

# 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

Terminally ill patients and their families experience many confusing and, at times, traumatic transitions. Examples of such transitions include transitions from cure to comfort care, transitions related to loss, changes in care settings, and psychosocial and spiritual transitions. 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.

and their families as transitions and goals of care change and how oncology nurses can provide support. A composite case study from actual clinical cases will provide an illustrative framework for the discussion.

## 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

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