Chapter 15
A Look Back, A Look Now, and A Look Forward

This book has presented many concepts and techniques of end-of-life care. While addressing some of the physical domain of that care, the book has emphasized the psychological, social, spiritual, and familial domains. I believe those last four domains deserve more attention than they ordinarily get. This concluding chapter steps back from the details of the five domains to gain an overview of the whole end-of-life care field. This overview aims to review where the field has come from in recent years and to suggest where it might go in the near future. The health professionals (HPs) delivering that care have the responsibility to attend both to the details of current care and to the future of the whole field.

The chapter begins by reviewing how modern end-of-life care has developed and how this book fits into that process. The chapter then summarizes the answers of HPs and patients to two questions key to that care, What is dying well? and What is quality end-of-life care? Those answers suggest, I believe, that modern end-of-life care does a better job of addressing the physical and psychological domains of dying than of addressing the social, spiritual, and familial domains. Accordingly, the answers suggest avenues for future research. The chapter closes by presenting a new vision for end-of-life care. That vision not only differs from mainstream curative medicine but also encourages changes in current end-of-life care. The vision emphasizes *all five* domains of care and universal responsibility for them among HPs. Quality end-of-life care under this new vision considers all five domains interconnected and equally vital. I offer a few suggestions at the end of the chapter for how to realize this new vision.

A Look Back: A Recent History of Developments in End-of-Life Care

I imagine the modern development of end-of-care as divided into three phases. I have sketched some of that development in several places in this book already but review the development again for purposes of this overview.

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The First Phase

Infections and injuries killed most people for many centuries [1]. The medicine of this phase initially offered little palliation and almost no cures, and dying typically took a rapid downhill course. However, the explosion of medical scientific discoveries in the mid- to late twentieth century dramatically changed dying in the developed world. New treatments (including antibiotics, vaccines, and modern surgical techniques) allowed people to survive infections and injuries that would have killed them before. People lived longer only to face the killers of old age including atherosclerotic heart disease, cancer, chronic lung diseases (such as emphysema), and dementia. Medical science responded by developing powerful life-prolonging treatments such as intensive care units, vascular bypasses and stents, ventilators, cancer chemotherapy, and major organ replacements. For the first time, people could survive a long time treated with these diseases. But people, of course, still eventually died [2]. Furthermore, the initial awe at the new life-prolonging treatments waned as the public began to see the "miraculous" treatments not as saving lives but as prolonging deaths. The prospects of dying on life-prolonging treatments, especially the machines, alarmed many.

The Second Phase

Alternative ideas to using fully aggressive life support to the end initiated the next phase in the development of modern end-of-life care. The right-to-die and death-with-dignity movements arose in the 1960s and 1970s to counterbalance modern medicine's "technologic imperative," the powerful inducement to use life-prolonging technologies even for patients intolerably suffering or irreversibly dying. These movements, paralleling the rise of modern medical ethics, championed a strong say for patients in their end-of-life care. Courts soon followed by recognizing patients' universal right to refuse life-saving treatment even if they died by exercising that right.

In the mid-1970s the modern hospice concept spread from England to North America. Grassroots support from outside mainstream medicine championed the early hospices here. They offered a style of end-of-life care radically different from technology-driven hospital care. They promoted aggressive pain control; attention to patients' illness experiences beyond just the physical; and death at home if possible [2]. Once hospice care took firm root in the USA, Congress agreed to pay for it through Medicare. (This important milestone, however, occurred for the wrong reason: Congress passed the Medicare hospice benefit not primarily to humanize care but to save on federal medical expenses.) Public demand and established reimbursement soon persuaded mainstream American medicine to adopt many hospice practices.

Twenty years later the landmark Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT) [3, 4] formally reassessed critical and end-of-life care in the USA. The investigators monitored the care of seriously ill and dying patients in American hospitals (where most Americans still die). Beginning with its first publications in 1995, SUPPORT provided disappointing evidence that many patients were still receiving “unsatisfactory” end-of-life care. Of all patients who died within six months, 38 % spent more than 10 days in intensive care units, and more than 50 % of the patients who died in the hospital suffered at least moderate pain for much of their last three days of life. Furthermore, for the 31 % of study patients who wanted no cardiopulmonary resuscitation (CPR), doctors knew about those wishes less than half the time.

These findings prompted the SUPPORT investigators to design a follow-up intervention that informed doctors about the prognoses and treatment wishes of their seriously ill patients. Though logical, that intervention produced no measurable improvement in any outcome including doctor–patient communication about resuscitation status, doctor knowledge of patient wishes for do-not-resuscitate (DNR) orders, timing of those orders, level of reported pain, or medical resource use.

Another study published in 1995 provided additional disappointing results, this time about actual patient dissatisfactions with critical and end-of-life care. Guyatt et al. [5] solicited opinions about such care from elderly patients who had survived life-threatening illnesses or from relatives of patients who had died from such illnesses. The patients had usually had “moderate to severe” pneumonias or exacerbations of chronic heart or lung disease. The researchers categorized the deceased patients by whether they had or did not have decision-making capacity before they died. While respondents expressed many satisfactions with their care, they also expressed some important dissatisfactions. Table 15.1 shows the dissatisfactions cited by more than 30 % of any group. Two dissatisfactions concerned the arduousness of critical care or the dying experience. (“Patient went through a lot.” and “Patient went through more than expected.”) Better care may not have been able to alleviate those dissatisfactions. However, better care might have alleviated other dissatisfactions. Two concerned the patients’ having a say in care (“Health professionals made decisions without involving the patient” and “The healthcare system controlled the level of care.”) and occurred for all the kinds of patients. Still other dissatisfactions occurred for only deceased patients with decision-making capacity or for their relatives. According to the relatives, many of these patients felt that they did not know what was going on with their care, that they were insufficiently listened to by HPs, and that the care situations were spinning out of control. Many of the relatives felt that they also did not know what was going on with the patients’ care and that the patients did not receive enough comfort measures or best-quality care soon enough.

The Third Phase

Results from the SUPPORT study, the Guyatt study, and similar studies published shortly afterward severely undercut the optimism of the time that dying patients were finally getting some say in their care and that care was generally improving.

Table 15.1 Patient and family dissatisfactions with critical or end-of-life care

Sources of dissatisfaction	Elderly[a] patients who survived life-threatening illnesses (n = 102) (%)[b]	Family of deceased, capacitated patients (n = 75) (%)[b]	Family of deceased, incapacitated patients (n = 78) (%)[b]
Patient went through a lot.	50	77	54
Patient went through more than expected.	46	57	–[c]
Health professionals made decisions without involving patient/Healthcare system dictated level of care.[d]	46	44	40
Patient did not know what was going on with care.	–	49	–
Patient felt the care situations were out of control.	–	43	–
Family member did not know what was going on.	–	41	–
Patient felt the health professionals were not listening to him or her.	–	37	–
Patient did not receive enough comfort measures.	–	32	–
Patient did not receive the best care soon enough.	–	31	–

Calculated from frequencies in Tables 1, 2A, 2B, and 2C in Guyatt et al. [5]

[a] "Elderly" here means older than 64 years.

[b] The table lists only those items mentioned by more than 30 % of respondents of a group.

[c] A dash means the datum did not meet this threshold.

[d] The tables from the original article pegged "Health professionals made decisions without involving patient" only to elderly patients who survived life-threatening illnesses and "Healthcare system dictated level of care" only to family members of deceased patients, both capacitated and not. I combined these two items as virtually identical.

The results of these studies dismayed patients, HPs, and the general public alike. Professional healthcare organizations responded by redoubling their efforts to examine, evaluate, and improve end-of-life care. The Institute of Medicine reviewed the state of the field and published *Approaching Death: Improving Care at the End of Life*, something of a manifesto calling for further, widespread reforms. Prominent funding organizations including the National Institutes of Health, the Robert Wood Johnson Foundation, and The Open Society underwrote additional empirical research and innovative demonstration projects in end-of-life care [1, 6, 7]. And many professional organizations concerned about aging and dying formulated guidelines for such care.

Those efforts have prompted considerable progress in the intervening years. I firmly believe dying patients get better physical, psychological, social, spiritual, and familial care now than they did in 1995. But gaps in those end-of-life care domains and in their quality still exist. This book tries to assess current gaps in the last four domains and to point toward possible future improvements. Of course, any attempts at improvement must have clearly defined goals, reflect up-to-date knowledge of the field, and take account of available resources (such as time; material support; and qualified, available HPs).

Because everyone dies, everyone has a stake in these improvements. But the public relies on HPs to lead the way. To help HPs prepare for that leadership role, the next two sections address the questions key to improving end-of-life care, What is dying well? and What is quality end-of-life care? Those questions are similar but not the same. The first question addresses a broad topic about the patient's experience of dying; the second, a narrower topic about what caregivers do for the patient while he or she is dying. I devote a separate section of text to each question. But the answers I give are not my own: They come instead from recent research studies involving the main participants of end-of-life care—dying patients, their family survivors, doctors, and other HPs. I believe the direct involvement of these people in end-of-life care earns them the greatest say in how such care should evolve.

These next sections rely on three tables—Tables 15.2, 15.3, and 15.4—to summarize people's answers to the two questions. The tables categorize answers under either the four familiar patient care domains (the physical, the psychological, the social, and the spiritual) or two additional domains (the familial and the procedural). While some answers may logically fall under several domains, I have placed each answer under the domain I judged suits the answer best. The tables are admittedly detailed. I, therefore, urge the reader to avoid becoming lost in the details but to try instead to see general patterns. The boldfaced type and shading that highlight the high-importance items should help. The accompanying text, too, describes some patterns I see in the data.

A Look Now: What Is Dying Well?

Tables 15.2 and 15.3 give answers to this question from various end-of-life care stakeholders. The tables focus on five studies, published from 1993 to 2007. One study used national surveys of doctors, other HPs (including nurses, social workers, chaplains, and hospice volunteers), seriously ill patients, and recently bereaved family members [7]. Three other studies used local surveys of terminal patients, most of whom had cancer [8–10]. Some patients in two of those studies were already receiving hospice care [9, 10]. The fifth study used a local survey of family survivors of recently deceased patients [11]. Drawing on these studies, Table 15.2 summarizes answers about items of dying well that mainstream medicine already addresses well, and Table 15.3 summarizes answers about items that mainstream medicine does not yet address well (and might never be able to address) [12].

Table 15.2 Dying well: importance ratings by various respondents for items that mainstream medicine already addresses well

Items of dying well	Doctors	Other health professionals	Patients				Family survivors	
	Steinhauser[a] 2000 [21]	Steinhauser[a] 2000 [21]	Fryback [a] 1993 [8]	McMillan [a] 1994 [9]	Byock [a] 1998 [10]	Steinhauser [a] 2000 [21]	Steinhauser[a] 2000 [21]	Norris[a] 2007 [11]
The patient's physical domain								
Staying clean	**High**	**High**	–[b]	–	–	**High**	**High**	–
Feeling no pain	**High**	**High**	**High**	Mod.[b]	–	Mod.	**High**	Mod.
Feeling no breathlessness	Mod.	Mod.	–	–	–	Mod.	Mod.	–
Having no constipation	–	–	–	Mod.	–	–	–	–
Sleeping well	–	–	–	Mod.	–	–	–	–
Functioning well	–	–	**High**	Mod.	–	–	–	Mod.
Receiving physical touch	Mod.	**High**	**High**	Mod.	–	Mod.	Mod.	–
The patient's psychological domain								
Maintaining dignity	**High**	**High**	**High**	–	–	**High**	**High**	–
Having a doctor who knows one as a person	Mod.	**High**	–	–	–	Mod.	Mod.	–
Being supported by the doctor	–	–	–	**High**	–	–	–	–
Feeling no depression/anger	Low	Mod.	–	Low	–	Mod.	Mod.	–
Feeling no anxiety	Mod.	Mod.	–	Low/Mod.	**High**	Mod.	Mod.	–
The patient's social domain								
Trusting the doctor	**High**	**High**	**High**	–	–	Mod.	**High**	–
Being comfortable with the nurse	Mod.	**High**	–	–	–	**High**	**High**	–
Not dying alone	Low	Mod.	–	Low	–	Low	Mod.	–
The patient's spiritual domain								
Knowing the doctor can talk about death	Mod.	**High**	–	–	–	Mod.	Mod.	–

(continued)

Table 15.2 (continued)

Items of dying well	Doctors	Other health professionals	Patients				Family survivors	
	Steinhauser[a] 2000 [21]	Steinhauser[a] 2000 [21]	Fryback[a] 1993 [8]	McMillan[a] 1994 [9]	Byock[a] 1998 [10]	Steinhauser[a] 2000 [21]	Steinhauser[a] 2000 [21]	Norris[a] 2007 [11]
The family domain								
Knowing the family is prepared for one's death	Low	Mod.	–	–	–	Mod.	Mod.	–
The process-of-care domain								
Being cared for by skilled professionals	–	–	**High**	**High**	–	–	–	–
Being cared for by one's personal doctor	Low	Low	–	–	–	Low	Low	–
Having access to doctor or nurse after hours	–	–	–	–	–	–	–	**High**
Knowing what to expect from the illness	Mod.	Mod.	–	–	–	**High**	Mod.	–
Having named a proxy	**High**	**High**	–	–	–	**High**	**High**	NS[b]
Having written out treatment wishes	Low	Mod.	–	–	–	Low	Mod.	NS
Having some control over care	–	–	**High**	Mod.	–	–	–	NS

[a] Four of the five studies cited in the table asked respondents to rate the importance of items against each other. The other study, the one by Norris et al., compared importance ratings for items among decedents with poor, fair, or good qualities of life during the week before death (as reported by family). The Norris items listed here differed significantly among the three quality-of-life groups except for items labelled "NS." The Norris items labelled highly important had large positive associations with the good quality-of-life group. Other items showing no significant differences among the quality-of-life groups and not included in this table were receiving visits from clergy, praying, listening to music, and enjoying nature. The other studies reported no data on those items.

[b] "Mod." means moderate; a dash means no data; and "NS" means no significant differences in ratings among decedents with poor, fair, or good qualities of life during the week before death (as reported by family informants to Norris et al.)

Table 15.3 Dying well: importance ratings by various respondents for items that mainstream medicine does not yet address well

Items of dying well	Doctors	Other health professionals	Patients				Family survivors	
	Steinhauser[a] 2000 [21]	Steinhauser[a] 2000 [21]	Fryback[a] 1993 [8]	McMillan[a] 1994 [9]	Byock[a] 1998 [10]	Steinhauser[a] 2000 [21]	Steinhauser[a] 2000 [21]	Norris[a] 2007 [11]
The patient's physical domain								
Having no fatigue	–[b]	–	**High**	Low	–	–	–	–
Eating well	–	–	–	Mod.[b]	–	–	–	–
The patient's psychological domain								
Having someone to listen	Mod.	**High**	–	–	–	**High**	**High**	–
Being allowed to discuss fears	Mod.	Mod.	–	–	–	Mod.	Mod.	–
Reviewing accomplishments in life	Low	Mod.	–	–	–	Low	Low	–
Enjoying some activities	–	–	–	Mod.	–	–	–	Mod.
Being mentally prepared to die	Low	Mod.	**High**	–	**High**	Low	Low	–
The patient's social domain								
Enjoying personal relationships	Mod.	**High**	–	–	**High**	Mod.	Mod.	**High**
Being visited by family	**High**	**High**	–	–	–	Low	**High**	**High**
Feeling supported by family and friends	–	–	**High**	**High**	–	–	–	**High**
Saying things that need to be said	**High**	**High**	–	–	–	Mod.	Mod.	**High**

(continued)

Table 15.3 (continued)

Items of dying well	Doctors	Other health professionals	Patients				Family survivors	
	Steinhauser[a] 2000 [21]	Steinhauser[a] 2000 [21]	Fryback[a] 1993 [8]	McMillan[a] 1994 [9]	Byock[a] 1998 [10]	Steinhauser[a] 2000 [21]	Steinhauser[a] 2000 [21]	Norris[a] 2007 [11]
The patient's spiritual domain								
Communicating with God	–	–	**High**	**High**	–	–	–	–
Believing life is still good	–	–	**High**	**High**	–	–	–	Low
Feeling at peace	–	–	–	–	**High**	–	–	–
The familial domain								
Having finished business with others	Mod.	**High**	–	–	–	Mod.	Mod.	–
Having financial affairs in order	Mod.	Mod.	—	–	–	Mod.	Mod.	–

[a] Four of the five studies cited in the table asked respondents to rate the importance of items against each other. The other study, the one by Norris et al., compared importance ratings for items among decedents with poor, fair, or good qualities of life during the week before death (as reported by family). The Norris items listed here differed significantly among the three quality-of-life groups. The Norris items labelled highly important had large positive associations with the good quality-of-life group.

[b] "Mod." means moderate; a dash means no data.

All four kinds of respondents in Table 15.2 recognized important items about dying well that mainstream medicine already addresses well in five of the six end-of-life domains. Not surprisingly, more of those items fall into the patient's physical domain than into any other. They include staying clean, feeling no pain, feeling no breathlessness, and receiving physical touch. The physical domain may include the most items for dying well because that domain fits best the established physical care models of medicine and nursing [13–15] and because the new palliative care specialty further emphasizes those items. Items in the psychological domain for dying well include maintaining the patient's dignity, having a doctor who knows the patient as a person, and feeling no anxiety; such items in the social domain include trusting one's doctor and being comfortable with one's nurse. Items of dying well in the spiritual domain include knowing one's doctor can talk about death; items in the process-of-care domain include knowing what to expect from the illness and having named a proxy. According to these data, only in the familial domain is there not at least one important item for dying well that mainstream medicine addresses well.

The items with unexpectedly few data or low ratings here warrant further research. Those items include having no constipation, sleeping well, functioning well, being supported by one's doctor, having no depression or anger, not dying alone, knowing one's family is prepared for one's death, having confidence about being cared for by skilled HPs, being cared for by one's personal doctor, having access to HPs after hours, and having prepared an instructional advance directive. Some of these items need precise definitions as well as prevalence assessments. Items unexpectedly appearing rarely in the table may also warrant future research. One example is the patient's having some say, or control, in his or her own end-of-life care. That item's infrequent mention surprises me due to the recent political and legal movements promoting patient decision-making. Further research should test the intuition that that item and others are indeed important. The research should also help clarify the relative importance of *all* items for dying well so that HPs can set priorities in care accordingly.

Unlike Table 15.2, Table 15.3 lists items of dying that mainstream medicine does not yet address well [15]. Few of those items, as judged by all respondent groups, occur in the patient's physical domain, and none occur in the process-of-care domain. However, two of these items occur in the patient's psychological domain: having someone to listen and being allowed to discuss fears. Two more occur in the patient's social domain: enjoying personal relationships and saying things that need to be said; a third, being visited by family, occurs there for all respondent groups except, surprisingly, patients. Three others, rated highly only by patients, occur in the spiritual domain: communicating with God, believing life is still good, and feeling at peace. Two other items occur in the familial domain: finishing business matters involving others and having one's financial affairs in order. Some of these items certainly lie beyond mainstream medicine's ability to change. For example, mainstream medicine probably cannot boost patients' ability to enjoy interpersonal relationships. But I believe mainstream medicine *can* help relieve more of other problem areas than HPs might immediately think. HPs can invite patients to discuss their fears of dying, and be ready to listen when patients do so. HPs can also encourage families to visit, patients and families to say things that need to be said, and patients to finish up important business and financial matters before the patients die. Such coaching on how to die well, I believe, should be a basic part of HPs' end-of-life care.

Both Tables 15.2 and 15.3 can serve as informal checklists for HPs as they monitor a dying patient's overall well-being. If some items in these checklists appear neglected or otherwise problematic, HPs might address them with the patient, family members, or HP consultants and implement interventions to try to help [16, 17]. Still, clinicians often demur on nonmedical matters, not appreciating how much good sense they as clinicians have about human nature and how much influence they have with patients and families. A clinician's simply expressing concern about a nonmedical problem may be impetus enough to prompt patient or family to seek help about it. The clinician may sometimes even have sufficient informal expertise to provide all the help the patient or family need. If not, the clinician can arrange for professionals with special expertise to consult. For example, if the patient wants spiritual guidance, the clinician can ask the patient's personal clergyman or the hospital's chaplain to visit.

Table 15.3, like Table 15.2, contains items that deserve further study. Items mentioned as highly important by only one or two groups are prime examples. I wonder whether most studies to date have simply not asked about these items, not asked about them in revealing ways, or have asked and found only negative results that have not been published. Examples drawn from Table 15.3 include being free from fatigue, being mentally prepared to die, feeling supported by family and friends, communicating with God, and feeling at peace. HPs need future research to clarify the importance of these items to dying patients.

What Is Quality End-of-Life Care?

Table 15.4 gives answers of various groups to the other important question for improving end-of-life care: What is quality end-of-life care? Drawing on several prominent articles, the table summarizes people's views about 17 aspects of that care. Those views come from "experts" (writing in consensus guidelines or giving their personal opinions), practicing doctors, other HPs, patients, and family survivors [18–20]. I classify 5 of those aspects of care as general "domains of care," 10 as individual care items under "the process-of-care domain," and 2 as types of satisfaction—the patient's and the family's. The table displays the breadth of recognition and the importance ratings of each aspect among the various respondent groups.

For the five general domains of care at least some of *all* respondent groups said attending to the patient's physical well-being and psychological well-being is moderately or highly important in quality end-of-life care. Several groups, but oddly not the experts or the nondoctor HPs, said attending to the family's

Table 15.4 Quality end-of-life care: importance ratings by various respondents of care domains and of individual care items

Domains or items of care	Experts (Teno 2001) [18][a]	Practicing doctors (Curtis 2001) [19][b]	Other health professionals (Curtis 2001) [19][b]	Patients (Singer 1999) [20][c]	Patients (Curtis 2001) [19][b]	Family survivors (Curtis 2001) [19][b]	Family survivors (Teno 2001) [18][d]
Domains of care							
Attending to the patient's physical well-being	**High**	Mod.[e]	Mod.	Mod.	Low	Mod.	**High**
Attending to the patient's psychological well-being	**High**	**High**	**High**	–[e]	**High**	**High**	–
Attending to the patient's social well-being	Mod.	–	–	Mod.	–	–	–
Attending to the patient's spiritual well-being	Mod.	–	–	–	–	–	–
Attending to the family's overall well-being	Low	**High**	Low	Mod.	Low	**High**	**High**
The process-of-care domain: individual care items							
Arranging for ready access to care	Low	Mod.	Mod.	–	**High**	**High**	–
Demonstrating technical competence	–	Low	Mod.	–	**High**	Mod.	–
Providing coordination and continuity of care	Mod.	**High**	**High**	–	Low	Low	–
Communicating well with the patient[d]	–	**High**	**High**	–	**High**	**High**	**High**
Educating the patient and family about what to expect in dying	–	Low	Mod.	–	Mod.	Mod.	**High**
Respecting the patient's values about dying[b,c]	Low	Mod.	Low	**High**	Mod.	Low	–
Respecting the patient's decisions about dying[c,d]	**High**	Low	Low	Mod.	Low	Low	**High**

(continued)

Table 15.4 (continued)

Domains or items of care	Experts (Teno 2001) [18][a]	Practicing doctors (Curtis 2001) [19][b]	Other health professionals (Curtis 2001) [19][b]	Patients (Singer 1999) [20][c]	Patients (Curtis 2001) [19][b]	Family survivors (Curtis 2001) [19][b]	Family survivors (Teno 2001) [18][d]
Helping the patient prepare to die	Mod.	–	–	–	–	–	–
Attending to family grief	Mod.	–	–	–	–	–	**High**
Addressing the financial impact of the illness	Low	–	–	–	–	–	–
Overall satisfaction with care							
Paying attention to patient satisfaction	**High**	–	–	–	–	–	–
Paying attention to family satisfaction	Mod.	–	–	–	–	–	–

[a] Teno et al. reviewed the published guidelines of professional organizations and the opinions of individual experts about the domains and individual items of quality. The authors identified 14 domains or items mentioned by at least 16 of the 30 sources. I rated these domains or items as having high, moderate, or low importance according to whether they had more than 70% mention (i.e., in 22–30 sources), 66–70% mention (i.e., in 20-21 sources) or 50-65% mention (i.e., in 16–19 sources), respectively.

[b] Curtis et al. asked focus groups of health professionals (including doctors, nurses, and social workers), potentially fatally ill cancer or AIDS patients, and family survivors of recently deceased patients to describe doctor attitudes and behaviors that make for quality care. Transcript analyses revealed 12 frequently mentioned domains or items. The authors ranked these domains or items by the number of spontaneous comments about each one within participant groups. I grouped the domains or items according to their rankings, high importance (rankings, 1–4), moderate importance (rankings, 5–8), and low importance (rankings, 9–12). These labels correspond roughly to greater than 10%, 6–10%, and less than 6%, respectively, of comments within a particular participant group. I combined three of the authors'original items—"respect and humility," "personalization," and "attention to patient values"—into this table's "respecting the patient's values about dying." I then calculated that item's ranking by averaging the rankings of the original three items.

[c] Singer et al. asked seriously ill patients and nursing home residents to name key domains or individual items of quality of care. Only five received more than 5% mention among participants. The table lists those five. I labeled them as having high, moderate, or low importance according to whether they were mentioned by greater than 40%, 20–39%, or 5–19% of participants, respectively. Deciding based on the example quotes in the authors' text, I classified the authors' original item "avoiding inappropriate prolongation of dying" under "respecting the patient's values about dying," and their original item "achieving a sense of control" under "respecting the patient's decisions about dying."

[d] Teno et al. elicited from recently bereaved family members their views on domains or individual items of quality care. The authors identified five. I split one of the original items into two, based on the authors' descriptions in the text: "Achieving control over everyday decisions and shared control over treatment care decisions" became "respecting the patient's decisions about dying" and "communicating well with the patient." Because the authors provided no rankings of care domains or items, I labeled all six as having"high importance."

[e] "Mod." means moderate; a dash means no data.

well-being domain is also moderately or highly important. (I doubt that experts or nondoctor HPs *really* consider attending to family well-being *un*important. These unexpected results, coming from one study, may be only happenstance and deserve further testing.) For the other two general domains of care, the patient's social well-being and spiritual well-being, only the experts rated both of those domains at least moderately important; most respondent groups did not rate those domains at all.

For individual care items under the process-of-care domain, the groups showed no universal agreement about items' importance in end-of-life care. Four items—arranging for ready access to care, communicating well with the patient, educating the patient and family about what to expect in dying, and respecting the patient's decisions about dying—came closest to universal agreement.

The experts were generally the rating outliers over all 10 care items. For example, unlike the other respondent groups the experts rated (moderately) important helping the patient prepare to die (including performing advance care planning) and attending to family grief, but rated relatively unimportant arranging for ready access to care. The experts surprisingly did not rate at all demonstrating technical competence, communicating well with the patient, or educating the patient and family about what to expect in dying. Yet the experts, and they alone, *did rate* as important paying attention to patient and family satisfaction.

Despite the apparent puzzlements of the Table 15.4 results, they may actually show some coherence. For example, among all domains of care, attending to the patient's psychological well-being received consistently the highest importance ratings. And among individual care items, arranging for ready access to care, communicating well with the patient, educating the patient and family about what to expect in dying, and respecting the patient's decisions about dying also had consistently the highest importance ratings. Many respondents, therefore, may consider these care items as key ways to achieve a dying patient's psychological well-being.

Still, I urge readers to interpret all these importance ratings cautiously. Personal perspectives may influence them greatly. For example, experts may rate high the domains of attending to the patient's social well-being and spiritual well-being because those experts enthusiastically support the corresponding hospice principles. In contrast, the experts may *not* rate the care items of demonstrating technical competence, communicating well with the patient, and educating the patient and family about what to expect in dying because they—the experts—think of those items as an inherent part of all end-of-life care. Family survivors, on the other hand, may rate as important attending to the family's overall well-being, and the HPs' communicating well with the patient, educating the patient and the family about what to expect in dying, respecting the patient's decisions about dying, and attending to family grief because those aspects affect families most in an end-of-life experience. Table 15.4, then, may serve mostly as a reminder that the same end-of-life experience can have different important aspects for different people. Care should adapt accordingly.

A Look Forward: Comparing Views on Dying Well and Quality End-of-Life Care

Comparing views about dying well and quality end-of-life care (Tables 15.2, 15.3, and 15.4) gives clues about how end-of-life care already serves patients and families well and how it might serve them even better in the future. Among the domains of end-of-life care, the patient's physical well-being and psychological well-being already have a firm foothold in today's mainstream clinical medicine [14, 21–23]. The family's overall well-being has a somewhat firm foothold. Many stakeholders in the dying process agree on the importance of these domains and surely spend considerable time, effort, and material resources on them. In contrast, the patient's social well-being and spiritual well-being domains rest on shakier grounds. Despite consistent expressions of support in the professional literature, those two domains command relatively little attention in practice [7, 14, 21–26].

Why this difference? I believe it arises largely from the "fit" of the various patient-focused end-of-life care domains within mainstream clinical medicine: The patient's physical well-being and psychological well-being fit relatively neatly into the priorities of that medicine; the patient's social well-being and spiritual well-being do not [15].

As I have described it before, the history of twentieth-century clinical medicine provides some support for this idea. Medical science over the twentieth century made wondrous advances in explaining, diagnosing, and treating physical and psychological diseases. At first that science achieved cures for some physical diseases and significant palliation of symptoms for many others. Then medical science discovered the chemical imbalances that cause many psychiatric diseases. Advances in diagnosing and treating them followed as new treatments proved able to correct those imbalances. All the amazing successes stoked clinicians' confidence in the new, scientifically based diagnostics and therapeutics, and the scientific model came to dominate mainstream clinical medicine.

But, as acute diseases (especially the infections) yielded to treatment, the chronic and terminal diseases emerged in prominence late in the century. Clinicians responded by carrying over the previously successful scientific medical model to those diseases. End-of-life care often benefitted. New treatments, for example, reduced the pain, nausea, shortness of breath, depression, and anxiety that dying patients may experience. I believe those successes have raised the physical and psychological domains of care to dominance in end-of-life care just as those successes did earlier in acute care. But the social and spiritual domains have been simultaneously pushed into the background.

Meanwhile the domain of the family's well-being has also gained some prominence in end-of-life care but for other reasons. Clinicians directly engage the family during a patient's dying process: Clinicians notify family members about the patient's life-threatening illness, explain it to them, often secure from them decisions about treatment, notify family members again at or near the death, and initiate through them the disposition of the body after the patient dies. Furthermore, attending clinicians and other HPs often witness directly the family's distresses during the patient's dying experience. Family grieve the progressive losses of the patient's function and companionship. Family may also have to confront long-dormant relational pathologies, which surface under the stress [27]. HPs may identify with those family distresses. And, of course, patient well-being and family well-being are invariably intertwined. HPs, therefore, often must help the family in order to help the patient.

I conclude that modern mainstream clinical medicine and the social and spiritual domains of end-of-life care differ sharply. In fact, clinical medicine and those domains seem to occupy totally separate worlds. Most clinicians are uncomfortable with those domains and feel inadequately prepared to address problems in them. Clinicians also worry that trying to address such problems only opens a Pandora's box of patient questions clinicians cannot answer and patient emotions they cannot control [6]. Clinicians, therefore, build for themselves a mental barrier between the physical, psychological, and familial domains of care on one side—the turf of traditionally trained, scientifically oriented clinicians—and the social and spiritual domains of care on the other—the turf of social workers, psychotherapists, and clergy. During care of the dying, clinicians tend to keep to the physical, psychological, and familial side; to refer social and spiritual problems to specialists on the other side; and eventually to lose track of those problems altogether.

My literature review, however, weighs strongly against this compartmentalized approach to end-of-life care. The dying patient's social well-being and spiritual well-being should concern *all* attending HPs, even the scientifically trained clinicians. I agree with the experts who rate the patient's social well-being and spiritual well-being as *at least* moderately important (and roughly as important as the family's well-being) in end-of-life care (Table 15.4). I believe the opinions of the general public support that view. Furthermore, some process-of-care items *surely do* affect the social and spiritual domains of dying (Table 15.2): trusting one's doctor, feeling comfortable with one's nurse, knowing one's doctor can talk comfortably about death, and not dying alone. And other process-of-care items *may* affect those domains: enjoying personal relationships (including with HPs), saying important things (such as good-byes or expressions of forgiveness to others) perhaps at the encouragement of clinicians, being assured that life is still good, and feeling at peace (Table 15.3). I also believe that the attitudes and behaviors of HPs can powerfully affect the social and spiritual experiences of dying patients.

Even if recognizing their opportunity to affect the social and spiritual domains of dying, some clinicians may disagree with my point that they have a duty to try to act on that opportunity. Clinicians might argue they have only scientifically based clinical expertise and must practice within its bounds. They might also insist that efforts to improve the dying patient's social and spiritual well-being will prove excessively complicated, time-consuming, and emotionally draining. The efforts might also prove ineffective. Clinicians might argue they may not succeed at bolstering the depressed dying patient's belief in the goodness of life or at convincing the disinterested family to visit the patient. Furthermore, clinicians might claim that many patients and family members want clinicians to confine their caregiving to physical and psychological issues and to leave social and spiritual issues alone. These patients or family members may fear intrusions into their personal privacy. The possibility of unwanted proselytizing, after all, is a common argument against clinicians' discussing religion or praying with their patients.

Other factors within medicine may also create obstacles to convincing clinicians to pay as much attention to the social and the spiritual as to the other domains of end-of-life care. Mainstream clinicians, so used to pursuing cure for physical disease, may have difficulty reigning in those deeply ingrained, though well-intentioned impulses and refocusing on other goals when a patient becomes terminal. Furthermore, medicine's current emphasis on "evidence-based" practices and on quantitative performance measures to justify reimbursement may convince clinicians (and insurers) that only observable, measurable outcomes matter. While physical care offers many discrete goals and measurable outcomes and psychological care offers some, social care and spiritual care offer almost none [2, 28–30]. Today's predominantly scientifically based, quantitatively driven medical model simply does not accommodate well those nonmainstream domains of care [31].

Specialization within medicine also creates an obstacle to social and spiritual care at the end of life. That specialization, a clear trend over the last 80 years, creates compartmentalization of care. Most clinicians, especially the doctors, specialize now. Specialist clinicians get used to focusing only on problems within their specialty and to leaving other problems to other HPs. The cardiologist addresses only problems concerning the heart; the colostomy nurse, only problems concerning the colostomy; the discharge clinical social worker, only problems concerning discharge planning. Compartmentalization of care follows, causing compartmentalization of responsibility. Because no clinician has any special expertise in social or spiritual care, no clinician oversees those aspects of the dying patient's care and accepts responsibility for them. They often get lost as a result.

Even forces outside medicine conspire against attending to the dying patient's social well-being and spiritual well-being. High personal mobility, high divorce rates, and other factors often fray Americans' social support networks. HPs may not be able to locate a dying patient's social support people when that patient needs them most. Furthermore, the emphasis of contemporary medicine and Western medical ethics on rationality, personal privacy, and patient self-determination may inadvertently magnify the dying patient's sense of isolation and frustrate caregivers' efforts to nurture social and spiritual support for the patient. In addition, increasing secularization in America, the simultaneous decline in church membership, and ever more idiosyncratic spiritual beliefs may deprive caregivers of readily identifiable ways to engage dying patients in the spiritual domain. Some commentators claim that even hospice no longer adequately addresses spiritual care [32].

Despite all these counterarguments I agree with one prominent end-of-life care expert who says, "Serious illness, dying, caregiving, grieving, and death cannot be completely understood within (such a highly specialized, highly scientific) framework" [15, 22, 33]. End-of-life care, I conclude, must contain two basic components: a "total care" treatment plan encompassing all five domains of care [34, 35], and a "universal responsibility" ethic holding *every* HP attending a dying patient responsible for seeing that each domain is addressed for that patient. The idea of "total care" treatment is, of course, not new. End-of-life care philosophies, especially hospice, have long espoused it. But the idea of "universal responsibility" is new.

Embedding genuine "total care" and "universal responsibility" into everyday end-of-life care will require a significant change in care practices. But end-of-life care must adapt to dying patients' wishes, not the other way around [20]. The next two sections suggest how to accomplish that lofty goal.

Needed: A Different Guiding Vision for End-of-Life Care

Implementing a genuinely "total, universally responsible" end-of-life care requires a different guiding vision than the typical guiding visions of current mainstream medical care. To help formulate that vision, I contrast three images of patients and their caregivers. The broken-down car represents the patient under current acute medical care, the torn cloth represents the patient under current chronic or end-of-life care, and the sick strawberry represents the patient under a genuinely "total, universally responsible" end-of-life care. Each caregiver—the car mechanic, the weaver, and the strawberry farmer—views his or her duties differently. From my perspective the strawberry farmer provides the best guiding image for quality end-of-life care [36].

The Broken-Down Car

This patient image, sometimes called the "mechanical" image, dominates today's acute care medicine. The broken-down car needs repairs, say, replacement of punctured or worn out tires. The owner brings the car to the mechanic at the tire store. The mechanic focuses exclusively on the defective tires. He replaces them but looks for no other problems with the car. He assumes all other parts are functioning perfectly. He engages the car owner only to describe the necessary repairs, get paid, and hand back the keys.

The mechanical image of patients served early modern medicine well, reflecting the first widely curable problems such as infections and traumatic wounds. This image, however, has never suited end-of-life care well. As I suggested in the last section, the mechanical image focuses end-of-life caregivers on the physical domain of dying (by treating symptoms such as pain, shortness of breath, or nausea) but does not much encourage or equip them to address the other three patient domains of dying [35]. This image simply ignores those domains. Under it, once all treatments for physical problems fail, clinicians may think they have nothing more to offer the dying patient. So they just "disappear" as other authors imply [37]. Patient and family feel abandoned despite having strong wishes for ongoing, meaningful, and supportive relationships with the clinicians.

The Torn Cloth

Some recent articles appear to use a patient image like this. A cloth tears when its cross-woven threads weaken and fray. The weaver hired to make the repairs homes in on the tear site. She examines it, identifies the different threads requiring repair or replacement, and performs the necessary reweaving. She may not notice other worn areas. If she does, she may not examine them or attend to them. They may be serviceable at the moment, may never cause problems, and, if so, can be repaired later.

I think this patient image reflects current chronic or end-of-life care. As for end-of-life care, recent improvements in standards and training have prepared caregivers to recognize and address some "worn areas," or problems, in addition to the physical ones. Caregivers may now notice some psychological or familial problems in dying but perhaps not others such as social or spiritual problems. Even if the scientifically trained clinicians do notice social or spiritual problems, the clinicians may consider those problems outside their expertise or their clinical responsibility. They may either not address the problems at all or refer them on to other professionals without further thought. The clinicians thereby disengage themselves from the problem-solving process in those domains. Just as with the broken-down car image, the torn cloth image does not adequately lead to fulfilling patient and family wishes for ongoing, meaningful, and supportive relationships with caregivers. The image surely does not inspire "total" care in the way I foresee it.

The Sick Strawberry

Believe it or not, I think this patient image fits best the idea of total, universally responsible end-of-life care. (I choose strawberries as my concrete image here because an area of South Texas near my home famously grows them.) The farmer knows that a strawberry must have all its defining characteristics to sell as a strawberry in the market. Those characteristics include size, shape, color, texture, taste, and smell. Drought or fungal infestation sickens the strawberry by affecting all those characteristics at once. The farmer must, therefore, "treat" all of them to make the strawberry healthy again. He or she cannot try to treat color without affecting taste, or taste without affecting smell, or size without affecting texture. And, to treat the whole strawberry, the farmer must water, spray, prune, and fertilize the whole strawberry plant. Once the strawberry regains all its defining characteristics, the farmer can sell it as a strawberry.

I believe a person, like the strawberry, consists of many inextricably intertwined characteristics. The four patient domains of end-of-life care reflect those characteristics. A patient has physical characteristics, but they do not define the whole person. The patient also has psychological, social, and spiritual characteristics, and they are inseparable from each other. Therefore, especially with a chronic or terminal illness, treating the patient requires addressing all the domains of the person.

Many studies assume this view of a patient as a multidimensional, indivisibly whole person. One study, seeking to identify "states worse than death" asked patients to name the elements necessary to make life worth living. Patients mentioned conditions from all four patient care domains. Eighty-two percent mentioned high physical function; 73 % mentioned freedom from pain, sleeplessness, and other physical symptoms. Seventy-three percent also mentioned the spirit or desire to live; 61 %, being needed by others, interacting meaningfully with others, or being useful to society, and 48 %, a spiritually meaningful existence (such as living to God's plan or some other good purpose). Sixty-one percent mentioned the lack of being a physical, emotional, or financial burden on one's family or on society in general; and 41 % mentioned being able to give and receive love [38]. As these study patients suggested, everyone lives in the psychological, social, and spiritual domains that along with the physical domain define our lives.

I believe these domains of a person are indivisible. Each domain affects the others. Thus, the dying patient does not fall ill in just one domain but in all of them simultaneously. Physical pain, for example, affects the patient's psychological, social, and spiritual domains. It may cause depression or despair (the psychological domain), hinder communication with others (the social domain), and raise existential questions about why suffering occurs (the spiritual domain). The patient's physical pain also affects the familial domain by causing family members to suffer vicariously. Though present in every illness, these nonphysical domains gain special prominence near the end of life.

The New Expansive Role for End-of-Life Health Professionals

No HP giving end-of-life care, therefore, can ignore the four patient domains and one family domain involved in it. One cannot give adequate care by addressing only some of the domains; one must address them all even if only to refer and then to monitor from afar the problems associated with them.

But the idea of total, universally responsible end-of-life care may trouble some HPs. It obviously requires expanding each HP's role within the end-of-life care team. But I believe such care entails little extra attentiveness, time, and effort. Each HP participating in that care—whether doctor, nurse, social worker, chaplain, administrator, or someone else—tracks all five care domains for the patient. Such universal responsibility for total care sometimes lands the HP outside his or her area of expertise. A doctor may observe harmful family dynamics, a nurse may perceive a patient's spiritual crisis, a social worker may notice increasing physical symptoms, or a chaplain may discover depression as the cause for a patient's hopelessness. Nonetheless, all HPs attending the patient accept *some* responsibility for all domains of that patient's care. No one abandons any domain automatically to other HPs. Furthermore, total, universally responsible care requires that every HP's contribution in any domain be taken seriously. Naturally, each HP must appreciate the limits of his or her expertise and, when necessary, request help from others in addressing specific problems [2, 7, 9]. For that reason the care team provides each HP an important professional safety net, giving collective support and ready access to others' expertise.

I realize that a patient or family member might occasionally object to a HP's crossing usual professional boundaries to address an end-of-life domain outside the HP's formal training. The HP, therefore, might need to request permission to address sensitive matters, whether inside or outside one's discipline. Chaplains already set a good example in this way: chaplains routinely ask patients for permission to pray with them. Nonetheless, I believe serious objections occur rarely so long as the HP behaves with sensitivity and respect. However, whenever firm objections do arise, the HP should honor the bounds the patient or the family member sets.

Suggestions for Future Practice and Research

What specifically, then, does total, universally responsible end-of-life care suggest that HPs attending dying patients do? Tables 15.2, 15.3, and 15.4 provide ideas in all four patient domains and in the familial domain. These ideas address some of people's most common worries about dying.

First, HPs should, of course, ensure the best physical care possible. Clinicians (and other HPs to the extent they can) should monitor dying patients' physical needs. Unrelieved pain and soiled, incontinent states must be considered emergencies. Any HP who notices such needs must take immediate action to get them met. Some doctors, for example, change soiled patient linens themselves without making patients wait for nurses or nurse's aides to do so. And every end-of-life HP should practice respectful therapeutic touch when appropriate. It need only be holding the patient's hand or resting one's own hand on the patient's shoulder during a conversation. Still, that touch powerfully communicates sincere caring and comforts patients.

Second, HPs should cultivate good end-of-life communication skills [1, 39]. Doctors, in particular, must learn to discuss death comfortably with patients [7, 40, 41]. Partly to that end, communication training is gaining prominence in undergraduate and postgraduate medical education curricula. Such training should be grounded in patient preference [42] and expert experience, should offer opportunities for supervised practice, and should provide constructive feedback on performance.

Third, HPs should address the anxieties people have about dying. HPs—especially doctors—must be willing to address the uncertainties that patients and families have [39]. Many people want to know what lies ahead. Though unable to give *exact* predications in specific cases, HPs can often give general predications based on past experience. For example, they might answer concerns about terminal suffering by saying, "I have seen many people die. They do not appear to suffer at the end. In fact, they seem to die just by going peacefully to sleep." HPs may sometimes need to repeat such comments more than once over time because they may not "sink in" for patients and family members the first time. And HPs should update for patients and family members any clinical predictions that change dramatically as patients' conditions change [10, 12].

Fourth, HPs should conscientiously try to learn dying patients' choices about dying and to implement them [20, 39, 43] even though Table 15.4 suggests doing so does not always rate a high priority for doctors or other HPs. Allowing patients some say helps personalize their care. For example, liberalizing visiting hours for family, allowing pets to visit, or granting a patient's wish to die at home can give patients enormous satisfaction.

Fifth, all HPs should emphasize to dying patients and their families the importance of the nonphysical domains of care [15, 21, 34, 44, 45]. In that way doctors and other HPs can legitimize those domains. HPs might explain that despite physical symptoms and short remaining life spans the end of life can offer patients and families significant opportunities for personal growth. Accordingly, HPs might invite questions, problems, and fears for discussion. HPs might also encourage patients to say important good-byes, to name trustworthy medical proxies, to put their financial affairs in order, and to tap into spiritual resources to the extent they wish to. And HPs might urge families to visit patients and to conduct life reviews with them.

Sixth, HPs should do everything possible to eliminate barriers to access, coordination, and continuity of end-of-life care [1, 12]. Dying patients and their distressed families do not deserve unreasonable institutional or professional barriers to care. Simply providing a reliable 24-h contact number for getting clinical advice can relieve people's anxieties and prevent unnecessary hospitalizations.

Conclusion

End-of-life care has improved greatly over the last 40 years but is still not ideal [6]. The impetus for this book came partly from my sense that the nonphysical domains do not yet get the attention they deserve in end-of-life care. The summary of the professional literature for this chapter supports that view.

Many articles in that literature urge "total" end-of-life care including adequate attention to the psychological, social, spiritual, and familial domains as well as the physical domain. But actual care—especially that delivered by traditionally trained clinicians—often focuses exclusively on the physical domain with its concerns about symptoms, palliative treatment regimens, chemotherapy, intensive care unit stays, and resuscitation decisions [28–30, 45]. Only some of the care addresses patient psychological problems such as depression or anxiety [46]; only a little addresses familial problems such as the emotional burden of proxy decision-making [47], and almost none addresses patient social or spiritual problems such as saying important good-byes or achieving inner peace. Too often, nonphysical problems at the end of life are overlooked, given only cursory attention, or considered adequately addressed strictly as psychological problems. This underemphasis dissipates the sense of responsibility many HPs, especially clinicians, feel for those nonphysical problems. HPs' involvement with them may reduce to the social worker's processing a hospice placement, the doctor's notifying the family when the patient's death is imminent, or the chaplain's saying the occasional brief prayer [30, 48]. Such an approach robs end-of-life care of its comprehensiveness, balance, and fulfillment.

We must do better. Again, approximately 3.5 million Americans die every year. Each death is unique. It presents its own combination of unanswered questions and mysteries, many of which touch the psychological, social, spiritual, and familial domains this book emphasizes. Not all those questions or mysteries are impenetrable. This book suggests areas for further exploration either as formal research studies or as conscious observations by individual practicing Health professionals. Those of us who attend dying patients owe it to them to engage the learning opportunities within both the physical and nonphysical domains of care.

But we must not limit our learning to techniques—even those, say, to treat symptoms, to communicate sensitively, or to recognize social and spiritual factors in dying. Such know-how learning can easily entrance us into forgetting the equally important learning about the meanings of end-of-life care as we give it and will eventually receive it ourselves. We must constantly broaden our perspectives to include techniques *and* meanings alike. The gravity of end-of-life care demands we address both.

The best learning experiences will require us to travel with our dying patients along their paths to death even though we cannot fully understand what is happening. We must pledge full involvement in that journey. That involvement must incorporate *all* domains of end-of-life care. And we must constantly try to improve our care. Past successes must not blind us to the need for future advances [11, 49]. We must continually rededicate ourselves to testing our fundamental ideas about end-of-life care [2, 13], to stoking anew our passions for it, and to increasing our efforts to improve it [24, 50]. We should start now.

Summary Points

1. Current end-of-life literature emphasizes patient physical and psychological care over patient social and spiritual care and family care.
2. Health professionals who attend dying patients should ensure that all five domains of care are addressed to the extent patients and family members wish.
3. Future research and care innovations should give special, increased attention to patients' social and spiritual care while continuing to address the other domains, too.

To Read More …

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