Hospice Decision Making: Diagnosis Makes a Difference

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Purpose: This study explored the process of decision making about hospice enrollment and identified factors that influence the timing of that decision. Methods: This study employed an exploratory, descriptive, cross-sectional design and was conducted using qualitative methods. In-depth in-person semistructured interviews were conducted with 36 hospice patients and 55 caregivers after 2 weeks of hospice care. The study was guided by Janis and Mann’s conflict theory model (CTM) of decision making. Qualitative data analysis involved a directed content analysis using concepts from the CTM. Results: A model of hospice enrollment decision making is presented. Concepts from the CTM (appraisal, surveying and weighing the alternatives, deliberations, adherence) were used as an organizing framework to illustrate the dynamics. Distinct differences were found by diagnosis (cancer vs. other chronic illness, e.g., heart and lung diseases) during the pre-encounter phase or before the hospice referral but no differences emerged during the post-encounter phase. Implications: Differences in decision making by diagnosis suggest the need for research about medical care during the later stages of a terminal illness. Consideration of hospice enrollment is a central element of the end-of-life decision-making process (Bloomer, Tan, & Lee, 2010; Prince-Paul, 2009). Hospice provides interdisciplinary team-based care for people who are terminally ill and their families. The goal of hospice care is to alleviate physical, psychological, and existential distress. Hospice can relieve distress in late-stage illness through pain and symptom management and coordinate care among multiple providers and across settings with a focus on respecting the person’s preferences (Lorenz, Asch, Rosenfeld, Liu, & Etten, 2004). People with terminal conditions become eligible for hospice when their illnesses are expected to result in death within 6 months (Centers for Medicare and Medicaid Services, 2010). The length and timing of hospice enrollment are variable in advanced chronic illnesses, and short periods of hospice enrollment are common. In 2009, the median length of hospice utilization was 21 days and 34.4% of hospice patients died within 7 days of enrollment (National Hospice and Palliative Care Organization [NHPCO], 2010). Shorter admissions have been associated with more unmet needs, higher reported concerns, and lower satisfaction (Teno et al., 2007). Although most hospice patients remain enrolled for less than 6 months, the length of utilization ranges between 1 and 210 days and trends indicate that longer periods of enrollment are increasing for people with noncancer diagnoses (MedPac, 2008). The prevalence of both short and long hospice enrollment suggests a bimodal pattern of utilization.

Key Words: End-of-life care, End-of-life decision making
Optimal use of the hospice benefit is important to consider in end-of-life decision making, but the factors that influence decisions about the timing of hospice enrollment are not well understood.

The transition from curative to palliative care can be one of the most difficult decisions that people and their families face in the later stages of an advanced illness (Siminoff, Rose, Zhang, & Zyzanski, 2006). Political, cultural, and legal factors have been associated with decision making about hospice services (Hill, 2005; Mazanec, Daly, & Townsend, 2010), but psychosocial and family dynamics also clearly influence the decision-making process (Casarett & Quill, 2007; Hirschman, Corcoran, Stratton, & Kapo, 2010; Waldrop, 2006). Decision making about options for care at life’s end can be influenced by differences in patient and caregiver stress, varying perceptions of the illness and prognosis, increasing needs for care, previous communication difficulties, and family conflict (Chen, Haley, Robinson, & Schonwetter, 2003; Kramer, Kavanaugh, Trentham-Dietz, Walsh, & Yonker, 2010; McAuley, Buchanan, Travis, Wang, & Kim, 2006; Meeker, 2004; Schmid, Allen, Haley, & Decoster, 2010; Siminoff et al., 2006). Straightforward, honest, culturally sensitive, unbiased communication with health care providers about prognosis, available treatments and their consequences, typical outcomes, and options for care at the end of life can help people who are ill and their families with decision making (Caldwell, Arthur, & Demers, 2007; Kwak & Haley, 2005; Matsuyama, Reddy, & Smith, 2006).

Effective means for end-of-life decision making are central to meet patient and family goals (Hirschman et al., 2010; Lorenz, Lynn, et al., 2004) and of universal importance to growing numbers of older adults who are living longer and facing multiple, often complex, choices for care at life’s end (Parekh & Barton, 2010). How people and their families think about the transition to hospice care is largely unknown. The purpose of this study was to describe the process of decision making about hospice enrollment and to identify factors that influence the timing of the decision.

Conceptual Framework

Decision making about hospice enrollment can involve conflict between hoped-for outcomes and the reality of an advancing illness. The conflict theory model (CTM) of decision making posits that when people think about vital affect-laden issues, they experience intense thoughts and emotional distress (Janis & Mann, 1977). Decisional conflicts occur when a person has to make an important choice and can involve hesitation, vacillation, feelings of uncertainty, and signs of acute emotional distress. The CTM comprises five stages of decision making that can be applied to understand the context of an advanced illness: (a) appraisal of the challenge—disturbing information signals an approaching threat and the possibility of serious risks (e.g., functional decline); (b) surveying the alternatives—with recognition of the challenge, possible options are considered (e.g., disease progression); (c) weighing the alternatives—the pros and cons of possible choices are evaluated (e.g., considering hospice utilization); (d) deliberations—assessing the outcomes of the choice and its effect on others (e.g., how hospice may influence caregiving); and (e) adherence to the decision—the choice continues to be reappraised in the context of additional new threats and challenges (e.g., continuing in hospice care; Janis & Mann, 1977).

Methods

Study Design

This study employed an exploratory, descriptive, cross-sectional design and was conducted using qualitative methods to answer two research questions: (a) How do older adults and their families make the decision to enroll in hospice? and (b) What factors influence the timing of the decision?

Participants

Purposeful sampling was used to identify potential participants who had recently made the decision to enroll in hospice (Padgett, 2008; Strauss & Corbin, 1998). Recruitment for research at this tenuous time in life is complicated by the challenges of advanced illness and by the limitations of federal (Health Insurance Portability and Accountability Act [HIPPA]) and organizational policies. Protocols were developed with the leadership teams at two participating hospices and focused on inviting participation and interviewing newly admitted hospice patients and caregivers as soon after admission as possible. The study was approved by the University at Buffalo Social and Behavioral Sciences Institutional Review Board, and a HIPAA partial waiver of authorization was approved to allow the investigator to receive contact information.
The study’s inclusion criteria were that the hospice patient was 65 years or older, had been on the program for 2 weeks prior to recruitment, and had a Palliative Performance Scale (PPS) score of 40 or above. The PPS is a 100-point scale of functional decline that precedes death. People who score below 40 are often unable to communicate and generally expected to be actively dying (Anderson, Downing, Hill, Casorso, & Lerch, 1996). The inclusion criteria of age 65 years was selected because this is the age of eligibility for Medicare benefits and thus for the Medicare Hospice Benefit. Family caregivers were invited to participate because the decision to enter hospice care is often made in the family context (Hirschman et al., 2010).

Setting

The two participating hospice organizations are located in a northeastern U.S. state. One hospice provides care for a mixture of urban, suburban, and rural areas and serves more than 3,900 patients yearly. The other hospice serves more than 700 patients yearly.

Procedures

Information sheets about the study were placed in all hospice admission packets during the recruitment phase, which lasted for 12 months. Lists of patients and caregivers were provided to the principal investigator (PI). Invitation letters were mailed by the PI and interested participants returned a response form. Interviews were arranged, confirmed by phone, and rescheduled if the patient was not feeling well. Interviews lasted 55–90 min and were audiotaped with permission. Participants were given a $25 supermarket gift card as thanks for participation. All interviews were conducted by the first author who is a licensed social worker.

Data Collection

Qualitative data were collected during a single-session interview. Patients and family members were interviewed at the same time. Interviews were guided by a semistructured interview instrument with four categories of questions: (a) illness trajectory (e.g., questions about symptoms, diagnosis, treatment), (b) social support (e.g., questions about family and the social network), (c) hospice decision making (e.g., questions about who made the decision, how and when it occurred), and (d) advice for others (e.g., suggestions for other families and providers). Interviews continued until saturation occurred.

For the purpose of building rapport and developing comfort with the researcher, interviews were conducted in a conversational manner. Hospice patients and their family members were asked the questions at the same time. Answers were offered by each individual and identified as “patient” or “caregiver” in the transcripts.

Data Analyses

Interviews were professionally transcribed and entered into ATLAS.ti 6.2 for data management and coding (Scientific Software Development, Gmbh). Data reduction and coding began while the data collection process was ongoing. Demographic data were entered into SPSS 19 and descriptive statistics were calculated (IBM SPSS, Inc.).

Each interview transcript was read and summarized into an effects matrix or visual display of participants (rows) by decision dynamics (columns; Miles & Huberman, 1994). The columns were labeled “diagnosis,” “hospice decision” (e.g., how it was made), and “hospice role” (e.g., purpose for hospice enrollment). These categories were developed by the PI to identify preliminary patterns.

First-line coding was conducted with a list of systematic codes that reflected key concepts from the interview questions (e.g., diagnosis, functional and psychosocial changes). Coding was completed by two student research assistants and the PI. Memo writing was used to insert thoughts and ideas that emerged from interacting with the data (Padgett, 2008). Intercoder reliability was calculated by comparing five coded transcripts for the number of agreements. Reliability was calculated by dividing the number of agreements by the sum of the total number of codes and determined to be 80%. Coding discrepancies were reconciled with discussion. Distinct patterns of differences in the hospice enrollment decision process between participants with cancer and those who had other chronic illnesses emerged early in the coding.

Pattern analysis, or the grouping of associated codes, was used to create code families, reduce the large number of codes into a smaller number of analytic units, and identify the relationships between them. An example of pattern coding was to combine the codes chemotherapy, radiation, and surgery into “treatment.” Pattern codes were aggregated or condensed to identify the factors that influence
decision making (Patton, 2002). The assignment of codes was not mutually exclusive.

Next, guided by the concepts in the CTM (Janis & Mann, 1977), we conducted a directed content analysis (Hsieh & Shannon, 2005). Focused coding (Charmaz, 2006) was used to examine the data and assign the coded data into concept bins in ATLAS.ti (Coffey & Atkinson, 1996; Padgett, 2008) titled appraisal, surveying the alternatives, weighing the alternatives, deliberations, and adherence. The hospice decision-making process was assessed by a series of 10 open-ended questions that incorporated the concepts in the CTM and a series of 10 categorical questions about the hospice experience (e.g., factors that contributed to the decision) and open-ended questions about how the decision was made (appraisal). Participants were asked about other alternatives that were considered (surveying alternatives), what they thought about hospice enrollment (weighing the alternatives), and the outcomes of their decision to enroll (deliberations). The advice-for-others segment was a series of three open-ended questions about reflections on the hospice decision-making process (adherence).

Document families (e.g., cancer and other) were created in ATLAS.ti to create an effects matrix of diagnostic group by decision process (Miles & Huberman, 1994). Finally, axial coding or the specification of the properties of the categories was used to integrate the factors and stages of decision making (Padgett, 2008; Strauss & Corbin, 1998). A model of hospice enrollment decision making was adapted from the CTM.

Rigor was upheld in the data analysis by (a) observer triangulation, or co-coding; (b) interdisciplinary triangulation and interpretation; (c) constant comparative analysis or the systematic search for similarities and differences across interviews (Padgett, 2008; Strauss & Corbin, 1998); and (d) the use of an audit trail or a field journal of analytic decisions (Padgett, 2008).

Results
Sample

A total of 249 invitation letters were mailed and 62 responses were received from the mailing for a response rate of 24.8%. Interviews were conducted in 62 families. Joint interviews were conducted with 27 patients and 28 family caregivers. Individual interviews were conducted with 27 caregivers of 26 patients who were unable to participate (demographic and diagnostic information were gathered). Nine patients with no live-in caregivers were interviewed alone. A total of 36 hospice patients and 55 caregivers were interviewed (91 participants, 62 interviews; Table 1).

Interviews with people in the cancer group involved 21 patients and 29 caregivers (n = 50/91, 55%); those in the other chronic illness group involved 15 patients and 26 caregivers (n = 41/91, 45%) of the participants. Caregivers were spouses (n = 28/54, 52%), adult children or children in law (n = 21/54, 39%), siblings (n = 2/54, 4%), and others (nieces, nephews, grandson; n = 3, 5%; Table 2).

### Table 1. The Number and Type of Interviews Conducted With Hospice Patients and Caregivers

<table>
<thead>
<tr>
<th>Interview type</th>
<th>Hospice patient participants</th>
<th>Caregivers&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Hospice patients who could not participate&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joint patient–caregiver interviews</td>
<td>Cancer: n = 16</td>
<td>Cancer: n = 16</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Other: n = 11</td>
<td>Other: n = 12&lt;sup&gt;a&lt;/sup&gt;</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Total: n = 27</td>
<td>Total: n = 28</td>
<td>—</td>
</tr>
<tr>
<td>Patient-alone interviews</td>
<td>Cancer: n = 5</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Other: n = 4</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Total: n = 9</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Caregivers alone (patients could not participate)</td>
<td>—</td>
<td>Cancer: n = 13</td>
<td>Cancer: n = 13</td>
</tr>
<tr>
<td></td>
<td>Other: n = 14&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Other: n = 13&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Total: n = 27</td>
</tr>
<tr>
<td></td>
<td>Total: n = 27</td>
<td>Total: n = 27</td>
<td>—</td>
</tr>
<tr>
<td>Total&lt;sup&gt;c&lt;/sup&gt;</td>
<td>36</td>
<td>55</td>
<td>26</td>
</tr>
</tbody>
</table>

<sup>a</sup> Two caregivers from one family participated.

<sup>b</sup> Patients were unable to participate because of illness progression or they had died after the letter was sent.

<sup>c</sup> Face-to-face interviews were conducted with a total of 91 people. The hospice patients who could not participate because of the effects of late-stage illness or death are not included in this number.
illustrated in participants’ words. There were similarities in responses from patients and caregivers, which are presented together unless otherwise noted. Decision making during the pre-encounter phase was distinctly different for people with cancer and those with other chronic illnesses (Figure 1).

Pre-encounter Phase

Families experienced uncertainty and hesitancy as they observed physical, functional, and psychological changes. Appraisal of the challenge and surveying the alternatives are reported by diagnostic group and in succession.

Appraisal of the Challenge: Cancer \( (n = 35/62, 56\%) \).—The changing clinical picture was a central factor in the decision-making process. Appraisal of the intensifying challenges of the illness included situations where: (a) patient declined treatment, (b) curative treatment was unavailable, and (c) diagnostic eligibility accompanied late-stage disease.

Curative treatment was unavailable. Nineteen of 35 (54\%) of the cancer patients who had completed one or more courses of curative treatment were told that nothing further was available. Participants in this group commonly reported hearing variations of the sentence, “There is nothing more I can do for you, call Hospice” from physicians. In these situations, the end of cancer treatment was linked to a hospice referral. A patient’s son described how her physician arranged the transition to hospice,

He was saying you are at the stage that the debilitation of your body and what your scans were showing and that you’ve gotten so many treatments over the years and you’re not responding; you need supportive treatment.

Reaching the end of treatment, either by choice or the lack of additional curative treatment, led to the response—it was time to contact hospice.

Patient declined treatment. The decision to decline or end treatment was made by 6 of 35 (17\%) cancer patients who felt that treatment had become burdensome. People who made this decision repeated a version of the statement, “I was done with chemo” or “I’d had it.” A woman with ovarian cancer illustrated, “I don’t want chemotherapy. I don’t want surgery. I’m 83 years old. I lived my life. I had a good life. I wish you a life

### Table 2. Diagnosis, Age, Gender, Race, and Religious Preference of Study Participants (2007–2008)

<table>
<thead>
<tr>
<th>Hospice patient’s diagnosis, n/N (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer(^a)</td>
<td>35/62 (56)</td>
</tr>
<tr>
<td>Genitourinary(^b)</td>
<td>12/35 (19)</td>
</tr>
<tr>
<td>Respiratory(^b)</td>
<td>5/35 (8)</td>
</tr>
<tr>
<td>Bone, skin, breast(^b)</td>
<td>6/35 (10)</td>
</tr>
<tr>
<td>Digestive(^b)</td>
<td>5/35 (8)</td>
</tr>
<tr>
<td>Other(^b)</td>
<td>7/35 (11)</td>
</tr>
<tr>
<td>Other chronic illness(^a)</td>
<td>27/62 (44)</td>
</tr>
<tr>
<td>Lung disease(^b)</td>
<td>12/27 (19)</td>
</tr>
<tr>
<td>Heart disease(^b)</td>
<td>12/27 (19)</td>
</tr>
<tr>
<td>Neurodegenerative(^b)</td>
<td>3/27 (6)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age in years, ( M (SD) )</th>
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<tbody>
<tr>
<td>Patient</td>
</tr>
<tr>
<td>Cancer</td>
</tr>
<tr>
<td>Lung disease</td>
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<tr>
<td>Heart disease</td>
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<tr>
<td>Neurodegenerative</td>
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<tr>
<td>Caregiver</td>
</tr>
<tr>
<td>Cancer</td>
</tr>
<tr>
<td>Lung disease</td>
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<tr>
<td>Heart disease</td>
</tr>
<tr>
<td>Neurodegenerative</td>
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<table>
<thead>
<tr>
<th>Gender, n/N (%)</th>
</tr>
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<tbody>
<tr>
<td>Patients(^d)</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Caregivers</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient race n/N (%)(^d)</th>
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</thead>
<tbody>
<tr>
<td>Non-Hispanic White</td>
</tr>
<tr>
<td>African American</td>
</tr>
<tr>
<td>Native American</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Patient religious preference n/N (%)(^d)</th>
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</thead>
<tbody>
<tr>
<td>Nondenominational Christian</td>
</tr>
<tr>
<td>Catholic</td>
</tr>
<tr>
<td>Denominational Christian</td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td>Jehovah’s Witnesses</td>
</tr>
<tr>
<td>Jewish</td>
</tr>
</tbody>
</table>

Notes: Palliative Performance Scores ranged between 40 and 60. A total of 36 of 62 patients (58\%) participated; 26 of 62 (42\%) did not.

\(^a\)N = whole sample.
\(^b\)N = diagnostic group.
\(^c\)Patient’s age ranged from 66 to 98 years. Caregivers’ ages ranged from 32 to 86 years.
\(^d\)N = combined sample of hospice patients who were interviewed and those who could not participate due to advanced illness or death.

Diagnostic Trajectories

The hospice enrollment decision process occurred in two phases: pre-encounter or before hospice contact, and post-encounter. Concepts from the CTM are used as an organizing framework to illuminate the dynamics. Concepts are described and then illustrated in participants’ words. There were similarities in responses from patients and caregivers, which are presented together unless otherwise noted. Decision making during the pre-encounter phase was distinctly different for people with cancer and those with other chronic illnesses (Figure 1).

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like that.” Patients who chose to end treatment because of physical distress had symptoms such as nausea and vomiting, fatigue, and debility. A patient with liver cancer described deciding she could tolerate no further treatment:

They wanted me to have another CT. I got down there, drank that awful stuff, and I said, I just can’t do this. It was so cold and my son took me back up and that was the end. I didn’t want to hear anything; I didn’t want to do anything more.

People who declined treatment did so because of intensifying physical symptoms or psychological and existential reasons.

**Diagnostic eligibility.** Six of 35 (17%) cancer patients were diagnosed with late-stage, metastatic, or lethal forms of cancer that triggered hospice eligibility. The words of a patient’s wife underscored the connection:

We were told right at his diagnosis that he was eligible for Hospice because he was at Stage IV and that we could call Hospice for assistance because of the metastatic condition and staging of the disease.

The diagnosis of advanced metastatic disease was equated with the appropriate timing for a referral to hospice by participants’ physicians.

**Surveying the Alternatives: Cancer.**—During this phase, the threat of the illness became real and there was awareness that the decline was irreversible, leading to the consideration of options for care. Surveying the alternatives in advanced cancer involved recognition of (a) steady decline and (b) hospice availability.

**Steady decline.** All participants described increased symptom burden and functional decline. A participant described her husband’s illness progression as including “increasing fatigue, weakness, and anemia; he was so tired he could hardly walk.” The husband of a woman with metastatic breast cancer illustrated her increasing needs, “The situation was becoming desperate. I certainly could not handle it anymore.” He went on to explain how her functional decline made it unsafe:

It was very difficult going in the car. One day she collapsed in the garage and I called 911. Another time she was going to the bathroom and collapsed. I couldn’t pick her up.

The words of a hospice patient illustrated how pain and fatigue became burdensome, “I ache all over. I have a painful back and I can’t stand or walk to any extent. This has been going on for some time but it’s gotten more difficult.” Functional decline motivated the search for additional support.

**Hospice availability.** During the process of surveying alternatives, hospice became a viable option and discussion of appropriate timing was prevalent. The preexisting belief that hospice enrollment
is only for the last few days of life was expressed in 12 of 35 (34%) of the families of cancer patients. Participants expressed a version of this statement, “I knew about Hospice but I thought it was for those who were actively dying.”

The perspectives of patients, families, and physicians were sometimes dissimilar. When her physician suggested hospice to a patient and her husband, he described their disbelief by saying, “We didn’t understand . . . to us Hospice was a death warrant. We were angry with him.”

An 83-year-old with leukemia did not want her children to know of her diagnosis. When her physician convinced her to tell them, she described feeling that she was not ready for hospice, “I thought it’s too early and they said no. I understood hospice to be when you are lying in bed dying.” The erroneous belief that hospice is only appropriate for the very last few days of life was present among cancer patients in this sample.

**Appraisal: Other Chronic Illnesses (n = 27/62, 44%) of the Hospice Patients.** — The disease trajectory of other chronic illnesses was characterized by intensifying challenges that were different than with cancer: (a) symptom exacerbations and (b) hospitalizations.

**Symptom exacerbations.** The illness trajectories of participants with lung and heart diseases (24/62, 39%) involved episodic symptom exacerbations such as shortness of breath or fluid overload that became increasingly burdensome. A hospice patient explained unpredictable symptoms by saying, “With COPD anything can happen. Your lungs just shut down and they won’t take in or let out any air. You never know when it’s going to happen.” Symptom exacerbations such as shortness of breath, chest pain, and fluid overload can be frightening. Participants in the neurodegenerative disorders group (3/62, 5%) did not describe symptom exacerbations.

**Hospitalizations.** Participants reported that all patients (24/62, 38%) with lung or heart disease made between 2 and 10 visits to an emergency department or hospital for uncontrolled symptoms during the time before hospice became involved. The discussion of a hospice referral became a component of discharge planning for people who had multiple hospitalizations. Hospice enrollment was identified as a means for avoiding hospitalization.

The fragility of people who are in a cycle of crisis–hospitalization–recovery is illustrated in the words of a patient’s daughter, “She got pneumonia last January. She was in the hospital for 3 weeks. She wasn’t home 12 hours, got sick, and I took her back.”

Three participants with chronic illnesses experienced a brush with death when they were hospitalized but refused life-sustaining treatment. Considered to be imminently dying, they were offered hospice. Hospice was considered when a person with a chronic illness no longer wanted to return to the hospital.

**Surveying the Alternatives: Other Chronic Illnesses.** — Surveying the alternatives in other chronic illnesses involved (a) recognition of terminality and (b) prognostic eligibility.

**Treatment futility.** Growing recognition that the recurring cycle of symptom crises, hospitalizations, and curative treatment was futile was expressed in 20 of 24 (83%) of the families who were dealing with lung or heart disease. The daughter of a 73-year-old woman with emphysema and chronic obstructive pulmonary disease (COPD) described her recognition that there would be no recovery:

The last 2 years were hard for her . . . she would get so out of breath. She was back in the hospital for 2–3 weeks, home roughly 2 weeks and got sick again—back and forth. As time progressed, it got worse and worse.

Recurrent symptom crises and the decreasing ability to recover led to the recognition of the futility of continued curative treatment.

**Prognostic eligibility.** The belief that hospice enrollment is only for people with cancer was expressed in 12 of 27 (44%) of the families who were dealing with noncancer illnesses. For these participants, hospice eligibility was linked to a diagnosis of cancer rather than a prognosis of 6 months or less. The caregiver of a woman with Alzheimer’s disease illustrated, “I always envisioned hospice being for people who are on their deathbed with cancer. I had no idea it was available for people with Alzheimer’s.” Decision making was facilitated by family and provider understanding that hospice eligibility was related to a terminal prognosis.
Post-encounter Phase

After the initial encounter with hospice, participants in both diagnostic groups had similar experiences during the subsequent phases of the decision-making process: weighing the alternatives, deliberations, and adherence. No differences by diagnosis emerged in the post-encounter phase.

Weighing the Alternatives.—Growing awareness of the challenges of the advancing illness led participants to weigh the pros and cons: (a) relinquishing treatment/hospitalization and (b) hospice versus other programs.

Relinquishing treatment/hospitalization. The decision to end treatment and hospitalization was processed differently. In a majority (47/62, 76%) of the families, the transition was described as a natural next step on the illness trajectory (cancer: 28/35, 80%; other: 20/27, 74%). People who felt certain about seeking no additional treatment or hospitalization were not conflicted about hospice enrollment. However, in 15 of 62 (24%) of the sample (cancer: 7/35, 23%; other: 7/27, 26%), reluctance was expressed about this transition in care (e.g., not calling 911). Hospice admission was chosen specifically to help participants avoid future hospitalization in 11 of 62 (18%) of the participating families (cancer: 4/35, 11%; other: 7/27, 26%). An important component of the decision-making process was the meaning of treatment and hospitalization. For example, 3 of 62 (5%) of the hospice patients made hospital visits for a condition that was unrelated to the terminal illness (e.g., broken bones). Two of 62 (3%) of the patients revoked hospice care to resume cancer treatment. Although all patients and families in this study elected hospice, decisional conflict was not necessarily resolved at the time of enrollment.

Hospice versus other programs. Hospice services were compared with or preceded by the use of other services in 26 of 62 (42%) of the hospice patients (cancer: 15/35, 43%; other: 11/27, 41%). Hospice services were utilized by 14 of 62 (31%) of the families to avoid nursing home care (cancer: 7/35, 20%; other: 7/27, 26%). Rehabilitation preceded the use of hospice care for 12 of 62 (19%) of the hospice patients (cancer: 5/35, 14%; other: 7/27, 26%). A daughter’s words describe her consideration of rehabilitation to build her mother’s strength before she came home, “They wanted her to go to rehab because she was so weak . . . I said ‘Mom, if you just get a little stronger I’ll take you home.’” When her mother could not participate in therapy because of weakness and advanced disease, hospice was engaged. Nine of 62 (15%) made the decision to use hospice instead of home health (cancer: 4/35, 11%; other: 5/27, 19%). A daughter illustrated how she compared hospice and home health care:

Now that I think about it, this was the key . . . we said “why don’t we take her home with home health care.” A social worker said “if you call a VNA and at 2 am when she is short of breath . . . they have to tell you to go to the ER. If you call Hospice in the same circumstances they will come.” Because she didn’t want resuscitation we chose Hospice.

Participants described weighing the pros and cons of choosing hospice particularly by comparing eligibility criteria for different programs, considering the hoped-for outcomes and services that best met their needs.

Deliberations.—Participants assessed the outcomes of the hospice enrollment decision and its effects on others. Deliberations about hospice enrollment involved consideration of (a) perceptions of the hospice approach, (b) caregiver role changes, and (c) privacy, autonomy, and control.

Perceptions of the hospice approach. The beginning of services from the hospice team was described as bringing immediate welcome relief for 30 of 55 (55%) caregivers (cancer: 15/35, 43%; other: 15/27, 56%). A patient’s wife described her sense of immediate relief by saying, “I picked up the phone and gave them the information. By the next morning, everything was happening. It was so fast and they were so good.” Similarly, a patient’s son described his father’s hope for hospice, “Hospice was a great relief. It took a load off mentally. He wanted the truth desperately and hoped that they would tell him what his life expectancy would be.”

However, uncertainty or distress from the entry of new professionals into their home and changed care routine was expressed in 24 of 54 (44%) of the interviews (cancer: 13/35, 37%; other: 11/27, 41%). The daughter of a hospice patient who was overwhelmed by the initial rush of activity described her perception:
I was grateful for Hospice, but when they first start, they bombard you with people. You’re overwhelmed with this disease to begin with, and you’ve got everybody coming here and it’s too much . . . and then when you get the comfort pack . . . I got hysterical over that.

A comfort pack is a combination of medications such as morphine and ativan that can be used to relieve symptom crises. Participants’ first perceptions of hospice were formed at times that were fraught with intense emotions.

Caregiver role changes. Over the trajectory of an advanced illness, caregivers assumed increasing responsibility for a loved one’s intensifying needs for physical care and emotional support. Forty-seven of 55 (85%) caregivers expressed feeling gratitude for the help they received with the changes in their caregiver roles through a version of the statement, “Hospice has been absolutely phenomenal.” However, a small number of caregivers who had been managing the person’s total care (6/55, 11%) renegotiated family relationships in the context of professional assistance (and expressed disappointment of guilt with a version of the statement, “I wanted to do it all”; cancer caregivers: 4/29, 14%; other: 2/26, 8%). A patient’s daughter describes her father’s negative response:

My dad, the guy who never changed a diaper was . . . amazing. Mom felt more comfortable with Dad and she wanted him to do it. He was against Hospice coming in. He felt he was giving up a task that had been assigned to him, which was to take care of her. I think there was a lot of guilt.

Two of 55 (4%) caregivers expressed dissatisfaction about the limited amount and frequency of the assistance and wanted more help with caregiving. Participants expressed responses ranging from relief to unhappiness about surrendering parts of the caregiving role.

Privacy, autonomy, and control. People who are in the end stage of a terminal illness lose the ability to manage the activities of daily living. The loss of privacy, autonomy, and control with the entry of hospice was expressed by 17 of 36 (47%) of the hospice patients (cancer: 9/35, 26%; other: 8/27, 30%). The loss of privacy resulted from the team’s regular oversight of the patient’s functioning. The loss of autonomy and control emerged from instructions for the caregiver to call the team with emergencies, not 911. The dialogue with a patient and his wife about the transition to hospice illustrated their perspectives on lost privacy,

Husband: If anything changes in my condition, I have to call them.
Wife: He has a hard time with that. They said if something is bothering him, they want to know. He gets cranky because he doesn’t think they have to know everything. But it’s for his benefit that they know what’s going on.

A patient’s wife expressed ambivalence about maintaining control by saying, “I want to be in control but I also want them to make sure I’m doing the right thing.” The transition from family-managed to team-managed care was not immediate but participants became accustomed to the new routine.

Adherence. — Adherence or the decision to continue utilizing hospice care was illustrated by four overlapping and not mutually exclusive themes: (a) reassurance and guidance, (b) needs met, (c) trust in hospice providers, and (d) increasing comfort.

Reassurance and guidance. Caregivers (26/55, 47%) gave specific examples of how the hospice team provided reassurance and guidance, particularly because staff is available by phone and in person if necessary 24 hours a day and 7 days a week (cancer: 14/35, 40%; other: 12/27, 44%). A participant expressed the sentiment by saying, “Knowing that they are there if it’s 2 am, is so reassuring.”

Needs met. Participants described the importance of having their needs for additional physical care, symptom management, information, and support met by hospice in 21 of 62 (34%) situations (cancer: 10/35, 29%; other: 11/27, 41%).

Trust in hospice providers. Examples of the special, endearing personal qualities of the hospice professionals that engendered trust were illustrated in 13 of 62 (21%) situations (cancer: 7/35, 20%; other: 6/27, 22%). A patient’s husband said, “It’s the sense of security I have that no matter what happens I can turn to these people to help and guide me.” The availability of professional assistance as needed was a key factor in families’ adaptation to hospice.
Increasing comfort. Comfort increased over time as participants got to know their team and visits became part of the routine in 24 of 62 (39%) of participants (cancer: 11/35, 31%; other: 10/27, 37%). A caregiver described her mother’s response:

At first she didn’t want all these people around interrupting her day. That attitude changed once she got people that she felt comfortable with. Now she’s fine with it and wants more.

Participants credited the team oversight as a central component of their adherence to the hospice enrollment decision; however, 2 of 62 (4%) of the families discussed revoking hospice service during the interview.

Discussion

In-depth semistructured interviews that focused on the dynamics of hospice decision making enabled 36 hospice patients and 55 caregivers to illustrate the factors that influenced their enrollment decision. Unexpected differences were found by diagnosis (cancer vs. other chronic illness) during the pre-encounter phase, but there were no differences after the hospice admission. The CTM of decision making offered an organizing framework for examining the elements of decisional conflict. The preliminary results of this exploratory study provide insight about how the end-of-life decision-making process may vary by diagnosis. These findings also underscore how individual dynamics define optimal hospice utilization and suggest the importance of disease-specific information to facilitate end-of-life decision making.

Diagnostic Trajectories

Cancer treatment is cure focused and clearly defined as chemotherapy, radiation, and/or surgery with distinct beginning and end points. The point at which cancer treatment becomes unavailable signaled the transition to the end-stage of the disease. Comparatively, the treatment of other chronic diseases is not cure focused, is less well defined, and involves the ongoing emergency management of symptom exacerbations such as shortness of breath or fluid accumulation. Neurodegenerative disorders have even less distinct parameters for treatment/management. The end of cancer treatment was a clear turning point associated with hospice enrollment but because symptom management in other chronic illnesses continued, there was no parallel hospice enrollment decision point.

The advanced stages of chronic illness were accompanied by intensifying—but different—challenges by diagnostic groups in this study. Advanced cancer was accompanied by steady functional decline and increasing symptoms of pain, fatigue, and debility that led to the need for assistance with distress management from hospice. In comparison, people with heart and lung diseases experienced symptom exacerbations and precipitous hospitalizations. This repeated cycle of crisis and recovery led to the recognition of treatment futility and consideration of hospice.

These preliminary findings build on and extend the literature about situation-specific end-of-life care. The trajectories of end-stage illness are known to vary by diagnosis and directly shape the experience of dying (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). People who are dying of cancer experience a sharp functional decline during the last months of life, whereas those who die of other chronic illnesses have a more gradual decline (Teno, Weitzen, Fennell, & Mor, 2001). The differential diagnostic trajectories of decision making found in this study support the need for guidance that is “titrated” at critical periods that vary with diagnosis (Goldstein, Back, & Morrison, 2008).

Hospice eligibility is determined by prognosis not by diagnosis. The results of this study suggest that misinformation about eligibility creates barriers to optimal hospice utilization. The theme of “prognostic eligibility” illustrates the common belief that hospice is only available for people who have cancer. The theme of “hospice availability” underscores the common misunderstanding that hospice care is only available for the last days of life. Both misunderstandings contribute to the underutilization of hospice care (Iwashyna & Chang, 2002; Teno et al., 2007).

Hospice Enrollment

Hospice admission brought a shift from cure-focused to palliative care. Participants weighed the pros and cons of relinquishing treatment/hospitalization. Although this transition was welcomed by 76% of the participants, this underscores the decisional conflict that remained for others. The decision to utilize hospice was a pragmatic straightforward comparison of the benefits and services to identify the most efficient way to care for a loved one in 42% of the families. Hospice enrollment involved the transition from family- to team-based care, and initial perceptions of this choice ranged...
from instant relief to unhappiness with some reluctance. The importance of this variation cannot be minimized; tremendous changes accompany end-stage disease and people are particularly vulnerable to intense emotions at this time. These findings build on and add to our growing knowledge of how caregivers accommodate to their role during the phases of an illness (Phillips & Reed, 2010; Prince-Paul, 2009).

**Limitations**

This study had several limitations. The data were cross-sectional and retrospective. Future longitudinal studies would yield important knowledge about how perspectives may change over time. The participation rate was low (24.8%) and 42% of the patients could not participate. This indicates missing perspectives and illustrates the fragile nature of late-stage illness, highlighting the challenges in end-of-life research (Hirschman et al., 2010). The ways in which study participants differ from those who declined participation is unknown. Only people who chose hospice were interviewed, suggesting the importance of a study about those who decline hospice. A majority of participants were White (97%). This reflects national disparities in hospice utilization and the need for additional research with both racially and ethnically diverse populations to further explore the similarities or differences that may exist in the transition to accessing hospice services (Lepore, Miller, & Gozalo, 2011; NHPCO, 2010; Schmid et al., 2010).

**Implications for Practice**

Gerontological practitioners play key roles in initiating conversations with older people and their families about their understanding of an illness and their desires for care. Discussions about the optimal timing and utilization of hospice are important across the trajectory of an illness, not just when treatment is no longer available (Goldstein et al., 2008). The number of people with noncancer illnesses who utilize hospice is increasing (NHPCO, 2010), suggesting the importance of recognizing how different illnesses can influence the nature and timing of end-of-life decision making. The optimal times for and lengths of hospice enrollment may be illness related. People make end-of-life decisions with their families; thus, better ways for guiding discussions about palliative care are needed. Preparing families for comprehensive home-based care can ease this transition. Privacy, autonomy, and control are essential elements of palliative care.

**Implications for Research**

The preliminary finding of difference in decision making between people with cancer and other chronic illnesses suggests the need for further focused exploration of the differences in decision making in congestive heart failure, COPD, and neurodegenerative disorders. Future study using a comparative design to explore differences in decision making by diagnosis would extend the understanding of the differential needs by illness trajectories. The development and evaluation of means for tailored communication that is diagnosis focused would enhance the effectiveness of family-provider communication at life’s end.

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