ABSTRACT

EXAMINING ADVANCE CARE PLANNING ACTIONS AMONG COMMUNITY DWELLING OLDER ADULTS

by Candace E. Burch

Advance care planning (ACP) is defined as having an advance directive, durable power of attorney, or having discussed preferences for end of life with a next of kin. ACP has been studied in populations that are institutionalized or terminally ill and near end of life, with the goal of cost savings for end of life care. Limited research has been done with community dwelling older adults. This exploratory study used the health belief model to assess local, community dwelling older adults’ sociodemographic characteristics, perceived benefits of ACP, perceived barriers to ACP, health values at end of life, and preventive health actions, and the reasons participants did or did not engage in ACP. Results reveal that a majority of participants had heard of each of the five ACP documents, but completion rates varied. Sources of information were most commonly attorneys, family members, and doctors. Participants most frequently indicated their completion of an ACP document was to ease the burden on their family, and most frequently indicated their lack of completion was because they hadn’t gotten around to it yet. Findings have implications for educating individuals about how they can control their own death experience through their ACP documents.
This Thesis titled

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by

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Acknowledgements

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Background and Literature Review

Importance of Advance Care Planning

Advance care planning (ACP) is defined as having an advance directive, durable power of attorney, or having discussed preferences for end of life with a next of kin (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013). It is important for people of all ages to take part in ACP, especially with the increasing number of self-reported chronic conditions (Paez, Zhao, & Hwang, 2009). Bischoff et al. (2013) revealed that end of life care tends to be associated with the preferences expressed in individuals’ advance directives. Additionally, Detering, Hancock, Reade, and Silvester (2010) found that the end of life wishes were known and respected for 86% of participants’ who completed ACP, compared to only 30% of those who did not complete ACP. Thus, there is evidence that advance care planning increases the likelihood that individual’s end of life care wishes will be met.

Advance care planning is important because it helps individuals determine and document their end of life preferences (e.g., the type of care they prefer, the location in which they prefer the care be delivered). By stating their end of life preferences, unwanted care and treatment will be reduced. Although not a focus of this study, cost saving is also associated with advance care planning. The ultimate goal is to honor one’s wishes about his/her end of life care and treatment.

Community Dwelling Adults Advance Care Planning

Research on ACP in the U.S. is limited, and there is little consistency across studies with respect to study approaches and samples. Khosla, Curl, and Washington (2015) hypothesized greater SES led to more access to resources and higher completion of ACP. They used data from the Health and Retirement Study (HRS) to investigate trends in ACP from 2002 to 2010 to test their hypothesis. The sample represented community dwelling adults that included 6,052 proxies of deceased individuals. Results revealed an increase in ACP completion over the years (about an12% increase for discussions and written instructions and 23% increase for identifying a legal decision maker), but limited support that SES was a predictor of ACP completion. The results also suggest that the most successful approach to increasing ACP completion was for health care providers to have multiple conversations with patients and attempt to make the subject more comfortable.

Havens (2000) examined community dwelling adults in Vermont to explore differences in those who have and have not executed advance directive (ADs), another term for ACP.
Results of the mailed survey revealed that those who executed ADs were older; had had more conversations with a doctor about ADs, were more knowledgeable about ADs, and had more personal experiences with illness or death of a loved one; and were more religious. Preferences for autonomy and support, death anxiety, concern for family and their exposure to media reports about use of ADs did not distinguish those who had executed ADs from those who had not.

Braun, Onaka, and Horiuchi (2001) investigated ADs completion rates and end of life (EoL) preferences in Hawaii. They examined four questions about ADs and assisted death that were added to the 1998 Behavioral Risk Factor Surveillance System (BRFSS) survey and three questions regarding death and dying that were added to the 1999 OmniTrak survey. The BRFSS survey sample consisted of 2,153 adults and the OmniTrak survey sample consisted of 700 adults. Results revealed that 29% of Hawaii residents had a living will and 22% had a health care power of attorney (HCPOA), with AD completion rates increasing with age. For example, only 5% of those aged 18-24 had completed a living will and 6% a health care power of attorney compared to 62% and 49% of those aged 65 and above, respectively.

Jackson, Rolnick, Asche, and Heinrich (2009) investigated attitudes toward, experiences with, and preferences about ACP among members of a managed care organization. Results revealed that completion rates increased with age (age 20-29: 0% completion and age 60 and above: more than 50% completion). Moreover, of those with ACP completed, 44% reported discussing their wishes with someone. Many participants (62%) thought it was up to them to start the conversation with their doctor; however, 70% reported they would be comfortable if the doctor initiated the conversation. The results also indicate that having a personal experience with someone dying did not significantly increase the likelihood of completing ACP.

Outpatients at a hospital and members of the general public were recruited for a 1991 study (Emanuel, Barry, Stoeckle, Ettelson, & Emanuel) to investigate ACP, ACP-related attitudes, and barriers to completing ACP. Results revealed that 93% of the patients and 89% of the general public wanted to complete some sort of ACP; however, only 15% of the patients and 18% of the general public has actually done so. The most common barriers cited by participants were the expectation that a doctor should start the conversation and feeling like they were too young or too healthy for ACP. Schickedanz, Schillinger, Landefeld, Knight, Williams, and Sudore (2009) investigated barriers to completing ACP among participants recruited from a general medicine clinic in San Francisco County. Their interviews with 143 participants
revealed six main barriers: 1) perceiving ACP as irrelevant (i.e., too healthy), 2) personal barriers (i.e., emotional issues or work responsibilities), 3) relationship concerns (i.e., doesn’t have a good relationship with family or doesn’t want them involved), 4) information needs (i.e., doesn’t know what their choices are), 5) health encounter time constraints (i.e., my doctor is too busy), and 6) problems with ACP (i.e., needs help understanding forms).

Participating in ACP helps ensure that one’s end of life wishes are known and increases the likelihood that those wishes will be honored. Despite this, evidence suggests that few individuals have actually completed ACP. Data from 7,946 community survey respondents revealed that only 26.3% had completed ACP (Rao et al., 2014). These researchers also found that the most common reason for not having completed ACP is lack of awareness.

**Physician Orders for Life Sustaining Treatment versus Traditional Practices**

Hickman, Nelson, Perrin, Moss, Hammes, and Tolle (2010) investigated attitudes of community dwelling older adults on physician orders for life sustaining treatment (POLST) versus traditional practices (i.e., having a DNR, CPR status, and/or living will). POLST is a program that was designed for persons with progressive chronic illness or frailty (Hickman et al., 2010). POLST is thought to be more informative in clinical settings as it expands on the DNR/CPR statuses to give more in-depth information on treatment preferences such as antibiotic use and artificial hydration/nutrition. Hickman et al. (2010) found a series of differences between patients with POLST versus traditional practices, including patients with POLST were less likely to get care they did not actually want. Additional research comparing nursing facility residents who have POLST versus nursing facility residents with only traditional practices indicate that traditional practices generally do not provide details on the treatments wanted or not wanted (Alano et al., 2010; Hickman et al., 2010).

**Limitations of Existing Research**

There are several limitations associated with the existing research on ACP. Despite the examples of several research projects described above, the majority of research on ACP relies on samples of ill and/or frail older adults who were recruited from patient populations or residents of long-term care facilities (e.g., Catt, Blanchard, Addington-Hall, Zis, Blizard, & King, 2005; Rao et al., 2014; Seymour et al., 2004; Kwak & Salmon, 2007; Hickman et al., 2010). Thus there is relatively little information on how many community dwelling older adults have engaged in the process of ACP and whether they have shared their ACP with family and/or physicians. A
The second limitation is that the focus of much of the research has been on the cost savings associated with end of life care, and, as a result, we have limited research on advance care planning among community dwelling older adults who are considered to be relatively healthy. Third, previous research has not explored where individuals get information about ACP (e.g., formal or informal network members), and their reasons for engaging/not engaging in ACP (e.g., personal values, easing the burden on family, not having sufficient time).

The Health Belief Model

The health belief model serves as a conceptual framework for this research, the purpose of which is to explore the association of sociodemographic characteristics with ACP among community dwelling older adults. The health belief model was developed in the 1950s as a way to explain health actions (Janz & Becker, 1984). According to Rosenstock (1974), several assumptions need to be made in order for an individual to take a particular action. First, he or she needs to believe that they are personally susceptible to a particular outcome. Second, he or she must believe that the occurrence of the outcome would have potentially serious consequences (i.e., pain or suffering). The third assumption is that taking a recommended action would be beneficial to them and help them avoid the relevant outcome.

The health belief model has five main components to explain or predict behaviors: 1) perceived severity, 2) perceived susceptibility, 3) perceived benefits and barriers, 4) perceived threat, and 5) cues to action. Taken together, these components indicate the likelihood that an individual will perform a particular action (see Figure 1).

Figure 1. Health Belief Model

According to Janz and Becker (1984) perceived severity refers to the individual’s belief about the seriousness or severity of an outcome he/she may contract or the consequences if left untreated. This construct also captures medical consequences such as disability or pain, and social consequences such as effects on family life or social relations (Janz & Becker, 1984).
Perceived susceptibility refers to how vulnerable an individual might feel to an outcome or his/her perception of the risk of experiencing a outcome (Janz & Becker, 1984; Rosenstock, 1974). Together, the individual’s perception of susceptibility and severity of the outcome determine perceived threat of their condition. If the threat is high enough, he/she will be more likely to take a recommended course of action (Janz & Becker, 1984). Perceived benefits refer to an individual believing action will lower the threat of an outcome and taking action to prevent or treat an outcome. (Rosenstock, 1974). The benefit must outweigh the effort it takes to complete the action (Janz & Becker, 1984). Perceived barriers are considered to be the negative aspects of an action; these could be the cost of an action or the time consuming nature of an action (Janz & Becker, 1984). Cues to action serve as a stimulus for decision making and considering the benefits and barriers to a health action (Janz & Becker, 1984). Cues to action can vary in intensity and can be internal, such as bodily symptoms, or external, such as a reminder from a health care provider (Rosenstock, 1974). If an individual believes that he/she is highly susceptible, a cue of very low intensity may be enough to cause the individual to take action (Rosenstock, 1974). All of these components of the health belief model determine whether an individual takes part in a preventive health action.

In this investigation, the outcome of interest is experiencing a bad death. A bad death can be described as one that is not consistent with an individual’s preferences regarding the type of care that is provided, where and by whom the care is provided, and all other aspects of the death process. According to the health belief mode, if one believes he/she is at risk for a bad death experience, he/she will be more likely to engage in ACP actions to decrease the chances of a bad death. When considering the perceived benefits of a health action, one will assess how useful this new behavior will be in decreasing the chances of a bad death (e.g., receiving unwanted treatment or being kept on life support). When thinking about ACP, a barrier might be that one finds it difficult to think about death and how they want to die. The cues to action in ACP might be the death of a family member, or learning about ACP documents from a doctor or a friend for the first time. All of these pieces lead to the preventive health action, or a health behavior change. In the case of ACP, the action would be engaging in ACP to avoid a bad death.

Purpose of the Research and Research Questions

The research applies three main components of the health belief model: 1) benefits 2) barriers, and 3) preventive health actions. Benefits and barriers affect whether an individual will
participate in a preventive health action. Although not a specific component of the health belief model, health values were included in the research because they can inform both benefits and barriers, two key components of the model. In this exploratory study, I assessed local, community dwelling older adults’ perceived benefits of ACP, perceived barriers to ACP, health values at end of life, and use of ACP tools. Additionally, basic sociodemographic characteristics were collected, which have been included in previous research.

This research fills a gap in existing research by investigating a local, community dwelling sample of relatively healthy older adults. Additionally, this research will contribute by revealing the association between sociodemographic characteristics of community dwelling older adults and the reasons they do or do not engage in ACP. The following research questions guided this research.

1) To what extent are community dwelling older adults aware of specific ACP documents?
2) Where do community dwelling older adults learn about ACP documents?
3) To what extent do community dwelling older adults engage in specific ACP?
4) What reasons do community dwelling older adults give for engaging and not engaging in ACP?
5) What psychosocial and sociodemographic factors are associated with ACP?

Understanding ACP use on a local level is important to investigate because it can help local providers determine what type of education and assistance (cues to action) may be needed to increase the number of adults engaging in ACP (preventive health action. The aim of this study is to understand relatively healthy, local community dwelling older adults’ sociodemographic characteristics associated with ACP behaviors, what ACP documents they have completed, where they heard about the document and the reasons why they did or did not engage in ACP.
Methods

Participant Recruitment

Data for this exploratory study were collected between November 2015 and January 2016 in Oxford, Ohio, and surrounding areas. After obtaining approval from the Miami University IRB, participants were recruited from Oxford Seniors Inc. (the local senior center) and Miami University’s Institute for Learning in Retirement (ILR). A flyer that consisted of a brief description of the research and the researcher’s contact information was distributed to senior center members via the monthly newsletter and posted at the senior center. In addition, the researcher attended a luncheon at the senior center and made an announcement about the research. The ILR coordinator emailed a similar flyer to ILR members via the ILR list serve. Several rounds of flyers were sent to potential participants; the latter flyers included a direct link to the Qualtrics survey (see Appendices A-C for the various flyers; Appendix D for the survey).

Measurement of Independent Variables

Perceived Benefits to Advance Care Planning. Participants were asked the extent to which they agreed that advance care planning will: a) reduce uncertainty about my end of life care, b) reduce anxiety about my end of life care, c) help avoid confusion and conflict among my loved ones, d) will give peace of mind to the person who will make decisions for me, e) will give me peace of mind, and f) will ensure my wishes are met. For each item, participants indicated on a 5-point likert scale (0 = “strongly disagree,” 1 = “somewhat disagree,” 2 = “not sure,” 3 = “somewhat agree,” 4 = “strongly agree”). The ratings for the six items were summed, resulting in a possible score ranging from 0 (no benefit) to 24 (very beneficial).

Perceived Barriers to Advance Care Planning. The survey assessed three barriers to advance care planning. Comfort with death was assessed by having participants indicate how comfortable they are with each of the following end of life issues: a) talking about death, b) writing your own will if you thought your death would occur soon, c) thinking about life after death (0 = “not at all comfortable,” 1 = “not very comfortable,” 2 = “not sure,” 3 = “somewhat comfortable,” and 4 = “very comfortable”). The ratings for the three items were summed, resulting in a possible score ranging from 0 (no barriers) to 12 (maximum barriers).

The second barrier, lack of knowledge of cause of death, was assessed by asking the following: “Do you find it difficult to complete advance care planning when you don’t know what your cause of death will be” (1 = “yes,” 0 = “no”). Not sure responses were coded as
Health Values at End of Life. Four health values at the end of life were assessed: controlling one’s death experience, logistics of planning, spiritual comfort, and social relationships. Controlling one’s death experience was assessed with four items. Participants were asked how important it was when dealing with their own death to: 1) be able to die in your preferred location, 2) be physically comfortable, 3) be free from pain, and 4) be off machines that extend life such as life support. The possible range for controlling one’s death was 0 (not a health value) to 16 (a high health value). Logistics of planning was assessed with three items. Participants were asked how important it was when dealing with their own death to: 1) plan your own funeral; 2) be able to complete your will; and 3) get your finances in order. The possible range for logistics of planning was 0 (not a health value) to 12 (high health value). Spiritual comfort was assessed with two items. Participants were asked how important it was when dealing with their own death to: 1) be comforted by a religious or spiritual person and 2) be at peace spiritually. The possible range for spiritual comfort was 0 (not a health value) to 8 (high health value). Finally, social relationships was assessed with three items. Participants were asked how important it was when dealing with their own death to: 1) have things settled with my family, 2) not be a burden to loved ones, and 3) know how to say goodbye. The possible range for social relationships was 0 (not a health value) to 12 (high health value). Participants rated each item for each health value on a 5-point likert scale (0 = “not at all important,” 1 = “not very important,” 2 = “not sure,” 3 = “somewhat important,” 4 = “very important”). The ratings for each health value were summed.

Measurement of Dependent Variables

The survey assessed five preventive health behaviors associated with advance care planning. Participants were asked if they had heard of each of the following documents: a) health care power of attorney (HCPOA), b) living will, c) funeral or burial pre-plans, d) MOLST, and e) Do Not Resuscitate Order (DNR). Response options were “Yes, I have heard of this” and “No, I haven’t heard of this.” If participants had heard of the document, they were asked, “Where did you learn about this document?” Next they were asked, “Have you completed this document?” Response options were “Yes, I have completed” and “No, I haven’t completed.”
Finally, they were asked “Why did you complete this document” or “Why haven’t you completed this document.”

Response categories for each of the five preventive health behaviors were identical. Response choices for the source of information where they were: “family,” “friend,” “doctor,” “attorney,” “clergy,” “magazine/TV,” “other,” and “don’t recall.” Response choices for the reason they completed each document were: “to ensure my wishes are met,” “my doctor told me to,” “my family wanted me to,” “because of the death of someone I know,” “it’s important to me,” “to ease the burden on my family,” and “other.” Response choices for why they haven’t completed the document were: “I have never heard of it,” “I don’t think I’ll need it,” “I don’t know where to get this document,” “the document is too hard to understand,” “it takes too much time to complete,” “I haven’t gotten around it/too busy,” “I’m too young to need it now,” “I’m too healthy to need it now,” “I’m in the process of completing it,” “someone else will take care of it,” “I don’t have anyone to make decisions for me,” and “other.” For each question, participants were asked to indicate all that apply.

**Data Collection**

Of the approximately 425 members of Oxford Seniors, a total of five responded to the research flyer (about 1% response rate). Of the approximately 1,200 members of ILR, a total of 37 responded to the research flyer (about 3% response rate). Twenty-four participants responded to the research flyer via attached survey link. As such, it is unknown from which location they were recruited. Multiple modes of data collection were employed (i.e., participants individually completed an online, Qualtrics survey (n = 56); met with the researcher so that she could guide them through the Qualtrics survey (n = 8), or were administered the survey via telephone by the researcher, who then entered the responses into the survey (n = 2)). After eliminating eight of the online surveys where participants opened the survey but did not proceed past the consent page, the sample consisted of 58 participants.

Survey items were selected primarily from four existing surveys: 1) the 2003 AARP North Carolina End of Life Care Survey, which was administered to AARP members age 50 and older, living in North Carolina; 2) the 2003 AARP Minnesota Advance Directives survey, which was administered to residents age 18 and older in Minnesota; and 3) The Pew Research Center’s (2013) “Views on End-of-Life Medical Treatments” telephone survey of a national sample of adults age 18 and above. A fourth survey used is the work of Rao et al. (2014) in which
HealthStyles survey questions were used to examine completion of advance directives among U.S. consumers. The HealthStyles survey is a mailed survey in which a nationally representative sample of adults aged 18 and older are asked about general media habits, product use, interests, lifestyle, and health practices.

The survey was organized in five sections: 1) the benefits of ACP, 2) barriers of ACP which include an individual’s comfort with death, lack of knowledge of cause of death, conversations with loved ones, 3) health values at end of life, which include: controlling one’s death experience, logistics of planning, spiritual comfort, and social relationships, 4) preventive health actions (i.e., completion of five ACP documents and for what reasons individuals completed the documents or not), and 5) sociodemographic characteristics.

Data Analysis

Data analysis was conducted in several stages. First, descriptive statistics (i.e., frequencies for categorical data; means, standard deviations, ranges for continuous variables) were computed for all variables. Second, composite indices were computed for key constructs (i.e., benefits, barriers and health values). In all analyses, all dependent variables were dichotomized (0 = has not done the ACP action, 1 = has done the ACP action). In subsequent analyses, each of the five ACP actions: HCPOA, Living Will, Burial Pre-Plans, MOLST, and DNR, was examined separately. Nonresponses were coded as missing and eliminated from analyses.
Results

Sample Description

Participants were asked to indicate their age (in years), gender, if they were Hispanic, Spanish, or Latino, their race, and their marital status (1 = “single, never married,” 2 = “married,” 3 = “living together as if married,” 4 = “separated,” 5 = “divorced,” 5 = “widowed”). Participants were also asked to indicate if they consider themselves religious or spiritual (1 = “very religious/spiritual,” 2 = “somewhat religious/spiritual,” 3 = “not very religious/spiritual,” 4 = “not at all religious/spiritual”). Finally, participants were asked to indicate how they rated their own health (1 = “excellent,” 2 = “very good,” 3 = “good,” 4 = “fair,” 5 = “poor”) and if they ever worked in the health care field (1 = “yes,” 2 = “no,” 3 = “not sure”).

Demographic characteristics of the participants are summarized in Table 1. As can be seen in the table, most participants were highly educated females, with very good or excellent self-rated health. Approximately 24% had worked in the health care field at some point and most of the participants resided in Ohio (94.8%) for at least part of the year.
Table 1. Sociodemographic Characteristics of Participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>57 – 74</td>
<td>30</td>
<td>52.6</td>
</tr>
<tr>
<td>75 – 100</td>
<td>27</td>
<td>47.4</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>15</td>
<td>26.3</td>
</tr>
<tr>
<td>Female</td>
<td>42</td>
<td>73.7</td>
</tr>
<tr>
<td>Marital Status</td>
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<td></td>
</tr>
<tr>
<td>Single, never married</td>
<td>3</td>
<td>5.3</td>
</tr>
<tr>
<td>Married</td>
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<td>50.9</td>
</tr>
<tr>
<td>Living together as if married</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Divorced</td>
<td>13</td>
<td>22.8</td>
</tr>
<tr>
<td>Widowed</td>
<td>11</td>
<td>19.3</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school graduate</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Some college or technical training</td>
<td>6</td>
<td>10.7</td>
</tr>
<tr>
<td>College graduate</td>
<td>5</td>
<td>8.9</td>
</tr>
<tr>
<td>Post-graduate degree</td>
<td>44</td>
<td>78.6</td>
</tr>
<tr>
<td>Race</td>
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<td></td>
</tr>
<tr>
<td>White</td>
<td>57</td>
<td>100</td>
</tr>
<tr>
<td>Spiritual</td>
<td>48</td>
<td>84.2</td>
</tr>
<tr>
<td>Self-Rated Health</td>
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<td></td>
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<tr>
<td>Poor</td>
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<td>1.7</td>
</tr>
<tr>
<td>Fair</td>
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<td>8.6</td>
</tr>
<tr>
<td>Good</td>
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<td>24.1</td>
</tr>
<tr>
<td>Very Good</td>
<td>20</td>
<td>34.5</td>
</tr>
<tr>
<td>Excellent</td>
<td>18</td>
<td>31.0</td>
</tr>
</tbody>
</table>

Table 2 presents the descriptive statistics for the summary variables from the health belief model. As can be seen in the table, on average participants saw positive value (i.e., perceived benefits) in ACP, as indicated by the relatively high mean score for perceived benefits; the same is the case for participant’s perception of barriers to ACP. Specifically, participants on average highly rated comfort with death. With respect to health values, participants rated each of these variables as highly important.
Table 2. Descriptive Characteristics of Summary Variables from the Health Belief Model

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>% Perceiving this as a Barrier</th>
<th>Possible Range</th>
<th>Actual Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived benefits of ACP</td>
<td>20.8</td>
<td>5.3</td>
<td>0 (low) -24 (high)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived Barriers to ACP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comfort with death</td>
<td>10.6</td>
<td>12.0</td>
<td>0 (low) -12 (high)</td>
<td></td>
<td>3-12</td>
</tr>
<tr>
<td>Lack of knowledge of cause of death</td>
<td></td>
<td></td>
<td>12.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conversations with loved ones</td>
<td></td>
<td></td>
<td>71.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Values</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controlling one’s death experience</td>
<td>14.6</td>
<td>1.6</td>
<td>0 (low) -16 (important)</td>
<td></td>
<td>9-16</td>
</tr>
<tr>
<td>Logistics of planning</td>
<td>10.16</td>
<td>1.86</td>
<td>0 (low) -12 (important)</td>
<td></td>
<td>4-12</td>
</tr>
<tr>
<td>Spiritual comfort</td>
<td>6.18</td>
<td>2.22</td>
<td>0 (low) -8 (important)</td>
<td></td>
<td>0-8</td>
</tr>
<tr>
<td>Social relationships</td>
<td>11.14</td>
<td>1.47</td>
<td>0 (low) -12 (important)</td>
<td></td>
<td>6-12</td>
</tr>
</tbody>
</table>

**Descriptive Analyses**

Participants’ awareness of specific ACP documents is presented in Table 3. As can be seen in the table, all participants had heard of HCPOA, living will, and DNR documents. All but two participants had heard of burial pre-plans and just over half had heard about MOLST documents.
Table 3. Percent of Participants Aware of Each Type of ACP Documents (n = 56)

<table>
<thead>
<tr>
<th>Type of Advance Care Planning Document</th>
<th>HCPOA</th>
<th>Living Will</th>
<th>Burial Pre-Plans</th>
<th>MOLST</th>
<th>DNR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, I have heard of this</td>
<td>100</td>
<td>100</td>
<td>96.4</td>
<td>51.8</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 4 summarizes the various sources where participants learned about ACP documents. As can be seen in the table, a majority of participants heard about each of the five documents from either a family member or an attorney, followed closely by a friend. About 20% of participants had heard about all ACP documents except burial pre-plans from their doctor. Several participants did not recall exactly where they originally learned about each document or other, but knew they had heard of it. Across all sources, participants heard most frequently about living will, DNR, and HCPOA; burial pre-plans and MOLST were less frequently talked about.
Table 4. Percent of Participants who Heard About Each Type of ACP Document from Various Sources (n=56)*

<table>
<thead>
<tr>
<th>Information Source(s)</th>
<th>Type of Advance Care Planning Document</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HCPOA</td>
</tr>
<tr>
<td>Attorney</td>
<td>48.2</td>
</tr>
<tr>
<td>Family</td>
<td>30.4</td>
</tr>
<tr>
<td>Doctor</td>
<td>21.4</td>
</tr>
<tr>
<td>Friend</td>
<td>10.7</td>
</tr>
<tr>
<td>Magazine/TV</td>
<td>7.1</td>
</tr>
<tr>
<td>Clergy</td>
<td>1.8</td>
</tr>
<tr>
<td>Other</td>
<td>21.4</td>
</tr>
<tr>
<td>Don’t Recall</td>
<td>19.6</td>
</tr>
<tr>
<td>Total</td>
<td>90</td>
</tr>
</tbody>
</table>

*Because participants could select all sources that apply for each ACP document, column totals vary.

The frequencies of participants who have/have not completed ACP documents is presented in Table 5. Although all of the participants had heard about HCPOA, living will, and DNR documents, not all had completed these documents. The most frequently completed ACP document was HCPOA (79%), followed by living will (86%). Just over half of participants had completed a DNR document, while the least frequently completed documents were burial pre-plans (45%) and MOLST (37%).
The sociodemographic characteristics of participants who completed each of the five ACP documents are presented in Table 6. As can be seen in the table, a higher proportion of females completed each of the documents, as did those with more education, and those with good self-rated health. Findings regarding marital status were mixed. Specifically, a higher proportion of married participants had completed all but burial pre-planning, compared to those who married.

Table 6. Sociodemographic Characteristics of Participants Who Completed Each Type of ACP Document

<table>
<thead>
<tr>
<th>Type of ACP Document</th>
<th>HCPOA (n = 48)</th>
<th>Living Will (n = 44)</th>
<th>Burial Pre-Plans (n = 20)</th>
<th>MOLST (n = 13)</th>
<th>DNR (n = 31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>29.2</td>
<td>27.3</td>
<td>20.0</td>
<td>46.2</td>
<td>29.0</td>
</tr>
<tr>
<td>Female</td>
<td>68.8</td>
<td>70.5</td>
<td>80.0</td>
<td>46.2</td>
<td>67.7</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than College</td>
<td>2.1</td>
<td>2.3</td>
<td>5.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>College Graduate and above</td>
<td>93.8</td>
<td>95.5</td>
<td>95.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>58.3</td>
<td>54.5</td>
<td>40.0</td>
<td>61.5</td>
<td>51.6</td>
</tr>
<tr>
<td>Not Married</td>
<td>39.6</td>
<td>43.1</td>
<td>60.0</td>
<td>30.8</td>
<td>45.2</td>
</tr>
<tr>
<td>Self-Rated Health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor Health</td>
<td>10.4</td>
<td>11.4</td>
<td>10.0</td>
<td>15.4</td>
<td>12.9</td>
</tr>
<tr>
<td>Good Health</td>
<td>89.6</td>
<td>88.7</td>
<td>90.0</td>
<td>84.6</td>
<td>87.1</td>
</tr>
</tbody>
</table>

Participants’ reasons for engaging or not engaging in ACP behaviors are presented in Tables 7 and 8, respectively. As seen in Table 7, regardless of the type of document, participants...
overwhelmingly identified easing their family’s burden and ensuring that their needs and values are met. Among those who had a HCPOA, for example, 81% of participants reported doing so to ease their family’s burden, 77% did so to ensure their wishes were met, and 73% said having HCPOA complete was important to them. A similar pattern was observed for the other four ACP documents.

Table 7. Percentages of Participants who Endorsed Each Reason for Completing the ACP Documents

<table>
<thead>
<tr>
<th>Reason for Completion</th>
<th>Type of Advance Care Planning Document</th>
<th>HCPOA (n = 48)</th>
<th>Living Will (n = 44)</th>
<th>Burial Pre-Plans (n = 20)</th>
<th>MOLST (n = 13)</th>
<th>DNR (n = 31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>To ease the burden on my family</td>
<td></td>
<td>81.3</td>
<td>88.6</td>
<td>60.0</td>
<td>69.2</td>
<td>71.0</td>
</tr>
<tr>
<td>To ensure my wishes are met</td>
<td></td>
<td>77.1</td>
<td>81.8</td>
<td>65.0</td>
<td>61.5</td>
<td>83.9</td>
</tr>
<tr>
<td>It’s important to me</td>
<td></td>
<td>72.9</td>
<td>79.5</td>
<td>50.0</td>
<td>61.5</td>
<td>64.5</td>
</tr>
<tr>
<td>My family wanted me to</td>
<td></td>
<td>25.0</td>
<td>20.5</td>
<td>10.0</td>
<td>15.4</td>
<td>19.4</td>
</tr>
<tr>
<td>Because of the death of someone I know</td>
<td></td>
<td>14.6</td>
<td>22.7</td>
<td>15.0</td>
<td>15.4</td>
<td>19.4</td>
</tr>
<tr>
<td>My doctor told me to</td>
<td></td>
<td>4.2</td>
<td>6.8</td>
<td>0</td>
<td>0</td>
<td>3.2</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>4.2</td>
<td>2.3</td>
<td>10.0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>134</td>
<td>133</td>
<td>42</td>
<td>29</td>
<td>81</td>
</tr>
</tbody>
</table>

*Because participants could select all sources that apply for each ACP document, column totals vary.

Participants who did not complete any of the five ACP documents were asked the reasons why they did not complete each document (see Table 8). Participants overwhelmingly indicated that the reason for not completing each of the documents was because they hadn’t gotten around to it yet or they were too busy. One person was in the process of completing all of the documents except MOLST. Burial pre-plans (61%) and DNR (45%) documents were the most likely to not be completed, most frequently citing that they haven’t gotten around to it yet/too
busy or they don’t think they will need it. Across all ACP documents, participants had the most reasons for not completing burial pre-plans and DNR, while they named the least number of reasons for not completing HCPOA, living will, and MOLST.
Table 8. Percentages of Participants who Endorsed Each Reason for Not Completing the ACP Documents

<table>
<thead>
<tr>
<th>Reason for not Completing Document</th>
<th>Type of Advance Care Planning Document</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HCPOA (n = 8)</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>I haven’t gotten around to it / too busy</td>
<td>50.0</td>
</tr>
<tr>
<td>I don’t think I’ll need it</td>
<td>0</td>
</tr>
<tr>
<td>I don’t know where to get this document</td>
<td>25.0</td>
</tr>
<tr>
<td>I’m too young to need it now</td>
<td>12.5</td>
</tr>
<tr>
<td>I’m too healthy to need it now</td>
<td>0</td>
</tr>
<tr>
<td>Someone else will take care of it</td>
<td>0</td>
</tr>
<tr>
<td>I have never heard of it</td>
<td>0</td>
</tr>
<tr>
<td>I’m in the process of completing it</td>
<td>12.5</td>
</tr>
<tr>
<td>The document is too hard to understand</td>
<td>0</td>
</tr>
<tr>
<td>It takes too much time to complete</td>
<td>0</td>
</tr>
<tr>
<td>I don’t have anyone to make decisions for me</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>37.5</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
</tr>
</tbody>
</table>

*Because participants could select all sources that apply for each ACP document, column totals vary.*
Discussion

The purpose of this study was to gain an understanding of relatively healthy, local community dwelling older adults’ awareness of ACP documents, their source(s) of information about ACP documents, the extent to which they engage in specific ACP, the reasons they do or do not engage in ACP, and what psychosocial and sociodemographic factors are associated with ACP. The research was guided by three main components of the health belief model: 1) benefits, 2) barriers, and 3) preventive health action. This study revealed that local community dwelling older adults are not equally familiar with all of the ACP documents. Nonetheless, participants learned about most of the ACP documents from a variety of sources. Despite their awareness of the APC documents, participants had not necessarily completed them. In general, higher proportions of females, college graduates, and those with better self-rated health completed various ACP documents. Participants identified multiple reasons for why they had or had not completed the various documents.

All of the participants had heard of a HCPOA, living will, and DNR. A majority had heard of burial pre-plans and about half had heard about MOLST. Participants most frequently learned about these ACP documents from attorneys or family, followed closely by doctors, friends, and magazines/TV. This is consistent with existing literature citing the main sources of information about ACP to be family, doctors, and friends (Bischoff et al., 2013; Musa et al., 2015; Seymour et al., 2004). That participants also learned about these documents from an attorney and magazines/TV is a new finding that contributes to the literature. An interesting question is whether more sources may lead to higher completion of ACP.

It is possible that burial pre-plans and MOLST are less frequently heard about than living wills, DNR documents, and HCPOAs because they are less routinized, albeit for different reasons. Attorneys and physicians have ready access to living wills, DNRs, and HCPOAs; they are easily downloadable from multiple websites and relatively easy to complete. In contrast, burial pre-planning is less structured and more personal. In addition, MOLST is relatively new in the state of Ohio, which may contribute to why participants were less familiar with it. MOLST is also aimed at the more clinical side of EoL, which may be intimidating for participants who are unfamiliar with clinical language and procedures.

Despite their knowledge of the various ACP documents, participants differentially engaged in the specific preventive health actions. Almost all participants had completed
HCPOA and living wills, a little over half had completed DNR documents and less than half had completed burial pre-plans and MOLST (preventive health action). Completion rates in this study are much higher than in previous research that investigated community dwelling adults and reported completion rates ranging from 15% to 62% (Braun et al., 2001; Emanuel et al., 1991; Khosla et al., 2015). The higher completion rates in this study may be due to the recruitment strategy used in this research. Specifically, participants who were already interested in end of life issues and had completed ACP may have self-selected into this research, in contrast to previous research that used large representative samples and/or collected data on ACP as part of a more general survey.

With respect to participants’ perceived benefits of ACP, participants who completed documents most frequently did so to ease their family’s burden during the death process, ensure their wishes are met, and because the particular planning document was important to them. Engaging in these behaviors also has the potential to lessen the perceived threat of a bad death. The survey used in this research did not record whether participants had actually had conversations with their loved ones and openly discussed what their wishes were as opposed to simply completing documents because they had been advised to by a medical or legal professional. In previous research, discussions with loved ones were associated with higher completion of ACP (Havens, 2000). Those who take the time to think through their end of life wishes and make them known are more likely to have their wishes met (Detering et al., 2010).

In general, participants in this research perceived high levels of benefits, and low levels of barriers, associated with ACP. In addition, with respect to health values, participants felt strongly that they be able to control their own death, and the logistics of their death and the spiritual and social support that they receive during the death process were important to them. This again suggests that this sample was biased, in that it was comprised of people who were already interested in ACP.

Sociodemographic characteristics influenced who completed the various ACP documents. It is not clear why a higher proportion of women completed ACP documents. With respect to marital status, those who were married were more likely to complete all of the documents except burial pre-plans. One might speculate that married participants may have more motivation to discuss and complete ACP to ease the burden on their spouse. Another interesting finding is that a higher proportion of participants who completed each of type of ACP
document reported good self-rated health. This seems counter-intuitive, but again might reflect the biased sample.

With respect to barriers to completing ACP, the most frequently cited reason for not completing any of the five ACP documents was because participants “hadn’t gotten around to it yet,” which is inconsistent with previous research. Previous research has most commonly cited reasons such as participants believed they were too young or too healthy to need it (Emanuel et al., 1991) and lack of awareness (Rao et al., 2014). In addition, Schickedanz et al. (2009) found six main barriers: 1) perceiving ACP as irrelevant (i.e., too healthy), 2) personal barriers (i.e., emotional issues or work responsibilities), 3) relationship concerns (i.e., doesn’t have a good relationship with family or doesn’t want them involved), 4) information needs (i.e., doesn’t know what their choices are), 5) health encounter time constraints (i.e., my doctor is too busy), and 6) problems with ACP (i.e., needs help understanding forms). Limited research has asked specifically about completion of each ACP document, however Braun et al. (2001) investigated HCPOAs and living wills, and found completion to be relatively low (49% and 62%, respectively), which was not the case in this research. The difference in completion rates could potentially be due to the large sample that was representative of the state of Hawaii, where as this research used a small and potentially biased sample.

One could speculate participants are more willing to complete HCPOA and living will documents because they are appointing others to make decisions should they themselves not be in a position to do so, which could potentially be viewed as a temporary measure. It could be extremely difficult for some to think about or actually complete documents such as burial pre-plans, MOLST, and DNR, because these documents instruct loved ones what to do upon and after their death. Not only were these the least frequently completed documents; participants also gave the most reasons for not completing these documents. One could speculate that participants avoided talking about their death and life after death, potentially because they are afraid of death. One could also argue that those who have not engaged in ACP are not necessarily against planning for end of life; they simply have not made time to complete the ACP documents, as indicated by participants in this and other research (Schickedanz, 2009). In an effort to lessen perceived barriers, professionals should be urged to discuss the importance of having these documents prepared in an effort to increase overall completion rates. Other research has found that participants would be comfortable with the doctor or medical professional initiating the
conversations about ACP (Jackson et al., 2009). Even if one is healthy, there are many unexpected events that could cause these ACP documents to be needed.

**Limitations**

This research has several limitations. First, results cannot be generalized due to the small, homogenous sample and low response rate. The sample primarily consisted of individuals who are non-Hispanic white, female, highly educated (college degree or higher), with good, very good, or excellent self-rated health. Second, the possible selection bias of the sample has already been discussed. Previous research with community dwelling adults that used more representative samples supports the biased nature of this sample (Braun et al., 2001; Khosla et al., 2015). A related third limitation is that there was little variability in completion rates of ACP documents in this sample. When compared with previous research, this study produced overwhelmingly high completion rates. It was very surprising to learn that nearly all participants had completed HCPOA, living will, and DNR. Fourth, the survey created and used for this study was based on four existing surveys. The existing surveys looked at a wide variety of EoL topics, including ACP. In hindsight, it may have been better to design a more narrowly focused survey with consistent response categories across constructs. However, the survey did yield valuable information about participants’ familiarity with, source(s) of information about, and reasons for having or not having completed various ACP documents. A final consideration is whether a qualitative study might have provided additional insight and a better understanding of the ACP process. Being able to sit down and have a long discussion about ACP instead of pre-determined answer choices in a survey would have allowed participants to expand further on items for sources of information and the reasons for engaging or not engaging. For example, a participant may have been able to explain more about what he/she learned from a doctor and if it was an ongoing conversation, or he/she may have been able to expand on what exactly it means to “ease the burden on my family.” With these in depth conversations, we would not have been left to speculate about participants’ situations and their decision-making processes.

**Implications and Future Research**

Even though many of the participants had heard about each of the five ACP documents from several different sources, they had not consistently completed all of the documents. This could potentially be due to a difference in personal values and beliefs about EoL care and ACP. It could also be due to an individual’s differential levels of comfort with specific aspects of EoL
care and ACP. For example, based on their health values, it might be that some individuals are comfortable completing a standardized living will, DNR or HCPOA, but they are not comfortable making specific burial arrangements. It may also be that completing non-standardized documents are more time consuming, and/or it is difficult to find information about how to complete them. The current findings notwithstanding, there is a body of research that suggests that talking about end of life and what one wants can be an intimidating and confusing process that is avoided by many. A potential starting point to address this situation may be for professionals such as doctors and attorneys to frame ACP in the context of its’ perceived benefits: that it affords an individual the opportunity to control her/his death experience, manage the logistics of the death, and have the spiritual comfort and social relationships at the end of life that reflect his/her health values.

Further, in light of Musa, Seymour, Narayanasamy, Wada, and Conroy’s (2015) finding that respondents believed that discussing ACP was an informal process and they would be more likely to discuss their wishes with a family member who they trust more than a medical professional, professionals might consider framing ACP as a family conversation. Consistent with previous research that identified the importance of discussing end of life care preferences with someone one trusts (Kwak & Salmon, 2007; Rao, Anderson, Lin, & Laux, 2014), professionals could serve as initiators and facilitators of ongoing conversations among families. This is especially important given Seymour, Gott, Bellamy, Ahmedzai, and Clark’s (2004) finding that older adults’ preferences for end of life change; and that ACP discussions must be ongoing and will benefit from the development of trust and understanding with family and doctors. Taken together, these findings suggest that it is possible that, by talking with individuals and their family about each of these aspects, professionals could help make the ACP process less intimidating and more relatable to laypeople and their families.

Although not as frequent, participants did cite magazines/TV and clergy as sources for learning about ACP documents. This area has not been focused on in previous research and may be a new venue from which medical professionals could promote ACP and educate community members about its’ importance. Brief ads could make the public aware of such documents and guide them to seek out assistance in getting and completing these ACP documents. Churches and clergy could also become educated about ACP documents and advertise their knowledge via flyers and brochures, initiating the topic and letting people know where to get information.
In summary, based on the findings from this research, future research might focus on quantitative studies that employ large representative samples of relatively healthy community dwelling adults, as well as qualitative investigations to gain as complete an understanding as possible about the process of ACP. With respect to practice, identifying and educating frequent sources of information about aspects of ACP will prepare professionals to meet the informational needs of their clients. In addition, health educators could enhance advertising and education about these documents. Older adults will likely need ACP documents before younger adults, but research needs to study all adults living in the community to examine what they perceive to be benefits and barriers, and cues to action to completing ACP documents (preventive health action). If these benefits and barriers, and cues to action can be exposed, professionals and educators may be able to increase knowledge of the general public about the importance of completing ACP documents at any age. An increase in knowledge could potentially increase completion rates and give people the power to control their own death experience through their ACP documents.
References


Appendix A

*Have you thought about your preferences for care as you near the end of life?*

Are You Age 60 or Over?

If yes, please consider participating Miami University’s Research Project

“Advance Care Planning Behavior in Community Dwelling Older Adults”

The ultimate goal of this research is to better understand the Advance Care Planning (ACP) behaviors of healthy community dwelling older adults.

Participation involves completing a questionnaire that takes approximately thirty to forty-five minutes. During that time, you will:

- Share your thoughts about and experiences with (ACP)
- Explain to us why you have or have not completed (ACP)

Interested in Participating? Contact Candace Burch (715-781-5167; *burchc@miamioh.edu*) or Dr. Jennifer Kinney (513-529-2915; *kinneyjm@miamioh.edu*)
Scripps Gerontology Research

Miami’s Scripps Gerontology Center plays an active role in ILR by providing intern opportunities, ILR lectures and classes, and an ex-officio member on the ILR Board. Candace Burch, a student in the Master of Gerontological Studies Program, has been approved by Miami’s Institutional Review Board to conduct her master’s thesis research on advance care planning among older adults. Participation in this research with Candace will be conducted in a private location of the participant’s choice. Your interest in participating would be appreciated.

Have you thought about your preferences for care as you near the end of life?

Are You Age 60 or Over?

If yes, please consider participating in the Research Project: "Advance Care Planning Behavior in Community Dwelling Older Adults"

The ultimate goal of this research is to better understand the Advance Care Planning (ACP) behaviors of healthy community dwelling older adults. Participation involves completing a questionnaire that takes approximately thirty to forty-five minutes. During that time, you will:

- Share your thoughts about and experiences with (ACP)
- Explain to us why you have or have not completed (ACP)

Interested in Participating? Contact Candace Burch (715-781-5167; burchc@miamioh.edu) or Dr. Jennifer Kinney (513-529-2915; kinneyjm@miamioh.edu)
Appendix C

*Have you thought about your preferences for care as you near the end of life?*

**Are You Age 60 or Over?**

If yes, please consider participating Miami University’s Research Project

*“Advance Care Planning Behavior in Community Dwelling Older Adults”*

The ultimate goal of this research is to better understand the Advance Care Planning (ACP) behaviors of healthy community dwelling older adults.

Participation involves completing a questionnaire that takes approximately thirty to forty-five minutes. You can choose to participate in person, over the phone, or with the survey link below.

https://miamioh.qualtrics.com/SE/?SID=SV_8q2CAr6cwt0PgCF

Interested in Participating? Contact Candace Burch (715-781-5167; burchc@miamioh.edu) or Dr. Jennifer Kinney (513-529-2915; kinneyjm@miamiOH.edu)
Appendix D

Advance Care Planning (ACP) and End of Life

The purpose of this research is to better understand advance care planning among adults. Advance care planning refers to having an advance directive, durable power of attorney, or having discussed preferences for end of life with a next of kin. Participation consists of completing an online survey that should take no longer than 30 minutes. Your participation is entirely voluntary, and the information you provide will be kept confidential in that your name will not be associated with your data in any way.

Participating in the research possibly presents the risk that you might feel uncomfortable thinking about end of life issues. The benefits are that you will contribute to a better understanding of advance care planning among community dwelling older adults.

This survey allows you to complete part of the survey and return to finish later. The survey automatically saves your progress and as long as you use this link in the same browser that you started the survey in, it will return to where you ended during your previous session. If you would like assistance while completing the survey, you can contact Candace Burch at 715-781-5167.

Please contact Candace Burch (715-781-5167; burchc@miamioh.edu) or Dr. Jennifer Kinney (513-529-2915; kinneyjm@miamioh.edu) or if you have questions about the procedures used in this research. Please contact the Office for the Advancement of Research and Scholarship (513-529-3600; humansubjects@miamioh.edu) for questions of concerns about your rights as subjects.

I understand that by completing this survey I have consented to participate in the research.

In what city do you currently reside?

How old are you?

What is your gender?

☑ Male
☑ Female
☑ Other
Are you Hispanic, Spanish, or Latino?
- Yes
- No
- Not Sure

What is your race? Check all that apply
- White or Caucasian
- Asian
- Black or African American
- Native American or Alaskan Native
- Other ______________________

What is your current marital status?
- Single, never married
- Married
- Living together as if married
- Separated
- Divorced
- Widowed

What is your highest level of education?
- Less than a high school diploma
- High school graduate or equivalent
- Some college or technical training beyond high school
- College graduate (four year degree)
- Post-graduate or professional degree (e.g., M.A., M.S., JD, MD, PhD)

Do you consider yourself...?
- Very religious or spiritual
- Somewhat religious or spiritual
- Not very religious or spiritual
- Not at all religious or spiritual

If Not at all religious or spiritual Selected, Then Skip To In general, how would you rate your o...
How often do you attend religious or spiritual services?
- Regularly
- Occasionally
- Rarely
- Never

How often do you find strength in your religion or spirituality?
- One or more times a day
- A few times a week
- A few times a month
- Once a month or less
- Never

In general, how would you rate your own health right now?
- Excellent
- Very Good
- Good
- Fair
- Poor

Have you ever worked in the health care field?
- Yes
- No
- Not sure
How comfortable are you with each of the following end of life issues?

<table>
<thead>
<tr>
<th>Issue</th>
<th>Not at all Comfortable</th>
<th>Not Very Comfortable</th>
<th>Somewhat Comfortable</th>
<th>Very comfortable</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talking about death</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Writing your own will if you thought your death would occur soon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thinking about life after death</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Do you find it difficult to complete advance care planning when you don’t know what your cause of death will be?
- Yes
- No
- Not Sure

Are your loved ones willing to discuss your end of life wishes?
- Yes
- No
- Haven’t tried talking to them
- Not Sure

How much attention do you think doctors and nurses pay to patients end of life wishes?
- A lot of attention
- Some attention
- Very little attention
- No attention
- Not Sure
Below are several possible benefits to advance care planning. How strongly do you agree or disagree with the following statements? Advance care planning will...

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Somewhat agree</th>
<th>Strongly Agree</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduce uncertainty about my end of life care</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Reduce anxiety about my end of life care</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Help avoid confusion and conflict among my loved ones</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Will give peace of mind to the person who will make decisions for me</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Will give me peace of mind</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Will ensure my wishes are met</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
How important would each of the following be to you when dealing with your own death?

<table>
<thead>
<tr>
<th></th>
<th>Not at all Important</th>
<th>Not Very Important</th>
<th>Somewhat Important</th>
<th>Very Important</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being able to die in your preferred location (home, assisted living, nursing home)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Being comforted by a religious or spiritual person</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Planning your own funeral</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Being able to complete your will</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Having health care professionals visit you</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Getting your finances in order</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
How important are each of the following to you when you think about dying?

<table>
<thead>
<tr>
<th></th>
<th>Not at all Important</th>
<th>Not Very Important</th>
<th>Somewhat Important</th>
<th>Very Important</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being physically comfortable</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Being free from pain</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Having things settled with my family</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Being at peace spiritually</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Not being a burden to loved ones</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Knowing how to say goodbye</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Being off machines that extend life such as life support</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

Have you ever had any personal experience with someone dying?
○ Yes
○ No
○ Not sure

If Yes Is Selected, Then Skip To Was this a relative or close friend?If No Is Selected, Then Skip To End of Block

Was this a relative or close friend?
○ Yes
○ No
○ Not Sure

If No Is Selected, Then Skip To End of Block
Did the issue of withholding life-sustaining treatment come up?
- Yes
- No
- Not Sure

When this happened, did you help at all in making decisions about how much medical treatment should be given?
- Yes
- No
- Not sure

Next you will be asked about seven specific documents that people sometimes complete to assist medical professionals and loved ones in making choices when they are unable to speak for themselves. For each, please indicate whether you have heard of it or not. If you have heard of it, please indicate if you have completed it and why.

1. A Health Care Power of Attorney (HCPA) in which you name someone to make decisions about your health care in the event that you are unable to do so.
   - Yes, I have heard of this
   - No, I haven't heard of this

If Yes, I have heard of this Is Selected, Then Skip To Where did you learn about a Health Care Power of Attorney (HCPA)? Check all that apply.
- Family
- Friend
- Doctor
- Attorney
- Clergy
- Magazine/TV
- Other __________________________
- Don't recall

If Where did you learn about a... Is Greater Than or Equal to 1, Then Skip To 1. Have you completed A Health Care P...
Have you completed A Health Care Power of Attorney (HCPA) in which you name someone to make decisions about your health care in the event that you are unable to do so?

- Yes, I have completed
- No, I haven't completed

If Yes, I have completed Is Selected, Then Skip To Why have you completed a HCPA? Check ...If No, I haven't completed Is Selected, Then Skip To Why haven't you completed a HCPA? Che...

Why have you completed a HCPA? Check all that apply

- To ensure my wishes are met
- My doctor told me to
- My family wanted me to
- Because of the death of someone I know
- It's important to me
- To ease the burden on my family
- Other ____________________

If Why have you completed a HCPA... Is Greater Than or Equal to 1, Then Skip To 2. A living will in which you state t...

Why haven't you completed a HCPA? Check all that apply

- I have never heard of it
- I don't think I'll need it
- I don't know where to get this document
- The document is too hard to understand
- It takes too much time to complete
- I haven't gotten around to it / too busy
- I'm too young to need it now
- I'm too healthy to need it now
- I'm in the process of completing it
- Someone else will take care of it
- I don't have anyone to make decisions for me
- Other ____________________

If Why haven't you completed a... Is Greater Than or Equal to 1, Then Skip To 2. A living will in which you state t...
2. A living will in which you state the kind of health care you want or don't want under certain circumstances.

- Yes, I have heard of this
- No, I haven't heard of this

If Yes, I have heard of this Is Selected, Then Skip To Where did you learn about a living will?...If No, I haven't heard of this Is Selected, Then Skip To 3. A will or last will and testament ...

Where did you learn about a living will? Check all that apply.

- Family
- Friend
- Doctor
- Attorney
- Clergy
- Magazine/TV
- Other _____________________
- Don't recall

If Where did you learn about a... Is Greater Than or Equal to 1, Then Skip To A living will in which you state the ...

Have you completed a living will in which you state the kind of health care you want or don't want under certain circumstances?

- Yes, I have completed
- No, I haven't completed

If Yes, I have completed Is Selected, Then Skip To Why have you completed a living will?...If No, I haven't completed Is Selected, Then Skip To Why haven't you completed a living will...

Why have you completed a living will? Check all that apply

- To ensure my wishes are met
- My doctor told me to
- My family wanted me to
- Because of the death of someone I know
- It's important to me
- To ease the burden on my family
- Other _____________________

If Why have you completed a li... Is Greater Than or Equal to 1, Then Skip To 3. A will or last will and testament ...
Why haven’t you completed a living will? Check all that apply

- I have never heard of it
- I don’t think I’ll need it
- I don’t know where to get this document
- The document is too hard to understand
- It takes too much time to complete
- I haven’t gotten around to it / too busy
- I’m too young to need it now
- I’m too healthy to need it now
- I’m in the process of completing it
- Someone else will take care of it
- I don’t have anyone to make decisions for me
- Other ______________________

If Why haven’t you completed a... Is Greater Than or Equal to 1, Then Skip To 3. A will or last will and testament ...

3. A will or last will and testament that controls how your assets are to be distributed.

- Yes, I have heard of this
- No, I haven’t heard of this

If Yes, I have heard of this Is Selected, Then Skip To Where did you learn about a will or l...If No, I haven't heard of this Is Selected, Then Skip To 4. Funeral or burial pre-plans in whi...

Where did you learn about a will or last will and testament? Check all that apply.

- Family
- Friend
- Doctor
- Attorney
- Clergy
- Magazine/TV
- Other ______________________
- Don’t recall

If Where did you learn about a... Is Greater Than or Equal to 1, Then Skip To Have you completed a will or last will...
Have you completed a will or last will and testament that controls how your assets are to be distributed?
☑ Yes, I have completed
☑ No, I haven’t completed

If Yes, I have completed Is Selected, Then Skip To Why have you completed a will or last will and testament? If No, I haven’t completed Is Selected, Then Skip To Why haven’t you completed a will or last will and testament?

Why have you completed a will or last will and testament? Check all that apply
☑ To ensure my wishes are met
☑ My doctor told me to
☑ My family wanted me to
☑ Because of the death of someone I know
☑ It’s important to me
☑ To ease the burden on my family
☑ Other ____________________

If Why have you completed a will... Is Greater Than or Equal to 1, Then Skip To 4. Funeral or burial pre-plans in wh...

Why haven’t you completed a will or last will and testament? Check all that apply
☑ I have never heard of it
☑ I don’t think I’ll need it
☑ I don’t know where to get this document
☑ The document is too hard to understand
☑ It takes too much time to complete
☑ I haven’t gotten around to it / too busy
☑ I’m too young to need it now
☑ I’m too healthy to need it now
☑ I’m in the process of completing it
☑ Someone else will take care of it
☑ I don’t have anyone to make decisions for me
☑ Other ____________________

If Why haven’t you completed a... Is Greater Than or Equal to 1, Then Skip To 4. Funeral or burial pre-plans in wh...
4. Funeral or burial pre-plans in which you plan or purchase in advance any goods or services for yourself
   ○ Yes, I have heard of this
   ○ No, I haven't heard of this
   If Yes, I have heard of this Is Selected, Then Skip To Where did you learn about a funeral o...If No, I haven't heard of this Is Selected, Then Skip To 5. Documents to have your organs and/

Where did you learn about a funeral or burial pre-plans? Check all that apply.
   ☐ Family
   ☐ Friend
   ☐ Doctor
   ☐ Attorney
   ☐ Clergy
   ☐ Magazine/TV
   ☐ Other ______________________
   ☐ Don't recall
   If Where did you learn about a... Is Greater Than or Equal to 1, Then Skip To Have you completed funeral or burial ...

Have you completed funeral or burial pre-plans in which you plan or purchase in advance any goods or services for yourself?
   ○ Yes, I have completed
   ○ No, I haven't completed
   If Yes, I have completed Is Selected, Then Skip To Why have you completed funeral or bur...If No, I haven't completed Is Selected, Then Skip To Why haven't you completed funeral or ...

Why have you completed funeral or burial pre-plans? Check all that apply
   ☐ To ensure my wishes are met
   ☐ My doctor told me to
   ☐ My family wanted me to
   ☐ Because of the death of someone I know
   ☐ It's important to me
   ☐ To ease the burden on my family
   ☐ Other ______________________
   If Why have you completed fune... Is Greater Than or Equal to 1, Then Skip To 5. Documents to have your organs and/...
Why haven't you completed funeral or burial pre-plans? Check all that apply

- I have never heard of it
- I don't think I'll need it
- I don't know where to get this document
- The document is too hard to understand
- It takes too much time to complete
- I haven't gotten around to it / too busy
- I'm too young to need it now
- I'm too healthy to need it now
- I'm in the process of completing it
- Someone else will take care of it
- I don't have anyone to make decisions for me
- Other ______________________
- I can't afford it

If Why haven't you completed f... Is Greater Than or Equal to 1, Then Skip To 5. Documents to have your organs and/...

5. Documents to have your organs and/or tissue donated after you die.

- Yes, I have heard of this
- No, I haven't heard of this

If Yes, I have heard of this Is Selected, Then Skip To Where did you learn about these docum...If No, I haven't heard of this Is Selected, Then Skip To 6. MOLST/POLST (medical orders for li...

Where did you learn about these documents? Check all that apply.

- Family
- Friend
- Doctor
- Attorney
- Clergy
- Magazine/TV
- Other ______________________
- Don't recall

If Where did you learn about t... Is Greater Than or Equal to 1, Then Skip To Have you completed documents to have ...
Have you completed documents to have your organs and/or tissue donated after you die?

- Yes, I have completed
- No, I haven't completed

If Yes, I have completed Is Selected, Then Skip To Why have you completed these document...If No, I haven't completed Is Selected, Then Skip To Why haven't you completed these docum...

Why have you completed these documents? Check all that apply

- To ensure my wishes are met
- My doctor told me to
- My family wanted me to
- Because of the death of someone I know
- It's important to me
- To ease the burden on my family
- Other ______________________

If Why have you completed the... Is Greater Than or Equal to 1, Then Skip To 6. MOLST/POLST (medical orders for li...

Why haven't you completed these documents? Check all that apply

- I have never heard of it
- I don't think I'll need it
- I don't know where to get this document
- The document is too hard to understand
- It takes too much time to complete
- I haven't gotten around to it / too busy
- I'm too young to need it now
- I'm too healthy to need it now
- I'm in the process of completing it
- Someone else will take care of it
- I don't have anyone to make decisions for me
- Other ______________________

If Why haven't you completed t... Is Greater Than or Equal to 1, Then Skip To 6. MOLST/POLST (medical orders for li...
   ○ Yes, I have heard of this
   ○ No, I haven’t heard of this

   If Yes, I have heard of this Is Selected, Then Skip To Where did you learn about MOLST/POLST...If No, I haven’t heard of this Is Selected, Then Skip To 7. Do Not Resuscitate Order (DNR)

Where did you learn about MOLST/POLST? Check all that apply.
   □ Family
   □ Friend
   □ Doctor
   □ Attorney
   □ Clergy
   □ Magazine/TV
   □ Other __________________________
   □ Don’t recall

   If Where did you learn about... Is Greater Than or Equal to 1, Then Skip To Have you completed MOLST/POLST (medic...

Have you completed MOLST/POLST (medical orders for life sustaining treatment/physician orders for life sustaining treatment)?
   ○ Yes, I have completed
   ○ No, I haven’t completed

   If Yes, I have completed Is Selected, Then Skip To Why have you completed MOLST/POLST? C...If No, I haven’t completed Is Selected, Then Skip To Why haven't you completed MOLST/POLST...

Why have you completed MOLST/POLST? Check all that apply
   □ To ensure my wishes are met
   □ My doctor told me to
   □ My family wanted me to
   □ Because of the death of someone I know
   □ It's important to me
   □ To ease the burden on my family
   □ Other __________________________

   If Why have you completed MOL... Is Greater Than or Equal to 1, Then Skip To 7. Do Not Resuscitate Order (DNR)
Why haven't you completed MOLST/POLST? Check all that apply.

- I have never heard of it
- I don't think I'll need it
- I don't know where to get this document
- The document is too hard to understand
- It takes too much time to complete
- I haven't gotten around to it / too busy
- I'm too young to need it now
- I'm too healthy to need it now
- I'm in the process of completing it
- Someone else will take care of it
- I don't have anyone to make decisions for me
- Other ____________________

If Why haven't you completed M... Is Greater Than or Equal to 1, Then Skip To 7. Do Not Resuscitate Order (DNR)

7. Do Not Resuscitate Order (DNR)

- Yes, I have heard of this
- No, I haven't heard of this

If Yes, I have heard of this Is Selected, Then Skip To Where did you learn about a Do Not Re...If No, I haven't heard of this Is Selected, Then Skip To End of Block

Where did you learn about a Do Not Resuscitate Order (DNR)? Check all that apply.

- Family
- Friend
- Doctor
- Attorney
- Clergy
- Magazine/TV
- Other ____________________
- Don't recall

If Where did you learn about a... Is Greater Than or Equal to 1, Then Skip To Have you completed a Do Not Resuscita...
Have you completed a Do Not Resuscitate Order (DNR)?
- Yes, I have completed
- No, I haven't completed

If Yes, I have completed Is Selected, Then Skip To Why have you completed Do Not Resusc...If No, I haven't completed Is Selected, Then Skip To Why haven't you completed Do Not Resu...

Why have you completed Do Not Resuscitate Order (DNR)? Check all that apply
- To ensure my wishes are met
- My doctor told me to
- My family wanted me to
- Because of the death of someone I know
- It's important to me
- To ease the burden on my family
- Other ______________________

If Why have you completed&nbsp... Is Greater Than or Equal to 1, Then Skip To End of Block

Why haven't you completed Do Not Resuscitate Order (DNR)? Check all that apply
- I have never heard of it
- I don't think I'll need it
- I don't know where to get this document
- The document is too hard to understand
- It takes too much time to complete
- I haven't gotten around to it / too busy
- I'm too young to need it now
- I'm too healthy to need it now
- I'm in the process of completing it
- Someone else will take care of it
- I don't have anyone to make decisions for me
- Other ______________________

If Why haven't you completed&n... Is Greater Than or Equal to 1, Then Skip To End of Block

How much thought have you given your own end of life wishes?
- A great deal of thought
- Some thought
- Not very much thought
- No thought at all

Do you have any final thoughts or comments?