ethical, clinical, and cultural aspects of end-of-life care lend themselves to both cognitive and emotional forms of this interpretive method. Indeed, in her recommendations for a national research agenda in end-of-life care, Koenig (1997) noted that “culture and cultural influences are most effectively studied using the interpretive techniques of the social sciences and humanities” (pp. 372-373). Hence, this approach was used to explore the meanings that individual patients attributed to the concepts of control and end-of-life care.

Setting and Sample

After obtaining institutional review board approval for the protection of human subjects, we used a purposive sampling strategy to recruit study participants from throughout the state of Texas. Texas is the second most populous state in the United States and has a diverse population: the three largest racial/ethnic groups are non-Hispanic Whites (48%), Hispanics (35%), and African Americans (11%) (United States Census Bureau, n.d.). Similarly, these are the most prevalent groups to develop new cancers in Texas each year (Texas Cancer Registry, 2009). Given the nature of the study aims, we sought a sample of community-dwelling adults with an advanced cancer diagnosis from these three groups who were willing to talk about their thoughts, concerns, and desires about how they wished their final days to unfold. A person with advanced cancer was defined as someone who was no longer receiving curative treatment, but who might be receiving other forms of noncurative treatment for supportive care. No limit or boundary was set for life expectancy of the participants. Because of the sensitive nature of the interviews, we asked advanced practice oncology nurses to identify and approach potential participants about the possibility of joining the study. Only those patients who had verbalized an understanding of their diagnosis and prognosis were approached. Patients who indicated an interest mailed a reply form to the principal investigator, who then contacted these individuals and explained the study details.

Sample size in studies guided by hermeneutic phenomenology depends on the question asked and the phenomenon of interest (Cohen et al., 2000). Although the final sample size was determined by analytic findings that revealed redundancy, we estimated our sample size based on a variety of recommendations. Cohen et al. suggested use of both previous studies and clinical experience to estimate sample size. Morse (1994) suggested a sample size of approximately 6 people, and Creswell (1998) suggested up to 10 people, depending on saturation, a view that one has obtained enough data to have a complete description of the experience under study (Cohen et al.). Given that we wanted to obtain a diverse sample of people with advanced cancer, we planned for interviews to continue until repetition or redundancy of findings occurred across groups of patients. This process yielded a final sample size of 20 participants.

We interviewed participants in their homes at a time of their choosing. After giving written consent, they completed a short demographic survey and participated in a tape-recorded interview. Each interview lasted 1-2 hours; timing was tailored to the participant's comfort and fatigue levels. Although studies guided by hermeneutic phenomenology often include multiple visits and interviews, we planned for one in depth interview per patient because we anticipated that many of our participants would be frail, uncomfortable, in hospice care, or near death.

We designed our open-ended interview questions to elicit participants' thoughts about the meaning of control within the context of facing the end of life within an advanced cancer diagnosis. We followed Holstein and Gubrium's (1995) process of the active interview, a flexible process intended to elicit narrative production and meaning making from the participant. The active interview process "incites" the production of meanings that address issues pertaining to the research concern (Holstein & Gubrium, p. 17). Thus, the active interview provides a conceptual fit for data collection in this hermeneutic phenomenological study. According to Holstein and Gubrium, the interviewer might suggest ways of conceptualizing issues and making connections depending on the study's focus. The challenge for the interviewer is to guide and direct the participant's narratives to the research question without eliciting predetermined or preferred responses to the interview questions. The interviewer must create an environment and devise questions that will enhance the participant's interpretive abilities.

The opening question was, "Some people think that humans want to have control or power over happenings or situations in their lives. What do you think about that?" This question was designed to introduce the concept of control and prompt general ideas about personal control. A transition question was designed to orient the participant to the concept of control within a cancer diagnosis: "Some people who have cancer think about the ways they want the final months of their lives to go. Do you ever think about that? If you do, what would you want that time to be like?" The following question brought together the two concepts of control and the end-of-life experience: "Tell me about whether you would want to have control or power over what your final months of life might be like. Is there anything in particular that you would want to have control over during that time? Is there anything in particular that you would not want control over?" These questions also invited the participant to think about control from differing perspectives. Probes and follow up questions elicited thick descriptions of the participants' meanings and interpretations of their experiences with control and desire for control when they faced uncertain futures.

Our sample of 20 participants was derived from urban and rural settings throughout Texas. Most were either in hospice care or undergoing experimental treatments. Their mean age was 62 years (range = 34-87); race/ethnicity included seven African Americans, four Hispanics, and nine Whites. Cancer diagnoses included gastric, lung, breast, chronic lymphocytic leukemia, prostate, cervical, melanoma, liver, colorectal, and renal cell; gender was evenly divided. Nineteen participants indicated a Christianity-based religious affiliation; the other participant had no current affiliation. Most participants indicated that their personal income was either insufficient (9) or adequate to meet personal needs (11). The group was reasonably well educated with a mean of 13 years (range = 5-20) of schooling.

Analysis

The audiotaped interviews were transcribed verbatim; we analyzed the data according to Cohen et al.'s (2000) method of hermeneutic phenomenological analysis. After reviewing the transcripts against the audiotapes for accuracy, we began a process of immersion in the data by a line-by-line review of each interview. We repeated this process several times while key phrases and ideas were highlighted. We assigned tentative codes to the highlighted ideas in each transcript (first level coding). This process of inductive analysis continued by grouping the first level codes into like categories (second level coding) for each transcript. Within each racial/ethnic group, we compared and refined second level codes. We then compared second level codes across groups and constructed the resultant study themes.

We enhanced study trustworthiness via two strategies. First, we maintained an audit trail of study activities and included field notes from each interview, and a log of analytic practices and decisions. We also used a minority nurse researcher consultant with expertise in both

clinical practice and research involving minority populations of cancer patients in Texas. Our consultant advised us about interview practices and assisted with the data analysis phase. Data analysis was an iterative process that involved discussion of the analytic decisions with our colleagues and the study consultant.

Results

The analysis revealed a duality about what study participants wanted to control that emerged as two themes common across the three racial/ethnic groups. This duality was expressed in a quote from an African American woman: “It is mine to keep together, but God controls our lives.” That is, one can, and should control or “keep together” events, choices, and personal behavior in daily life. However, the ultimate control over fate, including developing cancer, responding to treatment, and dying, is in the hands of a higher power. A description of these two themes and representative quotes follows. Participants’ names have been changed to protect their identity.

It is Mine to Keep Together

This theme refers to the everyday control at the end of life that participants discussed. While they reflected on the concept of control and its meaning within their own contexts, they told stories of encounters and discussions with health care team members, other cancer patients, friends, and family. Some of the participants expressed puzzlement and sadness when they experienced resistance from individuals who were hesitant to discuss end-of-life issues with them. Within the informed consent process, the interviewer always assured participants that they could decline to answer any questions that made them uncomfortable. This often promoted questions from some participants about why their physicians and nurses did not explore their end-of-life preferences and worries. Other participants described family members (usually adult children) who were reluctant to discuss advance care planning and the looming prospect of their loved one's death. Nonetheless, in the context of our interviews, the issues that participants wanted to control included treatment decisions and participation in care, family issues, final days of life, and control of arrangements after death. They described a desire to maintain active involvement in the daily decisions in their lives.

Although some of the participants were receiving chemotherapy to slow the spread of advancing disease or within the context of a clinical trial, most were receiving supportive care interventions for symptom management only. All of the participants talked about what it meant to have control over their medical treatment decisions. Many recounted stories of discussions they had had with health care professionals regarding decisions to refuse more cycles of chemotherapy. Ms. J., a Hispanic woman with end-stage cervical cancer, discussed the progression of her illness despite ongoing treatment. She became angry and agitated when she described her decision to refuse another cycle of chemotherapy:

I want to be able to have control or say about my illness, whether I think I should take chemo or not. The doctors tried to talk me out of it [her decision to stop treatment], and it's just like, it's MY body. I feel it's not going to do anything for me. It's making me sicker so why do it? I felt that it was important for me to have control over that.

Mr. S., a White man, recounted his discussion with his oncologist about refusing chemotherapy:

Me not taking chemo, that's control. I have asked a number of people, “Do you know anybody that has ever been cured of liver cancer [metastases]?” And it is always, “No.” So I feel there is no need for me to go through the pain of taking

chemo for several months or a year to get 3 months or maybe a year sick. So that made me decide to go to the dance hall. In a way, I feel like I'm copping out by not taking the chemo, but it takes a hell of a lot of courage to do what I am doing.

He smiled when he described his love for dancing, and how he resumed this activity soon after he lost his wife to cancer 20 years earlier. Mr. S. had cared for his wife at home when she underwent several months of aggressive chemotherapy that sapped her energy and decimated her quality of life in her final months. He interpreted that experience as a lesson to guide his own decisions regarding treatment. Because he believed that he would suffer a similar fate, he preferred to receive supportive care measures only.

All of the participants spoke about their need to actively manage and participate in various aspects of their medical care. An African American woman shared that “the most important thing I can think of is to try to become self-disciplined, especially keeping your appointments on time. Out of those years I have had cancer, I have never missed one appointment.” Similarly, a White woman expressed her need to watch all aspects of her chemotherapy treatments closely:

I got a hand in what is going on. I got to know what's in the bottle; I got to know how long it's going to take. I got to know what tests they are doing and why they are doing that test. Why are they doing this? What are they looking for?

Many participants brought out reams of paperwork associated with laboratory tests, diagnostic radiology reports, and pathology findings, and chronicled their journeys with cancer during their interview. This seemed to reflect a sense of pride in showing how they controlled their cancer experience by tracking and maintaining voluminous records that revealed a sad trajectory of progressing disease over time.

All of the participants discussed their families within the context of describing their preferences for control within the context of advanced disease. An African American man with lung cancer, Mr. W., described his concerns about the possibility of needing physical care beyond what his immediate family could provide for him:

In case something would happen, my family would have to take care of me [at home] in a way as much as they can, as long as they can. But I always told them I don't want them to be worried if I get to needing a nursing home. I will not have a problem with that. My wife and kids know that is going to be one of the things I'm going to write up and I expect it to be followed to the letter.

He recounted a previous experience of placing his father in a nursing home while in the midst of caring for his mother when she died from liver cancer at home. He grew tearful when he exclaimed that, “I haven't forgotten that look [in his mother's eyes]. I guess I never will. I don't want my kids to go through that with me.” While he recounted his mother's death and described what that meant to him, he wanted to ensure that his children did not have to endure caring for him at home. His decision to institutionalize his own father remained a painful memory. Although he expressed a desire to die in his own home, he wanted to make the decision about the potential for his own nursing home placement and save his children from that distress.

Most of the participants expressed a concern about being a burden on their family caregivers. Similar to Mr. W., they worried about the possibility of needing more care than their families could handle. Ms. Z., a White woman with renal cancer, shared that, “I just want to keep on going as I am right now and not have people have to wait on me hand and foot. I don't want them to suffer.” She recounted that her husband had recently suffered a heart attack, which she attributed to the stress of caring for her, working, and managing all of the household responsibilities. Ms. Z. worried that her symptoms were worsening and

keeping her from doing her share of her previous responsibilities such as preparing the family meals. The participants seemed concerned that they die in a place that provided good comfort care with lessened stress for their family. They did not seem concerned about whether that place would be home, nursing home, freestanding hospice, or hospital. However, four participants (two White, two Hispanic) who had dependent children living at home were certain that they did not want to die at home.

I don't know how the end of life happens, and hopefully, I will go to sleep and that will be it. But since I have kids, I really don't want to be at home. I see it happening in the hospital with my family and friends there, with candles and music and not scary with the lights dimmed.

Only one individual did not express concern about impact on family. Mr. A. was a single African American man who lived alone and seemed distant from his immediate family. His apartment was devoid of photos or other memorabilia that typically reveal contextual elements or symbols associated with a person's culture and life history. He talked about how his friends started disappearing after he was diagnosed with cancer, but he maintained contact with a sister who lived in another state and served as a "conduit of information" for other family members. He stated that, "one thing I don't want is everybody to get concerned and set up a cancer watch. You know, that's all a jive." That is, he seemed to carefully control the information that family received and did not want them to be actively involved in the daily aspects of his life or his disease. The idea of a "cancer watch" stemmed from his interpretation of behaviors he had witnessed when other patients and friends had died from the disease.

Many of the participants spoke freely about their plans for controlling arrangements for their bodies after death. Their conversations revealed a sense of the meaning of ultimate control after death. Ms. Y, a White woman with metastatic breast cancer, was quite animated in her description of making burial arrangements for both herself and her ailing husband. She described standing outside under the hot Texas sun in a cemetery while she negotiated with a salesman:

I said, "We just want to buy some plots." And he [cemetery salesman] said, "What kind of plot are you interested in? You can have it under a tree, which costs more than being by a bush, which costs more than being out here facing the highway. If you're close to the statue of Jesus, that costs more." And I said, "Well, if I hadn't gotten together with Jesus by now, I don't think laying dead by some statue is really going to cut it."

Indeed, she reflected on the meaning of spiritual peace within the context of managing the details of burial arrangements, and she indicated that she was at peace with her relationship with Jesus.

Other participants spoke of planning for funeral services, including the selection of venue, music, and readings. Ms. C., a Hispanic woman, was quite concerned about planning for her physical appearance:

I already have my dress, my hose, and everything I am going to wear. I told the funeral home that I do not want my casket open. I said you can put all those pictures of me there, but I do not want my casket open. I says because I don't want them to look at me. I want them to remember me how I was before.

She brought out her funeral dress during the interview and laughed while she described how she had asked a close friend to apply her makeup before the funeral. Although Ms. C. wanted a closed casket, she knew that her family would want to view her body before the

funeral service and did not trust the mortician to make her look “natural.” Her desire for control was manifested by the need to portray herself in death just as she appeared in life.

But God Controls our Lives

This theme reflects discussion about the ultimate control over one's life. Participants shared an acknowledgment that although there are everyday events that one can control, there are larger issues that one cannot control. Thus, the meaning of control took a more existential turn and revealed that the participants believed a higher power controls the occurrence of cancer, prognosis, and the timing of the ultimate outcome of death.

Actually, I don't think you can have control. I think you are given an opportunity, because you can't control something you can't heal, and you can't control something you can't make. Only the good Lord can do that. But you do to other people, help other people.

This African American man reflected on the importance of “doing to other people” as an important part of daily living. He shared stories of visiting with fellow patients in waiting rooms and encouraging them to maintain a positive attitude. He also acknowledged that he could not control the fact that he developed cancer or how well his disease responded to treatment.

Another African American man told a story of being displaced from his home in New Orleans by a devastating hurricane. Shortly after he was relocated by a charitable organization to Texas, Mr. J. was diagnosed with advanced liver cancer and lost much of his eyesight to glaucoma. He spoke in great detail about how he controlled his daily affairs and shared copies of his lab work and other diagnostic tests to illustrate his involvement in monitoring his response to treatment. However, he also indicated the role of the Lord in overseeing his fate:

The Lord knew I had cancer even before I did. Already knew what I had before the storms [Hurricane Katrina]. And He wanted me to be in a place [Texas] where He knew I could be taken care of. All the storms were putting me in another a place where He knew I could be taken care of. I don't know when You gonna decide to take me away from here. It may not be the cancer that takes me. That's up to Your hand.

His interpretation of his new life in Texas was that the hurricane, his cancer and the Lord's intervention all came together in a way that produced a better life for him. Even though he was facing a lethal diagnosis, he expressed a sense of peace with placing his fate in his Lord's hands.

The Hispanic and White participants also shared the same sense of acknowledgement of a higher power controlling one's life and the outcome of a cancer diagnosis. Ms. T, an Hispanic woman dying of metastatic breast cancer observed that:

I've always felt like we have a big responsibility in the way our lives go because we have a choice whether or not to do the right thing or the wrong thing. But I also know we have no real choice when it comes down to the big scheme of it all, the whole ultimate design of our life. I feel like God is always letting me know answers and reasons why things happen. There is a design and a reason for what's happening [with the progression of the cancer] and I'm just waiting around to see what God is going to bring me.

Similarly, Mr. N, a White man with lung cancer, explained his need to control his daily health by sharing his arsenal of self-managed complementary nutritional supplements with the interviewer. He believed that such measures would enhance his immune response to the

cancer and promote a sense of well-being until the cancer finally took his life. However, he juxtaposed this practice with his belief in God's role in his health when his cancer reoccurred:

When this hit me the last time, I said, "God, if You have something for me to do, something for me to finish, let me know what it is." I said, "You take care of the cancer," and I turned it over to God.

All but one of the participants used the term "Lord" or "God" to refer to their concept of a higher authority who controlled their futures. All of these individuals indicated on their demographic forms that they had various forms of Christian religious affiliations. However, Mr. A., the African American man who was distanced from his family, indicated that he had no religious affiliation and no longer believed in God. When he spoke about his coping mechanisms, he described that he engaged in a type of prayer-like activity. He called this a "direction of thought to a good purpose which can have an effect" on his health. He explained,

I don't know what I do exactly but you are putting yourself in a position knowing that you are wishing this to someone. You want to see this come through [response to treatment] to whatever extent that it seems to be and you accept that.

While he reflected on the meaning of personal control within his current circumstances, he seemed to direct his wishes to "someone" and did not use any other terminology to refer to this other unseen recipient of his wishes.

Discussion

The study findings revealed thoughts about control that encompassed both day-to-day life events and one's ultimate destiny controlled by a higher power. While participants explored the meaning of control within the context of an advanced cancer diagnosis, they revealed a variety of dimensions within these two themes. The preference for maintaining everyday control is consistent with Lewis's (1987) concepts of processual and behavioral control over aversive events. For example, the participants voiced a preference for maintaining control over treatment decisions and participation in care. When they discussed interactions with their health care providers, they highlighted their own responsibility for affecting aversive events, including disease progression and uncontrolled symptoms. In addition, the concept of behavioral control was exemplified by actions they took to affect the outcome of an event; these actions ranged from symptom management to control of arrangements for after their deaths. Conversely, awareness of control by a higher power is consistent with the concept of existential control. That is, the potential threat of death was lessened by an attribution of ultimate control over response to treatment and timing of death to a higher power. Although these examples illustrate components of Lewis' control typology, they do not provide evidence that the typology could be used to predict behaviors specific to control at the end of life.

The analytic codes and themes were consistent across the three racial/ethnic groups and suggest that study participants had much in common regarding control preferences. This consistency parallels Seal and van der Geest's (2004) observation that conceptualizations of a "good" and "bad" death have considerable overlap among differing cultures and societies. Although participants used varying language when they described their experiences and desires, this likely reflected an interaction between education, race, ethnicity, geographic locale, and dialect.

Similar to Johnson et al.'s (2008) conclusion that "within cultural differences" exist in beliefs about end-of-life care, the present study revealed differences in specific control

preferences among the three racial/ethnic groups that also connected across the groups. For example, all of the participants spoke about the need to maintain everyday control. This finding is similar to that of a grounded theory study of adjustment to recurrent, advanced breast cancer. In this Swedish study, Sarenmalm and colleagues (2009) observed that their participants established wellness by maintaining control over daily routines, duties, and participation in medical treatments. In addition, most of our study participants expressed concern about controlling the impact of their disease on their family. The White and Hispanic participants who had dependent children all shared a common desire not to die at home (none of the African American participants had dependent children). This commonality between some of the Whites and Hispanics likely was not driven by shared racial/ethnic values, but by family circumstances. Unlike Tang's (2003) findings regarding home as a preferred place of death, the other participants did not express a particular preference for site of death and indicated that being comfortable was more important than the site. Hence, clinicians might be cautious about promoting death in the home setting as an optimal goal for quality end-of-life care (Murray, Fiset, Young, & Kryworuchko, 2009). Instead, sensitivity to cultural differences and avoidance of racial/ethnic stereotyping should be promoted by exploring individual preferences for care.

Given our study design and sample size, our findings cannot be construed as evidence that no differences in control preferences exist between the three ethnic/racial groups included in our study. Rather, the study themes represent the meanings of control in a diverse group of people with an advanced cancer diagnosis. Consistent with Gaston and Mitchell's (2005) conclusion that advanced cancer patients want complete information about their disease and treatment, all of our participants were actively engaged in working with their health care team and seemed well-informed about their prognosis. Many showed us their extensive collections of lab work, diagnostic imaging reports, and email communications with their care providers.

Our study participants' desire to control their end-of-life decisions is contrary to Pardon et al.'s (2009) findings. Only half of their study participants expressed such desire. Cultural issues could explain this difference, because the Pardon study participants were Belgian. However, differences in study design could also account for the variation in findings. The Belgian study used a semi-structured interview format that featured a control preference scale that included forced-choice responses to questions about end-of-life care. Participants were subsequently invited to discuss "real life" decisions they had made within 2 months of the interview. Hence, these data collection processes could have prompted different responses than did our interview questions.

Our participants' desire to maintain everyday control is consistent with Volker et al.'s (2004b) study of control preferences in people with advanced cancer. Although specific types of everyday control varied somewhat between the two studies, both groups of patients expressed a desire to control decision making for clinical care and end-of-life planning. Both groups also wanted to control the impact of their disease and death on their loved ones. However, the Volker study data did not include any manifestation of the current study's theme, "But God controls our lives." This could be perplexing, because both studies employed similar interview questions and included participants from the same geographic area. Although the current study's participants were more diverse (50% non-White) than those in the earlier study (14% non-White), increased diversity is an unlikely explanation of the differing findings because both groups had substantial proportions of White participants. Instead, the difference could be attributed to the nature of hermeneutic phenomenological work and its emphasis on understanding the lived experience the people in a particular study. Study results reveal the unique experiences of that group and are not intended to be generalizable.

The consistency of study themes across the racial/ethnic groups could be explained by a shared experience within the American medical culture and health care system. That is, our participants received all of their cancer care in the United States. Consistent with the Western bioethical emphasis on autonomy, they all described active involvement in, and desire to have, some control over decision making about their treatment plans. Although all of the participants spoke English, we did not collect any information about participants' birthplaces nor levels of acculturation to the United States. Hence, it is unclear whether these items could have influenced the study's findings. Of those participants who described their decisions to stop treatment, a strong sense of the individual right to refuse medical interventions was evident. The desire for involvement in decision making might manifest in a different manner in individuals who are not acculturated to U. S. medicine. More studies including such individuals are warranted.

The study participants shared a belief in ultimate control by a higher power. This ultimate control was characterized as a spiritual or religious force that controlled their cancer occurrence, response to treatment, and timing of death. The idea that God had control over one's cancer and its outcome is consistent with other study findings. For example, in a qualitative study of Mexican Americans' perceptions of cancer care delivery, Campesino (2009) described a value of self-responsibility and determination in conjunction with the belief that God decides health outcomes. Similarly, in a review of studies of the influence of African Americans' spiritual beliefs on treatment preferences at the end of life, Johnson, Elbert-Avila, & Tulskey (2005) found that the belief in divine intervention and God's power to decide life and death were common. Thus, acknowledging the importance of spiritual and religious beliefs of patients and providing spiritual support are essential elements of end-of-life care.

The idea of attributing ultimate control over fate to an external, higher power is consistent with components of some control theories. Wallston, Wallston, and DeVellis (1978) described the concept of external health locus of control as an individual's belief that an event is under the control of fate or a powerful other; conversely, an internal locus of control indicates a belief in one's own ability to control events. For the participants in this study, a belief in both loci of control was evident. Maintaining both beliefs might represent a means of maintaining psychological well-being within the presence of an advanced cancer diagnosis. In a literature review of illness adjustment in patients with cancer, Thuné-Boyle and colleagues (2006) concluded that religious or spiritual coping strategies are beneficial to some and harmful to others. Given that perceived control is an important predictor of quality of life in terminally ill cancer patients (Peters & Sellick, 2006), more research into strategies to promote a realistic and beneficial sense of control within both realms is indicated.

The preference for control at the end of life via an advance directive or hospice care did not emerge as a code or theme in this study. This might be a reflection of the choice of hermeneutic phenomenology as a methodological approach. The interview questions were designed to elicit narrative production and meaning-making activity from the participants, while avoiding solicitation of predetermined or preferred responses (Holstein & Gubrium, 1995). Hence, because we did not ask participants to share their thoughts about specific preferences identified in other studies, we cannot conjecture that they did not value those choices.

Limitations

Although they represented the three largest racial/ethnic groups in the United States, the participants in this study all resided in Texas, which might reflect a regional perspective. Although we found no differences in control preferences between our groups of participants,

one cannot conclude that such differences do not exist. Larger studies to investigate this possibility are warranted. All of the participants were screened and referred by advanced practice nurses and thus might represent a bias reflecting nurses' values regarding who to refer to the study. They might have selected patients who represented a particular perspective or who were more open and communicative. Nothing is known about the patients who were eligible for the study, but who were not approached for participation. In addition, the study participants were not receiving curative treatment and might have had differing views than advanced cancer patients who were receiving such treatment. Because we interviewed each participant only once, no information is available about the possible evolution of their control preferences over time. Future longitudinal studies in end-of-life populations would be useful but carry inherent methodological challenges because patients' declining health and poor prognosis create problems with study attrition.

Conclusion

The advanced cancer patients who participated in the study shared concerns about personal control at the end of life. Although the sample was half White and half Hispanic/African American, participants likely shared a view of end-of-life concerns that were characteristic of American cultural norms regarding the value of autonomy. Hence, additional study of control preferences of dying individuals who are not acculturated to American medicine is warranted. Although some studies have revealed that people with advanced cancer might have differing control preferences based on ethnic origin, clinical care providers must not make assumptions about such preferences based on racial or ethnic stereotypes. Rather, an individualized approach for each person with advanced cancer should be established based on careful assessment and collaboration with the person and family members regarding their unique needs. In particular, our study participants clearly valued and assumed that they had a right to control their treatment-related choices. Although fostering a sense of control is an important component of quality care during the final months of life, health care providers must be cautious about offering realistic control options. Given that the United States faces a burgeoning financial challenge to curtail health care costs, the choice of aggressive, potentially futile treatments at the end-of-life could soon become unsustainable. However, many other options for achieving a sense of control over the dying process should be made available to all.

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