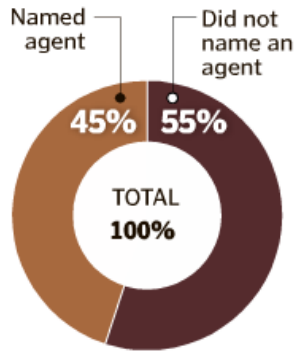


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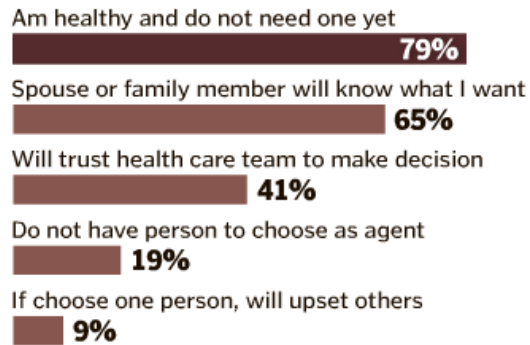
Dying wishes often unspoken, unmet

Respondents who named a health care agent to make decisions when they could not

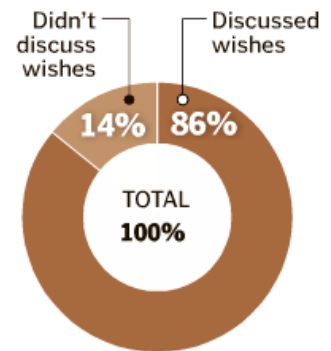


SOURCE: University of Massachusetts Medical School

Reasons for not naming a health care agent



Those with an agent who had discussed their wishes for care



JAMES ABUNDIS/GLOBE STAFF

By Felice J. Freyer

GLOBE STAFF

When hundreds of Massachusetts residents were asked about end-of-life medical care, the results revealed widespread failure by doctors and patients to prepare for illness and death.

Consider: One-third of people with a relative who had died recently said that medical professionals did not fully carry out the dying person's wishes, according to the survey.

The poll results are expected to be released Thursday, at the first meeting of a consortium pledging to ensure that the state's adults get care that fits their preferences. The Massachusetts Coalition for Serious Illness Care consists of 58 health care groups organized by Blue Cross Blue Shield of Massachusetts and leaders in improving end-of-life care.

The coalition's formation signals widening concern about the painful and often unwanted treatments delivered by a medical system that's driven to intervene — as well as a new willingness to tackle a scary and uncomfortable topic.

"This is the right time, and this is the right community in which to do it," said Andrew Dreyfus, the president of Blue Cross.

He likened the coalition's formation to the discussions that led to the landmark Massachusetts law expanding access to health insurance. The coalition wants to work with health care organizations and patients to ensure that people can easily express their desires for care and to guarantee those wishes will be followed.

The telephone survey, of a representative group of 1,851 Massachusetts residents between March 8 and April 3, found that one in five rated their loved one's end-of-life care as fair or poor.

The findings also suggest why the final days can be marked by turmoil and misunderstanding: a lack of planning and communication, by doctors as well as patients.

Eighty-five percent of the respondents said doctors should discuss end-of-life wishes with patients, but only 15 percent had ever had such a discussion with a medical provider. Even among those with a serious illness, only 25 percent had talked about their wishes.

Fifty-five percent had failed to name a representative who would make health care decisions if they were incapacitated.

In one ray of good news, among those who had named such a proxy, 86 percent had discussed their wishes with that person. But barely more than half had told their doctors.

Len Fishman, director of the Gerontology Institute at the University of Massachusetts Boston, learned firsthand the value of such planning when his 86-year-old mother, suffering from dementia and living in a nursing home, developed pneumonia in 1999. When a doctor proposed admitting her to the hospital for exploratory surgery, Fishman initially considered agreeing.

Only when his sister reminded him of their mother's clearly expressed wishes did he realize that hospital admission would be a disastrous betrayal. Instead, his mother spent her last days surrounded by children and grandchildren.

“Everybody is better off when the conversation has happened.”

LEN FISHMAN
Director of the Gerontology Institute at the University of Massachusetts Boston, referring to end-of-life wishes

“She ended up having the most peaceful, beautiful death,” said Fishman, who is also co-founder of the Conversation Project, a group that promotes end-of-life discussions. The Gerontology Institute and the Conversation Project are members of the new coalition.

End-of-life care

Survey of Massachusetts residents reveals failure to plan, disappointment with care.

Experiences talking to health care providers about end-of-life issues

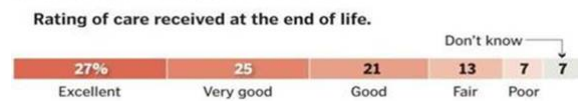
Think doctors should discuss end-of-life issues with patients



Ever had a conversation with health care provider about own end-of-life wishes



Among those with death of loved one in Massachusetts in the past 12 months:



Extent to which loved ones' wishes were followed and honored by health care providers at end of life.



SOURCE: University of Massachusetts Medical School

JAMES ABUNDIS/GLOBE STAF

“Everybody is better off when the conversation has happened.”

“What it drove home to me,” Fishman said, “is that a very natural human reaction, that is reinforced by the medical establishment, is to default to the most conservative thing” — more treatment and intervention. “Everybody is better off when the conversation has happened,” he said.

The survey, commissioned by Blue Cross and conducted by the research firm SSRS and the University of Massachusetts Medical School, illuminates reasons why those conversations don't take place.

Large majorities of respondents said they weren't sick and didn't think it was necessary to talk with their doctors about end-of-life preferences, to designate a health care representative, or to talk to someone other than a health care provider. Many expressed confidence that family members and

health care providers would know what's best.

But often they don't, said Dr. Atul Gawande, the surgeon and writer who is cochairman of the new coalition and author of the best-seller "Being Mortal: Medicine and What Matters in the End." His book describes a woman who was astonished to learn — when she finally asked — that her erudite father would be happy to keep living as long he could eat chocolate ice cream and watch football on television.

"It was the best living will ever: 'As long as I can do these things that matter to me, give me everything — if not, let me go,' " Gawande said.

When people voice their wishes and doctors honor them, Gawande said, patients spend less time in intensive care and more time at home, suffer less at the end of life, and even live longer.

But the coalition is not focusing just on the elderly and the dying. It intends to ensure that all people 18 and older in Massachusetts get the care they want throughout life — because serious illness can strike at any age, and tough health care decisions are often required, even for those who will survive.

Maureen Bisognano, the coalition's cochairwoman and senior fellow at the Institute for Healthcare Improvement, recalled the death of her brother from lymphoma at 17. One day, doctors crowded into his hospital room, talking over him about his next treatment, though everyone knew he

was dying. After they left, one doctor came back to ask Johnny what he wanted.

He wanted to go home.

The doctor carried the boy to his sister's car, and he died a few weeks later at home, surrounded by his parents and eight siblings.

"Once people go through this with a family member, they want to take some action," said Bisognano. ■