

Sharing End-of-Life Care Preferences with Family Members

KEY FINDINGS: Healthcare providers can be a source of knowledge and can help with decision-making about end-of-life care wishes. However, providers need to understand the key differences between patients who do or do not wish to talk about the end-of-life care they would want.

BACKGROUND

Research has described the benefits of people letting others know about the care they would want if they were seriously ill and unable to speak for themselves. While policy makers have promoted advance care planning, concerns persist about whether patients' end-of-life wishes are being honored. This has sparked interest in having older adults talk to family about their end-of-life care wishes. Many people welcome these discussions, but others avoid them. This study explored the experiences and attitudes of those who had discussed their EOL care wishes with family and those who had not.

STUDY METHOD

Participants were solicited from six West Central Florida senior centers and service organizations for a project funded by the Center for Hospice, Palliative Care, and End-of-Life Studies at USF. Thirty-six people participated in focus groups, answering questions about what inhibited and encouraged discussion of one's end-of-life care wishes with family or friends. Meeting recordings were transcribed and coded into categories based on recurrent themes.

RESULTS

Of the 36 participants, 17 had talked to family members about their end-of-life care wishes; 19 had not. Those who had not were younger, less educated, and less likely to have completed

written advance directives compared to those who had engaged in family discussions.

Five themes emerged from the focus groups:

1. Proactive vs. passive/reactive
2. Comfort in talking about death
3. Response to family resistance
4. Knowledge acquired
5. Health care providers role

Proactive-reactive

Those who had discussed their end-of-life care wishes were more proactive in their daily lives and talked about advance care planning as a responsibility. In contrast, participants who had not discussed end-of-life wishes or completed advance directives, seemed less concerned about planning in general.

Quote: *"People who get their ducks in row. I hate people like that. Plan, plan, plan.... Why can't you just have a good time and live life."*

Talking about death

Participants who had talked about their wishes also talked openly about the value of discussing death, particularly with their adult children. Those who had not engaged in end-of-life care discussions felt talking about death was too risky or that their family wouldn't take it well.

Quote: *"You don't talk about it, because if you talk about it, it will happen."*

Response to family resistance

Those who had discussed their care wishes (compared to those who had not) described being forceful with family members in expressing what they wanted.

Quote: “*They certainly would never bring it up themselves....When I force it on them, they listen.*”

Knowledge acquired

Many who had talked about their wishes had learned about advance care planning from previous family experiences.

Quote: “*My mother was diagnosed with lung cancer when she was about 84....They wanted to do surgery and she said, 'No. I've had a good life,' and we took care of her. That was one learning experience.*”

In contrast, those who had not discussed their end-of-life care wishes had had different experiences with loved ones who had died.

Quote: “*(My mother) never did tell me. She had 4th stage and it was incurable. So when I realized what was going on, (she was) too sick...to ask.*”

Healthcare providers role

A majority of participants indicated they were open to healthcare providers being involved in family end-of-life care discussions, as well as

acting as a figures of authority and information within the discussions.

One participant said, “*They should do that just like they prescribe medicine...say something like 'you have an obligation with your family to talk about these things.'*”

A participant who had not shared her end-of-life care wishes said, “*It would have to be a doctor I trusted, and the question I would have is, 'if you can explain (ACP) to me, I'm having problems explaining to my children.'*”

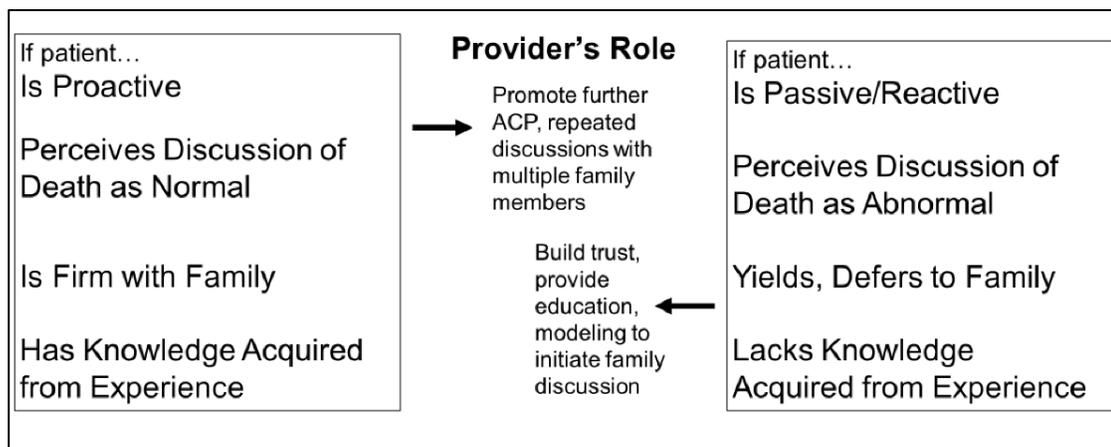
FUTURE IMPLICATIONS

The findings concerning older adults with proactive vs. avoidant communication styles provide a basis for future studies on interpersonal health communication among healthcare providers, patients, and their families.

The model below proposes different approaches for a provider to use to encourage end-of-life care conversations between patients and their family members.

- Amy Haywood

The Dual Approach Model of Health Care Provider Involvement with Family EOL Care Discussions



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