

Internal Medicine Grand Rounds

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Improving the Life of the Dying Patient: The Role of the Physician



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This is to acknowledge that Mary Elizabeth Paulk, MD, has disclosed no financial interests or other relationships with commercial concerns related directly or indirectly to this program.

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Cover illustration: *Death and the Physician* (1545), Hans Holbein. Woodcut.
From *Devils, Demons, and Damnation* (1971), Dover Publications.

I.) Introduction

Every human life eventually ends in death. Where and how that happens in America has changed dramatically over the last century. People are living longer, with longer periods of disability. As physicians, we are increasingly called upon to find the fine line that allows us to avoid doing harm while trying to preserve life for patients with incurable illness. Medical training provides little preparation for this dilemma, and, overall, physicians are not doing a very good job. Many have left behind the historical role of the physician as a companion at the bedside of the dying, familiar with death and knowledgeable about what lies ahead. Instead, some have become proficient technicians fighting against death, but leaving the field when the battle appears lost. The purpose of this discussion is to clarify the important issues facing dying patients and their families, to identify shortcomings within the medical field, and to propose some avenues of improvement. The three most important components of change are 1.) better communication amongst patients, families, and physicians, 2.) improvements in undergraduate and post-graduation medical education, including an improvement in role-modeling, and 3.) increasing the sense of individual accountability for patient quality of life. These solutions will help not only our patients, but also allow us, as physicians, a chance to reclaim the compassion, idealism, and close relationships with patients many find lacking in the practice of clinical medicine today.

A Century of Change		
	1900	2000
Age of death	46 y	78 y
Leading causes of death	infection accident childbirth	cancer heart disease CVA/dementia
Site of death	home	hospital
Expenses	paid by family	paid by Medicare
Disability before death	not usually	>4 years, on avg.

Table 1

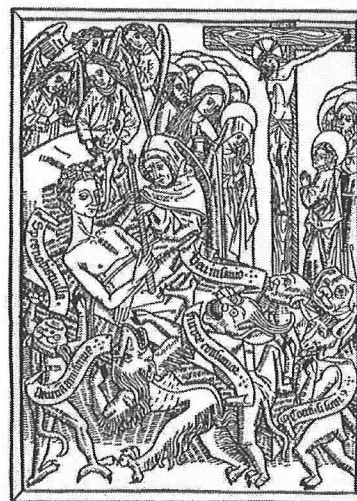


Figure 1: *The Goodman on his Deathbed* (1471)

II.) Changes in the last century

In 1900, the average life expectancy was 46 years (Table 1). There were no antibiotics, mechanical ventilation, CPR, dialysis, chemotherapy, or solid organ transplantation. When faced with overwhelming infection, organ failure, or malignancy, the role of the physician was to provide comfort during the patient's death, and support for the family during and after the death. The physician had a familiar relationship with death that was sometimes adversarial, sometimes collaborative (see cover illustration). Acute illness prevented lingering death, and dying was seen as a natural part of the life cycle. Works of art portraying death, at least in Western culture, often focused on the liberation of the soul to a higher plane of existence (Figure 1).

As the ability of Western Medicine to stave off death has improved, the attitude of the average American has also changed. There is a saying that, "The English view death as imminent, Canadians view death as inevitable, and Americans view death as optional." However, while Americans want to be kept alive as long as possible, they also fear being kept alive "artificially," that they will lose control over their lives in the face of critical illness, and that dying will be prolonged and impersonal (Figure 2).(1) These fears are well founded. The progress in public health and clinical medicine in the U.S. has, for some patients, resulted in prolonged dying, accompanied by substantial emotional and financial expense.(2;3) 75% of people die in acute care facilities(4), and over 90% of people die at the end of a period of decline, with the average length of disability at about 4 years.(5) The course of illness during the disability is variable, and difficult to predict. Patients with cancer generally undergo a slow decline followed by a rapid degeneration in health just before death (Figure 3). Patients with more chronic conditions like CHF or COPD have courses punctuated by multiple exacerbations and recoveries (Figure 4).(5-10). In both cases, patients and families go through periods of time characterized by uncertainty, and increasing medical, social, psychological and spiritual needs that we as a profession are ill equipped to handle.

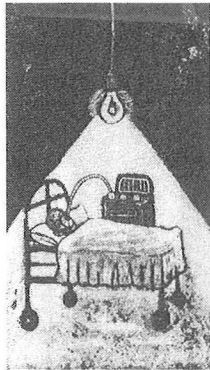


Figure 2: Detail of *AIDS Patient* (1989)
Luis Cruz Azaceta.

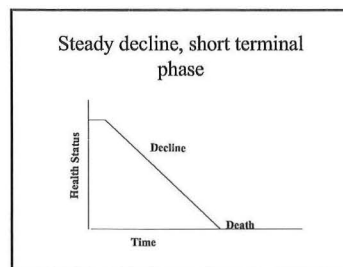


Figure 3

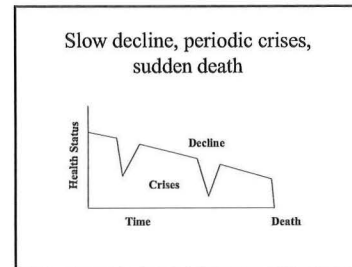


Figure 4

III.) A New Model of Care

The first documented study of end-of-life care in the United States was William Osler's 1906 work, in which he reviewed 486 deaths at Johns Hopkins Hospital and wrote commentary on how care of the patients might have been improved.(11) Despite those early efforts, end-of-life care is still a young field of study. We have some data about patient preferences for end-of-life care, and how well the health care field is responding to those concerns. The areas of concern for patients are pain and symptom management, preparation for death, minimizing burden on family, participation in decisions about treatment preferences, and treatment as a "whole person."(12;13) Awareness of these issues contributed to the development of the concept of Palliative Care (Figure 5). The WHO defines Palliative care as shown in Figure 6. It is an emerging multi-disciplinary approach to care of dying patients and their families that divides realms of care into social, physical, and psychological and spiritual. This paper will include discussion of major patient concerns in each of the realms of care. It should be noted that hospice and palliative care are complementary services, but are not

identical. Hospice is a benefit defined by the Medicare system, under which patients who have a life expectancy of six months or less receive pain and symptom management. Patients do not have to be “DNR” to receive hospice benefits, but they cannot be undergoing treatment of their disease (for example, patients receiving palliative radiation or chemotherapy are not eligible). There is a common misconception that hospice services are provided in dedicated facilities. While there are inpatient hospice services in other areas, we do not have residential hospices in the Dallas area at present (except for patients with AIDS).

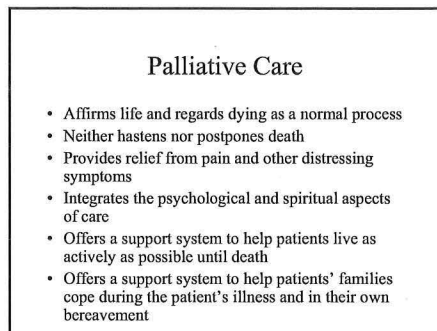


Figure 5

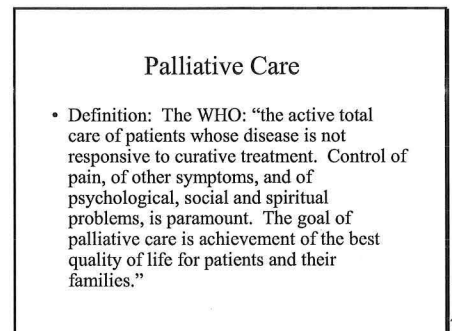


Figure 6

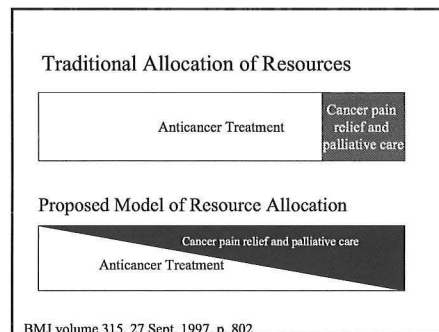


Figure 7

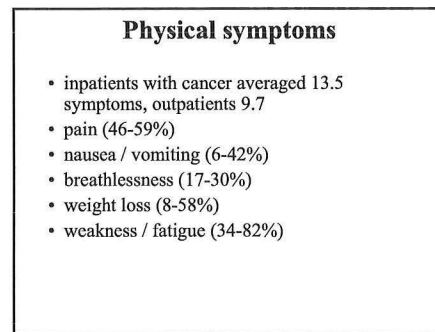


Figure 8

IV.) When is a patient “dying”?

Any discussion of care for the dying must begin with a definition of “dying” and “terminally ill.” There is surprisingly little consensus on this point, as demonstrated by Christakis, et al. (1998) who surveyed Internists regarding their impressions of when a patient becomes “terminal ill”. The average was prognosis of 13.5+/-11.8 weeks, but responses varied substantially, from 1 to 75 weeks.(14) Even if there were a strict definition of “dying” in terms of time, the unreliability of prognostic estimates suggests that it is unlikely that physicians would recognize when that time had arrived.

Much of the data we have regarding prognostic assessment is from SUPPORT: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment.(4) 9105 adults hospitalized with life-threatening diagnoses were followed prospectively. Estimates of prognosis were regularly recorded, and correlation with time of death then calculated. The results were not encouraging. Amongst patients with lung cancer, the course of which is among the most predictable of the common causes of death, patients later found to be a week away from death were given a 50-50 chance of

living an average of two more months.(7) Estimates of prognosis were even worse for patients with COPD or congestive heart failure. Three days before death, patients who died of congestive heart failure were predicted to have an 80% chance of living 6 more months, and, on the day before death, they were predicted to have a mean chance of 62% to survive 2 more months. Patients with chronic obstructive pulmonary disease who died within two days of an estimate were predicted to have a mean chance of 62% to survive 2 months.(6) Fox, et al, confirmed the inaccuracy of physicians' prognostic estimates in a separate study(8). 42% of patients considered too healthy for hospice died within six months of evaluation, and 41% of those considered very unlikely to survive for more than six months did exactly that. Other studies show that estimates of prognosis get marginally better with experience, but actually get worse the longer the physician has known the patient. Accuracy does not correlate with confidence in the estimate. Overall, physicians tend to overestimate survival by a factor of 5.3.(15) What these data suggest is that even if a particular life expectancy were defined as the threshold for "dying" or "terminally ill" (for example, under the Medicare hospice eligibility guidelines) physicians could not be relied upon to recognize when that point occurred. This hypothesis is borne out by the persistent lateness of referral to hospice by physicians, the median length of stay declining from 36 days before death in 1995 (16% died < 7 days of admission) to 20 days before death in 1998.(5)

It seems prudent, then, to abandon the concept that a clear line can be drawn at a given point, beyond which patients should receive only comfort measures. Instead, as patient care needs increase, and chance of recovery declines, palliative care measures can be gradually introduced. The traditional allocation of resources, in which aggressive care aimed at cure is continued until the patient is indisputably dying, and then abruptly withdrawn, should be supplanted by a model in which pain relief and palliative care begin early, and increase or decrease based on the patients needs (Figure 7).

V.) Physical Symptoms

Regardless of whether or not a patient is technically "dying," any person with a chronic, debilitating illness faces a variety of problems, social and psychological as well as physical. Cancer patients referred to an outpatient clinic had an average of 9.7 symptoms (Figure 8). The most common were pain (46-59%), nausea and vomiting (6-42%), dyspnea (17-30%), weight loss/anorexia (8-58%), and weakness/fatigue (34-82%).(5) Other symptoms reported in a separate study were insomnia (59%), constipation (33%), sweating (28%), dysphagia (20%), neuropsychiatric symptoms (20%), urinary symptoms (14%), dyspepsia (11%), paresis (10%), diarrhea (6%), pruritus (6%), and dermatological symptoms (3%).(16) The number of physical symptoms escalates as disease progresses, as demonstrated in Figure 9. (3;17;18)

Number of Symptoms Other than Pain Volunteered per Patient 4 Wk Before Death and 1 Wk Before Death (N = 90)		
Number of Symptoms	N (%)	
	4 Wk Before Death	1 Wk Before Death
1	7 (8)	7 (8)
2	19 (21)	17 (19)
3	26 (29)	22 (24)
4	26 (29)	19 (21)
5	7 (8)	13 (14)
6	4 (4)	6 (7)
7	1 (1)	3 (3)
8	0 (0)	2 (2)
9	0 (0)	1 (1)

Figure 9: Number of physical symptoms other than pain in dying patients at 4 weeks before death, and one week before death.(17)

A.) Pain: Evidence of Under treatment

Healthy persons repeatedly describe fear of pain as their greatest concern related to dying, and dying patients confirm that pain is their most bothersome symptom(12;13;16). Most of the data we have about pain management has been gathered from cancer patients. About 30% of patients with cancer have pain at the time of diagnosis, and 65 to 85% have pain when their disease is advanced. This pain is easily controlled with oral medications using the WHO guidelines for cancer pain management (Figure 10) in 85 to 95% of patients if medications are used appropriately.(19;20;20) Despite the presence of this simple and effective algorithm, multiple studies indicate that pain is being inadequately treated in the dying(3;9;20-28). In SUPPORT, 3205 patients were interviewed about their preferences for pain management at the end-of-life.(26) 1607 (50.1%) reported that they were “very unwilling or would rather die” than be in pain for the remainder of their lives. 48.6% preferred a course of therapy aimed at relieving pain even if it meant a shorter life. Unfortunately, these preferences had little effect on the actual treatment of pain in these patients. Among those who said they would prefer aggressive pain management even if it meant a shorter life, 23.9% reported extremely or moderately severe pain at later interviews (as opposed to 22.7% in the group who preferred less aggressive management). Family members reported that 50% of conscious patients who died in the hospital experienced moderate to severe pain at least half the time.(4) The data are similar for the outpatient population.(29) Patients seen at centers that treated predominantly minorities were three times more likely than those treated elsewhere to have inadequate pain management.(22)

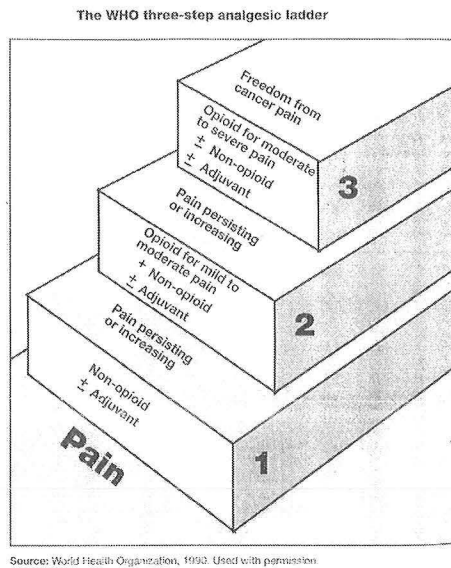


Figure 10

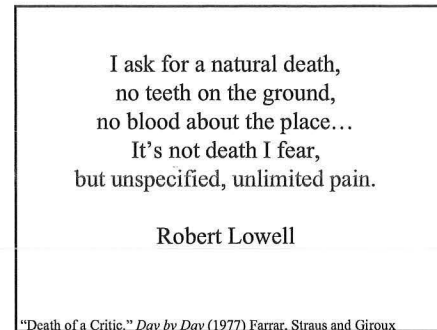


Figure 11

B.) Pain: Barriers to Management

Why is pain management such a difficult problem? There are barriers on multiple levels; some related to patients, others related to physicians, and some related to the medical system (for example, pharmacies in low income neighborhoods are much less likely to have the appropriate medications for pain management(30)).

1.) Patients: Patients are often fearful about taking opioid medications.(31) Among the most prevalent worries are fear of addiction, concern about tolerance, concern about side effects (Figure 12), and desire to be a "good" patient.(32) Age, low level of education, and low socioeconomic status correlate with a belief that "good" patients do not complain of pain, putting these patients at increased risk for incomplete pain management. There is evidence, too, that fear of reporting pain may be justified. A multivariate analysis of the pain data from SUPPORT found that though only 26.7% of patients communicated their preferences for pain management to their physicians, that communication actually correlated with higher pain levels at later assessment.(26)



Figure 12

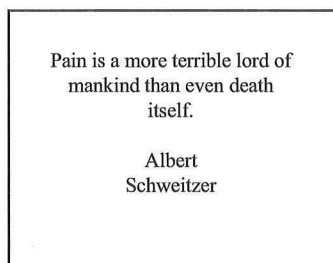


Figure 13

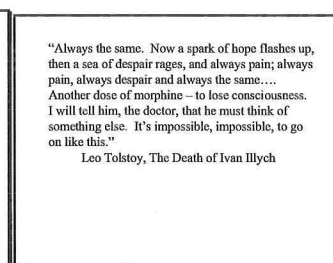


Figure 14

2.)Physicians: There are also barriers to pain management amongst physicians.

Regulatory barriers: There are complex laws and regulations governing the prescribing of opioids that make physicians fearful of prescribing controlled

substances.(25) The State of Texas requires licensed M.D.'s to have supervision from both the Department of Public Safety and the Drug Enforcement Agency, and prescriptions have to be written on triplicate prescription pads ordered from Austin.

Educational Barriers: There is a lack of education about the nature of pain and the appropriate use of opioid therapy, in the medical community as well as amongst the general public.(20) Physicians tend to hesitate in prescribing adequate amounts of opioids at appropriate dosing intervals (Figure 15,16).(25) 61% of physicians in the Eastern Cooperative Oncology Group (ECOG) reported reluctance to prescribe opioids as a barrier to pain management. Concerns about side-effect management and tolerance were also reported as limiting analgesic prescribing.(31) Physicians may also be unaware of the pain and discomfort that apparently simple procedures can cause.(33) Patients in Morrison & Siu's study(33) found arterial blood gasses the most painful procedure performed on them, and nasogastric tubes among the most uncomfortable.(Figure 17, 18)

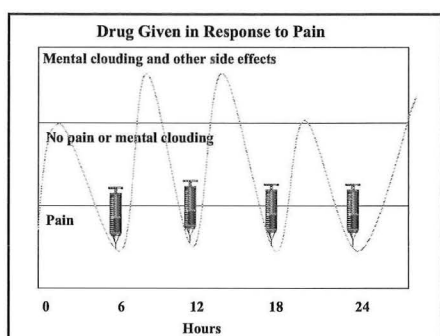


Figure 15

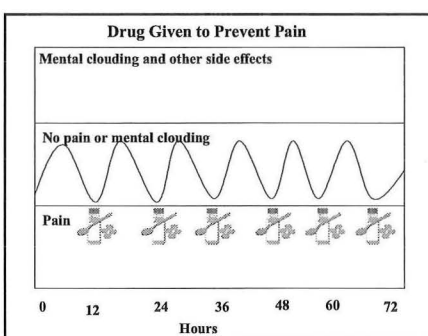


Figure 16

Figure 15: Inappropriate dosing of pain medication, on a prn basis. Peak levels are too high, cause side effects, and troughs are too low, allowing pain to occur between doses.(98)

Figure 16: Correct dosing of pain medications at regular intervals, so that a steady state develops keeping peaks and troughs within range to control pain without causing undue side effects.(98)

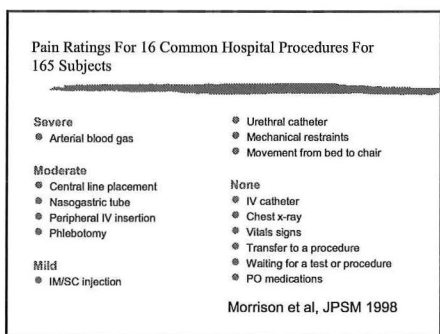


Figure 17

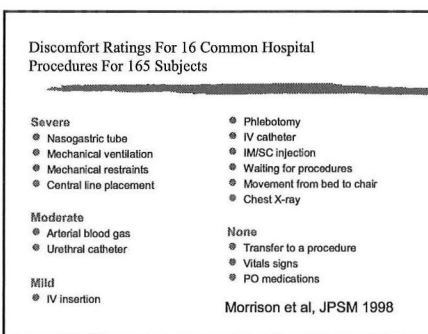


Figure 18

Communication failure: Poor communication may contribute by leaving physicians unaware of the patient's discomfort, as cited above. Poor pain assessment was rated by 76% of physicians in ECOG as the single most important barrier to adequate pain management(31). However, in SUPPORT, trained pain assessment nurses regularly communicated pain ratings to the physicians and there was no statistical improvement at all. This suggests that physicians simply are not making pain management a priority. An alarming confirmation of this hypothesis comes from the ECOG study as well: 86% of

the physicians they surveyed felt that the majority of patients with pain were under medicated. Only 51% believed the pain control in their practice setting was good or very good.(31) Even when a community-wide initiative to improve pain control was undertaken, there was little improvement in physician pain management.(34)

Lack of Objective Data: Part of the reason that physicians under treat pain may be related to the lack of objective data. The patient's report is the only indicator of pain, and there is no objective index of response to medication. Physicians and other care providers may be skeptical about the patient's report, particularly if the pain seems out of proportion to a given injury. Discrepancy between patient and physician in judging the severity of the patient's pain was predictive of inadequate pain management(18), as was a sense on behalf of the patient that the physician was less concerned about the pain.(35) Patient characteristics that correlated with inadequate pain management included pain that physicians did not attribute to cancer, better performance status, age of 70 years or older, and female sex (Figure 19). Sharp pain, and pain that has both constant and intermittent elements are less likely to be treated, as are bony pain and pain related to lymphadenopathy.(35) Perhaps these patients were less likely to complain, had small lesions that seemed unlikely to cause the amount of pain reported, or looked well enough that the physician underestimated their discomfort. Some physicians may feel that patients constantly asking for pain medications are being manipulative.

VARIABLE	PERCENTAGE OF PATIENTS IN CATEGORY	PERCENTAGE WITH NEGATIVE SCORE	ODDS RATIO†	95% CONFIDENCE INTERVAL	P VALUE
Patient-physician discrepancy in estimate of pain severity			2.3	1.6-3.5	<0.001
Underestimate	65	46			
Adequate estimate	35	30			
Cause of pain			1.9	1.2-3.3	0.01
Not cancer	15	56			
Cancer	85	38			
ECOG performance status			1.8	1.2-2.5	0.003
Good	52	46			
Poor	48	34			
Racial or ethnic group			3.1	1.7-5.5	<0.001
Minority	11	59			
Nonminority	89	38			
Age (yr)					
18-52	25	35			
53-62	25	34	1.2	0.7-2.0	0.54
63-69	24	43	1.6	0.9-2.7	0.09
≥70	26	50	2.4	1.4-4.0	0.001
Sex					
Female	59	42	1.5	1.0-2.3	0.03
Male	41	38			

*Complete case information for predicting the scores was available for 538 patients.

†The odds ratios in the age category are for the comparison with the youngest age group. A higher odds ratio is associated with a greater likelihood of the undertreatment of pain.

Figure 19: Factors associated with poor pain management. (35)

Legislative imperatives to improve: The Joint Commission on Accreditation of Hospitals has established a list of guidelines for the management of pain to help physicians and other caregivers assign greater significance to pain management . Caregivers are expected to(25):

- 1.) Recognize the right of patients to appropriate pain assessment and management,
- 2.) Assess pain in all patients
- 3.) Record the results of the assessment in a way that facilitates regular reassessment and follow-up;
- 4.) Educate relevant providers in pain assessment and management;
- 5.) Determine competency in pain assessment and management during the orientation of all new clinical staff;

- 6.) Establish policies and procedures that support appropriate prescriptions and/or medications orders;
 - 7.) Assure that pain does not interfere with participation in rehabilitation;
 - 8.) Educate patients and their families about the importance of effective pain management;
 - 9.) Include the need for symptom management in the discharge planning process;
 - 10.) Collect data to monitor the appropriateness and effectiveness of pain management.
- The goal for implementation of these standards is 2001, so theoretically these principles should be guiding the clinical management of patients with pain, and be documented as such. Each physician is obligated to maintain proficiency in pain management skills.

Pain is multi-factorial: Part of the frustration many clinicians may feel in dealing with pain management is that the patient's experience of pain is multi-factorial (Figure 16).(36) Patients often report pain as being physical that is from a variety of other sources, including depression, loss of social status or family role, anger, frustration with the healthcare system in general or the physician in particular, fear of death, fear of pain, and worry about family or finances. Failure to address these contributing factors inevitably results in lack of satisfaction with pain management from the patient's perspective, because perceived pain is not relieved. This is particularly likely become a problem when a patient has a history of "coping chemically" with psychosocial problems through alcohol or other drugs.(37)

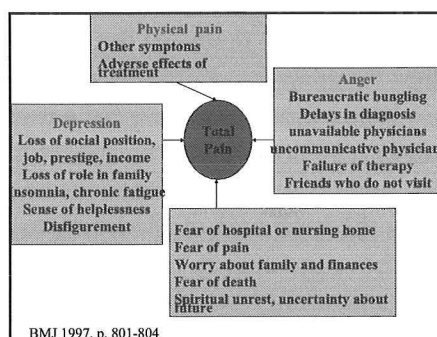


Figure 20

VI.) Social Issues: Although social issues are not traditionally considered the province of the physician, the care provider for dying patients ignores the social aspects of the patient's condition at his own peril. A broad range of social problems face Americans living with terminal illnesses, including concerns about care taking, financial burdens, site of care, advanced care planning, family well-being, and patient, physician, and family communication.(12;13;38-44) Having a physician simply listen to these concerns helps lessen the burden.(45)

A.) Care taking concerns: A need for assistance was reported by 86.8% of dying patients in one survey.(46) They required help with transportation (62.0%), homemaking services (55.%), nursing care (28.7%), and personal care (26.0%). Patients who are predominantly bed bound, or in pain, can use public transportation only with difficulty, and generally cannot keep up a house or prepare their own meals. This can prevent patients from picking up necessary medications, or maintaining adequate nutritional intake to tolerate therapy or allow for wound healing. These problems are particularly prevalent here in the United States, where people tend to live alone or in

couples, and have few family members around to help with these practical concerns.(5) Patients with substantial care needs were more likely to consider euthanasia or physician-assisted suicide. Caregivers of these patients were more likely to have depressive symptoms (31.4%) and to report that caring for the patients interfered with their lives (35.6%).

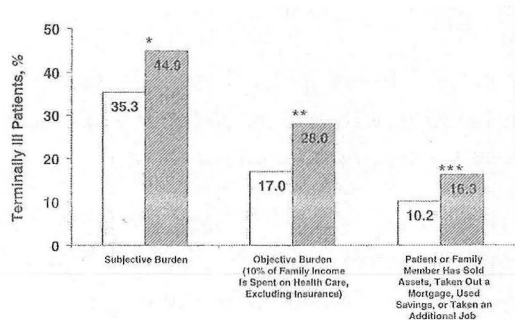


Figure 21

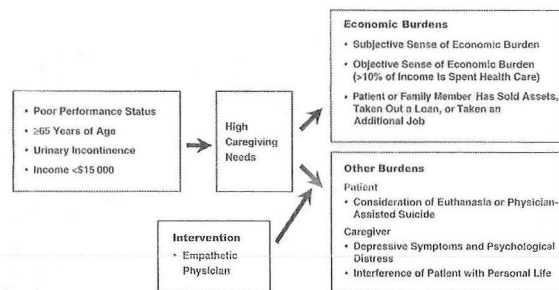


Figure 22

Figure 21: Effect of care needs and economic burdens on terminally ill patients. White bars indicate patients with few care needs; striped bars indicate patients with substantial care needs. * $p=0.005$; ** $p=0.001$, *** $p=0.004$.(45)

Figure 22: A model explaining a mechanism for economic and other burdens that terminal illness places on patients and caregivers.(45)

B.) Financial Concerns: The magnitude of the financial burden on families caring for a member with terminal illness is one of the most disturbing facets of end-of-life care, and anxiety regarding finances has a significant negative impact on quality of life for patients.(12;13;38;43) Many families caring for a member with terminal illness end up financially devastated(45): 20% of family members quit work to provide care, 31% lose their family savings, and 40% become impoverished (Figures 17,18).(45) Contributors to the problem are the high cost of medications, and loss of wage earner, either because the patient was the wage earner, or because the spouse must stop working. Many of the services that most commonly benefit dying persons, including maintenance physical therapy, spiritual counseling, pain management, in-home services, and family emotional support, are not regularly included in insurance benefits.(45) The situation may also be complicated by homelessness, lack of qualified caregiver, drug or alcohol addiction, or mental illness. Hospice is mostly available to adults with predictable solid cancers, homes, families with enough wealth to provide unpaid care indefinitely, and no treatment options to extend life. Ironically, ICU services would be covered under Medicare, but a home visit to treat constipation would not.(47)

Many of the financial problems are illustrated by a clinical case. D.D. is a 60-year-old man who is retired after a lifetime of work at an aluminum plant, which closed three years ago. He has a pension of \$1700/month, and lives at home with his wife. One day he comes down with severe back pain, and work-up reveals adenocarcinoma of unknown primary with metastases to bone. He declines to receive chemotherapy. He has no insurance, but would like to continue seeing a physician for end-of-life care. What are D.D.'s options?

- 1.) D.D. can apply for Medicaid, a federally funded, state-administered program to assist the medically indigent. However, because he gets too

much money from his pension (income cannot exceed \$500/mo), and owns his own house, he is not eligible.

- 2.) D.D. can apply for Medicare. He is not already enrolled, because he is not yet 65. Even if he has worked the requisite number of consecutive months in the past and is approved, there is a mandatory waiting period of five months before he can begin receiving his benefits (Social Security Disability check), and then a 24-month waiting period during which he has no healthcare coverage. Were he to survive that long, the cost of his medications would not be covered
- 3.) D.D.'s 60-year-old wife could go back to work. However, this would leave him home alone all day, and he is no longer well enough to get to and from the bathroom or feed himself without assistance. The family cannot afford to hire anyone to stay with him.
- 4.) D.D. can pay for his medications and services out of pocket until his resources are exhausted, and then apply for Medicaid.
- 5.) D.D. can seek all of his care from the Emergency Room, where he cannot be turned away.

While D.D. is in a particularly bad situation, many other patients suffer similar fates. A panel backed by the Institute of Medicine and the National Cancer Advisory Board said that federally funded health programs like Medicare and Medicaid “are not structured to allow for effective pain management for dying patients.”(48)

C.) Preference for Site of Care: Site of care, and site of death are other important social concerns. Despite the assertion by the majority of patients that they want to die at home, 75% of the patients in SUPPORT died in the hospital(4). There is wide national variation, though, in the rates of hospitalization at the end of life, sometimes resulting in a difference of up to sevenfold. This is not, as one would hope, the result of patient preference, but is largely determined by the availability of hospital beds in the area where the dying patient lives. In areas where there are more beds, patients are much more likely to die in the hospital.(49) This difference has been attributed to the lack of pressure to provide good outpatient care for patients when hospitalization for more marginal indications is considered profitable. It should be noted that many older patients (48%) state they would prefer to receive terminal care in the hospital.(50) In areas where these beds are not available, patients often end up in nursing homes. Residential hospices would be an excellent alternative if they were available.

D.) Advanced care planning is another important aspect of end-of-life care. Patients want their wishes for care to be respected, but often they are not, for a variety of reasons. The first, and most remediable, is that patients and physicians rarely communicate about the patients' wishes. SUPPORT revealed the following: 39% of patients reported discussing cardiopulmonary resuscitation with their physicians, 34% of those physicians acknowledged having received that information, and only 47% of the physicians whose patients wished to avoid CPR were aware of that wish.(4) Even more alarming is the news that physicians generally have opinions about the patient's wishes (regardless of communication on that subject with the patient) that correlate only weakly with actual preference.(51) Even if physicians and patients communicate about end-of-life preferences, the information must be documented somewhere easily accessible in order to be of use. Historically this has been especially problematic when patients are

transferred from one care setting to another. One attempt to solve this problem here in Texas is the Out-of-Hospital DNR form and bracelet. EMS must perform CPR on any person who is potentially salvageable, regardless of the patient's previously expressed wishes, unless they have a doctor's order to the contrary. The Out-of-Hospital DNR form serves this purpose, and can help prevent unwanted resuscitation for people who die at home. Happily, community-wide efforts increase awareness of Advance Directives (a list of the various Advanced Directives is included in Appendix B), and to improve the compliance of health professionals with them, have been very successful when they have been undertaken. In LaCrosse, WI, 85% of the entire population has written advance care plans, their wishes are clearly documented, and are respected by health care personnel.(52)

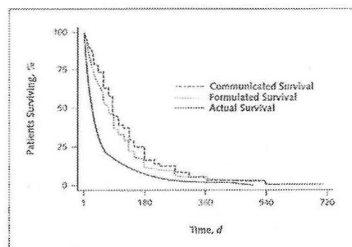
E.) Communication: The efforts in LaCrosse notwithstanding, the issue of advanced directives highlights the single biggest obstacle to good end-of-life care: poor communication. While physicians may feel they are doing a good job on this front, there is reason to suspect that the needs of patients to that end are not being met.(22;24;53) Patients and their spouses cite lack of information about what to expect, lack of personal control and inadequate or untimely information as their greatest sources of stress amongst patient, family, and physician.(38) The aspects of communication deemed important by patients were information about disease prognosis, feelings of being accepted and respected, and the ability to ask questions as desired and understand the answers.(38;39;41)

What is it patients want to know? They generally want to know about prognosis,(38;54-56) and left to their own devices, they are statistically likely to come up with a more optimistic estimate than even the physician.(57) Physicians also tend to give patients prognostic estimates that are more optimistic than their own (Figure 19),(58) perhaps altering their decision-making process.(59-62) Fortunately, evidence now suggests that patients do not need a specific estimate regarding the risks of death to make thoughtful decisions - they just need to understand that they are anything less than 90% likely to live for six months.(63) In one study, physicians commonly cited the differences in treatment expectations between family members, patients, and physicians as barriers to optimum care. Improved communication could theoretically ameliorate this problem.

Patients also want to know that they are accepted and respected by their health care providers, and that they are viewed as "whole" persons, rather than cases or diseases.(38) They also want to know that their physicians are communicating with each other. Unfortunately, interventions directed at improving communication skills amongst end-of-life care providers have not been very effective.(64) However, even patients who'd had difficulty communicating with previous care providers felt comfortable communicating with the Palliative Care team, suggesting that a multi-disciplinary environment may be more effective for addressing the wide range of patient concerns.(65)

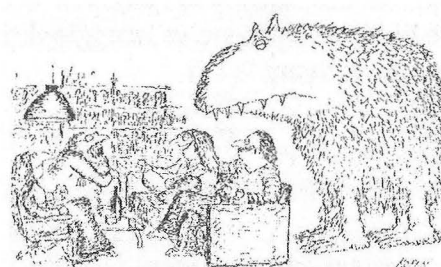
Patients also want to be able to communicate better with their families as they face the end of their lives. They want to be able to resolve issues that are unsettled, and find a sense of completion about their lives.(12;13) This can be very difficult for families or friends, who often feel that they should not let a patient talk about death, or do not feel comfortable discussing it themselves. There is a sense that the subject of death is

taboo.(66) The dying patient in Sunshine(67) wrote of this experience: " I think I have accepted death as well as anyone can. But what makes it hard is when I try to talk to people close to me and tell them what I'd like done - with Jill and Sam and my things. They refuse to listen and then I feel funny. It's such a hassle..." Solzhenitsyn refers in Cancer Ward to the way in which a man becomes barricaded away from his family and friends by his tumor:(68) "But in a few days this whole close-knit, ideal Rusanoff Family had receded until it had vanished on the other side of the tumor. No matter what happened to the father, they were alive and would go on living. No matter how they might worry, exhibit concern, or weep now, the tumor had divided him from them like a wall, and he remained alone on this side of it." Patients often feel an extraordinary sense of isolation as they contemplate the end of their lives. They want to be able to talk with someone about what dying will be like, or how things will be after they are gone, and generally it is not helpful for others to be discouraging of such conversation.(12)



The differences between actual survival, formulated survival, and communicated survival in 300 terminally ill patients with cancer are shown. The median actual survival was 20 days, the median formulated survival was 75 days, and the median communicated survival was 59 days.

Figure 23



"We deal with it by talking about it."

Figure 24

VII.) Psychological/Spiritual Issues: Existential sense of well being is just as important a predictor of the quality of life of cancer patients as was physical well being.(69) The major psychological stressors for patients facing terminal illness include changing family roles, physical decline with subsequent threat to psychological well being, sexuality, feelings of guilt associated with perceptions of being a burden, and communication difficulties.(38) Mood disorders are often present in cancer patients, transiently in about 1/3, and persistently in about 1/4, but they are not the norm.(70) Psychological interventions can be effective in reducing emotional distress, enhancing coping and improving adjustment.(71;72) For example, patients with breast cancer enrolled in cancer support groups lived, on average, 18 months longer than controls not enrolled in such a group.(73) Many patients report that coming to peace with God is a priority for them as they contemplate the end of life,(13) or that they need to achieve a sense of continuity with the world, spiritually or otherwise.(74)

Overall, the biomedical structure of our current care delivery system is generally inadequate to meet the psychosocial needs of the dying patient and his family.(44) However, even if we as caregivers were to approach every death as well as humanly possible, we would still encounter a number of difficulties. It is never going to be easy to help everyone through this process. This difficulty is a function of the very basic human desire not to be dead. For example, even among patients who estimated their own chance of survival as 25% or less, more than half still wanted attempted CPR. Bremnes, et al.

(1955) found that cancer patients are much more likely to want to take intensive chemotherapy, even if the potential for benefit is very small, than are doctors and nurses.(75) 33.5% of dying patients in SUPPORT preferred a course of therapy aimed at extending life and were at least somewhat willing to live the rest of their lives in pain.(26) A telephone survey found that 2/3 of the public and oncology patients believed that PAS or euthanasia was acceptable for patients in unremitting pain, but patients experiencing pain were less likely to endorse that belief.(76;77) As caregivers, and certainly as house officers, we are inclined to view this as irrational,(78) but just as millions of people everyday buy a lottery ticket with an infinitesimal chance of winning, when faced with the prospect of death, many will always choose to take their chances, even if that means undergoing what others may consider an inordinately burdensome course of treatment. Finucane, in a 1999 JAMA article writes, “A cornerstone of the relationship is to understand and respect a patient’s desire to fight to stay alive, even if treatment is burdensome, expensive, and unlikely to succeed...Encouragement, support, fidelity, and realism remain the cornerstones of good care. But even with this and with flawless technical proficiency in symptom management, patients, physicians, and family members are likely to continue to struggle through the decisions that must be made as gravely ill becomes dying.”(79)

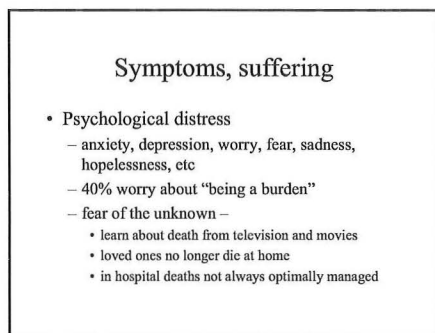


Figure 25

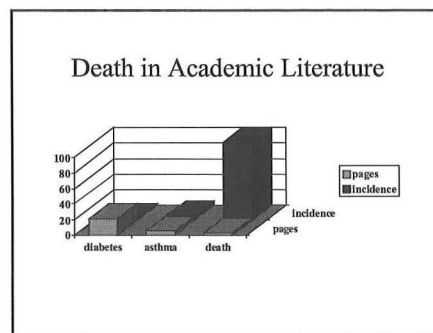


Figure 26

VIII.) Training: The vast majority of our training as physicians is about how to keep people alive. Dr. J. Cohen points out, in a 1997 editorial, that “Doctors have a hard time with death because of a traditional orientation to death as the evil enemy of good medicine. We are taught to be the guardians of life, not the ushers of death.”(1) However, given the incidence of death in our society (presently at 100% and holding steady), it seems prudent to address the ways in which we die, and how they can be made easier. Deficiencies are apparent on several levels: textbooks, medical schools, and residencies.

The incidence of diabetes in America right now is about 1.5%,(80) and that of asthma is about 5.6%.(81) If you look at the number of pages dedicated to each subject in Harrison’s Principles of Internal Medicine, 13th Ed., 21 pages are devoted to diabetes, three to asthma, and fewer than five to death and dying (Figure 26).(82) The discussion of death and dying there is limited to ethical questions rather than pathophysiology or symptom control for death from a particular process.(83) A representative statement regarding end-of-life care for a given condition is “supportive care is usually all that can be offered at this point” without a description of what that support would entail. Some

authors are so evasive on the subject of death that dead persons are referred to as “non-survivors.”(83;84) As a group, the textbooks with the highest percentages of absent content were in surgery (71.8%), infectious diseases and AIDS (70%), and oncology and hematology (61.9%). Textbooks with the highest percentage of helpful end-of-life care content were in family medicine (34.4%), geriatrics (34.4%), and psychiatry (29.6%) (Figure 27).(85)

Much of medicine is learned through clinical practice. However, the wards are not any more fertile a learning ground for end-of-life care than are textbooks. In fact, they may be a place where end-of-life care takes a giant step backwards, particularly in terms of attitudes toward patient care.(86-89) Anderson provides a palling anecdote from his experience with the death of his wife: "After having taken care of her every want and need for five years, I was forced out of the room a second after she died by an intern I had never seen before who wanted to be alone while he pronounced her dead."(90) The research of Billings and Block confirms that the atmosphere on the wards can be poisonous to students trying to learn about care for the dying: “Excellent preclinical teaching about end-of-life care is often ‘untaught’ during the clinical years. Studies of undergraduate medical education indicate that gains in humanistic attitudes and skills (attention to the patient's experience of illness, effective communication, awareness of the impact of psychosocial and spiritual factors on patients and families, appreciation of ethical issues, tolerance for diversity) in the first 2 years of medical school are regularly reversed during the last 2 years of school and in residency training.”(87) Many third-year students reported dissatisfaction with their actions and ethical development: 67% had felt bad or guilty about something they had done as clinical clerks; 62% believed that at least some of their ethical principles had been eroded or lost.(91)

Erosion of ethical principles is not the only problem. There is not adequate role modeling, or teaching of the medical principles of caring for the dying. In a 1998 survey of 162 fourth-year medical students at Georgetown, only 41% of students thought their education regarding end-of-life issues had been adequate, and 80% favored more education about end-of-life issues.(92) Role models are important in determining the extent to which students feel they have been adequately taught about end-of-life care, and yet a 1997 study showed that attendings were no more able than interns to make determinations about whether a patients were willing to undergo CPR, and how willing the patients were to live with possible outcomes such as chronic pain, and tube feedings.(93) Courses in end-of-life care are very popular when they are available, and have the benefits of reducing excess hopelessness about cancer, lowering of "death anxiety," and teaching communication skills. "A sense of aversion, helplessness, and hopelessness often pervades the management of terminal illness in the modern academic health center, reinforcing students' natural reluctance to come close to suffering."(87) A table listing the core competencies in end-of-life care that a student should obtain in the practical years is shown in Table 2.(94)

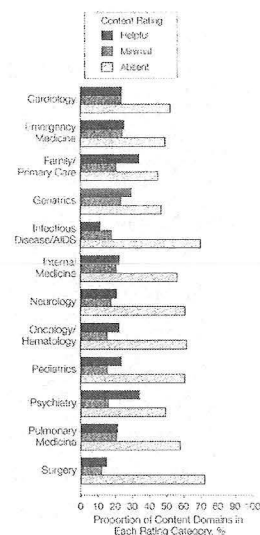


Figure 27: Helpful, Minimal, and Absent Content Scores for textbooks, arranged by specialty.(85)

End-of-life Care Skills and the Preclinical Curriculum	
The preclinical curriculum should enable all students to	
1. Understand the psychological, sociologic, cultural, and spiritual aspects of death and dying:	
a. suffering	
b. loss	
c. bereavement	
d. ritual and meaning at the end of life	
2. Develop basic interviewing and communication skills essential to end-of-life care:	
a. how to listen to the impact of illness on life	
b. how to explore hope, hopelessness, and fear	
c. how to discuss loss and grief	
d. how to discuss spiritual concerns	
3. Understand the pathophysiology and management of common symptoms at the end of life:	
a. pain	
b. shortness of breath	
c. dehydration	
d. depression	
4. Identify significant points of consensus and controversy in the ethical aspects of end-of-life care:	
a. withholding/withdrawing treatment, assisted suicide, and euthanasia	
b. pain management	
c. allocation of resources and access to high-quality palliative care	
d. non-abandonment of patients	
5. Improve their ability to reflect self-critically on their personal and professional experiences around death and loss:	
a. death in their personal experience	
b. views of the afterlife	
c. the goals of medicine	
d. the role of the doctor and the health care team in caring for the dying	

Table 2

IX.) The Root of the Problem

The data presented so far suggest that physicians are not treating pain, not communicating well with patients, and are failing to teach students and residents a better way of doing things. Physicians theoretically spend most of their lives communicating with patients in order to learn information that will allow them to help a patient with a problem. However, when it comes to end-of-life care, physicians tend to be profoundly avoidant, as do many other healthcare workers.(84)

Why do physicians have such a difficult time with dying patients? It is easy to blame shortcomings on a medical system that includes so much paperwork, so little time to talk to patients, and so little reimbursement for doing so. Certainly, this is a factor. Palliative Care services are very time consuming, and are not well reimbursed (if they are reimbursed at all).(48) Patients with complicated medical problems often have more than one provider, often at least a primary care provider and a specialist related to the disease that is limiting the length of life. This leaves each provider with the argument that discussion of end-of-life issues does not fall within his purview. For example, a cardiologist could easily argue that the primary care provider knows the patient better, and is better equipped to deal with the myriad social and psychological problems that accompany such a discussion. The primary care provider could argue that no one knows better than the cardiologist what is likely to happen in terms of disease progression, and how symptoms should be managed. Ultimately, the patient is sacrificed in the shifting of accountability.

However, even if the system is a problem, we are the ones who have allowed it to develop. Sandra Bertman writes, of this problem, "To the physician, dying patients

present threats on two counts: they are messengers of *memento more*, who remind the physician of personal annihilation; at the same time, they confront the physician with his or her own helplessness, with tangible proof of professional 'failure,' and the limitations of medicine." These ideas are borne out by research of physician attitudes toward caring for the dying. Physicians today often perceive a patient's death as a failure.(2) They report being frustrated by family dysfunction, significant pain or other symptoms, and the incurable, progressive nature of the patients' diseases,(95) and they tend to provide more extensive treatment to seriously ill patients than they would choose for themselves,(96) perhaps out a need to find something to do. A sense of personal loss and the sense of futility of medical treatment also precipitate negative feelings.(95) In short, dealing with dying patients makes physicians feel bad, and they generally avoid it. When Elisabeth Kubler-Ross was looking for patients to interview in preparation for her book On Death and Dying,(97) she was told that there were no dying patients in the hospital (further scrutiny revealed this statement inaccurate). However, when provided with adequate skills to meet the patient needs and to communicate effectively with the family, physicians felt good about the care they had provided.(95) The ACP-ASIM has endorsed a group of core principles (included in Appendix A) to encourage the development of skills for caring for dying patients. Hopefully, with the acquisition of the skills, physicians will feel more comfortable caring for patients at the end of life, and consequently care will be better.

X.) Conclusion

What are the most important tasks for physicians in helping to lessen the burden of dying for our patients? The challenge is not one simply of education, though lack of adequate information is a barrier to care, and every physician is obligated as a matter of professional competence to master the basics of pain management. We must also recognize that care for an illness alone is inferior to care for a multi-dimensional person living with illness, who faces social, psychological, and spiritual burdens that are unique. Finally, there must be a change in the culture of medicine, and part of the change must be introspection on the part of every physician as to his or her own goals of practice, and fears about the end of life. It is incumbent upon us to find a way to cope with our own fear of death, and frustration with perceived failure, so that we ourselves do not become obstacles to good care of our patients. Deborah Fahnestock, a social worker terminally ill with non-small cell lung cancer, wrote, "It is simply a matter of taking up a more priestly and simultaneously human mantle in extending care."(74) Many bemoan the loss of the physician-patient relationship as anything more than a fee for service business arrangement, but by combining the best elements of care from an older model of medicine with the extraordinary technical options available to us, we have an opportunity to reclaim one of the greatest rewards of medical practice - an intimate and caring relationship between two mortal and fallible people. Albert Schweitzer wrote, "It is our responsibility to remember that medicine is not only a science, but also the art of letting our own individuality interact with the individuality of the patient." The arena of end-of-life care provides us with the opportunity to provide optimal care by becoming the physicians we want to be.

A parting gift to my body:
just when it wishes,
I'll breathe my last.

**We must all die.
But that I can save...[someone] from
days of torture, that is what I feel is my
great and ever privilege.**

Albert Schweitzer

Appendix A:
Core Principles of End-of-Life Care
As Adopted by ACP-ASIM

- 1.) Respect the dignity of both patient and caregivers;
- 2.) Be sensitive to and respectful of the patient's and family's wishes
- 3.) Use the most appropriate measures that are consistent with patient choices;
- 4.) Make alleviation of pain and other physical symptoms a high priority;
- 5.) Recognize that good care for the dying person requires quality medical care, but also entails services that are family and community based to address, for example, psychological, social, and spiritual/religious problems;
- 6.) Make continuity of care a priority (that patient should be able to continue to be cared for, if so desired, by his/her primary care and specialist providers);
- 7.) Advocate access to therapies which are reasonably expected to improve the patient's quality of life, and provide that patients who choose alternative or nontraditional treatments not be abandoned.
- 8.) Advocate access to palliative care and hospice care;
- 9.) Respect the patients' right to refuse treatment as expressed by the patient or an authorized surrogate.
- 10.) Respect the physician's professional judgment and recommendations to discontinue some treatments when appropriate, with consideration for both patient and family preferences;
- 11.) Promote clinical and evidence-based research on providing care at the end-of-life.
- 12.) Recognize that although medical care has a critical role to play in supporting patient (and families) at the end-of-life, dying is fundamentally a profoundly personal experience and part of the life cycle.
- 13.) Encourage health care professionals to work within their care environment to help ensure the provision of quality care and accountability for performance.

Appendix B:
Definitions of Advanced Directives

- 1.) Directive to Physicians and Family or Surrogates (Living Will): A directive which authorizes withholding or withdrawal of life sustaining therapies from terminally ill adults. This directive is authorized by the Texas Advance Directives Act.
- 2.) Medical Power of Attorney: A directive which designates a third party to make health care decisions should the principal become incapable of making health care decisions. This directive is authorized by the Texas Advance Directives Act
- 3.) Declaration for Mental Health Treatment: A directive which allows a person to inform health care providers of the preferences and institutions regarding his/her mental health care treatment in the event s/he becomes incapable of making health care decisions. Declaration for Mental Health Treatment expires three years from the date it is signed. This directive is authorized by Texas Law, Senate Bill 972.
- 4.) Out-of-Hospital Do Not Resuscitate: A directive which allows a terminally ill patient to refuse cardiopulmonary resuscitation and instructs emergency medical personnel and other health care professionals not to initiate life sustaining measures. This directive is authorized by the Texas Advanced Directives Act.

Table 1: Changes in the last century.(5)

Figure 1: *The Goodman on his Deathbed* (1471), Anonymous. Woodcut. Illustration from German Bibliotheque des Arts Decoratifs, Paris. Blockbook edition of *Ars Moriendi*, Bibliotheque des Arts Decoratifs, Paris.

Figure 2: Detail of *AIDS Patient* (1989) Luis Cruz Azaceta. Acrylic on canvas, 48 X 36. Frumkin/Adams Gallery, New York.

Figure 3: Course of illness typical of cancer.(5)

Figure 4: Course of illness typical of CHF or COPD.(5)

Figure 5: Palliative Care

Figure 6: WHO definition of Palliative Care

Figure 7: Traditional and modified allocation of resources for dying patients.(36)

Figure 8: Sources of suffering, modified from (5)

Figure 9: Number of physical symptoms other than pain in dying patients at 4 weeks before death, and one week before death.(17)

Figure 10: WHO pain ladder(24)

Figure 11: "Death of a Critic." *Day by Day*. Robert Lowell (1977). Farrar, Straus, Giroux.

Figure 12: (New Yorker cartoon, "High as a kite..")

Figure 13: (Quotation from Albert Schweitzer)

Figure 14: (Quotation from Leo Tolstoy)

Figure 15: Inappropriate dosing of pain medication, on a prn basis. Peak levels are too high, cause side effects, and troughs are too low, allowing pain to occur between doses.(98)

Figure 16: Correct dosing of pain medications at regular intervals, so that a steady state develops keeping peaks and troughs within range to control pain without causing undue side effects.(98)

Figure 17: (Morrison et al, Pain ratings slide)

Figure 18: (Morrison et al, Discomfort ratings slide)

Figure 19: Factors associated with poor pain management. (35)

Figure 20: Elements contributing to the patient's experience of pain.(36)

Figure 21: Effect of care needs and economic burdens on terminally ill patients. White bars indicate patients with few care needs; striped bars indicate patients with substantial care needs. * $p=0.005$; ** $p=0.001$, *** $p=0.004$.(45)

Figure 22: A model explaining a mechanism for economic and other burdens that terminal illness places on patients and caregivers.(45)

Figure 23: Relationship between communicated, formulated, and actual survival in 300 terminally ill patients. Median actual survival=26 days, median prognosis as formulated by M.D. = 75 days, and median prognosis communicated to patient = 90 days.(58)

Figure 24: Drawing by Edward Koren (1975). The New Yorker Magazine, Inc., New York.

Figure 25: Psychological distress.(5)

Figure 26: Incidence of Diabetes, Asthma, and Death and Dying in America, and number of pages devoted to each in Harrison's Principles of Internal Medicine, 13th Ed.

Figure 27: Helpful, Minimal, and Absent Content Scores for textbooks, arranged by specialty.(85)

Table 2: End-of-life Care skills for students.(94)

Figure 28: (Quote from Albert Schweitzer – we must all die...)

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