

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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The positive outcomes documented through the case study included a strong sense of satisfaction and closure for the patient and his family; the family was left with a sense of rightness about their decision making and a deeply felt sense of having made every effort to fulfill the needs of the dying patient. An orientation toward living rather than dying pervaded the experience for the family.

Post-traumatic stress, regrets, and spiritual pain, the more expected outcomes of terminal care in hematology, were not evident in the case. The caregiver was left well supported and nourished by the experience—a firm foundation for coping with the challenges of bereavement. The positive outcomes from the case study pointed to the possibility of effective integration of palliative care into hematology and, thus, indicated a need to extend the work to a national study.

Consolidating the Model: A National Study

Because research to date has been built on insights from consumers (McGrath, 1999c, 2000a, 2001a, 2001b, 2002a, 2002c, 2002d; McGrath & Joske, 2002), the researchers sought funding to complete the cycle by integrating the experiences and insights of the full multidisciplinary range of healthcare professionals involved in adult hematology. The Australian National Health and Medical Research Council funded a two-year national study to establish a model for EOL care in adult hematology. Representatives from the nursing profession were key participants in the study. Nursing participants, including nurse practitioners, managers, and educators, were enrolled from acute care hematology wards and palliative care services of public and private hospitals in a diversity of geographic locations in three separate states in Australia. The nursing data collection and analysis are complete. Data saturation has been reached on all issues that nursing participants identified as significant; that is, no new insights on the same issues would be uncovered by interviewing additional participants.

The following discussion provides an overview of a model for successful integration of palliative care into adult hematology developed from the insights of the nursing participants in the study. Because the data collected are rich and extensive, the discussion provides only a summary of the major issues. The full empirical findings will be published separately in articles dealing with the significant themes.

Model Development Process

The full details of the multidisciplinary sample of participants in the study are published elsewhere (McGrath & Holewa, 2006). Ethical consent to conduct the study was obtained from the Central Queensland University (CQU) Human Research Ethics Committee and the ethics committees of all of the hospitals participating in the study. Participants were informed verbally of their rights in research, and written consent was obtained for participation.

Data Collection

Data were collected through an iterative, phenomenologic, qualitative research methodology using open-ended interviews conducted at the time and location of each participant's

choice. A researcher interviewed 25 nurses (21 acute care and 4 palliative care) from nine hospitals, public and private, in three states in Australia (Queensland, Western Australia, and Victoria). The criterion for selection: Each nurse was presently working in a clinical situation, either acute or palliative, that involved the care of patients with hematologic malignancies.

The interviews were conducted by a psychosocial researcher who had a background in hematology and was employed by CQU; thus, the interviewer was independent of the hospitals. The participants were encouraged to talk about their experiences with hematology and to describe factors they considered important to include in a model for EOL care. The interviews were informed by the principles of "phenomenologic reflection" as outlined in the work of Van Manen (1990). The line of questioning included the techniques of probing, paraphrasing, and silence to explore participants' experiences (Gaskill, Henderson, & Fraser, 1997). The interviews lasted for approximately one hour each and were recorded on audiotape. A research assistant independent of the hospitals transcribed the interviews verbatim.

Analysis

The language texts were entered into the QSR NUD*IST (Qualitative Solutions Research, Melbourne, Australia) computer program and analyzed thematically. All of the participants' comments were coded into "free nodes," or category files that have not been preorganized but are freely created from the data. The list of codes was transported to Microsoft® Word® (Microsoft Corp., Redmond, WA) and organized under thematic headings. The coding was established by an experienced qualitative researcher and completed by a team of two research assistants with extensive experience coding qualitative data. Having worked together on many major national grants, the experienced team has developed a highly refined process of coding all statements into free nodes labeled with names that reflect participants' statements. Through the process, the coding captures participants' meaning as closely as possible and does not try to theorize. The original codes were established by the qualitative researcher as the starting point for the team, who added further codes as necessary. Constant checking and comparing of coding labels occurred throughout the process to ensure coding agreement. The team reached complete agreement on the coding and emergent themes. The nursing transcripts created 238 free nodes, which form the basis of the model presented in this article. The themes then were diagrammatically translated into a visual model, as outlined in Figure 1.

Peer Review of the Model

The model was reviewed by expert audiences in hematology, oncology, social work, palliative care, and acute medical care in Australia (McGrath 2005a, 2005b; McGrath, Joske, Holewa, & Fournier, 2005). In addition, the model was reviewed through two teleconferences, the first with a panel of nine professional experts in the area of hematology and the second with eight consumers. The process involved the presentation of the model to reviewers, stimulation of discussion about the model, and feedback from participants. The model was affirmed enthusiastically by all of the groups, who indicated that the insights resonated with the reality of healthcare professionals' experiences in hematology.

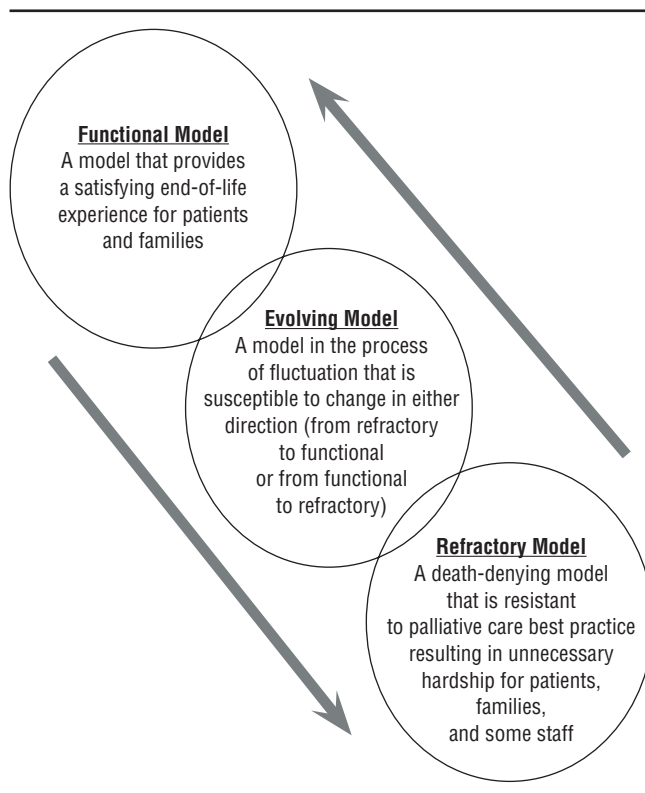


Figure 1. The Model of Care

The Model

As outlined in Figure 1, an understanding of EOL care in hematology needs to be set in a trilogy of overlapping models that address the complexity of issues associated with professional and hospital culture. Leininger (2001) defined culture as the learned common and transmitted values, convictions, norms, and ways of life that direct people's patterns of thinking, decision making, and actions. For example, hospice is described as a specific care culture with a humanistic base and set of values reflecting the meaning of life and death, whereas the cure-oriented biomedical culture usually does not take existential or spiritual issues into consideration (Andersson-Segesten, 1989; Hermansson & Ternstedt, 2000; Ternstedt, Andershed, Eriksson, & Johansson, 2002). As Andershed and Ternstedt (2001) concluded, the manner in which staff members act toward a patient and relatives influences the patient's possibility for appropriate death, the relatives' possibilities for involvement, and the possibilities the staff have to give good care.

At the positive end of the continuum, extensive texts by nurses described experiences and practices indicating the appropriate integration of best-practice palliative care into the acute hematology setting. The insights into the positive practices were labeled the Functional Model and, by definition, include an overview of processes that ensure satisfying terminal care for patients with hematologic malignancies and their families. At the other extreme were extensive texts by nurses describing factors that blocked appropriate referrals to palliative care. The latter model was labeled the Refractory Model. Both the functional and refractory insights are posited from participants' professional experiences and

are accompanied by anecdotal details. As such, the model reflects a summary of the wide diversity that presently exists in Australian hematology departments.

Linking the two polarities of the Functional Model and the Refractory Model are descriptions of the factors that create the possibility of change, labeled the Evolving Model. Depending on the particular factors that come into play in a culture, the evolution can be either in a constructive direction (from the Refractory Model toward the Functional Model) or can be a negative change (from the Functional Model toward the Refractory Model).

Changes between the functional and refractory paradigms can occur relatively quickly as the result of a change in management or culture. For example, if a hematology unit appoints a new hematologist with knowledgeable and respectful attitudes toward palliative care service provision as department head, the leadership may be able to influence a previously refractory hospital culture toward openness to best-practice EOL care. Conversely, a change of leadership to a department head who is not comfortable with death and dying issues can undermine the efforts of medicine, nursing, and allied healthcare professionals committed to integration of palliative care.

A prerequisite for successful palliative care practice is a positive cultural acceptance of the ideas. According to the evolving model, even nurses who bring experience in palliative care will not be able to work effectively in a refractory culture and will have to modify their practice. Similarly, palliative care teams on acute care wards can be instrumental in creating positive change or can be thwarted in their attempts by a refractory situation. Nurses noted that the personality attributes of palliative care staff are important in this regard; staff members able to patiently establish rapport and build satisfying collegial relationships are more likely to be catalysts for constructive change. Conversely, examples were provided of less-satisfying experiences with palliative care staff, such as criticisms that acted as obstacles to referrals to palliative care.

The nurse participants indicated that baccalaureate and graduate courses in nursing increasingly are addressing palliative care philosophy and practice in course material, so new graduates who are confident in their understanding and clinical skills in terminal care are among the significant agents for change. However, the nurses said that enthusiasm and insights of new graduates can be thwarted by the power structure of seniority in clinical settings.

Palliative care practice indicates the importance of early, positive experiences with patients receiving palliative care on acute hematology wards. If palliative care experiences are successful and demonstrate positive outcomes for patients and their families, those unsure of the value of such EOL care will be open to further involvement. Unfortunately, early, negative experiences can create obstacles to further referrals to palliative care.

The Mirror Image: Same Issues, Opposite Perspectives

The nurse participants' statements, which formed the basis for the Functional and Refractory Models, are mirror images of each other, created by a distorted mirror that reflects the image of the same issue but is accompanied by the opposite attitudes or practices (see Figure 2).

Functional Model

Issues of death and dying are addressed openly and sensitively.

"All you can do is give them all the options and give them all the information, be honest."

"I just think, let's start talking about it, and most people, when you do, are actually fine with it."

Leadership—positive attitudes toward palliative care

"Most of the doctors acknowledge the fact that you have that knowledge [of palliative care], and if you ring them, and if you're concerned, they'll let you go with it. So I think we're lucky in that respect where we work."

Positive experiences with palliative care

"Our consultant's absolutely fantastic—our palliative care one. And he delivers news in such a way that it is magic. It is beautiful to watch. I have never seen anybody do it in such a way that he has been able to do it. I think that they need that sort of experience as well, and it is not something that you can just learn, I understand that, but you get better at it the more often you do it."

Best-practice end-of-life care

"I think it's important that the nurse very much stays as the patient advocate."

"It's all in communication, isn't it? Everything is communication."

Hope—complexity understood

"There's always hope in giving them quality of life."

"We are honest about it and not giving false hope."

"The hope button, that won't actually help them deal with it."

Organizational issues—democratic, collaborative, and inclusive

"There has to be a healthy respect between all members of the collaborative team, an acknowledgment that each member has a role to play and no one person is any more important than the next one."

"We have a lot of autonomy as nurses; we do a lot of referrals."

"We are a functional, very well-supportive group of people. We support each other quite well. I don't ever feel burned out."

Appropriate and timely involvement of palliative care

"To bring palliative care into the forefront early on in everybody's treatment. So suddenly going off to palliative care area is not a death sentence, it is just a continuation of care from day one. Our hematologists actually refer earlier on than medical oncology. And that is just the way it is, and it is fantastic."

Integration of cure and palliation

"I think that the pall [sic] care team should be just part and parcel naturally of any of these types of conditions. They have a role to play throughout the disease health continuum. They often have valuable input right throughout. And they should be involved right throughout."

Specific issues regarding patients with hematologic malignancies are addressed.

"Palliative care would be quite capable of managing hematologic patients. Palliative care basically are quite capable of doing things like assessing and ordering blood transfusions to help manage fatigue, especially where anemia is an issue."

Refractory Model

Issues of death and dying are denied.

"So it is really a cure culture even though the writing's on the wall."

"What we do is cruel, but it's not nice, put it that way. And then you try and make an 80-year-old go through that."

Leadership—negative attitudes toward palliative care

"And so you have a system where you can't have palliative care coming in because they don't want to stand on the hematologist's toes, so trying to get the lamb and the lion together is very, very hard."

Lack of positive experiences with palliative care

"It's really important for the palliative care doctors to educate and educate in the way that they can help the hematologist understand this is a really positive process. It's not giving up or it's not a soft option. It's actually a positive, strong option."

Lack of best-practice end-of-life care

"I think there are a core number of us who time and time again think, 'What are we doing?' And it is an ethical issue, we're not at ease with it, and it just makes you feel like you're not doing the best for the patient. And you're just not doing the best for the profession either; it's just all wrong. And you just wish that somebody would listen to you."

Hope—simplistic, black-and-white understanding of "hope equals cure"

"You can't [introduce palliative care] because you would take away their hope."

"They're not offering hope of cure, then they are not offering hope."

Organizational issues—medicentric, paternalistic, and hierarchical

"But I still think that it's still very much the nurse is seen as the handmaiden and the doctor still as the paternal father."

"I've been told that can be a bit of a medical territory issue. It's got to do with the pecking order, and palliative care is down on that pecking order, rather than just realizing that that's multidisciplinary team approach, that's all about patient needs."

Lack of appropriate or timely involvement of palliative care

"Because we are too busy treating them without actually saying 'Maybe it is time to pull out,' let them die peacefully and without this myriad of machinery and technology, and where do they want to die?"

Lack of integration of cure and palliation

"It's very territorial."

"Palliative care are not utilized enough for the knowledge and the experience and skills they have."

Specific issues regarding patients with hematologic malignancies are seen as an obstacle.

"I would be reluctant to be giving a blood transfusion at home by myself. And I think a lot of nurses are reluctant to do that."

Figure 2. Same Theme But Opposite Beliefs and Practices

Issues of death and dying: Although considered difficult, the issues of death and dying are handled openly and sensitively in the Functional Model. Honest information giving and communication skills are valued. Thus, patients and their families are given information to make informed choices about EOL care and are assisted with the difficult process of coming to terms with the terminal trajectory.

By way of contrast, the Refractory Model is death denying. The focus remains on cure, and patients and families are not

assisted with the difficult work of coming to terms with life-threatening prognoses.

Leadership: In the Functional Model, those with decision-making power are informed about the philosophy and practice of palliative care and support such EOL best practice on the ward. However, nursing participants indicated that, in the Refractory Model, hematologists are uninformed about palliative care and hostile to its integration into the care continuum.

Experience with palliative care: In the Functional Model, nurses provided vignettes of their positive experiences with palliative care service providers and talked about how the experiences provide role models for the quality of care that can be achieved. In contrast, nurses in the Refractory Model conveyed their lack of positive experiences with palliative care, which demonstrated that a significant obstacle to be overcome in moving from a refractory to a functional situation is an understanding of the importance of palliative care. Giving nurses the opportunity to have direct exposure to the provision of palliative care likely will assist in increasing their understanding of the benefits of effective palliative care.

Best-practice end-of-life care: Throughout discussions with nurses whose insights contributed to the development of the Functional Model, extensive references were made to satisfying experiences with best-practice EOL care that fostered patient advocacy, choice, and communication. Hematology is different than other oncology areas because of the many therapeutic options with varying degrees of efficacy that can be offered to patients along the continuum from cure to palliation. For this reason, ongoing honest and clear communication was noted as essential at all points of the disease and treatment trajectory to ensure that patients and their families are aware of issues relating to prognosis and the possible side effects of treatments.

The direct opposite was recorded in the nursing text in the Refractory Model. Instead of statements of practice satisfaction, lengthy texts described the stress of working in situations that were not patient centered and did not respect quality-of-life (QOL) issues. Thus, in the Refractory Model, nurses whose insights informed the Refractory Model reported a sense of being ethically compromised because of their involvement in administering treatments to patients who were unaware of and unprepared for the seriousness of the side effects, with unrealistic expectations of cure and with QOL seriously compromised.

Understanding hope: The understanding of the phenomenon of hope has a richness and complexity in the Functional Model and changes over time. Hope is related to an array of QOL issues, and a firm distinction is made between realistic and unrealistic hope in terms of prognosis and treatment. Providing unrealistic hope to patients is referred to as the “hope button” and is perceived as problematic because it interferes with the transition to palliative care.

The opposite of this understanding of hope is posited in the Refractory Model. Hope is simplistically seen in black-and-white terms as being solely about cure. Such an attitude about hope drives an unrealistic optimism and pressure to be positive, which inhibits patients and their families from dealing with significant EOL issues.

Organizational issues: The description of organizational issues in the Functional Model highlights satisfying aspects of hospital culture. The nurses reported feeling respected working in democratic, collaborative, inclusive work environments. The polar opposite was described in the Refractory Model: The hospital culture was described as driven by medicocentrism, paternalism, and hierarchical power. In such a system, hematologists who are not sympathetic to palliative care philosophy and practice are seen as gatekeepers thwarting access to the palliative system. This is viewed as a hierarchical system based on “pecking order” rather than democratic, multidisciplinary team work.

Appropriate and timely involvement of palliative care: In the Functional Model, the palliative care team is involved from the early stages of treatment, often for pain and symptom management, and so members of the team have the opportunity to build positive relationships with patients and their families before the dying trajectory, which helps to lessen the dichotomy between curative treatment and palliative care services. In the Refractory Model, the focus is maintained on cure; the palliative care team has no involvement, or the involvement is too late for constructive outcomes.

Integration of cure and palliation: In the Functional Model, participants indicated an integration of cure and palliation, with the palliative care team respected and included as part of the multidisciplinary team. By way of contrast, the Refractory Model had no integration; territorial issues dominated. The ongoing curative approach focuses on the minutia of daily clinical concerns rather than stepping back and viewing the significant implications of EOL issues.

Specific hematology issues: A number of clinical issues exist in terminal care specific to patients with hematologic malignancies, such as the need for blood products, the problem of catastrophic bleeds, and the significant side effects of treatment, such as graft-versus-host disease after allogeneic blood or marrow transplantation. The findings of the model show a mirror reflection in terms of how the professional and hospital cultures respond to such issues. In the Functional Model, participants spoke with enthusiasm about the clinical strategies used to address and overcome the special clinical issues. For example, descriptions were given of protocols for dealing with blood products and catastrophic bleeds during inpatient and home-based care. In contrast, the Refractory Model framed the special hematologic clinical issues as obstacles blocking the possibility of integrating palliative care provision. The special clinical issues were given as reasons to justify the lack of referral to palliative care and to exclude any possibility of patients with hematologic malignancies having the opportunity to return home to die if that was their wish.

Discussion

Australian healthcare services, especially specialist services, are disproportionately concentrated in major urban areas (Humphreys & Murray, 1994). Consistent with that pattern, specialist hematology treatment services are concentrated in a small number of major metropolitan areas. Thus, a significant issue for many Australian patients with hematologic disorders receiving specialist treatment during the dying trajectory is that care will be taking place away from the comfort and familiarity of home and family (McGrath, 1999a, 1999b). Such patients and their families not only have to negotiate referral to the palliative system but also need to engage in planning to ensure that patients have the opportunity to return home to die if that is their wish. The minority of hematology patients who are successful in obtaining referral to the palliative system have access to palliative care specialist teams for consultation, hospital or hospice inpatient palliative care units, and the possibilities of community-based hospice care and domiciliary nursing services. However, to date, most hematology patients die on acute wards of specialist metropolitan treating hospitals.

The present findings affirm Harstade and Andershed’s (2004) model, which points to the importance of safety,

participation, and trust as core categories for palliative care service delivery. However, the insights provided by nurse participants in the present study highlight the difficulty of implementing such a model in a refractory hospital culture where death and dying are denied and where the orientation remains inappropriately on cure rather than integration of palliation. As Harstade and Andershed emphasized, a prerequisite for effective palliative EOL care and good dying is an openness regarding the dying person's situation and how he or she would like to spend the last days of life.

Hall's (1964) early work, which defined nursing through a model consisting of three connecting circles with the patient in the center and opposing circles of "cure" (medical therapy) and "care" (comfort), still is evident and relevant. Sahlberg-Blom, Ternstedt, and Johansson (1998) extended Hall's model to include notions of two cultures. The cure-oriented culture refers to an acute care setting where the aim is cure and rehabilitation, whereas the care-oriented culture refers to comfort-oriented settings such as hospices and nursing homes. As Sahlberg-Blom et al. (2001) argued, the different cultures have different qualities for supporting an individual's possibilities for optimal QOL and appropriate death. The model outlined in this article begins to describe for nurses the reality of working in hospital situations at the interface of the two cultures.

Presently, the most common model for palliative care in acute care settings is based on the notion of a continuum, with palliative care and curative treatment coexisting (Beach, 2004). The continuum ideally involves a palliative care specialist working early in a patient's illness to determine and implement goals of therapy (Beach). The present findings indicate that the implementation of such a model will be determined largely by factors associated with the culture of the acute care setting. The present model resonates with Yabroff, Mandelblatt, and Ingham's (2004) research, which identified provider-level barriers to optimal EOL care, including poor communication, under-referral to specialists and hospice care, and lack of available training in palliative care. Similarly, Yabroff et al.'s work showed that physicians usually play the role of gatekeeper to EOL services. Research indicates that physicians tend to avoid discussion about death and dying and feel poorly prepared to provide information about expected prognoses (Christakis & Iwashyna, 1998; Lamont & Christakis, 2002). Frequently, physicians' survival estimates

for patients with incurable cancer are inaccurate and overly optimistic (Christakis & Lamont, 2000; Mackillop & Quirt, 1997; Vigano, Dorgan, Bruera, & Suarez-Almazor, 1999). Another factor influencing the lack of physician participation in discussion about EOL care is reluctance to admit "failure" to cure and, thus, acknowledge that a patient's condition is terminal (Mount, 1986; Seravalli, 1988). However, during EOL care, the "comfort" rather than "cure" culture must prevail, as Barbato (2005) strongly argued.

Dying is not something we can ignore and the suffering that accompanies it cannot be treated within a biomedical framework. . . . Dying is the most significant time in any person's life. Its meaning may be lost within a system that has as its solitary goal the need to preserve life. In such a system, the drive to prolong life and maintain homeostasis can become so deeply entrenched that it takes precedence over matters of the soul, casting a pall over those who are dying (p. 637).

Conclusion

The insights of nurses from a variety of sectors of service delivery, including acute care, palliative care, and supportive care, have contributed to an outline of the important factors affecting the likelihood of patients with hematologic malignancies and their families receiving best-practice EOL palliative care. The nurses' insights posit the constructive possibility that palliative care can be integrated successfully into the care of all patients with hematologic malignancies along with evidence of the stress associated with working in clinical situations where such access is denied. This obviously is a topic where nurses have much to offer, for as one participant stated, "This is an area where we really should have nursing leadership."

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