What Matters Most to You?

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BACKGROUND

It is important to talk to your family and loved ones about the medical care that you would want or not want at end of life. In a survey from The American Journal of Preventive Medicine, of the 7946 respondents, only 26.3% had an advance directive. The most frequently reported reason for not having one was lack of awareness. As a result we focused on providing education and tools to the elderly population regarding advance care planning.

Integra Community Care Network, an Accountable Care Organization (ACO) within the Rhode Island based Care New England Health System, was founded in May 2014 to serve an attributed population of 130,000 Medicare, Medicare Advantage, Medicaid and Commercial patients. The Integra Complex Care program (CCM) currently serves the top one to five percent of the highest utilizers of health care dollars as well as the most clinically complex patients. The majority of the attributed population is over 65 years of age and lacking advance directives and goals of care for end of life. Though our community involvement, we discovered that most people don’t like to talk about dying, especially their own death. Our patients verbalized that two of the barriers for not completing advance directives are: access to health care education on advance care planning and denial and procrastination.

We aimed to address common barriers to completing advance directives by creating and delivering a curriculum to seniors in a community-based setting by a registered nurse certified in palliative and hospice care. We anticipate that with increased education around having conversations about goals of end of life, we can increase the number of advance directives in the state of Rhode Island, thereby improving care at end of life.

METHODS

Through the identification of the advance care planning needs for this population of patients, Integra CCM launched an educational program on advance directives and advance care planning in the spring of 2017. Outreach was conducted to senior centers located in Rhode Island. Response rates were high and largely positive.

Advance care planning education was provided in the community setting (by a registered nurse certified in palliative and hospice care) at local senior centers across the state. Grant funding from the Geriatric Workforce Enhancement Program (GWEP) and tools from The Conversation Project were able to provide education to select senior populations providing: education on the importance of advance care planning, tools to use with family and physicians on how to express their wishes for care, providing the confidence to start a conversation with their family about what matters most to them concerning their health care now and when they are unable to speak for themselves.

The objectives of the curriculum were to enable participants to:
1) Understand why having conversations about their wishes is important,
2) Have tools to use with family and doctor to express their wishes,
3) Have confidence to start talking to their family about what matters most to them.

Community sessions included a one hour power point presentation, a showing of videos from The Conversation Project, and a question and answer period.

RESULTS

The program has been well received in the senior settings as well as the medical community. At the time of this publication, the program was delivered at five senior centers in Rhode Island. To date, a total of 50 seniors received the “What Matters Most to You?” curriculum. Participants were surveyed at the end of each session to help us evaluate the program. We asked participants to assess the degree to which the learning objectives were met. On a scale of 1 to 5, with 5 being “Outstanding”, participants overwhelmingly rated the presentation as having met the learning objectives.

Participants were also asked to answer three questions about their experience and comfort with advance directives before and after the session. These questions were added to the survey at a later time, therefore we present results from one senior center site. Half of respondents reported that they had not talked to their love ones about their wishes for end of life, 70% of respondents reported that they do not have a living will, and 91% reported that they feel comfortable having “the conversation” with loved ones as a result of the presentation.

Lastly, participants were asked to rate the speaker’s effectiveness and teaching strategy. Those results will be presented elsewhere.

CONCLUSION

The local senior centers embraced our outreach and acknowledged there was a need for education on advance care planning and having goals of care conversations with loved ones. Local seniors were receptive to the presentation, and were often compelled to share their stories involving their experiences with family and friends at end of life. As a result of our community outreach we were able to bring together populations of seniors and through their story sharing and our community outreach; we were able to provide education on the importance of advance care planning. We will continue to evaluate the effectiveness and acceptability of the curriculum for seniors in community settings in Rhode Island. Additional sessions have been scheduled, and outreach will be conducted to all 50 senior centers in Rhode Island.

NEXT STEPS

Our questionnaire reflects that many seniors did not rate or complete what their next steps will be in advance care planning. As a result, we are conducting follow-up visits to each site to assist participants with completion of DPOA (durable power of health care). The follow-up session will be lead by a registered nurse certified in palliative and hospice care and a trained social worker. We will be meeting with seniors one-on-one and assisting them with completing a DPOA and obtaining required signatures. The senior centers will assist participants in providing copies of their DPOA to their family and health care team. During this session, we will also provide additional education on having continued conversations with their family and loved ones on their goals for health care.

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