Initial Efficacy Testing of an Autobiographical Memory Intervention on Advance Care Planning for Patients With Terminal Cancer

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Purpose/Objectives: To test the efficacy of a novel intervention to facilitate advance care planning.

Design: Exploratory, quasiexperimental pilot study with two independent groups.

Setting: A large hospice located in the southwestern United States.

Sample: A convenience sample of 50 participants with terminal cancer enrolled in hospice.

Methods: An autobiographical memory (ABM) intervention used the participants' experiences with cancer and end of life for the purpose of directing advance care planning.

Main Research Variables: Two domains of advance care planning, decision making and communication, were measured in relation to 11 variables: living will, ventilators, oxygen, feeding tube, IV therapy, blood transfusions, antibiotics, designated surrogate, out-of-hospital do-not-resuscitate form, resuscitation, and calling 911.

Findings: The ABM intervention was nonthreatening, short in duration, and easily completed with participants as they recalled, without hesitation, specific personal memories of family and friends who had died and their advance care plans. The Mann–Whitney nonparametric test revealed that participants in the experimental group had a higher average rank than those in the control group for communicating the decision about antibiotics, as well as exhibited a trend toward significance for five other advance care planning variables.

Conclusions: Findings showed that directive ABMs may be effective in influencing the decision making and communication of advance care planning for terminally ill patients with cancer.

Implications for Nursing: The current level of understanding about using the ABM intervention suggests that nurses can initiate an advance care planning conversation using this approach.

About 65%–85% of people with cancer, including those in hospice care, will die without an advance directive or even a discussion about preferences for care (Houben, Spruit, Groenen, Wouters, & Janssen, 2014; Kierner, Hladschik-Kermer, Gartner, & Watzke, 2010). The process of obtaining information on life-sustaining treatments, deciding on the treatment, sharing the decision with others, and completing an advance directive for the end-of-life period is called advance care planning. For more than two decades, research has provided a limited understanding of end-of-life and advance care planning, despite the efforts of several nationally funded initiatives. The need to find a successful intervention to facilitate end-of-life discussions and decision making is paramount, particularly with today's death statistics and as the population ages (National Hospice and Palliative Care Organization [NHPCO], 2017). Eighty-seven percent of all cancers in the United States are diagnosed in individuals aged 50 years or older (American Cancer Society, 2017). No effective evidence-based educational intervention exists to facilitate advance care planning decision making or communication. People seeking care in the U.S. healthcare system must undergo

questioning about advance directives and receive education on advance care planning. Although people are educated about advance care planning, solutions must be found to address the lack of such planning. An autobiographical memory (ABM) approach, which includes problem solving combined with the natural process of reconciliation of one's life when death is unavoidable, is one potential solution. Research findings using ABMs show promise as a means of influencing and directing future decisions and communications for individuals in circumstances other than end of life or advance care planning (Pillemer, 2003). The purpose of this exploratory study was to test the efficacy of a novel ABM intervention to promote advance care planning, including decision making and communication, in older adults with cancer receiving hospice care.

Literature Review
Advance Care Planning

A systematic review by Houben et al. (2014) determined that less than 35% of people have some form of advance directive. Legally binding advance directives vary by name across the United States and are grouped into two categories: (a) the living will, which is also known as a healthcare directive or a medical declaration outlining permissible medical interventions, and (b) the medical power of attorney, which is also called a healthcare proxy that names a surrogate decision maker. Kierner et al. (2010) reported that 85% (n = 92) of 108 people with terminal cancer did not make a decision about an advance directive, citing full trust in their physician (22%), optimism about their prognosis (15%), fear of undertreatment (8%), a need for more information (7%), deferment of the decision to a family member (7%), and mistrust of their physician (4%); in addition, 5% noted other reasons, and 32% responded with "no comment." However, having an advance directive does not resolve the need for communication about these decisions with the designated surrogate, family, friends, and healthcare providers before incapacity occurs (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014; Jones et al., 2011).

Poor communication with patients and the uncertainty of when to hold end-of-life discussions have been identified as the major reasons for insufficient communication about advance care planning (Hebert, Moore, & Rooney, 2011). Disagreement may exist between patients and their families regarding preferences at the end of life (Teno et al., 2004), as well as confusion over the one person who will act as the decision maker (Dizon, Gass, Bandera, Weitzen, & Clark, 2007). Researchers and end-of-life experts (Brinkman-Stoppelenburg et al., 2014) have identified the need for better communication between the patient and his or her family and advise against depending on the written and legally executed advance directives to convey the emotional feelings and reasons of the patient's wishes. It is the difference between the written (legal) language of the advance directive and the verbal reasons for the advance directive. A systematic review by Durbin, Fish, Bachman, and Smith (2010) showed a weak association between an educational intervention and the completion of an advance directive.

Agreement exists in the literature concerning patients' need to be aware of their prognosis to make informed end-of-life decisions. Although physicians often discuss cancer staging and prognosis, many avoid the topic of advance care planning (Barnes et al., 2011; Piers et al., 2013). Social workers provide valuable information and resources on advance care planning that are needed by the patient and his or her family (Black, 2006), and oncology nurses are in an ideal position to have discussions about advance care planning (Cohen & Nirenberg, 2011).

Autobiographical Memory

The use of ABMs has been studied in disciplines other than nursing. A synthesis of pertinent research studies formed the basis of the ABM intervention for this study. ABMs are snapshots in time of unique and highly personal life experiences (Beike, 2007; Pillemer, 2003). Initially identified within the hierarchy of ABM are specific and general memories. Specific memories are theorized to be constructed with precise details (e.g., person, place, time) and are positioned at the bottom of the hierarchy (Kyung, Yanes-Lukins, & Roberts, 2016). At the top of the hierarchy are general memories. General memories fall into two types: Categorical memories describe multiple occurrences of the same event, and extended memories describe events occurring during a period of time (also referred to as lifetime periods by Conway and Bekerian [1987] and Thomsen [2015]). Different levels of hierarchical memories were elicited from participants in the current study based on the wording of questions and participants' cognitive abilities.

A unique function of ABMs is to recall a problem or situation that occurred in the past in order to apply what was learned to the present (or future) issue; this function is called directive (Bluck, 2003). Pillemer (2003) drew attention to the importance of this directive function of ABM with his work on traumatic memories, noting that the role of memory in human adaptation and problem solving using past experiences emphasized the evolutionary significance and practical importance of directive function memories. The directive function of ABM is helpful from the standpoint of not repeating a mistake, changing one's life, or gaining insight into a situation.

A study by Bluck, Dirk, Mackay, and Hux (2008) has provided the most compelling evidence that adaptation occurs after a death-related experience. This study was conducted with 52 hospice volunteers aged 20–86 years and involved comparison of a novice group with a more experienced group; the researchers determined that when hospice volunteers more frequently remembered their real-life experiences with death, they experienced lower levels of death anxiety and avoidance (Bluck et al., 2008). Participants in this study reported that death-related memories of an actual death experience were adaptive or directive in nature when measured by the Thinking About Life Experiences questionnaire (Bluck, Alea, Habermas, & Rubin, 2005). These types of experiences were reported as landmark or momentous events that altered the volunteers' lives from that point forward (Pillemer, 2001).

The use of a detailed script with highly visual and familiar cue words, along with a single facilitator for the intervention, is associated with improved retrieval of ABMs, which provide a means to define and understand present problems and generate solutions (Goddard, Dritschel, & Burton, 1997; Vandermorris, Sheldon, Winocur, & Moscovitch, 2013). Eade et al. (2006) used simple instructions and highly visual cue words to retrieve more specific memories ($p < 0.001$). In a study by Eade et al. (2006), participants retrieved more specific memories when directed to "be specific" with the use of highly visual cue words than participants receiving general instructions.

In the current study, the ABM intervention drew from the participants' memories of the death of a family member or close friend, which was considered a life-changing event on many levels and was described as a turning point in one's life or a momentous event that influenced all future events. The value of the life-altering event is thought to be so important that it will be revisited by the individual at intervals throughout his or her life in memories or narratives told to others (Pillemer, 2001).

ABM research demonstrates that a directive function can serve as a means of adapting and problem solving. The directive function of ABMs has not been used as an intervention at the end of life but has been studied as an adaptive function with hospice volunteers.

Research Questions

This exploratory study examined the initial efficacy of a novel ABM intervention to promote advance care planning among older adults with terminal cancer who were recently enrolled into hospice care:

- To what extent does the ABM intervention increase the likelihood of decision making with respect to the 11 variables of advance care planning and the likelihood of communicating that decision to a surrogate decision maker?

- What are the perceptions of the intervention by participants at study completion?
- What are the observations of the research team associated with the utility and implementation of the ABM intervention (feasibility, utility, and satisfaction)?

Methods
Design

This was a quasiexperimental pilot study approved by the Clinical Cancer Investigations Committee at the Huntsman Cancer Institute and the institutional review board at the University of Utah, both in Salt Lake City, as well as the ethics committee at Houston Hospice in Texas. The quasiexperimental approach was used for several reasons. For instance, doing so avoided the threat of contamination from the hospice team, the members of which were aware of the study, and the threat of compensatory rivalry, because the participants in the ABM intervention would be viewed as getting something desirable that the control group did not. The author agreed with other researchers who identified randomization as a patient burden for hospice and palliative care research, determining that it would be too complex for this group of patients with terminal cancer.

Two independent groups of participants (control and experimental) took part in this study. Participants in phrase 1 (control group) consented and completed the advance care planning survey from January to June 2011, whereas participants in phase 2 (experimental group) consented, participated in the ABM intervention, and completed the advance care planning survey by telephone, with the option of providing feedback on the intervention, from July to December 2011. The principal investigator delivered the intervention and completed a postintervention researcher's observation survey, with detailed field notes for each participant, after the ABM intervention. In addition, the principal investigator tracked numerous procedural outcomes with respect to the study design (e.g., time spent on the consent procedure, time spent using the ABM intervention).

Sample

An a priori power analysis was used to calculate the sample size using G*Power, version 3.1.0. To estimate the sample needed to determine a difference between two independent groups, this study used an alpha of 0.1, a power of 0.8, and a large effect size (Cohen's d) of 0.7. The a priori alpha level was set at 0.1, which was reasonable to determine whether a large enough signal was associated with the intervention, as compared

with the control group, from this feasibility study to warrant further research (Bartlett, Kotrlik, & Higgins, 2001). Based on this analysis, a total of 50 participants were needed, with 25 participants in each group. A convenience sample was recruited from Houston Hospice in Texas.

Setting

Interviews were conducted in the participants' homes where privacy was maintained. The participant's home was identified as any place he or she called home (e.g., single-family dwelling, institution such as a personal care home or nursing home). All participants were enrolled in a Medicare-approved hospice program located in a metropolitan area; however, three of the four home team offices served patients in the suburbs and outlying rural areas. The hospice reported that about 65% of the 2,000 admissions in 2009 were cancer related, which was felt to be a sufficient sample for study enrollment. Common diagnoses were breast cancer, lung cancer, and a variety of gastrointestinal cancers. The average length of survival for individuals with a cancer diagnosis who were enrolled in routine home care at this hospice was 50.1 days, with a median length of survival of 16.5 days.

Eligibility Criteria

To be eligible to participate in this study, individuals had to have terminal cancer and be recently enrolled in hospice, be receiving hospice care in the home, be able to speak and read English, be aged 55 years or older, be cognitively intact (as judged by the admission nurse through pain and neurologic assessment and the dementia Functional Assessment Staging Test), and have a score of 30% or greater on the Palliative Performance Scale (which means the patient is bedbound, unable to do any activity, has evidence of extensive disease, requires total care, has a normal or reduced intake, and has full conciousness or drowsiness, with or without confusion). Exclusion criteria consisted of having a diagnosis of HIV, dementia, Alzheimer disease, or clinical depression in addition to cancer and having an executed living will or a medical power of attorney at the time of consent. A living will and medical power of attorney are the legal documents for advance directives in the state of Texas, where the study was conducted.

Intervention

This study used ABM to facilitate advance care planning in patients with cancer at the end of life. Participants focused on the specific memories of a single episodic event, the lesson learned from that experience, and how these ABMs can help in the participant's present-day situation. The ABM intervention consisted of a highly structured procedure involving open-ended questions and talking points to encourage the participant to recall memories and experiences of family members and close friends who had died of cancer, as well as their memories of advance care planning and end-of-life decisions; they were also asked how these memories had influenced their cancer treatment decisions. Participants were encouraged to tell a story about their family member that was meaningful to them and make a comparison to their current situation (being enrolled in hospice care). The authors expected that participants would talk about a family member's cancer trajectory and the dying experience, as well as how it affected and influenced their own life. These types of events, known as episodic events, are personal in nature, with vivid sensory-perceptual-affective information, and are oriented to a particular person and time (Conway, 2001). For this study, the episodic event was constructed memories from the participants' perspectives.

The script followed a deliberate sequence of nonthreatening questions (e.g., demographics, clinical characteristics) to more sensitive topics (e.g., cancer diagnosis and treatment) and finally to more specific questions about end-of-life decisions. This time enabled the principal investigator to form a bond with participants, as well as understand their ABMs and how the memories influenced their decision making and communications. Verbal and nonverbal prompting (e.g., nodding, using phrases like, "Tell me more") were part of the intervention to encourage ABM details. Strict adherence to the script using the intervention checklist (used so the person who is conducting the interview will do the same thing every time) and recording of observations using postintervention notes were used as data to evaluate the intervention's efficacy.

The ABM intervention involved opening, middle, and closing stages; all were conducted at the first and only home visit (in addition to obtaining study consent). During the closing stage, the principal investigator summarized the session (the memories the participant recalled and the answers given about his or her advance care plans) and arranged for the participant to complete the advance care planning survey. The principal investigator was prepared to refer the participant to a social worker or a chaplain within the hospice for counseling, but no referrals were made.

Procedures

A structured and successful recruitment procedure was followed to screen and enroll participants in the

study. The study design included an initial screening of patients by the principal investigator at the time of their admission to hospice, with a review of the clinical assessment in the electronic health record. As part of the screening procedures, the principal investigator confirmed demographic data and clinical characteristics, including the initial Palliative Performance Scale score. This a valid and reliable prognostic scale that is predictive of the length of survival of terminally ill patients with cancer and severity of illness (Downing et al., 2007; Harrold et al., 2005; Moody & McMillan, 2003). Patients who met the eligibility criteria, as confirmed by the principal investigator, were called by an independent hospice representative and approached for enrollment into the study. If the patient agreed to enroll, the principal investigator then arranged for a home visit to obtain written consent; the process of obtaining consent for this study included a clear description of the intervention. After this visit with the participant, a separate evaluation with a research nurse (advance care planning survey) was completed. The principal investigator kept detailed field notes on the procedures and intervention observations. The research team consisted of the principal investigator, a quality assurance assistant employed by the hospice, and a research nurse.

Instruments

No published instrument exists for measuring the likelihood of advance care planning or the actual decision making and communication process associated with it. The advance care planning survey used for this study was originally constructed based on the following resources:

- The Agency for Healthcare Research and Quality's *Advance Care Planning: Preferences for Care at the End of Life* (Kass-Bartelmes & Hughes, 2003)
- Input of experts in the field of hospice care
- Language used in the Texas Advance Directives Act of 1999
- The National Comprehensive Cancer Network's guidelines on palliative care (Levy et al., 2009)
- NHPCO's 2008 *Facts and Figures: Hospice Care in America* publication

The generic words used on the advance care planning survey include *living will*, *medical power of attorney (name of the surrogate decision maker)*, and *out-of-hospital do-not-resuscitate order*. Content and face validity were established by a group of experts within the Texas hospice; the survey was further refined and validated by the experts on the researcher's dissertation supervisory committee. The advance care planning survey was pretested with three people diagnosed with cancer, and no recommendations for

change were made (Fried et al., 2012). However, the survey had not previously been validated in research.

The 22-item advance care planning survey asked each participant to rate his or her decision making about and communication with a surrogate decision maker for each of the following items: living will, ventilator, oxygen, feeding tube, IV therapy, blood transfusions, antibiotics, surrogate, out-of-hospital do-not-resuscitate form, resuscitation, and calling 911. For example, each participant was asked, "On a scale of 1–6, how likely are you to make a decision about blood transfusions?" This question was followed by, "On a scale of 1–6, how likely are you to communicate that decision to your surrogate decision maker?" The advance care planning survey was scored on a six-point Likert-type scale ranging from 1 (not at all) to 6 (done). The word "done" in the advance care planning survey indicates that the participant had completed the task of decision making or communication. This scale measured the likelihood of making a decision and communicating with others.

A reliability analysis was conducted on the advance care planning survey using SPSS®, version 20.0, on 50 cases to examine the internal consistency. The Cronbach alpha coefficient for the 22 variables was 0.88, and the domains of decision making and communication ranged from 0.8–0.85, respectively. The reported Cronbach alpha coefficients indicate that the advance care planning survey instrument showed good internal consistency. Caution is reserved because this was the initial testing of this instrument.

Two instruments were designed to evaluate the ABM intervention. The first was an open-ended 10-question instrument with an eighth-grade reading level developed to elicit participant feedback regarding the intervention's effectiveness, process, outcome, design, and use. The second was an observation instrument used by the researcher to evaluate participant adherence, receptivity, initiation, prompting, encouragement, flow of memories, overall sense at the end of the ABM intervention, and the amount of time required to complete the ABM intervention. The observation instrument was completed by the principal investigator immediately following the ABM intervention.

Data Analysis

Data were entered into the REDCap database in the College of Nursing at the University of Utah (Harris et al., 2009) for the 165 participants approached for study enrollment, then data were exported to SPSS using the Microsoft Excel® option in REDCap reports. The principal investigator and research nurse verified the accuracy and completeness of the data in REDCap using visual examination and in the Excel spreadsheet

using sorting procedures. Chi-square tests, t tests, and Mann–Whitney tests were used, as appropriate, to compare the control and experimental groups. Descriptive and inferential analyses were used to analyze the data.

TABLE 1. Demographic and Clinical Characteristics by Group

Characteristic	CG (N = 25) n	EG (N = 25) n	χ^2
Age (years)[a]			–
55–64	7	8	
65–75	12	6	
76 or older	6	11	
Comorbidity[b]			5.76
Yes	39	42	
Education			0.74
High school or less	12	9	
Some college or more	13	16	
Ethnicity or race			0.1
Caucasian	18	17	
Other	7	8	
Gender			0.32
Female	10	12	
Male	15	13	
Hospice diagnosis			–
Lung cancer	6	7	
Pancreatic cancer	3	5	
Colon cancer	1	3	
Breast cancer	3	3	
Prostate cancer	3	1	
Ovarian cancer	1	–	
Other	8	6	
Income ($)[c]			3.6
Less than 25,000	7	13	
More than 25,000	17	10	
Insurance			0.005
Medicare	16	11	
Other	9	14	
Length of time from diagnosis to hospice			0.86
One year or less	9	6	
More than one year	16	19	
Marital status			2.01
Married	16	11	
Not married	9	14	
Occupation			2.38
Executive, management, or professional	5	10	
Other	20	15	
PPS score (initial)			1.31
60% or greater	3	6	
50%	9	8	
40%	10	9	
30%	3	2	

[a] t = –0.7
[b] Participants could select more than one comorbidity.
[c] One participant in the CG and two participants in the EG declined to answer the question.
CG—control group; EG—experimental group; PPS—Palliative Performance Status

The data analysis plan included two inferential statistics with an independent sample t test to compare the control group with the experimental group as the initial choice for the advance care planning survey, as well as a Mann–Whitney U test if the data findings were not meeting assumptions of the independent sample t test. Researchers planned for an alpha-level adjustment to correct for an increased risk of a type I error because of the multiple comparisons with the t test or the Mann–Whitney test (Pett, 1997). Using the global scores (a calculated average for all communication items per participant) for communication and decision limited the adjustment (alpha/n = 0.1/2 or 0.05). In addition, using multiple comparison tests for each item in the advance care planning survey (alpha/n = 0.1/22 or 0.0045), researchers determined that an alpha level of 0.0045 would be too restrictive for this feasibility study and that an alpha level of 0.01 would be conservative enough to avoid finding significance where none exists. The alpha was adjusted to 0.01 for this study.

Results
Demographic and Clinical Characteristics

Fifty individuals with terminal cancer completed this study, with 25 in the control group and 25 in the experimental group. Although 115 individuals approached for study recruitment did not participate in the study, demographic and clinical data were obtained from them as part of the screening process. No statistical differences in demographic information were reported with the larger group of 165 patients; of note was a standard residual of 2.3, with the nonconsenters in the experimental group showing an overrepresentation of a 30% Palliative Performance Scale score with 20 observations (as compared to the 12 that were expected). There were more nonconsenters that had Palliative Performance Scale scores of 30%; they were closer to imminent end of life and did not consent.

Demographic data and clinical characteristics and statistical analyses were carried out using chi-square tests, except as indicated in Table 1. No statistically significant differences were noted between the control and experimental groups with respect to age, gender, ethnicity or race, marital status, health insurance, income, level of education, and occupation. Participants in the control group had an average age of 69.4 years (SD = 8.53, range = 55–85 years) compared to an average age of 70.5 years in the experimental group (SD = 10.5, range = 55–88 years). Cardiac, hypertension, and secondary cancers were the most common comorbidities for each group. In addition, the participants' time from diagnosis to hospice enrollment did not differ by group (χ^2 [1, n = 50] = 0.86, p. = 0. 36).

No statistical differences (p > 0.1) were found between participants in the control group and those in the experimental group with respect to Palliative Performance Status score, comorbid conditions, and length of time from diagnosis to hospice enrollment using chi-square statistical analysis. The two most frequent initial Palliative Performance Status scores for each group were 40% or 50% (which indicates that participants were able to get out of bed with some assistance; were unable to work or perform most activities, including their care needs, without assistance; and had normal to reduced intake).

Autobiographical Memory Intervention

The memories shared by the participants described their experiences of family members who had died of cancer and how this had affected their life. One man enrolled in the study shared that his father had been diagnosed with pancreatic cancer at age 55 years and died within three months. He shared his father's cancer journey from diagnosis to chemotherapy to death in the intensive care unit, explaining his distress over the decision to remove life support and his regrets regarding encouraging his father to undergo chemotherapy. When this man was diagnosed at age 57 years with pancreatic cancer, the memories of his father and grandfather, who was diagnosed with pancreatic cancer at age 50 years, were vivid and life-changing, and they helped him to make decisions. "I know I will die from pancreatic cancer like my grandfather and father before me," he said. After one round of chemotherapy, the harrowing side effects prompted his decision to stop treatment and enroll in hospice care. The man's memories of his father connected to life support in the intensive care unit involved something that he did not want to happen to him. He had signed a do-not-resuscitate form, which was displayed in a frame on the mantel at his house. The man spoke openly about his decisions and was comfortable with his friends being present during the conversation between himself and the principal investigator. He had no immediate family members remaining.

Advance Care Planning Survey

All 22 variables on the advance care planning survey were answered by the participants. Eleven variables were related to decision making for advance care planning items, and 11 variables were related to communication. Descriptive statistics showed the distributions of all variables as asymmetrical with negatively skewed results. The scores for decision making were 3–5 and 2–5 for communication.

TABLE 2. Mann–Whitney Results for Advance Care Planning Survey by Group

Variable	CG (N = 25) $\bar{X}$	CG (N = 25) Rank	EG (N = 25) $\bar{X}$	EG (N = 25) Rank	Mann–Whitney U Test MW	Mann–Whitney U Test Z	Mann–Whitney U Test p
Decision making living will	5.12	25.46	5.16	25.54	311.5	−0.023	0.981
Communication living will	5.64	25.08	5.6	25.92	302	−0.304	0.761
Decision making ventilator	5.28	23.4	5.84	27.6	260	−1.597	0.11
Communication ventilator	5.72	23.96	5.96	27.04	274	−1.435	0.151
Decision making oxygen	5.72	25.44	5.72	25.56	311	−0.052	0.959
Communication oxygen	5.96	25.52	5.88	25.48	312	−0.029	0.977
Decision making feeding tube	4.56	22.24	5.36	28.76	231	−1.858	0.063
Communication feeding tube	5.16	22.38	5.94	28.62	234.5	−2.373	0.018
Decision making IV therapy	4.04	21.12	5.04	29.88	203	−2.278	0.023
Communication IV therapy	5.4	23.46	5.76	27.54	261.5	−1.418	0.156
Decision making blood transfusions	4.84	25.92	4.72	25.08	302	−0.224	0.823
Communication blood transfusions	5.36	23	5.76	28	250	−1.676	0.094
Decision making antibiotics	5.2	24.94	5.32	26.06	298.5	−0.323	0.747
Communication antibiotics	5.48	21.44	5.96	29.56	211	−2.827	0.005*
Decision making surrogate	5.92	26.04	5.72	24.96	299	−0.504	0.615
Communication surrogate	5.84	24.5	6	26.5	287.5	−1.429	0.153
Decision making OOHDNR	5.72	26.48	5.52	24.52	288	−0.745	0.456
Communication OOHDNR	5.68	23.5	6	27.5	262.5	−2.062	0.039
Decision making resuscitation	5.6	24.82	5.88	26.18	295.5	−0.547	0.584
Communication resuscitation	5.88	24.98	5.96	26.02	299.5	−0.613	0.54
Decision making calling 911	5.48	24.36	5.8	26.64	284	−0.868	0.386
Communication calling 911	5.6	24.08	5.8	26.92	277	−1.323	0.186

* p < 0.01
CG—control group; EG—experimental group; MW—Mann–Whitney statistical test; OOHDNR—out-of-hospital do-not-resuscitate form
Note. Scores for all variables ranged from 1–6, with 1 indicating "not at all likely," 2 indicating "somewhat unlikely," 3 indicating "neutral," 4 indicating "somewhat likely," 5 indicating "very likely," and 6 indicating "done."

Inspection of the scores indicated skewness, with most of the median scores being 6; as a result, a non-parametric test was used to analyze the data (see Table 2). Using a Mann–Whitney U test with an alpha level of 0.01 to adjust for multiple comparisons, the experimental group, which had received the ABM intervention, had a higher statistically significant likelihood of communicating about the decision for receiving antibiotics (U[48] = 211, Z = –2.83, p = 0.005) compared to the control group. A meaningful trend toward significance was noted with five other variables: making decisions about a feeding tube (U[48] = 231, Z = –1.86, p = 0.063); making decisions about IV therapy (U[48] = 203, Z = –2.28, p = 0.023); and communicating about the decision for a feeding tube (U[48] = 234.5, Z = –2.37, p = 0.018), blood transfusions (U[48] = 250, Z = –1.68, p = 0.094), and an out-of-hospital do-not-resuscitate form (U[48] = 262.5, Z = –2.06, p = 0.039). These results are consistent with findings from Brinkman-Stoppelenburg et al. (2014) regarding improved communication when discussion about advance care plans occurs with the family members.

All participants in the ABM intervention were asked to recall memories of the 11 variables measured on the advance care planning survey. The study did not include a correlation of recalled memories during the ABM intervention with the advance care planning variables. Correlation analysis of the memories of the specific variables of decision making and communication with the results of the advance care planning survey would be useful in a future study to determine the direction and strength of the relationship between the ABM intervention and participants' decision making and communication.

Study criteria excluded candidates with a living will or a surrogate power of attorney. All the participants in this study had previously been educated on an advance directive by the healthcare facility during the workup for cancer and by the hospice team; however, when they enrolled into hospice, they did not have an advance directive. The first question on the advance care planning survey asks about the participant's likelihood of making a decision about a living will; further in the survey is a question about his or her likelihood of making a decision about a surrogate decision maker. The mean scores for the control group and the experimental group were 5.12 and 5.16, respectively, for the likelihood of making a decision about a living will and 5.84 and 6, respectively, for the likelihood of making a decision about the medical power of attorney; these results showed that participants had made decisions about living wills and the medical power of attorney but had not put it in writing. The principal investigator confirmed during the initial visit that participants did not have advance directives during the study. It is unknown if any of the participants signed legal advance directives before they died. Having the advance care planning discussion with the designated surrogate decision maker does not require the execution of advance directives.

Participant Perceptions

This study provided the first evidence that an ABM intervention for advanced care planning can be used with individuals with terminal cancer who are aged

TABLE 3. Participant Evaluation of an ABM Intervention (N = 12)[a]	
Item	**n**
You were asked to recall memories of close family or friends and their healthcare decisions.	
Yes	12
No	–
Was it difficult to talk about healthcare decisions before the memory intervention?	
Yes	–
No	12
Was it easier to talk about healthcare decisions when using the ABM intervention?	
Yes	12
No	–
Did you find it easier to talk to others about your healthcare decisions if you told them about a previous experience?	
Yes	7
No	3
Not sure	2
Did you spend time using memories to think about the future after the session?	
Yes	7
No	2
Not yet	2
No response	1
Would you change this process?	
Yes	–
No	12
Did anything about recalling memories make you uncomfortable?	
Yes	–
No	12
Did you find that other people or family members shared your same memories? Did you share these memories with others?	
Yes	11
No	1
Do you have any suggestions after the research experience?	
Yes	–
No	12
Is there anything else you want us to know?	
Yes	–
No	12

[a] Some participants were too fatigued to answer any additional questions following the advance care planning survey. ABM—autobiographical memory

55 years or older. All participants (N = 25) engaged in the ABM intervention. Most participants (n = 22) responded positively to the question about ABMs of family members or friends with cancer. All participants recalled memories of their family or friends who had died. Participant feedback showed that the ABM intervention was quick and easy to do, caused no harm, and stimulated more discussion with family members about healthcare decisions. These results support the previous findings that autobiographical episodic events are personal (Thomsen, 2015) and that the memories of these events can be used as a means for problem resolution (Vandermorris et al., 2013) when used as a directive function (Bluck, 2003). See Table 3 for participant evaluations of the ABM intervention.

Research Team Observations

The principal investigator's observations corroborated the participants' feedback, as well as previous findings related to the hierarchical specificity of ABM (Conway & Bekerian, 1987; Thomsen, 2015), types of memories (cancer and end of life), prompting of ABM, and study findings. A total of 55 memories were recalled by 25 participants; the average number of memories was 1.95, ranging from 1–4 memories. Thirteen participants recalled specific memories, five recalled general memories, and seven recalled specific and general memories. This approach with participants confirms the value of using detailed instructions for eliciting specific and rich hierarchical memories. See Table 4 for researcher observations of the ABM intervention.

The time between consent and evaluation of the advance care planning survey was concurrent with the original study design and showed no statistical difference (p > 0.1). The time from informed consent and the intervention to the advance care planning survey (p > 0.1) and the time from hospice admission to the advance care planning survey were not significant between the control group and the experimental group, as determined by a chi-square statistic (p > 0.1) (see Table 5).

Discussion

Fifty participants took part in this pilot study, which was conducted during a 12-month period. Statistical analysis showed no difference in participants' demographic and clinical characteristics between independent groups (p > 0.1). The demographics are reflective of the national hospice population statistics in terms of gender, ethnicity or race, and insurance (NHPCO, 2017). The Palliative Performance Scale was useful as a screening tool for including participants who engaged in conversation and decision making while being cognitively intact.

The results of this intervention with participants diagnosed with terminal cancer show preliminary support for using an ABM intervention to facilitate advance care planning discussion and decision making based on the statistical significance. The intervention may be useful for certain aspects of advance care planning, such as making decisions about a feeding tube and IV therapy, as well as communicating about the decision for a feeding tube, blood transfusions, antibiotics, and an out-of-hospital do-not-resuscitate form. The finding that these variables trend toward significance may stem from participants' involvement with decision making during diagnosis and the treatment phase. Some participants seemed genuinely surprised when asked on the advance care planning survey about these decisions. However, questions pertaining to making decisions about a living will, ventilators, oxygen, blood transfusions, antibiotics, surrogate, out-of-hospital do-not-resuscitate form, resuscitation, and calling 911 did not appear to surprise them.

As expected and as found in previous ABM research, participants were able to recall specific memories of family and close friends with cancer who had died by using highly visual cue words (Eade et al.,

TABLE 4. Researcher Observations of an ABM Intervention (N = 25)

Item	n
Did participant adhere to the ABM intervention?	
Yes	25
No	–
Receptivity to the grand tour question	
Positive	22
Neutral	3
Negative	–
Amount of prompting for ABM intervention	
Minimal	17
Moderate	8
Type of prompting for ABM intervention[a]	
No verbal or nonverbal prompting	11
1–2 direct verbal promptings	8
More than 2 direct verbal promptings	4
Nonverbal gesturing	5
Redirected to topic	1
Amount of encouragement needed for the ABM intervention	
Minimal	17
Moderate	8
Were you able to initiate the ABM intervention?	
Yes	25
No	–
Overall sense at the end of the ABM intervention of its implementation	
Positive	17
Neutral	8

[a] Multiple types could be used with one participant.
ABM—autobiographical memory

2006), and they were able to do so without hesitation. Most participants told narratives about their first- or second-degree family members. They were able to provide more details about their experiences when prompted or encouraged, and they completed all steps of the ABM intervention, including answering questions about the items in the advance care planning survey as they pertained to the family member or close friend who had died. All participants adhered to the ABM intervention and were able to spontaneously initiate the ABM intervention. The study results provided preliminary evidence that the ABM intervention was easy to implement and relatively short in duration. According to results of the participant evaluation, the ABM intervention was a nonthreatening and comfortable approach to advance care planning discussions.

Twelve participants agreed to answer questions about the ABM intervention, and seven participants reported using ABMs to think about their future. Although two participants said they hadn't used memories to think about the future and two said they hadn't yet done so, the answers to this question may have changed if more time had passed between the ABM intervention and the evaluation. Three participants said they did not find it easier to talk to others about their healthcare decisions if they used ABMs, and two participants said they were not sure if it helped. According to the field notes, the principal investigator and the research nurse noted that these 12 participants who answered questions about the ABM intervention said they were comfortable with conversations about death and dying prior to the ABM intervention; the two participants responding that they were unsure of whether the intervention had made it easier to talk to others about these decisions said they had not tried to recall memories with their family members.

The ABM intervention did not cause any injury to the participants, as evidenced by participants' feedback and no psychosocial referrals. Participants indicated that the intervention, which was accomplished in one visit, was easy and enjoyable, and the principal investigator reported that most participants had a positive experience at the end of the ABM intervention. The results of the advance care planning survey, triangulated with participants' feedback and researchers' observations, showed the ABM intervention to be a potentially effective means of initiating advance care planning conversations.

Limitations

This study had several limitations. The quasiexperimental approach was designed to compare a control with an experimental group that received the intervention. Rigorous attention paid to the design of the methods (e.g., screening, eligibility criteria, timelines, processes) and to the implementation of the procedures was a means of keeping the groups homogenous for comparison and for generalizing the results.

Although the advance care planning survey was developed from clinical practice standards and input from experts and was tested on people with cancer, the instrument had not been tested for reliability or validity prior to this study. A dichotomous scale with "yes" or "no" responses for advance care planning variables was too restrictive to measure the degree of decision making and communication. The advance care planning survey involves a six-point Likert-type scale with balanced negative and positive responses and is intended to measure how strongly the participant felt about the likelihood of making a decision about the advance care planning variables according to the two domains of decision making and communication.

The negatively skewed data and the mean range of 4–6 on the advance care planning survey for participants in the control and experimental groups may indicate a ceiling effect, which may be attributable to several issues or a combination of these issues. Participants who did not have legal documents for advance directives in place at the time of consent may have made or were in the midst of making decisions and communicating about advance care planning decisions, as indicated by a response of somewhat likely, very likely, or done. The participants knew they were dying and had prior experience with advance care planning questions from the time they were admitted to hospice. They may not have had the time to decide or communicate these plans, or they may have been avoiding the topic altogether. The negatively skewed distribution may be related to the participant's social

TABLE 5. Results of Study Schema

Characteristic	CG (N = 25) $\overline{X}$	EG (N = 25) $\overline{X}$
Time to complete interview or intervention (minutes)[a]	46	43
Time to consent (minutes)	–	5.6
Time from admission to informed consent/intervention (days)	8.7	10
Time from informed consent/intervention to ACP survey (days)	1.3	1.6
Time from admission to ACP survey (days)	10.1	11.7

[a] The time range for the control group interview was 20–90 minutes, and the range for the experimental group intervention was 25–120 minutes.
ACP—advance care planning; CG—control group; EG—experimental group

desirability of responding to the research nurse with agreeable answers. The left shift could be attributable to the instrument design as a Likert-type scale, and the words of the likelihood scale may not be different enough from one another. The negatively skewed advance care planning survey data for participants in the control and experimental groups may have resulted from a combination of factors, including the targeted population's being in hospice with no advance directive, having past experience with the end of life, and knowing that the amount of time to live is limited.

The participant evaluation and researcher observation instruments were specifically designed for this study. Both instruments will require further testing in future research; the researcher observation will require interrater reliability testing when more than one nurse is facilitating the ABM intervention. Generalization is limited with the small sample size (patients with terminal cancer from one hospice) and the quasiexperimental two-group design.

A potential threat to this study's internal validity involves the effect of history (meaning that participants can be influenced during the study period) on the participant during the 12-month study duration. The study was conducted in 2011, and at the end of 2010, as this study was being evaluated by the University of Utah's institutional review board, a copious amount of media attention was being devoted to the Patient Protection and Affordable Care Act, particularly the "death panels" used for rationing healthcare resources and physician reimbursement for end-of-life discussions. The effect that this media coverage had on the study is uncertain because the advance care planning reimbursement had been removed from the legislation, and media attention had diminished prior to initiation of the study. To control for the effects of participation maturation with advance care planning as a second threat to internal validity, the principal investigator visited with the participant immediately after the hospice team had completed its visits.

Recruitment and attrition challenges for research in hospice and palliative care can be contained by using eligibility criteria identifying participants who can complete an intervention study. All participants in the experimental group talked about end-of-life memories, and the author assumed that the eligibility criteria of individuals aged 55 years or older would have at least one death experience and memory of a family member or close friend; however, the principal investigator observed three participants who had only general memories of friends, with few details. Individuals uncomfortable with talking about end-of-life experiences may have chosen not to participate in this study. In future research, the ABM intervention

should be modified to include end-of-life experiences of those other than family members and close friends (such as the death of a well-known celebrity, politician, or businessperson).

Implications for Nursing

Findings from this study suggest that oncology nurses are in a unique position of having a relationship over time, serving as an advocate, and being a trusted member of the healthcare team to interact with people with cancer across the continuum of care about advance care plans. Using a sensitive and compassionate approach to the topic of advance care planning is key to facilitating these conversations. This ABM intervention can be conducted individually with the patient or be inclusive of family and friends. Using this intervention can open the door to more extensive conversations between the patient and his or her family. ABMs used in a directive function have shown promise in influencing the current situation in regard to advance care planning. The significance of the findings in this study has shown the potential utility of this instrument as a baseline of decision making and communication from which clinicians could begin a conversation about advance care planning.

This study explored the efficacy and perceptions of an ABM intervention focused on advance care planning with older adults facing death from cancer. It aimed to provide a reasonable, efficacious intervention to improve decision making and communication of advance care planning for people with a terminal illness that was congruous with the resolution period at the end of life. Oncology educators can provide instruction to novice nurses on how to engage in advance care planning conversations with patients and families using this intervention.

If the advance care planning survey was completed early in the cancer trajectory, participants would then have the luxury of time to make advance care plans and discuss their choices with their oncology

Knowledge Translation

- People with terminal cancer are able to convey their decisions about advance care plans with the autobiographical memory intervention.
- Sharing memories of family and friends who have died was easy and spontaneous for people with terminal cancer when asked.
- Past experiences with cancer and death enable people with terminal cancer to make decisions about their advance care plans.

nurse, oncologist, family, and, most importantly, surrogate decision maker. Acting in concordance with the patient's decisions will improve quality of life and decrease healthcare expenditures.

More research is needed with the ABM intervention—and particularly with a larger and more diverse sample of participants. This study has provided the groundwork for a future randomized clinical trial using an ABM intervention to facilitate advance care planning for people with cancer and other life-limiting diagnoses. The advance care planning survey requires further evaluation of its reliability and validity with a large group of people with cancer.

Conclusion

This pilot study provided evidence that directive ABMs influenced the decision making and communication regarding advance care planning for a small sample of terminally ill participants with cancer. The results indicated that an ABM intervention was initiated with minimal prompting or encouragement and inflicted no apparent harm on intervention participants. The ABM intervention approach to advance care planning stimulated communication between the study participant and his or her family after the intervention ended. However, an ABM intervention is not a replacement for advance care planning education.

The ABM intervention was nonthreatening, easy to do with the participants (they engaged in it without hesitation), revealed highly personal information about family members and friends who had died of cancer, and was completed in less than an hour. When people have the knowledge of advance care planning but are not ready to make decisions or reconcile these wishes, ABMs of family members and close friends provide a safe context for people to think about advance care planning (rather than them think specifically about themselves). Additional research with a larger sample and with participants who are earlier on in the disease trajectory needs to be done to establish ABM as an effective intervention.

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