

Description of an Australian Model for End-of-Life Care in Patients With Hematologic Malignancies

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Purpose/Objectives: To present a model for end-of-life care in adult hematology that has been developed from nursing insights.

Data Sources: Insights obtained from 25 nursing interviews during a two-year, qualitative, Australian National Health and Medical Research Council research study.

Data Synthesis: The nursing insights indicate that an understanding of end-of-life care in hematology needs to be set in a trilogy of overlapping models (labeled functional, evolving, and refractory) that address the complexity of issues associated with professional and hospital culture.

Conclusions: The authors have used the findings of their national research study to develop a useful, working model to assist with the integration of palliative care into adult hematology.

Implications for Nursing: The model develops a new language for understanding and fostering the integration of palliative care and hematology.

During the past decade, increasing research evidence has indicated that the discipline of palliative care, recognized as excellence in end-of-life (EOL) care, is not integrated adequately into adult hematology. Research on the experience of patients dying from hematologic malignancies has indicated that they are most likely to die in care environments where the goal is cure, exposed to an escalation of invasive technology, aware that they are dying but with no knowledge of or referral to palliative care, in hospital situations that are not designed to be responsive to the support or spiritual needs of terminally ill patients and their families (Hunt & McCaul, 1998; Maddocks, Bentley, & Sheedy, 1994; Mander, 1997; McGrath, 1999c, 2001b, 2002a, 2002d; Shapiro et al., 1997; Stalfelt, Brodin, Pettersson, & Eklof, 2001). In the United Kingdom, patients with leukemia, lymphoma, or myeloma are unlikely to receive community-based palliative care services (Addington-Hall & Altmann, 2000). A high proportion of caregivers of such patients suffer post-traumatic stress related to their experiences and are left unsupported to deal with regrets and spiritual pain (McGrath, 1999d, 2002b, 2002c, 2002e).

The difficulties are compounded for patients who have to relocate from regional, rural, and remote areas for specialist treatment because they often are separated from their support networks of family members and friends and have to re-establish contact with their support networks when they return home after treatment (McGrath, 1999a, 1999b, 2000b, 2001c, 2001d).

Key Points . . .

- ▶ The factors that facilitate the successful integration of palliative care in hematology include an openness to addressing death and dying; leadership supportive of palliative care; positive staff experiences with dying; best-practice end-of-life care; a realistic and sensitive understanding of hope; a democratic, collaborative, and inclusive staff organization; appropriate and timely involvement of palliative care services; and confidence in dealing with issues specific to hematology.
- ▶ The factors that deflect integration of palliative care in hematology include denial of death and dying; negative leadership attitudes toward palliative care; lack of positive end-of-life experiences; an absence of best-practice terminal care; a simplistic approach to hope; a medicocentric, paternalistic, and hierarchical organization; delayed referral; and fear and avoidance of issues specific to hematology.
- ▶ The varying professional perspectives, rather than the unique circumstances of hematology, create the difference between services that do or do not integrate palliative care.

Initial Response: A Pilot Case Study

McGrath and Joske (2002) used a case-study approach to identify and document one instance where palliative care was integrated successfully into the treatment of a patient with a hematologic malignancy, in an effort to begin to address the concerns raised by the documented lack of palliative care integration in adult hematology. The case study showed that patients with hematologic malignancies could experience all of the satisfactions of dying at home that usually are associated with hospice care, including the intimate sharing with close family and friends and the respect and dignity that can be afforded to patients in their own homes.

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