

End-of-Life Care

Summary: This project examines the care provided at the end of life, with special emphasis on the practices in intensive care units and related to euthanasia and physician-assisted suicide.

Section: Ethics and Health Policy— Unit on Bedside Ethics

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Background: Over the last few decades, one of the central areas of bioethics research has been end of life care. The issues raise concerns about respect for patient autonomy, the nature of the physician patient relationship, the use of scarce medical resources, and defining what constitutes optimal health care.

The general perception has been that the dying process is over medicalized with excessive emphasis on high technology interventions. A series of court cases and state laws regarding terminating life sustaining treatments,

advance care directives, and proxy decision makers throughout the late 1970s and 1980s have made it clear that terminating care is ethical and legal. Over this period the medical profession became much more comfortable stopping respirators, withholding cardio-pulmonary resuscitation and other interventions. This change led to several important developments in the early 1990s. First, despite changes in attitudes and practices, there was still a perception that care for the dying was less than optimal. Many patients were still dying in the hospital; many were still experiencing pain and other symptoms; hospice was underutilized. Despite much research there was still a narrow focus in considerations of death and dying. High technology interventions, the intensive care unit, pain of the dying process were heavily emphasized, but there was a lack of understanding about the full experience of patients and their caregivers. Besides pain and other physical symptoms, we hardly knew what were the experiences of patients and their caregivers. Further, much of the available data was from cancer patients; there was very little known about the experience of patients dying from other terminal diseases.

Many people thought there was important need to change “the culture of death.” It was felt that more could be done by the medical profession to improve care of dying patients. While willingness to stop life-sustaining treatments was an important advance, optimal end of life care required more of doctors. One challenge was to define what changes in practices were needed and how to train physicians in this area.

Simultaneously, having secured the right to terminate life sustaining care, especially with the Supreme Court’s ruling in *Cruzan*, some began advocating the legalization of euthanasia and/or physician-assisted suicide. Throughout the 1990s euthanasia and physician-assisted suicide became highly controversial topics of medical practice. In this debate, many claims assumed certain empirical facts, such as what motivates requests for euthanasia or physician-assisted suicide, how frequently requests are made, and the effect of performing these interventions on physicians and families. Despite the many claims, there was woefully little data about attitudes and practices toward euthanasia and physician-assisted suicide.

Most of this research was initiate prior to the researchers arrival at the NIH although certain aspects have been explored further at the NIH. We report here all the work that has been published while the investigators have been at the NIH.

Objectives:

- 1) To define and empirically characterize the full range of patient and caregiver experiences at the end of life.
- 2) To define the optimal role of palliative care in the care of dying patients, especially hospitalized and research patients.

- 3) To define attitudes and practices toward euthanasia or physician-assisted suicide of terminally ill patients, physicians who might be called upon to perform these interventions, and the public.
- 4) To identify predictors of the attitudes and practices toward euthanasia or physician-assisted suicide.

Methodology: There were a number of empirical studies that began prior to the researchers arrival at the NIH that were utilized to address these objectives. The first was the Commonwealth-Cumming Project that aimed at developing a comprehensive characterization of the experience of patients and their primary caregivers at the end of life. In order to develop an appropriate survey instrument both reflection on the full dimensions of end of life care and focus groups were utilized to define the appropriate domains. A survey instrument was developed in conjunction with National Opinion Research Center (NORC, Chicago) that covered: 1) physical symptoms; 2) psychological symptoms; 3) social supports; 4) communication; 5) spirituality; 6) need of assistance; 7) end of life care plans; 8) economic burdens; and 9) attitudes and plans regarding euthanasia and physician-assisted suicide. The goal was to interview a representative sample of terminally ill patients. To obtain a sample it was decided that physicians would be asked to identify such patients, as many terminally ill patients are not hospitalized at the end of life and physician identification is the routine in clinical practice, such as hospice referral. Five sites were randomly identified from the 4 Census regions—4 urban areas and one rural county: Birmingham, AL; Brooklyn, N.Y.; Mesa County, CO; St. Louis, MO; Tucson, AZ; and Worcester, MA. Within these sites physicians were recruited to identify terminally ill patients defined as those who in their view had less than 6 months to live. Patients were contacted and an interview was requested; the patients were asked to identify their primary caregiver who was also interviewed. A total of 988 patients were interviewed (response rate 87.4%) and 893 caregivers (response rate 97.6%). If a patient died, the caregiver was reinterviewed (256, response rate 90.5%); if a patient did not die he or she was reinterviewed after 2-6 months (650, response rate 95.3%).

The second was a survey conducted for the American Society of Clinical Oncology of their membership which constitutes about 85% of all oncologists in the United States regarding their end of life care practices, with special emphasis on practices of euthanasia and physician-assisted suicide. The survey was developed in conjunction with the Center for Survey Research (CSR, Boston) and covered 8 domains including training in end-of-life care, experience in end-of-life care, scenarios, and attitudes and experiences with euthanasia and physician-assisted suicide.

In addition to surveys, there have been both critical literature reviews and development of consensus statements. The critical literature reviews entailed systematic reviews of all articles found through Medline searches to assess the

validity of their conclusions. Consensus development involved the modified use of the elements of the nominal group process. First, group participants list their ideas with comment from others, then a group discussion of the listed ideas is conducted to clarify and evaluate them. The ideas are then organized to inform a draft statement. The draft statement is then criticized and revised multiple times.

Results: In trying to develop the survey instrument to comprehensively assess the experiences of dying patients, it became clear that too much focus has been placed on pain. Through focus groups and thinking, it became clear that the important aspects of the experience were more diverse. A consequence is the development one of the first frameworks for defining the important domains of the dying experience. The six domains are: 1) physical symptoms; 2) psychological symptoms; 3) social relationships and support; 4) economic demands and caregiving needs; 5) hopes and expectations; and 6) spiritual and existential beliefs. Once specified, these domains appear obvious, yet when first delineated they were not clear.

The Commonwealth-Cummings project sought to evaluate patient experiences in each of these domains and has produced important data. One of the more important contributions focuses on the caregiving and economic burdens at the end-of-life. Among the important findings, it demonstrated that about one third had substantial need for care, including:

	Transportation	Nursing	Homemaking	Personal
Needed a lot or moderate amount of help	62.0%	28.7%	55.2%	26.0%
Had unmet needs	NA	18.2%	23.1%	NA
Care provided by family and friends	76.8%	42.4%	66.3%	50.3%
Care provided by paid caregivers only	9.5%	24.2%	12.9%	27.9%

Overall, nearly three quarter of all family and friend caregivers were females. Similarly, we found that patients with terminal illnesses other than cancer had more substantial needs for care and more unmet care needs than terminally ill cancer patients.

We also found that high caregiving needs were associated with greater economic burdens, subjectively and objectively in spending more income on health care. Furthermore, the high caregiving needs led to greater caregiver depression and psychological distress and a sense that the patient was interfering with the caregiver’s personal life. Empathetic physicians were seen to reduce these psychological stressors.

The Commonwealth-Cummings study also demonstrated important facts about euthanasia and physician-assisted suicide. Overall, 10.6% of terminally ill patients seriously considered euthanasia or physician-assisted suicide for themselves. Among predictors African-Americans and the elderly were less likely to consider these interventions, while patients with depressive symptoms and substantial caregiving needs were more likely to consider them. However, patients, especially those with depressive symptoms, were more likely to change their minds. Overall we found that 5.6% of patients had discussed asking the physician for euthanasia or physician-assisted suicide, 2.5% had hoarded drugs for suicide and just one patient (0.4%) had died by euthanasia or physician-assisted suicide although 1 other had unsuccessfully attempted suicide and 1 had repeatedly requested it but her family and physicians refused.

The survey of oncologists demonstrated that support for euthanasia and physician-assisted suicide among oncologists had declined substantially between 1994 and 1998. Furthermore, the data demonstrated that physicians who were opposed to euthanasia and physician-assisted suicide were less likely to prescribe opioids for pain management probably because they were worried this might be considered euthanasia if the patient died. Indeed, overall physicians who had received better end of life care were less likely to perform euthanasia or physician assisted suicide. Finally, the data suggested that there was some link between physicians' inability to obtain optimal care for their patients and their willingness to perform euthanasia and physician-assisted suicide.

In addition, to these original empirical studies, Dr. Emanuel has assembled comprehensive reviews of all the empirical data on euthanasia and physician-assisted suicide and interpreted these data in light of the public debates in a number of fora.

The Department has been among the leaders in describing proper role of palliative care in care of terminally ill patients especially those in the intensive care unit and terminally ill patients who enroll in research studies. While there was once thought to be a clear distinction between The basic argument is that the old distinctions between quality and quantity of life and between the critically and terminally ill are false. All extensions of life should aim for optimal quality. Therefore, palliative care should not be mutually exclusive with life extending interventions, care in the intensive care unit, or research on life-extending treatments. It is more important to emphasize palliative care regardless of the aggressiveness of the medical interventions to prolong life. Palliative care needs to be integral to all aspects of caring for patients.

Along with symptom management, communication of preferences and goals of care are necessary ingredients of all critically ill patients. Using strategies that are considered ideal teaching methods of adult learners, the department has published a set of principles, knowledge, attitudes and skills that

should be taught to foster ideal end-of-life care in the intensive care unit. Strategies for overcoming barriers to optimal care in the ICU are also suggested.

Future Directions: In collaboration with other investigators funded by the Robert Wood Johnson Foundation's Program on Excellence in End-of-Life Care, on-going studies will include 1) surveys of nursing and medical leadership of intensive care units to determine the existing barriers to providing optimal end of life care and 2) developing standard administrative policies and patient chart forms that will improve end of life care in the intensive care unit. The projects related to euthanasia and physician-assisted suicide are largely legacy projects. While a few additional papers will be appearing from these research projects, and some commentaries may arise, these are areas of research that in general the Department has decided not to pursue further.

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