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# End-of-Life Conversations

## Evolving Practice and Theory

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FOR PATIENTS AND FAMILIES FACING advanced illness, the medical interventions and quality of life that lie ahead are largely determined through a series of conversations they have with their physicians and other health care providers. These discussions occur between initial diagnosis and death and include many emotionally charged topics, such as unfavorable prognoses and treatment failure,<sup>1-3</sup> treatment choices and family responses to them,<sup>4</sup> advance care planning,<sup>5,6</sup> concerns about one's ability to cope, life goals and other life-closure issues,<sup>7</sup> anticipatory mourning,<sup>8</sup> and the meaning of the illness and the suffering it creates.<sup>9-11</sup> When these often difficult discussions are avoided or are managed poorly, the quality of remaining life for patients can be seriously jeopardized.

Recent investigations of hospital care of the seriously ill highlight the need for more timely and effective end-of-life discussions. Numerous studies reveal that (1) patients are dying after prolonged hospitalization or intensive care, often in unrelieved pain; (2) preferences concerning life-sustaining treatments are not adequately discussed, documented, or adhered to; and (3) referrals to hospice and home care, which could address these shortcomings, occur late or not at all.<sup>12-14</sup> Only about 20% of patients who die in the United States receive hospice care.<sup>15</sup> The admission criterion of having a prognosis for survival of less than 6 months has inhibited referrals to hospice, and an increasing trend of late referrals further limits use of hospice care.<sup>16</sup>

This article examines the evolution of and need for "end-of-life conversations." Barriers to end-of-life discussions that have been identified in patients and families, health care professionals, and health care systems can seriously interfere with the quality of remaining life for terminally ill patients. Strategies for enhancing end-of-life discussions are most productively linked to (1) physicians' interpersonal communication skills, (2) a patient-centered model of care, (3) a focus on quality of remaining life, and (4) innovative clinical models for implementing these discussions earlier in the care process. We conclude that end-of-life conversations must become a routine, structured intervention in health care and that advance care planning is best viewed as one component in a series of ongoing end-of-life discussions. Randomized trials are needed to examine new approaches and models for enhancing end-of-life conversations.

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These disappointing results and the demands of a baby boomer generation for greater control during life's final passage are galvanizing widespread efforts to improve end-of-life care.<sup>13,17,18</sup> As critical components of this care, end-of-life conversations are a major focus of these efforts.

### BARRIERS TO END-OF-LIFE CONVERSATIONS

An expanding literature explores reasons that end-of-life conversations often do not occur or are conducted poorly. Barriers to end-of-life discussions have been identified in patients and families, health professionals, and the structure of the medical care system.

#### Patients and Families

Most analyses of failed communications in end-of-life contexts attribute failures almost exclusively to the health care professional. However, recent findings emphasize the role of patients, who often manage to keep conversations away from certain topics.<sup>19-21</sup> Patients may conceal the full extent of their pain, feelings of self-blame, anger, loss, fears

about prognosis, and other difficult experiences that could be the content of end-of-life discussions.<sup>22,23</sup> Often patients avoid end-of-life discussions because of the stigma and embarrassment they associate with these topics.<sup>24</sup> Shyness, confusion, fears of death and dying,<sup>25,26</sup> and cultural prohibitions<sup>27</sup> can also inhibit such discussions. Family members and significant others can also block or complicate end-of-life conversations when they are unable to discuss and accept the advanced nature of the patient's disease or the patient's preferences concerning end-of-life care. They can overestimate the chance of cure or fear potential regret<sup>28</sup> and unreasonably demand that the physician "do everything."<sup>29</sup> Medical information available to patients and families through the Internet and popular me-

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dia can further complicate these discussions.

### Health Care Professionals

According to Morrison,<sup>3</sup> physicians might avoid end-of-life conversations because they (1) fear causing pain and bearing bad news, (2) lack knowledge of advance directive laws and training in delivering bad news, (3) view death as an enemy to be defeated, (4) anticipate disagreement with the patient or family, (5) have medical-legal concerns, and (6) feel threatened by such discussions.<sup>3(pp123-128)</sup>

Physicians and other health care providers are less likely to initiate end-of-life discussions when they believe they lack the needed interpersonal skills. A survey of physician trainees found that residents felt competent to discuss “do not resuscitate” orders but felt less competent to discuss a hospice referral and did not feel competent to discuss treatment withdrawal or to conduct family conferences.<sup>30</sup> The authors concluded that physicians-in-training lack competence and comfort in key areas and that these areas should be emphasized in end-of-life educational programs for residency training.

### Medical Care System

The structure of the medical care system also discourages productive end-of-life conversations. First, end-of-life discussions are not a routine part of care, and clinicians rarely have a structure for discussing end-of-life issues within their busy schedules.<sup>31</sup> Coordination of these conversations, which becomes more necessary as the illness progresses, is also not a routine part of care. Second, care is frequently conducted by multiple physicians in multiple sites (eg, office, hospital, home), and it is often unclear who is responsible for initiating and documenting the discussions. Third, the US medical system does not significantly compensate physicians for psychosocial conversations, including end-of-life discussions.<sup>24,32,33</sup> Finally, decreasing contact time and fewer long-term relationships between physicians and pa-

tients are additional barriers to end-of-life discussions. A recent study of how physicians communicate about advance directives showed that the conversations about advance directives averaged 5.6 minutes and physicians spoke for two thirds of this time.<sup>34</sup> Although advance directives were introduced, patients' values and attitudes toward uncertainty were infrequently dealt with, rendering the discussions less useful in decision making. When end-of-life conversations do occur, these discussions require that the physician sensitively probe the patient's concerns, questions, and needs.

### ENHANCING END-OF-LIFE CONVERSATIONS

How can the barriers to end-of-life conversations be overcome? Evolving theory and practice suggest that the quantity and quality of these discussions will in the future be closely linked to improving physicians' communication skills, adopting a patient-centered model of care, focusing on improving the quality of remaining life, and developing clinical models and programs designed to support such discussions earlier in the health care process.

#### Interpersonal Communication Skills

An assumption in the field is that the quantity and quality of end-of-life discussions can be improved by teaching communication skills to health care professionals working in end-of-life care.<sup>35</sup> There is agreement that outcomes in end-of-life care are strongly related to communication between clinicians and patients, and numerous training programs exist to address skill deficits.

The American Medical Association has produced an extensive training program: Education for Physicians on End-of-life Care (EPEC).<sup>36</sup> The program teaches communication skills that are critical to a wide spectrum of end-of-life conversations. The standardized core EPEC curriculum teaches fundamental skills in communication, ethical decision making, palliative care, pain

and symptom management, and other end-of-life treatment issues. The EPEC curriculum addresses the gap in training for care of the dying in medical education.<sup>37</sup> Other palliative care educational programs for medical students and practicing physicians have been developed.<sup>35,38-42</sup>

Specific end-of-life discussions are targeted by other training programs. Buckman and Kason<sup>1</sup> present a guide for breaking bad news, with a detailed discussion of skilled responses and guiding principles for physicians in these situations. They offer guiding principles to physicians. For example, when responding to despair, clinicians are advised not to promise anything they cannot deliver, to always allow the patient to express his or her despair, and to reinforce that the patient will not be abandoned.<sup>1(p146)</sup>

Specific recommendations for more effective end-of-life discussions with patients and family members can help physicians in their daily practice. Lo et al<sup>43</sup> stress the importance of active listening and empathy as the physician assesses symptoms, family issues, and spiritual concerns, when voiced. A simple question directed at specific end-of-life issues and followed by active listening responses (eg, follow-up questions or paraphrases that use some of the patient's own words) is often most effective. They suggest asking questions that can be helpful if appropriately timed: “How is treatment going for you and your family?” “What has been most difficult about this illness for you?” “As you think about the future, what is most important to you?” “Is faith (religion, spirituality) important to you in this illness?” Lo et al also emphasize the value of gently sustaining a focus on palliative care while disease-remitting treatments continue.

We have suggested<sup>44</sup> a framework for initiating appropriate end-of-life discussions that respond to the realities of advancing illness and changing treatment goals that includes (1) focusing on the patient's unique experience of the disease and the patient's decision-making process by asking such ques-

tions as, “Can you tell me about the history of your illness?” “What do you understand as your treatment options?” and “What are some of the concerns you have at this time?”; (2) helping the patient to confront fears and take control by asking, “What, if anything, are you worried about or afraid of?” “If you’ve lost family members or other loved ones, how did they die, and what was that like for you?”; (3) addressing practical issues, including advance care planning and family communication by asking, “What practical problems is your illness creating for you?” “Are there any family members or loved ones who need to know what’s going on?”; (4) shifting to a palliative focus in care at the appropriate time by refraining from saying, “There is nothing more I can do for you,” and instead saying, “There is a lot I can do for you at this time to control your pain, keep you comfortable, and help you live each day to the fullest extent that you can”; and (5) helping the patient to achieve a peaceful and dignified death by responding, “Sometimes people want to be sure to say good-bye to the people they love. If that is something you feel a need to do, how might you do that?” or “Are there any incomplete aspects of your life that you want to bring some closure to?”

The question of how to sensitively implement end-of-life conversations earlier in the process of advancing illness remains a pivotal challenge. For example, discussing palliative care issues while disease-remitting treatments are continued without creating a perception of abandonment requires the utmost empathy and skill.<sup>43</sup> A more refined assessment of how both patient and physician view the current medical plan (curative vs uncertain vs palliative) could provide the guidance needed for the content and timing of end-of-life conversations.

Advance care planning is the most widely discussed and studied of all end-of-life conversations. Although many strategies are currently used to increase completion rates among the general public and patient populations, fewer than one quarter of patients have an advance

directive.<sup>5</sup> Although discussion and documentation of advance directives is a critical end-of-life conversation, it is just one of the many end-of-life conversations needed to adequately prepare patients for the predictable problems advancing illness presents. Zuckerman and Wollner<sup>45</sup> suggest reconfiguring the advance planning model because it focuses almost exclusively on what should be avoided (cardiopulmonary resuscitation, feeding tubes, ventilator use), not on “what can be anticipated, planned for and embraced, in a positive, proactive way.”<sup>45(p99)</sup> For example, in end-of-life discussions, physicians could focus on foreseeable mental status changes, anticipated pain, or other symptoms that might require palliative care, as well as anticipated changes in functional capacity. Optimal end-of-life care requires open dialogue and direct attention to emotional issues and frequently avoided topics.<sup>43,46</sup> Although people want varying amounts of information about their health care and levels of involvement in their treatment,<sup>47-49</sup> all deserve the opportunity to prepare for—and cope with—the realities of advancing illness.

Finally, quality end-of-life care and conversations must be family-centered and address the complexities of working with both patients and their loved ones. Rothchild<sup>4</sup> discusses the range of family responses to decision making on withholding or withdrawing life-sustaining treatment. Physicians are encouraged to involve family members as early as possible, to keep explanations as simple as possible at each step until more detail is needed, to keep them informed throughout changes in the patient’s condition, and to share responsibility by recommending a preferred care plan.<sup>4(p257)</sup> Small group meetings with the family are recommended. Interventions with children are also called for. Research indicates improved bereavement outcomes for children if they are prepared for a sibling’s death.<sup>50</sup>

Physicians are uniquely responsible for breaking bad news and must strive to engage patients and family members in expanded conversations at the

end of life. However, no matter how dedicated and interpersonally skilled physicians are, the family, spiritual, ethical, cross-cultural, practical, and existential issues that rapidly rise in importance in end-of-life care will present formidable challenges to their time and expertise. Other professionals (nurses, social workers, clergy, psychologists) can, and perhaps must, play key roles in facilitating these diverse conversations. In addition, a new professional role in health care might be called for that includes responsibility for orchestrating and documenting end-of-life conversations. The person in this role (a nurse or social worker) could work under the physician’s direction and could supplement the physician’s ongoing end-of-life discussions with the patient. A recent review of best practices in chronic illness–coordinated care highlights the potential of such a model for the integration of care fragmented by setting or provider and its potential for raising the overall quality of health care<sup>51</sup>; coordinated care for advanced illness and end-of-life care might show similar results.

### Patient-Centered Care

End-of-life conversations are supported by medical practice that is patient-centered.<sup>52,53</sup> Research and theory on effective interpersonal care are identifying elements of patient-centered medicine characterized by mutual-participation relationships that encourage informed choice and patient autonomy. At the heart of the patient-centered approach is the need to understand the meaning of the illness for the patient, a central goal of any whole-person approach to end-of-life care.<sup>54</sup>

Roter and Fallowfield<sup>46</sup> see patient-centered medicine as broadening the biomedical view to one that “sees through the patient’s eyes” and appreciates the web of relationships and contexts within which a patient suffers. This approach recognizes that it is the patient who must ultimately make the decisions that will determine the outcomes in his or her life; it seeks to empower the patient to make the best

choices, given his or her values and needs. Key to a patient-centered clinical method is responding in a way in which patients sense that their ideas, feelings, expectations, and fears are understood<sup>54</sup>—essential elements of all end-of-life conversations. Patient-centered communication skills are also essential to physicians because they enable physicians to develop the positive relationships and emotional connections with patients that predict physician satisfaction.<sup>46</sup>

Successful end-of-life conversations help patients and family members overcome the “collapse of personal efficacy”<sup>55(p302)</sup> and loss of a sense of control that frequently accompany the diagnosis of serious illness. The beliefs people have about their capabilities—their self-efficacy beliefs—are critical determinants of the goals they pursue and the control they are able to exercise over their environments.<sup>55</sup> In end-of-life care, clinical interventions can be viewed as strategies for enhancing patients’ self-efficacy for coping with advanced illness and dying.<sup>56</sup> Key coping tasks facing patients with advanced illness can be assessed, such as coping with treatment-related adverse effects, maintaining a positive attitude, and seeking and understanding medical information.<sup>57</sup> Other tasks for the end of life, such as reconnecting with one’s family, making funeral and/or burial plans, or finding meaning in the dying experience, can be conceptualized within a framework of lifelong human development that helps physicians anticipate the issues patients might be struggling with but that could be overlooked if the patient’s distress is the sole focus.<sup>10</sup>

The view that we can cope better or less well with death and dying is relatively new to our culture. In the past, coping with advanced illness and dying has typically been viewed as a crisis that overwhelms normal coping processes and precludes notions of “manageability.” This shift in perspective, combined with public and community awareness efforts presenting a different image of dying, is an essential

element in the evolution of end-of-life conversations.

### **A Focus on Quality of Life at the End of Life**

A shift toward a quality-of-life focus is occurring throughout medicine and is part of the patient-centered model of care. In this approach, clinicians respond to issues of greatest importance to patients and their families. It is known that bereaved family members express dissatisfaction with end-of-life discussions and pain control and that they would like physicians to have a greater bedside presence. Research shows that patients and families tend to value clear communication about the patient’s condition, effective symptom management, preserving autonomy and a sense of control, avoiding prolongation of dying, minimizing burden to one’s family, strengthening relationships with loved ones, attending to issues of spirituality, and attention to site of death.<sup>58-60</sup> Clearly, a broad spectrum of discussions is essential to successful end-of-life care that is responsive to these quality domains. Reviewing their survey findings on quality end-of-life care, Singer et al<sup>59(p167)</sup> suggest that clinicians ask themselves: “Am I adequately treating pain and other symptoms?” “Am I inappropriately prolonging dying?” “Am I helping patients achieve a sense of control, relieve burdens on their families, and strengthen relationships with loved ones?”

A focus on human development during the crisis of advanced illness and dying has recently been articulated in the end-of-life literature.<sup>10,26,61</sup> Growth in these contexts consists of successful adaptation and shifts in personal experience toward peacefulness and a sense of wellness.<sup>10</sup> Dying well cannot be ensured. However, it is crucial for clinicians to recognize that personal growth can occur during life’s final stage and that it is valued by patients and their loved ones. With meticulous symptom management, opportunities for personal development can be preserved. By gently exploring issues of most importance to patients and fami-

lies and by skillfully guiding opportunities for interpersonal communication and self-determined life closure, clinicians can facilitate this developmental process for patients and their families.

### **Innovative Programs and Models for Enhancing End-of-Life Conversations**

Skillful, patient-centered, and comprehensive end-of-life care may be necessary, yet not sufficient, conditions for the enhancement of end-of-life conversations. Models of clinical care that support these discussions and extend their impact may also be needed. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) investigators underscored this when they concluded their seminal report with a call for more “proactive and forceful” interventions.<sup>12</sup> A search for more forceful clinical models for implementing end-of-life conversations that occur earlier in the care process and that are better integrated with host institutions<sup>62</sup> has led to a variety of expanding palliative care services, including: palliative care centers of excellence, hospice consultation teams,<sup>63</sup> prehospital and care management programs,<sup>17</sup> advance directives efforts,<sup>6,31,64,65</sup> models for facilitating structured end-of-life conversations,<sup>3,14,44</sup> and advanced illness coordinated care programs.<sup>66</sup>

### **CONCLUSIONS**

This overview of the evolution of end-of-life conversations points to several conclusions. First, where culturally appropriate, end-of-life conversations should become a routine part of health care delivery. They cannot be initiated solely in response to disclosures by patients because patients and health care professionals tend to avoid these uncomfortable discussions.

Second, structured and content-based interventions are needed to ensure that critical aspects of the patient’s physical, psychological, and spiritual experience are not excluded from care. A more seamless transition

from curative to palliative care can be effected when end-of-life conversations occur within a patient-centered model of care and a framework of anticipatory care planning that strengthens patients' and family members' sense of control and personal efficacy.

Third, because these skills and topics receive little attention in medical and nursing training, health care professionals require additional training in conducting end-of-life conversations. The emotional and time demands of these discussions must be acknowledged and addressed in clinical training and practice.

Fourth, our review of the literature on end-of-life conversations suggests that no single health care professional can successfully undertake all aspects of this challenge. The necessary discussions can draw on the expertise of several disciplines, and the creation of a new professional role specializing in this area might be considered.

Fifth, advance care planning must be viewed not as a final outcome but as one component in a series of ongoing conversations that together can assist the patient with advanced illness to approach death in accord with his or her own values and wishes.

Sixth, randomized trials examining new approaches and models for enhancing end-of-life conversations must be conducted. These trials would include measures of the frequency and quality of end-of-life discussions, perceived control, quality of life, and pain management. Combined with a cost-benefit analysis, they would provide the data needed for a reimbursable end-of-life care management strategy.

Finally, extensive community awareness and educational programs are needed to lay a foundation for successful end-of-life conversations in advanced illness.<sup>67</sup> As Field and Cassel<sup>13(p265)</sup> note, "It seems that this nation has not yet discovered how to talk realistically but comfortably about the end of life, nor has it learned how to value the period of dying as it is now experienced by most people." As a nation, we must move from a stance

characterized by avoidance and powerlessness to one in which this most significant life event is approached with the same kind of planning, emotional preparedness, sense of efficacy, and active involvement that we strive for in other domains of life. The evolution of conversations at the end of life may hold the key to this transition.

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The transition between life and death should be gentle in the winter of life. Death, under these conditions, is invested with a certain grandeur and poetry, if it comes to a man when he has completed his mission. . . . There is nothing to fear, nothing to dread.  
—Rudolph Matas (1860-1957)