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Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy



ADVANCE CARE PLANNING AND PUBLIC ENGAGEMENT

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Office of the Assistant Secretary for Planning and Evaluation

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I. INTRODUCTION

Despite local, state, and national efforts since the mid-1970s to adopt health care advance directives as the central tool to ensure that one's health care wishes are known, only a minority of Americans have adopted this formal approach to detail their wishes and name their proxy.¹ Meanwhile, medical innovation and technological complexity has rapidly advanced without attendant progress in integrating preferences into care decisions.^{2,3} For many Americans what can be done should be done: there is comfort in knowing that "we did all we could." The risk posed by prospectively limiting treatments in health care directives means possibly missing out on an intervention at some unspecified future date, especially in an environment of rapidly changing technology. Few Americans recognize that this unfettered dependence on technology creates "mechanical paths to death,"⁴ that prolong suffering and dying.⁵

Complicating the uncertainty of consumers, recent studies also demonstrate that physicians lack adequate tools to assist with prognosticating outcomes for individual patients.⁶ Physicians systematically and substantially overestimate patient survival. The survival rates of cancer and other formerly acute progressive diseases have markedly improved and morbidity has been significantly ameliorated by medications (e.g., chronic mental illness,⁷ HIV⁸). Chronic conditions are now the leading cause of death in the United States and will remain so indefinitely.⁹ In addition, despite a general unwillingness to make treatment limitation directives, with the increased incidence of dementia and age-related cognitive impairments many individuals make treatment decisions long before end-of-life decisions are needed. For these individuals, capacity may ebb and flow, with questions arising about whether the advance directive with proxy decision making, should be invoked.

¹ Pew Research Center (2006). *More Americans Discussing -- and Planning -- End-of-Life Treatment*. Available at <http://people-press.org/reports/display.php3?PageID=1029>.

² Postman N (1992). *Technopoly: The Surrender of Culture to Technology*. New York, NY: Vintage Books. Postman argues three interrelated reasons why Americans are enamored with medical technology: (1) The American entrepreneurial character embraces technology (i.e., innovation and invention are basic goods); (2) Technological innovation equates to progress, resulting in the development and proliferation of medical technologies; (3) American culture has gradually adopted the belief that technology is the foundation of the medical profession.

³ Callahan D (1987). *Setting Limits*. New York, NY: Simon and Schuster. p143.

⁴ Knaus W (1996). *The SUPPORT Project: To improve Care at the End of Life*. Fanlight Productions, video, ISBN 1-57295-177-X, Catalog # DVD-177.

⁵ Casarett D, Kapo J, Caplan A (December 15, 2005). "Appropriate use of artificial nutrition and hydration -- Fundamental principles and recommendations." *New England Journal of Medicine*, 353(24):2607-2612.

⁶ Christakis NA (1999). *Death Foretold: Prophecy and Prognosis in Medical Care*. University of Chicago Press.

⁷ Fleishman M. *Economic Grand Rounds: Issues in Psychopharmacosocioeconomics*.

⁸ Schackman BR, et al. (November 2006). "The lifetime cost of current human immunodeficiency virus care in the United States." *Medical Care*, 44(11):990-997.

⁹ Centers for Disease Control (2007). *The State of Aging and Health in American 2007*. Available at http://www.cdc.gov/aging/pdf/saha_2007.pdf.

This broadening of the dialogue in care planning and treatment decision making engages family members in a more expansive social structure that highlights the significant interrelationship between patient autonomy and the growing concerns of caregiving. Finally, even with documented evidence of patient wishes, research conducted during the past quarter century clearly shows that medical professionals and family surrogates often ignore or override patient preferences, with no consequence.¹⁰

The mix of these phenomena results in a social reality in which persons rely more on the “prevailing reality” of “default surrogacy” than any formal approach to advance directives.¹¹ The intention to state one’s final treatment wishes with certainty in most cases is a more fluid and tentative expectation that surrogates will formulate and modify decisions in the shifting sands of time-limited clinical interventions. This situation makes the advance directive seemingly unnecessary for many and only a guide, important as it may be, for those who find themselves in roles to decide.

This transfer of decision making authority does, however, underscore the increased importance of naming a proxy to act as substitute decision maker and informing that individual about personal preferences and wishes. Although it fundamentally alters the approach of applying previously stated wishes at a later time, this process-oriented approach attempts to address the dynamic and systemic considerations consumers prefer.

Health care professionals must ensure, nonetheless, that patients and surrogates understand that the increasing complexity of their chronic disease does not necessarily threaten the possibility for continued personal growth. Nor do increasing disability, diminishing capacity, and complexity in disease management threaten the patient’s sense of dignity. The burden of disease and care is a legitimate consideration by patients thinking about discontinuing treatment, but it is not a reason for surrogates or providers to devalue those lives.

This paper provides an overview of the dynamic between the social and medical dimensions that has evolved over the last three decades in end-of-life decision making generally and in care planning specifically. Current challenges and opportunities for promoting the goals of advance care planning have moved away from legally worded directives to the more nuanced world of treatment goals and outcomes, and the more complex realm of cultural and personal preference within a diverse American society.

¹⁰ Perkins HS (July 3, 2007). "Controlling death: The false promise of advance directives." *Annals of Internal Medicine*, 147:55-57. See also: "The SUPPORT principal investigators. A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)." *JAMA*, 274:1591-8 (1995). Galambos CM (1998). "Preserving end-of-life autonomy: The Patient Self-Determination Act and the Uniform Health Care Decisions Act." *Health Soc Work*, 23:275-81. Volicer L, Cantor MD, Derse AR, Edwards DM, Prudhomme AM, Gregory DC, et al. (2002). "National Ethics Committee of the Veterans Health Administration. Advance care planning by proxy for residents of long-term care facilities who lack decision-making capacity." *J Am Geriatr Soc*, 50:761-7.

¹¹ Sabatino CP (October 2007). *Advance Directives and Advance Care Planning: Legal and Policy Issues*. Commissioned Paper. Available at <http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.htm>.

Critical to this discussion is the acknowledgement that those who do not have ready access to health care differ in their views on this issue. The “right to refuse”¹² treatment, the tenet on which much of the advance care planning movement is based, carries significantly different meaning. In fact, representatives from disability rights groups and life protection organizations, contend that the issue of “overtreatment” from which the right to refuse emanates; *causes* incidents of “undertreatment” or premature discontinuation for disabled and vulnerable populations.¹³

To appreciate the impact of the social engagement dimension of advance care planning and in particular Americans’ readiness to engage in or avoid the delicate nature of those discussions, we begin with a recap of the historical aspects that led to the adoption of policies and legislation. Following the review, we discuss how recent changes in the way we die affect treatment options including financial incentives for providers. We also highlight efforts of advocacy groups and coalitions.

¹² *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261, 110 S.Ct. 2841 (1990). *aff’g Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. 1988).

¹³ *Participant discussion: Take Stock Summit*. Oak Brook: IL. (June 29, 2007).

II. MANAGING OUR MIRACLES AND THE EMERGENCE OF A SOCIAL CONSENSUS

The management of the effective use of penicillin in the early 1940s is often described as one of the most important moments in the history of medicine.¹⁴ This turning point in medical treatment provided physicians the capacity to intervene routinely in the “natural process” by eradicating lethal infection. The effect was to elevate the “science” over the “art” of medicine and propel it on its way toward conquering disease and zeroing in on death as the enemy.¹⁵

Over the next two decades, other remarkable inventions and discoveries followed, such as the advent of implantable pacemakers. By the early 1960s, dialysis treatment had expanded from a treatment for acute renal disease to include treatment for those with chronic conditions. By the early 1970s, it had become a benefit within the Medicare program.

As diagnostics and treatments improved, so did attempts to surgically replace or mechanically repair failing organs. Transplantation of vital organs, such as kidney, lung, liver, and heart, made significant strides during the 1960s, and by 1968 the Uniform Anatomical Gift Act was in place. Life-extending tube feedings for children introduced by Dr. J. Rhoads¹⁶ and colleagues in 1968 provided further evidence of medicine’s capacity to intervene on behalf of dying patients and complicate end-of-life care decisions. These advances led to additional questions about the appropriate time to retrieve organs from donor patients. In 1968, after seven months of deliberation, the ad hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death¹⁷ argued that a new definition of death to replace the previous one based on the permanent cessation of heart activity was necessary in the wake of resuscitative efforts that made a beating heart a false and untenable sign of life. “What immensely complicated the issues surrounding brain death was the fact that, although the patient was no longer viable, the patient’s organs were.”¹⁸

¹⁴ Lax E (2004). *The Mold in Dr. Florey’s Coat: The Story of the Penicillin Miracle*. New York, NY: A John Macrae Book/Henry Holt & Co.

¹⁵ Callahan D (October 2003). *What Price Better Health? Hazards of the Research Imperative*. Berkely, CA: University of California Press.

¹⁶ Chernoff R (August 2006). "An overview of tube feeding: From ancient times to the future." *Nutrition in Clinical Practice*, 21:408-410.

¹⁷ "Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain-death." *Journal of the American Medical Association*, 205:337-340 (1968).

¹⁸ Rothman DJ, et al., eds. (1995). *Medicine and Western Civilization*. Rutgers University Press. p421.

Within the next five years doctors in England coined the term “persistent vegetative state” and the initial descriptive account of the syndrome by Drs. Jennett and Plum¹⁹ appeared in *Lancet* in 1972.

At about this same time, state legislatures began weighing in. They formulated policy and adopted their own statutes that defined at what point death actually occurred and what obligations providers owed to patients being sustained by “artificial life support.”

In early 1973, the American Hospital Association issued a patients' bill of rights.²⁰ “Although the 12-point bill was vague and general, it was the first such document and included many basic concepts of patients' rights, such as the rights to receive respectful care, to be given complete information about diagnosis and prognosis, **to refuse treatment**, to refuse to participate in experiments, to have privacy and confidentiality maintained, and to receive a reasonable response to a request for services.”²¹

As a result of the explosive growth in medical technology during the 1950s and 1960s, moral theologians, thanatologists, and philosophers began grappling with social impact of these “advances.”

Herman Feifel, editing the seminal work, *The Meaning of Death*, in 1959 revealed the differing attitudes of doctors and patients toward death, finding that many patients welcomed honest discussions about death and their conditions despite physician reluctance.²² By far, the most widely known and referenced document on the ethical dimensions of life sustaining treatment was authored by Pope Pius XII in response to a question put to him by anesthesiologists at an international congress in 1957.²³ The allocution, which makes ethical distinctions for both professionals and patients on issues of ordinary and extraordinary care as well as excessively burdensome treatment provided guidance for most Catholic and many non-Catholic health care institutions during the latter half of the century.

In the late 1960s, medical and ethical interpretations of the scientific “advances” were coming into focus as the Euthanasia Educational Council developed the first “living will” in 1967.²⁴

¹⁹ Jennett B, Plum F (1972). "Persistent vegetative state after brain damage. A syndrome in search of a name." *Lancet*, 1:734-7.

²⁰ Annas GJ (1975). *The Rights of Hospital Patients*. New York, NY: Avon.

²¹ Annas GJ (March 5, 1998). "A National Bill of Patients' Rights." *New England Journal of Medicine*, 338(10):695-700 (**author's emphasis**).

²² Feifel H, ed. (1959). *The Meaning of Death*. New York, NY: McGraw-Hill.

²³ Pius XII (November 24, 1957). "The prolongation of life: Allocution to the International Congress of Anesthesiologists." *The Pope Speaks* 4.4, (1958):395-398.

²⁴ Hecht MB, Shiel WC Jr. *Advance Medical Directives*. Accessed on July 26, 2007 at <http://www.medicinenet.com/script/main/art.asp?articlekey=7814>.

In 1975, America experienced its first “right-to-die” case. Karen Ann Quinlan, a 21-year-old coed in a drug and alcohol induced coma, became the subject of a court case pitting her parents against the hospital and state appointed guardian. Failing to convince the Superior Court of the argument allowing their daughter to be removed from the respirator and die naturally from her injuries, the family appealed and received a favorable ruling by New Jersey’s Supreme Court. As a result of that decision, Quinlan’s father was appointed guardian and the family was allowed to make the determination to withdraw the respirator. By that time, however, Karen’s condition was such that her weaning from the machine allowed her to breathe on her own. She died nine years later from the effects of pneumonia at the age of 31.

In a memoir, her mother writes:

Karen became the symbol of abuse of technology in this technological age. She gave both fields, law and medicine, a case they could not avoid. She gave the public an issue that was pertinent to their lives.

For the first time in history, people were made aware of the decisions that had to be made. Moreover, Karen’s situation showed us all that what happened to her could happen to anyone at anytime.²⁵

The Quinlan case was the first of many, as Americans came to grips with the real issues of advancing technology, life threatening illness, and the fates of patients whose wishes were unknown.

In an effort to address many of the complicating issues resulting from the progress of science and research, the *President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research* published its works during the early 1980s. Among other issues the Commission addressed the difficult topics of defining death, patients with permanent loss of consciousness, the withholding and withdrawing of life sustaining treatment, and the importance of advance directives.

The Commission issued two reports on these subjects in 1981 and 1983.^{26,27} Congress specifically assigned the commission to start with “the matter of defining death” because of the decade long debate on the subject, and “a broad agreement existed on how it should be resolved both medically and legally.”²⁸

²⁵ Duane Quinlan J (2005). *My Joy, My Sorrow: Karen Ann’s Mother Remembers*. St. Anthony Messenger Press.

²⁶ President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (July 1981). *Defining Death: A Report of the Medical, Legal and Ethical Issues in the Determinations of Death*. Washington, DC: US Government Printing Office.

²⁷ President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (March 1983). *Deciding to Forego Life-Sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions*. Washington, DC: US Government Printing Office.

²⁸ Capron AM (2002). *The Legal Column. Governmental Bioethics Commissions: The Nature of the Beast*. (Capron served as executive director of the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research during its entire existence, 1979-1983.) Accessed on July 26, 2007 at http://www.lahey.org/NewsPubs/Publications/Ethics/JournalFall2002/Journal_Fall2002_Legal.asp#.

In describing the work of the Commission some years later, Alexander Morgan Capron, its executive wrote:

The commission brought together groups whose competing statutory proposals had stymied action in most states orchestrating agreement on a uniform proposal, which was then adopted generally across the country. This facilitated the leading medical authorities on the subject to promulgate what was recognized as the accepted medical criteria for declaring death.²⁹

As an offshoot to this assigned topic, the Commission decided to undertake another large study on the situations in which patients, families, and physicians must decide whether to forgo life-sustaining treatment. Medical thinking, case law, and public awareness on this topic were all rather rudimentary at this time. "Living wills" had been around for about 15 years but few people had them and only 15 states had "Natural Death" statutes authorizing the use of "directives to physicians." Moreover, most people -- including many health care providers -- operated from the assumption that it was wrong (and even illegal) ever to discontinue life-support, perhaps even when the patient's wishes to do so were known. Drawing on the best ethical and legal analysis, the Commission articulated why this was not the case, provided a framework for hospital ethics committees (which were just being widely instituted), and urged states to formulate and adopt durable power of attorney for health care statutes (which nearly all of them did over the decade that followed).³⁰

Nearly a quarter century has passed since the publication of those reports; yet, estimates now suggest that only about 30 percent of adult Americans have initiated documents appointing proxy decision makers.³¹

The social consensus or "generally adopted agreement" cited by Capron that emerged from 30 years of medicine, religion and ethics was finally codified in the adoption of the Patient Self-Determination Act adopted by Congress in 1990.³² Obligations of health care providers were clearly spelled out, requiring health care institutions to:

1. Provide to patients at the time of admission, a written summary of
 - a. health care decision making rights (each state has developed such a summary for hospitals, nursing homes, and home health agencies to use); and
 - b. facility policies with respect to recognizing advance directives.
2. Ask about an advance directive and document that fact in the patient's medical record (if yes, it is up to the consumer to ensure the institution receives a copy).

²⁹ Capron, *ibid.*

³⁰ Capron, *ibid.*

³¹ Pew Research Center, *op. cit.*

³² *Federal Patient Self Determination Act 1990*. 42 U.S.C. 1395 cc (a).

3. Educate institutional staff and community about advance directives.
4. Never discriminate against patients based on whether or not they have an advance directive. Thus, it is against the law for the institution to require any patient either to have an advance directive or not have one as a condition of treatment.³³

Since the early 1990s, health care educators, palliative care and hospice practitioners, and end-of-life coalition leaders have worked to educate Americans about the importance of making their wishes known and naming someone to speak on their behalf when they can no longer speak for themselves. While the “right to refuse” treatment has become a fundamental element of end-of-life decision making in the United States -- unequivocal in cases where the patient clearly sets it forth or by substitution in a named proxy -- the citizenry remain conflicted about “when” it is proper to refuse treatment in cases where levels of consciousness and disability are questionable.

Since the U.S. Supreme Court ruling in the Nancy Cruzan case in 1990, which allowed for the withdrawal of nutrition and hydration from those in vegetative states, little has changed in the public policy arena. Despite multiple challenges over a number of years, and especially during the protracted Terri Schiavo case in Florida, consensus has remained.

Americans have reached consensus that: (1) people have a right to refuse life-sustaining medical interventions; and (2) interventions that can be terminated include artificial nutrition and hydration. The one unresolved issue is how to decide for mentally incompetent patients. Only about 20 percent of Americans have completed living wills, and data show that family members are poor at predicting patients’ wishes for life-sustaining care. Despite court cases and national consensus that these are private and not legislative matters, the Schiavo case is unlikely to change practices except to increase the number of Americans who complete living wills.³⁴

So, if the consensus is clear and the benefits to naming a proxy are known by Americans, why have more adults not completed the documents? Clearly it is due to the reliance by many Americans on the prevailing reality of default surrogacy; they depend on their loved ones and healthcare professionals to make these decisions for them.

Most health care consumers trust their loved ones and their medical practitioners.³⁵ Even those without family trust their providers.³⁶ The issue is not a

³³ American Bar Association, Division for Public Education. Accessed on July 27, 2007 at http://www.abanet.org/publiced/practical/patient_self_determination_act.html.

³⁴ Hampson LA, Emanuel, EJ (2005). "Perspective: The prognosis for changes in end-of-life care after the Schiavo Case." *Health Affairs*, 24(4):972-975. (Author’s note: Discrepancy in the percent of Americans listed by the authors of this 2005 article versus the numbers cited in the current report is due to difference data sources and their timing.)

³⁵ Commonwealth Fund survey data.

political one to be resolved in courts, and evidence points to the fact that providers are unlikely to change their practice of withholding or withdrawing treatments once they have made a clinical determination to do so.³⁷ However, clinical practice improvements may benefit both patients and proxies alike in translating complicated medical terminology, survival assessment and the realities of living with advanced disease states. Discussion and treatment techniques, such as time limited treatment options and focusing on treatment goals rather than treatment modalities hold some hope in helping to determine timely end-of-life decision making.³⁸

What remains central to resolving this dilemma is how to engage Americans in meaningful dialogue about these issues. Such dialogue must be timely, culturally sensitive, sufficiently customized, yet uniformly recognized as grounded in the principles of autonomy and informed consent. It must also include the clinical practitioner in a more holistic discussion of the benefits of treatments and care. It must include a more descriptive and realistic notion of the medical benefits of palliative care. The intersection of those crossroads between the medical and social dimensions of end-of-life decision making is the core of the problem at hand. They are interrelated and codependent.

³⁶ *Annals of Internal Medicine* Article (2007).

³⁷ Hampson and Emanuel, *ibid.*

³⁸ Linda Emanuel personal communication (July 19, 2007).

III. BARRIERS IN THE SOCIAL REALM

A. Social Dimensions of the EOL Decision Making Process

Reducing death to a clinical event inappropriately diminishes the personal and social dimensions of dying. Although dying occurs more often than not within a clinical setting and is nearly always “attended” by a physician, it nevertheless contains a human existential element. Humans are social beings -- all of us live and die within the context of social structures or systems, families of choice or origin, communities, and other groups, even homeless shelters. The hospice movement has made significant strides in recapturing the humanness of the dying process.³⁹

The evolution of advance care planning within the medical world initially developed as a check on or response to advancing technology and treatment, thus focusing more on the interventions themselves than on broader questions of patient preferences or quality of life distinctions that ailing patients may hold. The “good” offered by advances in medical technology was rarely refused until the unintended consequences of interventions left patients in conditions that either they or their surrogates experienced as untenable or overly burdensome. This led to the advance directive tool being used as an instrument to limit or refuse care rather than a guide to what the patient sought in the final stages of illness.

Doctors focus on curing disease and direct their clinical skills at accomplishing that, but social imperatives prevalent in health care are also in play. The principle of autonomy and the value of individual rights combined with obligations of privacy and informed consent fuel an emphasis on the disease process with less attention on the broader quality of life distinctions that the patient may value. Furthermore, the job of the clinician is to consider only the patient’s wishes regarding specific treatments. Much of the time, the advance directive was either overly broad or too narrowly specific to be useful when actual dying occurred.⁴⁰

Additionally, patients often do not share their advance directives with persons outside the medical practitioners who ask about them. This limitation includes the proxy named by the patient. Some family members who are named are reluctant to discuss them with the patient, finding it difficult to “talk about death.” Evidence also points to family members not honoring patient wishes as specified or not predicting well what the

³⁹ Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V (2004). "Family perspectives on end-of-life care at the last place of care." *JAMA*, 291:88-93.

⁴⁰ Jennings B, et al., eds. (2005). "Improving end-of-life care: Why has it been so difficult?" *Special Report*. The Hastings Center. See also: Pearlman RA, Starks H, Cain KC, Cole WG (2005). "Improvements in advance care planning in the Veterans Affairs System: Results of a multifaceted intervention." *Arch Intern Med*, 165:667-74.

patient would have chosen.⁴¹ A number of groups have attempted to offer advance care planning instruments that focus more on these broader social dimensions.⁴²

One of the major barriers for this element of treatment planning is that the job of facilitating this discussion falls to no one within the traditional health care system. Both primary and specialty physicians focus their time on diagnosis, treatment, interventions, procedures and recovery. That is how they are trained and what they are paid to do. They focus on curing disease, and like other professions they pay attention to what they get paid for. For the most part, consumers are left to their own devices.

During the 1990s, when statewide end-of-life coalitions were active in many states, consumers had available abundant information on how to prepare for discussions or complete advance care planning documents, but those grass-root entities have, for the most part, either ceased to be or changed their focus as foundation and public dollars were redirected. Sustainability among those groups has been fragile and short-lived. State and local community coalitions must fundraise locally or seek sponsorship from public entities or health care industry sources. Coalition leaders report that charitable support is a necessary element of their ongoing efforts.⁴³ One recent report calls for a review of the “premature exit” of national funders from supporting the efforts of coalitions working directly with the public.⁴⁴

What remains a curious fact for some in the end-of-life field is the dearth of faith-based groups on a national level to assume a leadership role in addressing this issue among their congregations or members. Perhaps the issue is too private, too diverse, or too divisive. The societal, and for some, cultural bias against speaking about death encourages reticence.⁴⁵

Regardless of the reasons we use to avoid discussions about the end of life, most individuals are ill prepared to hold them. In the end, when we actually enter the final chapters of life most of us find blank pages, searching yet again outside rather than inside for the answers to what to do next. Our surrogates too, remain ill-equipped, exercising decisions based on principles of best interest rather than substituted judgment. Our inertia deprives those we love and those to whom we have entrusted our decision making of anything to guide them. Whether out of ignorance or inaction, we

⁴¹ Shalowitz DL, et al. (March 13, 2006). "The accuracy of surrogate decision-makers: A systematic review." *Archives of Internal Medicine*.

⁴² Sabatino CP (October 2007). *Advance Directives and Advance Care Planning: Legal and Policy Issues*. Commissioned Paper. Available at <http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.htm>.

⁴³ Center for Practical Bioethics (unpublished). *An End-of-Life Coalition and Leadership Survey, Ten Years of Work, 2006* [Preliminary Findings]. Reported at the Take Stock Summit, June 29, 2007.

⁴⁴ Miller S, et al. (July 2007). *Palliative Care/Hospice for Persons with Terminal and/or Chronic Progressive Illness: The Role of State and Federal Policy in Shaping Access and Quality for Persons Receiving Long-Term Care*. A Report Funded by the JEHT Foundation, Center for Gerontology and Health Care Research, Department of Community Health, The Warren Albert Medical School of Brown University.

⁴⁵ That is not to say that successful community based efforts such as Compassion Sabbath® or other individual faith based activities are without merit. But based on a thorough review of the literature there are no known broadly sponsored programs by major institutional religions in the United States within the past 25 years.

leave them with little or nothing to go on other than their notions of best interest. For a people so committed to the principles of autonomy and individual rights, the lack of clarity seems a bit out of character.

B. Clinical and Provider Impacts on EOL Decision Making

As recent as 50 years ago, the location of death for the majority of Americans was the home setting. That changed dramatically over the 30-year period from 1950-1980 so that by the mid-1980s more than half of all deaths occurred in hospitals throughout the United States.⁴⁶ Since its peak in 1983, there has been a slow and gradual decline of deaths in acute care settings, with the uptake occurring in homes and other institutional environments, most notably nursing homes.⁴⁷ Early decline in the number of hospital deaths was attributable to two causes, the care and treatment of specific diseases (most notably cancer and cardiopulmonary disease) and the introduction of Medicare's Prospective Payment System within hospitals, growth in health maintenance organization enrollment, and the introduction of the Medicare hospice benefit during the mid-1980s.⁴⁸ The dramatic decline in inpatient cancer deaths (from 70 percent to 37 percent during the 1980-1998 period) accounted for much of the increase in home deaths during that time, but the increase in nursing home deaths was shared among the other leading causes of death during this period. By 2000, about a quarter of all deaths occurred in homes, about a quarter in nursing facilities, and about four in ten in hospitals. The balance occurred in outpatient facilities or other unspecified locations. The trend in increased numbers of deaths outside hospitals is expected to continue.

A variety of factors help determine the location of death, including level of aggressive treatment of specific diseases and payment mechanisms. Other factors include the existence of an advance directive,⁴⁹ Out-of-Hospital Do Not Resuscitate Orders (OOH/DNR), and enrollment in hospice.⁵⁰ These treatment preferences (arguably in some cases a form of advance directive) impact the limits of treatment similar to DNR orders, which have been shown to diminish the likelihood of hospital admission for any reason.⁵¹ In the case of hospice enrollment in nursing facilities, there may be an echo effect for other residents as one study showed the presence of hospice contributes to the likelihood that other non-hospice nursing home residents will have their care managed in the facility, decreasing the likelihood of frail elderly patients with

⁴⁶ Flory J, et al. (2004). "Place of death: US trends since 1980." *Health Affairs*, 23(3):194-200.

⁴⁷ Flory et al., *ibid*.

⁴⁸ Sager MA, et al. (February 16, 1989). "Changes in the location of death after passage of Medicare's prospective payment system. A national study." *N Engl J Med*, 320(7):433-9.

⁴⁹ Degenholtz HB, et al. (2004). "Brief communication: The relationship between having a living will and dying in place." *Annals of Internal Medicine*, 141:113-117.

⁵⁰ Miller et al., *op cit*.

⁵¹ Miller et al., *op cit*.

end-stage disease being admitted to intensive care for aggressive end-of-life treatment.⁵²

Findings from the Dartmouth Atlas Project⁵³ points to major concerns regarding the care of frail elderly in acute care who die of chronic ailments (the leading cause of death in the United States). In its executive summary, the Dartmouth report states: “[t]he extra spending, resources, physician visits, hospitalizations and diagnostic tests” do not buy longer life or better quality of life.⁵⁴ The report further argues that the growing reliance of technological interventions, and “rescue medicine” imposed on those dying of chronic conditions is a major factor in overall healthcare outcomes. The report concludes, “[w]hen it comes to managing chronic illnesses, greater use of hospitals and physician labor doesn’t result in additional health; the problem is waste.”⁵⁵

Expecting consumers to understand this issue of waste and then to decline acute interventions in the final stages of chronic disease, places the burden of treatment options on the wrong side of the equation. For consumers, illness staging, especially as it advances, is unfamiliar territory. The complexity and fragmentation of the health care specialization process in which as many as eight physicians may attend to a patient dealing with multiple diagnoses does not help the decision making process.⁵⁶ Incentives to aggressively treat are endemic to the current system, both financially and culturally. As an alternative, palliative care programs have only recently been introduced within acute care settings.⁵⁷

As Americans become more familiar with chronic disease management, and as outcome and evidence-based research studies point to more effective treatment modalities, sophistication in palliative care programs will help consumers incorporate new “advances” into their treatment options. This shift in thinking, however, must rely on medical professionals to bridge those emerging options with current interventions, explaining both the benefits of the latter and the limits of the former. These distinctions in quality of life and quality of care blur as patients age, chronic conditions advance, and comorbidities arise.⁵⁸ The challenges in translating these new goals of care may prove as formidable to clinicians as to consumers, and the need to customize them to meet the needs of the individual patient may be an even more daunting task as uncertainty

⁵² Miller et al., op. cit.

⁵³ *The Care of Patients with Severe Chronic Illness: A Report on the Medicare Program by the Dartmouth Atlas Project*. Accessed on July 27, 2007 at http://www.dartmouthatlas.org/atlas/2006_Atlas_Exec_Summary.pdf.

⁵⁴ Dartmouth Atlas, *ibid*.

⁵⁵ Dartmouth Atlas, *ibid*.

⁵⁶ Multiple studies report this finding beginning with SUPPORT.

⁵⁷ Pan CX, Morrison RS, Meier DE, Natale DK, Goldhirsch SL, Kralovec P, Cassel CK (2001). *Journal of Palliative Medicine*. 4(3):315-324.

⁵⁸ Carney J (July 22, 2005). Testimony: National Commission on Quality Long Term Care, Public Hearing. Available at

<http://www.qualitylongtermcarecommission.org/meetings/722PH/pdf/txstmtAMPUBLICCOMMENTcarney07-19-05.pdf>.

increases with advancing disease. But to shirk from the responsibility of reconciling the distinctions is to abandon patients at their greatest time of need.

“Respect for person” obligations tie directly to the principles of autonomy and informed consent. American health care providers are sensitive to these principles first, before any medical procedure occurs. Absent the ability to secure consent (either from the patient or a named proxy) professionals rely on previously stated preferences or their own judgment on what is in the “best interest” of the patient. Historically and even in most cases today, interventions to save the life of the patient or to act to extend life is routinely considered as being in the best interest of the patient. In the past, heroic or extraordinary measures usually proved unsuccessful within a short time frame and the patient died. That is no longer the case.

Always aggressively intervening on behalf of the patient poses new risks for chronically ill frail elderly as noted above,⁵⁹ and also influences a wrinkle that has been added to advanced disease decision making process -- the shared family decision.

The social dimensions of advance care planning are evident in the care of patients with diminishing capacity. While the presumption of capacity obligates clinicians and the named or appointed proxy to assess the ability of the patient to consent to care, a growing number of patients affected by dementia or age-related cognitive impairment have surrendered their decision making to others. This transfer of decision making authority may be prompted by a clinical assessment of capacity or simply the patient’s desire for help in making healthcare decisions of all kinds. It may also be “triggered” by a single (or series of) “spring board” events pointing to the unreliability of the patient’s ability to make consistent decisions.

The requirement in most state statutes that incapacity be determined before any substituted judgment can be made complicates this matter. A proxy’s authority may vary with a patient’s clinical condition, requiring trust in the proxy’s sensitivity to the patient’s condition. However, regardless of how decision making authority is transferred, the phenomenon points to a growing trend in which advance directives are merely advisory, and substituted judgment (i.e., decision making based on patient instruction) is simply unavailable. The increased duties placed on family caregivers especially those looking

⁵⁹ Casarett et al, op. cit. See also: Gillick MR (2000). "Rethinking the role of tube feeding in patients with advanced dementia." *N Engl J Med*, 342:206-10. Shamberger RC, Brennan MF, Goodgame JT Jr, et al. (1984). "A prospective, randomized study of adjuvant parenteral nutrition in the treatment of sarcomas: Results of metabolic and survival studies." *Surgery*, 96:1-13. Popp MB, Fisher RI, Wesley R, Aamodt R, Brennan MF (1981). "A prospective randomized study of adjuvant parenteral nutrition in the treatment of advanced diffuse lymphoma: Influence on survival." *Surgery*, 90:195-203. Daly JM, Weintraub FN, Shou J, Rosato EF, Lucia M (1995). "Enteral nutrition during multimodality therapy in upper gastrointestinal cancer patients." *Ann Surg*, 221:327-38. Finucane TE, Christmas C, Travis K (1999). "Tube feeding in patients with advanced dementia: A review of the evidence." *JAMA*, 282:1365-70. Mitchell SL, Kiely DK, Lipsitz LA (1998). "Does artificial enteral nutrition prolong the survival of institutionalized elders with chewing and swallowing problems?" *J Gerontol A Biol Sci Med Sci*, 53:M207-M213. Meier DE, Ahronheim JC, Morris J, Baskin-Lyons S, Morrison RS (2001). "High short-term mortality in hospitalized patients with advanced dementia: Lack of benefit of tube feeding." *Arch Intern Med*, 161:594-9. McCann RM, Hall WJ, Groth-Juncker A (1994). "Comfort care for terminally ill patients: The appropriate use of nutrition and hydration." *JAMA*, 272:1263-6.

after the oldest old (>85), adds to this complexity since being cared for in similar surroundings by those whom they know and love are the most often cited “health needs” identified by patients as they age.⁶⁰

This trend will only increase over time. It is now estimated that one in three of all patients will be affected by some form of dementia, prior to death.⁶¹ The expanding role of family and proxies in decisions about what is in the best interest of compromised patients along a continuum of care points again to the broader social role of caregivers and a trusted community in end-of-life decision making.

Few question the expanding role of family and trusted loved ones in the care of patients who either lack capacity or may be challenged by diminishing ability. But what happens when there is no such group of trusted persons to rely on to make decisions about quality of care and quality of life for patients in advanced disease states? How do we ensure competent care for persons who have never had the ability to make decisions for themselves? These questions lie beyond the scope of this paper; nevertheless, they point to the broader social dimension of health care decision making.

Furthermore, studies in cultural competency point to the need for health care professionals to understand the perspective of patients when caring for diverse populations in order to provide care valued by the recipient.⁶² People with disabilities and life protection groups are concerned by what they see as a “false choice” in health care.⁶³ If any person’s life is valued less than another, that individual is inherently less likely to receive the same treatment options afforded the higher valued person. The false choice begins when one or more treatment options is removed from the available list of those offered to the more highly valued (i.e., “high functioning”) person. In general, persons with disabilities believe that clinicians will judge their quality of life to be less than optimal. As a result, limits to options are imposed and persons with disabilities are restricted in their access to care, imposing a “false choice” upon the patient.⁶⁴ This argument illustrates the mistrust and disaffection that disabled persons feel regarding their treatment and the risks they perceive in end-of-life decision making.

⁶⁰ AARP (May 2000). *Fixing to Stay: A National Survey of Housing and Home Modification Issues*.

⁶¹ Braynel C, Gao L, Dewey M, Matthews FE. *Investigators Medical Research Council Cognitive Function and Ageing Study, Dementia before Death in Ageing Societies -- The Promise of Prevention and the Reality*.

⁶² Harry B. *Developing Cultural Self-Awareness*. In CASAnet Library: Cultural Competency. Accessed on July 29, 2007 at <http://www.casenet.org/library/culture/culture-aware.htm>.

⁶³ Balch B. National Right to Life Committee comments made at the Take Stock Summit, June 29, 2007.

⁶⁴ Balch, *ibid*.

IV. SOCIAL ENGAGEMENT EFFORTS

A. Coalitions/Advocacy Organizations' Attempts to Address Advance Care Planning

Over the course of the last ten years, state and local community-based coalitions from more than two dozen states sponsored a variety of initiatives to promote advance care planning, primarily devoted to consumers.⁶⁵ Education was focused on encouraging completion of advance care planning documents in compliance with existing state statutes. A few initiatives reported activities aimed at updating legislation or reforms that allowed for a combination of advance health care directives and proxy appointments, but the overwhelming majority of coalitions focused their work on simply getting consumers to complete forms that had been adopted by legislatures during the two previous decades. Reported “success” measures in most instances were identified as numbers of forms distributed or resource materials requested by consumers in public forums, over the phone, or downloaded online.

Their numbers were collectively impressive. The combined request estimates reported by nonprofit groups that sponsored publications and tools to facilitate discussion or promote completion of documents ranged in the millions in the period immediately surrounding Terri Schiavo’s death. This was the only time in which some organizations actually tallied their distribution totals. Participating groups included the National Hospice and Palliative Care Organization⁶⁶ (Caring Connections[®] LIVE campaign), Aging with Dignity⁶⁷ (Five Wishes[®]), the Center for Practical Bioethics⁶⁸ (Caring Conversations[®]) and Sacramento Health Care Decisions⁶⁹ (Finding Your Way[™]).

In addition, public entities such as states’ Office of Attorneys General (e.g., Missouri, Oklahoma, Maryland and Rhode Island) and Departments on Aging (e.g., Tennessee) have been involved in ongoing advance care planning promotions during the past decade. The states’ Attorneys General efforts were supported in large measure by the National Association of Attorneys General,⁷⁰ which formally sponsored a multi-year project on end-of-life health care during 2003 and 2004. More recently, state public health officials have begun efforts to promote advance care planning as well. For the first time in its history, the Centers for Disease Control (CDC) identified “communicating

⁶⁵ CPB Coalition study results, *op. cit.*

⁶⁶ Available at <http://www.caringinfo.org/stateadownload>.

⁶⁷ Available at <http://www.agingwithdignity.org/>.

⁶⁸ Available at <http://www.practicalbioethics.org>.

⁶⁹ Available at <http://www.sachealthdecisions.org/publications.html>.

⁷⁰ See http://www.naag.org/end-of-life_healthcare.php for additional information and reports on the roles of Attorney General including the 2004 report in promoting best practice and the 2003 report on quality.

wishes about end of life” in its 2007 Call to Action, elevating the issue to one of CDC’s current health priorities.⁷¹

Only time will provide a true measure of how those activities benefited health care consumers. Previous efforts to assess actual completion rates of consumer requested documents, point to disappointingly low numbers, ranging from single digits to approximately 25 percent.⁷² However, consumers’ familiarity with the terms “living will,” “advance directive” and “durable power of attorney for health care,” has increased over time.⁷³

More recently, a number of successful statewide efforts to establish specific “health care decisions” days or weeks such as those sponsored by groups in Arizona, California, and Virginia have led to discussions about an effort to adopt a national movement. In May 2007 representatives from nearly two dozen organizations from across the country met via web-hosted simulcast and dial-in conference in Washington, Chicago, and Los Angeles to begin discussions.⁷⁴

Institutional sponsorship has also played an important role in organizational involvement and systemic approaches to promote advance care planning such as that developed by Gunderson Lutheran Medical Center (Respecting Choices®).⁷⁵ The American Bar Association has devoted concerted efforts to educating both the professionals and consumers through tool kit promotion.⁷⁶

One community coalition in San Jose, California, the Coda Alliance, took a more innovative approach to advance care planning promotion through the development of the “Go Wish” Card Game™, modeled after a popular children’s game. The game, designed for both solitaire and multiple players entertains, yet the players are required to think and talk about treatment options and values important in end-of-life decision making.⁷⁷

A number of public and proprietary registries have gained popularity within recent years. This listing compiled in mid-2007 includes both proprietary and public/non-profit sources. Data on the number of persons who register are unavailable or unreported by the host sites.

⁷¹ Centers for Disease Control, op. cit.

⁷² Perkins et al., op. cit.

⁷³ Pew, op. cit.

⁷⁴ *Modern Healthcare Magazine*, Aside and Insides (April 16, 2007).

⁷⁵ Available at <http://www.gundluth.org/eolprograms>.

⁷⁶ Sabatino CP (October 2007). *Advance Directives and Advance Care Planning: Legal and Policy Issues*. Commissioned Paper. Available at: <http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.htm>. See also: <http://www.abanet.org/aging>.

⁷⁷ Available at <http://www.codaalliance.org>.

- The U.S. Living Will Registry available at <http://uslivingwillregistry.com/> is a commercial registry (free) for consumers living in areas where registered partners sponsor listings.
- LifeLedger is a proprietary health care organization offering secured online storage of personal medical information managed by family (caregivers). Includes advance care planning information retrievable via password. Available at <http://www.elderissues.com/index.cfm>.
- Parting Wishes is a privately held company in Ontario, Canada formed in 2000, available at <http://www.partingwishes.com/>.
- My Health Directive is a privately owned company (Healthcare Directive Partners LLC) offering storage and retrieval services available at <http://www.myhealthdirective.com/index.jsp>.
- DocuBank is a service of Advance Choice, Inc., providing electronic document storage and emergency access to health care documents on a subscription basis. Available at http://www.docubank.com/advance_choice/advance_choice.asp.
- America Living Will Registry is available at <http://www.alwr.com>.
- FullCircle Registry is available at <http://www.fullcircleregistry.com>.
- GIFTS Advance Directive Registry of Gateway Files Systems Inc. is available at http://www.giftsdirectives.com/Articles_pps/Giftsbooklet.pdf.
- MedicAlert Foundation is available at <http://www.medicalert.com/Main/AdvanceDirectives.aspx>.

It is difficult to assess the true impact of social marketing efforts devoted to advance care planning during this time frame. Most statewide and community-based end-of-life coalitions reported advance care planning as one of many efforts they supported to improve end-of-life care. Many reported moderate success using measures they had developed, but many others used incidental or process measures rather than true outcomes. Given that no federal funding to support general public education in this particular area took place during this period, a nearly doubling of the numbers of Americans reported to have completed documents may be credible evidence of success. The fact remains however, that only about 30 percent of adult Americans now have documents in place.

B. Factors Contributing to Unresolved Issues in Social Engagement

At the end of 2004 the National Institutes for Health sponsored a conference of experts to clarify key questions regarding the definition of "end of life," and the factors that contribute to improved or worsened outcomes for patients and their families. The clarification was addressed to health care providers, patients and the general public. The conference issued a consensus statement⁷⁸ that underscored what participants perceived to be some of the difficult aspects of the American end-of-life experience. The specific items associated with advance care planning included:

- Circumstances surrounding end of life are poorly understood, leaving many Americans to struggle through this life event.
- Services are fragmented leading to lack of continuity, impeding quality interdisciplinary care.
- Ambiguity surrounding the definition of end of life hinders the development of science, delivery of care, and communications between patients and providers.
- Subgroups of race, ethnicity, culture, gender, age, and disease states experience end-of-life care differently, and these differences remain poorly understood.
- Enhanced communication among patients, families, and providers is crucial to high quality end-of-life care.
- The design of the current Medicare hospice benefit limits the availability of the full range of interventions needed by many persons at the end of life.

Understanding and communication about the end of life remains a central concern in American health care.

Patients and families are subject to mixed messages from and among specialists, primary care physicians and nursing professionals regarding what to expect and how to plan for end of life. Confusion often ensues. Social values of security and protection are difficult to reconcile with the uncertainty of serious illness and advancing disease. Professional reluctance or reticence to speak to patients about disappointing test results also impedes communication as well. Stress heightens mistrust, doubts, and skepticism and increases the risk of isolation. Anger and fear become primary motivators and creators of interference for planning and making decisions, even in the short term. Resources become stretched, and strained relationships get tested repeatedly.

⁷⁸ National Institute for Health. *NIH State-of-the-Science Conference Statement on Improving End-of-Life Care*. 21(3), December 6-8, 2004. Available at <http://consensus.nih.gov/2004/2004EndOfLifeCareSOs024PDF.pdf>.

Quality of life and quality of care distinctions blur as patients progress with advancing disease. What was once thought unendurable may become the norm. End-of-life decision making forces patients and families to face the most deeply held convictions about life's purpose and meaning. These are not easy times. Conflicts abound, internally as well as externally.

In a recent article in the *Annals of Internal Medicine*, Dr. Henry Perkins summarizes many of the shortfalls of advance care planning. He identifies "three faulty assumptions" that he contends proponents of advance directives miss.⁷⁹

- The first assumption is that people actually think about end of life. He cites the difficulty of the subject matter, the lack of courage we have to face it and our predilection to have someone else actually make such decisions.
- The second is that advance directives somehow control future medical care. He argues, "[I]n reality, critical illness thwarts the very purpose of advance directives through the many on-the-spot decisions necessitated by unpredictable, uncertain, and complex circumstances. Thus, advance directives simply promise more control than they can deliver. They provide an unrealistic but comforting "illusion of certainty."
- Finally, he asserts that advance directives actually complicate critical care, though we assume the opposite. Vague directives require deliberation and the ineptness of proxies may actually help confuse as opposed to clarify the issues. He adds that advance directives set standards that are too exacting to meet, and that they imply a good death fulfills a patient's every instruction, which is impossible for families and providers to achieve.

These faulty assumptions must resonate with anyone who has cared for a dying patient. However, even if we reject the notion that specific directives can be instructive or enlightening in terms of specific circumstances, proxy decision makers certainly benefit from insights and conversation with patients regarding their preferences, wishes, goals, values, and types of acceptable treatment outcomes. Proxy decision makers, though reluctant to accept their duties, often find their journey an intimate trek that presents them squarely with profound questions of life's meaning. Many are deeply affected, if not grateful, for this work once it is completed.

⁷⁹ Perkins, op. cit.

V. CONCLUSION

Both the medical and social dimensions need to be incorporated into single courses of action due to the dual nature of advance care planning. Social marketing that focuses solely on the consumer may, in its purest form, inform the process. However, if the last 30 years has taught us nothing else, the clinical considerations tied to advances in medicine and proxy decisions require their integration into the advance care planning process. The complexity of this effort is underscored by this thoughtful reflection:

Here then is the most poignant dilemma faced by caregivers:
not wishing to condemn the worth of people's lives,
yet not wanting to bind them to the rack of their growing misery;
not wishing to say they are better off dead,
yet not wanting always to oppose their going hither.

Under these circumstances,
with no simple formulas for finding the best course of action,
individuals and families must find their way,
case by case and moment to moment,
often with only unattractive options to choose from and knowing that whatever
path they choose, they will feel the weight of the path not chosen.

Eric Cohen & Leon R. Kass
Cast Me Not Off in Old Age

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