

State Initiatives *in* End-of-Life Care

Issue 12, November 2001

Focus: Advance Care Planning—Part 1

Approaches for Patients from Marginalized Groups

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Photographs by Connie Thomson

Left to right: Linda Fountas, mental health consumer, Meredith Hanrahan-Boshes, RN, and Mary Ellen Foti, MD, Area Medical Director, Metro Suburban Area, Massachusetts Department of Mental Health, pilot test the MacCAT-P screening tool to determine capacity to complete a health care proxy. Ms. Fountas completed the screening successfully and later designated two brothers as her proxy and alternate proxy. Experts say advance care planning could benefit many Americans in socially stigmatized and marginalized groups who now have little or no chance to influence their treatment at the end of life. Honoring and expanding existing decisionmaking capacity are the hallmarks of new approaches.

Advance Care Planning: Key Terms and Challenges

Advance care planning—thoughtful conversations and instructions aimed at directing future health care—is now almost a quarter century old in America. It remains one of the most important themes of the movement to improve care of the dying because it concerns our right to choose or refuse treatment that will largely determine the quality of life’s final chapter after we can no longer speak for ourselves (see glossary below).

An outgrowth of our uneasy awareness of medical science’s growing capacity to maintain bodily function in the midst of cognitive devastation, advance care planning enjoys widespread public support. Yet relatively few Americans use accepted advance care planning tools like the living will and medical power of attorney: no more than a quarter of those who could. While completion rates for specific populations such as the elderly and seriously ill may be as high as 40 percent, for many of society’s marginalized groups, rates are thought to be negligible, although data for these groups are totally lacking, say experts.

Issue 12 of *State Initiatives* begins a four-part series exploring challenges and innovations in advance care planning. This issue and a sequel on the guardianship system focus on people in several marginalized groups: very elderly Americans with diminished capacity and no family or advanced directives, those with severe and persistent mental illness, adults with developmental disabilities, inmates in prisons and jails, and people isolated by urban poverty.

Patients from these groups may have difficulty getting the end-of-life treatment they want for a variety of reasons: actual or perceived absence of decisionmaking capacity; lack of surrogates; stigma and discrimination; providers ill-equipped to serve them; fiscal incentives to undertreat; and gaps in the law. Uncertainty about decisionmaking capacity and patient wishes also creates practical and ethical dilemmas for health care professionals; experts say the result may be

too much or too little treatment. Lack of moral fortitude may further complicate difficult treatment decisions. “We allow things to happen to patients from these groups that are our own worst nightmares,” says Don Reynolds, JD, director of special projects at Midwest Bioethics Center, Kansas City, Missouri. “We take the path of least resistance and resuscitate them repeatedly, causing needless suffering, or, we withhold life-sustaining treatment prematurely.”

Demographic as well as moral imperatives are driving new efforts to avert the nightmares Reynolds describes: experts are projecting huge increases in elderly populations with dementias, and already noting the graying of prison populations as well as the rising survival rates for those with developmental disabilities. Promising advance care planning reforms are recognizing and expanding patient decisionmaking capacity when possible, and using ethics-driven teams to advise caregivers when capacity is lacking and surrogates are not available. ■

An Advance Care Planning Glossary

Advance Directives: refers to both the living will and the medical power of attorney and sometimes to less formal instructions such as oral expressions of health care preferences and descriptions of corroborating values and experiences.

Living Will: a legal document used to give instructions about if or when life-support treatments should be withheld or withdrawn; it may also express preferences regarding pain management, desired place of death, and organ donation.

Medical Power of Attorney (Durable Power of Attorney for Health Care): a legal document used to appoint a particular person to make medical decisions for someone who is incapacitated. The person appointed may be called a “surrogate,” “health care proxy,” “attorney-in-fact,” or “healthcare agent.”

Capacity/Incapacity: a clinical assessment of a patient’s ability to make meaningful health care decisions.

“Do-Not-Resuscitate” Order: instructions prepared by a physician directing health care providers to refrain from cardiopulmonary resuscitation (CPR) if patient has no breathing or heart beat.

Source for Key Terms: 2001 Last Acts fact sheets based largely on *Questions and Answers: Advance Directives and End-of-Life Decisions*, a publication of Partnership for Caring (1996).

Innovations in Assessing and Expanding Decisionmaking Capacity

Advance care planning depends on the capacity to make and express meaningful choices about health care treatment. This requires an ability to understand relevant information about options; deliberate about risks, benefits, and consequences; and communicate decisions.

While there is general agreement about the components of capacity, capacity assessment remains more an “art form” than a science, says Charles Sabatino, Assistant Director of the American Bar Association’s Commission On Legal Problems of the Elderly.

In large part the current status of capacity assessment results from a lack of agreed-upon, objective standards for measuring capacity and on inadequate clinician training and monitoring, according to *Guidelines for the Determination of Decisional Incapacity* developed by Midwest Bioethics Center.

Clinicians tend to depend on general mental status assessments, says Mathy Mezey, EdD, RN, FAAN, Director, Hartford Institute for Geriatric Nursing, NYU Division of Nursing. “They assess global capacity but not decision-specific capacity. It is like using an On/Off switch when what you need is a dimmer switch.” This dimmer switch view of capacity is the foundation of several new capacity assessment and advance care planning tools, as well as an emerging movement to uncover and enhance capacity in persons with very significant impairments.

Early pilot tests of these innovations suggest that many such patients are fully capable of completing medical powers of attorney if given the opportunity; still others can engage, with the right support, in comprehensive advance care planning. These findings challenge long-held social prejudices and argue for much greater emphasis on approaches that

preserve patient autonomy and avoid inappropriate treatment when capacity has temporarily receded or been permanently lost.

“Rarely is incapacity absolute; even people with impaired capacity usually possess some ability to comprehend, to communicate, and to form and express a preference.”

Mathy Mezey *et al*, JAGS 48 (2000): 179-187.

Dementia and Decisionmaking

While only four million Americans currently have Alzheimer’s disease and related dementias, by the year 2040, between 7 and 12 million persons will be afflicted and almost half will have advanced disease, say experts.

A new assessment tool, “Guidelines for Determining Capacity to Execute a Health Care Proxy,” promises to give many dementia patients a voice in their end-of-life care. The guidelines test nursing home residents’ ability to recall and paraphrase recent, relevant information; differentiate accurate from inaccurate statements; make a choice; and show that their preferences are consistent. The guidelines are based on techniques developed by Dr. Paul S. Appelbaum and Thomas Grisso of the Law and Psychiatry Program at the University of Massachusetts Medical Center.

The authors recently evaluated the “Guidelines,” using a random sample of 200 New York nursing home residents (Mathy Mezey *et al*, JAGS 48 (2000): 179–187). They found that more than 70 percent of testable residents—three-quarters of whom were cognitively impaired—had sufficient capacity to execute a proxy. Patients with dementias are often inaccurately assumed to be totally incapacitated, say Mezey and her co-investigators. “The results of this research. . . suggest that carefully screened persons with mild, moderate, and even severe dementia are able to demonstrate capacity to make some decisions, including the execution of a health care proxy.”

Continues on page 4



Jay Mangum

Innovations in Assessing and
Expanding Decisionmaking Capacity
continued

**Choice for Those With Serious
Mental Illness**

“End-of-Life Care for Persons With Serious Mental Illness,” a project of the Metro Suburban Area of the Massachusetts Department of Mental Health, may one day make patients’ final treatment preferences an important driver of system policy and practice. Since four of the ten leading causes of disability in the United States are major mental illnesses, such system-based innovations could have a significant impact.

The project has developed and studied two advance care planning assessment instruments: the MacCAT-P which determines competency to select a health care proxy and The Health Care Preferences Questionnaire.

Work on both instruments grew out of researchers’ frustration with the absence of relevant information on the end-of-life wishes of people with severe mental illnesses, and out of a strong conviction that “patients’ competence should matter, not their membership in a stigmatized group,” says Philip Candilis, MD, a co-investigator.

Staff is administering the MacCAT-P to approximately 40 inpatients with psychotic disorders and 40 controls who do not suffer from mental illness. The semi-structured interview probes for all dimensions of capacity, from

understanding what a proxy does to assessing the risks of proxy designation.

The Health Care Preferences Questionnaire (HCPQ), a separate but related research effort, combines direct questions with health crisis scenarios to discover what approximately 150 outpatients know about their current medical health, how much they trust their providers, and what their wishes are regarding proxies, medication, and end-of-life care.

While study findings are not yet available, Mary Ellen Foti, MD, principal investigator, is upbeat. “We have established that our population can participate in end-of-life decisions and that their concerns are no different from anyone else’s. Although the HCPQ scenarios are quite graphic, only a few patients—about one in six—were anxious during their interviews—far fewer than many professionals predicted and probably about the same as one would expect to find in the general population.”

A first round of team-building and training for 44 mental health and hospice care provider organizations has already been completed. Training the

When I Die

Sometimes life is troubling, sometimes I cry
Who will be there when I die,
in and out of hospitals, more and more pills
who will protect me, I am mentally ill,
I am afraid, it’s driving me insane
I want to be comfortable, feel no pain,
My family is the staff, I’m so confused
who will stop them if life sustaining
treatment is used
I can’t be a burden or live by a machine
a tube down my throat, is not so keen,
no one seems to listen, their smiles are fake
I pretend to be sleeping, when I am awake,
why should I wait, the fear I cannot bare
back in the hospital, acute care,
I don’t want to die alone with two hour checks
I want to remain home with dignity
and respect.

C.M.S., Southwick Project

two groups together helps hospice workers learn how to communicate better with psychotic patients, while mental health workers get eye-opening lessons in what death means to their patients.

The project’s three elements form a larger vision: “Once we establish the competencies and preferences of our population,” says Foti, “we want to have a network in place to help implement them in a real life way.” She and her colleagues hope research results will ultimately spark consciousness-raising conversations in the state mental health system.

Outside observers are also hopeful. “This project has the chance of revolutionizing the way we approach advance care planning for people with long-standing mental illness and the

**“If you take your medication and you do therapy,
and you have recovery, with the right support,
you can make a lot of decisions in your life—
like choosing a health care proxy. ”**

Linda Fountas (pictured on cover)

“The group gave me more confidence in myself and in my decisions.”

Ellen Williams, age 60, member, advance care planning group for persons with developmental disabilities

way people with mental illness are cared for when dying,” says Ira Byock, MD, Research Professor of Philosophy, University of Montana (Missoula), and Executive Director of the Promoting Excellence in End-of-Life Care initiative. The project is funded by a grant from The Robert Wood Johnson Foundation through the Promoting Excellence initiative.

Adults with Developmental Disabilities Plan for Life’s End

“The life expectancy of America’s 3.9 million people with developmental disabilities has exploded in the last half of the twentieth century,” says Don Reynolds. “Many of them will witness death, feel grief, and consciously face their own mortality.” (Developmental disabilities include mental retardation, cerebral palsy, autism, and other severe impairments that manifest before age 22.)

This trend, coupled with discrimination, has disability experts worried. “There is a lack of appreciation for their quality of life,” says Joe Young, Deputy Director of the New Jersey Protection and Advocacy, Inc. “The general perception is, ‘This person is a vegetable, why keep them alive?’”

A marriage of Midwest Bioethics Center’s expertise in advance care planning and “Person Centered Planning” as practiced by the Institute for Human Development at the University of Missouri at Kansas City is challenging prevailing myths and prejudices. Adults with developmental disabilities are demonstrating that they can make sound end-of-life treatment decisions with the aid of a group process model supported by a workbook called the “Health Care Preferences Journal,” role playing exercises, and hospital field trips to see patients on life support.

The model involves several steps. Mike McCarthy, Coordinator of Community Education for the Institute, leads individual participants, together with family members and friends, through an initial process to solve problems of daily life, build relationships, and conceptualize a “desired future.” MBC’s Reynolds supervises work on the 16-page “Journal,” helping individual participants and their caregivers think through and record responses to six typical end-of-life scenarios and many questions about personal fears, pleasures, memories of bereavement, attitudes toward life-sustaining treatment, and other end-of-life issues. The group as a whole meets for more general discussion. The process culminates in the completion of advance directives that get reviewed by surrogates and other “allies.” “Learning about advance directives is as much a matter of exposure as it is of cognitive ability,” says McCarthy.

While both McCarthy and Reynolds acknowledge that the model takes considerable time and effort, they are pleased with the results. “We wondered if preferences would be reliable,” says Reynolds. “Yet, participants knew exactly who they wanted to serve as surrogates, and there is a striking universality about the values they express.” The model has been adopted by Special Neighbors, a non-profit organization providing residential services to adults with developmental disabilities in Jackson County, Missouri. ■

Promoting Autonomy for Inmates

1.9 million Americans live in jails and prisons. Most are people of color; 283,800 have serious mental illnesses. With “three-strikes legislation” and determinate sentencing, more inmates are facing death while incarcerated.

Many forces conspire against advance care planning for them: inmates don’t want to believe they will die in prison and mistrust any attempts to limit curative treatment; family members often live far away and are unwilling to serve as surrogates; visitation rules and security practices may hinder compassion; and fully articulated advance care planning policies and practices are rare.

The Volunteers of America G.R.A.C.E. project may help change this. With a grant from The Robert Wood Johnson Foundation’s Promoting Excellence in End-of-Life Care initiative, the project has developed a set of standards for good prison and jail palliative care that strongly encourages advance care planning. Living wills have been the early focus of attention, but the more difficult issue of surrogate designation will also be addressed, says Liz Craig, G.R.A.C.E. project resource coordinator.

Readers interested in reviewing comprehensive advance care planning materials for the correctional setting may contact the Florida Department of Corrections (thomas.david@mail.dc.state.fl.us).



Philippe Cheng

Using Ethics-Driven Teams To Inform Treatment Decisionmaking

Some patients from marginalized groups simply do not have the capacity to complete advanced directives. In these cases, responsible providers attempt to determine patient values and decisionmaking history so that a “substituted judgment” likely to reflect patient wishes can be made. When this is not possible, a “best interest” judgment must be made on the basis of a careful analysis (some experts suggest that “best interest” can be determined by a consensus of thoughtful people). Often these judgment calls require a complex mix of ethical, medical, and legal perspectives that may only be available from ethics-driven consultation teams.

The Metropolitan Washington Bioethics Network

When probate judges of the District of Columbia’s Superior Court face difficult end-of-life decisions arising out of guardian petitions, they can call on the Metropolitan Washington Bioethics Network for court visitor investigations and advisory recommendations. The Network comprises some 40 volunteers who are professionals from a variety of disciplines.

Court consultations are triggered by orders from a probate judge. Any one of the Network’s consultation panels may respond. “The court benefits from appointing them to respond to issues and questions that the court defines,” says Cheryl M. Long, who as

Presiding Judge of the Probate Division of the Superior Court of the District of Columbia helped develop the service. “The court is in the driver’s seat, and no one is being pressured. It’s additional information from a logical, neutral source.”

Cases typically involve wards or prospective wards who are predominantly female, elderly, African-American, infirm and of uncertain capacity. Since many are isolated and on medicaid, and have difficulty getting around, they are especially vulnerable to early nursing home placement, says Joan Lewis, Senior Vice-President of the District of Columbia Hospital Association and a founder of the Network. “This is a whole class of people who’ve never had anyone speak for them—no one who looked at them and said, ‘I wonder what she would have wanted.’”



“The Network has given me more comfort and confidence about making end-of-life decisions. I don’t see why it couldn’t be set up in any jurisdiction. Probate judges really should do this.”

Judge Cheryl M. Long, Superior Court of the District of Columbia

Advising the court on whether wards should stay at home or go to nursing homes is a frequent issue that panels investigate. They also weigh the fitness of guardianship candidates, advise the court about guardians’ performance, and raise questions about excessive reliance on feeding tubes and ventilators for terminally-ill patients, when guardians duck these difficult issues.

Network panels pride themselves on being free of the institutional biases that may hinder in-house ethics teams and on going out into the community to get street-level information. “Sometimes it’s just problems with communication, not big ethical issues,” says Lewis.

Panels also provide incremental education to judges, guardians, and health care providers about what is appropriate end-of-life care for dying patients. “You can get a call at 4:00 a.m. and never have had a case like this before,” says Judge Long. “It’s a pretty awful experience. The Network can give you perspective.”

Montefiore Medical Center’s Ethics Team

The ethics team of Montefiore Medical Center, Bronx, New York, took focus after Nancy Dubler, LLB, director of the hospital’s bioethics division, noticed a flood of patient transfers from nursing homes distressed by the prospect of having gravely ill patients die on their premises. “They were ‘revolving door admissions’—a 95-year-old woman, for example, blind, deaf, ten years post-stroke and without family who was being sent in for amputation after amputation. These are solitary patients for whom no one cares deeply. Since there’s no concerned

“We are making these patients the focus of the best minds we can bring together.”

Nancy Dubler, LLB,
Director of Bioethics, Montefiore Medical Center, Bronx, New York



Bastienne Schmidt

daughter, someone in the system has to say, ‘Wait, guys! What about comfort care?’ Otherwise the system will continue to say, ‘Well, we’ve done this, so why not do that?’ New York case law asks only, ‘What is medically appropriate?’ It’s better to ask, ‘What is ethically appropriate?’”

To answer these questions and to provide the necessary but labor-intensive analysis, Dubler and her colleagues in the bioethics division spearheaded the development of an ethics consultation team with representatives from the division, patient services, risk management, house staff, fellows, primary nursing and social work staffs, and the attending physician. Members of the bioethics division, not physicians, chair the meetings—a departure from common practice.

The team process has replaced an automatic “administrative consent-to-treat,” with nuanced discussions aimed at developing clear goals of care after all medical and ethical bases have been covered, says Dubler. A plan of care is then recorded in the patient’s case notes. “We are committed to dispute resolution and consensus building—reaching common ground within accepted ethical principles,” says Dubler. “We are making these patients the focus of the best minds

we can bring together. A process is the best thing you can do to protect patients from over-treatment and undertreatment.”

Ethics Input for the Florida Department of Corrections

“We’re well beyond the time when

nobody knows what goes on behind prison walls,” says David Thomas, MD, JD, director of health services for the Florida Department of Corrections. “Bioethics committees help make these walls transparent and offer a forum of non-correctional professionals to give different perspectives to issues we may take for granted.” The seven-year old Office of Health Services Bioethics Committee, thought by Thomas to be the only one of its kind, is made up of representatives from the Florida Bioethics Network as well as clergy and medical personnel. It meets quarterly to advise on larger issues such as advance care planning policy and offers regular consultation on difficult cases.

New Jersey’s Disability Ethics Consortium

Gary Stein, JD, MSW, Executive Director of New Jersey Health Decisions, has recently convened and facilitated ethics training for a 25-member Disabilities Ethics Network composed of staff from a broad range of organizations serving people with disabilities and chronic illnesses, together with experts in bioethics and disability law. Stein is now seeking funding to allow the Network to develop a protocol for bedside ethics consultation in northern New Jersey. ■

Directions for Policy and Research

Knowledge about the health care preferences of people from marginalized groups is very limited, and initiatives to enhance their autonomy and improve their end-of-life care—though promising—are new and little tested. Experts suggest the need for new policy initiatives and an expansive research agenda.

There is a broad consensus that advance care planning in all populations needs to be further encouraged and that the importance of surrogacy designation through the medical power of attorney needs greater emphasis. Some believe that policy initiatives may be needed to achieve these aims: putting teeth in The Patient Self-Determination Act or ratcheting up regulatory pressure on large caregiving institutions, for example. There is also agreement on the need for universally understood and accepted standards and practices for clinical capacity assessment—and for such assessments in judicial proceedings.

End-of-life decisionmaking for many people from marginalized groups ends up in the hands of guardians—family members or non-family members appointed by the courts to speak on behalf of incapacitated persons. In a number of states and the District of Columbia, guardians do not have the same legal rights as surrogates to consent to the withholding or withdrawal of life-sustaining treatment. Advocates for change believe that this legal inequality often leads to unnecessary overtreatment of patients with guardians.

The lack of policy-relevant data and research are obvious barriers to progress. First, there is a need to

Continues on page 8

know much more about the groups in question. How many persons from various marginalized groups without living wills and surrogates are there? How many die annually? What are their health care preferences? Could community standards for their end-of-life care be developed? Questions related to proposed policy initiatives also call for study. What are appropriate standards for capacity assessment? What are the best ways to encourage advance care planning?

Ethics-driven teams and committees enjoy broad support, but their fairness and effectiveness have not been studied. "There is a big disconnect between 'unbefriended' populations and the composition of ethics committees," says Joan McIver Gibson, PhD, Director of the Health Sciences Ethics Program at the University of New Mexico. "I'm not sure just formally trained ethics people without roots in the patient's community can

really get a sense of what might be important to the patient."

This may be especially true for patients whose disabilities are not related to aging. Ethics committees should include knowledgeable persons with disabilities, according to Adrienne Asch, Henry R. Luce Professor in Biology, Ethics and the Politics of Human Reproduction, Wellesley College. She and others pose tough questions about ethics committees:

- Are they covering up for doctors?
- Are they properly constituted?
- Can they ask the right questions?
- What instructions do they get?
- How can they avoid dominance by extreme views?
- What is the proper role of people with disabilities on these committees?
- How can information about life with disabilities be best conveyed? ■

Funds for Projects on Surrogacy

Partnership for Caring expects to make future grants as part of its Strengthening the Process of Health Care Agency initiative (funding to be provided by the Fan Fox and Leslie R. Samuels Foundation). Projects that address the needs of culturally diverse populations and socially-isolated groups are of special interest. Applicants must be from New York City or have a collaborative relationship with a New York City-based organization or investigator. To be put on the mailing list for future RFPs, contact Julio Urbina, PhD, MPH, Program Officer, Partnership for Caring: American's Voices for the Dying, 475 Riverside Drive—Room 1852, New York, New York, 10115, Phone: 212-870-2003, Fax: 212-870-2040, E-mail: jurbina@partnershipforcaring.org.

Additional sources for cited statistical data: 1. Karen Kaplan, "Improving the Process of Health Care Agency: Expert Opinion on Needs" (New York: Choice in Dying, 1999). 2. Diane E. Meier, "Voiceless and Vulnerable: Dementia Patients Without Surrogates in an Era of Capitation," *JAGS* 45 (1997):375-377. 3. Christopher J. L. Murray and Alan D. Lopez, eds., *The Global Burden of Disease* (Cambridge: Harvard University Press), 1996. 4. Allen J. Beck and Paige M. Harrison, *Prisoners in 2000*, Bureau of Justice Statistics Bulletin (Washington, D.C.: U.S. Department of Justice), August 2001. 5. Paula M. Ditton, *Mental Health and Treatment of Inmates and Probationers*, Bureau of Justice Statistics Special Report (Washington, D.C.: U.S. Department of Justice), July 1999.

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Information About the Series

"Advance Care Planning—Part 1: Approaches for Patients from Marginalized Groups" is the twelfth in a series of briefs profiling promising new policies and practices in end-of-life care.

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We urge readers to send comments and suggestions regarding this and subsequent briefs via letter or e-mail.



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