Panel III:
Special People-Special Issues
SYMPOSIUM: Freedom of Choice at the End of Life
Panel III: “Special People, Special Issues”

2:15 – 2:20 ... Sue Porter: Welcome, introduction of panelists and format.

2:22 – 2:37 ... Alicia Ouellette: *Disability rights and why this has been a difficult issue.*

2:39 – 3:04 ... Carl Koenigsmann: *Health services in correctional institutions; DNR’s and Proxies.*

3:06 – 3:11 ... Brian Fischer: *Medical parole and providing medical and non-medical needs.*


3:30 - 3:45 ... Martha Jacobs: *Religious traditions regarding the overall sense of end-of-life issues; there isn’t one stance.*

3:47 – 4:15 ... Sue Porter: Moderate Q & A and wrap-up.
Brian Fischer
END OF LIFE SYMPOSIUM

- THE DIANE ABBEY LAW CENTER FOR CHILDREN AND FAMILIES, JUSTICE ACTION CENTER AND THE NEW YORK LAW SCHOOL LAW REVIEW

- PRISON MANAGEMENT ISSUES

- NOVEMBER 16, 2012
PRISON MANAGEMENT ISSUES

- **LIFE WITHOUT PAROLE**
  - SENTENCED TO LIFE WITHOUT THE OPTION OF RELEASE

- **MEDICAL PAROLE**
  - RELEASE BASED ON MEDICAL CONDITION

- **MANAGEMENT CONCERNS**
  - PROVIDING MEDICAL AND NON-MEDICAL NEEDS
DEMOGRAPHICAL CHARACTERISTICS

AGE AT TIME OF CRIME / MURDER

- 16-18: 10
- 19-20: 29
- 21-29: 83
- 30-39: 80
- 40-49: 30
- 50+: 8
# Life Without Parole

## Demographical Characteristics

- **Male (232) / Female = 8**

### Ethnicity

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LIFE WITHOUT PAROLE

DEMOGRAPHICAL CHARACTERISTICS

CURRENT AGE (1/1/12)
- 21 - 29: 25
- 30 - 39: 96
- 40 - 49: 84
- 50-59: 26
- 60+: 9
Medical Parole

- The Board of Parole Authority

- Terminally ill by reason of physical disease, condition or syndrome

- Non-terminally ill if so debilitated that they are either physically or cognitively incapable of presenting any danger to society
Case of B.D.

- Sentenced 8 & 1/2 to 10 years
- Earliest release 1/2018
- 52 year old, African American male
- Terminal gastric cancer
- Requires assistance with all ADL functions
- Requires frequent hospitalizations
- Confined to prison hospice unit
- 30 year crime history; New York, New Jersey, Alabama
  - Arson, Robbery, DWI,
Case of W.R.
Sentenced 12 to Life
Earliest release 1/2014
41 year old, African American male
Multiple sclerosis and diabetes
Needs institutional assistance with basic living needs
Cognitive condition: paranoid schizophrenic
Repeat offender; robbery, attempted murder, assault
MANAGEMENT CONCERNS

- MEANINGFUL PROGRAMS
  - MEDICAL
  - MENTAL HEALTH
  - EDUCATION
  - VOCATIONAL

- DAILY LIVING AND ACTIVITY
  - FAMILY RELATIONSHIPS
  - QUALITY OF LIFE
Reverend Dr. Martha R. Jacobs
Freedom of Choice at the End of Life:

Patients’ Rights in a Shifting Legal and Political Landscape
Special People, Special Issues

Rev. Dr. Martha R. Jacobs, BCC
Various religious traditions
versus
those who follow those traditions
- there isn’t one stance
In end-of-life care, religion and religious traditions serve two primary functions:

- the provision of a set of core beliefs about life events;
- the establishment of an ethical foundation for clinical decision making.

Placing Religion and Spirituality in End-of-Life Care, Daaleman & VandeCreek,
*JAMA.* 2000;284(19):2514-2517
“The goal of a quality comfortable death is achieved by meeting a patient’s physical needs and attending to the social, psychological and now recognized spiritual and religious dimensions of care.”

Placing Religion and Spirituality in End-of-Life Care, Daaleman & VandeCreek, JAMA. 2000;284(19):2514-2517
Dynamics of human life and the human condition and belief system of each person affects how they make decisions and whether or not they understand the tenets of their religious tradition.
Three religious traditions have actively participated in the public discourse about issues that accompany end of life e.g. palliative care, advanced life support and advance care planning:

- National Conference of Catholic Bishops
- Unitarian Universalist General Assembly
- Judaic Views
- United Church of Christ
National Conference of Catholic Bishops

*Ethical and Religious Directives for Catholic Health Care Services*

(5th Edition published in 2009)
USCCB Committee on Doctrine and Committee on Pro-Life
Activities regarding The Holy See’s Responses on Nutrition and Hydration for Patients in a “Vegetative State”

1) Patients who are in a “vegetative state” are still living human beings with inherent dignity, deserving the same basic care as other patients; and

2) nutrition and hydration, even when provided with artificial assistance, is generally part of that normal care owed to patients in this state, along with other basic necessities such as the provision of warmth and cleanliness.
“The Church has long taught that one is not obliged to employ extraordinary or disproportionate means to preserve one’s life.”

BUT, “for modern societies with advanced medical services the administration of nutrition and hydration by artificial means to patients in a “vegetative state” who need such assistance to survive is generally neither extraordinary nor disproportionate.”
There are medical situations in which it is moral to withhold nutrition and hydration. “For example, a patient in the last stages of stomach cancer is already dying from that condition. Such a dying patient, or others who can speak for the patient, may decide to refuse further feeding because it causes pain and gives little benefit.
The administration of nutrition and hydration in this case would pose a burden on the stomach cancer patient that is disproportionate to its benefit. By contrast, the “vegetative state” is not in itself a case of imminent dying, and the reception of nutrition and hydration itself does not generally constitute a burden for him or her.”
There are also possible cases when it would be moral to withhold or withdraw nutrition and hydration from the patient in a “vegetative state.” “They could be withheld if the available means for administering nutrition and hydration were not effective in providing the patient with nourishment...
(for example, because the patient can no longer assimilate these), or if the means itself constituted a burden (for example, because the feeding tube is for some reason causing persistent infections).”

http://www.uua.org/statements/statements/14486.shtml
“Guided by our belief as Unitarian Universalists that human life has inherent dignity, which may be compromised when life is extended beyond the will or ability of a person to sustain that dignity and
believing that it is every person's inviolable right to determine in advance the course of action to be taken in the event that there is no reasonable expectation of recovery from extreme physical or mental disability; and
WHEREAS, medical knowledge and technology make possible the mechanical prolongation of life; and

WHEREAS, such prolongation may cause unnecessary suffering and/or loss of dignity while providing little or nothing of benefit to the individual; and

WHEREAS, such procedures have an impact upon a health-care system in which services are limited and are inequitably distributed;
WHEREAS, differences exist among people over religious, moral, and legal implications of administering aid in dying when an individual of sound mind has voluntarily asked for such aid; and

WHEREAS, obstacles exist within our society against providing support for an individual's declared wish to die; and

WHEREAS, many counselors, clergy, and health-care personnel value prolongation of life regardless of the quality of life or will to live;
THEREFORE BE IT RESOLVED: That the Unitarian Universalist Association calls upon its congregations and individual Unitarian Universalists to examine attitudes and practices in our society relative to the ending of life, as well as those in other countries and cultures; and
BE IT FURTHER RESOLVED: That Unitarian Universalists reaffirm their support for the Living Will, as declared in a 1978 resolution of the General Assembly, declare support for the Durable Power of Attorney for Health Care, and seek assurance that both instruments will be honored; and
BE IT FURTHER RESOLVED: That Unitarian Universalists advocate the right to self-determination in dying, and the release from civil or criminal penalties of those who, under proper safeguards, act to honor the right of terminally ill patients to select the time of their own deaths; and

BE IT FURTHER RESOLVED: That Unitarian Universalists advocate safeguards against abuses by those who would hasten death contrary to an individual's desires; and
BE IT FINALLY RESOLVED: That Unitarian Universalists, acting through their congregations, memorial societies, and appropriate organizations, inform and petition legislators to support legislation that will create legal protection for the right to die with dignity, *in accordance with one's own choice.*
Judaic Perspectives

*Bioethics for clinicians: 22. Jewish bioethics*
Gary Goldsand, Zahava R.S. Rosenberg, Michael Gordon
“Jewish bioethics in the contemporary era emerges from the traditional practice of applying principles of Jewish law (*Halacha*) to ethical dilemmas. The Bible (written law) and the *Talmud* (oral law) are the foundational texts on which such deliberations are based.

*Interpretation* of passages in these texts attempts to identify the duties of physicians, patients and families faced with difficult health care decisions.
Jewish law is an integral consideration of religiously observant Jews; secularized Jewish patients often welcome the wisdom of their tradition when considering treatment options.

“Jewish bioethics exemplifies how an ethical system based on duties may differ from the secular rights-based model prevalent in North American society.”
“Jewish bioethical inquiry appeals to the principles found in Jewish scriptures and commentaries and applies them to clinical decision-making. In doing so, it takes a duty-based approach rather than the predominately rights-based approach characteristic of contemporary secular bioethics.”
Bioethical questions are treated by Jewish bioethicists in a variety of ways, which reflects different orientations toward Judaism and degrees of strictness in the interpretation of Talmudic texts and cases.
“Pioneering work in contemporary Jewish medical ethics in the 1960s and 1970s came primarily from Orthodox Judaism, in which the authority of God, as expressed through the Torah and Talmud, underlies the deliberative process. Much Jewish bioethics literature comes from this perspective, which assumes that, through the proper *interpretation* of Talmudic texts and commentaries, answers to the most difficult questions can be discovered.”
In practice, the rabbi whose opinion is sought for an ethical answer serves as an “expert counselor” to physician and patient, interpreting Halachic law for the situation in question.

Inspired by these Orthodox sources, Jews from the more liberal Reform and Conservative movements have used interpretative methods and texts that are basically the same, but “their rulings are often more flexible than those provided by Orthodox rabbis.”
United Church of Christ

- People need to be informed to make their own decisions – education is best approach
- Between them and God
- Must be mindful of those who feel that a slippery slope will develop if Physician Aid in Dying is legalized
Various religious traditions versus those who follow those traditions - there isn’t one stance
Can conservative theological values co-exist with patient choice?

- Some people will rely on their religious “authority”
- Others will rely on their conscience and what they believe their loved one would want.
- Why it is so important for people to talk about how they want their body treated as they near the end of their life.
- Ultimately – it will be between the person and their God.
Resources:

Appendix 2  - “Denominational Links to End-of-Life issues and Other Denominational Resources”
Website: www.aclergyguidetoendoflifeissues.com

Resources:


Placing Religion and Spirituality in End-of-Life Care
Timothy P. Daaleman; Larry VandeCreek

http://jama.ama-assn.org/cgi/content/full/284/19/2514

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Placing Religion and Spirituality in End-of-Life Care

Timothy P. Daaleman, DO
Larry VandeCreek, DMin

In 1995, the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) trial stimulated a reexamination of systems of care for seriously ill and dying patients. This study has accelerated efforts to improve end-of-life care and has indirectly promoted a rapprochement among religion, spirituality, medicine, and health care. The goal of a quality comfortable death is achieved by meeting a patient’s physical needs and by attending to the social, psychological, and the now recognized spiritual and religious dimensions of care. This perspective is highlighted in a recent consensus statement that includes the assessment and support of spiritual and religious well-being and management of spiritual and religious problems as core principles of professional practice and care at the end of life. Yet multiple ethical and pragmatic issues arise. For example, should physicians identify patients’ spiritual and religious needs and intervene in clinical settings? The roles and responsibilities of patients and physicians in this scenario are unclear. An understanding of religion and spirituality within the context of end-of-life care, quality of life, and patient-clinician interactions may illuminate the problems and potentialities for both patients and clinicians.

Religion: The Provision of Belief and the Establishment of an Ethic

The distinction between religion and spirituality is an important and nuanced one. From its Latin roots (religio), religion has been associated with various connotations: the totality of belief systems, an inner piety or disposition, an abstract system of ideas, and ritual practices. In end-of-life care, religion and religious traditions serve 2 primary functions: the provision of a set of core beliefs about life events and the establishment of an ethical foundation for clinical decision making. Religious doctrine and belief systems provide a framework for understanding the human experience of death and dying for patients, family members, and health care professionals. Intuitively, strong religious beliefs, whether expressed or privately held, should be associated with a decreased fear of death and greater acceptance of death. However, research that has examined the interaction between religious belief and attitudes toward death has produced controversial results that generally do not support this assumption.

In addition, religious traditions include substantial normative and ethical issues in end-of-life care. Ethics in this context spans a wide range of human interaction from interpersonal to organizational levels and represents the moral response to approaching and encountering death. Religion-based ethics provides a point of reference for clinical decision making and many religious groups, such as the National Conference of Catholic Bishops, the Unitarian Universalist General Assembly, and the Conservative Movement’s Committee on Jewish Law and Standards, actively participate in public discourse about issues that accompany the end of life (eg, palliative care, withdrawal of advanced life support, advance care planning). Although these sources provide an ethical framework for decisions at the end of life, religion-based ethics can both facilitate and impede clinical decision making, which reflects a dynamic interplay among patients, family members, clinicians, and institutions.

The issues of physician-assisted suicide (PAS) and euthanasia exemplify the complex interaction between religious belief and ethical decision making in end-of-life care. Recent studies have found an inverse association between measures of religiousness and attitudes toward PAS. A survey of physicians, nurses, and social workers in New York City found that respondents who had lower levels of religious belief were more willing to endorse assisted suicide than those who reported higher levels of belief. This finding is consistent with a national study by Emanuel et al who found that oncologists who report high or moderate levels of religious belief were less likely to perform euthanasia or PAS than those who reported no religious belief. In a national survey of US physicians representing specialties most likely to receive patient requests for assistance with suicide or euthanasia, Meier et al reported that physicians who have no religious affiliation were more likely to be willing to provide assistance and to have complied with a patient request for PAS than those with a religious affiliation.

Author Affiliations: Departments of Family Medicine and History & Philosophy of Medicine, Center on Aging, University of Kansas Medical Center, Kansas City (Dr Daaleman); and The Healthcare Chaplaincy, New York, NY (Dr VandeCreek).

Corresponding Author and Reprints: Timothy P. Daaleman, DO, Department of Family Medicine, University of Kansas Medical Center, 3901 Rainbow Blvd, Kansas City, KS 66160-7370 (e-mail: tdaalema@kumc.edu).

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These findings parallel those from patient populations as well. A study of patients with amyotrophic lateral sclerosis living in Oregon and Washington found that respondents who scored higher on a scale measuring the importance of religion were less likely to consider assisted suicide than those with lower scores. In 2 studies of older adults, the degree of self-reported strength of religious beliefs or role of religion in life was inversely proportional with more permissive attitudes toward assisted suicide. For both patients and physicians, these studies suggest that religious belief may have a significant effect on ethical decision making at the end of life.

**Spirituality: Resources for Personal Meaning**

Spirituality may or may not be linked to religious beliefs, religious practices, or communities that support those practices and beliefs. Terminally ill patients acknowledge a greater spiritual perspective and orientation than both nonterminally ill hospitalized patients and healthy patients. Although there are multiple interpretations of spirituality within health care settings, constructs of meaning or a sense of life’s purpose have been suggested as primary components. For example, in women with advanced breast cancer, maintaining a purpose or meaning in life has been identified as an important aspect of self-transcendence and spiritual well-being. The coping literature delineates 2 forms of meaning: implicit meaning and found meaning. Implicit meaning is an appraisal process that involves the gathering and processing of medical information. Found meaning, or meaningfulness, interprets and places this information into a larger life context. Antonovsky describes this generally positive, pervasive way of seeing the world, and one’s life in it, as a “sense of coherence,” lending comprehensibility and manageability.

Psychological states and quality-of-life outcomes have been the primary end points in end-of-life care studies that have incorporated a measure of spirituality. For example, among oncology patients, modest correlations have been found between spirituality and lower levels of anxiety and psychosocial distress. Additional studies suggest that spirituality is also positively associated with subjective well-being and quality of life to the same degree as physical well-being.

**Quality of Life**

In clinical and research settings, quality-of-life assessment examines the social, physical, and psychological influences on patient illness, health, and well-being. Measures of religiousness and spirituality that are specific to end-of-life care vary in their content, validity, and reliability, which reflect the developmental state of work in this area. The McGill Quality of Life Questionnaire incorporates items to assess achievement of life goals and personal meaning, while the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being scale contains questions that measure the comfort and strength derived from religious faith, in addition to a sense of meaning, purpose, and peace in life. The Systems of Belief Inventory, which was designed for use in quality-of-life and psychosocial research examining illness adjustment, measures religious and spiritual beliefs and practices and the social support that accompanies those beliefs and practices.

Religion and spirituality potentially can mediate quality of life by enhancing patient subjective well-being through social support and stress and coping strategies. Theoretically, religious and spiritual beliefs may enhance subjective well-being in 4 ways: promoting a salubrious personal lifestyle that is congruent with religious or personal faith traditions, providing systems of meaning and existential coherence, establishing personal relationships with a divine other, and ensuring social support and integration within a community. Social support has been suggested as an intervening factor between quality of life and religion and spirituality. The positive impact of social support and support groups on survival in cancer patients generated considerable interest in the early 1990s, although follow-up studies have failed to replicate earlier findings. Religious and spiritual beliefs have been found to be beneficial when examined within theoretical models of stress and coping. Research on religious approaches to coping and problem solving have been predictive of successful psychological adjustment to stressful life events. For example, Jenkins and Pargament report that cancer patients who attribute more control over their illness to God have higher self-esteem and are more adjusted to their disease state than those who do not attribute such control to God.

**Patient-Clinician Interactions and Interventions**

Assessment of quality of life raises some practical and ethical issues regarding the clinician’s role in spiritual and religious support during end-of-life care. How do physicians and nurses frame religious and spiritual concerns within health care settings? Are religious and spiritual concerns subsumed within social and psychological constructs and domains that comprise an individual’s experience of illness and disease, or are spirituality and religion conceptualized and viewed a priori? This tension is highlighted by recommendations and initiatives that incorporate religion and spirituality in plans to improve care at the end of life. For example, assessment guidelines for palliative care plans developed by the Institute of Medicine embed spiritual assessment within measures of emotional status. However, a report from the Commonwealth-Cummings project lists spiritual and existential beliefs as an independent modifiable dimension of the patient’s dying experience.

The inconsistent orientation and lack of conceptual clarity that accompany religion and spirituality raise several secondary questions relative to the operationalization of any guideline or recommendation. Who is responsible for assessing and meeting the spiritual and religious needs of...
dying patients: physicians, nurses, social workers, psychologists, or clergy and health care chaplains? Some have advocated that physicians or other members of the health care team should address these issues. Yet within the patient-physician relationship, physicians wield a power that is largely positive and salutary, and this power may result in a loss of patient autonomy if left unchecked or unguarded. In the development of treatment goals and care plans, patient autonomy can be threatened when physicians’ religious convictions are dissonant with those of patients and family members. For example, studies that measured physician religiousness and PAS support the assumption that physicians’ religious belief may influence the patient-physician relationship. In light of these concerns, data from a US national survey suggest that clergy and professional pastoral care providers assume a primary role for religious and spiritual concerns in clinical settings. In this survey, more than 80% of family physicians reported that they refer to these clergy and pastoral care providers in conditions associated with end-of-life care. However, if quality of life is enhanced by the search for personal meaning, should physicians and other health care professionals also incorporate these aspects in care? Would physicians’ approaches differ from those of professional pastoral care providers tied to religious or faith traditions? These issues are fertile ground for future research.

Future Directions: Hospice as a Sentinel Model

The hospice movement provides a case study to examine the development of religion and spirituality within end-of-life care. The foundation of the modern hospice movement was grounded in a Western Christian religious tradition. This faith tradition served a primary function for hospice workers may move about among many different faith traditions.

Yet religion and faith traditions still occupy a substantial place in end-of-life care. From a social constructionist perspective, social determinants such as social support, education, gender, and religion are primary elements that facilitate the interpretation and understanding of death and dying. In this context, religious and faith traditions may be part of the scaffolding in the construction of meaning as death approaches. Spirituality may be viewed as the actions and interactions of an embodied human actor who is facing death and creating a personally meaningful social world, a constructed world that can be either a resource or an encumbrance. For hospice and palliative care this has several implications: a richer appreciation of the social and demographic determinants of a quality care at the end of life, a greater understanding of the psychological and theological processes involved in “meaning making,” and an emphasis on assessment strategies and interventions that are inclusive of these factors.
When viewed from either a constructionist or phenomenological perspective, the ties that bind hospice to palliative care in the assessment and management of spiritual concerns are best understood by examining the locus of care at the end of life. Multiple connotations of hospice exist, yet many associate this term with a physical place of respite and care. In the evolution of end-of-life care and the emergence of the disciplines of palliative care, there has been a shift in the common understanding of hospice from an institution that provides care to a philosophy that embodies the active, total care of the individual. Hospice and palliative care have negotiated much of the difficult terrain that accompanies religion and spirituality and medicine, and they have done so by moving the locus of care out of biomedical institutions back into the community. By offering a health care delivery model that incorporates a community-based approach while emphasizing the uniqueness of the individual, regardless of the importance of religion or spirituality in the individual’s life, hospice and palliative care provide a structure for and facilitate the processes that are involved in this most basic of human experiences, that of dying.

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REFERENCES
Bioethics for clinicians: 22. Jewish bioethics

Gary Goldsand,* Zahava R.S. Rosenberg,† Michael Gordon‡

Abstract

JEWISH BIOETHICS IN THE CONTEMPORARY ERA EMERGES from the traditional practice of applying principles of Jewish law (Halacha) to ethical dilemmas. The Bible (written law) and the Talmud (oral law) are the foundational texts on which such deliberations are based. Interpretation of passages in these texts attempts to identify the duties of physicians, patients and families faced with difficult health care decisions. Although Jewish law is an integral consideration of religiously observant Jews, secularized Jewish patients often welcome the wisdom of their tradition when considering treatment options. Jewish bioethics exemplifies how an ethical system based on duties may differ from the secular rights-based model prevalent in North American society.

Mrs. L is an 85-year-old resident of a Jewish long-term care facility who has vascular dementia, controlled heart failure and diabetes mellitus. The gastrostomy feeding tube she received 2 years ago has begun leaking and needs to be replaced. Her daughter, who has become her surrogate since the recent death of Mrs. L’s husband, has indicated that if the tube were to come out, she would not consent to the insertion of a new tube: a decision she feels would be in accord with her mother’s true wishes. She would not, however, request that the tube be deliberately removed. The staff are concerned that, by not replacing the tube, they would be failing to maintain the current level of treatment. They feel that this would amount to taking the mother’s life without any substantial decline in her clinical condition. The daughter acknowledges the concern and devotion of the staff and her mother’s unchanged clinical status but reiterates her belief that her mother would prefer to be allowed to die rather than to continue with feeding through a gastrostomy tube.

What is Jewish bioethics?

Although discussions of medical ethics can be found in Jewish writings since ancient times, modern medical technologies have placed new challenges before interpreters of Jewish tradition.1–4 The zeal with which these questions have been addressed has given rise to the field of Jewish medical ethics over the past 40 years. In keeping with Jewish ethics generally, Jewish bioethical inquiry appeals to the principles found in Jewish scriptures and commentaries and applies them to clinical decision-making. In doing so, it takes a duty-based approach rather than the predominately rights-based approach characteristic of contemporary secular bioethics. As the late Benjamin Freedman pointed out, bioethical deliberations that are focused on rights may do well in solving the procedural question of who gets to decide a particular question, but they do not necessarily offer guidance as to what the best decision might be.5 Framing a dilemma in terms of the duties owed to those involved can clarify the issues and suggest a satisfactory course of action.

Interpersonal behaviour in Judaism is traditionally conceived as the execution of duties within the context of relationships. From this perspective, a preoccupation with rights implies the relative isolation of individuals making claims upon one another; this further implies an implicitly or overtly adversarial relationship. In a “regime of duty,” participants seek to enable each other to satisfy the obligations inherent within relationships,6 including professional relationships. Judaism urges one to perform mitzvoth (good deeds), that is, to act in accordance with one’s duties, and
this applies in the health care setting no less than anywhere else. The clinic thereby provides a relatively new arena in which mutual obligations between patients, physicians and families can be explored. Such explorations inevitably begin with the established norms of Jewish law and behaviour, collectively known as Halacha (literally, “the way”).

A variety of approaches

Traditional Jewish legal and ethical thinking is based on reading and interpreting 3 main sources, each of which is vast, varied and complex. The oldest and most authoritative is the Bible, which includes the 5 books of Moses (the Torah), the Prophets and additional writings. The second source is the Talmud, which is composed of multilayered commentaries on biblical texts and oral traditions by learned rabbis of the second to fifth centuries CE. To make the voluminous Talmud more accessible, several great codifications of Jewish law emerged that attempted to summarize the Talmud’s primary teachings. One of the most notable, the Mishne Torah, comes from Maimonides, the noted 12th-century physician and scholar. The third main source of Jewish legal authority is the Responsa literature, in which prominent Jewish scholars through the centuries have given opinions on contemporary matters as interpreted through the Bible and Talmud. Responsa are the continuation of a 2000-year-old interpretative tradition, which creates an intellectual link to the past, helping to keep the law relevant and vital to the present. (Descriptions of codes and responsa can be found in references 14 and 15, or in any general guide to the sources of Jewish law.)

Bioethical questions are treated by Jewish authors in a variety of ways, which reflect different orientations toward Judaism and degrees of strictness in the interpretation of Talmudic texts and cases. Pioneering work in contemporary Jewish medical ethics in the 1960s and 1970s came primarily from Orthodox Judaism, in which the authority of God, as expressed through the Torah and Talmud, underlies the deliberative process. Much Jewish bioethics literature comes from this perspective, which assumes that, through the proper interpretation of Talmudic texts and commentaries, answers to the most difficult questions can be discovered. In practice, the rabbi whose opinion is sought for an ethical answer serves as an “expert counsellor” to physician and patient, interpreting Halachic law for the situation in question. A local rabbi or chaplain may, in turn, consult more learned Halachic authorities in difficult cases.

Inspired by these Orthodox sources, Jews from the more liberal Reform and Conservative movements have also made contributions to contemporary bioethics. “The interpretative method and texts used are basically the same, but their rulings are often more flexible than those provided by Orthodox rabbis. Even within Orthodox Judaism there exist multiple interpretations of most texts, with a resultant variability of rulings. Jews of the Reform movement are often more open to “extra-Halachic Jewish ethical analysis,” in which Halacha becomes only one of several sources of moral authority.

Common principles

Although traditional Jewish scripture expresses many principles worthy of ethical consideration, there are a few foundational tenets that ground much of the Jewish bioethical tradition. One commentator identified 3 main principles: “human life has infinite value; aging, illness and death are a natural part of life; and improvement of the patient’s quality of life is a constant commitment.” Other important principles are that human beings are to act as responsible stewards in preserving their bodies, which actually belong to God, and that they are duty bound to violate any other law in order to save human life (short of committing murder, incest or public idolatry). Compared with secular values, these principles suggest a diminished role for patient autonomy. The duty to treat illness or preserve health overrides any presumed right to withhold treatment or to commit suicide.

In general, traditional Judaism prohibits suicide, euthanasia, withholding or withdrawal of treatment, abortion when the mother’s life or health is not at risk and many of the traditional “rights” associated with a strong concept of autonomy. For example, an observant Jew would not consider it his or her right to seek physician-assisted suicide as a way to avoid present or future suffering from metastatic carcinoma. Exceptions to these prohibitions are sometimes made in extreme circumstances.

The problem faced by Jews in end-of-life decisions is not usually in determining the appropriate Halacha; a greater challenge is determining the moment when hope for continued life is lost and the process of death has begun. Jewish law is relatively clear that life is not to be taken before its time. It is equally clear that one is not to impede or hinder the death process once it has begun. Lenient rulings in such cases may well be based on the same texts as strict rulings; one authority may see continued treatment as prolonging life, where another may see it as prolonging death. Working through this dilemma is a common feature of Jewish end-of-life decision-making. Both the duty to treat and the duty not to prolong death must be considered in light of the more general duty to care for one’s parents in old age or ill health.

Why is Jewish bioethics important?

To traditionally minded Jews, Jewish bioethics is a subset of Halacha, which guides all of their activities. To more secular Jews seeking guidance in difficult decisions about their health, Jewish bioethics offers helpful lessons and considered opinions from the sages. Many nonreligious Jews welcome traditional views to help ease the uncertainty inherent in difficult ethical decisions, even though they may not live according to traditional religious practice. Of the 360 000
How should I approach Jewish bioethics in practice?

Both Jewish and non-Jewish physicians can benefit from being acquainted with Jewish bioethics in caring for patients and their families when issues related to Judaism are raised. Table 1 summarizes essential points to keep in mind when providing care to Jewish patients.

The patient’s life history might have some bearing on the type of treatment approaches he or she requires. Older Jews not born in Canada might be more likely to appreciate a rabbi’s input, as they are often more traditional than their children. Also, there are still a significant number of Holocaust survivors in most Canadian cities, some of whom have significant psychological associations stemming from traumatic experiences.

Very traditional or religious Jews may have concerns about modesty in the health care setting, and many might appreciate being cared for by nurses or physicians of the same sex. Hospital attire that preserves modesty may be doubly appreciated by patients who are religious. Some Jewish patients may also appreciate brief periods set aside for prayer or other ritual obligations.

A physician treating a Jewish patient should not make assumptions about the extent to which he or she would like his or her care to be guided by Jewish tradition. It would be perfectly appropriate to ask a patient whether Jewish opinions are considered in the decision-making processes, and to consult with a rabbi — a specific one if so requested — when the patient wishes to explore the tradition’s wisdom on a particular matter.

The case

Mrs. L’s daughter is undoubtedly trying to respect her mother in not consenting to the insertion of a new gastrostomy feeding tube, but she will find it difficult to get rabbinical support for reducing or withdrawing treatment that would result in her mother’s death without a prior serious decline in Mrs. L’s overall condition. How best to respect

| Religious observance: Try to determine the patient’s degree of orthodoxy (observance). This information may help to determine the degree of adherence to Jewish laws, including dietary laws. Orthodox men will usually wear a head covering (yarmulke) at all times. Explore the needs for prayer and, whenever possible, facilitate such participation. During special “high holidays” (Rosh Hashanah and Yom Kippur) Jewish patients may want to have access to special religious services. Orthodox Jews should not “work” on the Sabbath (Saturday); however, necessary medical activities can be performed on the Sabbath. During Passover, special foods (unleavened bread) may be required. The patient may want to consult a rabbi when medical recommendations are made that affect dietary restrictions. |
| Privacy and modesty: Whenever possible, very personal care should be provided by a health care professional of the same sex, especially for female patients. Married Orthodox women may wear a wig in public as part of their adherence to the principle of modesty. |
| Consent: In general, the process of consent used in Western countries is also applicable to Jewish patients. Orthodox Judaism requires that a patient follow medical directions, but it is also expected that the best information be disclosed before the patient agrees to a procedure or treatment. Judaism promotes a strong commitment to the sanctity of life; as a result, there may be some difficulties when discussions take place about the withdrawal or withholding of treatments. |
| Rabbinical advice: Jewish people have a long tradition of asking a rabbi for advice when faced with difficult decisions. Families may present physicians with the results of rabbinical deliberations, which must be taken into account when decisions are made. It is always best to ask the patient or family if they would like the advice of a rabbi. |
| Life history: Many older Jewish patients may be Holocaust survivors. It is important to know this because such a history may affect their response to proposed treatments and their relationships with family members. |
her parent is not easy to determine, but usually Judaism teaches that prolonging life is more respectful than assuming an incompetent patient wishes to end her suffering prematurely. There is a clear duty to “cause to eat”28 in the Jewish tradition that her daughter should not, according to the Halacha, violate unless Mrs. L is deemed to be a goses (a person in the throes of dying), in which case treatment or feeding that would hinder the dying process would not normally be allowed. Even as death approaches, performing duties as articulated by Jewish law is the essence of traditional Jewish life, a source of joy and fulfillment for both patients and families, and Jewish bioethics suggests that the articulation and performance of such duties be the focus of clinical decision-making. The daughter agrees to have the gastrostomy tube replaced. She and the health care team determine conjointly the basis for future care within a palliative care framework. Mrs. L succumbs comfortably to pneumonia some months later.

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Reprint requests to: Dr. Michael Gordon, Medical Administration, Baycrest Centre for Geriatric Care, 3560 Bathurst St., Toronto ON M6A 2E1

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In July 2005, the United States Conference of Catholic Bishops submitted two questions for clarification (in the form of a dubium) to the Congregation for the Doctrine of the Faith about the meaning of the Address given on March 20, 2004 by Pope John Paul II to a Rome conference on patients diagnosed as being in a “vegetative state.” The Congregation responded to these questions in September 2007. The Responses (approved by Pope Benedict XVI) and a Commentary (approved by the Cardinal and Bishop members of the Congregation) will be publicly released on September 15 in L'Osservatore Romano. Following are questions and answers about these texts.

1) What do the Responses say?
They reaffirm two central teachings in Pope John Paul II’s Address of 2004: 1) Patients who are in a “vegetative state” are still living human beings with inherent dignity, deserving the same basic care as other patients; and 2) nutrition and hydration, even when provided with artificial assistance, is generally part of that normal care owed to patients in this state, along with other basic necessities such as the provision of warmth and cleanliness.

2) Does this represent a change in Church teaching?
No. These Responses reaffirm what was taught by Pope John Paul II in his 2004 Address, which itself is in continuity with the Holy See’s Declaration on Euthanasia of 1980 and other documents regarding the right of patients to receive normal or basic care. As the Commentary points out, in developing this teaching, the Church's Magisterium has paid close attention to “the progress of medicine and the questions which this has raised.”

3) The Church has long taught that one is not obliged to employ extraordinary or disproportionate means to preserve one’s life. Does this traditional form of reasoning not apply in the case of the person in a persistent “vegetative state”?
This form of reasoning does apply. However, for modern societies with advanced medical services the administration of nutrition and hydration by artificial means to patients in a “vegetative state” who need such assistance to survive is generally neither extraordinary nor disproportionate.

To apply this reasoning correctly we must recognize that all human life, not only a particular kind of life we might consider “normal” or “productive,” is precious and should be preserved. Those in a “vegetative state” suffer from a very severe disability, but they do not lose their human dignity. In this respect, as Pope John Paul II pointed out in his Address, even the term “vegetative state” is unfortunate and potentially misleading -- a human being must never be dismissed as having the status of a “vegetable.”

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1 As noted in the Holy Father’s Address, the term “vegetative state” is commonly used in medical practice but may unfortunately mislead some to think that patients in this state lack full human dignity; therefore it is cited in this text only with quotation marks. The Holy Father also noted in 2004 that there is confusion and disagreement among medical experts about the definition of the “vegetative state” and its diagnosis, and about the parameters for judging when to call such a state “persistent” or “permanent” (with the former term more often used in the United States).
4) Are there medical situations in which it is moral to withhold nutrition and hydration?
Yes. For example, a patient in the last stages of stomach cancer is already dying from that condition. Such a dying patient, or others who can speak for the patient, may decide to refuse further feeding because it causes pain and gives little benefit. The administration of nutrition and hydration in this case would pose a burden on the stomach cancer patient that is disproportionate to its benefit. By contrast, the “vegetative state” is not in itself a case of imminent dying, and the reception of nutrition and hydration itself does not generally constitute a burden for him or her.

5) Are there possible cases when it would be moral to withhold or withdraw nutrition and hydration from the patient in a “vegetative state”?
Yes. They could be withheld if the available means for administering nutrition and hydration were not effective in providing the patient with nourishment (for example, because the patient can no longer assimilate these), or if the means itself constituted a burden (for example, because the feeding tube is for some reason causing persistent infections). The Commentary notes that such situations are rare. It also notes that the obligation to provide artificially assisted food and fluids may not bind in situations of extreme poverty or in the absence of a modern health care system, because one is not held to do what is impossible.

6) May nutrition and hydration be withheld from patients in a persistent “vegetative state” because prolonged care for them may involve significant costs?
No, because in technologically advanced societies the costs directly attributable to the administration of nutrition and hydration are generally not excessive. To be sure, the costs and other burdens placed on families by the patient’s need for prolonged care may become very significant. However, this real problem must not be resolved by removing basic care so the patient will die. While one may act to reduce or remove a burden caused directly by the administration of nutrition and hydration if the benefit is not proportionate to the burden, we must not dismiss life itself as a burden even when its helpless state may call on us for other forms of care. To act to end life because life itself is seen as a burden, or imposes an obligation of care on others, would be euthanasia.

7) Who should bear the burdens associated with providing proper care for those in a persistent “vegetative state”?
Pope John Paul II insisted that families “cannot be left alone with their heavy human, psychological and financial burden.” He maintained that “society must allot sufficient resources for the care of this sort of frailty” and suggested a range of initiatives to provide assistance (see Address, no. 6). The Church likewise has an obligation to offer what assistance she can, which might involve stepping in where the support from society falls short, as well as providing the spiritual and pastoral aid that only she can give. This is an opportunity for the Church to bear witness to her commitment to serve human life from conception to natural death.

8) Could proper care for those in a persistent “vegetative state” impose significant financial burdens on Catholic health care facilities?
Yes, in the case of families who have limited financial means and no or insufficient health insurance. Catholic health care facilities recognize that at times they are obliged to bear the cost of providing health care to those who cannot pay for it. In the loving care that they provide to such persons, with the assistance of the entire Catholic community, they can provide concrete examples of the Church’s commitment to human life.
9) Are the Ethical and Religious Directives for Catholic Health Care Services in conformity with this teaching?
Directive 58 already speaks of “a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration.” The Address and the Responses clarify how this presumption applies to the patient in a “vegetative state” as to other patients, and provide further guidance as to how the Directives should be interpreted and implemented.
Dr. Carl J. Koenigsmann
NYS DOCCS
Health Care System

Deputy Commissioner: Carl Koenigsmann MD
Assistant Commissioner: Elizabeth Ritter RN
Director: Nancy Lyng MS
DESCRIPTION OF THE DOCCS HEALTH CARE SYSTEM

- 61 prisons housing approx. 57,000
- 4 reception sites
  - Classified by health, mental health and security needs
- Frequent moves
Levels of Health Care Presence

- Health presence in all facilities
  - Differing levels in spectrum of care
- Camps and minimum security facilities have ambulatory care 8 hours a day
- Some facilities have infirmaries provide 24 hour nursing care
- 5 Regional Medical Units provide sub-acute care
- Acute hospitalization in secure units of medical centers
- Specialized Healthcare Programs e.g. Unit for the Physically Disabled (UPD) @ GHCF, Merle Cooper Program & APPU @ Clinton, etc.
Services provided per year:
(all figures approximated)

- Over 1 million primary care visits
- Over 6000 ER visits
- 132,000 Specialty Care Provider encounters
Primary care by NYS Employees

- Physicians
- Nurse Practitioners and Physician Assistants
- Nurses
- Pharmacists
- X-ray
- Dental
- Mental Health
HIV-Related Death Rate in DOCCS
(Rate per 10,000)
We have an aging offender population with healthcare needs that represent the aging process.

- Increase in # of offenders over 50
  (baby boomers account for 80 million people in our society)

- By 2050 Alzheimer’s will be leading cause of death..... If no cure found!
The Aging of the Inmate Population

Inmate Population
- Inmates over 65 years old

2000:
- Total Inmate Population: 70,154
- Inmates over 65 years old: 429

2011:
- Total Inmate Population: 55,090
- Inmates over 65 years old: 869
Alzheimer's (UCI Fishkill Correctional Facility):

- 30 Bed unit specialized in the health care of incarcerated individuals with cognitive impairment.
- Dementia
- Medical issues
- Psych issues
- Discipline/Security
- Programming (merit time, etc)
- Staff continuing education
- Coordinating efforts between Medical, Security, Administration
Puppies Behind Bars

- Training Dogs as Service Dogs for returning military personnel
- Dogs also encounter patients with long term medical problems as a therapeutic intervention
Transition from prison to community

- Most offenders are released into society and will become a part of our community

- DOCS provides:
  - Chronic medications given at discharge
  - HIV/AIDS continuity program
  - Hepatitis C Continuity Program
  - Discharge information
  - Mental Health Continuity in services
Advance Directives - DNR

Policy:

- Health care providers in the Department of Correctional Services will honor patient requests for DNR orders as permitted under Article 29-B of the Public Health Law.
State of New York
Department of Health

Nonhospital Order Not to Resuscitate
(DNR Order)

Person’s Name ________________________

Date of Birth __ / __ / __

Do not resuscitate the person named above.

Physician’s Signature ________________

Print Name _________________________

License Number _______________________

Date __ / __ / __

It is the responsibility of the physician to determine, at least every 90 days, whether this order continues to be appropriate, and to indicate this by a note in the person’s medical chart. The issuance of a new form is NOT required, and under the law this order should be considered valid unless it is known that it has been revoked. This order remains valid and must be followed, even if it has not been reviewed within the 90-day period.

DOH-3474 (4/95)
Policy:

- Health Care Proxies are available to inmates as authorized by Article 29-C of the Public Health Law. Under the Proxy Law, any competent adult can designate an agent to make health care decisions on his behalf in the event that he or she becomes incapacitated.
Health Care Proxy

(1) I,

hereby appoint

(name, home address and telephone number)


as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(2) Optional: Alternate Agent

If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby appoint

(name, home address and telephone number)


as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely. (Optional: If you want this proxy to expire, state the date or conditions here.) This proxy shall expire (specify date or conditions):


(4) Optional: I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as stated below. (If you want to limit your agent's authority to make health care decisions for you or to give specific instructions, you may state your wishes or limitations here.) I direct my health care agent to make health care decisions in accordance with the following limitations and/or instructions (attach additional pages as necessary):


In order for your agent to make health care decisions for you about artificial nutrition and hydration (nourishment and water provided by feeding tube and intravenous line), your agent must reasonably know your wishes. You can either tell your agent what your wishes are or include them in this section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration.
Thank You for your attention.
NYS DOCCS Health Care System

A Continual Improvement Process
Hi. Good afternoon. I’d like to thank Alissa Kane and Sarah Hansel for arranging today’s fantastic symposium, Sue Porter for organizing this panel, and Peter Strauss for inviting me. Thanks to you for being here.

What do we mean when we talk about religion. Is it the ineffable? The things unseen? The things in this world but not of it? Or is it the feeling we get when we walk into a church or synagogue on high holidays? The ritual of kneeling? Who or what we talk to when we talk to ourselves? The smell of incense? The proximity to our people, our family, our community, our congregation? Is it the smell of our child’s hair, the rush of nausea and fear when we come close to death? The sticky sweetness of a Helen Steiner Rice poem? Is it absence? The rush of being in the presence of a masterpiece? Of hearing a perfect sonata? Is it what keeps us from pushing a rude passenger on the subway? What makes us visit our neighbor? Is it compassion? Is it in the words of the pope? Our rabbi? Our doctor? Our lawyer? Is it our morals? Our values? Is it “the stories we tell ourselves in order to live?”

I ask this -- What do we mean when we talk about religion? -- because we use the word religion as a shorthand for many things; often we behave as though religion is an opaque object, separate from society, culture, community. Or perhaps we talk about it as if it’s a pole, one that is located as far from another pole as possible, secularism. And because we talk about the religious and the secular as if they are poles, we mistake them for monoliths, free-standing and distinct. Yet we know instinctively that they are not opposites, we know from my examples above that they are not clearly
defined. What we call the secular has evolved out of the religious, and in the U.S. primarily out of Protestant Christianity. Even when you shake the idea that they are two poles contending for authority in our culture, their tension is still a relationship. They have related tasks and responsibilities, but one is as much a part of our culture, our politics, our social contract, our behavior, as the other.

Think, for instance, about our institutions. Ideas of law and justice are very much modeled on Christian ideas. So too medicine and the health care system.

Modern hospitals can trace their roots to way-stations set up by the Catholic Church to welcome soldiers home from the Crusades. The church today still calls their involvement in health care a mission. Hospice was established by Cicely Saunders, a devout Catholic, as a mission to care for suffering terminal patients (and, as she has written, as a way “to combat euthanasia”). When doctors find they can no longer cure a patient, their last call is to the chaplain, or priest -- a higher authority.

Terri Schiavo, a persistant vegetative state patient kept alive on a feeding tube, died in 2005 after an extensive and highly publicized legal battle. Four years later, the United States Conference of Catholic Bishops changed the Ethical and Religious Directives used to manage all of their 630 hospitals in the U.S. They removed the decision-making authority to end intubation from patients and their families to hospital directors. They also recategorized feeding tubes as comfort care, not medical care.

At the time of this change I was researching denominational health care and the Church’s opposition to reproductive rights, stem cell research, aid in dying and accepted medical treatments. I asked myself what other members of society had no choice of what medical services they could receive, specifically, of who could not decide when to be fed. The answer is this: There are two places in the U.S. where a person can be fed against their wishes: in a Catholic hospital and in a prison.
The modern American prison was established to counter what was considered the very un-Christian practice of execution in Europe. It was thought that a prisoner could be rehabilitated and returned to society. It’s a very Christian notion, one that follows the path of sin, contrition, punishment, and redemption. As Winnifred Fallers Sullivan writes in her excellent 2009 book *Prison Religion: Faith-Based Reform and the Constitution*:

*The modern state is also perhaps at its most religious when it exerts total control over its citizens and attempts to coercively remake them into new human beings. Religious and political authority and sovereignty in prison are homologous with each other in several ways: state/church, judge/god, crime/sin, prisoner/penitent. Even when explicitly religious language is absent, the sacred haunts the prison and all who work there.*

On October 23, 2008, eight prison guards, medical staff and corrections officers came for William Coleman. They led him from his cell into an examination room. They told him they were going to feed him with a tube. He told them he didn’t want to be fed but he saw that he clearly had no choice. They turned off the video camera, routinely used to record medical procedures, strapped him down on a vinyl examination table “at four points” and forced a tube up his right nostril. When the tube kinked Bill howled in pain. They thought he was resisting and placed a webbed restraint over his shoulders. One person held his head. Then they realized that the tube was bent so the interning doctor removed the first tube and successfully replaced it with a second. When it reached his stomach they filled it with a nutrient drink. Bill constantly gagged on the tube. As Bill was led back to his cell, he filled the cuffs of his grey sweatshirt with snot and liquid, blood and vomit.

I’ve never met Bill but we’ve been talking to each other since January. We write weekly letters and we speak on the phone most Tuesdays and Thursdays. Bill is a prisoner in MacDougall-Walker Correctional Institute in Connecticut. To protest his conviction -- he says he’s innocent -- he stopped eating solid food on September 17, 2007. That’s more than five years since he has chewed anything. But he’s survived by
drinking fluids, juice, water, nutrient drinks like Ensure. When he stops taking liquids to protest, the prison force feeds him. They’ve done so dozens of times since his first feeding in 2008.

Bill contacted the American Civil Liberties Union of Connecticut to sue to have the force feedings stopped but he lost the district case and in March the state Supreme Court ruled that the prison could continue the feedings.

In a forthcoming paper for Public Affairs Quarterly titled, “Force Feeding: Treatment or Torture?”, bioethicist Jacob Appel writes that feeding anyone against their will is a violation of standard medical ethics. Other bioethicists like Arthur Caplan concur. Lawyers in this room know that it should be illegal for a competent person to be given a medical procedure they do not consent to. Cases like *Cruzan v. Director* (1990, regarding the removal of a feeding tube) and *Washington V. Glucksberg* (1997, regarding the legalization of aid in dying) have clearly established that competent individuals possess the right to elect or deny any medical treatment, even if that decision means certain death. Not incidentally, the Catholic Church was on the losing side of both *Cruzan* and *Glucksberg* but to this day reserves the legal right to override patient choice regarding feeding tubes, thanks to a webwork of so-called conscience clauses.

What Bill’s case clearly demonstrates is that institutional power is derived from varying sources of authority, depending on the status, gender, race, health and age of the individual. While it should be illegal to force feed Bill, it is not. While it is medically unethical to force feed Bill, doctors -- in this case contracted from the University of Connecticut -- still perform force feedings.

Clearly, bodily autonomy in the U.S. is not settled. Clearly, opponents to bodily autonomy are not just sitting in the rectory or the Vatican. If we continue to relegate religion to it’s monolithic pole, we fail to see how religious authority still influences our so-called secular institutions, our cultural understandings, our social services, our
hierarchical structures. Religion, in the broadest sense, in all it’s residual guises, for both good and bad, still influences who we deem as “the most vulnerable,” how we assess dignity, human rights, morality, legitimacy of values and our very ideas of who deserves bodily autonomy. After all, Catholic Church leaders are not religion.

With regard to end of life and freedom of medical choice, it is all too easy to waive our finger at “The Church” or our monolithic conception of “religion.” As Bill’s case reminds us, we must examine the foundational institutions of our society -- authoritative ideas of law, justice, individual rights, medical rights, even culture -- and ask how we too are complicit.

Thank you.
Alicia Ouellette
Disability Rights and the End of Life: Why has it been so hard?

Alicia Ouellette
Associate Dean and Professor of Law
Albany Law School
The Debate:

Is it about choice in dying

or about disability discrimination?
From Disability Rights Activists

“Though often described as compassionate, legalized medical killing is really about a deadly double standard for people with severe disabilities, including both conditions that are labeled terminal and those that are not.”

Diane Coleman, JD, Founder, Not Dead Yet
“The state of Florida would not have authorized a man to have his non-disabled wife deprived of food and hydration and would not have caused her death that way. It was because of her disability that her death was thought to be appropriate.”
Not a fringe position

May 2012, the National Disability Rights Network report describes conversations between doctors and persons with disabilities and their families in which people with disabilities are “viewed as having little value as they are. They are considered not as fully human, endowed with inalienable rights of liberty, privacy, and the right to be left alone, solely because they were born with a disability.”
PWD in Health Setting: Then
PWD in Health Setting: Now
Not just controversial cases.
People with disabilities experience significant health care disparities and barriers to health care.
Significant health care disparities

- More likely to go without needed care
- More preventable emergency room visits and hospitalizations
- Significantly higher prevalence of secondary conditions
- Less preventative care
- Poorer overall health outcomes
Multiple barriers to care

- Issues with health insurance
- Communication barriers and lack of accommodations
- Architectural barriers in offices and facilities
- Lack of accessible medical equipment
- Stereotypes about disability
Equipment barriers

- Examination tables
- Weight Scales
- X-ray equipment
- Mammography
Unequal care

“When health care providers are unable to get an accurate weight or perform an appropriate examination because patients cannot use a traditional scale or cannot get onto or are not assisted in getting onto diagnostic, therapeutic, or procedural equipment, then patients may receive unequal health care.”
“There is an unfortunate stereotype that women with physical disabilities are asexual . . . This stereotype plays out in the assumption of some physicians that we are not sexually active and that if pelvic exams or mammograms are too much trouble because of inaccessible exam tables, they can be overlooked.”
Fear and Distrust

“Most people with a disability fear even the most routine hospitalization. We do not fear any of the commonplace indignities those without a disability worry about when hospitalized. Our fear is primal—will our lives be considered devoid of value?”

Disability Scholar William Peace, 2012
End of life—what to do?

- Become disability conscious
  - Question assumptions – quality of life
  - Read disability studies scholarship
  - Distinguish disability and terminal illness
  - Cultural competency for Physicians
  - Increase number of physician with disabilities
Much work to be done...

THANK YOU.
The message from the disability rights community in the debate over end-of-life decisionmaking is simple and compelling: the disabled are better off alive than dead. Any effort to terminate life-sustaining treatment for a person who finds him-or herself disabled is not only demeaning to all people with disabilities, it also constitutes legal discrimination. Thus, courts and legislatures must prevent the termination of medical treatment, especially nutrition and hydration, in cases in which the patient has no written living will. The message has traction. By engaging in major lobbying efforts and court cases to press their cause, disability groups like Not Dead Yet and activists like lawyer Harriet McBryde Johnson have shaken foundational principles of law and bioethics that have for at least thirty years made it permissible for individuals to choose to forgo life-sustaining treatment.

To some degree, the success of the disability rights movement in spreading its message is attributable to an unspoken rule that the disability rights community is untouchable. People outside the community who have not experienced the life of a person with disabilities dare not disagree with the disabled. The reluctance is somewhat justified: the able-bodied have not experienced the condescension and discrimination regularly inflicted on the disabled.
But to a very real degree, the lack of serious scholarly challenge to the position of the community is itself patronizing. Indeed, the "reflexive scorn" to the activists' message and the near silence in the legal literature in response to the avalanche of disability scholarship against the termination of end-of-life treatment is astounding. This silence further marginalizes the group whose marginalization moved it to action in the first place, and leaves unanswered the very real charge of disability discrimination made by those suffering the discrimination.

Equally troubling, the apparent deference to the community's message gives the activists legitimacy in their lobbying despite theoretical and practical flaws in their argument.

This Article seeks to answer the call from the disability rights community for a real debate on the role of disability in end-of-life decisionmaking. In the Article, I question whether the crusade by disability rights activists against freedom in medical decisionmaking is in fact in the best interest of people living with physical and mental challenges, and I conclude that it is not. I argue that in seeking to protect members of the disability community from perceived and real threats, the activists would limit options for all of us by declaring how we must, or, more correctly, how we must not die. In this way, Not Dead Yet, Harriet McBryde Johnson, and other disability rights activists pose a direct and immediate threat to the laws that give families choices in decisionmaking at the end of life. Their advocacy may well lead to perniciously paternalistic legal action that will disable all of us - people with and without disabilities - by eliminating medically appropriate and morally acceptable options for medical decisionmaking at the end of life.

I argue further that although the theory underlying the activist agenda has its roots in disability studies, it does not withstand scrutiny. The theory that laws allowing choice in dying perpetuate disability discrimination is flawed by conflation, inflation, misidentification, and a misplaced operational definition of disability. Specifically, the theory conflates dying with disability and misidentifies a persistent vegetative state as a disability that permits meaningful life. The conflation derives from a misplaced operational definition of disability that insists that all people fed by feeding tubes are the same. The conflation and misidentification allow the community to cast decisions to withhold or withdraw feeding tubes as disability prejudice, when such decisions are, in fact, an affirmation of autonomy and a showing of respect for individual values.

By disproving the underlying theory and exposing the negative practical implications of the disability agenda, I hope to derail the community's effort to turn back thirty years of progress in protecting patients and their families at the end of life. That said, my conclusion is not that the disability rights community has nothing of value to add to policy surrounding end-of-life decisionmaking. To the contrary, while I disagree with the extreme position of what I call the new activists, I argue that much of the community's message has merit. Judges, bioethicists, lawyers, legislators, and health care providers should take concrete steps to stop the palpable discrimination that triggered the political movement in the first place and to alleviate the fear and hurt that has driven scholars and activists to extreme positions. I argue that two steps are necessary to achieve this goal. First, courts, bioethicists, and lawyers must stop justifying autonomous decisions to refuse treatment as reasonable by devaluing life with disability. Second, health care providers and policymakers, including institutional ethics boards, should reevaluate the notion of informed consent in cases of sudden disability to incorporate the evidence from empirical studies by disability scholars.

Part I of this paper introduces the activists and scholars who make up the disability rights community, explores the history of the disability rights movement, and sets forth the message, theory, and demands of the activists with respect to end-of-life decisionmaking. Part II discusses how the community has effectively changed public discourse about choices in dying. Part III exposes the danger posed by the community's demands, and identifies the conflation, inflation, and misidentification that undermine the theory that choice in dying is disability discrimination. Part IV argues that although they should not erode laws that allow the disabled and their families' choice in dying, policymakers, scholars, judges, lawyers, and health care providers should heed much of the message coming from the community. In particular, judges should avoid perpetuating the tragic myth of life with disability and focus instead on autonomy and the process of informed consent. At the same time, scholars, policymakers, and providers should rethink what it means to obtain informed consent in cases of sudden disability in light of evidence generated by disability scholars. Part V concludes by issuing a challenge to both sides of the debate.
The disability rights community consists of both activists and scholars. Neither faction purports to speak for every person with a disability, but, as the following discussion shows, both groups present a remarkably coherent message. Moreover, the activists speak for what they have defined as the disability rights community.

It is not clear whether the activism around disability rights led to the field of disability studies or if the early disability scholars triggered activism among the ranks. In either case, the scholarship in the field nourishes the activist agenda, and the activism generates scholarly discussion.

A. Disability Studies: The Brain Behind the Machine

Disability studies deconstructs the myth of the tragic life of the person with disabilities. The field is rich and varied; it incorporates Marxism, feminist postmodernism, and poststructuralism. It emphasizes, among other things, the social oppression of the disabled and the cultural perception of life with disability.

From all perspectives, the central tenet of disability studies is the rejection of the medical model of disability as a foundation for effective understanding of impairment or disability. "The medical view of disability ... treats the individual as deficient and inherently inferior because she falls below an arbitrary physiological standard that delineates social acceptance and that can only be 'normalized' and incorporated into society through a medical cure." Falling below the physiologic standard is problematic, in the medical view of disability, because "impairments of normal species functioning reduce the range of opportunity open to the individual ... [to] construct a 'plan of life' or 'conception of the good.'" Thus, the medical view of disability essentially locates the problems caused by disability in the disabled individual.

Historic events provide vivid examples of how the medicalization of disability harms people with disabilities. The eugenics program in Nazi Germany may be the most obvious example - Nazi medical centers killed a quarter of a million disabled people because they were considered "useless eaters" - but the United States has also engaged in outright disability discrimination through forced institutionalization, sterilization, and eugenics. Notably, Justice Marshall compared this country's treatment of the disabled to the Jim Crow regime.

Similarly, Justice Holmes famously confirmed that the United States viewed people with disabilities as the problem when he sanctioned the forced sterilization of Carrie Buck:

We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough.

The "Baby Doe" cases provide another example of the problematic results of the medical view of disability. "Baby John Doe" was born in 1982 in Bloomington, Indiana. He had Down syndrome and an esophageal blockage. The blockage was treatable with a relatively minor surgical correction, but his parents opted against the surgery because of advice given to them by their physician about the dismal prospects for a person living with Down syndrome. The baby...
died of starvation at six days old. n30 In a similar case, the parents of "Baby Jane Doe" declined surgery for their daughter, who had been born with spina bifida and hydrocephalus, based on the advice of their physicians. n31 Both babies were denied treatment that could have alleviated certain of their medical problems because they had permanent disabilities that no medical treatment could cure. To disability [*132] rights scholars, the denial of treatment in the Baby Doe cases "represented a kind of discrimination against people with disabilities by the medical profession and frightened parents who were unable to imagine having a child with a disability as anything but a tragedy and disaster ... ." n32

Instead of a medical view of disability, disability scholars view disability as "a socially constructed condition, through which the 'problem' is defined as 'a dominating attitude by professionals and others, inadequate support services when compared with society generally, as well as attitudinal, architectural, sensory, cognitive and economic barriers.'" n33 As stated by one scholar:

The "socio-political" model of disability views disability as "a product of interaction between health status and the demands of one's physical and social environment," and "locates" disability in the interface between the individual and her environment. In doing so, the socio-political model of disability (and a related construct - the minority model) stand in stark contrast to the medical model of disability, "which regards disability as a defect or sickness which must be cured through medical intervention," and which expressly locates the "problem" in the disabled person. n34

Under a social view of disability, a paralyzed person who cannot get into a building because the entrance is at the top of the stairs is not "disabled" by his or her physical impairments. The disability results from the social failure to provide wheelchair accessible ramps. Thus, "the culprit is not biological, psychic, or cognitive equipment but the social, institutional, and physical world in which people with impairments must function - a world designed with the characteristics and needs of the nondisabled majority in mind" in which "an impaired arm becomes a manual disability or social handicap only because of the interaction of a particular physiology with a specific social, legal, and attitudinal environment." n35

The prevailing message in the scholarship is that life with disability [*133] is not tragedy. n36 Rather, the tragedy is the failure of social institutions to help people with physical impairments to lead productive lives. Thus, disability scholars argue that "rules, laws, means of communication, characteristics of buildings and transit systems, the typical eight-hour work day, and aesthetic preferences all exclude some people from participating in school, work, civic, or social life." n37 Given appropriate accommodation by society, a disabled person can have a rewarding life. n38

Disability scholars have proved their point in part through empirical studies that reveal that "people who experience disability - whether it be congenital or acquired, whether sensory, cognitive, motor, or other - can find considerable reward and satisfaction in their lives." n39 Indeed, studies have consistently shown that the number of people with disabilities who found satisfaction in their lives far exceeds predictions by health professionals. n40

Disability scholars view court cases involving medical decisionmaking as statements about the tragedy of life with disability. According to the literature, courts have accepted and perpetuated two incorrect assumptions in allowing people to forgo medical treatment and choose death over life with disability: "First, the life of someone with a chronic illness or disability ... is forever disrupted .... Second, if a disabled person experiences isolation, [*134] powerlessness, poverty, unemployment, or low social status, these are inevitable consequences of biological limitation." n41

The case of Elizabeth Bouvia tells the story. n42 Elizabeth Bouvia, a twenty-eight-year-old woman who had cerebral palsy and arthritis, asked a California court to remove a nasogastric tube and allow her to die of starvation. Bouvia was not terminally ill but the court granted her wish. n43 Lawyers and scholars pressing autonomy as the gold
standard in medical decisionmaking hailed the Bouvia case as a landmark victory because it affirmed that even those
who are not terminally ill can decline treatment, and that artificial nutrition and hydration is medical treatment. n44
Disability scholars read Bouvia very differently. They saw Elizabeth Bouvia as a person with disabilities who lacked the
social support necessary to allow her life to have meaning. n45 They pointed out that she demanded the right to starve
herself only after she had a miscarriage, her husband left her, her family abandoned her, the county failed to find a
suitable place to house her, and she was forced to withdraw from graduate school because the dean believed her
disability made her an inappropriate student. n46

[*135] Disability scholars saw Bouvia's plight as a classic case of society failing a person with disability. The
appropriate answer to Bouvia's situation, argued disability scholars, was social support and intervention, not
acquiescence to her demand for death. n47 The community saw the court's decision to allow Bouvia to starve herself as
judicial confirmation that lives with disability are not worth living.

The judge who authored Bouvia gave disability scholars many reasons to believe that the decision was not about
autonomy, but about disability discrimination. n48 The court went to great lengths to describe in painstaking detail the
physical elements of Bouvia's disability. It then explained that her decision that her life had no meaning was reasonable:
"Her mind and spirit may be free to take great flights but she herself is imprisoned, and must lie physically helpless
subject to the ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness." n49 Thus,
the judge asserted that disability had ruined Bouvia's life, that "such life has been physically destroyed and its quality,
dignity and purpose [are] gone." n50 Without exploring the implications of the social changes in Bouvia's life, the judge
characterized extending her life as "monstrous." n51

The functional limitations faced by Bouvia mirrored those of many disability rights leaders who could live for
decades with the assistance of medical treatment and technology. n52 Thus, unlike the earlier cases that involved
decisionmaking for people who were permanently unconscious or terminally ill, n53 the case got the [*136] attention
of disability scholars. They read Bouvia as confirmation that laws that provided patients choice in medical
decisionmaking were really a legal judgment that their lives were not worth living. n54

Following Bouvia, disability scholars started to question whether such cases were really about autonomy, a
principle cherished by the community, or about a new eugenics. n55 They argued that "[the nondisabled public] readily
concludes that the disabled person's wish to die is reasonable because it agrees with [the] preconception that the primary
problem for such individuals is the unbearable experience of a permanent disability.... If permanent disability is the
problem, death is the solution." n56 Disability scholars further observed that "when the nondisabled say they want to
die, they are labelled [sic] as suicidal; if they are disabled, it is treated as 'natural' or 'reasonable.'" n57

To disability scholars, the willingness of courts and the public to accept as reasonable the wish to die exemplified a
lack of social recognition for the value and validity of a disabled life. n58 From a disability perspective, courts failed by
focusing on limitations created by physical impairment, instead of focusing on the ways "in which law, medicine,
bioethics, and government programs failed to help traumatically disabled patients discover the financial, technological,
social, and psychological resources that could sustain them and provide the opportunity for rewarding life." n59

Thus the first right of people with disabilities became "a claim to life itself." n60 Laws that allow the refusal of
treatment became suspect. Disability scholarship came to question the emphasis in current law on autonomy as the
paramount concern in end-of-life cases. n61 The skepticism became especially pronounced when the [*137] nation
turned its attention to the question of physician-assisted suicide. n62 Disability scholars strongly opposed
physician-assisted suicide, arguing expressly that right-to-die cases "reflect a societal prejudice that devalues the worth
of disabled persons' lives." n63 As a result, scholars urged "clinicians and policy-makers to question how truly
autonomous is anyone's wish to die when living with changed, feared, and uncertain physical impairments." n64

In time, scholars criticized laws that allow family members to withhold treatment. n65 As one scholar noted, "Even
a demonstrably loving and involved family may be unable to put aside its own view of how limited life with disability is
to imagine such a life from the vantage point of someone with the impairment." n66 In keeping with its position, disability scholars applauded the New York Court of Appeals when it refused to allow the mother of a man with profound mental retardation the option of declining treatment for her son's cancer. n67 The mother had provided good care to her son throughout his life, but was concerned that the treatments were unduly upsetting to him. The court held that no one, not even a loving family member, could decline life-saving treatment for someone who has not expressed his or her own wish to refuse treatment. n68

[*138] In addition to questioning the ability of family members to make decisions for their disabled loved ones, some disability scholars question the notion of precedent autonomy. Precedent autonomy is the concept that supports living wills. n69 It allows people to decide in advance what medical decisions should be implemented if they later become unable to express their wishes, and requires health care providers to act on those decisions. Disability scholars are suspicious of such directives, believing that people who are not disabled cannot imagine that life with a disability would be rewarding. n70 According to the scholars, rather than blindly following advance directives, treatment should be evaluated from the viewpoint of the recently disabled individual. n71 If a person appears to take pleasure in her current state of disability, that current state should be maintained despite previously expressed wishes to avoid life in a disabled state.

Thus, disability scholarship calls into question the role of autonomy, families, and advance directives in end-of-life decisionmaking. The bottom line, argues scholar Adrienne Asch, is that "it is crucial for anyone seeking to advance the dignity and worth of people with all disabilities to promote their participation in life-and-death decisions and to circumscribe family decisionmaking on behalf of those who have less than full legal authority to make their own decisions." n72

B. The Birth of a New Advocacy

Disability studies is inextricably linked with disability rights activism. The thoughtful analysis of legal-medical issues by disability theorists has given rise to a political force. The early political activism of the disability movement, as supported by the developing scholarship, led to legislation like the Rehabilitation Act and eventually to the Americans with Disabilities Act. n73

The disabilities movement took on a different form - what I call a new activism - in the late 1980s and early 1990s. The original focus of the new activists was not medical cases; it was the [*139] Jerry Lewis Muscular Dystrophy Association Telethon. Disability activists consider telethons that trot out disabled children as mascots "demeaning and exploitative of disability as tragic and catastrophic." n74 Evan Kemp, Jr., former chair of the federal Equal Employment Opportunity Commission, presented the earliest public critique of telethons in a 1981 New York Times editorial, in which he stated that "by arousing the public's fear of the handicap itself, the telethon makes viewers more afraid of handicapped people.... The telethon's critical stress on the need to find cures supports the damaging and common prejudice that handicapped people are 'sick.'" n75 A decade after Kemp's critique was published, the early activists began to demonstrate against the telethons. n76 The activists' message was angrier than Kemp's. n77 One activist protested, "It's all about stirring up pity, when we don't want pity. And Jerry Lewis ought to be fired. He actually called people in wheelchairs 'half persons.'" n78

Having organized against telethons, the new activists turned their attention to court actions involving medical decisionmaking, where they participated with limited attention for many years. n79 The organized activity culminated, of course, in the case of Terri Schiavo. One of the most powerful voices in the Schiavo case was Harriet McBryde Johnson's. McBryde Johnson is a disability rights lawyer and activist who lives with a neuromuscular [*140] degenerative disease that has left her, in her words, "a jumble of bones in a floppy bag of skin." n80 She is not able to walk, stand, lift heavy objects, or swallow solid foods. n81 To keep herself upright in her chair, she leans forward, rests her rib cage on her lap and plants her elbows beside her knees. n82 She eats pureed food, lacks the physical strength to get out of bed on her own, and will someday soon need to eat though a feeding tube.
McBryde Johnson is anything but weak. Her mind has the strength and agility her body lacks. Her writing is wicked, sharp, insightful, and funny. Her oral presentations are equally compelling. She uses personal stories and insights strengthened by her physical weakness to advocate her positions on issues involving life and death. Specifically, she uses the strongest sort of identity politics, legal acumen, and powerful straight talk to argue against choice in medical decisionmaking. Her message resonates.

Harriet McBryde Johnson came to national prominence when she published a cover story in the New York Times Magazine. In the article, McBryde Johnson described her experience at Princeton University in which she confronted ethicist Peter Singer. She saw the debate with Singer as personal, stating:

[Peter Singer] doesn't want to kill me. He simply thinks it would have been better, all things considered, to have given my parents the option of killing the baby I once was, and to let other parents kill similar babies as they come along and thereby avoid the suffering that comes with lives like mine and satisfy the reasonable preferences of parents for a different kind of child.

McBryde Johnson first met Singer when she attended a lecture entitled "Rethinking Life and Death" in the spring of 2001 at the College of Charleston. She confronted him during the question and answer session, and their dialogue continued by e-mail over the next year. Eventually, Singer invited McBryde Johnson to debate him at Princeton. They worked out an arrangement for two presentations by McBryde Johnson. She detailed and reflected upon her talks in an article titled "Unspeakable Conversations," in which she challenged Singer's abstract philosophical thinking with her lived experience. The article became regular reading in bioethics, philosophy, and disabilities law classes across the country.

McBryde Johnson continued to argue against Singer's radical position in the years that followed. She presented numerous lectures and continued her work as a disability rights lawyer. She showed up on the national stage again during the Schiavo debacle.

Perhaps more than any other statement on the case, McBryde Johnson's short commentary titled "Not Dead at All: Why Congress Was Right to Stick Up for Terri Shiavo" succinctly and powerfully argued against the withdrawal of Terri Schiavo's feeding tube. In the commentary, she made ten points which can be summarized as follows: Schiavo was not terminally ill; artificial nutrition and hydration are not life support and are not treatment; since Schiavo was not suffering, her death could not be justified as relieving suffering; no one could determine what Schiavo's wishes were at the time the decision to terminate treatment was made; Schiavo had a federal constitutional right not to be deprived of her life without due process; terminating nutrition and hydration for Schiavo would violate the Americans with Disabilities Act; fear of feeding tubes is a form of disability prejudice; and the federal government did not take sides by passing a law to allow the federal courts to step into the Schiavo case after it had been resolved in the state courts.

McBryde Johnson's arguments paralleled those made in briefs to the court and in position papers by the disability rights group Not Dead Yet. Not Dead Yet is a national disability rights group that has taken the lead in opposing the legalization of assisted suicide, euthanasia, and the termination of life-sustaining treatment. The group stages noisy demonstrations with its members arriving at courtrooms, lecture halls, and rallies in a mass of wheelchairs. Members carry signs that say "Health Care Not Death Care" and "Medical Ethicists Are Not Ethical." Further, they submit briefs in court cases and lobby heavily in state legislatures.

Not Dead Yet showed up well before the media, President Bush, or Senator Bill Frist noticed Terri Schiavo. In fact, members of Not Dead Yet have actively opposed laws that permit people or their surrogates to terminate life sustaining treatment since 1983, when Elizabeth Bouvia obtained the court order that required the hospital to remove the
The group began its public activities in 1996 when Jack Kevorkian started providing assisted suicide to the public. In a 1997 rally, 500 people with disabilities gathered to chant "Not Dead Yet" in protest of Kevorkian's acquittal on criminal charges. The group's purpose is to prevent disability discrimination in end-of-life cases. It frames the issue of assisted suicide as follows:

Though often described as compassionate, legalized medical killing is really about a deadly double standard for people with severe disabilities, including both conditions that are labeled terminal and those that are not... Countless people with disabilities have already died before their time. For some, a disabled person's suicidal cry for help was ignored, misinterpreted, or even exploited by the right-to-die movement. For others, death came at the request of a family member or other health care surrogate. This is not compassion, it's contempt.

Working together with twenty-five national disability groups, Not Dead Yet took on a prominent and public role during the Schiavo case. The activists claimed Terri Schiavo as one of their own. As the group wrote in an amicus brief:

Ms. Schiavo's fate is intertwined with that of many people with disabilities who must rely on surrogates. If... Ms. Schiavo's "quality of life" - as determined by others - justifies her death, then one cannot distinguish Ms. Schiavo from anyone else who is "incompetent," including thousands who cannot speak due to developmental or physical disabilities.

Not Dead Yet filed several amicus briefs during the course of the Schiavo case, all of which raised three principal arguments: first, that the trial court had failed in its fact-finding role; second, that Terri Schiavo had a substantive due process right to receive treatment; and third, that the denial of medical care because of cognitive disability constituted illegal differential treatment under the Americans with Disabilities Act. The Schiavo briefs reiterated arguments made for years by the activists, but it was during Schiavo that they got the most attention.

In addition to making the legal arguments in courts, Not Dead Yet actively lobbied the Florida legislature, Florida Governor Bush, Congress, and the President on behalf of their cause. The results were stunning. The lobbying effort helped to achieve state legislation, federal and state court litigation, federal legislation, executive action, and twenty-four-hour media coverage for weeks on end. Through its involvement in the case, Not Dead Yet raised the profile of the disability rights movement and its message to a national stage in a very real way. Suddenly, the public was engaged in debates about persistent vegetative states, advance directives, and artificial nutrition and hydration. After the immediate furor over Schiavo subsided, Not Dead Yet began supporting a Model Starvation and Dehydration of Persons with Disabilities Prevention Act (Model Act). The Model Act would effectively take away the power of surrogate decisionmakers to withhold life-sustaining treatment, especially nutrition and hydration, in the absence of a written living will.

Thus, the agenda of many disability scholars and activists is very much the same with respect to end-of-life cases. The two groups appear united in their desire to prevent surrogates from withholding treatment, especially nutrition and hydration, at the end of a person's life. The community opposes such decisions because, in its view, they are based on and perpetuate the notion that a disabled person's life is not worth living. The acceptable alternative is to educate patients and their families about the potential value of life with disability, and to provide patients and their families the
support, accommodation, and tools needed to maximize the value of that life.

After Terri Schiavo died, the new activists brought their agenda to state legislatures across the country. The following Part discusses the impact of their actions.

II

Hearing the Message: How the Disability Lobby Has Succeeded in Changing Public Discourse

For at least twenty years, certain principles have been settled as matters of law and ethics. First, every competent person of adult years has a qualified right to decide what to do with her own body. That right, which is rooted in both constitutional and common law, includes the right to refuse medical treatment. Second, if a person lacks capacity to make medical decisions, someone else may make medical decisions for her. Third, the provision of nutrition and hydration to someone who cannot eat or drink on his or her own is medical treatment, just as the provision of air to someone who cannot breathe or insulin to a diabetic is a medical treatment. Fourth, a competent individual may voluntarily forgo life-sustaining nutrition and hydration in any state in the country. Fifth, the right to decline treatment is protected in all fifty states by statutes that ensure that a person's wish to forgo life-sustaining treatment can be carried out by a surrogate if the person loses competency.

The Schiavo case called all these principles into question. To be sure, the case did not itself result in a change in the law, but the activism of the disability rights community and the publicity the community created through Schiavo has had "lingering effects." The most vulnerable principles concern the provision of nutrition and hydration as medical treatment, and the ability of a surrogate to withhold such nutrition and hydration for a person who cannot speak on his or her own behalf. The activism resulting from the Schiavo case further weakened the resilience of these principles.

Professor Tom Mayo explained, "It apparently came as a surprise to a lot of members of Congress and the public that 'artificial nutrition and hydration' ('ANH') is deemed to be 'life-sustaining treatment' and therefore is an intervention that may be refused on behalf of an incompetent patient ... " During Schiavo, disability activists pressed the notion that ANH is not a medical treatment but a fundamental human right, and legislators became open to the disability rights argument. The disability rights community got additional support from the Vatican, which came out against the removal of Terri Schiavo's feeding tube. Pope John Paul II wrote in 2004 that "the administration of water and food, even when provided by artificial means, always represents a natural way of preserving life ... not a medical procedure." Because Schiavo was brain damaged but not brain dead, Vatican officials said she must be kept alive.

Building on the momentum of the Schiavo case, disability activists, together with unlikely bedfellows in the right-to-life lobby, began pressing the Model Starvation and Dehydration of Persons with Disabilities Prevention Act in state legislatures across the country. The Model Act would create a presumption that all people who lack the legal capacity to make their own "health care decisions [have] directed [their] health care providers to provide ... nutrition and hydration to a degree that is sufficient to sustain life." The presumption may be overcome only if withholding artificial hydration and nutrition is explicitly contemplated in the patient's living will or if there is "clear and convincing evidence that the person ... gave express and informed consent to [reject] nutrition or hydration in the applicable circumstances." Various versions of the Model Act have been introduced as bills around the country.

For example, a bill introduced in Kansas would make it more difficult for guardians of the disabled to withhold nutrition and hydration from people under their care. The bill, supported expressly by Not Dead Yet President Diane Coleman, would require "legal guardians for people who are incapacitated, disabled or unable to make some decisions for themselves ... [to] obtain permission from a judge or jury to withhold food and water if the people in their care had no living wills ... ."
The disability rights community's success in bringing attention to its message during the Schiavo case may affect more than the legal treatment of nutrition and hydration. Professor Kathy Cerminara points to four other ways in which the Schiavo case may yet change laws around disability at the end of life. First, legislatures may consider whether to "prevent persons who might inherit from a patient upon that patient's death from making decisions regarding withholding or withdrawal of life-sustaining treatment." This particular reform, if enacted, will affect close family members who, many would argue, are the most appropriate people to make health care decisions for incompetent patients.

Second, legislatures may consider whether courts must approve decisions regarding withdrawal of life-sustaining treatment, or whether courts must appoint a guardian ad litem for all patients who are subject to a decision to withdraw treatment. According to Professor Cerminara, such an option, "would force ... families, who are already facing gut-wrenching situations, to stake out contentious positions even more strongly than any of them may wish; these families should instead be focusing on what the patient would have wanted." 

Third, legislatures might reconsider the appropriateness of the substituted judgment standard and the use of what Norman Cantor calls "constructive preference" for the patient whose wishes are not known. Most states allow surrogate decisionmakers to use substituted judgment - that is, the surrogate is permitted to determine what the patient would have wanted had she been able to decide for herself. The standard does not require written evidence of the patient's wishes. Rather, the surrogate can make the determination based upon the patient's values, beliefs, and past choices. In some cases, the patient has never had the ability to express wishes for end-of-life medical care, or to form values or beliefs that would have shaped the decision. In such cases, surrogates are actually determining a 'constructive preference' for the patient - 'imputing choices to a formerly competent patient based on what the vast majority of competent persons would want done for themselves in the circumstances at hand.' Because most people favor termination of treatment in cases where they must "exist in a non-communicative state or a state in which they manifest little or no control over their surroundings or recognition or enjoyment of loved ones," a scheme allowing a decisionmaker to act on constructive preference will allow the termination of treatment in more cases than not. The mid-level appellate court in Schiavo expressly stated that use of the majority view was inappropriate in conducting a substituted judgment analysis. The Model Act shopped in Schiavo's wake would prohibit the use of constructive preference and substituted judgment altogether.

Finally, the case may trigger change in the way legislatures treat people in persistent vegetative states (PVS). Because Schiavo drew attention to the somewhat incongruous fact that someone in a PVS can appear awake and able to react to certain stimuli, legislatures could decide to revisit statutory definitions of a PVS, or, more alarmingly, revisit laws that allow the termination of treatment for a person in a PVS. For example, Lois Shepherd describes a bill that is pending in Ohio as making it "even more likely that the preferences for treatment withdrawal of a person in a permanent vegetative state would be ignored." The law would make the surrogacy process that ordinarily applies to patients who lack decisionmaking capacity inapplicable for patients in persistent vegetative states if someone who could potentially serve as a surrogate agreed in writing not to withdraw artificial nutrition and hydration. That person would be given the power over the patient regardless of what the patient might have wanted. The bill's effect would be "to nullify a patient's wishes to discontinue tube feeding by deferring to a surrogate who determined otherwise." 

The impact of the new advocacy will not be known for some time. In the meantime, a critical examination of both the agenda and its underlying theory is in order.

III

Danger, Conflation, Misidentification, and Pernicious Paternalism

The new advocacy by the disability rights community on end-of-life cases is theoretically flawed and dangerous. The community advocates laws that would make it virtually impossible for surrogates to terminate life-sustaining treatment
for people who lack capacity and have no living will. The community argues that such legislation is necessary to protect the disabled from discrimination that will force early death because of the judgment that disabled lives are not worth living.

Before the new advocacy took center stage in the disability rights movement, paternalism was the enemy of the community. Disability rights activist James Charlton explained, "paternalism lies at the center of the oppression of people with disabilities. Paternalism starts with the notion of superiority: We must and can control these 'subjects' in spite of themselves, in spite of their individual will, or culture and tradition." The new activists have focused on a new enemy - people who favor autonomy as the paramount concern in medical decisionmaking. Thus, a new activist charged, "If I were listing the most dangerous people in the U.S. today, bioethicists, aka medical ethicists, would top my list - way above skinheads, whose beliefs they appear to share."

How did the new activists stray so far from their roots in disability studies that they began pushing paternalistic laws that would disable individuals already facing disability? Kathy Cerminara argues that right-to-life advocates have co-opted the disability agenda. I disagree, at least in part. While the interests and activism of the two groups converged as early as 1983 with respect to the Baby Doe cases, the new agenda is the natural outgrowth of disability studies and identity politics.

Disability studies reframed common problems faced by people with physical and cognitive impairments as disability issues and brought together a diverse group that rallied together to become a political force. The activists, consisting of people with a wide array of physical impairments, joined together in a struggle based on the shared experience of injustice. The larger the group, the greater its power. The more universalized its agenda, the greater its impact. Thus, while the activists' purported goal, like that of their scholarly counterparts, is greater self-determination and the elimination of social obstacles to success for their constituents, their agenda relies on the recognition of disability as a political force. The cohesion of the group paid off, in a classic example of the power of identity politics, with the passage of the Americans with Disabilities Act (ADA).

The group's focus on a universal answer to end-of-life decisionmaking, however, is not a victory for its members. The new activists' agenda around end-of-life decisionmaking is plagued by paternalism that marks a departure from the scholarly focus on the importance of self-determination for people with disabilities.

In this Part, I argue that the disability activists' flawed agenda with respect to end-of-life decisionmaking is the result of the misuse of identity politics. That is, the activists' single-minded focus on disability, their need to claim all impaired persons as disabled, their effort to reframe all end-of-life cases as disability issues, and their claim of self-determination for the community regardless of its impact on individual members have led the group to its current posture - that of asserting that there is one single answer to disability.

The position taken by the disability activists is not only analytically flawed, it is also dangerous. If adopted, the laws they advocate would themselves discriminate against the disabled by making it impossible for anyone who lacks capacity - itself a kind of disability - from having access to a medically appropriate treatment. The result would not only physically hurt people, it would have the ironic effect of disabling the disabled.

I start by dispensing with the legal arguments advanced by Not Dead Yet and others that laws that allow surrogates to choose to withdraw life-sustaining treatment legally discriminate against the disabled. I then address the advocate's proposed legislation, and show how adoption of laws based on their model legislation would hurt all of us, especially those with disabilities. Finally, I explore the theoretical flaws - conflation, misidentification, social kinship, and assumption - that led the activists to their extreme positions.

A. Legal Flaws, Medical Errors, and Discriminatory Effect
The legal arguments pressed by the new activists in cases like Schiavo are easily dismissed. The principle underlying the arguments is that laws that allow surrogates to choose to withdraw or withhold treatment at the end of life violate the ADA and the due process rights of persons with disabilities. n150

[*153]

1. Americans with Disabilities Act

The new activists argue that allowing a surrogate like Michael Schiavo to deny food and water to someone who is too disabled to make her own health care decisions is disability discrimination that violates the ADA. n151

The purpose of the ADA was to "provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." n152 The ADA offers broader protection against disability discrimination than the protection provided by other federal laws. n153 The ADA provides that "no individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation ... ." n154 The ADA also forbids "utilizing standards, criteria, or methods of administration that have the effect of discrimination on the basis of disability." n155 Medical care clearly falls under the ADA's operation. n156

Families of people with disabilities and disability rights activists have successfully turned to the ADA to force health care providers to treat people with disabilities. n157 They have convinced [*154] courts that when the family or the patient's surrogate has consented to the care, a disabled person is entitled to all the medical care that would be provided to a nondisabled person. n158 A refusal by a medical provider to honor a request for treatment can constitute discrimination under the ADA. n159 Thus, an HIV-infected woman successfully sued under the ADA to force a dentist to fill her cavity in his office instead of in the hospital, n160 and the mother of an anencephalic infant was able to use the ADA to force a hospital to keep her baby alive through ventilation. n161 The courts in these cases reasoned that treatment available to the nondisabled must be available to the disabled. n162

Applying this reasoning in the case of Terri Schiavo, Not Dead Yet argued that removing Terri Schiavo's feeding tube would deny Schiavo the care that would be provided to people without disabilities because people without her disability would be provided nutrition and hydration. n163 Specifically, the group's amicus brief to the Florida District Court of Appeal in In re Schiavo argues:

Treating people differently based on health or disability status violates the rights of people with disabilities under the ADA. Absent proof that it is truly the person's decision, withholding medical care based on the belief that he or she would rationally want to die because of a disability is discriminatory. ... When health care providers deny people with severe cognitive disabilities the health care they need to live, but do not do so for others, they violate Title III of the ADA, governing health care providers and other "public accommodations." When state and local governments establish laws and policies that deprive people with cognitive disabilities of the care granted to "competent" persons, they violate Title II of the ADA. n164

The argument fails for several reasons. First, it wrongly assumes that Terri Schiavo was denied care that she would otherwise have received because of her disability. She was not. Terri Schiavo could not receive the care because no one with authority to authorize the continuation of artificial nutrition and hydration had consented to it. The United States Supreme Court decided the issue in Bowen v. American Hospital Association. n165 There, the Court was asked whether the Rehabilitation Act prohibited the withholding of medical treatment to handicapped infants. n166 The Supreme Court found no evidence that the hospitals had denied treatment on the basis of handicap. n167 Rather, treatment was denied
because of the absence of parental consent. Accordingly, the Supreme Court concluded, "A hospital's withholding of treatment [from a handicapped infant] when no parental consent has been given cannot violate [the Rehabilitation Act], for without the consent of the parents ... the infant is neither 'otherwise qualified' for treatment nor has he been denied care 'solely by reason of his handicap.'"

The Court's reasoning in Bowen applies equally in the case of Terri Schiavo. The case had nothing to do with disability discrimination. A hospital cannot administer medical treatment in the absence of a patient's consent or consent by a legal surrogate because without consent, the patient is not qualified to receive treatment. Under Florida law, Michael Schiavo was Terri Schiavo's legal surrogate. His refusal to consent to treatment on Terri Schiavo's behalf disqualified her for treatment and provided her physicians a reason to withdraw her treatment other than her disability. Thus, Schiavo was not a case about treatment refusal based on disability.

Secondly, the laws that gave Michael Schiavo the power to refuse treatment for his wife do not discriminate against people with disabilities; those laws give people with disabilities, like Terri Schiavo, a voice in their medical decisionmaking. Laws that give surrogates the power to make medical decisions are not analogous to a dentist's refusal to fill a cavity for an AIDS patient in a dentist's office. Whereas the dentist's refusal to fill a cavity constituted denial of access to appropriate medical care, the Florida surrogacy laws provided Terri Schiavo with access to medically appropriate options, including the option to refuse treatment.

Terminating treatment is part of good palliative care practice. Like a decision to provide pain-relieving drugs despite the fact that they might hasten death, a decision to terminate treatment may be made to increase patient comfort, to eliminate pain, or to stop bodily deterioration. The decision might also be made to implement the patient's own judgment about life in her current state. In any of these cases, standard medical care offers all adults the option to choose whether to terminate treatment.

Furthermore, people choose to terminate treatment in hospitals every day. Jehovah's Witnesses refuse blood transfusions. Cancer patients refuse chemotherapy. People in persistent vegetative states refuse nutrition and hydration through advance directives. Since Terri Schiavo had no advance directive and could not make her own health care decisions, she could access treatment options solely through her surrogate. Thus, the law that gave Michael Schiavo power to make medical decisions in Terri's stead gave Terri access to appropriate medical care.

Not Dead Yet's argument turns the ADA on its head. Laws that give people with disabilities access to choice between medically acceptable treatments protect the rights of people with disabilities - even if one of the choices is the termination of treatment. It is the denial of access to all available options that would violate the ADA. In fact, surrogacy laws ensure that the ADA's demand for access is fulfilled. Substituted-judgment and best-interests based statutes are reasonable accommodations. They give the people who lack competence to make their own health care decisions access to the same options available to those who have competence. In this way, surrogacy statutes can be compared to access ramps installed by building owners after the passage of the ADA. Just as ramps were not the equivalent to stairs (e.g., they might be located in the back of the building and take longer to traverse than stairs), surrogacy laws are not the equivalent to an actual exercise of medical decisionmaking by the disabled person. However, just like ramps allow the person with the disability to get into a building, surrogacy laws allow the patient access to all appropriate treatment decisions, including no treatment at all.

So long as a surrogate is choosing between medically acceptable options, the ADA has no role in a medical decisionmaking case. Palliative care medicine views the termination of treatment, including the withholding of nutrition and hydration, as medically appropriate when a person is terminally ill or permanently unconscious. Like dental treatment, palliative care is a public accommodation available to the general public. The activists' position would limit options for surrogates and thereby deny people who lack the capacity access to an acceptable option in palliative care, thus denying the disabled a public accommodation. The denial of access would be based on the patient's disability: the inability to form or express intent.
If the disability activists are right, and the ADA prohibits decisions to terminate treatment for people who cannot speak for themselves, then the ADA would prohibit the disabled from receiving appropriate palliative care. n176 The ADA should not be used to keep people with disabilities from accessing any medical choice. If it is applicable to end-of-life decisions at all, the ADA should ensure that people with disabilities have the same access to palliative care as all other patients. n177

2. Due Process

Not Dead Yet's argument that laws that allow the termination of treatment violate patients' due process rights is even less compelling [*159] than its discrimination argument. Not Dead Yet argues that the Supreme Court in Cruzan v. Director, Missouri Department of Health n178 specifically held that a patient's due process right to life is violated by allowing surrogates to make decisions to withhold treatment on anything less than "clear and convincing" evidence that the patient expressed the wish to terminate treatment. n179 The argument misconstrues the Supreme Court's Cruzan decision.

Nancy Cruzan was in a persistent vegetative state because of injuries she sustained during an automobile accident. n180 Her parents sought a court order directing the withdrawal of life-sustaining nutrition and hydration. The Supreme Court of Missouri held that her parents lacked the authority to make the decision because they could not produce clear and convincing evidence that Cruzan would have wanted to terminate treatment. n181 The Supreme Court "granted certiorari to consider the question whether Cruzan has a right under the United States Constitution that would require the hospital to withdraw life-sustaining treatment from her under these circumstances." n182

The Court carefully and narrowly defined the issue as whether Missouri's clear and convincing evidence standard infringed upon Nancy Cruzan's due process rights to refuse life-saving treatment. n183 The Court upheld the Missouri statute, explaining that when a patient is incompetent to assert her own wishes, "a State may properly decline to make judgments about the 'quality' of life that a particular individual may enjoy, and simply assert an unqualified interest in the preservation of human life." n184 Thus, the Court held that the Due Process Clause does not require the state to repose judgment with anyone but the patient herself on what is an acceptable quality of life. n185

Contrary to Not Dead Yet's interpretation of Cruzan, nothing [*160] in the decision remotely suggests that Missouri's high evidentiary standard is constitutionally required. The Court simply upheld Missouri's law as one acceptable state alternative. n186 In fact, Justice O'Connor explained in her concurrence that the Court's decision was "only that one State's practice does not violate the Constitution; the more challenging task of crafting appropriate procedures for safeguarding incompetents' liberty interests is entrusted to the 'laboratory' of the States, in the first instance." n187 Thus, other states have latitude to adopt schemes that differ from Missouri's, including ones that allow surrogates to make decisions on less than clear and convincing evidence. n188

To be sure, Cruzan would permit the limitations on surrogate decisionmaking that Not Dead Yet and its fellow amici (several disability rights groups joined the brief) sought in the Schiavo case. n189 What is curious, however, is that the activists oppose more generous surrogacy statutes that actually protect the due process rights of people with severe disabilities. Like all citizens, people with severe disabilities have the due process right to refuse medical treatment. n189 Norman Cantor identifies three components of that right: "(1) an interest in self-determination (i.e., in making a choice about treatment); (2) an interest in well-being (i.e., in having net interests advanced by a decision about treatment); and (3) an interest in maintenance of bodily integrity (i.e., freedom from unnecessary bodily invasion)." A well-intended surrogate is the best person to exercise the disabled patient's right to well-being and maintenance of bodily integrity. Although a surrogate cannot exercise a profoundly disabled person's right to self determination, "[a] conscientious surrogate can determine whether medical intervention will promote the well-being or net interests of a profoundly disabled patient and whether the patient's bodily integrity or dignity will be needlessly compromised by the contemplated medical procedure." n191

[*161] Disability activists fear that no surrogate is conscientious, and that no surrogate can be trusted to make a
decision to refuse treatment for reasons other than fear of disability. Thus, out of fear that surrogate decisionmaking could be abused, disability activists would create a right to life that would prevent surrogates from exercising an independent judgment for an individual patient about a particular person's well-being and bodily integrity. If adopted, the position could have serious negative consequences for anyone who has not issued an advance directive.

B. Danger: Substituted Judgment for Everyone

The legislative agenda being pushed by the new activists is blatantly paternalistic. Its purpose is to protect disabled patients. In effect, the activists are saying that individuals, their families, and their physicians cannot be allowed to make their own decisions, because people without disabilities cannot and do not understand and accept that life with disability can be a life with quality. Therefore, to protect people with disabilities, the new activists would take certain choices out of the hands of people without disabilities. This Part argues that adopting the agenda would not protect the disabled - it would harm them.

Major disability rights groups have adopted common resolutions that set forth the new activists' agenda. That agenda focuses on the power of surrogates to withhold nutrition and hydration, and could easily apply to any life-sustaining treatment. The legislation the new activists are proposing would essentially eliminate the ability of surrogates to use substituted judgment as a model for decisionmaking and impose, instead, the activists' judgment that continued life is the appropriate course. For example, the National Council for Independent Living has resolved to advocate for legislation that would "only allow for withholding of food and water in the presence of 'clear and convincing evidence' of the person's wishes or when the person's medical condition renders them incapable of digesting or absorbing the nutrition and hydration so that its provision would not contribute [*162] to sustaining the person's life." n192

The Model Starvation and Dehydration of Persons with Disabilities Prevention Act specifically imposes a presumption "that every person legally incapable of making health care decisions has directed his or her health care providers to provide him or her with nutrition and hydration to a degree that is sufficient to sustain life." n193 Thus, the Model Act expressly imposes a substituted judgment about what the person would want, regardless of the individual's values. The presumption could be overcome in very limited circumstances. "No guardian, surrogate, public or private agency, court, or any other person" would have the authority to terminate nutrition and hydration except if expressly provided for in a living will, or if the surrogate could produce "clear and convincing evidence that the person ... , when legally capable of making health care decisions, gave express and informed consent to withdrawing or withholding hydration or nutrition in the applicable circumstances," or if the nutrition and hydration is not medically possible, would hasten death, or would not contribute to sustaining the person's life. n194

The Model Act and the resolutions of various disabilities groups would impose laws very much like New York's. n195 New York is one of three states that severely limits the ability of family members to refuse life-sustaining treatment for patients who lack competence to make their own decisions in the absence of an advance directive. n196

New York law, much like the law proposed by the Model Act, [*163] makes it nearly impossible for the family of a person who lacks decisionmaking capacity to forgo life-sustaining treatment in the absence of a living will. n197 Under New York common law, a "patient alone had the right to decide on terminating life support systems." n198 Consistent with the personal nature of this right, the New York Court of Appeals took note of the "fundamental commitment to the notion that no person or court should substitute its judgment as to what would be an acceptable quality of life for another." n199 New York does not allow a third party to terminate life-sustaining sustenance for a person who has not stated a "specific subjective intent" n200 to forgo such treatment under the specific circumstances presented, a requirement that is so strict that it is almost never satisfied absent a written directive. n201 The rule applies with particular force to nutrition and hydration by prohibiting parents and guardians from making a "decision that would result in [the incompetent patient] starving to death, if such could be medically avoided, regardless of how soon he may or may not succumb from other causes." n202
Some patients, such as the profoundly retarded, the mentally ill, and those born with brain injuries, have never had the ability to express a specific subjective intention. Others simply did not express a specific subjective intention prior to becoming incapacitated. As to both groups, the Model Act and the resolutions similar to New York's law would require that life-sustaining treatment be provided.

The so-called protection afforded the disabled by the New York law and in the law sought by the new activists is dangerous. As discussed in Part II, eliminating choices available to surrogates will prevent people with profound disabilities from gaining full access to palliative care. Such limitations may very well violate the ADA. The limitations will, moreover, remove from the equation the disabled patient's right to bodily integrity and freedom from restraint. The experiences with such laws by disabled people in New York stand as cautionary tales to those who would spread them throughout the country.

1. Two Cautionary Tales

Two cases exemplify the problem with paternalistic laws like those being advocated by Not Dead Yet. Both cases arise in New York. The use of New York cases is appropriate because the new activists and disability scholars look to New York law as appropriately protecting the rights of the disabled through their strict limitations on surrogate decisionmaking.

Sheila Pouliot lived almost her entire life with severe disabilities and died after being subjected to New York's laws at age forty-two. Her story, which I have written about before, bears repeating because it stands as a terrible lesson about the cost to people with disabilities exacted by paternalistic laws. Contrasted to her story is that of Scott Matthews, another person at the center of a controversy over the imposition of a feeding tube. The two stories demonstrate persuasively the danger of paternalistic laws, the value of autonomy, and the need to allow people with disabilities mechanisms to avoid pain, degradation, and restraint.

Sheila Pouliot was admitted to a state-run hospital in upstate New York with bleeding in her gastrointestinal tract and what was initially diagnosed as aspiration pneumonia. For years, she had been fed through a gastrostomy tube, but because of her bleeding, Pouliot could no longer tolerate tube feeding. Physicians advised Pouliot's family "that she was suffering from what was likely to be her terminal illness, that she was in pain, and that further treatment would likely prolong the suffering." Initially, her physicians complied with the family's request to withhold all treatment and provide only pain relief. Six days after her admission to the hospital, however, a state agency informed the hospital that New York law did not allow her family to make the decision to terminate the provision of nutrition and hydration, and the hospital ordered the physicians to resume treatment.

The dispute ended up in court. Pouliot's family, physicians, and guardian sought permission to terminate treatment. The state attorney general argued in favor of continued treatment. The trial judge ordered the continuing provision of artificial nutrition and hydration based on a straightforward application of New York law and the consent of the family.

The treatment successfully sustained life functions, but Pouliot's condition deteriorated. Doctors provided Pouliot with as much nutrition and hydration as was possible over the course of two months. They were limited to providing what they could through intravenous lines because gastrointestinal bleeding prevented use of the feeding tube. The calories that sustained Pouliot's life caused her significant pain. As I describe in a previous article:

During that time, Ms. Pouliot's body began to catabolize her own tissue. The hydration provided through the [intravenous] tubes damaged her organs and caused her severe pain. Further, it caused her severe edema, which
stretched [Ms. Pouliot's] skin to the point where it fell off and left raw painful areas. She was in agony [and] spent the next two months moaning and curled in the fetal position. n216

Efforts to control Pouliot's pain were unsuccessful. After two months, one of her physicians stated in a consultation note that the continuation of ANH was "inhumane and ... causing suffering. From a medical standpoint, it [was] outside the bounds of ... medically indicated care." n217

Pouliot's guardian returned to court, this time arguing, with the agreement of the doctors and ethicists who had examined Pouliot, that terminating nutrition and hydration would lessen her pain. n218 The problem, said the attorney general, was that the treatment that was harming Pouliot was technically life sustaining, and New York law prohibited a third party, even a court-appointed guardian or loving family member, from making the decision to terminate life-sustaining treatment for another person. n219 The trial judge eventually issued an order permitting the withdrawal of treatment, despite his acknowledgment that New York law did not clearly allow such an order. n220 Pouliot died on March 6, 2000, days after the trial court issued its order. n221

The case of Scott Matthews had a happier ending. n222 Scott was a twenty-eight-year-old man with profound cognitive and physical disabilities. n223 At the time of the court case, Scott was described as "severely malnourished." n224 His disabilities, which included a swallowing disorder, made it very difficult for him to be fed orally. n225 He had been repeatedly hospitalized for dehydration, malnutrition, and aspiration pneumonia. n226 His physician opined that "Scott's malnutrition was life threatening and Scott 'does not and can not' get adequate nutrition and hydration from oral feeding." n227

Scott's parents went to court to fight an effort by his care providers and a state agency to surgically place a feeding tube in Scott. n228 Scott's parents objected to the placement of the feeding tube because of the possible medical complications of the procedure, and "the effect on Scott's emotional well-being if he was denied the social contact that feeding with others [has] provided." n229 Specifically, his mother explained "that Scott, who is quadriplegic, nonverbal and incontinent, makes no other purely voluntary decision than his choice to eat." n230 Replacing oral feeding with tube feeding would have taken away Scott's greatest pleasure.

The mother was supported by a second physician, who came to know Scott because of a fortuitous visit that occurred when Scott's regular physician was on vacation. n231 The second physician testified that it was reasonable to allow Scott to continue oral feedings given his parents' concerns. n232

The trial court found that Scott suffered from "profound life-threatening malnutrition." n233 Because Scott had never been competent to form and express an opinion about the use of a feeding tube under the clear and convincing evidence standard, the trial court ordered the use of a feeding tube. n234

The New York Appellate Division reversed, finding that the appropriate standard was not the clear and convincing evidence standard, but the best interest standard. n235 The court emphasized that even under this standard, New York law does not permit a parent to "deprive a child of life-saving treatment, however well intentioned." n236 It went on, however, to interpret the second doctor's testimony to support the conclusion that Scott's life could be maintained with oral feedings. n237 The court concluded that as long as Scott could sufficiently maintain his life through oral feedings, a more invasive feeding procedure would be premature. n238 The court cautioned, however, that had evidence been presented that Scott was being deprived life-sustaining treatment, it would have granted the request for the tube. n239

2. Lessons Learned

The stories of Sheila Pouliot and Scott Matthews teach several lessons. First, they show that paternalism can hurt. Pouliot's case is paradigmatic on this point. The paternalistic laws that protected her from unscrupulous guardians and
hidden eugenics caused her pain, bodily degradation, and an agonizing death. By focusing on protecting her life and her inability to express her own wishes, the laws took Pouliot's right to be free from invasions upon her bodily integrity and restraint out of the equation. [*169] Thus, she was forced to receive treatment that "sustained her life," but broke her body down at the same time.

Application of the Model Act to Pouliot would have generated the same result. Because Pouliot was not competent to make her own health care decisions, the Model Act would have created the presumption that Pouliot had "directed ... her health care providers to provide ... nutrition and hydration ... sufficient to sustain life." n240 None of the exceptions in the Model Act would have helped Pouliot. She had no advance directive, could not give express informed consent, and was not receiving treatment that was medically impossible, hastening death, or unnecessary to sustaining her life. n241

Pouliot's case is an extreme example, but other cases involving judgments about whether or how to treat the dying or the profoundly disabled also raise questions about the right to bodily integrity and freedom from restraint. The new activists' approach would eliminate individual choice about those values for people who lack decisionmaking capacity. n242

Applying the new activists' approach to Scott Matthews's case demonstrates the problem. He too would be subject to the presumption that he directed "his ... health care providers to provide him ... with nutrition and hydration to a degree that is sufficient to sustain life." n243 The Model Act would prevent his parents or any public agency or court from withholding nutrition and hydration. None of the Model Act's exceptions would apply. Thus, the Model Act would appear to require the implementation of the feeding tube based on the testimony that he was facing "profound life-threatening malnutrition." n244

Placement of the feeding tube in Scott would have required surgery that intruded on his bodily integrity. The surgery carried the risks of anesthesia, aspiration of vomit, skin irritation from the tube, ulceration and bleeding into the stomach lining, tube blockage over time, osmotic diarrhea, and that the feeding tube might migrate. n245 The statute takes into account none of these [*170] bodily invasions.

Even more troubling than the physical intrusion, the feeding tube would have restricted Scott's freedom to choose to eat, n246 and to enjoy the social companionship oral feedings allowed. With it, Scott would have been deprived of the one activity that brought him the most pleasure - oral feedings. Surely, at least some members of the disability rights community would support his family's effort to allow him continued access to that activity, even if pursuing that course shortened his life. Ironically, the law the new activists are pushing to combat a different problem would have deprived Scott of the pleasure of eating.

To be sure, a judge applying the Model Act to the Matthews case might have worked the evidence to find that the feeding tube was not needed to sustain life, like the New York Appellate Division did. However, one can easily imagine another case raising the same issue in which a family does not have the good fortune to find a doctor who would support its efforts to continue oral feeding. The result in such a case would necessarily be the imposition of the tube and the concomitant bodily intrusion and restraint.

The second lesson these cases teach is that family members and well-intentioned surrogates can be trusted. In both cases, the family members acted compassionately to protect the well-being of their disabled relative. The new activists would cut family members out of the medical decisionmaking process. Thus, like Pouliot's sister, family members would have to sit by helplessly and lose what is often a lifelong role as a patient's advocate.

Does the family's role deserve mentioning? The activists would surely argue it does not. From the perspective of the scholars and activists who believe that nondisabled caregivers cannot be trusted because they might believe the myth of the tragic life with disability, it is inappropriate to express concern for the impact of laws on family members. Under the approach adopted by the disability scholars and new activists, the central driving concerns should be
empowerment and protection of the disabled.

I believe, however, that families and caregivers are central positive driving forces for empowering the people under their care. Scott Matthews's parents and Sheila Poulion's family are but two examples. Many people with disabilities have loving families and caregivers who share the community's passion for protecting and enabling people with disabilities, particularly the disabled under their care. The new agenda does not even allow for the possibility that a family member might understand and know a loved one's wishes, values, strengths, or pain tolerance, and may actually be working in the individual's best interest.

The activists prefer to leave decisions to the courts. Thus, Not Dead Yet's Mary Johnson is supporting the Kansas bill that would require court review of any decision made by a third party to terminate treatment. Her support, I suppose, is based on the premise that judges are educable in a way that family members are not.

Again, the negative effects of this paternalistic bill would hurt the very people it is intended to help. The bill would have social and financial costs. Requiring court review of medical decisions would make public otherwise private decisions about health care, turn caregivers into adversaries, and divert financial resources from the patient at the center of the controversy to pay for lawyers. Such a system would cost the impaired person an unacceptable amount.

The third lesson these cases teach is that a right to choose no treatment can affirm a life well-lived. While laws such as New York's are designed to protect the disabled from bad choices made by their caretakers, the laws limit the choices available to people with disabilities. In Scott Matthews's case, his parents' choice empowered him: it gave him socialization and pleasure.

More importantly, perhaps, choice is power. Giving people with disabilities choice, even if that choice must be exercised through a surrogate, affirms the intrinsic worth of each individual. By contrast, paternalistic laws view the disabled as so weak and vulnerable that they need special protection. As disability scholar Anita Silvers states, "Characterizing a group as vulnerable further isolates its members from others in society. Doing so emphasizes their supposed fragility, which becomes a reason to deny that they are capable, and therefore deserving, of full social participation.”

The power of choice becomes evident from other cases as well. There are several documented cases of people who desperately sought the right to die, only to choose to live after winning the right to choose to refuse treatment. For example, Elizabeth Bouvia chose to live after she won her court battle. So too did Larry McAfee, another disabled plaintiff who sought a court order to remove life-sustaining treatment. Likewise, only 246 of the 390 people who went through the lengthy process to obtain a legal prescription for suicide between 1998 and 2005 under Oregon's assisted suicide bill ended up using the medication. In such cases, it is possible that once a person knows she can choose death if life truly does become unbearable, life may feel more valuable. Given options and control, people may become reluctant to give up that life, or at least less desperate to leave it. By contrast, limiting options for people with disabilities might actually lead to more deaths by more desperate people who feel cornered by life with a disability. In this way, laws protecting choice in dying may actually affirm life.

Like the telethons of old, the new activists portray people with disabilities as victims in need of saving. To the extent that the activists may be right, their proposed cure is worse even than the problem. Eliminating choice, infantilizing people by disempowering their families, and imposing destructive solutions by destroying choice, are not effective means of protecting people with disabilities.

C. Flawed Reasoning

Identity politics allows the new activists to see every problem, and to craft every solution through a single lens that focuses exclusively on disability. As to end-of-life cases, the new activists see every decision as a judgment about disability: a decision to live affirms life with disability as valuable, whereas a decision to refuse treatment, and thus die,
devalues and harms people with disabilities.

The attempt to explain end-of-life decisionmaking through the single lens of disability fails. End-of-life decisionmaking is anything but one-dimensional. What might work for the community might be wrong for the individual. For the new activists' position to be correct, each individual's choice (or that of a surrogate) must be about life with disability. Any rejection of medical treatment must be about rejection of life with disability. Every person at the center of an end-of-life case must be thought of first as a person with disability. n257 All of these assumptions have analytical flaws.

The arguments offered by the new activists conflate dying with disability, misidentify persistent vegetative states with other forms of disability that allow the real possibility of a sapient life, and insist on a social kinship of every person who uses a feeding tube. More importantly, they insist that the patient's status as a person with disability takes precedence over all other aspects of that person's life, and that perseverance is the only acceptable [*174] response to disability. The following discussion examines more deeply the analytical flaws behind the new agenda.

1. I See Disabled People Everywhere: The Problem of Conflation and Inflation

At the heart of the new activists' agenda, inextricably linked with the fear of eugenics and the social critique of society's response to disability, is the problem of the insult. When a person chooses death over life with disability, or when a person's surrogate makes that decision for a patient who lacks competence to make her own decisions, members of the disability rights community perceive an insult - a judgment that disabled lives are valued less than other lives. n258 The message received is that people would rather die than live as disabled persons.

The insult results in part from the conflation that plagues the agenda. Specifically, the activists conflate all potential forms of physical and cognitive impairment under the big tent of "disability." Their agenda applies equally to people with physical impairments like paralysis as it does to people who are in persistent vegetative states or who are terminally ill.

The problem is that physical impairments, PVSs, and terminal illnesses are not the same. Physical impairments that allow sapient life are fundamentally different from PVSs, and paralysis and blindness are fundamentally different from terminal cancer.

Disability scholars recognize the differences between disability and terminal illness. Indeed, the scholarship is built around the notion that disability is not all illness. One scholar noted, "The social model of disability disconnects our conceptualization of disability from illness and pain so as to ensure that no judgment [*175] about the lives of people with disabilities is distorted by uncritical assumptions about their suffering." n259 To be sure, terminal illness can disable a person. But dying people face different questions than people with other physical impairments do.

Likewise, people in PVSs need much of the same care required by quadriplegics. But the conditions are fundamentally different. Unlike other impairments, a PVS is the actualization of myth of the tragic life with disability. That myth says the person with disability can experience no joy or pleasure in life. For the PVS patient, the myth is reality. A person in a PVS cannot experience pleasure or pain, because the part of the brain that processes those functions is destroyed. The PVS patient is beyond disability.

This is not to say that a person in a PVS does not deserve respect or care. The decisions about their care should be made according to the wishes expressed by the patients in their advance directives or as interpreted by their surrogates. My point is merely that the condition of a PVS is different, and individual decisions about a PVS do not reflect on the value of life with disability.

The activists' conflation of PVS, terminal illness, and physical impairment artificially inflates the "insult" problem. Society has distinctly different views of life in vegetative states or with terminal illness than life with other physical impairments. Over ninety percent of people would not want to be kept alive in a PVS, n260 but no similar attitudes exist
with respect to life with blindness or paralysis. The different attitudes do not reflect disability prejudice, but the reality that not all "disabilities" are the same.


The new activists' agenda is not only overbroad, it also inflates [*176] the role of disability prejudice in individual end-of-life cases. Its insistence on continued life as the only answer to disability ignores the complexity of medical decisionmaking. It also ignores the reality that while life with disability (if properly defined to exclude PVSs) can and should be meaningful, physical impairments necessarily involve certain restraints and bodily degradation. Decisions to avoid restraint and protect bodily integrity are not in any way judgments about the value of people with disabilities.

The following examples demonstrate this disconnect. I enjoy driving. My act and enjoyment of driving in no way reflect a judgment about people who cannot or do not drive. I wear a seatbelt to avoid physical harm in the event of an accident. My safety precautions in no way reflect a judgment about those who have been harmed in car wrecks. I avoid seeing doctors. My aversion to going to the doctor's office in no way reflects a judgment about people who require constant medical care. My actions and preferences simply reflect personal choice; they do not reflect a judgment about others who live life differently.

End-of-life decisionmaking works in the same way. A decision to forgo medical treatment, even life-sustaining medical treatment, may involve decisions to avoid certain conditions that are part of the daily lives of many individuals with disabilities. But "because life-sustaining medical intervention constitutes both a bodily invasion and a personal choice regarding the appropriate response to an affliction," every person should have the right to reach his or her own decision about the medical choices. n261 A personal assessment about pain, bodily intrusions, physical limitations, bodily integrity, and freedom from restraint is no more a judgment about the value of people who live with disability than is the decision to wear a seatbelt. Those choices are personal and unrelated to the value of other people who live with the impairments.

3. The Rejection of Feeding Tubes Is Not Disability Prejudice

Feeding tubes deserve special attention. First, the attempt to remove Terri Schiavo's feeding tube triggered unprecedented attention and second-guessing of settled principles of law. Second, the activists have focused their immediate attention on feeding tubes.

[*177] Harriet McBryde Johnson explained the social kinship she, and others in the movement, feel with people fed with feeding tubes:

I watch nourishment flowing into a slim tube that runs through a neat, round, surgically created orifice in Ms. Schiavo's abdomen, and I'm almost envious. What effortless intake! Due to a congenital neuromuscular disease, I am having trouble swallowing, and it's a constant struggle to get by mouth the calories my skinny body needs. For whatever reason, I'm still trying, but I know a tube is in my future. n262

Because she may need a feeding tube someday, McBryde Johnson feels that no one should be denied one. Instead, she believes it is a piece of equipment, like a wheelchair, which should never be denied. n263

I agree that no one should be denied a feeding tube, but no one should be denied the choice to refuse a feeding tube either. In the first place, feeding tubes are not like wheelchairs. They cannot be used without surgical intervention and the accompanying risk of infection. n264 The tubes themselves have an impact on a person's bodily integrity that must
be balanced against their benefits. Moreover, feeding tubes limit a person's ability to take food orally, whereas wheelchairs do not limit a person's ability to walk. n265 For this reason, an individual's objection to a feeding tube might have nothing at all to do with disability.

Consider Scott Matthews. Scott's family asserted the desire to avoid a feeding tube so that he could continue the activity he enjoyed most in his life. The desire to eat, the social enjoyment of a shared meal, and the taste of food are to some so valuable an experience that losing those abilities would be devastating. Scott's parents' decision to avoid the feeding tube reflected values that were inherently personal to Scott; the decision had nothing to do with disability prejudice. The new activists' legislation would deny all of us the ability to decide that the social benefits of eating outweigh the risk of a premature death.

The argument that fear of feeding tubes is a form of disability prejudice focuses on the physical aspect of disability: the inability [*178] to eat. Disability scholars argue that the focus on the physical is misplaced, one stating, "Independence need not be viewed in physical terms; rather, self-direction, self-determination, and participation in decisionmaking about one's life are more ... authentic measures of desirable independence, or better, interdependence." n266 The focus on the physical aspect of the inability to eat improperly displaces the importance of self-determination in the decision to use or not use a feeding tube. Like with other decisions, an individual's decision to accept or reject a feeding tube should belong to the individual.

IV

Conversations Go Two Ways

On the one hand, I am critical of the new activists' agenda, and I firmly believe it should be rejected. On the other hand, I take no issue with much of the message propounded by the disability rights community. Indeed, I agree that society fails itself when it devalues the worth of people with disabilities by its collective attitude and actions. I also agree that the history and threat of eugenics and forced sterilization are too recent to suggest that the activists' fear of these things is outdated or unnecessary. n267 I do take issue, however, with the way the disability rights community has applied its theory to end-of-life decisionmaking and to the legal and advocacy positions that result.

I would argue, moreover, that the extreme positions that the new activists are taking in end-of-life cases give policymakers, bioethicists, health care providers, and scholars who favor autonomy rights a reason to dismiss the entire field of disability studies as fringe. Dismissing the field would be a mistake. n268 Disability theory has much to offer health policy.

First, disability theory identifies systematic failures with health care and health policy. Some of those failures come to light in end-of-life cases. The much-discussed case of Elizabeth Bouvia is a good example of systematic failures. Bouvia was socially isolated [*179] in a hospital by a system that dealt only with the medical aspects of disability. A system that focuses exclusively on cure has little to offer the permanently disabled. A greater focus on long-term and rehabilitative care could change the reality of existence for people with permanent physical impairments so they are not left alone in hospitals without any means of achieving their full potential.

Second, disability scholars call attention to the way in which judges and lawyers needlessly devalue the lives of people with physical impairments and perpetuate the myth of the tragedy of life with disability. The criticism of the Bouvia decision and ones like it is spot on. Bouvia's request to avoid medical treatment should not have been granted because her physical condition devalued her life. Her request should have been granted because it was her decision.

The cases involving treatment refusals by Jehovah's Witnesses provide a better model than the Bouvia decision for judicial opinions in treatment refusal cases involving people with disabilities. n269 In affirming the right of members of the Jehovah's Witnesses to refuse blood transfusions, the courts do not assess the reasonableness of the religious belief that one should not take blood. The courts ask only if the person is competent to make that choice. Similarly, when
asked to review treatment refusal cases involving disabilities, the courts need not justify the decision itself as reasonable by talking about the alleged hopelessness of life with disability. Courts need simply assess the competency of the decisionmaker to make an informed choice.

Third, and perhaps most important, disability scholars correctly note that there is a genuine need to question whether society is too quick to accept as reasonable the decision of a newly disabled person to die rather than to continue to live with a disability. I call this the Million Dollar Baby problem. In the film Million Dollar Baby, the character played by Hilary Swank [*180] asked for and received euthanasia shortly after suffering a catastrophic disability. n270 The disability rights community condemned the movie as perpetuating disability prejudice. n271 As is clear from the rest of this paper, I am not concerned with the character's ultimate decision. The problem, as I see it, is that the decision was precipitous.

Disability scholarship has produced hard evidence that people who face sudden catastrophic injury might not be able to give informed consent as quickly as previously thought. n272 The studies show that when people are in a "liminal state," that is, after they have lost their old identity as fully functioning but before they've accepted their new identity as a person with a disability, they may be unable to process information or recognize the potential for a quality life with disability. n273 Thus, they may be inclined to refuse treatment early after the change.

The scholarship suggests that the notion of what it takes to give informed consent should be revisited in cases of sudden disability. If individuals are truly unable to process information, how can they make informed decisions? Proposals for reforming the informed consent process n274 deserve further study, as does [*181] the suggestion for "disability consults" as a regular part of medical treatment. n275

The passion with which the new activists argue that medical decisionmaking at the end of life must be limited to protect the disabled from discrimination demonstrates the depth of the fear and distrust the community has in its own members, lawmakers, health care providers, and society itself. Some of that fear is provoked by individuals like Peter Singer who argue for the right of parents to kill severely "damaged" newborns. n276 But most of that fear and distrust can be linked to lived experiences of people with disabilities. n277 Attention to disability scholarship can only enrich end-of-life policy.

Conclusion

Arguing against the disability rights community on issues that concern disability rights is problematic. Community members speak with a power and authority born of experience. But the power the collective voice carries is the very reason the message must be examined critically. It would be a perverse irony if the legacy of the same community that established civil rights for persons with disabilities were the imposition of an absolute limitation on the liberty rights of all of us as we experience the dying process with our family members.

The purpose of this Article is not to suggest that disability is reason to kill. Nor is it to suggest that the disability rights community is wrong to express that it is dangerous and insulting to people living with disabilities to allow people to terminate their own or other people's lives because of a physical disability. To the contrary, ethicists, judges, and lawmakers should be very cognizant of those concerns. The purpose of this Article is to suggest that the solution proposed by the new activists is even more dangerous than the danger being fought against.

Taking away options and power in medical decisionmaking for people too disabled to run their own care is demeaning. By contrast, permitting people with disabilities, their family members, or other surrogates to make reasonable choices about medical [*182] care, including artificial nutrition and hydration, is a statement of profound respect for personhood. Giving all people a voice in their medical care respects and recognizes that all people bring to decisionmaking a lifetime of experience, pain thresholds, tolerance for intrusions of the body, the wish to sleep, the ability to sit still, prior relationships with doctors and hospitals, the depth of attachment to particular freedoms or abilities, and the other realities of the human condition. In some cases, the only way to give a person a voice is to give
that person a voice through a surrogate. In a real way, a surrogate decisionmaker for a mentally incapacitated patient is like a wheelchair for a person who cannot walk. It is not a perfect substitute, but it is the best possible accommodation. One person's preference to terminate treatment is not a judgment about the value of another person's life. It is a statement about that individual only: that for this person, with this history, this experience, and this existence, the treatment is not wanted. That said, judges, ethicists, and physicians have, for the most part, accepted as true the myth of the tragedy of life with disability. That myth should play no role in law or medicine.

I will conclude by issuing challenges to both sides of the debate. To disability rights activists, consider the possibility that medical decisionmaking is about more than disability, and that limiting options hurts all of us. Also, reconsider the practice of bundling terminal illness and persistent vegetative states into the scope of disability. The social model of disability hinges on the possibility of meaningful sapient life when adequate social support is available. The argument loses credibility in the case of the dying and permanently unconscious. And to scholars, judges, and policymakers who argue in favor of autonomy, listen to the disability movement. Consider how negative characterizations of life with disability such as the description presented in Bouvia demean the existence of millions of people who live and even thrive with similar conditions. Moreover, listen to calls for the incorporation of patient, family, and provider education about the real possibility for a quality life in all cases involving disability. That educational process will help all of us become informed about the realities of life with disability so that when we consent to treatment, the consent is based on real information, not fear and prejudice.

**Legal Topics:**

For related research and practice materials, see the following legal topics:
- Estate, Gift & Trust Law
- Powers of Attorney
- Living Wills
- Healthcare Law
- Treatment
- General Overview
- Public Health & Welfare Law
- Healthcare
- General Overview

**FOOTNOTES:**

n1. I use the term "disability rights community" throughout this paper to refer to the large number of disability rights activists and scholars that have come together in opposition to laws that allow choice in dying. See, e.g., Not Dead Yet, Articles and Issues, Terri Schiavo, http://www.notdeadyet.org/docs/articles.html#schiavo (last visited Sept. 23, 2006) (collating the collective responses of the disability rights community to the Schiavo case). These groups cannot, of course, speak for every person with a disability, and there has been discussion and dissent within the community. See, e.g., Andrew I. Batavia, Ideology and Independent Living: Will Conservatism Harm People with Disabilities?, 549 Annals Am. Acad. Pol. & Soc. Sci. 10, 11 (1997). Nonetheless, the unanimity of the major disability rights groups in opposition to laws allowing a family member or other surrogate to terminate life-sustaining nutrition and hydration is remarkable. See Lois L. Shepherd, Terri Schiavo and the Disability Rights Community, 2006 U. Chi. Legal F. (forthcoming 2006), available at http://ssrn.com/abstract=882480.

n3. Brief for Not Dead Yet et al. as Amici Curiae Supporting Appellants at 4, In re Schiavo, 851 So. 2d 182
[hereinafter Schiavo I Amici Brief].

n4. See, e.g., Position Statement, Nat'l Council on Indep. Living, Rights of People with Disabilities to Food
and Water (July 14, 2005), http://www.notdeadyet.org/docs/ncilres0705.html [hereinafter NCIL Position
Statement] (supporting "legislation that restores and maintains restrictions on surrogate decisions for
withholding of food and water via tube"); Position Statement, Ctr. on Human Policy, A Statement of Common
Principles on Life-Sustaining Care and Treatment of People with Disabilities, http://thechp.syr.edu/endorse
rights organizations).

n5. See Kathy L. Cerminara, Tracking the Storm: The Far-Reaching Power of the Forces Propelling the
Schiavo Cases, 35 Stetson L. Rev. 147, 159-76 (2005) (tracking procedural and substantive effects
(contemplating potential shift in decisionmaking by health care and judicial entities irrespective of statutory
modifications); Tom Mayo, Living and Dying in a Post-Schiavo World, Jurist, Dec. 3, 2005,
changes concerning the medical treatment); NCIL Position Statement, supra note 4.

n6. Disability scholars point out a simple truth: except for the few people who die suddenly, all people will
experience disability. Thus, some people suggest that those without disabilities should be called the "temporarily
abled." See, e.g., Carrie Menkel-Meadow, Commentary, And Now a Word About Secular Humanism,

n7. Harriet McBryde Johnson describes the reaction she receives from most people as "decidedly negative."
about strangers commenting to her that they "admire you for being out" because "most people would give up,"
or kill themselves if they had to live like she does. Id.; see also Joseph P. Shapiro, No Pity 12-40 (1993)
(classifying the treatment received by people with disabilities as either "Tiny Tims" or "Supercrips"). Shapiro
explains that:

often the discrimination is crude bigotry, such as that of a private New Jersey zoo owner who refused to admit
children with retardation to the Monkey House, claiming they scared his chimpanzees. It may be intolerance that
permitted a New Jersey restaurant owner to ask a woman with cerebral palsy to leave because her appearance
was disturbing other diners... In other cases, however, the discrimination at issue is more subtle because it is
based on the paternalistic assumption that disabled people are not entitled to make their own decisions and lead
the lives they choose.
Id. at 25-26. See generally Handbook of Disability Studies, supra note 2, at 351-512 (documenting the experience of disability).

n8. The lack of serious discourse appears to be a major source of frustration for both activists and scholars. See, e.g., Asch, supra note 2, at 320 (quoting the demand: "nothing about us without us ... we demand that we are included in all debates and policy-making regarding bioethical issues"); Adrienne Asch, Recognizing Death While Affirming Life: Can End of Life Reform Uphold a Disabled Person's Interest in Continued Life?, in Improving End of Life Care: Hastings Ctr. Special Rep., Mar.-Apr. 2003, at S31, S36 (Bruce Jennings et al. eds.) (noting that the "largely absent disability perspective could profitably enliven the world of end of life reform"); Not Dead Yet, What the Disability Rights Movement Wants, http://www.notdeadyet.org/docs/drmwants0305.html (last visited Oct. 5, 2006) (demanding "equal time in an open public discussion").


n10. To be sure, the bioethics literature contains acknowledgments of the importance of incorporating disability studies into bioethics. See Mark G. Kuczewski, Disability: An Agenda for Bioethics, Am. J. Bioethics, Summer 2001, at 36. However, there has been little express challenge to the disability perspective. A short article by Art Caplan addresses the issues of disability at the end of life head-on. See Arthur Caplan, Movie Asks the "Million Dollar" Question, MSNBC, Feb. 17, 2005, http://www.msnbc.msn.com/id/6970787. And Professor Kathy Cerminara argues the fear driving the movement is unfounded. Kathy L. Cerminara, Critical Essay: Musings on the Need to Convince Some People with Disabilities that End-of-Life Decision-Making Advocates Are Not Out to Get Them, 37 Loy. U. Chi. L.J. 343, 378-84 (2006); see also Norman L. Cantor, Deja Vu All Over Again: The False Dichotomy Between Sanctity of Life and Quality of Life, 35 Stetson L. Rev. 81, 82-83 (2005) (acknowledging the disability argument against quality of life considerations in end-of-life cases); Cerminara, supra note 5, at 159-77; Bonnie Steinbock, Disability, Prenatal Testing, and Selective Abortion, in Prenatal Testing and Disability Rights 108 (Erik Parens & Adrienne Asch eds., 2000) (arguing against the disability rights position on prenatal testing).

n12. I have been struck by the literal marginalization of disability scholars in health law and bioethics meetings that focus on end-of-life issues as well. I cannot claim to have attended all or even most of the meetings, but in those I have attended, sessions featuring disabilities scholars are often held at the end of a conference and attended primarily by members of the community.


n14. See, e.g., Not Dead Yet, supra note 8 (demanding "equal time in open public discussion").

n15. I use the term "new activists" to distinguish the new breed of disability rights advocates, like those involved with Not Dead Yet, from the less militant activists who worked for passage of the Americans with Disabilities Act.

n16. See Adrienne Asch, Distracted by Disability, Cambridge Q. Healthcare Ethics, Jan. 1998, at 77, 81. Asch explains the difficulties with defining a disability rights community, but asserts that:

what people with disabilities share is the experience that their departure from what is species typical makes them the objects of unequal treatment such as denial of employment or education for which they qualify... More than half of the respondents [to a 1994 survey] perceived themselves to be a member of a minority and accepted the
notion that they were indeed members of a disability community.

Id.

n17. The loudest dissenting voice from within the disability rights community is Andrew Batavia’s. Batavia started an organization called Autonomy that “represents the interests of people with disabilities who wish to exercise choice in all aspects of [their] lives, including choice at the end of life.” See Autonomy, Mission & Principles, www.autonoumynow.org/mission.html (last visited Sept. 21, 2006).


n19. For a more thorough overview of the growth of the disability rights movement and its impact on federal law, see Shapiro, supra note 7, and Jonathan C. Drimmer, Comment, Cripples, Overcomers, and Civil Rights: Tracing the Evolution of Federal Legislation and Social Policy for People with Disabilities, 40 UCLA L. Rev. 1341 (1993). See also David L. Braddock & Susan L. Parish, An Institutional History of Disability, in Handbook of Disability Studies, supra note 2, at 44 (citing to writings of blind Americans in the 1950s as introducing the theoretical basis for the social construction of disability).

n20. See, e.g., Mary Johnson, Make Them Go Away: Clint Eastwood, Christopher Reeve and the Case Against Disability Rights (2003) (marrying the activist agenda of Not Dead Yet, of which Johnson is the founder, to disability theory).

n22. Gareth Williams, Theorizing Disability, in Handbook of Disability Studies, supra note 2, at 124.

n23. Id.

n24. Drimmer, supra note 19, at 1348; see also Asch, supra note 2, at 300 (noting that some define a person as "healthy if the person's organism performs species-typical functions with statistically typical efficiency").


n26. Stephen L. Mikochik, Assisted Suicide and Disabled People, 46 DePaul L. Rev. 987, 999 (1987). Mikochik points to a quote from Leo Alexander, chief medical consultant at Nuremberg, who observed the Nazi atrocities:

Whatever proportions these crimes finally assumed, it became evident to all who investigated them that they had started from small beginnings, ... at first merely a subtle shift in emphasis in the basic attitude of physicians. It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as a life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually, the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted and finally all non-Aryans. But it is important to realize that the infinitely small wedged-in lever from which this entire trend of mind received its impetus was the attitude toward the non-rehabilitable sick.

Id. at 999 n.82 (citing Joan R. Bullock, Abortion Rights in America, 1994 BYU L. Rev. 63, 69 n.30).


n32. Asch, supra note 2, at 304.


n34. Rovner, supra note 33, at 1044 (footnotes omitted).

n35. Asch, supra note 2, at 300.

n36. Id.

n37. Id. Adrienne Asch criticizes bioethics thus:

Bioethics insists that individuals should be able to determine the situations under which they find life intolerable
but has never challenged them to ask themselves what they found intolerable. Nor has bioethics suggested that what was unacceptable might not be inherent in quadriplegia, stroke, or a degenerative neurological disorder but instead could result from the social arrangements facing people living with such conditions.

Asch, supra note 2, at 299.

n38. Id. The Americans with Disabilities Act was a major victory for disability scholars and activists. 42 U.S.C. §12101-12213 (2000). It adopted as law the rule that society had the obligation to offer people with disabilities a better quality of life and the opportunity to contribute meaningfully to society.

n39. Asch, supra note 2, at 301. The evidence shows that "even those who work most closely with the disabled underestimate their quality of life." Kuczewski, supra note 10, at 39.

n40. See Asch, supra note 2, at 301 (citing eleven such studies); see also National Organization on Disability, N.O.D./Harris Survey of Americans with Disabilities 85-90 (1994) (comparing life satisfaction of people with and without disabilities); Saroj Saigal et al., Self-Perceived Health Status and Health-Related Quality of Life of Extremely Low-Birth-Weight Infants at Adolescence, 276 J. Am. Med. Ass'n 453, 455-57 (1996) (evaluating self-assessed quality of life of adolescents who were extremely low-birth-weight infants).

n41. Asch, supra note 2, at 300.

n42. Bouvia v. Superior Court, 225 Cal. Rptr. 297 (Ct. App. 1986). Disabilities scholars frequently cite to two other cases to make the same point: Georgia v. McAfee, 385 S.E.2d 651 (Ga. 1989), and McKay v. Bergstedt, 801 P.2d 617 (Nev. 1990).

n43. Elizabeth Bouvia chose not to end her life after the court granted her wish to die. On a 1997 60 Minutes broadcast, she explained her decision:

Mike Wallace: (voiceover) After several attempts at starvation, Elizabeth told us, it just became physically too difficult to do. She didn't want to die a slow, agonizing death, nor to do it in the spotlight of public scrutiny. And she told us, with great regret, she quietly chose to live.
Ms. Bouvia: Starvation is not an easy way to go.

Wallace: Oh, no.

Ms. Bouvia: You can't just keep doing it and keep doing it. It really messes up your body. And my body was already messed up.


n44. See, e.g., S. Elizabeth Wilborn Malloy, Beyond Misguided Paternalism: Resuscitating the Right to Refuse Medical Treatment, 33 Wake Forest L. Rev. 1035, 1084-85 (1998) (“The approach provided in the ... Bouvia case[] reflects respect for the rights of patient autonomy.”); Jerry Menikoff, Demanded Medical Care, 30 Ariz. St. L.J. 1091, 1091 (1998) (noting that “patient autonomy is now accepted as the gold standard for ethical decision-making when recommended care conflicts with a patient's wishes”).

n45. See, e.g., Longmore, supra note 11, at 157.

n46. Asch, supra note 2, at 311.

n47. See, e.g., Longmore, supra note 11, at 144.

n48. The 1996 decision in Compassion in Dying v. Washington that supported physician-assisted suicide also portrayed life with disabilities as hopeless. The court referred to people with physical impairments as existing in "a childlike state of helplessness" exemplified by physical immobility or by their use of diapers to deal with incontinence. 79 F.3d 790, 814 (9th Cir. 1996), rev'd sub nom. Washington v. Glucksberg, 521 U.S. 702 (1997). Similarly, in Georgia v. McAfee, the court described the plaintiff, a ventilator-dependent man who been needlessly housed in a hospital ICU for months as being "incapable of spontaneous respiration, and ... dependent upon a ventilator to breathe. According to the record there is no hope that Mr. McAfee's condition will improve with time, nor is there any known medical treatment which can improve his condition." 385 S.E.2d 651, 651 (Ga. 1989).

n50. Id. The "monstrous" language used in Bouvia was quoted by the court in 

n51. Bouvia, 225 Cal. Rptr. at 305.

n52. Asch, supra note 2, at 312.

patient to refuse life-sustaining treatment); In re Quinlan, 355 A.2d 647, 672 (N.J. 1976) (allowing family to 
terminate treatment for permanently unconscious patient).

n54. See, e.g., Longmore, supra note 11, at 144.

n55. See Herr et al., supra note 11, at 36.

n56. Carol J. Gill, Suicide Intervention for People with Disabilities: A Lesson in Inequality, 8 Issues L. & 

n57. Compassion in Dying v. Washington, 49 F.3d 586, 593 (9th Cir. 1995) (citing Gill, supra note 56, at 
38-39), aff'd en banc, 79 F.3d 790 (9th Cir. 1996), rev'd sub nom. Washington v. Glucksberg, 521 U.S. 702 
(1997).

n58. See Asch, supra note 2, at 301.

n59. Asch, supra note 8, at S34.
n60. Asch, supra note 2, at 301.

n61. Asch, supra note 8, at S33 (pointing to the "danger of relying on a simple notion of patient autonomy when deciding to withdraw life-sustaining treatment").


n63. Adam A. Milani, Better Off Dead than Disabled?: Should Courts Recognize a "Wrongful Living" Cause of Action When Doctors Fail to Honor Patients' Advance Directives?, 54 Wash. & Lee L. Rev. 149, 198 (1997); accord Coleman, supra note 11, at 6; Fadem, supra note 11, at 987-88; Gill, supra note 11, at 528-32; Longmore, supra note 11, at 152, 166-68.

n64. Asch, supra note 8, at S33.

n65. Asch, supra note 2, at 310.

n66. Id. at 309.


n68. Id.; see also In re Westchester County Med. Ctr., 531 N.E.2d 607, 613 (N.Y. 1988) ("No person or court should substitute its judgment as to what would be an acceptable quality of life for another."). The Storar and Westchester decisions have been roundly criticized by people who advocate for self-determination as the paramount concern. E.g., Hon. Stewart F. Hancock, Jr., The Role of the Judge in Medical Treatment Decisions, 57 Alb. L. Rev. 647, 652-53 & n.25 (1994). Obviously, someone who has never been competent to express his
wishes could never refuse medical care.


n70. Asch, supra note 2, at 310.

n71. Id.

n72. Id. at 311.

n73. Rovner, supra note 33, at 1059-62.

n74. Sharon Barnartt et al., Advocacy and Political Action, in Handbook of Disability Studies, supra note 2, at 441 (referring to eighteen protests against telethons in 1992 and ten protests in 1993).

n75. Evan J. Kemp, Jr., Op-Ed., Aiding the Disabled: No Pity, Please, N.Y. Times, Sept. 3, 1981, at A19; see also Shapiro, supra note 7, at 23-24 (quoting id.).

n76. See Shapiro, supra note 7, at 24-26.

n77. See Harriet McBryde Johnson, Too Late to Die Young: Nearly True Tales from a Life 50 (2005). McBryde Johnson explains her reaction to telethons:

Together in the crip ghetto, my friends and I watched the annual parade of our little doppelgangers being publicly sentenced to death... . Later, having moved on to the mainstream world, I wanted to go to law school,
qualify for scholarships, get a job and a car loan, start a business. But dying children aren't allowed to do such things; they can't be trusted to fulfill their obligations.

Id.

n78. Id. at 48.

n79. Milani, supra note 63, at 209-12 (describing intervention by activists on behalf of Kenneth Bergstedt, a Nevada man who became quadriplegic and dependent on a ventilator as a result of a swimming accident at age ten). At age thirty-one, faced with the imminent death of his ill father, Kenneth petitioned the court to allow his father to turn off his respirator. See McKay v. Bergstedt, 801 P.2d 617, 624-25 (Nev. 1990).

n80. McBryde Johnson, supra note 7.

n81. Id.

n82. Id.

n83. She has a B.S. in history from Charleston Southern University, a Master's in Public Administration from the College of Charleston, and a J.D. from the University of South Carolina. Biography of Harriet McBryde Johnson, http://www.nd.edu/ndr/issues/ndr8/johnson/bio.html (last visited Sept. 6, 2006).

n84. See generally McBryde Johnson, supra note 77.

n85. Id.
n86. McBryde Johnson, supra note 7.

n87. Id. McBryde Johnson's description of Singer's position is accurate. See generally Helga Kuhse & Peter Singer, Should the Baby Live? The Problem of Handicapped Infants iii (1985) ("This book contains conclusions which some readers will find disturbing. We think that some infants with severe disabilities should be killed."); Peter Singer, Rethinking Life and Death: The Collapse of Our Traditional Ethics 128-31 (1994); Helga Kuhse & Peter Singer, Ethics and the Handicapped Newborn Infant, 52 Soc. Res. 505, 527-34 (1985) (advancing theory that infanticide "before the onset of self-awareness" poses no threat); Peter Singer, Which Babies Are Too Expensive to Treat?, 1 Bioethics 275 (1987).

n88. McBryde Johnson, supra note 7.

n89. Id.


n91. See id.


supra note 3.


n96. Bouvia v. Superior Court, 225 Cal. Rptr. 297, 298 (Ct. App. 1986); see supra text accompanying notes 42-51.

n97. Not Dead Yet, supra note 92.

n98. See id.

n99. Id.

n100. Id.

n101. See Cerminara, supra note 5, at 154-55 (noting several public interest groups took part in the Schiavo appeal).


n103. Id. See infra Part III.A for a response to these arguments.
n104. See, e.g., Diana Penner, Indiana Tackled Right-to-Die Issue in '91: In Schiavo-Like Case, Parents Agonized, then Chose to Remove Tube; A Legal Battle Followed, Indianapolis Star, Mar. 27, 2005, at 1A.


n106. See Cerminara, supra note 10, at 346, 348.

n107. See infra Part III.B (discussing the Model Act in detail).

n108. See, e.g., Lawrence v. Texas, 539 U.S. 558, 578 (2003) (holding that the Constitution protects the right of an individual to engage in intimate sexual conduct); Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261, 278 (1990) (stating that a constitutional right to refuse life-sustaining medical treatment could be inferred from the Court's prior decisions); Roe v. Wade, 410 U.S. 113, 154 (1973) (finding that the ability of a woman to have an abortion was within the realm of personal liberty protected by the constitution); In re Browning, 568 So. 2d 4, 10 (Fla. 1990) (citing Cruzan for the proposition that "[a] competent individual has the constitutional right to refuse medical treatment regardless of his or her medical condition"); In re Quinlan, 355 A.2d 647 (N.J. 1976) (holding that Karen Quinlan had a federal constitutional right to privacy to terminate life-sustaining treatment and that Quinlan's father could act on his daughter's behalf to order removal of the ventilator that aided her respiration).


n110. Cruzan, 497 U.S. at 284 (noting that while a state may impose evidentiary requirements for a guardian to make certain medical decisions, someone other than the patient may make medical decisions for a patient); Rasmussen v. Fleming, 741 P.2d 674, 682 (Ariz. 1987) (finding the right to refuse medical treatment, including artificial nutrition and hydration, is protected under United States Constitution, Arizona Constitution, and common law right to be free from bodily invasion); Barber v. Superior Court, 195 Cal. Rptr. 484, 486 (Cal. App. 1983) (allowing, in the first reported case, withdrawal of nutrition and hydration, and holding that doctors
not criminally liable for following family's wishes to discontinue artificial nutrition and hydration from man in "a deeply comatose state from which he was not likely to recover"); In re Browning, 568 So. 2d at 11 (holding that the constitutional right of privacy embraces the right to refuse all artificial means of life support). States have adopted differing mechanisms to give voices to surrogates. See generally Alicia R. Ouellette, When Vitalism Is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment, 79 Ind. L.J. 1, 3 n.7 (2004) (detailing the statutory provisions in each state that cover living wills, proxies, and surrogacy). Most states will enforce advance directives or the appointment of a health care agent. Id. Some states automatically appoint a surrogate. E.g., 755 Ill. Comp. Stat. Ann. 40/1-40/65 (West 1992 & Supp. 2006). Some states require a surrogate decisionmaker to make decisions for the patient considering only what is in the best interest of the patient. E.g., Cal. Prob. Code §§4711, 4714-4716 (West 1991 & Supp. 2006). Other states ask the surrogate to exercise "substituted judgment," that is, to decide what the patient would want if she could speak for herself. E.g., Md. Code Ann. Health-Gen. §5-605 (West 2002 & Supp. 2006); Superintendent of Belchertown State. Sch. v. Saikewicz, 370 N.E.2d 417, 431 (Mass. 1977). Some states have a hybrid model that allows for substituted judgment when the patient's wishes are known, but require a decision based on the patient's best interests where the wishes are not known or knowable. E.g., Del. Code Ann. tit. 16, §2507 (2003 & Supp. 2004).


n112. See Vacco, 521 U.S. at 800 (declaring that "everyone, regardless of physical condition, is entitled, if competent, to refuse unwanted lifesaving medical treatment"); Cruzan, 497 U.S. at 277 (indicating that competent persons have a constitutionally protected liberty interest in refusing unwanted medical treatment); see also Sell, 539 U.S. at 178 (recognizing a "'significant' constitutionally protected 'liberty interest" in avoiding forced medical treatment).

n113. See Ouellette, supra note 110, at 3 n.7 (citing living will statutes, surrogacy statutes, and health care proxy laws in all fifty states).

n114. See Shepherd, supra note 5, at 297-301.

n115. Cerminara, supra note 5, at 158-59.

n116. See Shepherd, supra note 5, at 301.
n117. Mayo, supra note 5.


n119. Id. (omission in original).


n121. Shepherd, supra note 5, 327-28 n.155.

n122. Model Act, supra note 120, §3(A).

n123. Id. §5(A).


n126. Id.
n127. Cerminara, supra note 5, at 159-76.

n128. Id. at 160.


n130. Hanna, supra note 125.

n131. Cerminara, supra note 5, at 164.


n133. See Ouellette, supra note 110, 48-55 app. (charting laws in all fifty states and revealing that substituted judgment is the majority model).

n134. "The substituted judgment standard has subjective and objective components. Through this standard, the surrogate attempts to ascertain, with as much specificity as possible, the decision the incompetent patient would make if he were competent to do so." Martin v. Martin (In re Martin), 538 N.W.2d 399, 407 (Mich. 1995).

n135. See Meisel & Cerminara, supra note 111, §4.02.
n136. Cerminara, supra note 5, at 165.

n137. Id. at 166 (citing Robert A. Pearlman, Insights Pertaining to Patient Assessments of States Worse than Death, 4 J. Clinical Ethics 33 (1993)).

n138. Cerminara, supra note 5, at 166.

n139. Id. at 176-77.

n140. Shepherd, supra note 5, at 318-19 & n.11 (citing H.R. 201, 126th Gen. Assem., Reg. Sess. (Ohio 2005), and noting that as of January 7, 2006, the Bill remained in committee).

n141. Id.

n142. See, e.g., NCIL Position Statement, supra note 4 (supporting legislation "that restores and maintains restrictions on surrogate decisions for withholding of food and water via tube"); CHP Position Statement, supra note 4 (stating that for those lacking capacity and a directive, "treatment should not be withheld or withdrawn unless death is genuinely imminent" or continued care "is objectively futile"). The exception that would allow termination of treatment if so requested in a living will reflects one of two things: respect for unambiguous statements of precedent autonomy, or, more cynically, a resigned acceptance that contesting the use of living wills is a losing cause. I suspect the latter. The theory behind the community's message against termination of treatment for people without living wills applies with the same force to living wills as it does to other methods of medical decisionmaking.

n143. See supra Part II.

n144. Charlton, supra note 21, at 54-55.

n146. Cerminara, supra note 10, at 370-84.

n147. See Asch, supra note 2, at 303.


n149. Identity politics is "the mobilization around gender, racial, and similar group-based categories in order to shape or alter the exercise of power to benefit group members." Martha Minow, Not Only for Myself: Identity, Politics, and Law, 75 Or. L. Rev. 647, 648 (1996).

n150. See Gonzales Amici Brief, supra note 94, at 10; Ashcroft Amici Brief, supra note 94; Wendland Amici Brief, supra note 94; Schiavo I Amici Brief, supra note 3. To be sure, the activists also challenged factual determinations in the individual cases, such as the finding that Terri Schiavo was in a persistent vegetative state and that there was clear and convincing evidence of her wishes. See Schiavo I Amici Brief, supra note 3. Those case-specific challenges are less important than the broader claims of disability discrimination that, if successful, would undermine basic legal principles of medical decisionmaking in future cases.

n151. See Schiavo I Amici Brief, supra note 3.


n153. Two federal statutes protect people with disabilities from improper discrimination. Section 504 of the Rehabilitation Act of 1973 provides that "no otherwise qualified individual with a disability ... shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance ... ." 29 U.S.C. §794(a). The
ADA's coverage is broader, applying to disability-based discrimination by employers and public accommodations such as doctor's offices and hospitals. 42 U.S.C. §§12112, 12181(7), 12182.


n155. Id. §12112(b)(3)(A).


n157. The most significant victory came not from the courts, but from a decision by the Health and Human Services Secretary to block the Oregon health care rationing plan on grounds it would violate the antidiscrimination laws. Letter from Louis W. Sullivan, Sec'y of Health and Human Servs., to Barbara Roberts, Governor of Or. (August 3, 1992) (with accompanying three-page "Analysis Under the Americans with Disabilities Act (ADA) of the Oregon Reform Demonstration"), reprinted in ADA Analyses of the Oregon Health Care Plan, 9 Issues L. & Med. 397, 409-12 (1994). The advocates have also had some court victories. See, e.g., Henderson v. Bodine Aluminum, Inc., 70 F.3d 958, 960 (8th Cir. 1995) (finding in a case of an insurance denial for a bone marrow treatment that "if the evidence shows that a given treatment is non-experimental - that is, if it is widespread, safe, and a significant improvement on traditional therapies - and the plan provides the treatment for other conditions directly comparable to the one at issue, the denial of that treatment arguably violates the ADA"); Carparts Distrib. Ctr., Inc. v. Auto. Wholesaler's Ass'n of New Eng., Inc., 37 F.3d 1216 (1st Cir. 1994) (applying ADA to denial of health coverage by employer health plan); In re Baby "K," 832 F. Supp. 1022, 1028-29 (E.D. Va. 1993) (requiring hospital to provide life support to anencephalic infant).

n158. E.g., In re Baby "K," 832 F. Supp. at 1028-29.

n159. The refusal by a medical provider to give treatment demanded by a patient or a patient's surrogate raises tough questions under the ADA that are not addressed in this Article. This Article focuses on the specific issue of disability activists' crusade to limit the ability of a patient's surrogate to forgo treatment. For further discussion of the role of the ADA in cases where demanded care is refused, see Mary Crossley, Becoming Visible: The ADA's Impact on Health Care for Persons with Disabilities, 52 Ala. L. Rev. 51, 57-68 (2000) (recognizing the ADA's possible application in cases in which an individual is denied care that she sought, and discussing the limits of a statute's applicability in rationing schemes) and Maxwell J. Mehlman et al., When Do Health Care Decisions Discriminate Against Persons with Disabilities?, 22 J. Health Pol. Pol'y & L. 1385 (1997)
(distinguishing the difficult question of the ADA's application to medical treatment decisions made by providers when a patient or patient's legally authorized representative declines treatment). The application of the ADA in cases when providers refuse care due to futility, or where rationing schemes make care inaccessible, are legally distinct from the one posed by the new activists in Schiavo. See Crossley, supra, at 75-77 (discussing Oregon's rationing scheme); Mary A. Crossley, Medical Futility and Disability Discrimination, 81 Iowa L. Rev. 179, 202-50 (1995) (arguing that the ADA is an inadequate tool for analyzing the merits of futility policies); Mehlman et al., supra, at 1389-92 (1997) (discussing futility disputes); David Orentlicher, Rationing and the Americans with Disabilities Act, 271 J. Am. Med. Ass'n 308 (1994); Philip G. Peters, Jr., Health Care Rationing and Disability Rights, 70 Ind. L.J. 491, 492 (1995) (considering how rationing "can be legally and ethically defended by proof that the excluded treatments are less effective than those which are provided"); Philip G. Peters, Jr., When Physicians Balk at Futile Care: Implications of the Disability Rights Laws, 91 NW. U. L. Rev. 798, 810-19 (1997) (discussing futility disputes); James V. Garvey, Note, Health Care Rationing and the Americans with Disabilities Act of 1990: What Protection Should the Disabled Be Afforded?, 68 Notre Dame L. Rev. 581, 601-02, 613-16 (1993) (evaluating the Oregon Health Plan's compatibility with the ADA).


n162. See id. at 1029.

n163. Schiavo I Amici Brief, supra note 3.

n164. Id. at 19.


n166. Id. at 612.

n167. See id. at 630.
n168. Id. at 630-31.

n169. Id. at 630; see also United States v. Univ. Hosp. State Univ. of N.Y. at Stony Brook, 729 F.2d 144, 161 (2d Cir. 1984) (holding that the Rehabilitation Act did not authorize government intervention overriding the private decision of parents to refuse consent to corrective surgery for a child born with spina bifida and hydrocephalus). Title III of the ADA does not contain the "otherwise qualified" language in section 504 of the Rehabilitation Act.

n170. The real issues in the case were whether Michael Schiavo should be disqualified as a guardian and, if not, whether he had proved what Terri's wishes were by clear and convincing evidence.


n172. See id. at 641. The dentist did not argue that his desire to treat the patient in a hospital rather than a dentist's office was medically appropriate for the patient. The dentist argued that the option was permissible under the harm exception to the ADA. See id. at 648.

n173. Obviously, the ADA does not prohibit medical treatment that is appropriate because of a patient's disability. As the First Circuit Court of Appeals noted:

Such a prohibition would not only be nonsensical; it would be unethical. ... "Ethical medical decisionmaking should take into account all medical factors - disability-related or not - affecting a patient's condition and prognosis. Thus, to read the ADA as prohibiting a medical decision-maker from considering medical factors flowing from a disability would put the disabled patient ... in a different, arguably worse, position than the nondisabled patient."

Lesley v. Chie, 250 F.3d 47, 53 n.6 (1st Cir. 2001) (quoting Mary A. Crossley, Of Diagnoses and Discrimination: Discriminatory Nontreatment of Infants with HIV Infection, 93 Colum. L. Rev. 1581, 1655 (1993)).
n174. See British Medical Association, Withholding and Withdrawing Life-Prolonging Medical Treatment: Guidance for Decision Making (2001); Frank D. Ferris et al., Ensuring Competency in End-of-Life Care: Controlling Symptoms, BMC Palliative Care, July 30, 2002, at 10, http://www.biomedcentral.com/content/pdf/1472-684X-1-5.pdf ("Most experts feel that dehydration in the last hours of living does not cause distress and may stimulate the release of endorphins ... "); Robert M. McCann et al., Comfort Care for Terminally Ill Patients: The Appropriate Use of Nutrition and Hydration, 272 J. Am. Med. Ass'n 1263, 1265-66 (1994) (recognizing that providing nutrition and hydration to terminally ill patients can cause unwanted and painful side effects and finding that terminating the treatment increases patient comfort); Robert J. Sullivan, Jr., Accepting Death Without Artificial Nutrition or Hydration, 8 J. Gen. Internal Med. 220, 222 (1993) ("It is likely that prolonged dehydration and starvation induce no pain and only limited discomfort ... ").

n175. See Ouellette, supra note 110, at 34, for further discussion on how the option to terminate treatment is essential to palliative care.

n176. See id. at 43.

n177. Id.


n180. Cruzan, 497 U.S. at 265.

n181. Id.

n182. Id. at 269.
n183. See id. at 280 (majority opinion); id. at 292 (O'Connor, J., concurring).

n184. Id. at 282 (majority opinion).

n185. Id. at 285-86.

n186. See id. at 286-87.

n187. Id. at 292 (O'Connor, J., concurring) (quoting New State Ice Co. v. Liebmann, 285 U.S. 262, 311 (1932) (Brandeis, J., dissenting)).

n188. See Ouellette, supra note 110, at 48-55 app. (charting laws in every state and revealing that more than half use a substituted judgment approach).

n189. It is worth noting, moreover, that Florida law provided Schiavo the protection of the clear and convincing evidence standard. Id. at 49 app. (citing Fla. Stat. Ann. §765.401(3) (West 1997 & Supp. 2003)).

n190. Cantor, Autonomy-Based Rights, supra note 132, at 43-44.

n191. Id. at 44. It is possible, moreover, that the Constitution provides a right to pain control, and the avoidance of medically inappropriate care. See Ouellette, supra note 110 at 32-36 & nn.203-04 (citing Robert A. Burt, The Supreme Court Speaks: Not Assisted Suicide but a Constitutional Right to Palliative Care, 337 New Eng. J. Med. 1234, 1234 (1997), and Alan Meisel, Pharmacists, Physician-Assisted Suicide, and Pain Control, 2 J. Health Care L. & Pol'y 211, 214-15 (1999)). Neither the right to pain control nor the avoidance of medically inappropriate care was at issue in Schiavo. Schiavo could feel no pain, and providing treatment was not inappropriate.
n192. *NCIL Position Statement*, supra note 4 (emphasis added). See also *CHP Position Statement*, supra note 4 ("Absent clear and convincing evidence of the desires of people with disabilities to decline life-sustaining care or treatment, such care or treatment should not be withheld or withdrawn unless death is genuinely imminent and the care or treatment is objectively futile and would only prolong the dying process.").

n193. Model Act, supra note 120, §3(A).

n194. Id. §§3(B), 5(A).

n195. New York has carved out a small exception to its vitalist laws because of the tragic case of Sheila Pouliot. See *Blouin v. Spitzer*, 356 F.3d 348 (2d Cir. 2004). The Health Care Act for Persons with Mental Retardation sets up the only available mechanism to terminate life-sustaining treatment for a person who has never had decisionmaking capacity. See N.Y. Surp. Ct. Proc. Act Law §1750-b (McKinney Supp. 2003) (allowing surrogate of person with mental retardation to terminate treatment). This statutory exception, by definition, does not apply to people incapacitated by brain injury, mental illness, minority, or other physical illness. Id.

n196. Along with New York, Michigan and Missouri also severely limit family members' ability to refuse life-sustaining treatment for people who lack decisionmaking capacity and have no living will. See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 285-86 (1990); *Martin v. Martin (In re Martin)*, 538 N.W.2d 399, 413 (Mich. 1995).

n197. See *Blouin v. Spitzer*, 213 F. Supp. 2d 184, 193 (N.D.N.Y. 2002) ("New York law does not allow a third party to decide that the quality of life of another has declined to a point where treatment should be withheld and the patient should be allowed to die."), aff'd, 356 F.3d 348 (2d Cir. 2004); *In re Westchester County Med. Ctr.*, 531 N.E.2d 607, 613 (N.Y. 1988). New York's protection of life yields to the express exercise of autonomy, except in cases involving cardiopulmonary resuscitation and for people with mental retardation. In all other cases, the general rule requiring treatment applies. See §1750-b.


n199. *In re Westchester County Med. Ctr.*, 531 N.E.2d at 613.
n200. Hancock, supra note 68, at 652 (citing In re Westchester County Med. Ctr., 531 N.E.2d at 613).

n201. In re Westchester County Med. Ctr., 531 N.E.2d at 608 (rejecting patient's statements that she would not like to live like a vegetable or be a burden on her family as insufficient to show clear and convincing evidence of her wishes).

n202. In re Matthews, 650 N.Y.S.2d 373, 377 (App. Div. 1996). As I have noted in a previous article:

New York's policy prohibiting third-party decisions to withhold life-sustaining treatment where the patient's wishes are not known or knowable is reflected in statute. In 1985, the legislature enacted Mental Hygiene Law Article 80, providing for "surrogate decision-making committees" to make health care decisions for incompetent residents of mental hygiene facilities who need "major medical treatment" and do not have family members, guardians, committees or conservators available to make those decisions. The types of "major medical treatment" within a committee's purview were explicitly defined to exclude "nutrition or ... the withdrawal or discontinuance of medical treatment which is sustaining life functions."

Ouellette, supra note 110, at 23 (footnotes omitted).

n203. See Blouin v. Spitzer, 213 F. Supp. 2d 184, 193 (N.D.N.Y. 2002), aff'd, 356 F.3d 348 (2d Cir. 2004); In re Westchester County Med. Ctr., 531 N.E.2d at 613.

n204. See supra Part II.B.

n205. For more information on the case of Shelia Pouliot, see Blouin v. Spitzer, 356 F.3d 348, 354-56 (2d Cir. 2004); Michael P. Allen, The Constitution at the Threshold of Life and Death: A Suggested Approach to Accommodate an Interest in Life and a Right to Die, 53 Am. U. L. Rev. 971, 984 (2004); Cantor, supra note 10, at 88 n.45; Cantor, Autonomy-Based Rights, supra note 132, at 46; Cerminara, supra note 10, at 375; and Ouellette, supra note 110, at 13-18.
n206. *Blouin*, 356 F.3d at 352.

n207. She had an acute abdomen, manifested by generalized, "severe abdominal pain and a nonfunctioning intestine." *Ouellette*, supra note 110, at 14.

n208. Id.

n209. Id.

n210. Id. at 15.

n211. As the New York District Court explained:

During the hearing, the treating physicians informed the court that there is a 14-day period during which it is medically appropriate to withhold nutrition and that it was their intention to do so while continually assessing Ms. Pouliot's readiness to receive nutrition. The treating physicians also testified that further treatment to provide nutrition to Ms. Pouliot would result in prolonging her agony without any significant health or medical benefits.


n212. See id. at 186.

n213. On January 3, 2000, the trial judge issued an order that all medical treatment for Pouliot be terminated, except for nutrition, as tolerated, and hydration care. *Id. at 187*. The next day, "the guardian ad litem and plaintiff commenced an Article 78 proceeding and petitioned the Supreme Court of New York to enjoin permanently the State of New York, its agents, officers and/or employees from further medical intervention, nutritional sustenance, or other life-sustaining treatment for Ms. Pouliot." *Id.* At the conclusion of the hearing, the trial judge "temporarily enjoined the named respondents from providing any medical intervention with
regard to nutritional sustenance." Id. Pouliot received hydration only until January 7. See id. Then, after the trial judge was made aware of the limitations in New York law, the family, guardian, and hospital attorneys agreed to provide Pouliot hydration and to attempt to provide 900 calories of nutrition, which was an amount sufficient to maintain life. See id. at 186-87.

n214. See Blouin v. Spitzer, 356 F.3d 348, 354 (2d Cir. 2004).

n215. Id. at 355 n.5.

n216. Ouellette, supra note 110, at 16 (footnote omitted).

n217. Blouin, 356 F.3d at 355 n.4; see also Ouellette, supra note 110, at 17.

n218. Blouin, 356 F.3d at 355.

n219. See id.

n220. See id.

n221. Id. at 356.


n223. Id. at 374.
n224. Id. (stating that his weight fluctuated between forty-three and forty-seven pounds).

n225. Id.

n226. See id. at 374-75.

n227. Id. at 375.

n228. Id. at 375-76.

n229. Id. at 374-75.

n230. Id. at 376 n.7.

n231. Id. at 375.

n232. See id.

n233. Id.

n234. Id. at 375-76.

n235. As the court explained:
In situations where an individual has always been incompetent to make his or her own decisions, resolution of consent to treatment issues would be guided by different principles than those in a situation where a formerly competent patient subsequently becomes incapable of rendering his or her own treatment decisions. Thus, in the case at hand ... the law relating to decisions as to life-sustaining treatment for infants is the only fair method by which Scott's rights can be assessed.

*Id. at 376-77* (citations omitted).

n236. *Id. at 377.*

n237. *Id. at 378.*

n238. *Id. at 379.*

n239. Id.

n240. Model Act, supra note 120, §3(A).

n241. Id. at §4(A)-(B).

n242. "In short, a policy demanding clear prior expressions as a prerequisite to withdrawal of life support is inhumane in disregarding the possible harm and degradation to the now-incompetent patient." Cantor, supra note 10, at 93.

n243. See Model Act, supra note 120, at §3(A).
n244. In re Matthews, 650 N.Y.S.2d at 375.

n245. Id. at 375 n.3.

n246. See id. at 376 n.7.

n247. For a compelling argument in favor of an increased role of families in medical decisionmaking cases, see Boozang, supra note 129.

n248. See Hanna, supra note 125.


n250. Milani, supra note 63, at 207-09.


n252. Int'l Task Force on Euthanasia and Assisted Suicide, 8 Years Under Oregon's Assisted Suicide Law, available at http://www.internationaltaskforce.org/orstats.htm. The annual reports on which the chart is based do not disclose why the patients did not ultimately use the prescription.

n253. See generally id. (cataloging patients' reasons for requesting assisted suicide).

n254. Kathy L. Cerminara, Therapeutic Death: A Look at Oregon's Law, 6 Psychol. Pub. Pol'y & L. 503,
514 (2000) (discussing empirical research that shows "the more choices we give individuals, the more they will act as mature, self-determining adults. If the physician presents choices to the patient and explains the benefits and consequences of each one of them, there is greater possibility that the patient will make a rational decision, thus decreasing the probability of 'irrational suicide' occurring out of fear or lack of information").

n255. Anita Silvers has likened the paternalistic views of disabled people to the historically paternalistic views of women. Portraying disabled people as especially vulnerable stereotypes the disabled as a definitely weak class similar to the historical view of women that kept them from high-stress jobs because they needed "special protection." See Silvers, supra note 249, at 135. Characterizing people with disabilities as incompetent, easily coerced, and inclined to end their lives places them in the roles to which they have been confined by disability discrimination. "Doing so emphasizes their supposed fragility, which becomes a reason to deny that they are capable." See id.

n256. Better options include improving the provision of services to people with disabilities during their lives, educating the public about the positive potential for life with disability, enacting safeguards to protect against unscrupulous surrogates, and perhaps revising our thinking about informed consent in future cases involving disability. See infra Part IV.

n257. Carol Gill expressly argues that "in order for people with disabilities to function well in this oppressive society, disability should be a 'positive and central' part of their identity." Adrienne Asch, Critical Race Theory, Feminism, and Disability: Reflections on Social Justice and Personal Identity, 62 Ohio St. L.J. 391, 415 (2001).


n260. As Norman Cantor wrote:

A permanently unconscious state is the principal example of an intolerably undignified status. Over ninety percent of people consistently say that they would not want to be preserved in this condition devoid of emotion or interaction with a human environment. In other words, an overwhelming majority of people would rather die than live "in such a physically, emotionally, and socially impoverished state."

Cantor, supra note 10, at 98 (footnote omitted).

n261. Id. at 85.

n262. McBryde Johnson, supra note 90.

n263. Id.


n265. In this way, feeding tubes are distinctly different from wheelchairs that enable mobility.

n266. Asch, supra note 2, at 313.

n267. Lightning rods like Princeton's Peter Singer, who advocate that in some situations parents should be allowed to euthanize their severely disabled newborns, see supra note 87, eliminate the contention that fear of eugenics is unfounded.

n269. See, e.g., Stamford Hosp. v. Vega, 674 A.2d 821, 824-25 (Conn. 1996) (involving refusal of blood transfusion by Jehovah’s Witness who had bled heavily after delivering child); Fosmire v. Nicoleau, 551 N.E.2d 77, 78-79 (N.Y. 1990) (involving the refusal of blood transfusion by thirty-six-year-old Jehovah’s Witness following cesarean section); cf. Thor v. Superior Court of Solano County, 855 P.2d 375, 382 (Cal. 1993) (affirming right of competent quadriplegic prisoner to refuse food, necessary medical care, and treatment). Norman Cantor points to these latter two cases as ones in which a court’s acceptance of a treatment refusal decision is not a value judgment about the reason for the refusal but rather is a personal self-determination for the patient. See Cantor, supra note 10, at 85 & nn.21 & 23.


n272. See, e.g., Gary L. Albrecht & Patrick J. Devlieger, The Disability Paradox: High Quality of Life Against All Odds, 48 Soc. Sci. & Med. 977, 980 (1999) (“Individuals, families, and communities are unprepared to recognize and seldom ready to accept disability.”); Asch, supra note 2, at 312-13 (quoting a 1987 report indicating that the onset of impairment may delay adaptation and comprehension); David R. Patterson et al., When Life Support Is Questioned Early in the Care of Patients with Cervical-Level Quadriplegia, 328 New Eng. J. Med. 506, 506 (“Patients frequently have a diminished capacity to make important decisions during the first several months after an injury ... .”)


n274. Arthur Caplan and others argue for an educational model of informed consent that stresses that a
patient needs an opportunity to experience the post-traumatic phase of care. The educational model of informed consent allows the treatment team to insist paternalistically on treatment during the initial period following a sudden-onset disability because the patient is not yet fully informed about the potential for quality life with disability. Arthur L. Caplan et al., Ethical & Policy Issues in Rehabilitative Medicine, 17 Hastings Ctr. Rep. Special Supp., Aug. 1987, at S1, S11-14.

n275. Asch, supra note 8, at S31.

n276. See supra note 87 and accompanying text.

n277. See, e.g., Johnson, supra note 20; McBryde Johnson, supra note 77.
A Conversation About End-of-Life Decisionmaking

Thaddeus Mason Pope
Widener University School of Law

Alicia Ouellette
Albany Law School

Timothy Quill
University of Rochester

Robert Swidler
Northeast Health

Nancy Dubler
Columbia University

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CONVERSATIONS ABOUT

• Hospital Combinations
• Medical Malpractice
• Fraud and Abuse
• Health Care Reform
• End-of-Life Decisionmaking
• Difficult Inpatient Discharge Decisions
# Table of Contents

A Message from the Section Chair ........................... 4  
*Edward S. Kornreich*

## Regular Features

- In the New York State Courts ............................................... 5  
- In the New York State Legislature ....................................... 12  
- In the New York State Agencies ......................................... 16  
- In the Journals .................................................................. 19  
- For Your Information ...................................................... 23

## Articles

### CONVERSATIONS

**Special Edition Editor: Peter J. Millock**

- Introduction ................................................................. 25  
  *Peter Millock and Robert N. Swidler*

- A Conversation About Hospital Combinations .................. 26  
  *Peter J. Millock, Robert Hall Iseman, Richard M. Cook, John F. (Jack) Gleason and Robert Wild*

- A Conversation About Medical Malpractice .................... 38  
  *Martin Bienstock, Edward Amsler, Bruce G. Clark and Susan C. Waltman*

- A Conversation About Fraud and Abuse ....................... 57  
  *Edward S. Kornreich, James G. Sheehan, Mark W. Thomas, Marcia B. Smith, Sean Cenawood, Rebecca Martin and Heidi Wendel*

- A Conversation About Health Care Reform ..................... 76  
  *James W. Lytle, Richard Gottfried, Elisabeth Benjamin, David Rich and Melinda Dutton*

- A Conversation About End-of-Life Decisionmaking .......... 91  
  *Alicia Ouellette, Timothy E. Quill, Robert N. Swidler, Thaddeus M. Pope and Nancy Dubler*

- A Conversation About Difficult Inpatient Discharge Decisions .......... 108  
  *Robert N. Swidler, Alyssa M. Barreiro, James D. Horwitz, James Fouassier, Rachel Godlberg, Marguerite Massett and Pamela Tindall O’Brien*

## Section Matters

- Health Law Section
- Summary Report on Healthcare Costs: Legal Issues, Barriers and Solutions .................. 126  
- Newsflash: What’s Happening in the Section ...................... 139

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**Cover artwork:**  
*Billing, Frederick William (1834-1914). Discussion at the Continental Arms, 1861*

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CONVERSATIONS

A Conversation About End-of-Life Decisionmaking

Moderator: Alicia Ouellette
Associate Professor of Law
Albany Law School
Albany, NY

Participants: Timothy E. Quill, M.D.
Professor of Medicine, Psychiatry and Medical Humanities/Center for Ethics, Humanities and Palliative Care
University of Rochester School of Medicine
Rochester, NY
Robert N. Swidler
General Counsel and Vice President for Legal Affairs
Northeast Health
Troy, NY
Thaddeus M. Pope, J.D., Ph.D.
Associate Professor of Law
Widener University School of Law
Wilmington, DE
Nancy Dubler
Professor Emerita, The Albert Einstein College of Medicine
Senior Associate, Montefiore-Einstein Bioethics Center
Ethics Consultant, New York City Health and Hospitals Corporation
New York City

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OUELLETTE: Welcome, I’m happy to see everyone here. Thank you all for joining us. I’m looking forward to talking with you over the next hour-and-a-half or so about end-of-life issues in New York. Before we begin I’d like to just do some quick introductions. If we can each give a little bit of background about ourselves, that would be great. I’ll start with myself, I’m Alicia Ouellette. I’m on the faculty at Albany Law School and in the Union Graduate College/Mount Sinai School of Medicine Program in Bioethics. At the law school I teach New York Practice and Bioethics. I spend most of my research time thinking about end-of-life issues, reproductive ethics, and disability rights. Robert?

SWIDLER: I’m Robert Swidler. I’m General Counsel to Northeast Health. We operate hospitals, nursing homes, home care agencies and other providers in the Capital District. In the past I was Counsel to the New York State Task Force on Life and the Law, an Assistant Counsel to Governor Cuomo for healthcare issues, and Counsel to the NYS Office of Mental Health. I’m Editor of the NYS Health Law Journal, and I’m also on the faculty of the Alden March Bioethics Center at Albany Med and the Union/Mount Sinai Bioethics Center at Union College.

OUELLETTE: Nancy?

DUBLER: I’m Nancy Neveloff Dubler. I am an attorney, presently Senior Associate at the Montefiore-Einstein Center for Bioethics, Ethics Consultant to the New York City Health and Hospitals Corporation and Professor Emerita at the Albert Einstein College of Medicine. I’ve written about end-of-life care, research ethics, bioethics consultation, and—especially—in the area of mediation in bioethics. I see many bioethical dilemmas as conflicts that need to be managed or resolved. I am a member of the New York State Task Force on Life and the Law and the New York State Stem Cell Ethics Research Board.

OUELLETTE: Thad?

POPE: I’m Thaddeus Pope. I’m a law professor at Widener University in Wilmington, Delaware, which is not in New York State. I teach Bioethics, Health Law: Quality & Liability, and Health Law: Finance & Regulation. I serve on a large hospital ethics committee in Delaware and on a regional long-term care facility committee in New Jersey. I’ve written quite a bit, recently, about medical futility disputes, about the health care ethics committee as a dispute resolution mechanism, and about advance directives. I am now on a task force to introduce MOLST (Medical Orders for Life-Sustaining Treatment) in the state of Delaware.

OUELLETTE: Great. And Dr. Quill?

DR. QUILL: Tim Quill. I’m a professor of medicine, psychiatry and medical humanities at the University of Rochester Medical Center and I direct its Center for Ethics, Humanities and Palliative Care. I’m a general internist with a long-standing interest in hospice and palliative medicine, and I now run a pretty large and growing palliative care program at the University of Rochester. I’m on the board of the American Academy of Hospice and Palliative Medicine. I’ve been the chairperson of their ethics committee for a year-and-a-half, and been involved in researching areas of doctor patient communication, doctor patient relationship, patient empowerment and thinking about areas of choice for patients who are struggling at the end of life.

OUELLETTE: All right. Thank you. We are going to talk about end-of-life decisionmaking. I do want to get to the
Family Health Care Decisions Act, which is, of course, a hot topic in New York law, but I wanted to start with a general question to put the discussion about end-of-life decisionmaking in context. My question is this: one of the things that I hear at academic conferences quite often is that it’s harder to die in New York State than it is anywhere else in the United States. Why do you think people say that? Do you think that it’s a fair statement?

DUBLER: They say it because it’s true.

OUELLETTE: How so?

DUBLER: Because medicine in New York has been constrained by and deformed by the law of the state. Case law, dating from the 1980s, which has never been overruled by the legislature, which places the burden on the patient to create the terms and conditions for death rather than permitting the patient’s family and physician to respond to the situation of, and the needs of the patient, as the patient nears death.

QUILL: As a clinician, I will say a positive with regard to end-of-life care in New York is a very strong penetration of palliative care in academic medical centers. There are many well-trained clinicians available to care for patients at the end of life. Probably more so than any other state in the country. On the other hand, if you have an ethically complex end-of-life decision in New York (or probably elsewhere), one of the operating principles is you almost never formally ask for a legal opinion or go to court. Because, in New York, you’re going to get answers that you don’t want to hear. In fact, the advice that I’ve been given is the courts don’t want us there. But if you get into court or ask a lawyer, you’re going to get information from case law and other sources that may not helpful to you. This creates a very restrictive environment because there is a lot of fear of the law in New York State which means that end-of-life care is extremely uneven. If you are lucky enough to be taken care of by someone with sophistication and experience, you’re probably going to be fine. And if you have somebody who’s fearful of the law, who goes to the law first, you could be in real trouble.

SWIDLER: I agree with the statements by both Nancy Dubler and Dr. Quill. I think one of the reasons that I’ve been a longtime supporter of the Family Health Care Decisions Act is that under the current state of the law providers have to choose between providing care that is medically and ethically appropriate on one hand, and care that is legally safe on the other hand, and they’re not the same thing. So we should be changing our legal requirements, not our ethical and medical standards. So, I agree with that.

But returning to the original question, “Is it harder to die in New York than anywhere else?” I would start by noting, without trying to be flippant, that I’m sure it’s hard to die anywhere. Even in Washington or Oregon, states which allow physician-assisted suicide, I’m sure patients often go through enormous pain and suffering before they get to that point where they get palliative care, withdrawal of life-sustaining treatment, or assistance in dying.

But on the issue of respecting decisions towards the end of life and fulfilling the kind of end-of-life course that a patient would want, I think New York is very strong on respecting the wishes of patients who either make their wishes known or appoint a health care agent or plan in advance. I know there are problems everywhere with overly aggressive treatments that are provided in defiance of patient wishes. I don’t think that’s different in New York than elsewhere. But I think that in New York providers are very respectful, and the law is very respectful, of patients who plan in advance or make their wishes known.

But the place where our law is really deficient and exceptionally harsh is in the rules governing patients who didn’t make their wishes known and didn’t plan in advance. That’s where I think we’re more harsh in end-of-life care than other states. So that’s what we need to correct.

DUBLER: The problems with that analysis, Robert, seems to me to be as follows: One, we know that most people don’t think in advance about what they want. Two, advance directives are very unevenly executed by patients. Three, there seems to be a correlation between socioeconomic status and executed advance directives. If you have a lawyer who does your will and arranges your estate, that lawyer will also suggest an advance directive. So that people who have property often have advance directives. I worked for 36 years in the Bronx. Most patients in the Bronx don’t have advance directives. Many have been without medical care in their lives; they don’t want to limit care at the end of life, which is usually the goal of an advance directive even if the concept is value-neutral; they want access to care. I always like to comment when talking about ethical issues, that access to care, fairness in health care and universal coverage by medicine complicate every problem including end-of-life care.

POPE: I was just going to say the problem results from a combination of not just the absence of the Health Care Decisions Act but also from the presumption in favor of treating. It’s the combination of the two that means, unless you have an advance directive, which 80% of the people don’t, or unless you have clear,
convincing evidence of what the patient wanted, then the presumption is to continue treating. Now, I think Dr. Quill implied, or suggested, that some people are less risk-averse and are willing to “polish” the family’s recollections of the patient’s preferences, so the current standard can be satisfied. Even today, where there is consensus and agreement, things work at some manageable level. So, I guess what I’m trying to do is “target down” exactly why it is so hard to have a “good death” in New York. In short, there is giant gap, a chasm between the law and what people think proper medical practice is. I am not suggesting this as a realistic option. But I do want to note that the gap might be narrowed or closed without legislative action, if providers were less risk-averse and more willing to fudge or polish evidence of patient preferences.

OUELLETTE: What do you mean by fudge and polish?

SWIDLER: I do a lot of fudging and polishing so I can answer that. It describes when hospitals, and hospital counsel like me, struggle to find a way to square the circle, to reconcile compassionate care with the unrealistically high clear and convincing evidence standard that the law demands for limiting life-sustaining treatment. So what we do, frankly, is find clear and convincing evidence in the strings and bits and pieces related to us by family members.

DUBLER: But, Robert, what you’ve just described is a dysfunctional system. It demonstrates precisely where the goals of medicine are deformed by the demands of the law. So everyone fudges and polishes and encourages family members to provide information that will permit compassionate and appropriate end-of-life care. Consider the case of a Yugoslavian immigrant family. A beloved 98-year-old matriarch of the family had experienced an overwhelming stroke. She had no possibility of recovery to a state where she could ever recognize or respond to loved ones. She was intubated, stitched together with wires and tubes. She had led a good life and was at the end of that life. The family was desperate to let her die. They stated, “How could she have told us that she didn’t want a ventilator? She never knew a machine like this existed.” What a terrible thing to do to families at the end of life. We basically encourage them to create a fiction to fall within the law. And what a terrible thing to do to physicians; we force them to think about these inappropriate legal stipulations when their goal should be compassion and care.

DR. QUILL: There’s no question that there is a large gap between what clinicians, patients and families are facing and what the law says to do in New York, making the system at times very dysfunctional. Some of the end-of-life legal standards in New York are completely unreachable clinically. For example, the “clear and convincing standard” for allowing for someone without capacity to forgo a ventilator or a feeding tube is in most cases impossible to attain. You will find huge variation in how much leeway families are given to refuse such treatments for their loved ones who may never have considered these options in the past. So, in that sense, the current system is completely dysfunctional and arbitrary in terms of how much discretion families are given to make these important decisions. The Family Health Care Decisions Act, if passed, will empower caring families and clinicians to make the best decisions they can under all that clinical uncertainty. In that sense, it is hugely important. In fact, it’s more important than advance directives because the data say that the way we imagine our future as healthy people is not necessarily the way we are going to want medical decisions to be made when we’re sick. So advance directives, even if completed, don’t rigidly solve these issues either. It’s still going to be this complex group of people sitting down and doing the best they can. And the Family Health Care Decisions Act, as I understand it, really is going to allow that to happen. So it’s going to close a lot of gaps where we are currently pretending to have more clear information than we really have. The application of standards of evidence is very arbitrary and inconsistent. Depending on the clinician’s personal values and fear about the law, you are going to see tremendous variation in how the “clear and convincing” standard is applied. And nobody wants us to get into court on these cases, as being a test case is potentially frightening to all involved.

OUELLETTE: Speaking of dysfunction, let’s turn to the New York Legislature. When we first planned the panel, Robert had assured me that this was the year that the Family Health Care Decisions Act would pass through the Senate. Our thought was that the panel would educate the Bar about the new law, but two days before we thought there would be a vote to pass the bill, there was instead a legislative coup. Things fell apart and business stopped, or had stopped until sometime around 10 o’clock or 11 o’clock last night, when business in the Legislature picked up again. So I’m going to ask Robert to fill us in about where we are with Family Health Care Decisions Act.

SWIDLER: Sure. The Family Health Care Decisions Act (FHCDA) is based on a proposal by the New York State Task Force on Life and the Law, and was set forth in a booklet in 1992, 17 years ago, called When Others Must Choose. The Task Force noted the same problem then that we’re noting now: that it’s unrealistic to expect clear and convincing evidence that a patient would want to forgo a particular treatment under a particular circumstance. And that as a result we’re putting physicians and families in an intolerable situation where they either have to get treatment that is unduly burdensome toward the end of...
life, or they have to go outside the scope of what the law permits to allow compassionate care.

The Task Force also recognized that that the problem of surrogate decisionmaking is the bigger part of the problem that will not be solved by advance directives, just as both Nancy and Dr. Quill recognize that this is a bigger part of the problem. So they proposed a surrogate decisionmaking law that says, “In the event that patient loses capacity and the patient didn’t appoint a health care agent and didn’t leave clear and convincing evidencing or make the decision themselves, then you go to specified family members for the decision, or if there’s no family member, then to a close friend, and the family member can make health care decisions for the patient based on the patient’s wishes if reasonably known, or else the patient’s best interests, and if it’s an end-of-life decision and the patient meets certain strict clinical criteria, then the family member can make the decision to withdraw or withholding of life-sustaining treatment, without clear and convincing evidence, but based on the patient’s wishes, if reasonably known, or it they’re not reasonably known, based on the surrogate’s assessment of the patient’s best interest.”

What’s interesting is that bill has been around now 16 or even 17 years and I think for the past six, seven maybe even longer years, there has been broad consensus on the need for the bill and the basic principles of the bill. But it was hung up on two ridiculous side issues, in fact on two ridiculous words. One was the word “fetus.” For years, the Senate wouldn’t consider the bill unless there was some recognition in it that if an incapable patient is pregnant, the surrogate should consider the impact of the decision on the fetus. The Assembly would not agree to that. The other word was “domestic partner.” Okay, that’s a phrase, not a word. Anyway the Assembly said when choosing the surrogate, a top category should be the “spouse or domestic partner.” The Senate wouldn’t address the bill with that phrase in there.

Well, the State Senate became Democratic in 2009, and the new Health Committee Chair, Tom Duane, went over and took the Assembly position on both those issues and put in a “same-as” bill identical to the 2008 Assembly bill. That resolved those two longstanding issues and really created the ground to get the bill passed this year.

As a result of that, there was a lot of activity in the Spring of 2009 with people now taking the FHCDA very seriously, and working on some of the technical questions with the expectation that it might really finally become the law.

So recently there have been new issues that have become the focus of discussion. But these are more the type of issues that arise when policymakers agree on the key substantive matters but are trying to anticipate and address the implications of a complex bill. One of the issues is how should the bill apply to persons with mental retardation or persons in mental health facilities because both of those populations already have surrogate decisionmaking laws, and those laws differ a little bit from the terms of the Family Health Care Decisions Act. And the resolution ultimately, and it may just be an interim resolution, was that the FHCDA should provide that, if you’re mentally retarded and a decision can be made for you under what’s called the Health Care Decisions Act for Mentally Retarded Persons, then that law applies, not the FHCDA.

And if you are mentally ill and you are hospitalized and OMH regs provided for surrogate decisionmaking for you, then those regs apply, not the FHCDA. But that approach was regarded simply as a placeholder until there is further study about bringing those populations within the scope of the FHCDA.

The only other issue that was the subject of a lot of discussion was the question of where this law should apply. Prior drafts had not been very clear about all the different settings in which the FHCDA would apply. It clearly applied in hospitals and nursing homes, and the bill designed many safeguards with those settings in mind, like the expectation that hospitals and nursing homes would convene ethics committees and have the ability to secure concurring opinions of incapacity from professionals with specific qualifications.

But it became much more complicated to think how would this apply to a surrogate decision for an incapable patient in a doctor’s office, or in home care, or in an ambulatory surgery center, or a physical therapist’s office. So the bill was amended in 2009 to specify that at least initially it applies only in hospitals and nursing homes. Then there was a lot of discussion about the extending the bill to at least cover hospice patients in whatever setting they are in. But for the moment it just applies to patients in hospitals and nursing homes.

So in May and June, I was invited to some of the legislative meetings on the bill as a technical resource. And on June 6, I was packing my briefcase to go to a meeting of Senate, Assembly, and Governor’s Office staff to walk through the bill one last time, to make sure that there were no final technical issues, and to reflect some of the comments that had come in the previous week. I was already thinking about the post-enactment party that we would have to celebrate it being passed. That was the day that there was a coup in the Senate, and then the Legislature became deadlocked and nonfunctional for a very long period. A situation that was just remarkable and unprecedented. Those of us who have been in Albany for a long time have never seen anything as chaotic as...
CONVERSATIONS

this. And it just brought a halt to all legislation, including the FHCD. This event was just about the only scenario that could derail the FHCD at that point, and indeed, it derailed it.

But there are still hopeful signs. In particular, the Senate recently updated its bill to reflect the Assembly’s 2009 bill, and is advancing it in the Senate. So I am still hopeful something will happen this session. Over the past three months what I’ve seen with this bill is, “It’s dead! No it’s alive! No wait, it’s dead! No it’s alive,” and this is another reiteration of that. It’s exciting, and I think the prospects have been resurrected for the moment and I’m hopeful that it will pass. And if it does pass, it will significantly alleviate the problem that we have, where good care is not lawful care. That’s simply not tolerable.

OUELLETTE: Okay, so how important is it that FHCD pass?

DR. QUILL: The only thing I would say is that this would reconcile New York State and the vast majority of other states, and put common sense back into the process. It would allow us to do what families want us to do, which is if a person is incapacitated, sit down with the family and try to achieve a consensus about how to make the best possible decisions we can under these very hard clinical circumstances that is respectful of the patient’s values and clinical situation. It is going to be a huge step forward in reconciling what we actually should do with good care and what the law said we should do. So there will still be a significant number of challenging cases where the law and good clinical care will still be somewhat at odds. People who never had capacity will still be a challenge legally and clinically, for example, but those numbers are very small and maybe those should be resolved in a more complex way. But I think that passage of the Family Health Care Decisions Act would be a huge step forward if it can finally be passed.

SWIDLER: Dr. Quill, can I ask you a question about this? One thing I often hear, particularly from doctors, “Well, it ain’t broke, so don’t fix it. I’m finding ways even within the constraints of the law to provide good care, I just don’t pay that much attention to the limits you’re talking about and I don’t want things to get more bureaucratic with some law that tells me I need to determine incapacity this way, then I need document that certain clinical criteria have been met, and so on.” I know there’s going to grousing and resistance about that. Is it worth it?

DR. QUILL: From my point of view, it is well worth it. When clinicians are not following standards—when we say we are going to ignore the standards and do the best we can on a case-by-case basis we know that the way decisions are made tends to be pretty uneven and unpredictable. And there are some agreed-upon, practical ethical standards to guide these decisions, so if you have good policy and good law, we ought to be able to document and carry out good clinical care. Under the Family Health Care Decisions Act, if you document good clinical care, you will meet the legal criteria, and I think reinforcing that is a good thing. There may well be some grousing about new bureaucratic requirements, but having your fear of the law guiding what you’re going to do clinically is just not tolerable.

DUBLER: I would add, I agree entirely. And I would add a number of other points to what Dr. Quill has said. One. Self-conscious care in making decisions at the end of life is a good thing. These are not decisions that should be made casually. The law has been most effective, when it raised consciousness regarding the gravity of the situations that are faced. Two. The burdens appear to be reasonable in this law. There are, however, always unanticipated negative consequences of any legislation. In this instance, I am concerned about home care and the hospice setting. Although I think the hospice setting is sufficiently self-conscious to not be disturbed by the law. What this new legislation will do, hopefully, is remove the law from the clinical setting. What the present legal structure has done is make it comfortable for lawyers to say we have a role in clinical-care decisions. And what I hope this bill will do is to return these decisions to the bedside where loved ones and physicians can jointly fashion a care plan that is appropriate and kind for this patient.

DR. QUILL: The home care gap is a huge issue in the sense that at the end of life generally you want to keep people out of the acute hospital, and many people would much prefer to die at home and not in a nursing home. Whatever the standards are for the hospital and the nursing home, they should be followed in the home care setting, even if that’s not what the letter of the law says. So this could be an area where there’s a small gap. But I don’t see having to admit somebody to the hospital to make a decision that could have been made at home. That would be ridiculous. But I do think if you had a standard in the nursing home and the hospital that people will generally follow that same standard at home, even if that’s not within the letter of the law.

DUBLER: The decisionmaking that goes on in the hospital as part of the discharge planning process will need to assume the burden of this decision. It will take some creativity to make it happen, but I, like you, Dr. Quill, think that it’s probably possible to set up some guidelines and standards that will extend the reach of legislative intention into the home.

SWIDLER: Nancy, I agree with you. That was the exact point, you made the same point I was going to make,
and better than I would have made it. But for your information, I had this question from the state hospice association: If, after the FHCDA is passed, the patient is in the hospital or nursing home, more likely hospital, and is discharged to home, with surrogate consent to a care plan that provides for palliative care and comfort care only, can the hospice program then honor that in the home? And I think the answer, clearly, is yes.

DUBLER: Yes.

SWIDLER: The decision was made lawfully per the FHCDA in the hospital setting by a surrogate. There’s nothing in the FHCDA that tells you that same decision should be disregarded when the person has stepped outside the hospital. But what we still need to do, though, is find appropriate ways with appropriate safeguards to extend the law to decisions that are initially made in the hospital and in the doctor’s office and in the ambulatory surgery center.

DUBLER: Yes.

SWIDLER: But I think there may be a need to think more about what those safeguards are. Because the safeguards in the hospital, for instance, the ethics committee, are not going to extrapolate well or easily to a decision made at home. So, we need to think about that.

DUBLER: I would suggest, however, that the “best is the enemy of the good.” At this point, 18 years into the process, I’m willing to take the good and proceed from there.

SWIDLER: Here, here. One other point Dr. Quill made is that there are still going to be a lot of problems this doesn’t solve. One of the biggest problems it won’t solve, and I think this is a source of misunderstanding, is the Terri Schiavo-type problem. The family dispute. People have come to me and said, “Oh, is this law designed to solve the Terri Schiavo type problem?” And it clearly is not. What this law does is enable a decision to be made where there isn’t a dispute, which I think is the main problem in New York. Right now we can’t even make end of life decisions when everybody is in agreement on it. But when there is very sharp disagreement and somebody wants to go to court, well, yes then there’s going to be a court proceeding. And the issue will be whether what reflects the patient’s wishes, if known, or the patient’s best interest if not known. And that could get litigated and that could get appealed and that could become politicized. So the FHCDA is not an inoculation against a Schiavo problem. It just makes good medical practice lawful.

DUBLER: Many disputes at the end-of-life can be mediated. By empowering the parties, hearing their voices, enlarging options and devoting focus and time to the project, many disputes can be resolved. However, some disputes cannot be either managed or resolved. Disputes that are animated by hatred, mistrust, and ideological chasms must be referred to courts for resolution. That is the usual and comfortable role for judges to play.

POPE: I certainly support the Family Health Care Decisions Act, like everybody else. But in a sense it not only fails to solve Schiavo-type problems, it also actually seems to create such problems. By demanding advance directives and clear and convincing evidence, the current law sets an unrealistically demanding standard. Still, it is a nice ideal, because it maximizes, we think, the idea that we’re best protecting the patient’s authenticity and the patient’s autonomy. We want—under current New York law—solid, very, very good evidence that what we’re doing is what the patient would have wanted. Absent that, we’re going to presume that life (in any almost any state of sentience or suffering) should be prolonged and that life-sustaining treatment should not be withheld or withdrawn. Now, under the proposed Health Care Decisions Act, merely by status, without any evidence, merely by status, the surrogate is empowered to make medical decisions on behalf of the patient. That should cause us a little pause because we know that the uniformly consistent evidence is that surrogate decisions diverge from patient instructions, preferences, and best interests. Surrogates often do not really know what the patient would have wanted. And even if they do know, they often choose treatment different than what the patient would have wanted. This is why I am suggesting the FHCDA may create more Schiavo-type conflicts. Under the FHCDA, you are going to have surrogates who are going to get challenged by both other family members and by providers. And even if they are not formally challenged, even if it never goes to litigation, we know, statistically, that there are going to be many surrogates, who are legally authorized decision-makers, who are probably not making the decision that the patient would have wanted. The overall good achieved by the FHCDA surely outweighs any problems that it creates. As Nancy suggested, this may be one of those things that while, not perfect, creates overall good on balance.

DUBLER: Thad, I think you’ve raised a number of very interesting problems. One is, the New York State case law that put us in the bind that we now find ourselves begins in 1981. In 1981 it was important to emphasize the autonomy of the patient. In the dynamic of the history of the doctor-patient relationship, it was important to say, at that time, autonomy rules. I’m one of the people who now think that autonomy as the single organizing principle of medicine has diminished power and force. Individual wishes are important. Individual rights are important. However, there are other equally valid issues in end-of-
life care. Like what the patient can foresee, what suffering the patient is undergoing, and what people of good will and skill can bring to a discussion of the patient’s best interest.

The default notion that death is to be avoided at all costs is, I think, morally deficient as a way of responding to the human condition. So I am comfortable in saying ethically, that autonomy, in and of itself, is the only factor that ever matters, which is basically what New York State case law states, is rigid, overly simplistic and deficient in nuance, compassion and a broadly humanitarian view of the human condition.

From my perspective as a communitarian, from someone who thinks that the greatest ethical problem in American medicine is the lack of access to care, for those people who are uninsured, the notion that individual rights should always trump is one that I find increasingly obnoxious. As we move into discussions of extending care and health care coverage, autonomy as the single defensible principle for distributing care must be re-examined.

I realize that one should never talk about rationing. But one has to talk about the fair disbursements of the goods of medicine. So from the perspective as a citizen in this nation and from one who looks at the struggles of physicians and families at the end of life, I’m not distressed by the notion that autonomy is not the only or even the single most important issue to be grappled with.

QUILL: I agree with you in general terms. In practical terms, working with a family to try to protect and represent the patient’s autonomy is still a very fundamental issue....

DUBLER: Absolutely.

QUILL: ...and as you’re trying to figure out what a person would have wanted when they cannot speak for themselves, getting a family together to imagine what the patient would say under this very special and particular circumstance is the fundamental challenge. If and when the Family Health Care Decisions Act is passed, the job clinically and ethically will be reconciled with the job legally. This will be a huge step forward for the state.

DUBLER: I agree entirely. Which is why when I sit down with a family, and I always sit down, the first question I ask is, “Tell me about momma.” Because the physicians are experts on medicine, but the family is the expert on momma. And they are experts not only because of what she said and made explicit in discussions, but because of who she was and what she presented to her family in the web of relationships that she established. So we agree entirely.

OUELLETTE: To follow up on this sort of scenario that we’re talking about, how would the Family Health Care Decisions Act help when there is a conflict in a Schiavo-type scenario, between what the appointed surrogate wants and what another family member wants? What’s the mechanism for challenging that decision? Does it involve ethics committees or going to court, as Nancy suggested?

POPE: Well, it could involve both. Initially, the FHCDA provides for an ethics committee to act in dispute mediation or make an effort at dispute mediation. I must also point out that nature has a way of solving an awful lot of these disputes. Many times, the patient dies during the course of the dispute, no matter what efforts are made. But under the mechanism of the Family Health Care Decisions Act, there is dispute mediation. If that doesn’t resolve the issue, the surrogate’s decision can be honored. But either party can go to court and try to get a different decision.

QUILL: Practically, there is a sequence that usually occurs. In these tougher cases, if you have palliative care consultation available, they get involved and try to mediate the dispute and achieve a consensus. If they can’t resolve the issue, then it’s the ethics committee that gets involved next. They try to reconcile the parties, and if that can’t happen, then it goes to court. So there are mechanisms for dispute mediation that don’t involve the courts that are actually quite sophisticated at most major medical centers. So in the cases that actually get to court, there’s already really been a lot of effort to find common ground and to invent solutions.

DUBLER: I just want to drop a footnote to Dr. Quill’s statement since I’ve written widely about bioethics mediation. I tremble, gently, to say that mediation requires skills. There is formal training in mediation and dispute resolution and a body of materials to be mastered; the reason I was drawn to mediation is because it contains a litany of skills that I can teach. And therefore I think it will be extremely important if this law passes to be certain that we really provide professionals with the skills to do the tasks that we ask them to do.

POPE: I have a comment and then a question. Mediation takes care of most end-of-life disputes—mediation in one form or another. But when these sorts of disputes do reach the courts, judges seem increasingly willing to replace errant surrogates. For example, surrogates who are asking for treatment that’s contrary to the explicit instructions in the patient’s advance directive are replaced with another substitute decision-maker. One example is the Dorothy Livadas case decided by a Monroe County court just last year.
CONVERSATIONS

In Ontario, they have a whole special mechanism just to do this: the Consent and Capacity Board. If an Ontario healthcare provider thinks that what the surrogate is asking for is contrary to the patient’s known preferences or (if we don’t know what those are) the patient’s best interests, then the provider can go to the CCB and have somebody else appointed as decision-maker for the patient.9

In New York, Massachusetts, and other states, this surrogate replacement is happening more and more. That case law is starting to cast a shadow on what happens in the informal, intramural resolution process.10

That is my comment; here is my question. I was wondering if and when the Family Health Care Decisions Act gets enacted, whether the sort of conferences that Nancy was talking about would change. In the FHCDA world, it seems there might be less incentive to try as hard. In today’s world, you don’t have anybody who’s legally authorized to make the decision. So you must get everybody together and get them talking. Now, under FHCDA, if the legally authorized decision-maker is daughter number two, it seems that you do not really need to talk to all these other people. You do not need to go through such an elaborate process. I am not suggesting that Nancy would do this. But some might slack off because there would be less incentive to be thorough.

DUBLER: I don’t think so, because as clinicians know, disagreements within the families are very disruptive to the process of providing care. And so it’s not the letter of the law that governs, but rather it is the comfort of the clinical setting. If there is real discord among the surrogates, that must be resolved for care to go forward even if one of the family is the legally appointed decision-maker. Some scholars have argued that surrogates decide as much on the basis of what they think their siblings and family will bear as what they think the patient wanted. That may be one of the reasons you see the data on the discrepancy in surrogate decisionmaking. Whatever the reason, discord within the family disrupts the provision of care. Therefore, you really have to intervene as aggressively as possible to try to resolve disagreements.

Even if there is a health care proxy that the patient has named, you are still, at a practical level, sitting down with that proxy and the rest of the family and imagining what the patient would want, even though the named person’s opinion of what the patient wants is given more weight perhaps than the others. If there is genuine disagreement and fulminating conflict, you’re then into trying to engage in dispute resolution and mediation: diffuse the anger, create a level of trust, maximize the options for agreement and construction a consensus. And so I don’t see this need changing at all with this law. I think even with a named proxy, it’s a tremendous task to make an end-of-life decision and it’s sufficiently weighty so that you really do need a consensus. And when there is not a consensus that characterized a difficult process, that will likely require more sophisticated second opinions and expanded ethics opinions, before making a decision. When there’s really a dispute in this process, I don’t see that the need for dispute resolution and mediation will diminish to any degree.

SWIDLER: I tend to agree with that. In America now, families typically are dispersed, and their level of contact with patients varies. And what I see is that there often are one or two close, involved family members, and then there are other family members who are not that close or involved. And in the absence of any clear law, when an end-of-life decision arises, providers have a self-protective inclination to go track down everybody and make sure that everybody’s on board with it. But if you have a law like the FHCDA, it makes it clear that any person who is in this priority class can provide a lawful decision. So if the priority class is adult children, then the provider can rely upon a decision from the closest-involved adult child, that would be the appropriate way to do it. And then you have a lawful decision from that person. There is no requirement to track down everybody, to take a vote or anything of that nature. Where several family members are closely involved, it would be only natural for the provider to discuss the matter with them together, but that would be a practice tip, not a legal requirement. So I think what the FHCDA does, ideally, is to make lawful the good practices that are currently going on.

In fact, the proposal I sometimes hear that providers should have to notify every family member of an end-of-life decision reminds me to place on the record the standard rant I have about against the “due processization” of health care decisions. [laughter]

I often talk to lawyers that conceptualize end-of-life decisions by family members as the deprivation of a right on the part of the patient. They say, “Well the most important right that a person has is the right to live, and you’re depriving them of that. So, at the very least, you should first provide procedural due process—such as, notice to a broad range of interested persons, legal representation for the incapable patient, an opportunity to be heard, an impartial decision-maker, a written decision, and an opportunity to appeal that. After all, we’re talking about life and death here.” And that argument, well it makes me just want to, you know, shake the person, and say, “You know, this is not a capital punishment case, this is a medical treatment decision!” No one is trying to “deprive” the patient; it’s not an adversarial proceeding. Rather, health care professionals and family members
are struggling to figure out the right thing to do for the patient. Those kinds of due process procedures, in my view, will harm the patients and the system through delays, expenses and burdens, will generate disputes where they did not exist before, and will likely to lead to a worse result than a better one, from both a patient’s rights and medical ethics perspective. So I think the due processization of health care is the road to damnation.

Nancy, I suspect you’re a kindred spirit in that rant.

DUBLER: Well, I couldn’t agree more. Involving clinicians is the key to getting guidelines that work. Death is often not the enemy. We don’t want to recreate old paternalistic, non-transparent structures in which “pneumonia was the old man’s friend” but patients die, and in this process of dying the task of medicine is to help them remain comfortable and to help their families grieve.

SWIDLER: And yes, there will be cases where family members disagree. And if the dispute is sharp enough, and can’t be resolved by mediation, well that’s when more formal procedures are needed.

DUBLER: These situations will demand robust interventions in mediating disputes performed by professionals who are experienced and skillful in dispute resolution. I offer one example.

I had a very interesting consultation once during which 17 family members were gathered together in a far-too-small room. One, who was the legal health care proxy, was demanding that mamma get the most aggressive care. Mamma was moribund, obtunded, and ventilator dependent following a massive stroke related to many co-morbid conditions. The proxy did not accept that mamma was dying. Many of the others could see that this powerful woman, who had been the center of the extended family both in this country and in another, was no longer there. They grieved. The proxy railed and raged. Finally, some many hours after our discussion began, he lessened in his rage at life and death and the hospital. There had been some vitamins that mamma had always taken at home, that he wanted to bring them in for her now. So I cut a deal with the pharmacy. I said “Would you analyze these vitamins and if there’s nothing wrong with them, can we give them to mamma?”

This family was in chaos. This mediation, over many sessions, with different family members over many days required someone dedicated to resolving the family dynamic of conflict. Resolving conflicts in the context of a dying patient is labor intensive. It required multiple conversations to reach agreement that mamma was dying and that her son, who was the most distressed, needed support. In the process the mediator did a lot of “stroking” [supportive admiration for their love and concern], maximizing of options for the care of mamma, small group conversations or caucuses and much listening. Was it worth the time and effort? Well, the process itself removed much of the strain from the ICU staff, lowered the tension among staff and family and ultimately permitted a family to come together and grieve together. I would argue that it was helpful.

OUELLETTE: One of the points that you raised earlier, Nancy, was about rationing care, and you made a critique of autonomy as being the driving force that keeps us as a country from talking about rationing. One of the places that rationing comes up is when a family wants everything done even when the health care team says enough, we’ve done what is appropriate. As I read the Family Health Care Decisions Act, that Act really doesn’t address that type of situation of demanded care or what some people talk about as the futility problem. Is that an area of concern for New York? Do we need some kind of futility law?

DUBLER: Oh no.

SWIDLER: The FHCD says that a surrogate can’t demand any care that the patient could not have demanded. So the surrogate’s rights are confined by the scope of what the patient’s rights would be and patients can’t demand futile care. But do we need a law in New York like Texas has, a law that would define this more clearly? I’d like to hear more about the Texas law first but it is an area of a lot of tension in New York.

DUBLER: I take a particular stance on issues of futility. Most of the time the use of the term “futility” demonstrates that the conversation between the family and the physicians has broken down. Futility is the trump that’s brought out to say, “We won’t do this.” I would argue that the “futility” issue should be solved in the way other disputes are solved—by mediating.

When families say “do everything,” they often don’t realize what that means. They often don’t accept the fact that the patient is dying. They often haven’t resolved conflicts between and among themselves. So futility is not the end of a discussion for me, it’s the beginning of a discussion. And my sense of the Texas law is that it’s been a dismal failure.

DR. QUILL: I actually agree with that completely. Truly futile care, care that has no value and will not work, does not need to be offered or even discussed. You don’t need a law for that. Surgeons don’t do surgery when the patient’s going to die on the table. They say, “I can’t do it because it would hurt the patient.” We don’t do truly futile care. What the futility controversy is about is treatments of very marginal utility. So a patient might live an extra few days or an extra week with a very expensive,
invasive treatment like being intubated and put on a ventilator. It seems like there will be a lot of suffering and expensive resource utilization with minimal gain to warrant putting the patient through such a treatment. Yet in the current medical environment, such treatments are within a patient’s rights to receive if they have even a tiny amount of utility and the patient or family wants it and is willing to put up with the consequences. Now, if we want think about fairness or justice and say as a society we are not going to offer certain kinds of treatment because they’re so minimally effective, they have such little utility that they make no sense from a cost effectiveness point of view, then that’s a whole other discussion. I believe that as a society we should have this discussion, but so far our culture in New York and elsewhere in the United States is no where near that. So, I think it’s a waste of our time to have that discussion right now with regard to individual cases since there is no consensus about setting limits on treatments of marginal utility, and there is no broader national discussion about limit setting of any kind. I doubt we will get near that discussion in the current debate about universal access because it is too easy to marginalize and polarize as we look for areas of consensus, but eventually we will need to have this discussion if health care expenses are going to be kept within any reasonable boundaries.

**POPE:** I want to espouse and elaborate on that last point. If you can barely pass the Family Health Care Decisions Act, then you surely are never going to have the New York Legislature enact a unilateral refusal statute. I also agree that may not be a big loss because you probably do not really need a unilateral refusal statute. The overwhelming number of futility disputes are resolved informally through better communication and mediation. On the other hand, not every facility has a Nancy Dubler to do that, so the success rate is going to vary. Let’s say you have clear evidence that a patient wouldn’t want certain kinds of things, and you have a surrogate who is demanding those things. Your moral and legal obligation is to carry out the patient’s wishes, so if mediation fails you are going to have to try to replace that surrogate. It takes a long time and a lot of legal resources to replace such a surrogate, and significant harm can happen to the patient during that period. So that is a real problem and the amount of moral distress that occurs around those cases in hospitals is tremendous because you feel like you’re doing things that are absolutely wrong, and your hands are tied not to do them until you get legal authorization to replace the surrogate.

**SWIDLER:** If I can get in on this one. I think the place that the rubber meets the road on the futility issue is in DNR decisions. And that’s the one area where I would advocate consideration for some narrow futility exception. We have an unfortunate AG opinion in New York that says that even when the doctor concludes that resuscitation would be futile, if the surrogate does not consent to the DNR order, then the DNR order can’t be written. So when there is no DNR order, if this patient’s heart stops, a physician responding to the code could perhaps make an on-the-scene clinical decision that this isn’t going to work, or it’s not working, so I don’t have to keep up the pretense. But I think it should be lawful to write a DNR order on a narrow ground of physiological futility irrespective of the patient’s or surrogate’s wishes, because people don’t have a right to demand a treatment that is not going to work.

**DUBLER:** But Robert, I have two responses to that. Number one, you know best that the Bar Association, the Medical Association and the Task Force on Life in the Law, in the early ’90s crafted a document which created that futility exception since the law had not. This case where you really can’t do that, where you have an intractable dispute and cannot even use the current available legal mechanisms: the religiously motivated case. The surrogate is saying, “The reason I want you to continue aggressively treating this patient is because this patient’s religion demands it.” You cannot replace that surrogate because the surrogate is acting as the patient’s good and faithful agent. The surrogate is a faithful fiduciary, doing what the patient would have wanted.12

There are many filters along the way, and very few cases will evade all available mechanisms. You can pass a law to handle those truly intractable disputes or, as Truog suggests, just suck it up, treat that patient, and live with it.

**QUILL:** The legal mechanism is in place to protect patients under some of these circumstances, but it takes a huge amount of time and energy to carry it out. Let’s say you have clear evidence that a patient wouldn’t want certain kinds of things, and you have a surrogate who is demanding those things. Your moral and legal obligation is to carry out the patient’s wishes, so if mediation fails you are going to have to try to replace that surrogate. It takes a long time and a lot of legal resources to replace such a surrogate, and significant harm can happen to the patient during that period. So that is a real problem and the amount of moral distress that occurs around those cases in hospitals is tremendous because you feel like you’re doing things that are absolutely wrong, and your hands are tied not to do them until you get legal authorization to replace the surrogate.
futility exception was the narrow physiologic definition of futility: (1) It will not work—like using an antibiotic for a virus, or (2) the patient will code repeatedly in a short period of time. That consensus stood as an informal guideline until the AG’s office decided to intervene. But please don’t solve a flawed law with another possibly flawed law. The reason we are confronted with this problem is that the law codifies thinking at a moment of time. It seemed to make sense in a moment of time to have a DNR law. I would argue to you that, in general, it’s a bad idea to have laws that address specific issues in medicine. The law should address general setting of standards. Let medicine evolve publicly through discussions in scholarly journals, through developing and analyzing empirical evidence. Don’t ossify a moment in the evolution of medicine by enshrining it in law. Let medical discussion create the climate to support emerging guidelines. Let us not throw another law at it.

DR. QUILL: Futility around DNR is a big problem. The patients and families who want “everything,” and we repeatedly (and generally futilely) try to convince them to make the patient DNR because we feel it is very unlikely to help the patient and very invasive. We’ve just written a paper on this subject basically trying to reconcile the possibility of doing a very short code under these circumstances, and if nothing reverses within one cycle you stop. So again, because the repeated discussions about DNR with patients and families who want “everything” are so counterproductive, they’re so undermining of any kind of trust, that it’s just not worth it—it’s much more painful than one cycle of CPR and much more disruptive. So anyway, that’s our recommendation around this issue. It’s a very tough issue.

DUBLER: And that makes perfect sense to me. And if it comes out in the literature, let’s hope it is widely accepted; that would be, I think, a reasonable way to go. Much more reasonable than attempting to fix a bad law by what might be another bad law.

SWIDLER: That sounds reasonable to me but it illustrates what the question is, namely: What is the province of the doctor and what is the province of the patient? You’re saying how long to do the code is the province of the doctor, not the patient. But I’m thinking, by that same rationale, why can’t a patient say, “I want to be resuscitated and don’t let me catch you doing one of those short codes on me, I want the full nine yards.”

DUBLER: But, Robert, it’s never the patient. It’s never the patient. It is almost always the family. If the patient were to say that to you, Dr. Quill, if the patient were to say, “I want a full code, no matter that I’m dying,” what would you do?

DR. QUILL: Well again, what we said in this paper, and this is actually what we would do, we would do a full code. One cycle of CPR. If after one cycle there is no response and a person who had a one-in-a-thousand chance of having any response from the beginning, and there is now one-in-a-million chance that they’re going to respond for a few hours, and that meets my criteria for absolutely futility. So again, that’s a medical decision. You stop a code when it’s not going to work any more.

DUBLER: Exactly.

DR. QUILL: So there are things you might find in a code at the beginning that might allow the patient to live longer; let’s say they have a mucous plug that you might suck out and they might live another week. And so you can’t use absolute futility to not do it in the first place. You could say, “It doesn’t make sense to me,” or that “I don’t want to do it” or it is “a bad use of resources,” but you can’t use absolute futility as a way to avoid trying CPR under these circumstances, at least according to my way of thinking about futility.

DUBLER: You might call that, I don’t know what you called it in your paper, but you might call that “demonstrated futility.”

DR. QUILL: Maybe.

OUELLETTE: The Texas futility law goes far beyond CPR, right? It applies to situations where there is ongoing treatment. There’ve been a couple of cases that have generated a great deal of public attention in which the law was invoked by hospitals to terminate ongoing treatment over the objection of the families. There seems to be consensus in the group here that it’s not a good law. Thaddeus Pope is an expert in medical futility. Could you just tell us a little about the Texas law so the people who read this transcript understand what that law does.

POPE: Sure. The Texas Advance Directives Act, of which the unilateral refusal provisions are just one small part, was originally drafted in 1997, but was vetoed by Governor Bush. Between 1997 and 1999, the law was redrafted through a true consensus process. Every single relevant stakeholder in Texas participated: the Catholic Bishops, right-to-life groups, disability groups, hospital associations, physician associations. The resulting product had unanimous support, and was thereby effectively “gift wrapped” when it was sent to the legislature. It was passed and Governor Bush signed it in 1999. So, this year marks the tenth anniversary of the Texas Advance Directives Act. Alicia is correct. TADA permits the unilateral refusal of not only CPR but also any other life-sustaining treatment. So if a surrogate—and it’s almost always a surrogate, since the patients we’re talking about don’t have capacity—is asking for treatment...
that the physicians think is not medically indicated, not medically appropriate, then the physician usually will try to mediate and have consultations, though that is not required by the statute. If that doesn’t work, then the provider may initiate the formal process of the statute, which is spelled out in Texas Health Safety Code 166.046. The first step requires the physician to give the family, the surrogate, at least 48-hours notice of an ethics committee meeting. Next, the ethics committee will meet and discuss the case. Almost always, the ethics committee agrees with the physician that the requested treatment is medically inappropriate. The ethics committee must memorialize its decision in writing. Unfortunately, the quality of the decision process and the written decision varies tremendously because the statute is silent on key issues such as the composition and functioning of the ethics committee. Next, after the surrogate has been served with the ethics committee’s written decision, the surrogate has 10 days to transfer the patient to another facility that is willing to provide the treatment that they’re asking for. Of course, the surrogate (and the provider) may have already been trying to do this. Almost always, the surrogate is unable to find a transfer because, for the same reasons that the current physicians at this institution don’t want to provide the requested treatment, nobody else does either. Plus, this is a case that is now patently prone to liability, conflict, and trouble. On the 11th day, if the patient is still in the provider’s facility, then the provider may stop life-sustaining medical treatment over and against the wishes of the surrogate, or the patient’s advance directive. So long as this process is followed, the Texas Advance Directives Act clothes the provider with civil, criminal, and disciplinary immunity. The statutory unilateral refusal process has been utilized many times across the state.14

Often, as Dr. Quill mentioned earlier, given the timing of things, you actually don’t need to override the surrogate, you don’t have to withdraw over objections. The patients who we’re talking about are so frail that they may not actually last the full 10 days. But sometimes if they do last, then there is unilateral withdrawal. Physicians are comfortable doing that because there’s no legal risk. That’s basically in a nutshell how it works. But it is hardly without controversy.

During the first eight years of the statute’s operation, right-to-life and disability groups found that transfers are very hard to make. I think that they initially thought that the ten-day transfer period was going to be a much more meaningful safety valve than it actually has proved to be. So, they tried to kill the statute in 2007. That failed, and then they tried again in 2009. That too failed, just a few weeks ago. The statute has also been attacked in the courts on constitutional grounds. This is an area where the due processization of the law might be appropriate because more than one-third of Texas hospitals are state hospitals, so we have the state withdrawing life-sustaining medical treatment. It is a deprivation of life and liberty. So, you want to have due process. Given obvious problems with notice and neutrality, among other things, section 166.046 has been repeatedly attacked as violating procedural due process. Still, no judgments have been issued because the patient invariably dies during the litigation. The family then loses interest in the case and voluntarily dismisses. Notwithstanding its due process defects, many people perceive TADA as a success because it’s an effective vehicle that permits physicians both to practice what they think is good medicine and to avoid being forced to practice bad medicine by the fear of liability brought to bear by surrogates. A lot of great data has been published by Bob Fine at Baylor. Other states have explored copying Texas’ unilateral refusal provisions: Wisconsin, North Carolina. The Idaho Senate passed a bill earlier this year.

**OUELLETTE:** So the upside of a TADA-type of law would be that it allows physicians to avoid practicing defensive medicine at the demand of surrogates. What’s the downside to it? Nancy, you said it is a bad law—why would it be a bad law?

**DUBLER:** The major downside, in my judgment, is that physicians will have far less incentive to really talk with patients and families. And again, it will be largely families. And I think, from experience, that that incentive will increase commensurately as the socioeconomic status of the patient and family declines. I am always concerned about the fact that American medicine is largely peopled by professionals who are white, and that people who happen to be of color or of a lower socioeconomic class, who don’t have the same language, the same intellectual fighting words, the same connections, or the same culture of discourse as we do, will be disregarded. I don’t know what the data shows on the sorts of families who’ve been trumped by futility discussions, but it makes me uncomfortable that this is a trump card that will not require physicians and the institution to engage in mediation and dispute resolution. It does not require the institution to be certain that families understand. I think it interferes with the good, although labor-intensive practice, of medicine at the end of life, which Dr. Quill so eloquently exemplifies.

**POPE:** I think you’re right. As you know, the people who are most adamant, most demanding of aggressive end-of-life care happen to be from a lower socioeconomic class, black, and Hispanic. So, those populations are most often the subjects of the implementation of the Texas Advance Directives Act. Now, there is zero evidence that the unilateral refusal provisions were used against a patient...
specifically because of their wealth or race. Correlation is not causation. Still, you’re absolutely right that they are overwhelmingly the population.

DUBLER: But that should give us huge pause. When the AIDS epidemic first came to the Bronx and there was a huge push in the white/gay community for advance directives, we had patients of color who weren’t concerned about limiting care at the end of life, they were concerned about “access” to care. And I come back to access to care. If you have a law that’s disproportionately used against people of color, that’s a bad law. And therefore, the fact that it would be considered by other legislatures in other states is, as far as I’m concerned, an outrage. I apologize for the outburst but I have some passion on this subject.

DR. QUILL: You simply can’t define futility in a way that makes sense clinically. You can say it did not work in the last 100 cases or the last 1,000 cases, but you can’t consistently define futility in a way that is clear enough to trump a family’s wishes. You do find tremendously variability about people’s threshold for what is considered futile care. And again, those thresholds may vary about whether you’re like me or different from me, white or black, rich or poor. So for me such definitions of futility are not helpful. Now if we’re talking about lack of utility and introducing issues of societal good and justice, that’s a whole other discussion, but we are not having that discussion as a culture right now in this country.

DUBLER: If we want to talk about futility in the terms that were framed by Atul Gawande, in the New Yorker piece of about a month ago, about the misuse of resources in Texas, or if you want to talk about David Leonhardt’s piece yesterday in the New York Times about how to deal with prostate cancer, if we want to talk about futility in terms of national policy that will affect all people equally, then I’m with Dr. Quill. Let’s have that discussion. But if you want to talk about trumping grieving families who have insufficient support at the end of life, I think that is moral outrage.

SWIDLER: I make a distinction here. I don’t think there’s any escaping the futility issue. Clearly if you’re looking at a PVS patient, that to me is a value judgment, not a futility issue. If a family believes that that existence has quality of life or the patient would want to be maintained as long as possible, that is a judgment call that belongs to the patient. On the other hand, when you get to the issue of whether somebody ought to have a heart transplant, there’s a big difference between a 60-year-old with heart trouble and a very frail end-stage Alzheimer’s patient with heart trouble. And the answer to that ….

DUBLER: But that’s not futility.

SWIDLER: Let me just finish. Of course, we wouldn’t offer this to the end-stage 95-year-old because it would be futile because they’re not clinically appropriate for it. All you’ve done is really say, “Here’s an example of pure futility so nobody would do this.” But there will be close cases concerning whether somebody is a candidate, where the doctors are saying they’re not and the family is saying they are.

DUBLER: But that’s a really good example of where the futility discussion is not relevant. There you have a clear algorithm for the allocation of scarce resources. And for this allocation of scarce resources, we have actually engaged in a national discussion which is reflected in the rules and the procedures of United Network for Organ Sharing. And therefore, futility simply doesn’t enter the discussion. You have guidelines and rules for who is appropriate for a heart transplant that does not involve futility but looks at the appropriate use of a scarce resource.

SWIDLER: And if I change the example to open heart surgery, would your analysis change?

DUBLER: It depends on whether open heart surgery is a scarce resource. And whether the surgeon thinks that he or she may benefit the patient. You may have an elderly patient who is otherwise healthy, who would be an appropriate candidate for open heart surgery. Now, if …

SWIDLER: I don’t want age to be a qualifier.

DUBLER: Okay.

DR. QUILL: This is a discussion about marginal utility. It’s about cost-benefit analysis. It is not about futility. I just consulted on a 95-year-old man, huge decubitus ulcers in the intensive care unit, on a ventilator from which he is not going to get off alive. Is a ventilator futile for him and should we stop? The consensus was that he would prefer to be on the ventilator and alive than off the ventilator and dead. He eventually regained capacity, and confirmed we were following his preferences. Now was it futile to put him on the ventilator? His quality of life was not something that I would found acceptable, but it was okay with him. It was probably not a good use of resources for us as a society, but for him as an individual it was clearly what he wanted under the circumstance. So we are not having any systematic societal discussion about limiting the resources being allocated to any individual patient. You can’t trump his request based on futility, and it can’t currently be overridden because it is not a good use of society’s resources. It’s a case of marginal utility. It’s a cost-benefit analysis that as a society we are not yet mature enough to have.

SWIDLER: I’m not sure I see the difference. You’re saying that a doctor cannot decline to provide requested care
CONVERSATIONS

based on futility, but can decline to provide requested care based on a cost benefit analysis. That seems to me to be the more problematic basis.

DR. QUILL: No. I’m saying you can’t deprive somebody of care in this society based on a cost-benefit analysis or marginal utility. That is a subject that has to be negotiated with the patient, or usually family, in these circumstances. And using futility to unilaterally avoid that discussion (which is a hard discussion) would be very tempting because it doesn’t make sense to me, and doesn’t seem like a good use of resources. But we don’t have a consensus as a society about these matters, and therefore I think we shouldn’t be using futility to override patient and family decisions because it’s going to be done very arbitrarily, and you get into everybody’s biases confounding the picture.

SWIDLER: Thank you. I have to say, it’s not like I have a strong view on this issue that I’m promoting. I’m struggling with the issue myself. And this is helpful. So thank you.

DUBLER: At this point I would like to contradict something that I stated earlier on. This is a circumstance in which autonomy does trump. It’s very difficult to say to a patient who is capable of making health care decisions and aware of his or her surroundings, “I will not keep you on this ventilator.” And I think in this instance that the patient’s wishes become the absolutely dominant factor in decisionmaking. But I want to emphasize what Dr. Quill said, which is, these legislative approaches to futility provide a club that permits physicians to beat back uncomfortable wishes of patients and families without engaging in the very difficult and time-consuming discussions that are required.

Furthermore, even this small vignette might change in the event of a swine flu epidemic. In the event of an epidemic it might be necessary to allocate ventilators and to remove some patients from ventilators even if the family objects. It will be even more difficult if the objecting agent is the alert and aware patient herself.

POPE: I would like to play the other side a little bit more. Your point assumes that surrogates don’t already have a club. I actually am very critical of the Texas mechanism as currently implemented, not in concept. But a strong argument in defense of a Texas-type mechanism flashed into my mind when Dr. Quill mentioned the code, although he may have been talking about something different than this. I remember the Queens Hospital grand jury indictment back in the early 80s. They were doing the purple dots and things like that; they were making unilateral futility judgments. “CPR is not appropriate for these patients.” They never got consent; never discussed it with the family. And I think that the current evidence suggests that, nationwide, there is significant “underground” unilateral refusal of life sustaining medical treatment. Providers often are not open about it. If you don’t think you’re going to get consent, or if you’ve already tried to get consent and failed, then you have to be secretive about it because it’s not really allowed. And so the argument in defense of a Texas-type mechanism is similar to one employed in defense of physician-assisted suicide. It is already being done, but covertly where it is far more subject to abuse. So, why not create a mechanism, so at least it can be done transparently, openly, and regulated by a fair process?

DUBLER: I think the reason for not so doing is that the creation of legislation reflects the values of stakeholders that may not necessarily reflect the values of medicine. We are now engaged in a much more transparent practice of medicine than we had in the 1980s. When I began working in a hospital we had boards with little dots on them indicating resuscitation status, and shift wars where a patient would be DNR from 8:00 in the morning to 4:00. It was ridiculous. But I think there is a generally accepted openness about ethically fraught issues in medicine today. Scholarship regarding the ethical guidelines for patient/family/physician decisionmaking is published in major medical journals. Discussions are held in public, in the media, in the press about these decisions. The danger of legislation is that you codify thinking at a moment in time which may not reflect later thinking.

DR. QUILL: There are some real challenges and subtext issues here because you want doctors to exercise clinical judgment, and there are things that don’t get offered because they are truly futile or because they don’t make sense. But when there are treatments of substance that are not going to be offered or that you are recommending against, you really do want that to be the subject of a discussion. CPR is a paradigmatic case. It is both a real issue and it’s a metaphor for talking about how sick and near death a patient may be. The patient is dying, but that does not give a clinician the right to unilaterally withhold potentially effective treatments even if effectiveness is marginal. If you’re not going to use antibiotics to treat pneumonia because the patient is dying and you don’t think it makes sense, that’s going to have to be discussed. If you’re going to stop checking bloodwork four times a day and instead you are going to do it once a day because it makes more sense in that circumstance, that seems to me a clinical judgment because otherwise you’re just burdening people with every conceivable possibility in making them make a decision. On the other hand, if you were to stop checking any bloodwork at all, that would be a substantial change that would need to be cleared with the patient or surrogate.
DUBLER: And also, it is mean. It’s mean to treat the family at the end of life as if they were some sort of junior consultant. They are not. They are grieving family. The skill and real honor of medicine is in the ability to make difficult decisions. What burden do I as a physician bear and where do I need to involve the family? And intruding into this delicate emotional and professional fabric with legislation does not generally help matters.

POPE: I think it’s worth mentioning that while we can use Texas as a convenient target, Texas merely codified the AMA policy on this. And the AMA is hardly the only national professional medical association to endorse a process where the last step in the process entails unilateral refusal.

DUBLER: I think they were wrong.

POPE: Okay. Right. I just wanted to flag that this isn’t just about Texas. There’s a much broader support for the concept of having a mechanism like Texas than it might appear, since only one state has a law like this.

OUELLETTE: And there are at least some cases that have come out of Texas that have wound up in the courts where there’s been young children or babies and the doctors really felt that the children were being harmed by the care that the mother was seeking. For example, there was the Baby Sun Hudson case, and the Emilio Gonzales case. I don’t think that the physicians in those cases were trying to do harm in the family in any way; they were trying to do what they thought was right for the patients. So it may be that legislation isn’t the right tool to address the problem, but there may be cases where providing the care that is requested that would prolong a life that is painful to someone who can’t speak for him or herself. That is really not something that should happen. So that there’s a huge difference, I think, between the case that Dr. Quill described where someone could speak for himself and say this is what I want and a case where there may be a child or someone who is being actually harmed by being kept alive.

SWIDLER: Well, Alicia reminds me that in New York we have had a couple of cases of babies or small children who had been declared brain dead where the hospital wanted to discontinue ventilation from the brain dead patient, but the parents objected to it. And in at least one of those cases the hospital was authorized to discontinue. It’s analogous to the futility case, but it is placing the hospital against the patient or against the family in that the hospital’s advocating the discontinuance of treatment.

DR. QUILL: In that circumstance, you have a societal consensus that if you can be declared brain dead, you are dead. There is a legal, ethical and medical consensus on that point. In other cases, whether it’s with children or with the elderly, clinicians are going to have to partner with families in deciding which treatments can be stopped. Physicians are not going to be able to unilaterally stop treatments that have an even minor utility, even if suffering is high and it seems harsh to continue with treatment, without an in-depth conversation with families. But if there is a family consensus that treatment is not serving the patient’s interests and therefore “futile” using a common sense definition and the doctor’s agrees, then you can stop. So I think there is some ability to stop treatment in New York, but you have a consensus-based definition that it’s futile or it doesn’t make sense because suffering is too high and the prognosis is too poor.

DUBLER: There is an ethical formula often used in cases with children that does not require legislation; if physicians determine that what the families are demanding would cause harm, pain and suffering to the child without compensating benefit then it is appropriate to say to parents, after a deep and engaging discussion, “We will not perform that intervention. You are welcome to take the child to another institution.” If parents refuse care that is clearly in the best interest of the child, is uncontroversial, and would relieve suffering, then it is appropriate to inform parents that the intervention will proceed. And, in the great, gray middle where uncertainty looms large, the parents must choose. However, implementation of this, and other such ethical/medical algorithms, does not require new legislation. These discussions evolve as our database increases and sophistication about decisionmaking is honed more finely. I would argue to you, Dr. Quill, that if the family for the 102-year-old patient wanted an intervention that you thought would cause great pain and suffering to the patient without compensating benefit, my guess is you would say no. But very few interventions fall in that narrow bright and brittle category.

DR. QUILL: And there are processes for working on those issues. I would say “no” and if the family really disagreed, then we would probably sit down together and see if we could find a common ground. If we could not achieve agreement about what we will do and what we won’t, and the differences were substantive, then we go to ethics consultation. Only if that failed, and we were really at an impasse again, would we go to the courts. Livadas would be a good example of that. In this case, there were clear clinical criteria for stopping treatment, and family would not consent to stopping. We went through this sequence. Now this process for Livadas took six months before we actually stopped treatment based on brain death criteria. So it took this long even in a clear-cut case. Now one could argue that the patient probably was not harmed because she was so brain injured in the
first place that she was not aware enough to experience suffering, but I don’t find much solace in that argument, and she clearly was harmed in significant ways. It’s a very long process to go through all these steps, and there is significant suffering all around in this process. And the staff providing care that was extremely invasive, seemed to be inducing suffering and didn’t make any sense to them for six months. They felt like we were working against this patient’s expressed wishes, and she was suffering significantly in a way that could only end in her death. So again, there are many layers of harm that can happen in these cases.

POPE: I think this is actually right in the Family Health Care Decisions Act, the bill. Say that you are a physician and the authorized decisionmaker asks you to do something that you think is medically inappropriate. You cannot convince them otherwise. In that case, transfer is a specifically mentioned vehicle. Transfer is always built in as this way to solve treatment disputes. So the real type of futility dispute for which a new special legal mechanism would be useful is the dispute in which you can’t transfer the patient. Here, I think it’s worth mentioning that there is a case right next door to New York, in New Jersey, the Betancourt v. Trinitas Hospital case. Basically, the patient is actively dying, has all sorts of multi-organ failure and all sorts of problems. The providers thought it was inappropriate and cruel to continue to treat the patient. But the trial court ordered them to continue to treat. ”Notwithstanding what you think is medically inappropriate, you must treat.” That ruling worries health care providers in New Jersey, because they were unable to use their medical judgment. Hopefully, there will be guidance from the Appellate Court in New Jersey. This may actually be one of the first U.S. appellate opinions that actually gives some much needed guidance as to the rights of the providers and surrogates in these sorts of situations.

OUELLETTE: We could talk about these topics for a long time, but at this point, we are out of time. We need to conclude what I think has been a really interesting conversation. I had hoped we would have time to discuss New York’s new Medical Orders for Life Sustaining Treatment (MOLST) law, which created a process for creating a single document that functions as a medical order covering a patient’s wishes for CPR and other life-sustaining treatment. The MOLST is effective and transportable in all health care settings. Unfortunately we don’t have time to discuss the impact of the MOLST or its importance in health care planning. Nonetheless, I hope our readers will educate themselves about the MOLST, which can be a very effective tool for end-of-life planning. I thank you all for participating today.

Endnotes
2. See In re Westchester County Medical Center (O’Connor), 72 N.Y.2d 517 (1988).
4. See NY Surrogate’s Court Procedure Act § 1750-b (Health Care Decisions Act for Mentally Retarded Persons); 14 NYCRR § 633.11 (medical treatment for residents of OMRRD facilities; 14 N.Y.C.R.R. §§ 27.9, 527.8 (medical treatment decisions for residents of OMH facilities).
5. Surrogate Court Procedure Act § 1750-b.
6. As of the publication date, the FHCDAA had been passed by the State Senate, but was still in the Codes Committee in the State Assembly.

Alicia Ouellette is Associate Professor of Law, Albany Law School. Prof. Ouellette’s research interests include end-of-life decisionmaking, disability ethics, pediatric ethics, disparities in health care, confidentiality of medical information, human reproduction, women’s health care, and ownership of the human body. Previously, Ms. Ouellette served as an Assistant Solicitor General in then-Attorney General Eliot Spitzer’s office.
Nancy Neveloff Dubler is Senior Associate Montefiore-Einstein Bioethics Center, Professor Emerita, the Albert Einstein College of Medicine and Ethics Consultant to the New York City Health and Hospitals Corporation. New York City. In addition to consulting with federal agencies, national working groups and bioethics centers, she lectures and has written extensively on termination of care, home care and long-term care, geriatrics, prison and jail health care, and AIDS. Her most recent books are: Coleman, Menikoff, Goldner and Dubler, The Ethics and Regulation of Research with Human Subjects (2005) and Dubler and Liebman, Bioethics Mediation: A Guide to Shaping Shared Solutions (2004). Ms. Dubler is a member of both the NYS Task Force on Life and the Law and the Empire State Stem Cell Board.

Timothy E. Quill, M.D., is a Professor of Medicine, Psychiatry, and Medical Humanities at the University of Rochester School of Medicine and Dentistry. He is also the Director of the Center for Ethics, Humanities and Palliative Care and a Board-certified palliative care consultant in Rochester, New York. Dr. Quill has published and lectured widely about various aspects of the doctor-patient relationship, with special focus on end-of-life decision making. Dr. Quill was the lead physician plaintiff in the New York State legal case challenging the law prohibiting physician-assisted death that was heard in 1997 by the U.S. Supreme Court (Quill v. Vacco).

Thaddeus M. Pope is Associate Professor of Law, Widener University School of Law (Wilmington DE). He teaches and writes in the areas of Health Law, Bioethics, and Torts. His most recent scholarship focuses on medical futility law, and on the definition and justifiability of hard paternalism in public health contexts. He tracks recent developments in end-of-life health law at medicalfutility.blogspot.com. His most recent publication is Surrogate Selection: An Increasingly Viable, but Limited, Solution to Intractable Futility Disputes, 3 St. Louis J. Health L. & Pol’y (forthcoming 2009).

Robert N. Swidler is General Counsel to Northeast Health, a not for profit health care system in New York’s Capital Region. Mr. Swidler is also Editor of the NYS Bar Association Health Law Journal. Previously, Mr. Swidler was Assistant Counsel to Governor Mario M. Cuomo, Counsel to the NYS Office of Mental Health, and Staff Counsel to the NYS Task Force on Life and the Law.