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The Developmental Transition from Living with to Dying From Cancer: Hospice Decision-making

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Abstract

Despite increasing utilization of hospice care, older adults with cancer enroll in hospice for shorter periods of time than those with other life-limiting illnesses. How older adults with cancer and their family members consider hospice is unknown. The purpose of this study was to compare decision-making in late-stage cancer in people who enrolled in hospice with those who declined. Concepts from the Carroll and Johnson (1990) decision-making framework guided the development of a hospice decision-making model. The study design was exploratory-descriptive, cross-sectional and used a 2-group comparison. Qualitative and quantitative data were collected in the same interview. Open-ended questions were used to explore the illness trajectory and decision-making process. The interrelationships between functional ability, quality of life and social support with hospice decision-making were assessed using the Katz, QLQ-30 and Lubben Social Network Scales. Study participants included 42 older adults with cancer who had been offered hospice enrollment (24 non-hospice and 18 hospice) and 38 caregivers (15 non-hospice and 23 hospice); N=80. The decisional model illustrates that the *Recognition of Advanced Cancer* and *Information and Communication Needs* were experienced similarly by both groups. There was interaction between the decisional stages: *Formulation of Awareness* and *Generation of Alternatives* that informed the *Evaluation of Hospice* but these stages were different in the hospice and non-hospice groups. The hospice enrollment decision represents a critical developmental juncture which is accompanied by a transformed identity and substantive cognitive shift. Increased attention to the psychosocial and emotional issues that accompany this transition are important for quality end-of-life care.

INTRODUCTION

People who are age 65 or older are more likely to be diagnosed with cancer and to die from it than younger people. Estimates indicate that 585,720 people over age 65 died from cancer in 2010 and that 53% of all newly diagnosed malignant tumors and 69% of all cancer deaths

occur in this age group (Howlader et al., 2012; Xu, Kochanek, Murphy, Tejada-Vera, 2010). As the population ages, cancer is expected to surpass heart disease as the leading cause of death in the US (Vogelzang et al., 2012).

Considering the end of active cancer treatment and the election of hospice and palliative care is a major transition on the cancer trajectory. Despite continued growth of hospice programs, the median enrollment period was only 18.5 days in 2013 and older cancer patients have shorter length of hospice utilization than people with other terminal diagnoses. The average enrollment period for hospice patients with cancer was 52 days in 2011 while it ranged between 74-137 days for people with other chronic illnesses (MedPac, 2013; National Hospice and Palliative Care Organization [NHPCO], 2013). Hospice enrollment for longer than one week has been associated with improved patient caregiver empathy and with greater alliance with a physician (Calvo, Palmieri, Marinelli, Bianco & Kleinbub, 2014).

Contrary to most models of medical decision-making, which assume that decisions are individual and involve rational, autonomous, deliberate, and systematic choices between alternatives (Elliott & Olver, 2005), the hospice enrollment decision has been found to be made collectively (Hirschman, Corcoran, Straton, & Kapo, 2010). However, the process by which older people with cancer and their families consider decisions about hospice enrollment is largely unknown. The purpose of this study was to compare the decision-making process about hospice utilization in late-stage cancer in older adults who were enrolled in hospice with those who declined. Our a priori hypothesis was that the hospice enrollment decision was delayed in people with late-stage cancer who remained eligible to receive cure-focused treatment. This paper describes how quality of life, level of function, and social support influenced hospice enrollment decisions in a 2-group sample of people over age 65 with late-stage cancer.

Cancer, Aging and Hospice Decision-making

Older adults with advanced cancer experience an interrelationship between normal age-related changes in physical, psychological, social and spiritual well-being together with disease-related challenges and functional decline which can cause distress during the final stages of life (Thompson & Chochinov, 2010). The major concerns of people with cancer have been found to include fear of death and pain, deep existential reflections, altered interpersonal relationships and financial challenges (Alifrangis et al., 2011; Lagerdahl, Moynihan & Stollery, 2014). People with cancer are more likely than those with other terminal illnesses to face higher symptom burden and to be less involved in decision-making at life's end (Pardon et al., 2013). Previous studies have reported between 6-20% continue to receive chemotherapy in the last week of life (Matsuyama, Reddy, & Smith, 2006) which may suggest neither readiness for nor acceptance of dying (Schroepfer, 2006).

Hospice enrollment decisions have been found to be made by family members who know little about hospice and have both substantial information needs and uncertainty (Casarett, Crowley, Stevenson, Xie, & Teno, 2005). The nature and timing of the decision to enter hospice has been found to differ between people with cancer and those with other chronic conditions (Waldrop & Meeker, 2012) and result in shorter utilization. Factors that

contribute to short hospice utilization have been found to include a late diagnosis of cancer or ongoing curative treatment until the final days of life (Morishima, Lee, Otsubo, Ikai, & Imanaka, 2013; Neider, et al., 2014). How older adults with cancer and their families think about hospice is unknown.

Hospice enrollment that occurs only in the last days or weeks of life has been viewed as inadequate for symptom management, maximizing comfort, for facilitating life closure and as an underutilization of the Medicare Hospice Benefit (Casarett et al., 2009). Caregivers have been found to feel overwhelmed and unprepared for managing pain and other skills at home (Mehta, Chan & Cohen, 2014). Moreover, caregiver skill in effective medication management, which is central to symptom relief, requires time for collaboration with hospice providers (Lau et al., 2009). Hospice enrollment that is considered by providers to be too short has in contrast been found to be at the right time by families; earlier hospice referral was not possible either because the person refused or suffered an acute episode that resulted in a rapid decline (Teno, Casarett, Spence, & Connor, 2012). A greater understanding of the hospice decision-making process can help providers uphold the end-of-life choices of older people and their families (Chen, Haley, Robinson, & Schonwetter, 2003).

Conceptual Framework—Decision-making is conceptualized as a dynamic process that occurs over time rather than at a specific point by which people make choices between alternatives. This study is guided by concepts from a framework developed by Carroll and Johnson (1990) which distilled several theories of decision-making into seven stages: (1) *Recognition* of the situation as a decision problem (e.g. the cancer is in an advanced stage); (2) *Formulation* of how the problem is separated from or combined with other concerns (e.g. the need for physical, psychosocial, or family care); (3) *Alternative generation* or the identification of resources (e.g. what is available and accessible); (4) *Information Search* (e.g. prognosis, endpoints of care); (5) *Judgment/choice* (e.g. the decision to enroll in hospice or not); (6) *Action* or what happened after the decision and, (7) *Feedback* about the outcomes of a decision.

METHOD

Study Design

The study design was cross-sectional and descriptive. The study was guided by three research questions: (1) How do older adults with advanced cancer decide to enroll in hospice or to decline?; and (2) What factors influence the timing of this decision?; (3) How is the decision-making process different for people who decide to enroll compared with those who decline hospice enrollment?

Naturalistic inquiry was used to explore the dynamics of hospice decision-making in the family context and social environment. Mixed methods were employed in a parallel-simultaneous design where qualitative data was dominant and quantitative data was less dominant (QUAL-quant) (Tashakkori & Teddlie, 1998). The rationale for choosing mixed methods was to study hospice decision-making in depth and detail by seeking the triangulation of data (Padgett, 2008). The data was integrated by using the qualitative data to

explore and describe the decisional process from participants' experiences and the quantitative data was used for complementarity to deepen understanding of how the lived experience of advanced cancer influences the decision-making process (Tashakkori & Teddlie, 1998). Quantitative measures of activities of daily living (ADLs), quality of life and social support were used as objective measures for comparability across groups (Miles & Huberman, 1994).

Study Procedures

Relatively little is known about the reasons that older adults with terminal cancer accept or reject hospice (Chen et al., 2003); thus a 2-group sample with which to compare the decisional processes of people who had accepted enrollment with a group that had declined it (hospice and non-hospice) was developed. Hospice enrollment had been offered to all participants and was considered as an indicator of late-stage cancer. Purposeful sampling was used to identify older adults with late-stage cancer who had considered hospice enrollment as close to the decision as possible and in real time rather than retrospectively; the rationale was to seek participants' clear recall about the decisional process. Family caregivers who were interested in being interviewed were included to explore how decision-making occurs in the family context. When the person with cancer was unable to participate, caregivers' answers were used as a proxy.

The study protocol and sample recruitment were developed in collaboration with a hospice and palliative care organization in a northeastern state which was the sole hospice provider for the county and had both a hospice and home-based palliative care programs. Roughly, 52% of all US hospices reflect a mixture of such service types (Smith, Seplaki, Biagtan, DuPreez, & Cleary, 2008). Initially, the identification and recruitment of a non-hospice sample with advanced cancer was developed from a database of people who had declined hospice enrollment. To increase the low number of responses we began to recruit potential participants who had declined hospice and were enrolled home-based palliative care program because they were receiving active cancer treatment. Invitation letters and mailed response forms were used to recruit both groups. The study was approved by the [Blinded] Institutional Review Board. Written informed consent was achieved before beginning the interviews.

Study inclusion criteria for both groups were: age 65 years or older and a cancer diagnosis. Age 65 was chosen because it aligns with eligibility for the Medicare and the Hospice Benefit. Potential participants were contacted only if they had a Palliative Performance Scale (PPS) score of 40 or above. The PPS ranges from 0-100 and is used to determine the progression toward death. A PPS of 40 indicates that a person has extensive disease activity, is mainly bedbound, and requires assistance with most activities (Anderson, Downing, Hill, Casorso, & Lerch, 1996). This value was chosen with specific regard for the tenuous and potentially difficult context of late-stage cancer. Hospice patients were contacted only if they remained in the program for 2 weeks to assure that contact about the study did not interfere with final-stage enrollment.

Interviews were scheduled at a time and location of participants' choices. All interviews were conducted in the home setting. In-person interviews were chosen to establish trust,

rapport and understanding about this intimate, emotional phase of a family's life together. The interviewers observed for and checked with participants about signs of fatigue, emotionality and distress. Interviews were conducted by the first two authors or a research assistant, all of whom were licensed healthcare providers. Three types of interviews were conducted: (1) participant alone, (2) joint participant-family caregiver, and (3) family caregiver alone. Interviews were guided by an instrument that consisted of both open-ended questions and scaled measures. Interviews lasted between 45-75 minutes and were audiotaped with permission. Four participants declined audiotaping so field notes were taken. Gift cards were given as thanks for study participation.

Qualitative Measures

The interview guide included open-ended questions in two domains: (1) the illness trajectory (symptoms, cancer diagnosis, treatment, disease progression, provider communication, timing of hospice referral) and (2) decision-making stages (Carroll & Johnson, 1990). Open-ended questions were developed to explore how participants moved through the decision-making process in late-stage cancer. Probing questions were used to elicit nuances about the decisional stages.

Quantitative Measures

Demographic questions were asked about age, gender, race, marital status, religious preference, education, family roles, diagnosis and co-existing conditions.

- The 6-item *Katz Scale* assessed dependence in bathing, dressing, toileting, transfer, continence, and eating; it has a demonstrated Cronbach's alpha of 0.95 (Kamisar, 2008).
- The 30-item *European Organization for Research and Treatment of Cancer Quality of Life (EORTC QLQ-C30)* assessed quality of life, self-reported health, symptoms and well-being (e.g. physical, emotional, cognitive, social and role functioning) and the presence of cancer related symptoms (e.g. fatigue, nausea/vomiting, pain, insomnia, appetite loss, constipation, dyspnea, diarrhea and financial problems); it has demonstrated a Cronbach's alpha of 0.75 (Jacobson, 2013).
- The 6 item *Lubben Social Network Scale (LSNS-6)* assessed social support from family and friends; it has demonstrated a Cronbach's alpha of .78 (Mahon, 2010).

Data Analysis

Qualitative Analysis: Interviews were audiotaped with permission and professionally transcribed. Transcripts were entered into Atlas ti 6.2 for data management and coding (Scientific Software Development, GmbH). Interview data from each type of interview (participant alone, caregiver alone and joint participant-caregiver) were analyzed together.

The qualitative data process was iterative and conducted by the first two authors. Initially, first-line coding was conducted with an *a priori* list of systematic codes developed to represent the core concept of each question on the interview guide (e.g. recognition). New

codes were created for concepts that did not align with the list (e.g. identity transformation). Memo writing was used to add notes of interpretation to the project in Atlas ti.

Next, we conducted a theory led thematic analysis which involved the extraction of a priori concepts as outlined by a theory (Hayes, 2000; Lagerdahl et al., 2014); we used the Carroll and Johnson (1990) model. The coded data were assigned into concept “bins” in Atlas.ti (Coffey & Atkinson, 1996) representing the decisional stages. Coded transcripts were then separated into two document families (a) hospice and (b) non-hospice to facilitate comparison. Finally, transcripts were grouped into combined data bins titled by the decisional stage and group (e.g. hospice × formulation; non-hospice × formulation). The last two stages (Action and Feedback) were excluded because they were assumed to unfold after the interview. This inductive process allowed differential patterns of decisional dynamics to emerge (Cresswell, 1994).

Codes with conceptual overlap were subsumed into themes that illuminated the dynamics of differential processes. Axial coding or the specification of the unique properties of each theme was used to describe decision-making in the hospice and non-hospice groups (Padgett, 2008). Constant comparative analysis or systematic searching was used to discern similarities and differences between groups (Tashakkorie & Teddlie, 1998).

Trustworthiness or the rigor of the qualitative data analysis was maintained by: (1) observer triangulation--co-coding and the development of agreement on the properties of the themes; (2) interdisciplinary triangulation-- interpretation by social work, nursing and medical researchers; (3) methodological triangulation-- the use of multiple data types; (4) memos noting interpretation; and (5) an audit trail for the documentation of decisions about coding and theme development (Padgett, 2008). Preliminary results were presented to an interdisciplinary consultant panel of hospice researchers and clinicians for interpretation.

Quantitative Analysis: Demographic data and scaled measures were entered into the Statistical Package for Social Sciences (SPSS v.21; IBMSPSS, Inc.). Frequencies and descriptive statistics were calculated on the demographic data. Scale and subscale scores were calculated following published scoring algorithms. Group differences in demographics and scale scores were calculated by using Independent Samples t-tests. However, the sample was not sufficiently powered to determine if they were statistically significant.

RESULTS

Sample

Interviews were conducted with 42 people with cancer (24 non-hospice and 18 hospice) and 38 caregivers (15 non-hospice and 23 hospice) for a total sample of 80 participants. Eight hospice patients were unable to participate in an interview. Ten non-hospice participants had no active family caregiver. Sixteen of the non-hospice participants had chosen to continue cancer treatment and were enrolled in the home-based palliative care program. Five non-hospice participants declined hospice and four were determined to be medically ineligible for reasons including a greater than 6-month prognosis (N=2), misdiagnosis of cancer, and active rehabilitation.

Participant and caregiver demographics are presented in Table 1. The Mean age of the participants with cancer was 77.6 years (SD=7.6) and of caregivers was 67.3 years (SD=13.1). The majority of the sample was Non-Hispanic White (98% of patients and 86% of caregivers). The largest numbers identified Roman Catholic as their religious preference (46% of patients and 36% of caregivers). Twenty-nine percent of the patients had education after high school while 71% of the caregivers had some higher education.

The types of cancer are presented in Table 1. Cancer of the respiratory system was most frequent (28%), followed by breast cancer (16%). The Katz scores indicate that participants in the hospice group demonstrated greater functional decline and more need for assistance with ADLs (Table 2). Participants in the non-hospice group reported higher levels of self-reported health and better physical, emotional, cognitive and role functioning than the hospice participants (Table 3). Hospice participants reported higher levels of fatigue, nausea and vomiting, pain, insomnia, and dyspnea than non-hospice participants. Participants in the nonhospice group reported higher levels of appetite loss, constipation, diarrhea and financial problems than those enrolled in hospice (Table 4). Hospice participants reported higher levels of social support from relatives and friends than those in the non-hospice group (Table 5).

Decision-making in Late-stage Cancer—Concepts from the Carroll and Johnson (1990) decision-making framework have been adapted to illustrate decisional states of hospice enrollment in late-stage cancer. The adapted model of hospice decision-making is described and illustrated with participants' words and presented in Figure 1. The adapted model presents the stages of *Recognition of Advanced Cancer* and *Information and Communication* as experienced similarly by both groups. There was interrelationship between the stages *Formulation of Awareness* and *Generation of Alternatives* that informed the *Evaluation of Hospice* but these stages were different in the hospice and non-hospice groups.

Recognition of Advanced Cancer—Recognition that the cancer was advanced had the same characteristics in both the hospice and non-hospice groups. Recognition that advanced cancer was a decision problem occurred suddenly for some and gradually for others. Sudden recognition of the cancer as advanced occurred at the time of a provider's initial discovery of late-stage disease or recurrence and when the news of a life-limiting diagnosis and poor prognosis was delivered to a person and family who were unaware of what was wrong. Hearing unexpected news of a terminal diagnosis was often described as shocking, breathtaking and physically assaultive. After hearing his diagnosis, one participant said, "It hits you like a ton of bricks." A participant's wife described her response, "The doctor took me aside one day and said you have to be prepared. Your husband is not going to make it. I got sweaty and sick to my stomach. I thought I was going to pass out." Sudden recognition of advanced cancer was an intensely emotional experience.

Gradual recognition of the cancer as advanced developed for participants who had lived with it for years. The diagnosis, symptoms, metastasis, prognosis, functional decline and provider encounters became synthesized into the realization that the situation had become serious. A non-hospice participant describes gradual awareness, "In 1999 I was diagnosed with breast

cancer and had a lumpectomy. In 2005 everything was good but then they discovered it had metastasized to the bone and shoulder. Now it's spread all over.” Recognition that the cancer was advanced signaled that decisions about care were becoming important.

Information Search and Communication—Participants in the hospice and non-hospice groups described the need for information from and communication with providers across the illness trajectory. Information needs in the later stages of the disease included symptom management, hospice and palliative care. The lack of understanding about hospice was pervasive in these data. This participant described his limited understanding of hospice, “I had heard of hospice before but I never heard of it the way it is now. The lady explained it to me as it was more or less to help me and it wasn't short term.” Misunderstanding of hospice and palliative care co-occurred with uncertainty about the program. A caregiver described her need for information,

How do we know when to call hospice? She said you can self-refer to hospice and that was the first I knew I could just call them and ask them to come. I knew hospice was out there but if I hadn't asked the question who would have said anything?

Misinformation and limited knowledge about palliative care is described by this hospice participant's daughter,

The doctor called me at my house at 7:30pm and he said I'm from Geriatrics and Palliative Care. I didn't know what palliative care was at the time and I'm thinking palate...like it has something to do with her swallowing... when I got off the phone my husband said...it might be like dying...

Participants in both the hospice and non-hospice groups expressed the ongoing need for information from and communication with their providers to help them understand the progression of their illness, what to expect and available options for care.

Formulation of Awareness

Non-Hospice: Formulation of awareness about the scope of the problem in the nonhospice group resulted in the perception that the cancer-related changes were manageable and not substantively life-changing. This participant illustrated, “I don't have specific pain. I mean sure, my liver's involved and I do have some bony involvement but it doesn't affect me. I don't walk as fast as I used to but I still can walk pretty good.” Participants in the non-hospice group described physical and functional changes that were not yet compromising quality of life.

Hospice: Formulation of awareness of the scope of the problem occurred for hospice participants and their caregivers when the disease progression was accompanied by substantive physical and functional changes that had become life-altering, diminishing independence and quality of life. Formulation of awareness developed from internal personal consciousness and externally from increased caregiving needs, the cumulative effects of multiple surgeries or interaction with a provider. This caregiver described external awareness from increasing care needs,

When we first found out he was more independent and as time has progressed we've been here because he needs us more and he has his good and bad moments. We take it day by day, sometimes moment by moment.

External awareness was facilitated by physicians who prepared caregivers for expected changes. This caregiver's words illustrate,

A month ago the doctor said he would be getting sicker any day. He got sick on Friday and has been sick a week. He hasn't been able to walk or go out and do things. All of a sudden, Dr. L was right –it is starting. He has no appetite and he hasn't eaten in all those days.

Formulation of awareness emerged from internal and external sources, the assessment of symptoms and progressive decline.

Alternative Generation

Non-Hospice: Alternative generation in the non-hospice group was directly related to the availability of continuing cancer treatment. The continuation of treatment was a central dynamic that contributed to the theme “treatment equals hope.” Many described hearing that the end of cancer treatment must precede hospice enrollment. Participants and caregivers perceived that providers also equated “doing something” with treatment, and the end of treatment was frequently linked with a hospice referral. This non-hospice participant's words illustrate, “They give you an alternative, you can go to hospice or you can continue chemo.”

The connection between cancer treatment and hope was expressed by many and is illustrated by this hospice participant whose lab values were too low for chemotherapy, “I'm hoping that it's [count] going to get high enough that I can start taking chemo-- that's all I'm waiting for. If I walked in there next week and they told me that it's up high enough I would start.”

Others decided to end cancer-focused treatment or had refused it altogether. Despite the availability of ongoing cancer treatment, this non-hospice participant describes knowing when he will decline continued treatment.

It's something that they can hold off for a certain amount of time but the inevitable will occur. I will stay with treatment until the symptoms are irreversible. Then I'll go to hospice. They told me what to look for as I progressed. I have not developed any of those symptoms yet. But I know they are coming.

Non-hospice participants equated available cancer treatment and limited symptom burden as a meaningful indicator that hospice enrollment was not yet appropriate.

Hospice: Alternative generation in the hospice group was directly related to awareness about the meaning of substantive physical and functional decline. Participants in the hospice group described the time at which treatment became unavailable or undesired as an indicator that led them to consider hospice as an alternative. The end of cancer-focused treatment and awareness that the cancer was terminal was illustrated by this participant,

I chose not to do any more chemo or radiation. Some people were in agreement with me, others weren't and I decided I was going to do what I wanted to do. I have

cared for everyone else all my life and it was my turn to be selfish and choose what I wanted. I'm done. I didn't want any of this. I don't want to go through with this anymore. I'm tired.

Participants described hearing oncologists' explanations that without cancer treatment "there is nothing that can be done." This caregiver's words illustrate uncertainty following an abrupt end of care that created a sense of abandonment,

The cancerous tumors had taken over her liver and chest. Her doctor said "I have no power over death and there is nothing else we can do." She wanted a second opinion so we went to [another hospital]. We needed somebody tell us what we were doing right and what we were doing wrong.

The equation of treatment with hope was a barrier to the consideration of hospice enrollment. The absence of additional treatment and consideration of hospice enrollment evoked emotional and existential distress and the recognition that death was approaching.

Evaluation

Non-hospice: Non-hospice participants had been presented with the possibility of hospice enrollment by a provider or they had asked about it but they had determined that it was not yet the "right time" for hospice and expressed the perception that they would know when it was time. There was awareness that illness-related changes would become more central in the future. This perception of future awareness was illustrated by this caregiver who said "We didn't think he would need it [hospice] until he got really sick."

Non-hospice participants described the perception that they would "know when" which was illustrated by a participant who said "I think I will know intuitively with everything we've gone through." After an initial intake interview with hospice, another participant responded by saying, "I told her it's very nice, but when I'm ready for the kinds of things that Hospice does, I'll let you know."

The theme of hospice following the end of treatment is illustrated by a participant who said, "The oncologist says I have 6 months without medicines and 12 with. So my choice was to stay with treatment. When I start seeing worsening symptoms I will go to hospice." This nonhospice participant illustrated the perception that cancer treatment is hope by saying, "Until the day the doctor says there's no hope, then I turn myself over to Hospice because once you're in Hospice, you're not going to get any treatments for any new medicines or anything like that." Non-hospice participants expressed the idea that there was a specific time of readiness and need for hospice which followed the end of cancer treatment.

Hospice: Hospice participants' decisions to enroll in the program were made in some situations by the participant but more often they were made collaboratively with families and providers. Collaborative decision making by a participant and caregiver was illustrated by the caregiver who simply stated, "We made it together." Another caregiver's words describe collaborative decision-making,

She really made the decision. We concurred and my son was here and I said to everyone I think it's time. I called Dr. S and he said ok, let's get it done. He told me that it was the right time."

The hospice referral was initiated by providers in many situations. This participant's words illustrate, "I had an appointment with Dr. M and told him what was going on. He called hospice and got me hooked up."

Hospice enrollment was described as a critical juncture that transformed identity and was followed by a substantive cognitive shift from living with to dying from cancer. Becoming a hospice patient became irrefutable evidence that the illness trajectory was unidirectional with no return to health. Hospice enrollment transformed participants' self-concept, self-image and sense of well-being. This hospice participant describes his cognitive shift, "I was feeling terrible. I saw my own funeral which was actually not my funeral it was a man's funeral. But in my mind it was mine." Another participant describes his cognitive shift, "There's no treatment. You're just going to die. I think every person that starts this [hospice] knows what's going to happen." Another hospice participant further describes the transformation in this way,

There's much more than the physical care. What they do comes from a place of very deep understanding of illness and so close to the end of life. I feel grateful." It's sort of like a big sigh of relief in the midst of all the anguish and upsetness.

This hospice participant further illustrated how hospice enrollment transformed her perspective,

The quality of my life...I take things a little bit different after getting sick and knowing how fast something can happen to you and how fast it can be taken away from you. It changes you. It takes little things you don't take little things for granted. It's simple-- appreciate everything around you and everything you have."

Hospice enrollment represented a turning point and transformed perspectives about life and death.

Considered together, the qualitative and quantitative data present a view of the hospice-enrollment decision as a critical juncture in advanced cancer when physical and functional changes and decreasing emotional, cognitive, and role functioning, the absence of active treatment and increasing dependency generates shared recognition of terminality and transition to end-of-life care. Despite higher levels of digestive problems (appetite loss, constipation, diarrhea) and financial problems, non-hospice participants perceived that their situation would ultimately worsen and treatment alternatives would diminish before they would be ready for hospice enrollment. Higher levels of social support in the hospice group was manifested as more frequent contact with both relatives and friends more ease talking about private matters and comfort in asking for help which reflects higher levels of family involvement and caregiving. Participants in the non-hospice group did not yet rely as heavily on others for assistance.

DISCUSSION

The study findings illustrate that the hospice enrollment decision-making process involved an interrelationship between multiple factors. Recognition that the cancer was advanced was precipitated by information from and communication with providers which influenced the formulation of awareness (changes are livable vs. life-changing). Whether cancer treatment was a viable alternative or unavailable was a central factor and the belief that “treatment equals hope” and a barrier to consideration of hospice. When active cancer treatment was an available alternative, it became an indicator that it was not yet time for hospice enrollment. Hospice enrollment was found to transform a person's identity and was followed by substantive cognitive shift from living with to dying from cancer. Identity changed as internal and external evidence became integrated. Becoming a hospice patient sharpened the realization that life was ending. Providers' understanding that hospice enrollment is transformative is important for helping people who are dying and their families make the transition to end-stage care. Recognizing this transition as a series of decisional stages rather than a static point in time can help providers attend to increased needs for information and communication at life's end.

The study findings suggest an important interrelationship between normal age-related changes and cancer progression. Study participants who had enrolled in hospice identified higher symptom burden, poorer functioning and the need for more assistance with activities of daily living. Chen and colleagues (2003) found that people with advanced cancer who were enrolled in hospice had more comorbid conditions and lower levels of activities of daily living than those who were not in hospice. Helping older adults with cancer understand the progression of their disease as well as options for palliative care across the cancer trajectory has the potential to ease distress from increased symptom burden. The American Society for Clinical Oncology has issued a clinical opinion supporting the integration of palliative care services into standard oncology practice at the time a person is diagnosed with metastatic or advanced cancer (Smith et al., 2012), which could improve quality of life and symptom management and promote the transition to hospice care.

The hospice enrollment decision involved a developmental process in which physical, emotional, social and existential factors came together at a time of ascendancy, signaling entry into a new life stage. Developmental psychologist Erik Erikson posited that life cycle stages are turning points at which a decisive shift is unavoidable (Agborsangaya, Lau, Lahtinen, Cooke, & Johnson, 2013). Similarly, other time points on the life course involve identity changes and a shift to prepare for a new phase of life (e.g. becoming a parent). Byock (1997) described the tasks of the final stage of life as a letting go, dissolving out of life and surrendering to the transcendent. The decision to enroll in hospice often prompted attention to those tasks. These results also suggest a connection to the development of “shared selves” through caregiving collaboration in older couples (Schindler, Berg, Butler, Fortenberry & Wiebe, 2010).

The study findings build on and extend the literature on healthcare decision-making in cancer. The widespread conceptualization of the “war on cancer” that has been accompanied by battlefield images of “not giving up,” “fighting” and “winning” has contributed to

expectations of successful treatment and to misperceptions of cure-focused treatment as the only way to treat cancer, thus perpetuating the invisibility of supportive care as an important form of treatment. The complex issue of late-stage chemotherapy has many contributing factors including physician practice patterns, patient desires, myths and realities of newer drugs and fiscal incentives (Behl & Jatoi, 2010).

The study results identify shortcomings in service delivery that have implications from a policy perspective. Growing interest in the integration of palliative care across the cancer trajectory and earlier introduction of hospice as a resource suggest the importance of establishing regulatory expectations of this as best practice. Moreover, curricular policy in medicine, nursing and social work education can address the need for all healthcare professionals to receive training in initiating conversations about end-of-life care with people who have late-stage disease. Finally, the often overlooked need for psychosocial support across the trajectory of cancer can be elevated to an expected standard of care for all who receive—and subsequently end cancer treatment.

The study had a number of limitations. Family members' answers to the quantitative questions were given as a proxy measure and may reflect inaccuracies in symptom and functioning assessment. There was insufficient statistical power to determine if the differences between the groups were significant. The use of a two-group sample for comparative analysis was important but recruiting people who were eligible for but had declined hospice enrollment was challenging and a mixed sampling technique became necessary. Naturalistic inquiry was important to explore how decisions about hospice were made in the family context. However, this resulted in non-equivalent groups of interviews with patients, patient and caregiver and caregivers alone. The sample is overwhelmingly White. Although this is consistent with NHPCO national utilization statistics which indicate that people from races other than White comprised only 5% of the hospice population nationally in 2012 (NHPCO, 2013) and represent 13.9% of the county served by the participating hospice (US Census Bureau, 2012).

CLINICAL IMPLICATIONS

The study results have clinical implications for practice with people who are facing life's end and those who care for them. Understanding the experience of and reaction to being offered hospice care is important to increase provider awareness and sensitivity about the timing and nature of this conversation. The presentation of hospice only as reflexive response at the end of treatment can be shocking when the hope for treatment success has prevailed. Making hospice referrals may be a regular activity for providers but it only happens once in the life of a person who is dying and may be accompanied by avoidant thoughts. Statements that approximate "there is nothing more we can do" can contribute a sense of abandonment, isolation and disenfranchisement when the last stage of life could bring important opportunities for life closure, relationship completion and quality life until death. Healthcare providers would benefit from increased knowledge of and information about hospice and palliative care to dispel myths and misunderstanding and to underscore the importance of symptom management.

CONCLUSION

These results suggest the need for more nuanced referrals to hospice and for attention to the psychosocial and emotional issues that accompany this transition. Prognostication has been described as both an art and a science and endorsed as essential for helping people and their families prepare for an approaching death (Glare & Sinclair, 2008). Families demonstrate a continuum of approach-avoidance strategies to cope with cancer (Hildenbrand, Alderfer, Deatrack & Marsac, 2014); thus information about prognosis and treatment can generate intense emotional responses and has been found to be most effective when it is personalized and tailored to the social context (Alifrangis et al., 2011). Being aware of the various changes that occur with aging and cancer can help healthcare professionals tailor interventions to promote dignity-conserving care and reduce the potential for suffering at the end of life (Thompson & Chochinov, 2010).

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Figure 1.
The hospice enrollment decision process.

Table 1

Sample Demographics

Age ^a	Hospice Patients		^a Hospice Caregivers		^a Non-hospice Participants		^a Non-hospice Caregivers	
	M(SD)	N (%)	M(SD)	N (%)	M(SD)	N (%)	M(SD)	N (%)
	77.84(7.5)		64.5(11.9)		77.44(7.7)		70.8(14.1)	
Race	Hospice Patients		Hospice Caregivers		Non-hospice Participants		Non-hospice Caregivers	
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
White	23 (92%)		20(80%)		25(100%)		15 (100%)	
Black	2(8%)		2(8%)					
Hispanic			1(4%)					
Education	Hospice Patients		Hospice Caregiver		Non-hospice Participants		Non-hospice Caregivers	
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Did not finish high school	2 (8%)		1 (4%)		13 (52%)		1(7%)	
Completed high school	13(52%)		7 (30%)		6 (24%)		5(30%)	
Some college	2(8%)		7(30%)		1 (4%)		3(2%)	
Bachelor's degree	2(8%)		3(13%)		2 (8%)		1(7%)	
Graduate degree	4(16%)		3(13%)		3 (12%)		5(30%)	
Missing	2(8%)		2 (9%)					
Religious Preference	Hospice Patients		Hospice Caregivers		Non-hospice Participants		Non-hospice Caregiver	
	N (%)	N (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Roman Catholic	12(48%)		11 (68%)		11 (44%)		8(53%)	
Other denominational Christian	9 (36%)		8 (35%)		8 (32%)		6(40%)	
Jewish	1 (4%)		1 (4%)		3 (12%)		1(7%)	
Non-denominational Christian	1 (4%)		0 (0%)		0 (0%)		0(0%)	
No preference	2 (8%)		3 (13%)		3 (12%)		0(0%)	

Cancer Type	Hospice Patients	Non-hospice Participants	Total
	n (%)	n (%)	N (%)
Respiratory	9(36%)	5(20%)	14(28%)
Breast	5(20%)	3(12%)	8(16%)
Digestive	4(16%)	7(28%)	11(22%)
Genitourinary	2(8%)	3(12%)	5(10%)
Hematologic	1(4%)	2(8%)	3(6%)
Head and neck	2(8%)	1(4%)	3(6%)
Other ^c	5 (20%)	5(20%)	10(20%)

Notes. Hospice patient demographics are inclusive of 8 who could not be interviewed to provide a complete profile.

^b (N%) the percentage of the total sample

^a (n%) reflects the proportion of the group (hospice or non-hospice)

^c Other included brain, skin, bone cancer and unknown primary.

Table 2**Katz Scores: Activities of Daily Living**

How much assistance is needed with:

	Non-Hospice M(SD)	Hospice M(SD)
Bathing	1.09 (.29)	2.0 (.76)
Dressing	1.04 (.21)	1.8 (.80)
Toileting	1.00 (.00)	1.4 (.73)
Transfer	1.04 (.21)	1.6 (.80)
Continence	1.00 (.00)	1.5 (.86)
Feeding	1.00 (.00)	1.3 (.72)
Overall score	6.20 (.50)	9.6 (3.9)

Notes: 1=Independent, no assistance needed

2=Some assistance with bathing

3=Dependent on another for help

Theoretical range is 6-18

Table 3

EORTC QLQ C-30 Scales

Scale	Non-Hospice M(SD)	Hospice M(SD)
Global Health Scale	49.5 (28.8)	45.0 (18.6)
Physical Functioning	62.3 (32.4)	37.2 (26.4)
Emotional Functioning	74.6 (20.0)	63.2 (32.8)
Social Functioning	44.7 (37.2)	40.4 (37.0)
Cognitive Functioning	67.4 (36.0)	55.0 (42.3)
Role Functioning	53.8 (37.4)	28.9 (33.3)

Note: Range =0-100; Higher scores indicate better functioning

Table 4

EORTC QLQ-30 Symptom Subscales

Symptom	Non-HospiceM(SD)	HospiceM(SD)
Fatigue	56.6 (25.2)	71.1 (30.9)
Nausea/vomiting	5.6(14.3)	8.3 (13.8)
Pain	25.0 (32.4)	27.2 (36.1)
Insomnia	27.3 (35.1)	46.7 (46.4)
Appetite loss	48.5 (36.7)	46.7 (43.8)
Constipation	26.1 (36.2)	23.3 (34.4)
Dyspnea	37.9 (40.2)	41.7 (43.1)
Diarrhea	20.3 (32.9)	15.0 (25.3)
Financial problems	40.9 (45.9)	24.6 (41.3)

Note: Range=0-100; Lower scores indicate fewer symptoms.

Table 5

Lubben Social Network Scale Scores

	Non-Hospice M (SD)	Hospice M (SD)
<i>How many relatives do you:</i>		
See or hear from at least once a month?	3.6 (1.7)	4.3 (1.2)
Feel at ease with that you can talk about private matters?	2.5 (1.8)	3.1 (1.5)
Feel close to such that you could call on them for help?	3.2 (1.7)	3.7 (1.5)
<i>How many friends do you:</i>		
See or hear from at least once a month?	3.3 (1.4)	4.0 (1.6)
Feel at ease with that you can talk about private matters?	2.1 (1.5)	3.1 (2.0)
Feel close to such that you could call on them for help?	2.4 (1.9)	3.6 (1.6)
<i>LSNS Total</i>	16.9 (7.7)	22.1 (5.8)
<i>Family Subscale Score</i>	9.24 (4.6)	11.1 (3.7)
<i>Friends Subscale</i>	7.8 (3.9)	11.0 (4.7)

Note: Responses: 0=none; 1=one; 2=2; 3=3-4; 4=5-8; 5=9+

Scale scores range from 0-30 and subscale scores range from 0-15