

# Results of HAP Literacy Study Reinforce Need for Family Health Care Decision Act

by Lois Steinberg, Pat Banta, and Marsha Hurst

The vast majority of American adults believe it is important to make their own decisions about health care, and wish to control those decisions even if they lose mental capacity at the end of life. Nevertheless, the percent of those having a health care proxy, living will or other legal document that indicates their wishes in case of such incapacity is estimated at between two and 30 percent. Many people believe they do not need such a document, assuming that their family or other loved ones will know their wishes and be able to make these decisions for them. Others may put off completing the form because they don't want to think about their own death.

These ideas about health care proxies may have serious and unforeseen

consequences for New York residents who are unaware that New York is one of only two states that do not allow family members who have not been named as agents in a health care proxy to make health care decisions for an incapacitated relative. In New York State, physicians are legally authorized to make recommendations about providing or withholding care which may or may not be consistent with what the patient would want. Some incapacitated patients are denied appropriate treatment, while others are subjected to burdensome treatments that violate their wishes and values.

The Health Advocacy Program recently conducted a study to determine whether advance directive literacy—the ability to read and understand patients' rights about medical decisions—has an impact on completing a health care proxy. The study was conducted among

210 elderly adults living independently in urban, suburban and rural counties in New York State. In addition to participating in a 25-minute interview about advance directives and end-of-life treatment decisions, respondents completed three types of tests to measure their own health literacy: basic health literacy, document literacy and advance directive literacy. Almost all respondents (87%) scored at the 9th grade level on basic health literacy, indicating they are capable of reading health care material.

The study's findings suggest that New York's law regarding end-of-life treatment decisions is inconsistent with the beliefs and preferences of many older residents. People who think their family will have the right to make treatment decisions for them see no need to sign a health care proxy or other legal document for this purpose. Furthermore, even educated residents with high scores

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## An Unusual Placement Experience

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didn't know quite what to do with me. With Marsha Hurst's encouragement, I proposed the idea of creating a project of my own. The initial idea was for me to interview the first-year interns to find out if they were learning and using the skills taught in the cross-cultural curriculum. After some back and forth, we decided that it would be better to find out directly from the interns what problems they faced in the doctor-patient encounter. The open-ended questions we asked were what general issues make the patient-doctor encounter difficult?; what specific social and cultural issues are difficult?; and is there any training they think would help them deal with these problems?

Armed with a tape recorder and the beeper numbers of all the interns, provided with a desk and phone several days per week, I was pretty much on my own. The participants were given a confidentiality statement to read. They were assured that their names would not be connected to their comments and that I would be the only one transcribing the tapes. I was a little nervous to start, but

soon realized that the interns had plenty to say. The challenge was probing for specific examples when general statements were made. It was slow going because I had to grab them in between patient visits in the clinic, before or after clinic, or up on the floors. After a couple of weeks, they brought in a research assistant to do some of the interviews and that was a big help.

While transcribing the interviews, I realized where I had missed opportunities to probe for more details. But we gathered a lot of good information and my supervisor and his colleagues were very excited about what these interviews revealed. An abstract based upon the material was presented last spring at a meeting of the Society of General Internal Medicine, entitled: "Sociocultural and linguistic barriers in an urban academic outpatient practice: Observations from doctors in training." (Sidebar, page 10.)

My site supervisor and others at the Center for Multicultural and Minority Health were great to work with. They were enthusiastic about their mission and treated me like a colleague. Unfor-

tunately, the supervisor, who was the driving force there, recently left the institution for another position out of town so it is unclear whether this will continue to be a placement site for HAP students.

I went into this internship already interested in cross-cultural issues. The philosophy of the HAP curriculum has influenced how I view cross-cultural problems in the medical encounter. The curriculum teaches us to reject cultural generalizations, and encourages doctors and other medical professionals to consider the social and cultural context of each individual. I have come to realize there is a role for advocates in medical education and the training of more humane doctors, and I hope to make a contribution to that training. ■

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# Results of HAP Literacy Study

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on a basic health literacy test have difficulty understanding the complexity of the New York law.

*Among the study's findings:*

- Most respondents did not have a health care proxy or other advance directive.
- Only one-third of respondents have a health care proxy designating an agent to make health care decisions for them. Thus two out of three seniors have not completed advance directives despite the fact that all of the research sites had conducted programs to educate residents about the importance of having a health care proxy.
- The most important predictors of having an advance directive are attitudes toward end-of-life decision making, living alone and advance directive literacy.
- People trust their families to make health care decisions for them.
- When asked whom they trust the most to make medical decisions for them, the vast majority (79%) mentioned a spouse or other family member.
- Those without a health care proxy were more than twice as likely to mention their spouse.
- Only 17 percent mentioned their physi-

cian.

- Many were confused about advance directive documents and New York State instructions.
- More than half (55%) of respondents have difficulty grasping the facts about NYS law pertaining to end-of-life treatment decisions.
- More than half indicated they believed family decision making was legal in NYS without a designated health care proxy even after reading a statement that the law states otherwise. Another twenty percent were not sure.
- More than a third do not understand that the family cannot make decisions if a non-family member is the designated decision maker.
- Even after reading a definition of the health care proxy, only 28 percent indicated a clear understanding of this document.
- A standardized assessment of document literacy showed that only six percent of respondents understood the NYS instructions for completing a proxy form. ■

*Lois Steinberg, Ph.D., M.P.S. devoted two HAP internships to the Family Health Care*

*Decision Act, the first at NYPIRG and the second as coordinator of a coalition of forty organizations that support passage of this bill in New York State. Together with Pat Banta and Marsha Hurst, Lois wrote the proposal for the literacy study that resulted in project funding from Pfizer, Inc. She is now conducting focus groups on palliative care for FRIA (Friends and Relatives of Institutionalized Aged) and the National Alliance for Caregivers, working under a grant from The Fan Fox & Leslie R. Samuels Foundation.*

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*Marsha Hurst, Ph.D. is Director of the Health Advocacy Program.*

## "Changing Social Policy" Accepted for Publication

Marty Mancuso, director of grassroots advocacy for the New England division of the American Cancer Society, received her M.A. in Health Advocacy in 2000. For her final internship, Marty did a fascinating capstone project on the fight to get adequate insurance reimbursement for ostomy supplies in the state of Connecticut. With two co-authors, Marty wrote a paper on the successful effort, "Changing Social Policy: Grassroots to Legislation," which has been submitted for publication in the *Journal of Wound, Ostomy and Continence Nursing*. The abstract follows.

*Changing Social Policy: Grassroots to Legislation*, by Liz Lemiska, R.N., B.S.N., C.W.O.C.N., Eileen M. McCann, R.N., B.S.N., C.W.O.C.N., and Margaret Mancuso, M.A.

*Never doubt that a small group of thoughtful citizens can change the world: indeed it is the only thing that ever does.*

— Margaret Meade

Healthcare in the United States has evolved into a multimillion-dollar business. As the healthcare industry has grown, so too has government regulation and involvement. As both insurers and patients vie to get the most for their healthcare dollars, federal and state governments attempt to mediate, prevent fraud and abuse, and protect all parties involved. Consumers feel the effects of this "tug of war" in the form of higher co-payments, premiums, out-of-pocket costs and often, denial of coverage. This denial of coverage sparked a very successful grassroots effort to stop commercial insurers in the state of Connecticut from defining ostomy supplies as cosmetic and thus denying reimbursement. A tremendous amount of collaboration between Connecticut Wound Ostomy and Continence (WOC) nurses, state legislators, local American Cancer Society advocates, United Ostomy Association (UOA) chapter members,

and health care providers resulted in a powerful mobilization and support for House Bill (HB) Number (No.)5120, which went beyond defining ostomy supplies as medically necessary, but also set a minimum rate for reimbursement. Social policy changed, improving the lives of Connecticut citizens with an ostomy. While many people fear they do not have the power to make necessary changes in government, this experience proved otherwise. The collaboration that occurred was patient advocacy at its best. This article describes the process that allowed this successful collaboration to take place to hopefully inspire others to get involved with patient advocacy through political involvement. It is the intention of this work to capture the essence of dedication of a grassroots campaign involving a small group of well-organized, highly focused participants who were responsible for changing public health care policy in the state of Connecticut. ■