

# The Shift to Early Palliative Care: A Typology of Illness Journeys and the Role of Nursing

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For the current study, clinical observations of communication between patients, families, and clinicians during chronic, serious, or terminal illness in a cancer care trajectory were examined for patterns and trends. Five communication characteristics were concluded, which informed a typology of illness journeys experienced by patients with cancer and their families. The isolated journey characterizes an illness path in which communication about terminal prognosis and end-of-life care options are not present; communication is restricted by a curative-only approach to diagnosis as well as the structure of medical care. The rescued journey signifies a transition between curative care (hospital narrative) to noncurative care (hospice narrative), challenging patients and their families with an awareness of dying. The rescued journey allows communication about prognosis and care options, establishes productive experiences through open awareness, and affords patients and families opportunities to experience end-of-life care preferences. Finally, palliative care prior to hospice provides patients and families with an illness journey more readily characterized by open awareness and community, which facilitates a comforted journey. Nurses play a pivotal role in communicating about disease progression and plans of care. The typology presented can inform a structured communication curriculum for nurses and assist in the implementation of early palliative care.

**P**alliative care aims to relieve suffering and improve quality of life for patients with serious, chronic, or terminal illnesses and their families. The World Health Organization (2011) adheres to the belief that palliative care is intended for all of the seriously ill, not just the actively dying. In other words, palliative care is a large umbrella that shelters modern protocols of treatment (curative and noncurative in nature) in addition to hospice care services. Patients with advanced cancer often require palliative care services (Johnsen, Petersen, Pedersen, & Groenvold, 2009; Retornaz et al., 2007). A significant point of debate within the global medical community is *when* palliative care should begin in a patient's treatment (Ragan, Wittenberg, & Hall, 2003).

In the United States, a simultaneous care model has been proposed, which calls for life-prolonging treatment and comfort care throughout illness so that patients and families are supported through diagnosis and side effects of treatment (Ferrell, 2005; Meier, 2009). However, palliative care infrastructure is in

## At a Glance

- ◆ Patients and families are not appropriately referred to palliative care because of a lack of services and communication about it on the part of physicians.
- ◆ Nurses can and do play a pivotal role in facilitating patients and families to engage in early palliative care.
- ◆ A typology of illness journeys (e.g., isolated, rescued, comfort) will be helpful to nurses in identifying the characteristics of care that patients and families are encountering and communicating about the most appropriate care.

its infancy, leaving patients and families with no guarantee of exposure to this type of care. In the absence of widespread palliative care and the existence of physician hesitancy to discuss dying (Epstein, Korones, & Quill, 2010), patient and family illness

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journeys can vary greatly. Nurses can play a pivotal role in patient and family illness and care awareness by facilitating palliative care communication and supporting the conceptual shift to early palliative care (Malloy, Virani, Kelly, & Munévar, 2010; Villagran, Goldsmith, Wittenberg-Lyles, & Baldwin, 2010; Wittenberg-Lyles, Goldsmith, Ragan, & Sanchez-Reilly, 2010). The purpose of this investigation was to determine which communication characteristics influence early palliative care and how these shape the patient's and family's healthcare experience. The authors' goal was to highlight the issues with communication characteristics to inform the instrumental role of nurses.

## Nursing and Palliative Care Communication

To date, only 12,000 nurses have received training through the End-of-Life Nursing Education Consortium, which is a national education initiative to improve palliative care. Nurses do not receive prescribed palliative care training either in undergraduate education or as continuing education. As a result, nurses may lack sufficient knowledge and competency about palliative care, specifically about interdisciplinary care; patient and family decision making; psychosocial, spiritual, and grief counseling; and patient and family communication (Schlairet, 2009). Nurses report the following communication education needs: (a) talking with patients once they have received bad news, (b) talking with physicians about palliative care issues, and (c) talking with patients about spiritual concerns (Malloy et al., 2010).

Nursing communication most often is classified mistakenly as serving only the educational ends of patients and families (Puchalski & Ferrell, 2010). In reality, patients, families, and nurses encountering complex serious illnesses such as advanced cancer demand communication about spiritual, physical, emotional, and psychological needs (Ferrell, 2006; Ferrell & Coyle, 2008; Ragan, Wittenberg-Lyles, Goldsmith, & Sanchez-Reilly, 2008). Families and patients engaged in a curative-only treatment trajectory when a more appropriate plan of care is clinically indicated require specific communication strategies for delivering new information and reinforcing old information (Tamayo, Broxson, Munsell, & Cohen, 2010). However, nurses often are unprepared to support this role, causing them moral and emotional distress (Ferrell, 2006; Tamayo et al., 2010).

## Theoretical Framework

When working with palliative-appropriate patients and families (please see indications for referral compiled by the Center to Advance Palliative Care, [www.getpalliativecare.org/clinicians](http://www.getpalliativecare.org/clinicians)), nurses must negotiate communicating the concept of *awareness of dying*, as originally proposed by Glaser and Strauss (1965) (see Figure 1). During an illness, suspicion awareness arises for the patient and family when the patient receives indirect information about failing health via symptoms, conversations, treatments, the Internet, and other sources. From that point, the patient and family might move into a *drama of mutual pretense* (closed awareness) in which all parties agree

### Awareness of Dying

The type of awareness (open or closed) a patient and family have about terminal status, which has a significant impact on communication and care choices

### Drama of Mutual Pretense

When a patient, family, or healthcare professional knows the patient is dying but behaves and communicates as though he or she is not

### Hospice Narrative

The patient, family, and clinician embrace an open awareness of dying and death; relocation from curative-only care to include comfort care (e.g., hospice, palliative care); comprehension of terminal status

### Hospital Narrative

Communication behavior reveals a closed awareness of dying and death; suppressed comprehension of dying and a blinding emphasis on curative-only and restorative care

## Figure 1. Definition of Terms

Note. Based on information from Wittenberg-Lyles et al., 2010.

to behave as if the patient is not seriously or terminally ill (Glaser & Strauss, 1965). An open awareness, on the other hand, is one in which a patient's chronic or terminal status is understood and communicated (although not necessarily accepted) by the patient, family, and healthcare professionals. Nurses face the difficult task of addressing the dominating standard in U.S. culture—closed awareness—and communicating the hopeful new pathway of early palliative care interventions as detailed in the simultaneous care model (open awareness). Further understanding of the communication nuances of an illness journey will illuminate future directions in palliative nursing.

## Setting

To capture the illness trajectory for palliative-appropriate patients, the authors conducted field research at two sites: a hospital-based palliative care service at a veteran's hospital and an inpatient hospice setting in the midwestern region of the United States. The authors conducted hospital-based palliative care team observations from January 2006 to May 2007, when services were delivered to more than 150 patients per month. In this setting, palliative care is a consultation service provided by an interdisciplinary team composed of physicians, nurses, social workers, psychologists, and chaplains. From January 2008 to January 2009, the authors conducted inpatient hospice observations, including family meetings and routine visits with patients by physicians, nurses, social workers, and chaplains. The agency had 500 home admissions in 2008, and the average length of stay was 74 days.

## Methods

Two forms of data collection informed the current study. The first data set consisted of direct observational field notes and reflective observation note development performed at both research sites. Portions of these observations (i.e., conversational dialogue) were written verbatim given the slow speech rate of the patient participants. Descriptive sections of the observations

that identify patients' and caregivers' cases are summaries of notes collected in palliative care or hospice team and family meetings, semistructured interviews with palliative care or hospice team members, and patient, team, and family interactions.

The second data set consisted of longitudinal interviews with six family caregivers of patients diagnosed with cancer. In two cases, the patient and family caregiver were interviewed together over the course of two years. Caregivers were selected using a convenience sample to capture the trajectory of the care experience on diagnosis and prognosis. Interviews took place every three months from August 2006 to July 2009 and were structured by an interview guide that accounted for changes in an illness trajectory while providing advancing information on family and caregiver illness experiences in a cogent form.

Institutional review board approval was granted at the supporting institution and clinical settings and included participation in and tape-recording of family meetings. All people and places were deidentified. At both medical settings, the researcher attended rounds with the medical team for about six hours per week.

Team meetings were conducted in a conference room, where patient cases were discussed. After the meetings, the researcher participated in rounds with the team. Family members often were present at the patients' bedsides in their rooms. During the observations, the researcher would stand at the end of the patient's bed and write field notes. On average, family meetings lasted 20–45 minutes.

Data Analysis

A grounded theory approach, which is an inductive qualitative method that generates theory from data (Glaser & Strauss, 1965), was used to review the data sets collectively. First, the researcher constantly compared the field notes to the interview transcripts (Coffey & Atkinson, 1996). Second, staff and interviewee feedback was collected and themes were discussed and adjusted according to the feedback. Two members of the research team individually coded 20% of the observational and interview data into mutually exclusive categories. Inter-coder reliability was compared and was more than 0.85 on all categories; therefore, coding was the same across two coders about 85% of the time. The data then were jointly reviewed to determine differences, and the two coders derived strict coding criteria. Each coder independently coded about half of the data set and reviewed the other half of the coded set. Once data were categorized by themes, five communication characteristics were identified in the observations and interviews: (a) curative-only approach and the diagnosis, (b) the structure and communication of medical care, (c) productive experiences (open awareness), (d) embraced opportunities to plan for end of life, and (e) community. Concerning reliability, interdisciplinary team members at both sites discussed and further shaped researcher-identified themes through open conversation and confirmed patterns of communication in both data sets.

The five communication characteristics ultimately formed three different types of illness journeys, shaping the final results and understanding of the setting (see Table 1). Data saturation was verified by evidence of study findings within social media narratives from the National Family Caregivers Association (2010) and the Association of Cancer Online Resources. This

article highlights the role of nurse communication within each journey; additional analysis of the role of family within the journey is discussed elsewhere (Wittenberg-Lyles et al., 2010).

Typology of Family Journeys

Isolated Journey

The isolated journey is one in which communication about terminal prognosis and end-of-life care options is not present. Families are separated from palliative care, hospice, and

Table 1. Overview of Nurse Communication Within Illness Journeys

COMMUNICATION CHARACTERISTIC	NURSING COMMUNICATION
ISOLATED JOURNEY: THE ABSENCE OF HOSPICE AND PALLIATIVE CARE	
<b>Closed awareness</b> Curative-only approach to diagnosis  Structure and communication of medical care	Talk is limited to health education. Focus is on treatment and side effects only.  Discussions about care are linear and discrete. (Care talk is not connected to a global picture.) The focus is strictly biomedical. Little to no collaboration occurs among specialists.
RESCUED JOURNEY: RESCUE FROM THE ISOLATED JOURNEY THROUGH SUDDEN REFERRAL TO HOSPICE	
<b>Closed awareness transitions to open awareness</b> Productive experiences  Embraced opportunities to plan for end of life	Prognosis discussions are explicit. Education is provided about the physiology of dying.  The limits of medicine are acknowledged. Advanced care planning is discussed openly. End-of-life planning occurs (e.g., funeral arrangements).
COMFORTED JOURNEY: PALLIATIVE CARE AND THEN LATER HOSPICE CARE	
<b>Open awareness</b> Productive experiences  Embraced opportunities to plan for end of life  Community	Prognosis discussions are explicit. Education is provided about the physiology of dying.  The limits of medicine are acknowledged. Advanced care planning is discussed openly. End-of-life planning occurs (e.g., funeral arrangements).  Specialists collaborate. Family caregivers are involved (e.g., family meetings). Decision making is shared. Pain management is holistic.
Closed awareness—all parties agree to behave and communicate as if the patient is not terminally ill; open awareness—a patient's terminal status is understood and communication (although not necessarily accepted) by all parties	

any systematized professional discussion of death and dying, giving rise to communication complexities and making the terminal context even more tortured. Two communication characteristics give rise to this journey—a curative-only approach to diagnosis and the structure and communication of medical care.

A curative-only approach to diagnosis focuses solely on treatment as the plan of care, often leading to medical futility. Faced with a medical crisis and acting on an unrealistic understanding about a disease's trajectory, patients and, most particularly, families enter into a cascading flood of interventions that can range from diuretics to surgery to cardiopulmonary resuscitation—all of which are certain not to affect a curative turn in a terminal disease. Patients and families engage in a *drama of mutual pretense* (closed awareness of dying) in which the possibility of a noncurative trajectory never is acknowledged.

The structure and communication of medical care further mask opportunities for communication about end-of-life care and can fortify the hope for a cure. Hope can be preserved in the dually held understanding of a life-limiting illness while striving for a miracle and can motivate individuals in the isolated journey. In the following narration, maintaining hope becomes evident as the isolated journey unfolds. S.H. wrote about her son's brain tumor as they continued aggressive therapies in his fifth year of illness. Living with aggressive metastatic glioma since age 8, B.H. died at age 12, just days after the following letter was written.

He is sleeping right next to me, and just the sound of his breathing comforts me. . . . As I lay here tonight, I have to try and find the words that are somehow tangled up in my mind. First, [B.H.] IS A MIRACLE!!!!!!!!!!!!!! He has defied the doctors time and time again. Even in July of this year after looking at [B.H.'s positron emission tomography] scan, Dr. S said that B.H. should be incapacitated on a morphine drip already. Now, she is just blown away. And the fact that the big tumors are growing "out" rather than "in" means that B.H. is still here with us! Thank you, Lord! Oh, I still pray for a miracle. To wake up and see [his] head perfectly round I just believe God could do it if He so desired. God is still on His throne. [B.H.] is still His child. My heart is breaking tonight and yet I refuse to stop praying for a full-blown miracle. . . . Dr. S said today, "Only God knows the time for [B.H.], not man; isn't that true of all of us?"

For S.H., her son's breathing is proof of his potential for a miracle. That is the argument she builds through her letter to close relatives just days before his death. B.H. lived with advanced metastatic disease for years, and each moment of survival and hope was generated with the assistance of medical therapies and interventions. S.H. emphasizes that her son might be a statistical outlier ("He has defied the doctors time and time again") or the recipient of a miracle (e.g., direction of tumor growth, religious testimony of oncologist). In the isolated journey, the patient and family engage the illness biomedically with the help of highly skilled specialists primarily working independently of one another. Oversight of the general care of the patient appears to be absent.

## Rescued Journey

Families and patients are rescued from an isolated journey when they somehow acquire end-of-life care (which may include delivering a prognosis) and transition from cure to care treatment. This journey is characterized by a sudden referral to hospice, either through a primary or secondary care physician, another healthcare provider, friend, or even a family member. In hospice, productive experiences and embraced opportunities for communication emerge as talk about the prognosis is present, education about death and dying is provided, and staff members address the demoralization and damage incurred on the isolated journey.

To facilitate communication and transition to the rescued journey, patients and families must assimilate from the already known *hospital narrative* to an unfamiliar *hospice narrative*. In the *hospital narrative*, a closed awareness exists of the transition into care for the dying (Glaser & Strauss, 1965), which fuels the isolated journey and is made possible when medical staff, family, friends, and the patient agree to behave as though the patient is not dying. In contrast, the *hospice narrative* is characterized by an open awareness of death and dying. This narrative showcases an understanding and awareness of the relocation in care. Although the inherent focus on preventive or curative-only medicine assumes an active role in care among the living (hospital narrative), patients and families must learn to identify the role of caregiving for the dying (hospice narrative).

Productive experiences can transpire from open awareness about death and dying and communication that acknowledges the limits of medicine. In communicating a prognosis, two kinds of hope can align with the hospital and hospice narratives—the specific hope for outcomes (hospital narrative) and generalized hope for a nonspecific sense of hopefulness (hospice narrative) (Whitney, McCullough, Frugé, McGuire, & Volk, 2008). For many families, a terminal prognosis eliminates specific hope, yet a sense of nonspecific hopefulness can be found within the introduction and transition to hospice and the hospice narrative, which reassigns what patients and families hope for.

By acknowledging the limitations of medicine, patients and families can embrace opportunities for communication and end-of-life planning. G.R., whose father was dying from prostate cancer, vividly remembered first addressing funeral planning with his father.

Driving home from a doctor's visit, we passed along a funeral home. [Name] funeral home has been in our community for years. Dad had never set foot into it. He looked at me and said, "Well, I suppose they will do for my funeral, what do you think?" Devastated that he brought it up, I agreed that it would do. He looked at me and nodded, saying, "All right." Enough said.

Open awareness enables communication about preferences for end-of-life care and can ease decision making when a loved one becomes unable to communicate. Opportunities for conversations about patient preferences and goals of care arise when communication about the transition between curative care (hospital narrative) and hospice care (hospice narrative) are shared with patients and families.



Patients and families with a comforted illness journey are characterized by open awareness and communication.



**Patient:** Yeah, I'd like that [hospice]. I didn't want to stay here forever. I'd like to leave tomorrow. I'm going to discontinue my treatments now . . . But again, she's my right hand [referring to his girlfriend]. She's been with me all the time and helped me any way she can. And if she likes the idea then I say yes.

A sense of community between the palliative care team and the patient and his girlfriend was established through pain management, relational trust, open conversation, and addressing future needs. The team demonstrated cooperation with the patient's care needs by first addressing his pain and prioritizing symptom management. The team's ability to promise and then deliver pain relief builds trust with the patient, particularly if prior physicians have not been able to adequately address pain management. By relieving pain, the team is able to create an opening for discussing other care-planning decisions. Although the patient decided to enroll in hospice, the family meeting provided a venue for openly stating that decision to his girlfriend, who would handle the majority of care. The palliative care intervention allowed him to ask his girlfriend to care for him, without the burden of having to initiate the discussion on his own.

## Comforted Journey

The comforted journey includes the provision of palliative care on cancer diagnosis, enabling life-prolonging treatment and comfort care throughout illness until and if hospice referral is appropriate. Patients and families with a comforted illness journey more readily are characterized by open awareness and communication than the isolated or rescued journeys.

The comforted journey provides a community of professionals who make the experience of the patient and family their primary concern and transition them through the stages of care and dying. For many, palliative care offers a first chance for patients and family members to talk about what they know and understand about the illness, voice their concerns, ask questions, and engage in decision making as members of the healthcare team. An adult daughter and caregiver of a palliative care patient recalled the difference that palliative care made for her father's cancer care.

Dr. P [palliative care physician] would answer all of our questions and I think she was just impressed with how much we knew, so she would address us. The other doctor [oncologist] would barely even look at us. . . . By May, my dad was 150% better because he would go every two weeks or three weeks with Dr. P and Dr. X was the new oncologist and we also had the nutrition folks who would talk to us about the food.

The integration of a palliative care team alongside cancer treatment established a community within health care for the family. Most notably, the palliative care physician embraced the patient as well as the family. The family felt that their time and energy spent developing literacy on the topic was acknowledged and they were included ("She would address us"). By scheduling a family meeting, the palliative care physician enabled the family to take an active role in the physician-patient consultation.

The following example depicts how community (and comfort) is established in palliative care prior to the initiation of hospice. On initial consultation, the palliative care team found the patient in acute pain, unable to concentrate on any discussion. Following administration of adequate pain and symptom management, the team returned the next day to discuss placement for care. The patient and his girlfriend were sitting in the hospital family room when the team entered. The palliative care physician (M.D.) was the only one to speak from among the team members present.

**M.D.:** How are you feeling? Yesterday we talked about pain and I promised you today it would be a little bit better. Did I fulfill my promise?

**Patient:** Well, the pain is still there, but not so severe.

*M.D. initiates discussion and explanation about hospice.*

## Discussion

Although the current study is limited by its exclusive qualitative data collection at one hospice agency and by a veteran patient population, it expands knowledge on the different journeys of the patients with cancer and their families to provide an authentic and detailed global perspective of the communication characteristics that influence the journeys. Based on the observations, the authors identified three types of journeys: isolated, rescued, and comfort. The curative-only approach, as described in the isolated journey, is evidenced by the established pattern for families of adult patients with cancer to overestimate survival probabilities and opt for aggressive therapies (Weeks et al., 1998). Similarly, prior research also has found a trend among oncologists to overestimate patient prognosis and express overly optimistic views about how patients will fare the disease process (Matsuyama, Reddy, & Smith, 2006).

The isolated journey also is characterized by the structure of medical care, which requires patients and families to have high health literacy. Health literacy involves receiving or acquiring information, understanding that information, and then using it in decision making about health-related issues. Health literacy encompasses visual (e.g., graphs, charts), computer (e.g., Internet search), information-seeking, numeracy (e.g., calculations, statistical reasoning), and oral components (interpersonal), among others in concert to navigate the shifting waters of serious or terminal illness (Nielsen-Bohlman, Panzer, & Kindig, 2004). Individuals with low or marginal health literacy are more likely to prefer aggressive care at the end of life than those with adequate health literacy (Volandes et al., 2008). Low health literacy and high dependency on medical staff contribute to an isolated journey.

As articulated in the rescued journey, the struggle to shift from curative to noncurative cancer treatment is well documented by prior research (Lorenz, Asch, Rosenfeld, Lin, & Ettner, 2004; Meier, 2009). However, productive experiences can emerge when communication with patients emphasizes what can be

done for symptom control and emotional support, realistic goals are set, and day-to-day living is the focus (Clayton, Butow, Arnold, & Tattersall, 2005; Ragan et al., 2008). These discussions extend beyond medical facts and include the difficult task of addressing emotions and values and embracing opportunities to discuss end-of-life care with the family (Weissman, 2001).

The comforted journey, which situates palliative care at the point of diagnosis, actuates the simultaneous care model by establishing a patient-centered community of healthcare professionals united with the family. Candid communication about treatment options in line with patient and family goals leads to fewer aggressive life-sustaining medical interventions near death, as well as better overall bereavement experiences for the family (Zaider & Kissane, 2009). Palliative care as a precursor to hospice supports patients and families through diagnosis and side effects of treatment by focusing care on quality of life and patient goals (Ferrell, 2005). The comforted journey, the path the authors advocate for patients, families, and clinicians, satisfies the deficits described not only in the current study's data, but in existing literature on clinician communication and advanced cancer (Gibbins, McCoubrie, Alexander, Kinzel, & Forbes, 2009; Huskamp et al., 2009; Smith & Hillner, 2010; Zhang et al., 2009).

Communication is considered a fundamental care component in palliative nursing and medicine (Kennedy-Sheldon, Barrett, & Ellington, 2006). However, being communicatively present and demonstrating listening have been perpetually obscured in perceptions of nursing as commonplace and routine—considered naturally embedded in the nurse professional (Kagan, 2008; Shipley, 2010). Engaging communication about disease progression with physicians, families, patients, and the rest of the healthcare team continues to challenge practitioners and scholars in the field (Dalgaard, Thorsell, & Delmar, 2010), yet no programmatic communication-based initiative addressing early palliative care has been detailed in research calling for intervention. Various survey tools, such as the supportive care plan (Thompson-Hill, Hookey, Salt, & O'Neill, 2009), identify the need for communication support during the illness trajectory—not simply at the end of life. However, clinicians lack pedagogical preparation before facing the realities of on-the-job challenges.

## Implications for Nursing

Nurses share extended communication with patients and families that, in the circumstance of advanced cancer, positions them to further explain care options and prognosis (Malloy et al., 2010). The demand on nurses to communicate with patients and families in this most difficult context is enormous and underrepresented in textbooks, peer-reviewed works, and training (Ferrell & Coyle, 2008). This typology recognizes the presence and profound role nurses play in shaping the experience and care choice for patients with advanced cancer and their families. Beyond oncology and nursing, other clinical specialties often are placed in the role of navigating information with patients and families after the terminal prognosis initially is relayed.

The typology of illness journeys and corresponding communication characteristics offered in this article provide support for an evidence-based communication initiative to support nurses with appropriate curricula and implementation at the

undergraduate and graduate levels. As the End-of-Life Nursing Education Consortium currently is the only end-of-life communication training provided to nurses, the authors recommend integration of the current study's findings into the curricula to help refine communication training. If nurses and their instructors can articulate the patterns and behaviors in communication that reinforce the less-desirable isolated and rescued journeys and, conversely, those communication patterns and behaviors that facilitate engagement with a comforted journey (building community), communications then can be initiated and enacted through the role of the nurse. Future research is needed to understand the role of communication in nursing in serious, complex, and terminal illness; identify pivotal points for pedagogical preparation in communication; and develop undergraduate, graduate, and continuing nurse education curricula that address the communication exigencies at each level. To expand palliative care services to all patients and families, the healthcare community must begin by educating current and future clinicians about ways to talk about and introduce the simultaneous care model to ensure the best quality of life for patients and families.

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