Issues in End-of-Life Care
Family Practice Faculty Perceptions

Stuart J. Farber, MD; Thomas R. Egnew, EdD; and Jan L. Herman-Bertsch, RN, EdD
Tacoma, Washington

BACKGROUND. Issues in end-of-life care in the United States are receiving increasing discussion in light of the aging population and the documented need to improve the quality of care for dying patients and their families. Family practice faculty are in a key position to contribute valuable information, given their missions to model necessary values, attitudes, and skills and directly teach quality end-of-life care.

METHODS. We conducted interviews with 20 family practice faculty members in 3 residencies, and verbatim transcripts were coded by the authors. We held a second round of 12 interviews in 3 different residencies to check validity and expand the themes emerging from the original interviews. Corrected and elaborated themes were presented to focus groups from 2 other residencies.

RESULTS. Themes of reaching consensus; establishing a treatment plan; mobilizing a caregiving system; dealing with relationships with patients, families, and the treatment team; and issues of personal domain were described as important in end-of-life care.

CONCLUSIONS. The discussion of quality end-of-life care and how to provide it emphasized traditional medical concerns of diagnosis and prognosis, treatment, and caregiver support. Opportunities for innovation and improvement exist within the less explored areas of the relationship between the provider, patient, and family, and issues of personal meaning and experience.

KEY WORDS. Palliative treatment; physician-patient relations; hospice care; grief; spiritualism. *(J Fam Pract 1999; 49:525-530)*

Discussions of the role of medical care at the end of life are as old as recorded history.[1] During the past decade, issues regarding the adequacy (or inadequacy) of medical care at this stage of life have become increasingly important to our society and to health professionals,[2-7] particularly family physicians who are committed to providing continuity of care throughout the life span. The recent Institute of Medicine report *Approaching Death*[8] documents that "too many people suffer needlessly at the end of life both from errors of omission, when [medical professionals] fail to provide palliative and supportive care known to be effective, and from errors of commission, when [medical professionals] do what is known to be ineffective and even harmful." The report also says, "The education and training of physicians and other health care professionals fails to provide them with knowledge, skills, and attitudes required to care well for the dying patient [and family]." The demographic changes caused by the "graying" of the baby boom generation add greater emphasis to the importance of this discussion.

Family physicians have an important role to play in the movement to improve the care provided to patients and families at the end of life[9] and in the development of curricula for health care professionals. A review of the medical and general literature reveals growing recognition of the importance of and need to improve practice and education in this area.[8,10] As these efforts proceed, it is important to explore the values, attitudes, and skills on which they are built. Much of the information comes from the hospice literature, the only organized system of end-of-life care in this country.[11] There is little on this subject in the family medicine literature. In recent studies,[12,13] surveys and semistructured interviews of 35 selected family physicians were used to validate a theoretical model for the end-of-life experience. The family physicians said that issues of communication, family dynamics, legal and ethical issues, coordination of care, personal responses to dying, and the influence and support of the physician were important aspects in end-of-life care.

Family practice residency faculty in community programs are in a key position to model the values, attitudes, and skills necessary for providing quality end-of-life care and are responsible for teaching such care to residents. Although some research has surveyed community practitioners, the perceptions of community residency faculty regarding end-of-life care have not been reported. This information is valuable for understanding the issues involved and for developing curricula. We report the findings of our qualitative study exploring important issues identified by community family practice residency faculty in delivering end-of-life care to patients and families.

TABLE 1

Interview Questions Designed to Elicit Faculty Experience with End-of-Life Care

Remember a case in which you provided care for a patient and family facing a chronic progressive terminal illness.

1. Using the case as a frame of reference, what are the important issues you face, as you care for patients and families at the end of life?

2. What approaches, strategies, or methods do you use to deal with these issues?

3. How successful are these approaches, strategies, or methods in dealing with these issues?

Note: A fourth question was asked ("What experiences should residents have to prepare them to provide patients and families with quality end-of-life care?"), but this research paper does not address the answers given to Question 4.

METHODS

The Family Practice Residency Network affiliated with the Department of Family Medicine, University of Washington School of Medicine, was used to recruit faculty from 8 community programs. Twenty semistructured 60- to 90-minute interviews[14,15] with faculty were conducted from a convenience sample at 3 sites. Interviews were conducted by the authors using open-ended questions, and were designed to uncover faculty experience (Table 1). Nonspecific prompts such as "tell me more" were used to enrich data and avoid interviewer bias. The interview was rehearsed with a medical school faculty expert in ethnographic research, field tested, and adjusted before final use. These interviews were tape-recorded and transcribed into Ethnograph software.[16] Using qualitative research analysis, the 3 investigators coded the interviews and developed themes and a conceptual model.

After the initial themes were identified, another 12 semistructured interviews were conducted at 3 different sites to validate and enrich the emerging themes in the same manner as the original interviews. The themes were further refined on the basis of the new data. Two 60- to 90-minute focus groups conducted with 10 faculty at 2 additional sites were used for final validation.

A total of 42 family practice faculty, in 8 community programs in 3 different states were involved in this study. The demographics of the study cohort are shown in Table 2. Throughout the study, data were constantly compared, and data collection and analysis occurred simultaneously.[17-23]

RESULTS

Five major themes (consensus, plan, caregiving, relationship, and personal domain) emerged from our analysis of the data. We identified 3 subthemes for each major theme (Table 3). These themes represent the basic threads of a complex multidimensional experience for everyone involved in the end-of-life journey. Patients and families have their own points of view and understanding of what is important, and these ideals

TABLE 2

Demographic Characteristics of Study Cohort

Study Characteristic	Study Cohort	Validation Cohort	Focus Group
No. in cohort	20	12	10
Men, no. (%)	13 (65)	9 (75)	8 (80)
Mean age, years (range)	42.4 (33-50)	44.75 (38-55)	45.6 (35-57)
Mean practice experience, years (range)	10.85 (4-20)	14.75 (6-25)	15.0 (2-29)
Mean faculty experience, years (range)	5.05 (1-10)	8.25 (1-23)	9.35 (1-26)
Number of deaths managed, no. (%)			
0-10	5 (25)	1 (8)	3 (30)
10-20	4 (20)	3 (25)	1 (10)
>20	11 (55)	8 (67)	6 (60)
Medical specialty, no. (%)			
Family practice	17 (85)	11 (92)*	6 (60)†
Internal medicine	—	1 (8)	1 (10)†
Pediatrics	2 (10)	1 (8)*	—
NP or PA	1 (5)	—	2 (20)
Behavioral science	—	—	1 (10)
Pharmacist	—	—	1 (10)
Ethnicity, no. (%)			
White	19 (95)	11 (91.7)	9 (90)
Hispanic	1 (5)	1 (8.3)	—
Basque	—	—	1 (10)

NP denotes nurse practitioner; PA, physician assistant.
*One physician boarded in both family practice and pediatrics.
†One physician boarded in both family practice and internal medicine.

TABLE 3	
Themes and Subthemes of End-of-Life Care Experiences	
Themes	**Subthemes**
Consensus	Acceptance, uncertainty, barriers
Plan	Comfort, path, responsibilities
Caregiving	Caregiver, team, support
Relationship	Commitment, connection, consciousness
Personal domain	Stress, rapprochement, transcendence

are embedded within their community. Physicians also have their own unique perspectives, generated by a deep immersion in the medical world and their own personal communities. Developing a process that brings patients, families, and physicians to a common understanding of what is wrong, what should be done, and what the ultimate goals are is an ever-evolving challenge. It is in the context of this challenge that the themes described must be understood, because they simplify the process by breaking it into smaller parts. When woven together, these themes closely approximate the rich experience described in the interviews. While focusing on any one theme, we must remember that they are all occurring simultaneously, and each affects the others (Figure).

We have defined the themes and subthemes of the process of understanding and providing quality end-of-life care. Selected quotes from the interviews amplify their meaning through our subjectsí own words.
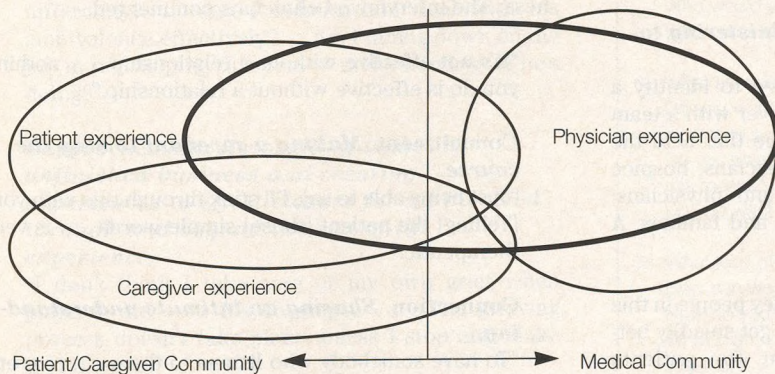
CONSENSUS: *Sharing the recognition that the patient's life is threatened*
Faculty described the challenge of having the patient,

caregivers, and physician develop a common understanding of what the medical illness means. Issues of accepting the seriousness of the illness and dealing with the uncertainty and unpredictability of the illness were repeatedly mentioned. Numerous barriers to reaching consensus were discussed and quotes related to providing or removing hope illustrate the multifaceted nature of barriers when viewed from differing perspectives. One faculty member said:

"Consensus may never be reached . . . we continue to work on it. And it will change as time goes on, as the disease progresses and the truth of the situation changes for the patient . . . As they experience their illness, patients change their ideas . . . that gets us back to the work of reaching consensus which continues and continues because it is a moving target."

Acceptance: *Understanding the meaning of the illness within the context of the biomedical model.*
"I try to be straightforward so that it's clear what the diagnosis is, but at the same time I always try to have some kind of hope. If it's not hope that we can do anything to treat the underlying disease, at least hope that we can get through this in the best way possible."

Uncertainty: *The inability to accurately predict the disease course for individuals.*
"I don't know. I can always give ranges, but I can't give time . . . miracles certainly happen, but I think if a miracle comes, it's not going to be from a doctor, and it's not going to be from the treatment. . . . It's from things we don't understand: prayer, nutrition, settling your affairs, from family being around."

Barriers: *Issues inhibiting agreement on the meaning of events.*
"We tend to get caught up in the nitty-gritty technical aspects of this, and that's not really what most patients are able to hear or want to hear."

"What's their understanding? What's their sense of how [they or] the patient is doing? What are their expectations? What are their fears? What are their hopes? What things are unsaid?"

PLAN: *Negotiating a common point of view on an initial management path*

FIGURE	

Common Relationships Between Physician, Patient, and Caregiver

Patient and caregivers share a significant relationship within both their personal and medical communities. The physician has a limited relationship with the patient only in the medical community and barely any relationship with the caregiver. We recommend expanding the physician experience (as shown in the bold oval) to promote a significant relationship in both the medical and patient/caregiver communities.

Patient experience

Physician experience

Caregiver experience

Patient/Caregiver Community ⟷ Medical Community

The faculty described the challenge of having the patient, caregivers, and physician develop a common understanding of how to medically manage the illness. Decisions about what path to take, particularly switching from aggressive curative treatments to palliative and hospice care, were often challenging. Providing physical and emotional comfort and delineating who was responsible for implementing the plan were emphasized. In one faculty member's words:

"Leave the silence, and let the patient ask the questions. . . . Once they start asking their questions or make their statements, it opens the doors for which direction you head."

Path. *Initiating the care plan.*
"It's not static, and it's always evolving. It's always subject to review and alteration. . . . I want to empower the patient . . . taking into consideration what I understand their wishes to be . . . I have to make the recommendations about what I think we should do."

Comfort. *Emphasizing physical and psychological comfort throughout the end-of-life journey.*
"All I'm going to do is make people comfortable and help them die a conscious, accepting and physically comfortable death, if those are at all achievable."

Responsibilities. *Agreeing on who does what to implement the plan.*
"Increasing the self esteem of family physicians to recognize that their contribution to the death process is equally as valuable as an oncologist's contribution and not to step aside when the oncologist, who has his professional credentials and confidence, steps in. . . . I've been in an uncomfortable position many times, and I have felt better about my role in this when I maintain my role with confidence and maintain good communication with the oncologist."

CAREGIVING: *Recognizing and ministering to the needs of sick persons.*
Faculty repeatedly emphasized the need to identify a family caregiver and support that caregiver with a team of providers. Support was often the glue that held the team together: patients supporting physicians; hospice nurses supporting patients, families, and physicians; physicians supporting nurses, patients, and families. A faculty member stated:

"I think physicians often are not the key people in this part, and that it's an area we need to get steadily better at, because it's so important for patients approaching the end of life."

Caregiver. *Identifying the person providing primary support in the patient setting.*
"I really try to identify the primary caregiver. Working with a lot of patients who are debilitated and going to be dependent on an individual means that they're only as good as their primary caregiver."

Team. *Rallying patient, family, community, and professional caregivers to support the care effort.*
"The one thing that is most supportive is to see the successful coming together of the team. . . if I can create a team, and then transfer all the work and duties to the team. Not because I don't want to do the work, but because if everyone else has come together to the point where they want to support this person, then we've been successful in creating the end-of-life event."

Support. *Rendering physical, emotional, spiritual, and social activities to make the care effort run smoothly.*
"And it is a tremendously emotionally involving . . . situation for all of them — to recognize and have everyone acknowledge the role that they all played and how people interacted and how they supported one another. . . . When the person dies the whole community of people who have come together around him doesn't just disappear."

RELATIONSHIP: *Bonding through time around the caring effort.*
The faculty members discussed in depth the special relationship shared with patients and families facing the end of life. They emphasized the elements of commitment to care for the patient and family through and beyond death, creating a special connection that allowed any topic of importance to be discussed regardless of whether it was medical. The relationship involves understanding the patient and family experience as well as the professional and personal meaning for the physician, within the changing context of illness. The interviewed clinicians commented:

"It's not effective without a relationship . . . nothing you do is effective without a relationship."

Commitment. *Making a covenant to stay the course.*
"Just being able to say, I'll stick through this with you. [Telling] the patient [those] simple words . . . is very therapeutic."

Connection. *Sharing an intimate understanding.*
"To have somebody who listens to them . . . to work with . . . a certain method of approach: a kindness and

a tone of voice, a genuine interest in what they're experiencing and what they are going through."

Consciousness. *Understanding self and other in context.*

"I think it's critical to being effective in the role of the primary care doctor to anticipate what the patients are thinking or what their concerns may be and help them articulate those and be open and honest about things including conflicts."

"Allowing myself to be vulnerable, allowing myself to let them see an emotional side of me, allowing myself not to be a doctor in front of them for just that moment."

PERSONAL DOMAIN: *Appreciating all those issues of personhood that fall outside the bio-medical model.*

The personal meaning of events at the end of life for the patient, caregivers, and physician were repeatedly discussed. The stressful nature of such care, the opportunities for closure and completion in life, and the transcendent and spiritual nature at this time in the life cycle were all explored. Faculty members spoke about their feelings:

"It reminds me of the preciousness of my life. It helps me renew my conviction that this is . . . one of the few opportunities to expand our consciousness in this life."

Stress. *Physical, emotional, spiritual, and social responses to threatened foreshortened life and death.*

"I think you have to understand that what makes you a healer is your wounds, not your knowledge. . . . When you are hurting and aching, this will help you. It is your wounds that make you accessible, and it is your resolution of your wounds."

"Am I doing the right thing? What should I be doing differently?. . . Am I helping him deal with his ambivalence effectively?. . . Am I falling down on the job in not helping this person understand what he's doing?"

Rapprochement. *Reconciling issues of unfinished business and creating experiences to effect closure for all involved through and beyond the end-of-life experience.*

"I don't think I take care of my own grief when patients die. . . . It's so empty. . . . The grieving process doesn't take place unless I stop and make that happen."

Transcendence. *Connecting to the world beyond self.*

"I think that the dying process can be as meaningful for people as the birthing process."

DISCUSSION

We believe there is particular opportunity for innovation in improving end-of-life care in the areas of relationship and personal domain. More than 50% of the text of our interviews addressed these 2 areas. Deep issues associated with attitudes and values surfaced in these areas that are essential in delivering quality care and motivat-

---

TABLE 4

Suggested Questions to Explore Personal Domain on End-of-Life Issues and Develop a Relationship Between the Patient, Family, and Physician

1. What is your understanding of your illness?
   What have the other doctors told you about your illness?
   What do you think is wrong with you?
   Why are you feeling ill?

2. What is important to you right now?
   What are your important issues?
   What do you see as your future?
   When you get up in the morning, what gives you the strength to get through the day?

3. What meaning do you ascribe to this illness?
   Why do you think you have this illness?
   How do you make sense of what has happened to you?
   How do you explain what has happened to you?

4. What are your past experiences with serious illness, loss, and death?
   Have you experienced serious illness before?
   Have you experienced the death of someone close to you?
   How have you dealt with serious stress and loss in the past?

5. Who are your social supports?
   Who would you define as your family?
   Who cares about what happens to you?

6. What are your goals of care?
   Do you want to live as long as possible even if that means increased pain and discomfort?
   Do you want to maximize comfort and quality of life even if this means you will die sooner?
   Do you want something in between?

7. What kind of relationship do you wish to share?
   How can we best work together?
   How do you want us to relate to each other?
   What can I do that will be most helpful as we work together?

ing providers to want to learn necessary skills. Nurturing and maintaining these essential attitudes and values is not easy. We suggest that family physicians ask themselves the following 4 questions: (1) What is our relationship with patients and caregivers? (2) What does this relationship mean professionally and personally? (3) What is our patient's or caregiver's relationship with us? and (4) What does this relationship mean to them personally and professionally? The answers will provide a perspective that will allow for the exploration of new and better ways to provide and teach vastly improved care for patient, caregivers, community, and providers at the end of life.[24,25]

Table 4 provides 7 questions grounded in the literature that can be used by physicians to explore the dimensions of personal domain and relationships of their patients.[3,6,7,9,11,26] It is important to appreciate how each involved individual (patient, family caregiver, and physician) understands what is wrong with the patient; what is important to deal with now; what is the meaning of these events; what are the past experiences with serious illness, death, and loss; who are the social supports; what are the ultimate goals; and how we are going to work together through this journey.

The interviewed faculty also emphasized the importance of reaching a common understanding of the meaning of the diagnosis and prognosis (consensus), the approach to treatment (plan), and developing support for the patient and family through the illness (caregiving). These are traditional areas of medical care that are well known to all of us and on which much effort has already been placed. Although we agree that these areas are important, by exploring the territory of relationship and personal domain family physicians will build a foundation that enables them to provide quality care in all these areas.

CONCLUSIONS

Committed family practice educators have insightful and important information to add to the discussion on providing quality end-of-life care that comes directly from their practice and teaching experience. Providing care to patients and families at the end of life is difficult and challenging, and there is great opportunity and need for improvement.

REFERENCES
1. Aries P. The hour of our death. Oxford, England: Oxford University Press, 1991.
2. Nuland S. How we die. New York, NY: Alfred A Knopf, Inc; 1994.
3. Cassell E. The nature of suffering and the goals of medicine. Oxford, England: Oxford University Press, 1991.
4. Humphries D. Final exit. Denver, Colo: Hemlock Society, 1991.
5. Quill TE. Doctor, I want to die: will you help me? JAMA 1993; 270:874-5.
6. Callahan D. The troubled dream of life. New York, NY: Simon and Schuster, 1993.
7. Byock I. Dying well. New York, NY: Riverhead Books, 1997.
8. Field M, Cassel C. Approaching death. Washington, DC: Institute of Medicine, 1997.
9. Geyman JP. Dying and death of a family member. J Fam Pract 1983; 17:125-34.
10. Billings JA, Block S. Palliative care in undergraduate medical education. JAMA 1997; 278:733-8.
11. Doyle D, Hanke GWC, MacDonald N. Oxford textbook of palliative medicine. Oxford, England: Oxford University Press, 1993.
12. Steinmetz D, Gabel LL, The family physicianís role in caring for the dying patient and family: a comprehensive, theoretical model. Fam Pract 1992; 9:443-6.
13. Steinmetz D, Walsh M, Gabel LL, Williams PT. Family physiciansí involvement with dying patients and their families. Arch Fam Med 1993; 2:753-61.
14. Crabtree BF, Miller WL. A qualitative approach to primary care research: the long interview. Fam Med 1991; 23:145-51.
15. Spradley JP. The ethnographic interview. New York, NY: Holt, Reinhardt and Winston, 1979.
16. Qualis Research Associates. The Ethnograph (version 4.0). Amherst, Mass: Qualis Research Associates, 1995.
17. Wolcott HF. Writing up qualitative research. Thousand Oaks, Calif: Sage Publications, 1990
18. Becker HS, Geer B, Hughes EC, Strauss AL. Boys in white. Chicago, Ill: University of Chicago Press, 1961.
19. Glaser B, Strauss A. The discovery of grounded theory. Aldine de Gruyter: Berlin, Germany: 1967.
20. Strauss A, Corbin C. Basics of qualitative research. Thousand Oaks, Calif: Sage Publications, 1990.
21. Seymour J, Clark D. Phenomenological approaches to palliative care research. Palliat Med 1998; 12:127-31.
22. Hunter KM. Doctors' stories: the narrative structure of medical knowledge. Princeton, NJ: Princeton University Press, 1991.
23. Toombs SK. The meaning of illness: a phenomenological account of the different perspectives of physician and patient. Dordrecht, the Netherlands: Kluwer Academic Publishers, 1992.
24. Steward M, Brown JB, Weston WW, McWhinney IR, Freeman TR. Patient-centered medicine. Thousand Oaks, Calif: Sage Publications, 1995.
25. Laine C, Davidoff F. Patient-centered medicine. JAMA 1996; 275:52-6.
26. Buckman R. How to break bad news. Baltimore, Md: The Johns Hopkins University Press, 1992.