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Having a Conversation About Health Care Wishes and Goals in Vermont

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DR. DONNELY AND DR. DAWSON

Problem and Need

- 90% of people say that talking with their loved ones about end-of-life care is important but only 27% have done so.[1]
- 60% of people say that making sure their family is not burdened by tough decisions is "extremely important" but 56% have no communicated their end of life wishes.[2]
- Approximately 1 in 3 US adults completes any type of advance directive for end-of-life care.[3]
- In the state of Vermont if you are 18 years of age or older there is no default person to make decisions for you (such as a spouse or next of kin) in the event that you would be unable to do so.[4]
- UVMMC General Internal Medicine quality improvement metric this year is to increase rate of some kind of advance directive completion for all patients over the age of 18.
- Dr. Dawson mentioned the need for improved patient understanding of advance care planning in the Thomas Chittenden Health Center community.

Public Health Cost

- 2.6 million people die each year in the United States.[5]
- About 25% of total health care cost to Medicare recipients occurs during the last year of a person's life.[6]
- Many aggressive medical interventions including CPR, intubation, and feeding tube insertion are unwanted by patients, may cause significant morbidity, and result in reduced patient quality of life.
- One of the most common reasons for an ethics consult in Vermont is to resolve the issue of a person being unable to make decisions for themselves, not having a health care agent, and with family members who cannot agree on what care they should receive. This results in a complicated ethical dilemma.[7]

Community Perspective

Cindy Bruzzese, Executive Director of Vermont Ethics Network and Clinical Ethicist

- One of only 5 states that does not have a default decision maker if someone does not appoint someone. This can make things difficult if your family is not in agreement. In other states, see American Bar Association for surrogacy laws.
- The transition from “living will” to breaking up advance care planning documentation into steps of assigning a health care agent, advance directive, and COLST forms has been a major advancement in the way we think about this subject.
- VT Ethics Network is currently working on a series called “get the facts” to educate patients on medical procedures such as CPR, ventilator, feeding tube, and dialysis. They are also working on resources to educate patients and families about navigating care in the ICU unit.
- One big difference that has come with the transition to population based health care is that having advance care discussions is now billable by physicians.

Community Perspective, cont.

Patricia Whitney, Palliative Care Physician at UVMMC and former Family Medicine Provider at Thomas Chittenden Health Center

- Dr. Whitney likes that the Vermont law does not have a default decision-maker. “It gives leeway to talk with people who know the patient best and sometimes that isn’t the default person.”
- Acknowledges that there is no requirement to inform someone that they are your health care agent. This does result in situations where someone is assigned as a health care agent, but they are not aware of this until the person assigning them is acutely ill, leaving no time for a conversation about wishes or goals.
- Identifies the clinician’s role in helping patients navigate health care goals and wishes: “We don’t have an agenda. We are there to help the patient clarify their goals and look at their condition with clear eyes.” She also reminds us that we should not just accept what the patient says for their wishes initially, but also counsel them on their choices.

Intervention and Methodology

- Implementation of educational pamphlet for patients on the subject of having a conversation with family members or friends about end of life wishes and goals to be given to patients in need of advance care planning documents by provider at the time of discussion of this topic with the idea of improving the quality of each patients care plan.
- Primary goal of reinforcing the importance of communication about end of life wishes to ultimately improve the quality of patient care by achieving new levels of understanding between patients and their families and friends about their end of life desires, resulting in fewer ethical dilemmas, lower health care cost on unwanted interventions, and de-stigmatization of end of life conversation among the general population.

Response

- Clinicians at Thomas Chittenden Health Center had an overwhelmingly positive response to this as an aid in helping patients work through the process of advance care planning.
- Some thought that this conversation is one that must be had anyways with the patient, but that this document would serve as a useful reminder to patients after the visit that actually having the conversation was important.
- Response could be quantified by administering a pre- and post-pamphlet questionnaire to patients during the visit and subsequent follow up visits to assess for an improvement in the number of conversations had and improvement in advance care planning

Effectiveness and Limitations

- Pamphlets contain minimal medical language, are easy to read, brief in nature, and are welcoming to patients.
- Accompanying these pamphlets with a provider conversation about the importance of having a conversation about end of life care wishes and goals improves the effectiveness of this adjunct.
- Patient interest in having this conversation, provider use and distribution of these documents are ultimately limiting factors.

Recommendations for future

- Efficacy of this intervention could be improved by an office-wide initiative to distribute them and monitor the degree of improvement in conversation and advance care document completion.
- Use electronic medical record to enhance implementation by tracking distribution and response.
- Improved training of healthcare providers on how to have conversations with patients about having a conversation, advance care planning, and use of accompanying resources such as these pamphlets.
- Continued conversation to normalize discussion of end of life so that it does not remain a taboo subject.

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