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Research Briefs

Assessing a Nurse-Led Advance Directive and Advance Care Planning Seminar

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ABSTRACT

Background: Advance directives (AD) and advance care planning (ACP) are critical to making patient-centered end-of-life decisions. Despite their importance, completion rates for AD in the United States remain low at about 18–36%. Lack of education related to AD and not understanding AD have been cited as key reasons for not participating in ACP or completing AD.
Purpose: The purpose of this quasi-experimental pilot study was to assess the effectiveness of a nurse led educational AD seminar that used the *Five Wishes* on attitudes related to AD, AD completion, and participation in ACP conversations.
Methods: A post-test repeated measures design was used.
Results: Of the 86 participants who attended the seminar, most ($n = 71$, 82.6%) found the seminar useful, and 97.7% ($n = 84$) reported that they were likely to complete an AD and participate in ACP conversations with family or friends. Overall attitudes about ADs were high. Older females were more likely to complete AD than their younger male counterparts, and women were more likely than men to have ACP conversations.
Conclusion: The results of this study lend support to the role of nursing-driven community-based educational interventions to improve AD completion and participation in the ACP process.

1. Assessing a Nurse-Led Advance Directive and Advance Care Planning Seminar

End-of-life (EOL) decisions are some of the most important decisions patients and families make. As medical technologies advance and the ability to sustain life increases, these decisions are increasingly complicated (Rogne & McCune, 2014). The Federal Patient Self-Determination Act (PSDA) of 1990 was enacted in response to an increased need for guidance related to EOL decisions. Despite this legislation, advance directive (AD) completion estimates range from 18% to 36% (U.S. Department of Health and Human Services, Assistant Secretary for Planning & Evaluation (DHHS), 2008).

Advance directives, a form of advance care planning (ACP), give patients the ability to share their preferences for future health care decisions (Black, 2014). It is ideal for patients and their surrogates to discuss care preferences before patients become critically ill and/or lose decision-making capacity (Johnson, Zhao, Newby, Granger, & Granger, 2012). Lack of education and not understanding ADs are reasons reported for AD non-completion; limited evidence suggests which types of educational interventions are most beneficial (Durbin, Fish, Bachman, & Smith, 2010; Johnson et al., 2012). Many studies on AD completion involve patients in acute and long-term care (Durbin et al., 2010). Therefore, the need for more information on effective AD education in community-dwelling adults is paramount. The purposes of this pilot study were to explore: (a) the feasibility of a nurse-led community-based educational AD seminar; and (b) attitudes toward AD, AD completion, facilitation of ACP conversations, and individual characteristics of those completing ADs and ACP conversations.

2. Methods

This pilot study used a quasi-experimental design. Participants attended an AD/ACP educational seminar that used *Five Wishes* (Aging with Dignity, 2013), a form of an AD known as a living will. Seminars were conducted in August 2011 in Wicomico County, Maryland and in October 2011 in Sussex County, Delaware. Data collection occurred immediately after the seminar and 1 month later. Data were collected between August 2011 and January 2012.

2.1. Subjects and recruitment

After obtaining institutional review board approval, a convenience sample of community-dwelling, English-speaking adults (≥18 years) was recruited to participate in the study. Participants were recruited using a variety of techniques that included: placing flyers in local businesses and churches, advertisement in local newspapers and

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online community calendars, ads on public radio, email to local senior citizen groups, and through word-of-mouth. Power analysis revealed that a sample size of 78 was needed for a medium effect size with 80% power and an alpha of .05.

2.2. Measures

Attitudes about advance directives were assessed using the Advance Directive Attitude Survey (ADAS) (Nolan & Bruder, 1997). The 16-item ADAS uses a 4-point Likert scale with responses ranging from 1 (strongly disagree) to 4 (strongly agree). Scores may range from 16 to 64; higher scores indicate more favorable attitudes towards AD. Alpha coefficients ranged from .74 to .86 in adult populations (Douglas & Brown, 2002; Nolan & Bruder, 1997). As the researchers were unable to find an existing instrument, a demographic instrument and an AD/ACP survey were developed. The AD/ACP survey included 9 multiple-choice and 3 open-ended questions related to AD completion, ACP conversations, and seminar effectiveness.

2.3. Procedure

Participants were informed about the purpose of the program: to provide education about EOL decisions, AD, ACP, and to collect data for AD/ACP research. Research participation was voluntary and not necessary to attend the seminar. Informed consent was implied through survey completion. A gift card raffle was incentive to complete the surveys.

The nurse-led, 1 and 1/2 hour educational seminar provided participants with information about EOL decisions, rationale for the importance of AD and ACP conversations, AD terminology, and the use of the five wishes as an AD. The seminar included lecture-style presentation, video, step-by-step overview of the five wishes, and time for questions. The local ombudsman, a mental health nurse, and local pastoral care representatives were available to share information and to answer participant questions. Upon completion of the educational seminar, participants had the opportunity to complete the ADAS, demographic instrument, and the AD/ACP survey. One month after the seminar, surveys (ADAS and AD/ACP survey) were mailed to participants who agreed to participate in the follow-up survey.

2.4. Statistical analysis

Descriptive statistics were used to analyze all variables. Analysis was conducted using SPSS version 16. Paired t-tests were used to compare the differences in mean ADAS scores immediately after the intervention and 1 month later. Logistic regression was used to assess if demographic variables predicted AD completion and ACP conversations. Results were considered statistically significant when $p < .05$.

3. Results

3.1. Sample characteristics

Of the 103 who were approached, 86 completed the initial surveys (response rate = 83.5%). Twenty-one of 86 completed the 1-month follow-up (response rate = 24.4%). Participant age ranged from 20–29 to 80–89 years. More than half were female ($n = 57$, 66.3%) and Caucasian ($n = 76$, 88.4%). The majority of the participants reported either completed college education ($n = 27$, 31.4%) or some graduate school education ($n = 28$, 32.6 %). Almost half of the participants had a chronic illness ($n = 39$, 45.3%).

3.2. Response to seminar

The majority of participants ($n = 71$, 82.6%) reported that the seminar was very useful. Participant comments included: “thank you for making this information available, it has been very helpful,” “this class was more informative than anticipated,” and “I had no idea advance directives were about end-of-life.”

3.3. Attitudes about AD

Of the entire group ($n = 86$), mean ADAS scores were 52.62 ($SD = 4.95$). Of the follow-up survey group ($n = 21$), mean ADAS scores were 52.05 ($SD = 3.60$) immediately after the seminar and 54.0 ($SD = 6.47$) 1-month post seminar. There was no significant difference in the follow-up survey group ADAS scores. Post-hoc power analysis revealed that the 1-month post survey sample was too small to detect any differences.

3.4. ACP experiences, AD completion, and ACP conversations

While 40.7% ($n = 35$) of participants had acted as a surrogate decision-maker, most had never made EOL decisions ($n = 59$, 68.6 %). One third of the sample had an AD ($n = 26$, 30.2%), and many had ACP conversations ($n = 59$, 68.6%) prior to the seminar. Logistic regression revealed participants who were older, and female were more likely to have an AD ($p < .05$) and women were more likely than men to have had ACP conversations ($p < .05$) prior to the seminar. After the seminar, 97.7% ($n = 84$) of the sample reported that they were likely to complete an AD and to have ACP conversations. Of the 21 who completed follow-up surveys, seven (33.3%) had an AD, 15 (71.4%) had ACP conversations, and 20 (95.2%) were very likely to complete an AD.

4. Discussion

Addressing AD and ACP in the community prior to the onset of critical illness is an ideal way to allow individuals time to carefully consider EOL wishes. A community-based seminar can facilitate and encourage ACP conversations. Nurse-led AD education can improve patient access to care planning (Detering, Hancock, Reade, & Silvester, 2010). The participants in this group had a positive response to the seminar. Using the five wishes as a guide for AD completion was well received by participants. Having other disciplines (legal, pastoral care, mental health) available helped address participant needs. Using a multi-modal approach may be a productive educational strategy to improve AD completion and ACP (DHHS, 2008; Durbin et al., 2010).

While we did not find significant differences in attitudes about AD 1 month after the seminar, overall AD attitudes were positive. Most stated the intention to complete an AD. Alano et al. (2010) found positive attitudes about AD correlated with AD completion. In this study, older females were more likely to have had an AD, and females were more likely to have had ACP conversations. Past research has shown that older females were more likely to complete an AD (Alano et al., 2010), while younger patients were less likely to complete AD (Johnson et al., 2010). In this study, an overwhelming majority of participants reported that they were likely to complete an AD and engage in ACP conversations. While lack of knowledge has been cited as a major barrier to understanding AD (Johnson et al., 2010), education seems to improve AD completion (Alano et al., 2010; Detering et al., 2010).

There are several limitations to this pilot study. The participants in this study were relatively homogeneous. Pre-seminar ADAS scores would have been helpful. Laws on AD and ACP vary from state to state, Maryland and Delaware have different AD regulations, having an ombudsman present was critical to assisting with these issues. We plan to incorporate what was learned from this study into future studies in other geographic areas that include larger, more diverse groups, specifically addressing the cultural implications of advance care planning.