Transitions and Shifting Goals of Care for Palliative Patients and Their Families

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According to the World Health Organization (2004), palliative care is “an approach to care which improves quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

Implied in the definition are myriad issues and transitions innate in the trajectory of a life-limiting illness; transitions that necessitate shifts in the goals of care. Transitions are ongoing processes characterized by change for an individual (Olsson & Ek, 2002). Examples of transitions experienced by palliative patients and their families are transitions (a) from cure to comfort care, (b) related to loss, (c) between care settings, and (d) of psychosocial and spiritual nature (Davies, Reimer, Brown, & Martens, 1995; Ronaldson & Devery, 2001). The transitions often occur concurrently and can be confusing and traumatic to palliative care patients and their families and close others (Ronaldson & Devery).

Nursing actions should be geared toward understanding and supporting patients through the transitions of illness (Olsson & Ek, 2002). What can oncology nurses do to support palliative patients and families as they journey through transitions? How can information be provided sensitively and accurately? The purpose of this article is to discuss the experiences of palliative patients and their families as they journey through transitions and how oncology nurses can provide support. Using a composite case study from actual clinical cases as a framework for discussion, the authors present examples of evidence-based strategies that can be used by oncology nurses. Critical points from the case study are:

- Adjustment to death is a process and cannot be rushed.
- The needs of a palliative patient and family should be heard, honored, and not questioned or challenged.
- A patient and family should remain in control of decision making, with the hospice and palliative care team acting as guides and facilitators.

Case Study: Transition to Palliation

Susan was a 46-year-old kindergarten teacher diagnosed with metastatic colon cancer. After unsuccessful treatment including participation in clinical trials, she; her husband, Jim; and children, Katie (age 20) and Matt (age 18), decided to focus on symptom management and quality of life. They completed an advance directive but declined hospice referral, stating that they did not want to think about death. They agreed, however, to meet with the palliative care advanced practice nurse.

Susan and her family did not want hospice care because they equated hospice with imminent death, rather than optimizing quality of life. Equating palliative care with death was a fear expressed by participants in a study describing the experience of transition from cure to palliative care (Ronaldson & Devery, 2001). The authors of the study described the experience from the perspective of patients and nursing staff and identified four major themes.

Pace and Timing

Patients and nurses believed that insufficient time existed to really consider and think about palliative care. Referral to palliative care often was suggested to patients within days and sometimes hours of their deaths. Participants in the study described how they were asked to decide whether they wanted palliative care when...
they were undergoing tremendous physical changes. At times, they felt that they were not included in the decision making and that their illness experience overtook their personal choice. However, skilled introduction to palliative care and adequate information about illness and services were important issues in helping them through the transition process. Other research studies have suggested that honest information about patients’ condition and options is extremely important to palliative patients and their families (Duggleby & Wright, 2004; Fallowfield, Jenkins, & Beveridge, 2002).

Fear and Misunderstanding

Patients and nurses described their own fears that palliative care meant imminent death, resulting in a reluctance to accept palliative care services. Some patients were very fearful, whereas others had no idea what the term palliative means. Patients’ fear of palliative care was short lived once they spoke with hospice staff members who were respectful, attentive, and caring.

Accepting Palliative Care

From feelings of fear and acceptance, patients spoke of their hopes for the future within the experience of transitions and deteriorating health. During the transition from cure to comfort, a shift of hope and expectations also occurred on the part of the patients interviewed. The shift in hope has been described in other studies on hope in palliative care patients (Benzein, Norberg, & Saveman, 2001; Duggleby & Wright, 2004; Herth, 1990). Terminally ill patients described shifting their focus from hope for a cure to hope for not suffering, living life to the fullest until they die, a peaceful death, and the future for their families.

Information About Palliative Care

Few participants described having access to information about palliative care until they met with hospice nurses. Although booklets and other sources of information were available for patients and acute care nurses, participants in both groups said that they were not aware of them. This made the nurses hesitant to approach patients and families about palliation.

Information about advance care planning remains scarce despite the requirement that healthcare organizations must ask patients if they have executed an advance directive (Hammes & Briggs, 2002). Although advance care planning may result in the completion of a directive or other document, discussion about goals of care, probable disease trajectories, and individual definitions of quality of life is far more valuable. Research indicates that as many as 50% of people cannot make their own decisions when they near death, and significant others often do not know their loved ones’ views without such a discussion. Most importantly, healthcare professionals traditionally continue to treat when uncertain about a person’s wishes (American Health Decisions, 1997; Covinsky et al., 2000; Mezey, Teresi, Ramsey, Mitty, & Bobrowitz, 2000). Nurses are in a key position to broach the topics of disease progression, goals of care, and quality of life and should be familiar with individual state advance directive laws.

In the case of Susan and her family, the nursing staff asked the advanced practice palliative nurse to visit them. The framework of care used by the palliative nurse in this case was

- Respectful listening and gentle exploration, with honest explanation of the options (including hospice and palliative care)
- Discussing what illness means to Susan and her family
- Discussing issues related to advance care planning (i.e., what “living well” meant to them)
- Gaining a clear understanding of Susan’s and her family’s goals, hopes, and needs

After a meeting with the advanced practice nurse, Susan and Jim agreed to a referral to the local hospice program.

Case Study: Transitions Related to Loss

Susan’s symptoms of pain and nausea were well controlled, but she was becoming increasingly weaker. Still working as a teacher, she believed that she needed to turn her attention to preparing her students for her departure from the school where she had taught for 21 years. As her farewell gift, her fellow teachers, students, and parents gave her a cruise vacation for her and her family.

Susan’s symptoms were controlled, except for fatigue. Although vigilant assessment and treatment of symptoms are standard for nursing practice in palliative care (Dahlin & Lentz, 2002), most research on symptoms in palliative care has focused on pain management. Very little published research has examined managing fatigue in palliative patients (McKinnon, 2002).

Susan was unable to continue working because of functional decline related to weakness. The inability to do things has been found to be a major concern for palliative patients (Maguire, Walsh, Jeacock, & Kingston, 1999). The transition to nonworking status resulted in a number of losses for Susan, such as role loss as a teacher and loss of relationships. The experience of loss for palliative patients is a major cause of suffering (Daneault et al., 2004). Palliative patients maintain hope primarily by shifting their expectations (Duggleby, 2000). In Susan’s case, the cruise became a symbol of hope. In recognition of this, her physician and hospice team shifted the goals of care. At that time, the framework of care for Susan and her family became

- Facilitating and honoring her wishes to go on the cruise despite her progressive illness and weakness, although her physician and hospice team believed the trip was inadvisable
- Advocating for her with the airline and cruise company and communicating with the physician and nurse on the ship as needed
- Encouraging Susan to spend time alone with each of her children on the cruise
- Susan and her family had a wonderful time on the cruise. She spent time alone with each of her children and returned believing that they would be all right after she died. She also prepared a tape on which she read her favorite children’s stories for hoped-for grandchildren.

Case Study: Transitions Between Care Settings

As time went on, Susan became progressively weaker. She also required brief hospitalization for a reversible bowel obstruction. After the hospitalization, she and her husband decided that they did not want any more hospitalization for any reason.

Movement of terminally ill patients among care settings compromises continuity of care (Sahlberg-Blom, Ternestedt, & Johansson, 1998). In a study of continuity of care for 56 palliative patients, 67% were cared for at two different sites and 9% were moved two to five times among three different sites during the last month of their lives (Sahlberg-Blom et al.). Other studies have suggested that when palliative patients are hospitalized, they receive nonpalliative treatments such as cardiopulmonary resuscitation, diagnostic tests, and antibiotics (Ahronheim, Morrison, Baskin, Morris, & Meier, 1996; Middlewood, Gardner, & Gardner, 2001; Warren, Emmett, Zinn, & Warren, 2002).

One outcome of transfers in and out of hospitals for palliative patients is a sense of loss of control. Maintaining a sense of
control is important to palliative patients (Volker, Kahn, & Penticuff, 2004). In a qualitative study of seven palliative patients with advanced cancer, participants described the importance of maintaining a sense of control (Volker et al.). Control involved decisions about treatment choices and how remaining time was spent, protection of dignity, and control over the dying process. Understanding this, the hospice team caring for Susan shifted goals of care to
• Revisiting Susan’s wishes in the context of her declining strength, understanding that she may have goals to accomplish before she died
• Supporting the concerns of Jim and the children when discussing how Susan’s illness may progress.

Case Study: Psychosocial and Spiritual Transitions

Susan continued to decline and became bed bound. She wanted her family to be involved in her care without outside visitors. When the hospice nurse was visiting, Susan shared her thoughts on the meaning and purpose of her life. Susan asked the nurse what she thought happened when someone died.

Examples of psychosocial and spiritual transitions are evident throughout this case. Other sections of the case study have discussed hopes and expectations and the importance of feelings of control. The issues became increasingly important to Susan and her family as she neared death.

Susan wanted to spend her time with her family. The wish to spend most of the remaining time at home with family was expressed by 77 palliative patients in a study exploring the experience of life-threatening illness (McSkimming et al., 1999). Spending time with people who are supportive has been described as a factor in decreasing suffering (Duggleby, 2000) and increasing hope at the end of life (Duggleby & Wright, 2004).

Spirituality, defined as finding purpose and meaning in life, is very important to palliative patients (Greisinger, Lorimor, Aday, Winn, & Baile, 1997). Phases of spirituality as described by palliative patients include reflecting on what is happening, focusing on relationships, and finding meaning in life (Thomas & Retas, 1999).

Listening to Susan, the hospice staff
• Asked whether Susan would like a visit from the hospice chaplain or clergy of her choice
• Encouraged Susan to reflect on her life and find meaning by sharing her thoughts with staff
• Provided Susan’s family with information and support to enable active involvement in her care
• Assisted the family in dealing with friends who wanted to visit by assigning a close friend to act as a contact person and establishing an e-mail list serve for updates.

Susan agreed to see the hospice chaplain because she had met him when she was admitted to hospice care. The chaplain was able to help Susan and her family discuss and decide on funeral and memorial arrangements.

Susan died early in the morning while her husband and children held her. The family was so well prepared for her death that they did not feel the need to call the hospice nurse until each of them had the time alone with her that they wanted. The family then helped to bathe and dress her in her favorite T-shirt and jeans, also her wish.

The goals of care shifted again as Susan neared death, and her family was engaged in her care. Her family began to prepare for her death and their grief experience by participating in early grief work and honoring Susan’s wishes.

Critical Points in the Case Study

In the case study, Susan appeared to progress smoothly through transitions by shifting the framework of care. Many palliative patients and families do not experience a smooth transition. However, Susan’s case and the discussion of shifting goals of care illustrate how oncology nurses can facilitate transitions.

Critical points in this case study and for shifting goals of care are
• Adjustment to death is a process and cannot be rushed. It is different for everyone.
• Susan and her family’s needs were listened to, honored, and not questioned or challenged.
• Susan and her family remained in control, with the hospice and palliative care team acting as guides and facilitators.

Caring for people and their families at the end of life is truly a privilege, arguably one of the most crucial roles for a nurse. It is, indeed, the essence of nursing. Close attention to individual needs and perspectives during this important time is critical so that dying people and their families can live life, maintain hope, and focus on relationships on their own terms.

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References


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- Although transitions can be traumatic for patients and their families at the end of life, nursing actions can be geared toward understanding and supporting people through transitions.
- Examples of transitions include cure to comfort care, transitions related to loss, changes between care settings, and psychosocial and spiritual transitions.
- Adjustment to death is a process.
- Hospice and palliative care patients and families should remain in control of decision making, with the healthcare team acting as guides and facilitators.


