IMPROVING END OF LIFE CARE

WHY HAS IT BEEN SO DIFFICULT?

A Summary of a Special Report Produced for the *Hastings Center Report**

Introduction

The public spectacle unleashed over the medical treatment of Terri Schiavo exposed a serious divide in the way the American people currently view end of life care. Despite 30 years of litigation, laws, and efforts by a range of groups to improve treatment for those near death, too many Americans still receive poor care at life's end and are dying "bad" deaths without adequate palliative care or dignity.

Further progress in improving care for those near the end of life will not hinge on the enactment of new laws or implementation of new regulations. If anything, end of life reform has been excessively driven by law. And current laws do not need to be abandoned. These laws will work if allowed to, says a new report from The Hastings Center, "Improving End of Life Care: Why Has It Been So Difficult?"

Litigation has significant limits as an instrument of systematic social change. While it would be naïve to advocate that litigation not continue, we must try to use other means of social change.

—University of Pittsburgh Law Professor Alan Meisel, "The Role of Litigation in End of Life Care: A Reappraisal"

A New Model of Care

What is needed, according to the report, is a new paradigm for improving end of life decision-making and care delivery that puts less emphasis on the specific medical decisions concerning the individual dying patient and instead fosters shared decision-making and communication among patients and loved ones. This new collective approach toward end of life care decision-making embraces the reality that people die as they live—in a web of complex relationships.

The argument is that care for dying people would greatly improve under a system that considers the values and needs of patients but also focuses on strengthening the ability of families and providers to be more effective decision-makers—especially for people, like the late Ms. Schiavo, who have lost the capacity to decide for themselves. In the future, the emphasis should be on promoting a system of care that offers much better coordination of services, treatment planning, and continuity of care and that sets parameters for better family dynamics and decision-making around end of life care issues.

The 60-page report, a supplement to the November/December 2005 issue of the *Hastings Center Report*, is a collection of 10 essays by some of the nation's leading experts, many of whom helped to shape the current ethical and legal framework for end of life care. In this issue, leaders in the progress that has been made over the past two decades take stock of what they have wrought, provide a candid assessment of its shortcomings, and begin to chart a course for the future [see attached descriptions].

*Bruce Jennings, Gregory E. Kaebnick, and Thomas H. Murray, eds., "Improving End of Life Care: Why Has It Been So Difficult?" *Hastings Center Report* vol. 35, no. 6, special report (2005).

The report is supported with a grant from the Robert Wood Johnson Foundation, which also funded the landmark SUPPORT study, the largest study ever conducted on how people die in large hospitals. Published in 1995, it exposed the alarming extent to which aggressive life-prolonging measures were still being used in medically futile situations or when unwanted by patients.

The report showcases the most important and influential developments in end of life care since 1976, and particularly since the 1990s. In its essays, medical, legal, ethics, and disability rights experts reflect on the state of care for the dying today and offer improved approaches for the future related to advance directives, palliative care, litigation, personal autonomy, health system reform, disability rights, and cultural and personal attitudes.

Applying the autonomy framework in end of life decisionmaking has had little practical effect and much fictitious posturing. Efforts to persuade people to execute advance directives to protect their autonomy if they should become incompetent have essentially failed.

—Yale University Law Professor Robert Burt, "The End of Autonomy"

Have We Made Progress?

Despite persistent problems, there has been significant progress made in end of life care over the past 25-30 years. The report notes, for example, that:

- today, people have much more control of their medical care at the end of life;
- palliative care is embraced and recognized as a medical specialty;
- about half of those who die each year receive hospice services for at least a brief period before death;
- roughly three-quarters of all deaths in hospitals come after an explicit decision has been made to forgo the use of a potentially life-prolonging intervention; and
- today, many people die without suffering unnecessary pain and are surrounded by friends and family in a setting that addresses their spiritual, emotional, and physical needs.

But this progress, and the individual rights upon which it is based, are in jeopardy. The political support for a framework of principles for end of life care decision-making built by the courts, the legislatures, and among providers and ethicists has not been universally embraced, and in fact is eroding. The authors call for a re-examination of assumptions linked with end of life care about autonomy, quality of life, trust, family dynamics, and the motivations of professionals and lay people. The 10 essays offer suggestions about how to bridge the gap between the legal and ethical framework of end of life care now widely but not universally embraced and the real world of decision-making and care that happens on the ground.

Only a minority—20-30 percent—of American adults have advance directives, and these have had limited effects on treatment decisions near the end of life.

There are many reasons why, including:

- **low completion rate,**
- **lack of clear understanding of the language related to end of life wishes,**
- **too much focus on autonomous decisionmaking, and**
- **no systematic effort to reopen discussions after a person's health declines.**

Overcoming the Challenges

Most people would rather not stare death in the face—especially their own death. Even those with life-limiting illnesses resist enrolling in hospice programs until very late in the game because it feels like they are relinquishing hope. Despite efforts to raise public awareness, only a small number of Americans have chosen to execute advance directives. And many of those that have done so have failed to provide their health proxy or family with enough clarity about their wishes or values to offer guidance. Even when advance planning is in place, it is not always followed by the health care proxy or physician(s) in charge of the case.

Key Elements of Successful Advance Directive Programs

1) A facilitated ACP process
2) Documentation
3) Timing of discussion
4) Systems and processes

What challenges need to be overcome to improve the current system of end of life care?

■ **Build a Better System.** More emphasis should be placed on educating and motivating health professionals and building an effective end of life care approach so that, as Dr. Joanne Lynn says, "just about the right things will happen for patients because they are 'built into the system' and are part of the expected pattern." An effective restructuring of end of life care, she says, would be to develop better continuity of delivery that addresses a broader population of patients for a longer period of time before death. This would serve people who end up dying after some years, as well as those who die soon after their diagnosis.

■ **Cast a Wider Net to Reach Consensus.** Advocates and policy-makers need to reach across color, class, disability, and religious beliefs to create a new consensus on end of life care that acknowledges feelings of mistrust, feelings of exclusion, and lived experiences of unequal treatment. A larger circle of people and a broader conversation are needed to continue improvements in end of life care and to protect it from potential bias and distortion. One example is offered by author Adrienne Asch, who notes that our approach to advance directives may be biased against the value and quality of living with disability and suggests that advance directive forms should be revamped.

■ **Recognize the Collective Responsibility of Deciding the Course of End of Life Care.** We need to rebuild, reinforce, and reinterpret laws, institutions, and practices to recognize that dying is an interpersonal affair that does not occur in isolation. Hospice already does this effectively by creating space for family and friends to be close to the dying person. Durable power of attorney strategies, too, can reflect the dying person's concerns for those whose lives will be affected by his or her death.

Charting a New Course

Given these challenges, what specific steps can be taken to put end of life care on a new and better course? The report highlights three areas of focus:

➔ improve the approach to end of life delivery systems;

➔ improve the approach to advance directives and surrogate decision-making; and

➔ improve the approach to managing conflict and disagreement.

1. Approach end of life care from a more collective perspective that is less individualistic and more family oriented. Instead of focusing on how to accommodate the idiosyncratic decisions of individual patients one at a time, address the needs dying persons generally have and design a system that will meet most of those needs for most people most of the time. In recent years, hospice has provided this kind of system.

Mediation is especially suited to conflicts at the end of life because time is of the essence and deciding not to reach a decision is not an option. . . . Mediation is the route that best respects differences in the cultures of patients, families, and health care providers.

—Nancy Dubler, Montefiore Medical Center, NYC, "Conflict and Consensus at the End of Life"

2. Re-evaluate advance directives and surrogate decision-making to more adequately and routinely factor in information that physicians are comfortable with. As Susan Hickman and colleagues suggest, there are many clinical models to draw from that promote staff education and advance care planning; delineate clearly defined roles and expectations of physicians; train advance care planning facilitators; and promote solid documentation of patient wishes. Quality improvement also is a critical component of these models. There should be a new focus on education, counseling, and other support for health care agents and family members to help them make better decisions on behalf of the dying patient.

3. Bioethics mediation and conflict resolution services, including pastoral counseling, should be provided by all health care institutions. Author Nancy Dubler argues that the majority of end of life conflicts could be avoided through use of medical mediators, who are uniquely suited to solving these kinds of disputes. One model cited by Dubler is the program at Montefiore Medical Center in New York City.

Conclusion

Although death is inevitable, dying badly is not. For end of life care to improve, there will need to be a steady investment in public education campaigns that engage communities and spur discussions at the family dinner table and within health care institutions about how to build an effective system of care that recognizes the broad social network that most people connect to. It is clear that the system of decision-making and care delivery near the end of life needs to be redesigned. Over the next years, the debate will need to shift away from a focus on process and procedure to a more serious and frank discussion about what to decide, not just how to go about deciding.

Successful AD Models That Ensure Treatment Wishes Are Known and Honored

- Five Wishes – www.agingwithdignity.org
- Let Me Decide – www.newgrangepress.com
- Respecting Choices – http://www.gundersenlutheran.com/eolprograms
- Physician Orders for Life-Sustaining Treatment – www.polst.org

Source: Hickman, Hammes, Moss, Tolle, "Hope for the Future: Achieving the Original Intent of Advance Directives"

Electronic copies of "**Improving End of Life Care: Why Has It Been So Difficult?**" may be downloaded from The Hastings Center website at: http://www.thehastingscenter.org/research/healthcarepolicy8.asp.

Individual print copies may be ordered by writing to: Publications Department, The Hastings Center, 21 Malcolm Gordon Road, Garrison, NY, 10524; e-mail: publications@thehastingscenter.org.