

Research probes seniors' plans for end-of-life care

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As a brain-damaged woman named Terri Schiavo lived her final days in 2005, her family's bitter feuding imparted a tragic lesson about the importance of specifying one's wishes for end-of-life medical treatment.

Yet, beyond headline-grabbing cases such as Schiavo's, what truly motivates people to plan for medical care at life's end" With record numbers of Americans - the Baby Boom generation - now reaching age 60, we still know surprisingly little about these decisions or the factors that shape them, says University of Wisconsin-Madison sociologist Deborah Carr.

A study by Carr and her Rutgers University colleague Dmitry Khodyakov now offers insight into a critical aspect of end-of-life planning: the choice to appoint a "health care proxy" who will make treatment decisions should a person become incapacitated. Writing in the June issue of the *Journal of Health and Social Behavior*, the researchers report that education, religious attitudes and experience with a loved one's death - especially a painful death - are all powerful influences on this decision.

The findings have important implications for policies and practices designed to encourage people to name a proxy, also known as a "durable power of attorney for health care" (DPAHC). Federal law currently mandates that patients entering a federally funded hospital or clinic be asked whether they have a DPAHC or a document called an advance directive. Medical personnel will also sometimes discuss the issue with

patients; however, they tend to employ abstract arguments or ask patients to imagine their future state of health, says Carr.

Her study suggests instead that having people recall a loved one's death and their feelings about it may be more convincing.

"Our results speak to the power of real world experience," says Carr. "Abstractions, literature, handouts are all great. But in the end, I think people respond more to visceral, emotional factors."

Carr and Khodyakov based their analyses on data from the Wisconsin Longitudinal Study (WLS), a unique 50-year study of more than 10,000 men and women, now in their mid-60s, who graduated from Wisconsin high schools in 1957. In 2003-04, a random subsample of more than 7,000 WLS participants completed phone interviews and mail questionnaires that probed their plans for end-of-life care.

Slightly more than half, or 53 percent, had named a health care proxy, the researchers found. People who had attained some college or a college degree were more likely than high school graduates to have a DPAHC. So were those who believed they could confide in a family member.

Personal beliefs also played a strong role. Conservative Protestants were only 65 percent as likely as Catholics to have executed a DPAHC. And not surprisingly, the odds of naming a proxy were lower for individuals who scored higher on a measure of "fear of death."

The study further examined whom people chose as their DPAHC. The overwhelming majority turned to either a spouse or child. But Carr and Khodyakov also recorded more than 25 different choices, including siblings, co-workers, clergy and physicians. Most of these idiosyncratic responses came from people outside traditional married relationships who had no kids.

"This suggests that when people have innovative family lives, they have to innovate about end-of-life issues, as well, because they can't just knee-jerk go to a spouse or a child," says Carr. With nontraditional families on the rise, she adds, "It's important for practitioners to think about family in an expansive way."

In the future, she hopes to explore another key question: Does end-of-life planning do any good? The assumption now is that having a DPAHC will reduce family suffering and ensure the loved one's wishes are carried out. But the true effectiveness of people's choices has yet to be examined.

"It's possible that bad planning is worse than no planning," says Carr. "Just because you name someone to make decisions for you doesn't mean they can do a good job, and it doesn't mean they have any clue what your preferences are."

That's why it's crucial for people to weigh their options carefully and honestly.

"The fact is, not all people go to their immediate next of kin," says Carr. "So, if you think the best representative for you is someone who's down the chain of command - maybe not a spouse, not a child, but a cousin or a friend - by all means, go with it."

Source: University of Wisconsin-Madison

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