

Improving Advance Directive Completion Rates: Utilizing Technology with a Virtual Platform

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Abstract

Advance care planning and advance directives guide patients in remaining autonomous when considering and planning for future healthcare. Improving the regularity of advance care planning as a preventative measure and increasing the number of individuals who have completed advance directives contributes to robust palliative care resources for patients. The purpose of this quasi-experimental, pretest- posttest design project was to determine if the evidence based advance directive intervention increased legal documentation and completion rates among adults in the community. A webpage was built to guide patients through education and decision making. Participants included adults over the age of 18 without a terminal illness diagnosis and with or without current advance directives. Follow up surveys were collected at 3 months' post intervention. The intervention was accessed by participants from home or other convenient location. The intervention implemented and included materials from the PREPARE for your Care program. Advance directive paperwork was downloadable at the conclusion of the educational intervention. There was a significant difference in advance directive completion status prior to intervention and post intervention. Increasing the prevalence and number of individuals who have advance care planning conversations and documentation can improve care provided to patients and client satisfaction. Nurse practitioners account for more than 600 million medical office visits per year in the United States. They are in a crucial position to educate, advocate, and support the completion of advance directives. Low completion rates of advance directives directly result in a higher level of Medicare spending, higher likelihood of in-hospital deaths, lower utilization of hospice care, and decreased quality of life.

Keywords: end-of-life care, advance directive, advance care planning, education, counseling, interventions

Improving Advance Directive Completion Rates: Utilizing Technology with a Virtual Platform

Advance care planning (ACP) and advance directives (AD) facilitate personal end-of-life care wishes to be recognized prior to a life-altering accident or debilitating disease. Increasing the prevalence of patients who participate in advance care planning and formulate an advance directive will enhance care delivered to patients nearing the end-of-life. The project concentrated on an intervention to increase completion rates of advance directives through counseling and education in the outpatient setting.

Advance care planning involves conversations with individuals, their healthcare provider, and their families to reflect on and discuss goals, values, and beliefs that may impact future provision of healthcare (Splendore & Grant, 2017). During advance care planning, documents are contracted between a patient and their loved ones to facilitate family members in knowing what medical treatments the patient would want for themselves. Advance directives embrace the promise of increasing the possibility that diagnostic, preventative, therapeutic, and palliative interventions will be provided to patients within their outlined desired preferences (Patel, Sinuff & Cook, 2004).

It is essential all people have medical management consistent with their values and desires. Advance care planning allows for these emotionally charged discussions to transpire between patients, medical providers and family members. These dialogs require reflection on particular illnesses, treatment options, and understanding of personal values, beliefs, and goals of care. This allows an individual to recognize their beliefs and wishes. Discussions surrounding the goals of care direct patients and their families to consider illness or disease, and the trajectory. Understanding these aspects of their care enables them to make decisions that are consistent with the patients' values and goals (Ahia & Blaisa, 2014).

At times, researchers have questioned the usefulness of advance directives, specifically with many changes in our health care systems (Silveira, Kim, and Langa, 2010). A study that investigated 3756 subjects in regard to decision making capacity and end of life care reported those with documented advance directives received the care that was within their delineated preferences and values (Silveira, Kim, & Langa, 2010). This study supports the continued use of advance directives and advance care planning. Advance directive discussions involving family and the patient with emphasis on patients' goals of care not only improve future end of life care and family stress, but also positively impact patient satisfaction (Spoelhof & Elliott, 2012).

As a whole, Americans are living longer and healthcare costs increase with age. Investigation of Medicare data conducted by the Kaiser Family Foundation found Medicare spending rises with age and peaks at age 96. Out of pocket cost for patients at age 96 is \$16,145, and this figure is more than double the per capita spending at age 70 (\$7,566) (Morrison, 2015). Care in the last year of life has been estimated to be approximately \$71,517 (Teno & Gozalo, 2014). It has been suggested, utilization of hospice drastically reduces healthcare costs and could offer a savings of \$9,000 per patient (Teno & Gonzalo, 2014). Advance directives can increase prevalence of patients choosing less invasive and intense treatments in the end of life. Education can better facilitate patients' understanding hospice and end of life care, ensuring more informed decisions regarding care they desire to receive.

Missouri State Department of Health and Senior Services does not currently track the completion of advance directives. In November of 2017, Missouri enacted a new law establishing the Advance Health Care Directives Registry, intended to safely store advance health care directives online for direct access by authorized health care providers (Davidson, 2017). This legislation supports the efforts to improve documentation of advance directives and

make these documents available to healthcare providers. Nationally, the Patient Self-Determination Act of 1991 was passed to assist in making a positive change in the United States between healthcare consumers and providers. The goals of the legislation were to provide education surrounding individual rights to make decisions concerning healthcare, stimulate greater formulation of advance directives, and reduce treatment costs at the end of life by preventing unwanted and unnecessary care (Duke, Yarbrough, & Pang, 2009).

Diversity was a key aspect to this Doctor of Nursing Practice (DNP) project. The evidence shows patients younger in age, those with a lower educational level, and individuals with low income level are less likely to have an advance directive as well as non-white population (Enguidanos & Ailshire, 2017). It is important to try and enroll these minorities in the study to increase their understanding and education regarding healthcare and end-of-life options. The area is a diverse city but neighborhoods are often grouped together with like people. For this project, the investigator's recruitment efforts considered diverse cultural, racial, spiritual, and geographical aspects.

Problem and Purpose

United States completion rates for advance directives are low at about 18-36% of all adults (Hinderer & Lee, 2014). Improving completion rates of advance directives has been acknowledged as a national priority and continues to be the subject of several healthcare practice, policy, and research initiatives (Enguidanos & Ailshire, 2016). Nurse practitioners are positioned to educate patients and continue to improve these rates, in turn improving patient centered care and increasing satisfaction.

The purpose of this DNP project was to determine if an evidence based advance directive intervention increases legal documentation and completion rates in healthy adults in Missouri.

The secondary purpose included investigating the role of an interactive webpage and digital delivery for the intervention.

The DNP project in a virtual interactive webpage was facilitated by creating partnerships with local primary care providers, community resources, and personal outreach to include patients in need of education. The main barrier to the implementation of the project was recruitment of a diverse population, participant follow up, and funding. The sustainability of this project will rely on ease of use of the webpage and resources to keep the webpage active. It was important to create partnerships with local provider offices to support enrolling patients and continue to impact patients after the program.

Review of the Evidence

The question investigated in this project was: In healthy adults without terminal diagnosis, does an interactive webpage advance directive counseling and education program compared to current practice of conversation with primary care provider, improve legal documentation and completion rates during a 3-month period in Missouri residents?

Search

An integrative review of qualitative and quantitative studies was performed. CINAHL, PubMed, Cochrane, Ovid Medline, and ERIC databases were surveyed. Keywords included counseling, education, advance directives, advance care planning, end-of-life care, aging, nurse practitioner, motivational interviewing, ethics, palliative care, and preventative care. Studies published in the English language between 2000 and 2017, that evaluated an intervention for advance directives, discussed completion rates of advance directives or considered of improvement of care surrounding end-of-life and advance care planning were further reviewed. Data regarding educational interventions or methods to improve advance directive completions

rates, knowledge and attitudes relating to advance care planning was extracted as these impact the successfulness of an education program. Exclusions were based on date of publication and language other than English. Data was compared in regards to population, age, setting, and design and themes were identified within the studies.

Synthesis

The results were further reviewed and revealed the following characteristics in regards to study design and level of evidence on 35 studies (Melnik & Overholt, 2015, adapted; Appendix A). Nine of the reviewed studies were level one evidence all of which were systematic reviews. Six studies were level two evidence randomized control trials. Three studies were found to be level three, one each of pre-posttest repeated measures, quasi-experimental, and descriptive correlational. There were two level four studies, one retrospective cohort, and one prospective single cohort. Three level five studies included two retrospective and one qualitative. The review found eight level six studies that included two quantitative descriptive, one mixed-methods(pre-post), three qualitative analyses, one quality improvement, and one observational study. Finally, three studies were level seven which included one narrative review, one review and technical brief, and one opinion of experts.

Themes evident in the research included counseling, decision making, knowledge, palliative care, empowerment, and autonomy (see Appendix B for key term definition). Decision making was an underlying theme in almost all the studies analyzed. The main goal of the student investigator's project was to educate and counsel patients on the important factors of advance directives. Many studies investigated education and counseling techniques to support implementation of advance directive paperwork (see Appendix C for evidence table). Using empowerment to encourage and stimulate adults to complete advance directives was seen as a

way to improve interventions. Lastly, autonomy is an underlying theme always associated with advance directives.

Counseling

It is believed healthcare counseling provides profound changes in the prevailing communication gap between health care professionals and patients (Nair, Leena, & Ajithkumar, 2016). Counseling in healthcare is often a measure used to support a patient to make an alteration that will help them transform their lifestyle, address maladaptive behaviors, or to work through emotions regarding healthcare decisions (Kealy & Lee, 2014). Studies with the dominant theme of counseling had predominantly positive results when reflecting on increasing understanding, knowledge, and completion rates of advance directives. Multiple interventions studied involved using a published resource to improve various aspects of completing advance directives. Splendore and Grant (2017) utilized the *Five Wishes* document in the intervention in which participants had significantly increased completion rates (48%) of advance directives at the one-month follow-up. Bravo et al. (2016) utilized a booklet *My Preferences* and the intervention group upon completion of the study had an 80% completion rate which was significantly higher than the 33% in the control group.

Multimodal, Multi-session

Interventions that are multi modal and multi-session were seen to be associated with statistically significant increase in completed advance directives (Bravo, Dubois, & Wagneur, 2008; Durbin, Fish, Bachman, & Smith, 2010; Patel, Sinuff, & Cook, 2004; Ramsaroop, Reid, & Adelman, 2007; Tamayo-Velaquez et al., 2009) Interactive interventions involving direct patient contact and live discussion with the provider were more successful than didactic education, signifying that a counseling approach as opposed to education alone is important when the goal

is to improve advance directive completion (Jezewski, Meeker, Sessanna, & Finnell, 2007; Salmond, 2005). Despite being more labor intensive and time consuming, accurate understanding of an advance directive purpose and implication was best achieved through repeated encounters with knowledgeable educators (Bravo, Dubois & Wagneur, 2008). This enables informed end-of-life decisions to be made.

Decision Making

Studies discussing interventions for advance directives often focus on decision making. A qualitative analysis found four factors as instrumental in preparing patients for decision making regarding advance directives: identifying values based on previous healthcare occurrences and quality of life, choosing surrogates judiciously and verifying they understand their role, informing family members and friends of ones wishes to prevent conflict, and deciding on granting leeway in surrogate decision making (McMahan, Knight, Fried, & Sudore, 2013). Targeting all participants including healthcare professionals and multiple stakeholders is important in increasing the completion rate (Litzelman et al., 2017; Walczak, Butow, Bu, & Clayton, 2015) These studies evidenced that the intervention should not only be focused on the patient but also the delivery of information in a clear way to guide the path for decision making. Use of decision aids was seen to provide guidance to patients when discussing end-of-life concerns. These decision aids enabled patients to obtain more information regarding conditions and care one might receive.

Use of the decision aids evidenced improved engagement of patients in the interventions (Butler, Ratner, McCreedy, Shippee, & Kane, 2014; Sudore et al., 2017). Butler et al. (2014) reported that condition specific aids improved understanding and general decisions aids were less likely to help patients consider their decisions. Similarly noted, those patients who were more

likely to have or complete advance directives had a more positive attitude towards advance directives and had higher scores on the advance directive attitude survey (Douglas & Brown, 2002).

Knowledge

Evaluating attitudes associated with advance care planning could guide intervention and improve decision making capacity. It is suggested in the literature that increased knowledge and positive attitudes regarding advance directives will be associated with increased completion rates of documentation. Kermel-Schiffman and Werner (2017) evaluated 37 articles investigating knowledge as related to advance directives and evidence shows that the general population knows some aspects of advance care planning, but comprehensive knowledge is lacking. Evaluating knowledge and improving understanding during intervention will contribute to success. An education intervention needs to focus on improved knowledge and using existing studies, methods and measures can be combined to create a more robust program to benefit patients.

Palliative Care

Studies have indicated patients who are nearing end of life are more likely to complete an advance directive, as are the patients who receive more robust palliative care referrals (Enguidanos and Ailsire, 2017; McDonald, 2016; Rao, Anderson, Lin, & Laux, 2014). House and Lach (2014) found significant differences in completion based on age. Patients 60 and older are 50% more likely to have advance directives than those younger than 60. Rao et al. (2014) indicate that in addition to considering age, data indicates that racial and education disparities exist and interventions need to take this data into consideration. Studies that did not implement a standardized advanced directive were able to still evaluate the success of the intervention.

Completion rates are only one component of advance directive but interventions can still measure completion or specification of power of attorney, a specific component of a full advance directive (Weathers et al., 2016; Clark et al., 2015). Engaging in palliative care and planning for end of life increases the likelihood of expressing wishes (81%) and appointing a surrogate (84%; Detering, Hancock, Reade, & Silvester, 2010). Satisfaction in both family and patients increased in intervention groups, also noting that family members of those who may have died, had significantly decreased worry, stress, grief and sadness than the control group (Detering, Hancock, Reade, & Silvester, 2010). It was critical that advance directives were developed by the patients before debilitation of neurological status. Discussions with caregivers are useful, but without knowing wishes caregivers were hesitant to formulate advance directives (Sampson et al., 2010)

Empowerment

Assisting patients to evaluate their values, beliefs, and desires for future healthcare can be a challenging task. Empowerment when considering group counseling and education can be described as realization of the capability of a group to attain its goals (Friend, 2015). It can be regarded mutually as a process and outcome. In addition, group empowerment is an active process, not just the momentary authority and responsibility of having a patient complete a task (Friend, 2015).

Evaluating and discussing life values, attitudes towards advance directives, and goals of care can be an important consideration when designing an intervention to increase completion rates. Evangelista et al. (2012) found that when patients used the Advance Directive Attitude Scale (ADAS) in combination with palliative care planning, ADAS scores increased over 20 points, and completed advance directives increased from 27.8% to 47%. Incorporating attitudes

and empowering patients to make decisions and evaluate their choices can improve not only the completion rates, but also patient care. Lankarani-Fard et al. (2010) suggest a simple card game can be applied as a decision making tool and empower patients to consider their preferences and improve discussion with a healthcare provider. These studies indicate that by targeting multiple aspects of advance care planning a comprehensive intervention could be more successful if various tools are used to empower patients in decision making.

Motivational Interviewing

Motivational interviewing when discussing end of life care and advance directives is applicable because it embodies the patients' abilities to make their own decisions instilling autonomy and self-determination. Using motivational interviewing allows individuals to recognize their uncertainty for advance care planning and review their values and beliefs (Ko, Hohman, Lee, Ngo, & Woodruff, 2016).

Theory

The health belief model is a psychology model that is often a borrowed theory in nursing. The model was developed as a way to explain why a limited number of people participate in health promotion programs that aim to prevent and detect disease (Butts & Rich, 2018). A group of social psychologists theorized an individual's personal health beliefs on whether they were susceptible to disease and perceptions about the benefits of preventing specific diseases influenced each person's willingness to act (Butts & Rich, 2018). The theory focuses on six main constructs that influence decisions related to health concerns. The six constructs are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue to action, and self-efficacy (Butts & Rich, 2018). Lott (2014) used the health belief model in a study to evaluate advanced directives in community dwelling adults ($N = 177$). The researcher found among the

population, the majority of people who participated viewed themselves as healthy, and therefore had a decreased perceived need for advance directives (Lott, 2014). This study did not evaluate the effects of counseling or education on the participants, but indicates the need for counseling to help people perceive the need for advance directives despite health status. It was essential to consider that people may not feel they are at risk and will have a decreased perception of need, which was an anticipated barrier.

Applying a theory that focuses on behavior change is supportive when discussing an intervention aimed at improving completion rates of advance directives (see Appendix D for theory application diagram). The theory that evaluates influencing factors of the behavior of completing an advance directive can contribute to providers being able to support their patient's end of life decisions (Campbell, Edwards, Ward, & Weatherby, 2007). The health belief model is an effective theoretical framework to use when developing and deploying health education or counseling strategies. The health belief model focuses on health motivation and is advantageous when applying to a problem that addresses behaviors which evoke health problems, like advance directives. This theory is primarily focused at the individual level, and as a result, interventional studies based on this theory also focus on the behavior change of individuals. The health belief model has been useful to apply to a broad range of health activities and focus populations. Three broad areas can be identified: preventive health behaviors, sick role behaviors, and clinic use (Conner & Norman, 1996).

Methods

The primary Institutional Review Board (IRB) for this project was the University of Missouri- Kansas City IRB. This DNP project met the UMKC research compliance office standards as human subjects research. Although it was intended to improve healthcare and

individual health, it was deemed research because it generates new knowledge and not just improvement to existing data. IRB approval was obtained through expedited review category seven (see Appendix E for approval).

Ethics

There were ethical considerations to account for when planning research. The major aspect of this DNP project was to ensure privacy and confidentiality. Participant data needed to be personal information, but ensuring privacy and ensuring the data was confidential to only the investigator was paramount. Protection of the participants was important as well. Discussing end-of-life care and advance directives can be a sensitive discussion, thus making sure the participants felt comfortable and protected was critical. Implied consent was obtained during enrollment in this project (see Appendix F for waiver of consent). In order to endorse a patient is competent to make informed decisions regarding advance directives, living wills, and Do Not Resuscitate (DNR) orders, these conferences and arrangements should not occur in a critical situation (Petty, DeGarmo, Aitchison, Aitchison, Wang, & Kharasch, 2013). This is a discussion that should take time and consideration, and involve personal medical information in order to individualize decision making, which supports why an interactive setting with involved family and friends was important. Autonomy was considered paramount. If participants involve loved ones, it was important to include them in the decision making process, but it was ensured that the patient was the center of the decision making. There were no perceived investigator conflicts of interest at the time of this study.

Funding

Funding for this project made the entire project more robust. Supplemental funds aside from the student investigator allowed for additional resources to not only support the project but

also assist with recruitment and retention. Funding was used for supply costs, webpage design and hosting (see Appendix G for Cost Table). The additional funds (\$186) were obtained from the UMKC Women's Graduate Fund.

Setting, Participants

The setting for the project was a virtual setting. An interactive webpage was built to guide patients through education and decision making. Telephone follow-up was offered to participants after completion of the intervention to ask additional questions or participate in further counseling, but no participants requested this aspect of the study. Participants included adults over the age of 18 without a terminal illness diagnosis and with or without current advance directives. The student investigator allowed anyone to participate in the intervention, but actual participants in the data collection excluded any terminal illness. The sampling method used was convenience sampling. This project required marketing and distribution of flyers to promote the webpage and recruit participants within multiple communities in the state of Missouri (see Appendix H for recruitment flyer). The project recruited 40 participants with 37 completing the intervention and follow up surveys. Descriptive statistics was performed on the demographic data collected from participants. The participants' responses suggested a diverse background pertaining to age, educational level and religious preference. Ethnicity was a limitation in regards to diversity.

Intervention

The evidence based intervention used for this community program involved comprehensive education and counseling regarding advance directives, including end of life care, benefits of advance care planning, and about the advance directive documentation specifically. Recruitment began upon IRB approval in October 2018. This included placement of

flyers in key community locations including healthcare facilities throughout Missouri. Healthcare facilities were approached for inclusion in recruitment and flyers placed once approved. Participants were recruited in a convenience sampling method. Flyers were available in key healthcare locations including primary care providers' offices, community health clinics, and hospital lobbies. Participants were encouraged to include their family or friends during the online interaction.

The intervention took place in an online format via an interactive website accessed by participants from home or other convenient location. Upon enrollment in the intervention, participants were informed about project and completed baseline data. Baseline data included demographic data, current advanced directive status, and an advance directive engagement survey. The intervention implemented and included materials from the PREPARE for your Care program (Sudore, 2017; Appendix I). This was a step-by-step video platform to support participants having a voice in their medical care, talking with providers, and facilitating questions being answered about their medical wishes. Advance directive paperwork was downloadable at the conclusion of the educational intervention. Follow up three months after the intervention included an email survey to determine if the paperwork had been completed and legally notarized (see Appendix J Intervention Flow Diagram; Appendix K Project Time Line).

Change, EBP, Sustainability

The change model utilized was the transtheoretical model. The model elicits behavior change by evaluating stages of change through delineated steps. An individual follows the process of pre-contemplation, contemplation, preparation, action, and maintenance (Butts & Rich, 2018). These stages of change can be used to not only describe why a patient may not be ready for change, but also to improve the success of a patient education intervention (Butts &

Rich, 2018). Ko, Homan, Lee, Ngo, and Woodruff (2016) conducted a pilot study evaluating a motivational interviewing intervention in relation to advance directives. The aim was to explore the feasibility and acceptability of motivational interviewing to create change in end-of-life communication, advance directive communication, and readiness to participate in advance care planning (Ko et al., 2016). The study found the transtheoretical model was compatible with motivational interviewing because it helped clinicians understand patients who were thinking about change but not actively seeking transformation (Ko et al., 2016). The evidence based practice model appropriate to the project was the Stetler Model. This model is known as the practitioner oriented model and the project proposed is geared toward an individual practitioner and should fit with this model. One of the assumptions of the model used research findings at the level of an individual clinician, indicating the individual continually updates his or her knowledge base (Stetler, 2001). It could certainly be used at the organizational level through policies and procedures, but the individual practitioner is a focus. Critical thinking plays a key role in the model as well as within the project (see Appendix L for Logic Model).

Sustainability of the project is achievable. The project is able to be managed by limited individuals and participants move through the education intervention seamlessly. The use of technology enables the intervention to be streamlined and delivered via the current setup, an app or interactive methods within a primary care office. Based on results of the study, this could become a useful tool to initiate conversations with patients during their preventative exams. Initial thoughts would be this could be delivered to patients while waiting in the waiting room and in the exam room. It is also possible it could be done before a visit with the primary care provider, while following up the conversation in the primary care provider office to further discuss and finalize as appropriate.

Design

The study design was a quasi-experimental, single group design with pre and post evaluation. It was considered unethical to have a randomized control trial with a control group that would not receive the benefits of an evidence based initiative of education and counseling on this crucial topic. Participants were evaluated prior to the intervention and again after the intervention to evaluate the impact of the education. The primary outcome was measured by an increased number of participants who had a legally documented advance directive. For the DNP project, the completion of advance directive documentation included legal notarization.

Validity

Potential threats to the data included participant sampling methods and attrition. Following up with patients after three months was challenging. Internal validity was important for this study as the premise is to see if the education intervention improves the documentation of advance directives. The critical question in internal validity was whether observed changes could be ascribed to the intervention. Ensuring the intervention was strictly related to advance directives and outside sources were not influencing participants, will increase validity and ability to show a causal relationship. External validity was the ability to generalize results to and across individuals, settings, and time periods. This was also imperative for the DNP project. External validity was needed to take into consideration population validity in ensuring the sample included diverse populations. Diverse populations were attempted during sampling but was unable to be tracked directly.

Outcomes, Measurement Instruments

The primary outcome was measured by self-report of legal completion of Missouri state advance directive paperwork. The Advance Care Planning Engagement Survey (see Appendix

M) was used to gain insight into what stage of behavior change participants were for advance care planning. The measurements were done upon enrollment. Permission for use of this instrument was obtained from the PREPARE for Your Care team. (see Appendix N for license agreement). The 34-item version of the survey included Behavior Change Process measures and took approximately 10-15 minutes to complete. This survey used a 5-point Likert response. The Behavior Change Process score was reported as an overall 5-point Likert score and synchronizes with behavior change stages. The Behavior Change Process measure includes validated subscales of knowledge, self-efficacy, and readiness reported individually as average 5-point Likert scales. Internal consistency was measured with Cronbach's alpha for the ACP process and was 0.94. Test-retest reliability for the survey was measured at 0.70.

A priori power analysis was performed to determine sample size to ensure the project produced meaningful and applicable results. The measurement was a 1 tailed hypothesis, power of 0.8, medium of 0.5, and alpha of 0.05 resulting in a total sample size of 102. The goal sample size for this project was 110 participants.

The measures of this DNP project are seen frequently in current research independently. Baseline data was collected upon enrollment in the study, the same data points were again collected after the intervention at time of follow up. There was a standard AD status question which was asked exactly the same way pre and post intervention to all participants (See Appendix O for data collection template and survey). Many studies evaluate one component (time, type of intervention, number of visits, setting) of the measurements, but not on all measures in the same study. Although it was not the goal of this current study to make correlations between them, future research could benefit from this. The data collected can be compared to published data, but correlation is limited.

Results

Participants and Setting

A total of 40 qualified participants were recruited during the three-month enrollment period between October 2018 and December 2018. These 40 participants all filled out the screening survey and were sent information to participate in the advance directive project. Of the 40 participants, 37 completed the baseline survey, educational intervention, and follow up survey. All results were based upon the 37 completed participants. The advance directive engagement survey was part of the baseline data collection in a separate survey. This data was collected from 32 of the 37 participants. The survey was refused by 5 participants. Participants were enrolled through UMKC REDCap during a rolling period and received information as they joined. Information was confidential in REDCap without identifiers. The student investigator was able to monitor completion status without identification of participants. Follow up surveys were also on a rolling basis approximately three months following completion of the baseline surveys and educational intervention, with all data being collected by March 2019.

Intervention Course

After enrolling in the project on the webpage, participants received an email with a baseline survey and instructions on accessing the educational intervention. Completion dates were recorded through REDCap and follow up surveys were sent based upon that date. November and December 2018 were the largest enrollment months with 18 enrolled participants by the end of November and 40 enrolled by December 2018. Participants received email reminders about completion of baseline data and the intervention once weekly until completed. Three participants did not respond, and were removed from the study. Follow up surveys were sent starting in January 2019, with the last of data collection being finalized in March 2019.

Outcome Data

Advance directive status. The baseline data collected indicated that 29.7% of the study participants already had an advance directive in place. After participation in the educational intervention at time of follow up, 70.3% reported having a completed advance directive. At follow up, 16 participants reported not having completed an advance directive, although 13 (81.3%) of the participants indicated they had plans to complete in the next 6 months. A McNemar test was conducted to compare advance directive completion status before and after the educational intervention. There was a significant difference ($p= 0.00006$) in advance directive completion status prior to intervention and post intervention (see Appendix P for data analysis table). Missing data included the three participants who did not complete the full study and follow up.

Advance directive engagement, behavior change. The Advance Directive Engagement survey was used to provide data regarding the stage of behavior change of the participants (see Appendix P for analysis table). Pre-Contemplation was the stage which yielded the greatest percentage (35%) of participants as classified. The contemplation and preparation stages each yielded 13.5%, while the action stage yielded 24.3%. The missing data was 13.5%. This data can be used to help tailor future interventions aimed at behavior change.

Discussion

The results suggest an educational intervention to counsel patients improves legal completion rates of advance directives. Specifically, when patients become interactive and proactive about their care, their autonomy is improved with an advance directive. The study was successful in supporting the interventions to increase patients' understanding of advance care planning as critical components to patient centered care. An online format was successful in

enrolling patients and providing participants with a new way to engage in their healthcare decisions. The online format allowed for ease of access and comfort of participants. Using a previously validated evidence based intervention (PREPARE For Your Care) ensured that participants were provided adequate information and support throughout the process. Surveys produced through REDCap allowed for participants to access via computer or smartphone and complete in a way that was most accessible for their personal preferences. This gave some flexibility to the intervention making the study less of a task to complete for the participant.

Comparison to Published Evidence

The data collected during the baseline survey aligned with current national trends. Current national statistics indicate that advance directive completion rates are no higher than 25-35%. This project indicated the study sample had a 29.7% completion rate prior to education. Splendore (2017) conducted a similar study utilizing a community workshop for the educational intervention and found similar findings as the current project. The study had 40 participants recruited by convenience sampling and showed a statistically significant increase in the number of participants completing an advance directive. After completion of the intervention in the study, 15 of the participants completed documentation, with an additional seven who had completed an advance directive prior to the workshop. Bravo et al. (2016) utilized a booklet *My Preferences*, indicating the intervention group upon completion of the study had an 80% completion rate which was significantly higher than the 33% in the control group. The study had a similar completion percentage as the current project, although the Bravo et al. study had a much larger sample size of 235 and included patients and their proxies. Hamayoshi (2014) study indicated that there was a significant increase in the number of people who completed an advance directive four months' post intervention. The study supports that an education program

may promote advance directive completion and improved attitude towards advance care planning (Hamayoshi, 2014).

Sudore (2107) developed the PREPARE website and video used in this DNP project intervention. This study was conducted with a larger sample size of 414, but similarly reported patients having higher advance care planning engagement and potential for advance directive completions after the website and video intervention. Schwartz (2002) evaluated the short term clinical utility of early ACP interventions with ambulatory patients. The community based study involved geriatric patients. Study results were similar to other published study results with the intervention group having an increased use of advanced directive documentation, 76% vs 55%.

Limitations

All efforts were made to create a valid study that would be impactful to improvement of healthcare now and in the future. Limitations of this project included a small sample size, unmonitored intervention, diversity and demographic of participants, convenience sampling, and unverified advance directive status. Although internal validity was improved with valid instruments and a standardized intervention process, the intervention was completed on the participants' time. It was a self-reported completion, but this could have been manipulated by the participant who may have watched some, all, or none of the video. At completion of the project, participants were asked via a survey if an advanced directive was completed. This was a standardized approach and was consistent with all participants, but no verification of a completed document was performed. It is important to consider that although this may limit internal validity, it could potentially invade participant privacy if the process included collection or viewing of Advance directive documents. The sample size was aimed to be over 100, but only 40 were obtained. Convenience sampling was used, and it is recognized that those who may not

have been interested in advance care planning, would have not enrolled and only those who were already amenable or interested would participate. External validity was improved with a diverse age range, educational level and religious preference, but ethnicity was limited (94.6% Caucasian). A diverse population was attempted with wide-reaching recruitment efforts and placement of information in many locations. These factors may limit the generalizability and application to populations unlike the project sample.

Sustainability

The improved completion rate seen in this study is a great success, but efforts must be continued on a daily basis in healthcare to continue with widespread improvement. Plans to continue improvement include keeping the website active with education material and direction to the PREPARE For You Care video and other evidence based resources. Links could be provided to direct patients to outside sources that are validated. Continued communication with patients and encouragement of advance directives in the community setting can be considered. It is possible to consider developing an APP to be used by patients when presenting to their primary care provider to facilitate advance care planning conversations. While this project did not target education of healthcare providers, this is considered a potential point that could improve future endeavors. Developing a provider education module to educate and teach how to conduct advance care planning discussions with patients would strengthen efforts started with this project.

Interpretation

Evidence evaluated throughout the project clearly suggested the success of educational interventions depends upon multiple factors. A majority of the studies support continued efforts to improve advance directive completion rates as they are usually successful. It was anticipated

the project intervention would be successful in improving the completion rate of advance directives. Despite the small sample size, which was less participants than planned, the intervention was successful, although power was less than .8 or 80%. Recruitment was considered a challenge in the project. It was very difficult to successfully have patients enroll in the project after discussion and being given a flyer. Many patients were excited to learn about the tool and left the office stating they would participate, but enrollment did not match interest. An effort to engage medical groups and offices in the Missouri area was also a struggle, and many responded to initial efforts and approval, but then lacked in communication about distribution of flyers. Three medical practices participated in distribution of flyers to potential participants. Direct mailing of flyers was a failure as the financial aspect was very cost prohibitive.

Intervention Revision, Settings

The online format contributed to effectiveness because it allowed for convenience for participants. Continued access to education materials at home and interventions aimed at supplementing discussions with primary care providers could create a more robust intervention. Opportunities for improving the current scientific evidence for this intervention include comprehensive education offerings in a community or primary care setting with the ability to involve and include friends or family. The intervention would benefit from a structured program, involvement of multiple health care team members, and using multi modal methods. Community settings can allow for more patients to participate in the education efforts that often require extended time, but a primary care office is also a consideration with follow up at home. Use of a values inventory and resources that elicit patients to reflect on their goals of care would improve the intervention. The use of decisions aids was seen in evidence to improve engagement of patients in the interventions (Butler, Ratner, McCreedy, Shippee, & Kane, 2014; Sudore et al.,

2017). Educational efforts with direct counseling and personal patient contact is evidenced to be most effective (Bravo 2008; Durbin 2010), and the student investigator recommends additional components and patient contact in the intervention without being too complex which may lead to additional improvement of AD completion.

Healthcare System, Economic, and Policy Considerations

The study was consistent with healthcare data suggesting advance care planning interventions are successful in improving community awareness, involvement, and completion of advance directives. This project raised awareness that additional health system and policy changes are necessary to create national impact. The project helped with identification of the need for sufficient infrastructure to support implementation of advance care planning, as well as need for national initiatives to improve care surrounding advance care planning. The costs of this project were less than anticipated although the major cost of anticipated mailing was terminated for that reason. Estimated total cost for the project was \$3,139 with the final cost of the project being \$1,268.39. Efforts were made to reduce cost without effecting the success of the project. Many costs associated with the project related to initiation of the webpage. It would be anticipated that costs related to sustainability would be significantly less considering it would mainly be a yearly fee for the website hosting. Economic sustainability would need to be a priority if improving the intervention was considered.

Conclusion

Advance care planning and advance directives facilitate personal end of life care wishes to be recognized prior to a life-altering accident or debilitating disease. Increasing the prevalence and number of individuals that have advance directive documents can improve the quality of care provided to patients at the end of life. Current research and this project support advance care

planning education and counseling interventions to increase the prevalence of Americans who have a completed advance directive. Interventions aimed at increasing knowledge through comprehensive material delivered through direct counseling with patients are shown to be more effective.

Success of this project may lead to future studies to correlate knowledge, attitudes, and completion rate when implementing an education and counseling intervention. It is theorized by the student investigator that an increased knowledge and higher attitude score after an intervention would improve completion rates of advance directives. Additional research is needed to support this hypothesis.

Dissemination of the project included a poster presentation at the Advanced Practice Nurses of the Ozarks annual conference in November 2018, and results will be disseminated at the Sigma Theta Tau International Research Congress in Calgary Canada in July 2019. A manuscript will be submitted to *The Journal of American Association of Nurse Practitioners*.

Nurse practitioners account for more than 600 million medical office visits per year in the United States. They are in a crucial position to educate, advocate, and support the completion of advance directives (Hinders, 2012). Low completion rates of advance directives directly result in a higher level of Medicare spending, higher likelihood of in-hospital deaths, lower utilization of hospice care, and decreased quality of life (Splendore & Grant, 2017).

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Appendix A

Rating System for the Hierarchy of Evidence For an Interventional Inquiry (Modification by Dr. Lindholm for course N5613)	
Level I	Evidence from a systematic review or meta-analysis of all relevant RCTs. <i>Evidence-based clinical practice guidelines based on systematic reviews of RCTs.</i>
Level II	Evidence obtained from a well-designed RCT. <i>Quantitative systematic review of well-designed controlled trials without randomization.</i>
Level III	Evidence obtained from a well-designed controlled trial without randomization (<i>quasi-experimental</i>). <i>Quantitative systematic review of case-control, cohort, or correlational studies.</i>
Level IV	Evidence from a well-designed case-control or cohort study or cross-sectional study.
Level V	Evidence from a systematic review of quantitative descriptive (no relationships to examine) or qualitative studies.
Level VI	Evidence from a single quantitative descriptive (no relationships to examine in the study) or qualitative study.
Level VII	Evidence from the opinion of authorities and/or reports of expert committees.

Melnik, B. M. & Fineout-Overholt, E. (2015). *Evidence-based practice in nursing and healthcare*. Philadelphia: Lippincott Williams & Wilkins.

**Italics, appropriate in this category, modification by LL2017 based on opinions from experts to place RCT at one level higher than single study design level.*

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Appendix B

Key Term Definitions

Advanced care planning	Process where patients communicate ideas and aims for future medical care (Sudore et al., 2017)
Advanced directive	Written documents used to verbalize and guide future medical care. Advanced directives encompasses living wills, power of attorney, and do not resuscitate orders (Splendore & Grant, 2017).
Decision Making	Cognitive process used to make decision (Cox & Graber, 2017).
Counseling	Counseling in healthcare is often a measure used to help a patient make an alteration that will help them transform their lifestyle, address maladaptive behaviors, or to work through emotions regarding health care decisions (Kealy & Lee, 2014). Counseling can provide a better provider patient relationship than education alone.
Palliative Care	Palliative care is a method of care that focuses on improving quality of life in patients facing illness. Palliative care involves addressing not only physical care but also including intellectual, social, emotional, and spiritual desires
Empowerment	Empowerment when considering group counseling and education, can be described as realization of the capability of a group to attain its goals (Friend, 2015). Active process, not just the momentary authority and responsibility of having a patient complete a task (Friend, 2015).
Knowledge	Knowledge concerns an individual having facts or information obtained through experience or education.
Autonomy	Making one's own decisions and being involved in care choices and treatment plans.

Appendix C

Gibbons Review of Evidence Table						
PICOTS: In healthy adults without terminal diagnosis (P), does an interactive webpage advanced directive counseling and education program (I) compared to current standards (C) improve legal documentation and completion rates (O) during a 3-month period (T) in Missouri residents (S)?						
First author, Year, Title, Journal	Purpose	Research Design¹, Evidence Level² & Variables	Sample & Sampling, Setting	Measures & Reliability (if reported)	Results & Analysis Used	Limitations & Usefulness
Theme: Counseling						
Splendore (2017) A nurse practitioner-led community workshop: Increasing adult participation in advance care planning. <i>Journal of American Association of Nurse Practitioners</i>	Increase understanding and participation in the ACP process in rural community	Pre-post repeated measures design Level 3 Variables: understanding, completion, discussion, dissemination of ADs and ACP	Sample: 40 people 18 and older Sampling: Convenience sampling Setting: Rural community	Measures: 19 item self-report questionnaire Intervention: 90-minute workshop Independent t-test, chi-square, and Fischers exact test	Results: 15 (48%) of the participants completed an AD as a result of the intervention Workshop significantly increased participants understanding of Living Wills paired-t tests	Limitations: Participation based on convenience Instruments: not validated Usefulness: show increase in completion of ADs
Bravo (2016). Promoting advanced care planning among community-based older adults: A randomized controlled trial. <i>Social Science & Medicine</i>	Test intervention to motivate adults in completing advanced directives	Randomized control trial Level 2 Variables of health education program and control of none	Sample: 235 patients (age >70) and their proxies Sampling: Random sampling of list from administrative database of Quebec universal health insurance plan Setting: Community setting	Measures: Accuracy score for each question in survey- three options Booklet <i>My Preferences</i> Reliability: not reported	Results: 80% of adults in the experimental group completed advanced directives Analysis: SAS Proc MIXED test used to test effect of health state on desire for treatment	Limitations: Population of only older adults Usefulness: educational interventions can be successful

<p>Ko (2016) Feasibility and acceptability of a brief motivational stage-tailored intervention to advance care planning: A pilot study. <i>American Journal of Hospice & Palliative Medicine</i></p>	<p>Explore the use of motivational interviewing with education concentrated on end-of-life communication, completion of advanced directives, and readiness for ACP</p>	<p>A pre-test –posttest design Quantitative descriptive Level VI 7 outcome variables:</p>	<p>Sample: 30 older adults Sampling: Participants were recruited from senior center in low income neighborhood Setting: community</p>	<p>Measures: Needs assessment to evaluate readiness for ACP Attitude: decisional balance scale Intervention: Stage matched motivational interviewing counseling and AD education Reliability: not reported</p>	<p>Results: 1/3 of participants had participated in EOL discussions before intervention, after was 46.7%, improved not statistically significant Analysis: Paired-samples t test</p>	<p>Limitations: Small sample size from one location Most participants were male Usefulness: motivational interviewing with education can improve inclination for AD</p>
<p>Hamayoshi (2014) Effects of an education program to promote advance directive completion in local residents. <i>General Medicine</i></p>	<p>An educational intervention to assist advanced directive completion, to observe effects on the AD completion rates</p>	<p>Quasi-experimental study- non randomized Level 3 Variables: completion rate, knowledge of dementia, attitudes associated with advanced directives</p>	<p>Sample: 169 Local welfare officers in 2 cities in Japan Sampling: Convenience sampling Setting: Communities in Japan</p>	<p>Measures: 2 indicators of completion and intention to complete advanced directive- yes or no answers AD knowledge test Reliability: Internal consistency using Cronbach's alpha was 0.79</p>	<p>Results: intervention showed a meaningful rise in the number of people with a completed AD 17% completion in intervention group Analysis: ANOVA</p>	<p>Limitations: Study done in Japan Completion rate was based off of self-report Population was limited to 2 cities Usefulness: education intervention was seen to improve completion rates</p>
<p>Durbin (2010) Systematic review of educational interventions for improving advance directive completion. <i>Journal of Nursing Scholarship</i></p>	<p>To investigate data surrounding outcome and percentage of completed advanced directives, focus on educational interventions.</p>	<p>Systematic review Level 1 Variables of educational intervention, completion of advance directives</p>	<p>Sample: 12 randomized studies 4 nonrandomized studies Sampling: Nursing, medical and social work text Published between 1991-2009 Setting: 2 studies inpatient, hospital based, 9 outpatient hospital based, and 1 community based</p>	<p>Measures: Review of literature Reliability: NA</p>	<p>Results: A multi-mode (video, verbal, and written) education intervention more effective than a single written intervention.</p>	<p>Limitations: Studies evaluated were all greater than 10 years ago Usefulness: question resource utilization-</p>

<p>Tamayo-Velazquez (2009) Interventions to promote the use of advance directives: An overview of systematic reviews. <i>Patient Education and Counseling</i></p>	<p>Reviews: effectiveness of interventions to increase advance directive completion.</p>	<p>Narrative review of literature Level VII Advanced directives, completion rate, interventions</p>	<p>Sample: 7 Systematic review of literature Sampling: 9 databases searched Setting: NA</p>	<p>Measures: NA Reliability: NA</p>	<p>Results: Most effective to use combination of explanatory methods and recurring discussions Analysis: NA</p>	<p>Limitations: narrative review, quality not discussed Usefulness: helpful to guide but should not base research off of findings in this article</p>
<p>Bravo (2008) Assessing the effectiveness of interventions to promote advanced directives among older adults: A systematic review and multi-level analysis. <i>Journal of Social Science and Medicine</i>.</p>	<p>Attempt to determine if a particular intervention for promoting advanced directives is more effective than another.</p>	<p>Systematic Review, multi-level analysis Level 1 Variables: Advanced directives, intervention</p>	<p>Sample: 55 studies, most studied a single group or were a RCT Sampling: 11 Setting: 51%outpatient 15% inpatient 11% nursing home</p>	<p>Measures: 2 reviewers analyzed and extracted data from studies Reliability: not discussed</p>	<p>Results: single-arm studies produced an AD completion rate of 45.6%. Multiple sessions the most successful. Analysis: multi-level-1 way ANOVA model with random effects</p>	<p>Limitations: Usefulness: These findings support the effectiveness of educational interventions in increasing the formulation of ADs and provide practical advice on how best to achieve this goal</p>
<p>Jezewski (2007) The effectiveness of interventions to increase Advance Directive Completion Rates. <i>Journal of Aging and Health</i></p>	<p>Synthesizes evidence in regards to interventions and their effectiveness in increasing AD completion rates</p>	<p>Systematic literature review Level 1 Advanced directives completion rates, intervention</p>	<p>Sample: 25 studies reviewed Sampling: Study needed to be published after 1994, measuring completion rates of AD Setting: NA</p>	<p>Measures: Gerrard's method for conducting systematic review Interventions: Didactic: information educational program or clinical encounter or by a mailing Interactive: person-to-person interaction Reliability: Not discussed</p>	<p>Results: Post intervention rates of AD completion were: didactic = no change to 34% increase; interactive = 23% to 71% increase. Analysis: NA</p>	<p>Limitations: no verification of legally completed AD, self-reported, convenience sampling Usefulness: Education without the ability to ask questions does not significantly increase the AD completion rate.</p>

<p>Ramsaroop (2007) Completing an advanced directive in the primary care setting: what do we need for success? <i>Journal of American Geriatric Society.</i></p>	<p>To review studies designed to increase AD completion in a primary care setting and to quantify their effects</p>	<p>Systematic review Level 1</p>	<p>Sample: 18 studies; 12 RCT, 2 quasi-experimental, 2 prospective trials, 1 observational, 1 retrospective cohort Sampling: 523 titles reviewed Setting: Primary care outpatient setting</p>	<p>Measures: Outcome: difference in completion rates between intervention and control arms.</p>	<p>Results: Statistically significant effects associated with intervention. direct patient-professional communications over multiple visits.</p>	<p>Limitations: none of the studies addressed comprehension of advanced directives Usefulness: interventions with direct patient interaction, involving more than one encounter were most effective.</p>
<p>Salmond (2005) Attitudes toward advance directives and advance directive completion rates. <i>Orthopedic Nursing</i></p>	<p>Identify significant attitudes and variables that impact completion of ADs in hospitalized adult patients</p>	<p>Descriptive correlational study Level 3 Variables: Knowledge, advanced directives, Attitude</p>	<p>Sample: 80 patients Sampling: Convenience sampling 1. At least 18 years 2. A&O x2 3. Able to speak and understand English Setting: adult hospitalized patients</p>	<p>Measures: ADAS survey adapted Test-retest reliability using persons product moment correlation coefficient was $r=0.79$ Internal consistency : Cronbach alpha 0.81</p>	<p>Results: 18% of the sample had completed an AD at baseline, 8% completed an AD after intervention 26% completion rate. The mean attitude toward ADs was slightly positive Analysis: not discussed</p>	<p>Limitations: hospitalized patients, Usefulness: Study shows that AD completion rates can be increased Simply passing out information is not helpful</p>
<p>Patel (2004) Influencing advance directive: Completion rates in non-terminally ill patients: A systematic review. <i>Journal of Critical Care</i></p>	<p>To determine effectiveness of educational interventions for patients without terminal illness on the completion rate of advance directives</p>	<p>Systematic Review Level 1 Variables: Advanced directive completion, intervention</p>	<p>Sample: 9 randomized control trials were included Sampling: pertinent retrieved articles. outcome needed to be reported as completion of Advanced directive</p>	<p>Measures: Cohens unweighted kappa and its 95% confidence interval Reliability: methodologic quality and reporting transparency were poor</p>	<p>Results: odds ratio: 3.71, statistically significant. Completion rate higher in patients receiving direct counseling. Analysis: Random effects, pooled odds ratio and 95% odds ratio</p>	<p>Limitations: excluded terminally ill patients Did not evaluate the quality of the process to obtain end of life care preferences Usefulness: supports a patient centered intervention involving direct counseling</p>

Theme: Decision Making						
Litzelman (2017) Impact of community health workers on elderly patients' advance care planning and health care utilization. <i>Medical Care</i>	To evaluate an intervention aimed at meeting the needs and priorities of patients with chronic diseases	Mixed methods, pre-post observational analysis Level VI Variables: NA	Sample: 818 patients age 65 and older Sampling: Convenience sampling Setting: Community	Measures: intervention increased ACP discussion Semi structured interviews Intervention: CCA received training to discuss ACP with patients, Reliability: not discussed	Results: ACP documentation rose from 3.4% to 47.9% Analysis: Qualitative: thematic analysis, Quantitative: chi squared test, Wilcoxon rank sum test	Limitations: not a randomized trial, Usefulness: unable to determine if the care provided by CCA attributed to increase documentation or decreased health utilization
Sudore (2017) Effect of the PREPARE Website vs an Easy-to-Read Advance Directive on Advance Care Planning Documentation and Engagement Among Veterans: A Randomized Clinical Trial. <i>JAMA Internal Medicine</i>	Determine efficacy of PREPARE program	Randomized control Trial Level 2	Sample: 414 Sampling: targeted recruitment after data obtained from VA Setting: San Francisco VA	Measures: validated surveys of behavior change process measures	Results: ACP 6 months after enrollment was higher in the PREPARE arm, 35% vs control 25% PREPARE resulted in higher self-reported ACP engagement Analysis: unpaired <i>t</i> tests, χ^2 , or Fisher exact tests	Limitations: only older veterans, 9% women PREPARE format is easy to use and could be an appropriate intervention for a community setting
Menon (2016) Use of a values inventory as a discussion aid about end of life care: A pilot randomized control trial. <i>Palliative and Supportive Care</i>	To determine the utility of a values inventory as a discussion aid to elicit patients' values and goals for end of life care in the outpatient setting.	Randomized control trial Level 2 Variables: Values inventory Advanced directive completion/discussion	Sample: 120 males, Sampling: Patients with 6-12-month life expectancy Setting: large VA medical center	Measures: Values inventory Reliability: not discussed	Results: 8 patients in control group, 13 in intervention group had EOL discussions. Not statistically significant. (p=0.77) Analysis: Qualitative content analysis	Limitations: conducted at VA facility, with only men. Usefulness: may be helpful to illicit values when planning intervention session

Walczak (2015) A systematic review of evidence for end-of-life communication interventions: Who do they target, how are they structured and do they work? <i>Journal of Patient Education and Counseling</i>	To identify and synthesize evidence surrounding interventions targeting end-of-life communication	Systematic Review Level 1	Sample: 45 studies Sampling: review of interventions Searched MEDLINE, Psych INFO, and CINAHL databases between 1950 and March 2014 Setting: NA	Measures: Interventions targeted patients ($n = 6$), caregivers ($n = 3$), healthcare professionals (HCPs $n = 24$) and multiple stakeholders ($n = 12$).	Results: interventions targeting all participants in end-of-life communication more appropriate and effective, no well-defined evidence of their advantage over interventions targeting one communication participant group Analysis: NA	Limitations: Interventions were aimed at communication Usefulness: applicable to development of future interventions
Butler (2014) Decision aids for advanced care planning: An overview of the state of the science. <i>The Annals of Internal Medicine</i>	Provides overview of advance care planning decision aids for adults	Review, technical brief Level VII	Sample: 11 unique decision aids, 16 studies involving these aids reviewed Sampling: Key informants were interviewed on phone for decision aids, databases searched for studies Setting: NA	Measures: IPDAS criteria Reliability: not discussed	Results: General decision aids delivered less information on choices than condition-specific aids. These were then less likely to help patients consider their decisions	Limitations: not a study, only reviewed and compared decision aids that exist Decision aids help patients to consider and document their preferences. Effective aids help to provide closure to family and loved ones.
McMahan (2013) Advance care planning beyond advanced directives: Perspectives from patients and surrogates. <i>J Pain Symptom Manage</i>	To understand what process best prepare patients and surrogates for decision making	Qualitative analysis Level VI	Sample: 13 focus groups 7 groups patients ($n = 38$), 6 groups surrogates ($n=31$) Sampling: study flyers and convenience sampling Setting: VA and community hospital and community	Methods: semi structured focus groups asked what activities best prepared them for decision making Reliability: Not discussed	Results: 4 themes identified in helping to prepare for decision making Analysis: thematic content analysis	Limitations: from one geographic location, half of participants contacted study staff in response to flyer-could indicate bias Usefulness: ACP activities ay better prepare patients and surrogates

Douglas (2002) Patients' attitudes toward advance directives. <i>Journal of Nursing Scholarship</i>	To understand hospitalized patients' attitudes towards advanced directives and reasons for completing/not completing.	Qualitative Study Level VI Variables: Advanced directives, Patients attitudes	Sample: 30 patients, 11 males and 19 female Sampling: Patients recruited from an oncology and medical telemetry unit of an academic facility in North Carolina. Convenience Sampling	Measures: Advanced directive attitude scale (ADAS) 16 item, 4-point Likert scale. Higher scores indicate more favorable attitude towards advanced directives Cronbach alpha was 0.74	Results: Completion rate for advanced directives in this study was 43% Analysis: discussed as percentage of participants, no advanced techniques used	Limitations: Small sample size, all hospitalized patients, no direct relationship was proven Usefulness: attitudes can be an important factor to evaluate
Theme: Knowledge						
Kermel-Schiffman (2017) Knowledge regarding advance care planning: A systematic review. <i>Archives of Gerontology and Geriatrics</i>	Review literature on knowledge of advanced care planning	Systematic review Level 1 Variable: Advanced care planning, knowledge	Sample: 37 articles: 35 quantitative, 1 qualitative, 1 mixed methods Sampling: keywords-knowledge AND advanced care planning OR advanced directive, peer reviewed journals in English Setting: NA	Review of literature in CINAHL, Ageline, PubMed, PsycINFO, and SocINDEX from 1994-2006 Reliability not addressed	Results: 17 studies found that the participants knew some aspects of ACP	Limitations: first review to summarize and critically evaluate knowledge associated with Advanced Directives No statistical techniques used Usefulness: Applied easily to intervention development to address knowledge improvement
Schwartz (2002) Early intervention in planning end-of-life care with ambulatory geriatric patients. <i>Archives of Internal Medicine</i>	Evaluate short term clinical utility of early ACP and assess feasibility of larger prospective study to document long term outcomes	Randomized control trial Level 2 Variables: state health care proxy form vs intervention (each patient discussed ACP with a trained nurse facilitator).	Sample: 61 participants Sampling: Convenience sampling Intervention: respecting choices program Setting: Community	Measures: baseline and 2 months later, and 1x from health care agent (2 months later) Knowledge questionnaire alpha reliability coefficient of .78	Results: 76% of intervention vs 55% of control group. Analysis: no statistical power to determine a large effect, results reports in term of effect size using formula of Cohen	Limitations: small sample, older adults Usefulness: indicated respecting choices is a beneficial program and additional larger study over extended period would be beneficial

Theme: Palliative Care						
Enguidanos (2017) Timing of advanced directive completion and relationship to care preferences. <i>Journal of Pain and Symptom Management.</i>	Investigate timing of AD completion and any relationships that may exist between time of completion and the documented care preferences	Retrospective study Level V Variables: Point in time of completion, care preferences	Sample: 2904 proxy reporters Sampling: Proxies interviewed 11 months after the death of family member. Setting: community	Measures: timing of AD completion from 0-591 months prior to death Reliability: NA	Results: 71% of ADs were completed greater than a year prior to death. Analysis: Logistic regression model	Limitations: retrospective Usefulness: Early documentation of care wishes may not be associated with an increased likelihood of electing aggressive care
Gilissen (2016) Preconditions for successful advance care planning in nursing homes: A systematic review. <i>International Journal of Nursing Studies</i>	Identify the preconditions related to advanced care planning, to help in the planning of future intervention programs	Systematic review Level 1 Qualitative studies analyzed	Sample: 38 publications investigating advanced directives Sampling: Used 4 electronic databases Setting: nursing homes	Measures: Quality evaluated using AMSTAR tool Reliability: not discussed	Results: 38 articles eligible, identified 5 domains of preconditions: Analysis: Inductive thematic analysis using qualitative data analysis package	Limitations: inclusions criteria intentionally narrow, considerable human judgement Usefulness: Could help provide guidance in developing an intervention to provide advanced directive program
McDonald (2016) Advanced directives in patients with advanced cancer receiving active treatment: attitudes, prevalence, and barriers. <i>Support Care Cancer</i>	Assess awareness and prevalence of AD among patients with cancer undergoing treatment to determine factors connected with AD completion	Qualitative study Level 5 Variables: NA	Sample: 193 patients surveyed, age >18 Sampling: Convenience sampling Setting: Outpatient cancer care clinic	Measures: questionnaire about completion and timing of ADs Perceived health: poor to excellent Symptom burden: ESAS scale Reliability: not reported	Results: Discussion of end-of-life care along with palliative care referral were associated with AD completion Analysis: Multinomial logistic regression analysis (p<0.10)	Limitations: recruitment from a single center, patients were advanced stage cancer. Only conclusions regarding association not causation Usefulness: indicates knowledge is important and supports education

Weathers (2016) Advanced care planning: A systematic review of randomized controlled trials conducted with older adults. <i>Maturitas</i>	Investigates impact of ACP on outcomes (symptom management, quality of care, healthcare utilization) in older adults across all healthcare settings	Systematic review of RCT Level 1 Variable: Advanced care planning and outcomes	Sample: Full text of 30 RCT, final of 9 studies Sampling: Inclusion of RCT, ACP intervention, Sample of older adults, any setting, English Setting: 7 studies in community setting and 2 in nursing homes	Measures: Rated using risk of bias criteria recommended by EPOC Review group. Oxford 5 point scoring system used Reliability: Not discussed	Results: Most studies did not implement a standardized ACD or measure the impact of quality of end-of-life care. 3 studies led to an increase in documentation of ACD, 1 study increased completion of POA, 1 study reports increase in patient knowledge of ACD.	Limitations: only 3 studies scored a 3 on oxford scale of bias, only 3 databases searched Useful in planning an intervention for ACD, although does not discuss impact on completion rates
Clark (2015) Advance care planning as a shared endeavor: Completion of ACP documents in a multidisciplinary cancer program. <i>Psycho-Oncology</i>	Examine role of oncology provider in advance care planning in a multidisciplinary program	Quantitative descriptive Level VI Variables: Providers important in care, ACP discussion, ACP completion	Sample: 240 women from the women's oncology program in Rhode Island, OBGYN cancer diagnosis for at least 3 months Sampling: Convenience sampling Setting: Outpatient oncology clinic	Measures: Standard definition of AD, "a set of written instructions in which you state the kind of health care you want or don't want under certain circumstances" Chart reviews to determine AD documentation Reliability: not reported	Results: 50% of the participants had an AD and or HPA (Healthcare Power of Attorney). More than 1 person involved in treatment increased odds of having and AD, Women who indicated a nurse practitioner as involved in their care were more likely to have an AD. Analysis: Monte Carlo permutation	Limitations: only women, only oncology patients , self-reported behaviors
Hayek (2014) End-of-life care planning: Improving documentation of advanced directives in the outpatient clinic using electronic medical records	Assess effectiveness of an EMR based reminder to improve AD documentation rates	Prospective quality improvement study Level VI Variables: AD documentation, EMR reminder	Sample: Records of 157 patients were reviewed Sampling: Convenience sampling Setting: Resident run clinic in Atlanta, GA	Measures: Plan-do-study-act methodology , test of change Reliability: NA	Results: EMR based reminders improved documentation rates. Rates improved from 11.5% to 75% when implementing EMR reminder. Analysis: Chi squared test	Limitation: Only tested documentation, and no patient involvement Usefulness: May need additional research to see if this helps improve in a larger sample and affects costs of care

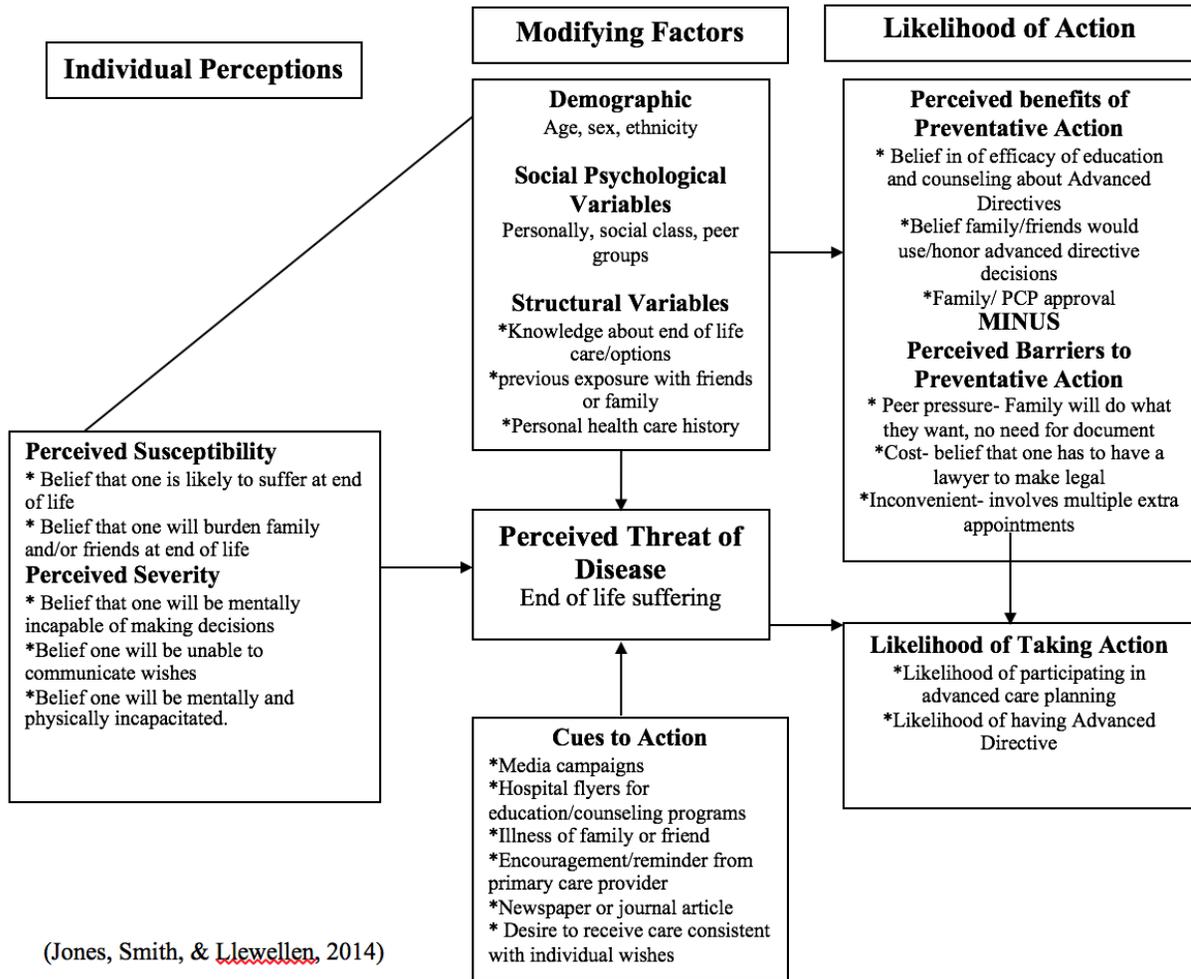
House (2014). Advance directives in hospitalized patients: A retrospective cohort study. <i>The Journal for Nurse Practitioners</i>	Examine processes for advanced directives in hospitalized patients to improve practice	Retrospective Cohort Study Level IV Patient Variables: age, sex, ethnicity, language, religion, zip code Process Variables: Patient has AD, Patient has AD, but not in chart, Patient no AD, Patient would like information	Sample: 5330 Patients admitted to hospital between 18 and 89 years' old Sampling: Records review of patients admitted to medical, surgical unite or intensive care Setting: One academic catholic faith based hospital	Measures: Review of medical records Reliability: not reported	Significant differences were found in AD completion based on age. Analysis: Data imported into SPSS- the chi-square test of independence P<0.05	Limitations: Data set only from 1 hospital Some variables had incomplete data entry Only explored nursing process Usefulness: Could be applied to other hospitals Opportunities exist for increasing AD education
Rao (2014) Completion of advance directives among U.S. consumers. <i>American Journal of Preventative Medicine</i>	To determine factors associated with advanced directive completion	Retrospective study Level V	Sample: 7946 respondents in 2009 and 2010 Sampling: Convenience sampling Setting: NA	Measures: Healthstyles survey- 5 end of life questions 5 EOL questions derived from a systematic review of EOL survey Reliability: Not discussed	Results: 26.3% had an advance directive. Reason for not having one: lack of awareness. Analysis: Likelihood ratio tests to examine associations Multivariable logistic regression	Limitations: community dwelling Cross-sectional: causality cannot be determined Usefulness: data indicate racial and educational disparities
Detering (2010) The impact of advanced care planning on end of life care in elderly patients: randomized control trial. <i>BMJ</i> .	Investigate impact of advance care planning on end of life care in elderly patients	Randomized control trial Level 2 Variables: usual care vs usual care plus facilitated advance care planning	Sample: 309 medical inpatients age >80 Sampling: Convenience sampling after determination of competence Setting: Single center study in Australia	Measures: primary outcome: patient's wishes were known and respected, patient and family satisfaction reliability not discussed	Results: intervention group 81% received advanced care planning, 84% expressed wishes or appointed a surrogate. Patient and family satisfaction higher in intervention group Analysis: continuous data- t-tests or Mann-Whitney U tests Categorical data: Chi squared or Fischer exact tests	Limitations: Single center study Older adult population Usefulness: improved care with advanced care planning

Sampson (2010) Palliative assessment and advance care planning in severe dementia: an exploratory randomized controlled trial of a complex intervention. <i>Palliative Medicine</i>	Assess the practicability of a 2 component intervention to improve end-of-life care for people with advanced dementia	Randomized controlled trial Level 2 Variables: Palliative care needs assessment, advanced care planning	Sample: 33 patients and care givers Sampling: convenience sampling in hospital Setting: Patients age >70, London teaching hospital, all with advanced primary degenerative dementia	Care giver measures: KD10 for distress score, EQ-5D, DCS for uncertainty and difficulties in decision making, SAS for anger scale, LSQ life satisfaction scale, SWC-EOLCD Reliability: Not discussed	Results: only 7 care givers developed an ACP, they found discussion useful but were hesitant to formulate AD Analysis: not discussed	Limitations: study needed to be changed during the study, advanced dementia status of patients, overall negative research but could be helpful in considering implementing ACP before dementia diagnosis
Schickendanz (2009) A clinical framework for improving the advance care planning process: Start with patients' self-identified barriers. <i>Journal of American Geriatric Society.</i>	Understand barriers to ACP and identify themes that prevent older adults from engaging in the process	Descriptive study (qualitative) Level VI Advanced directives and barriers	Sample: 143 participants Sampling: Convenience sampling, Setting: General medicine clinic in San Francisco	Measures: degree of engagement in ACP steps, discussions with family and friends, discussions with clinicians, and documentation were assessed. Reliability: Not Discussed	Results: 40% did not consider ACP, 46% did not discuss with family or friends, 80% did not discuss with PCP, and 90% did not document wishes. Six barrier themes emerged: Analysis: Chi squared and t-tests used	Limitations: participants had been previously introduced to ACP in previous study, one medical clinic, and presenting patients list of barriers prior to open ended questions may have created bias. Usefulness: target populations and educate to address barriers
Theme: Empowerment						
Evangelista (2012). Does Preparedness Planning Improve Attitudes and Completion of Advance Directives in Patients with Advanced Heart Failure? <i>Journal of Palliative Medicine</i>	Determine intervention that helps improve patient preparedness and attitudes that influence completion of advanced directives	Prospective single cohort study, quantitative Level 4	Sample: 36 patients participated in palliative care consult in hospital and follow up telephone calls at 3 post intervention Sampling: Convenience	Measures: Advanced Directive Attitude scale- 17 questions regarding advanced directives and their effects Reliability not reported	Results: Participants who completed Ads increased from 27.8% to 47% Analysis: t tests. Statistical significance was set for p<0.05 for all analyses	Limitations: Small sample size, limited inclusion population, recruited from a single tertiary facility, Usefulness: attitudes towards ADs in an intervention could help make it more specific

Lankarani-Fard (2010) Feasibility of discussing end-of-life care goals with inpatients using a structured, conversational approach: The <i>go wish</i> card game. <i>Journal of Pain and Symptom Management</i>	Practicability of using the <i>Go Wish</i> card game with seriously ill patients in the hospital	Observational study Level VI	Sample: 33 patients Sampling: Physician referral Setting: A tertiary care academic hospital in LA county	Measures: The patients were surveyed before the intervention, and recorded again after card game. Reliability: not discussed	Results: study suggests that the <i>Go Wish</i> card game as a decision-making tool The average dialogue time with the intervener was 21.8 minutes Analysis: SPSS	Limitations: all male patients, patients were high mortality probability due to medical conditions, Did not directly address advanced directives Usefulness: ease of use and low cost
Theme: Autonomy						
Winzelberg (2005) Beyond Autonomy: Diversifying end-of-life decision-making approaches to serve patients and families. <i>Journal of American Geriatrics Society</i>	Discuss autonomy when concerning end of life decision making	Opinion of experts Level VII Variables: Autonomy, end of life decision making	No sample	NA	Autonomy has not regularly served the comforts of patients and families.	Limitations: The PCP is not involved in end of life decision making using while patient is in the hospital. Hospital based physicians may not have records regarding conversations Time Usefulness: limited

Appendix D

Theory Application Diagram



Appendix E
IRB Approval

UMKC
5319 Rockhill Road
Kansas City, MO 64110
TEL: (816) 235-5927
FAX: (816) 235-5602

NOTICE OF NEW APPROVAL

Principal Investigator: Dr. Lyla Lindholm
UMKC Health Sciences Building
Kansas City, MO 64108

Protocol Number: 18-271
Protocol Title: Adult Community Counseling on Advanced Directives to Increase Completion Rate
Type of Review: Designated Review
Expedited Category #: 7

Date of Approval: 10/05/2018

Date of Expiration: 10/04/2019

Dear Dr. Lindholm,

The above referenced study, and your participation as a principal investigator, was reviewed and approved, under the applicable IRB regulations at 21 CFR 50 and 56 (FDA) or 45 CFR 46 (OHRP), by the UMKC IRB. You are granted permission to conduct your study as described in your application.

- Waiver of documentation of Consent Version Date 09/12/18

- Your protocol was approved under Expedited Review Regulatory Criteria at 45 CFR 46.110 or 21 CFT 56.110 under Category #7 as follows: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

- Your protocol was approved for a waiver of documentation of consent under regulatory criteria at 45 CFR 46.117(c) having met either of the following criteria:

1. That the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Each subject will be asked whether the subject wants documentation linking the subject with the research, and the subject's wishes will govern; or
2. That the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.

In cases in which the documentation requirement is waived, you may be required to provide subjects with a written statement regarding the research.

This approval includes the following documents:

Attachments

ACP Engagement Permission
AD Status Survey
Demographic Survey



UMKC
5319 Rockhill Road
Kansas City, MO 64110
TEL: (816) 235-5927
FAX: (816) 235-5602

SF2013-168 - NonExclusive License Agreement - PREPARE - UCSF-UMKC
ACP Engagement Survey 34 Item
Missouri Advanced Directive
FU Survey example script
Link to PREPARE movie
PREPARE FOR YOUR CARE STEPS OUTLINE
Website progression flowsheet
ACP Screening Survey 09 12 2018
Request to Distribute Flyer
Recruitment Flyer, Sites and Mailing
Gibbon DNP Proposal Project Approval

If a consent is being used in this research study you may find the stamped version in section 16 of your application.

The ability to conduct this study will expire on or before 10/04/2019 unless a request for continuing review is received and approved. If you intend to continue conduct of this study, it is your responsibility to provide a Continuing Review form prior to the expiration of approval or a final report if you plan to close the study.

This approval is issued under the University of Missouri - Kansas City's Federal Wide Assurance FWA00005427 with the Office for Human Research Protections (OHRP). If you have any questions regarding your obligations under the Board's Assurance, please do not hesitate to contact us.

There are 5 stipulations of approval:

- 1) No subjects may be involved in any study procedure prior to the IRB approval date or after the expiration date. (PIs and sponsors are responsible for initiating Continuing Review proceedings).
- 2) All unanticipated or serious adverse events must be reported to the IRB.
- 3) All protocol modifications must be IRB approved prior to implementation unless they are intended to reduce risk. This includes any change of investigator.
- 4) All protocol deviations must be reported to the IRB.
- 5) All recruitment materials and methods must be approved by the IRB prior to being used.

Please contact the Research Compliance Office (email: umkcirb@umkc.edu; phone: (816)235-5927) if you have questions or require further information.

Thank you,

A handwritten signature in black ink, appearing to read "C. Thompson".

Cynthia Thompson

Appendix F
Waiver of Consent

CONSENT FORM FOR PARTICIPATION IN A RESEARCH STUDY

Adult Community Counseling on Advanced Directives to Increase Completion Rate

Lyla Lindholm, DNP and Megan Gibbons, MSN

Introduction

You are being asked to volunteer for a research study. This study is being conducted at the location of your choice via internet.

The researcher in charge of this study is Megan Gibbons who is in the Doctor of Nursing Practice program at the University of Missouri Kansas City. While the study will be run by her, other qualified persons who work with her may act for her.

The study team is asking you to take part in this research study because you are a healthy adult over the age of 18 who does not have any life-threatening illness. Research studies only include people who choose to take part. Please read this consent form carefully and take your time making your decision. The study doctor or staff will go over this consent form with you. Ask him/her to explain anything that you do not understand. Think about it and talk it over with your family and friends before you decide if you want to take part in this research study. This consent form explains what to expect: the risks, discomforts, and benefits, if any, if you consent to be in the study.

Background

Advanced care planning (ACP) and advance directives (AD) helps one make personal end-of-life care wishes to be followed by healthcare providers. The United States completion rates for advance directives are low at about 18-36% of all adults. Completing an advanced directive allows a person to receive care that they wish at end of life. This study will provide you with the opportunity to complete an advanced directive through counseling and education through this website.

Purpose

The purpose of this research study is to determine if an online (website) education program on advance directives increases completion rates and legal documentation of advance directives in Missouri.

As a whole, Americans are living longer and healthcare costs increase with age. Education can better help patients understand end of life care and foster informed decisions regarding care they wish.

Missouri State Department of Health and Senior Services does not currently track the completion of advanced directives, and this study could help to establish the importance of tracking completion of advanced directives.

You will be one of about 110 subjects in the study in Missouri. To be in this study, you must be 18 years of age or older and legally responsible for self. Also, you must not have a diagnosis of advanced dementia or Alzheimer's disease.

Study Procedures and Treatments

The advance directive education program will involve education and counseling regarding advanced directives including end of life care, benefits of advance care planning, and advanced directive documentation.

Participation:

The intervention will take place in an online format via an interactive website used by participants from home or other location as you wish.

1. Upon consent that describes the study, the participant will complete baseline data. Baseline data will include demographics (age, ethnicity, education, marital status, and religious preference), current advanced directive status, an advance directive engagement survey, and contact email address. Demographic data is collected because research has shown that these factors may affect advanced directive decision making. The advance directive engagement survey has 34 questions and takes approximately 10-15 minutes to complete online by selecting an answer that applies to you.
2. After completion of the baseline data, the education will include materials from the PREPARE for your Care© program. This is a step-by-step video to support participants having a voice in their medical care, talking with providers, and asking questions to be answered about medical wishes.
3. Upon completion of the educational content, the participant will access the Missouri State Advanced Directive paperwork. The participant will be instructed on the steps to complete the form and how to have it legally notarized.
4. Follow up will occur three months after the intervention with an email that will state a link to a survey to determine if the advance directive paperwork has been completed and legally notarized.

If you agree to take part in this study, you will be involved in this study for the period required to complete the online education (about 1 hour), the 15-minute survey, the 10-minute follow up at 3 months, and the advanced directive that is legally notarized.

When you are done taking part in this study, you will have access to your personal advanced directive, if you complete.

Possible Risks of Taking Part in this Study

Watching the educational video may cause emotional stress for some people when thinking about and talking about serious health decisions, end of life, and death.

There is a minimal risk of breach of confidentiality.

Possible Benefits for Taking Part in this Study

Completion of an advanced care planning conversation and advanced directive that is legally notarized can improve care provided to the person at end of life. If the advanced directive is not complete, then this education provides you with information about your voice in end of life decisions.

Education can better help patients understand end of life care, fostering informed decisions on desired care. This would indirectly help contribute to the Advance Health Care Directives Registry. This 2017 Missouri legislation supports the efforts to improve documentation of advanced directives and make these documents available to healthcare providers

Costs for Taking Part in this Study

You will not have to pay for access to advanced directive paperwork that you get during this study.

Payment for Taking Part in this Study

You will not receive any monetary compensation for your participation in this study.

Alternatives to Study Participation

The alternative is to not take part in the study. If you decide not to participate, you will still have access to the advanced directive education that is available to the public. You may also view the video education.

Confidentiality and Access to your Records

The results of this research may be published or presented for scientific purposes. You will not be named in any reports of the results. Your study records that have your identity in them may be shown to the UMKC Institutional Review Board (IRB, a committee that reviews and approves research studies), or other governing agencies. This is to prove which study procedures you completed and to check the data reported about you. The study team will keep all information about you confidential as provided by law, but complete confidentiality cannot be guaranteed.

If you leave the study or are removed from the study, the study data collected before you left may still be used along with other data collected as part of the study. For purposes of follow-up studies and if any unexpected events happen, subject identification will be filed through the University of Missouri Kansas City for access to REDCap, a secure record keeping program, under appropriate security and access limited to research personnel only.

UMKC AHS IRB #

If you sign this consent form, you are allowing the study team and these other agencies to see your study records.

Contacts for Questions about the Study

You should contact the IRB Administrator of UMKC's Adult Health Sciences Institutional Review Board at 816-235-5927 if you have any questions, concerns or complaints about your rights as a research subject. You may call the researcher Megan Gibbons at xxx-xxx-xxxx or email at xx if you have any questions about this study. You may also call her if any problems come up.

Voluntary Participation

Taking part in this research study is voluntary. If you choose to be in the study, you are free to stop participating at any time and for any reason. If you choose not to be in the study or decide to stop participating, your decision will not affect any care or benefits you are entitled to. The researchers may stop the study or take you out of the study at any time

- if they decide that it is in your best interest to do so,
- if you experience a study-related injury,
- if you no longer meet the study criteria, or
- if you do not comply with the study plan.

They may also remove you from the study for other administrative or medical reasons. You will be told of any important findings developed during the course of this research.

You have read this Consent Form or it has been read to you. You have been told why this research is being done and what will happen if you take part in the study, including the risks and benefits. You have had the chance to ask questions, and you may ask questions at any time in the future by calling *Megan Gibbons* at xxx-xxx-xxxx.

By participating and completing the baseline data with survey, you are implying your consent to participate in this research study.

Appendix G

Advanced Directive Initiative Budget

Expenses

	Estimated	Actual
Total Expenses	\$3,139.00	\$1,268.39

Website	Estimated	Actual
Webhosting fee (\$14/month)	\$150.00	\$168.00
Design cost	\$0.00	
Domain Private Registration	\$0.00	\$9.90
Total	\$150.00	\$177.90

Materials	Estimated	Actual
Binder/supplies	\$135.00	\$21.90
Total	\$135.00	\$21.90

Marketing	Estimated	Actual
Postcards (Direct Mailing Campaign)	\$550.00	\$0.00
Flyers	\$500.00	\$198.59
Material design	\$250.00	\$9.99
Total	\$1,300.00	\$208.58

Honorium	Estimated	Actual
Gift Cards (\$15)	NA	\$0.00
Total	\$0.00	\$0.00

Patient follow up	Estimated	Actual
Address Labels	\$35.00	0
Envelopes (box of 500)	\$16.00	\$0.00
Stamps	\$100.00	\$0.00
Phone (\$30/month)	\$300.00	\$20.00
Total	\$451.00	\$20.00

Miscellaneous	Estimated	Actual
Proposal Poster		\$67.06
Results Poster	\$75.00	
Total	\$75.00	\$67.06

Project Dissemination	Estimated	Actual
APNO Conference	\$450.00	\$450.00
Hotel	\$478.00	\$289.14
Travel	\$100.00	\$33.81
Total	\$1,028.00	\$772.95

Appendix H Recruitment Materials



Virtual Advanced Directive Workshop

Let Your Wishes be Known: Develop an Advanced Directive

Please consider participating in the online virtual advanced directive educational event that will help you facilitate forming an advanced directive and guide conversations with your loved ones.

This is a FREE offering that is sponsored by Megan Gibbons, a nurse practitioner who is pursuing her Doctor of Nursing Practice. This is a research study as part of the requirements in fulfillment of the Doctor of Nursing Practice degree.

This project utilizes the PREPARE For Your Care program to provide comprehensive education regarding the decision making process. Optional counseling will be available via phone if requested at completion of the workshop.

Your participation will involve participation in an online survey, 1-hour video, and 1 follow up survey 3 months after completion of the video.

Please go to the below website to get any additional information and to participate!



www.missouriadvanceddirectiveproject.com

This research study has been approved on 10/5/2018 by the University of Missouri- Kansas City IRB Protocol number 18-271

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Appendix I Intervention Example

Step 4 Tell Others About Your Medical Wishes

This will help you get the medical care you want.

How to say it:

To your decision maker and doctors:
 "This is what is most important in my life and for my medical care..."

To your doctor and family and friends:
 "I chose this person to be my decision maker and I want to give them (TOTAL, SOME, or NO) flexibility to make decisions for me."

Your doctors can help you put your medical wishes on an advance directive form.



Step 5 Ask Doctors the Right Questions

- Write down questions ahead of time.
- Bring someone with you.
- Tell doctors at the start of the visit if you have questions.

How to say it:

If your doctor recommends something, ask about the:

- **Benefits** – the good things that could happen
- **Risks** – the bad things that could happen
- **Options** for different kinds of treatment
- **What your life will be like after treatment**

Make sure you understand:
 "What I'm hearing you say is..."
 "Is this right?"

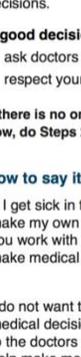
Your Action Plan

By _____

I will _____



A program to help you make medical decisions for yourself and others



Step 1 Choose a medical decision maker.

Step 2 Decide what matters most in life.

Step 3 Choose flexibility for your decision maker.

Step 4 Tell others about your medical wishes.

Step 5 Ask doctors the right questions.

www.prepareforyourcare.org

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Step 1 Choose a Medical Decision Maker

Choose someone you trust to help make decisions for you in case you become too sick to make your own decisions.

A good decision maker will:

- ask doctors questions
- respect your wishes

If there is no one to choose right now, do Steps 2, 4, and 5.

How to say it:

"If I get sick in the future and cannot make my own decisions, would you work with my doctors and help make medical decision for me?"

OR

"I do not want to make my own medical decisions. Would you talk to the doctors and help make medical decisions for me now and in the future?"



Step 2 Decide What Matters Most in Life

This can help you decide on medical care that is right for you.

Five questions can help you decide what matters for your medical care:

1. **What is most important in life?**
Friends? Family? Religion?
2. **What experiences have you had with serious illness or death?**
3. **What brings you quality of life?**
Quality of life is different for each person. Some people are willing to live through a lot for a chance of living longer. Others know certain things would be hard on their quality of life.
4. **If you were very sick, what would be most important to you:**
 - To live as long as possible even if you think you have poor quality of life?
 - Or, to try treatments for a period of time, but stop if you are suffering?
 - Or, to focus on quality of life and comfort, even if your life is shorter?
5. **Have you changed your mind** about what matters most in your life over time?

Step 3 Choose Flexibility for Your Decision Maker

Flexibility gives your decision maker leeway to work with your doctors and possibly change your prior medical decisions if something else is better for you at that time.

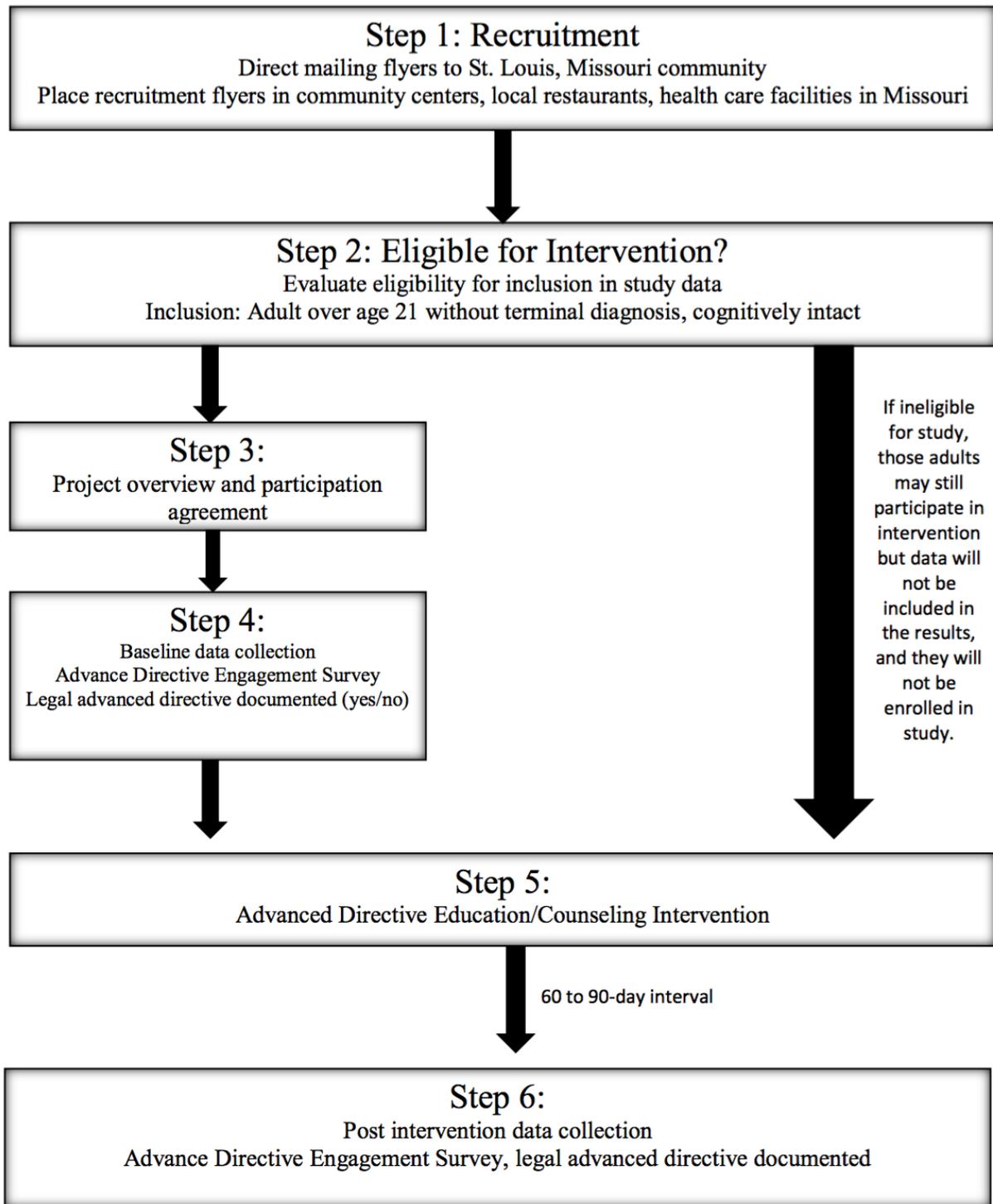
How to say it:

Total Flexibility:
 "I trust you to work with my doctors. It is OK if you have to change my prior decisions if something is better for me at that time."

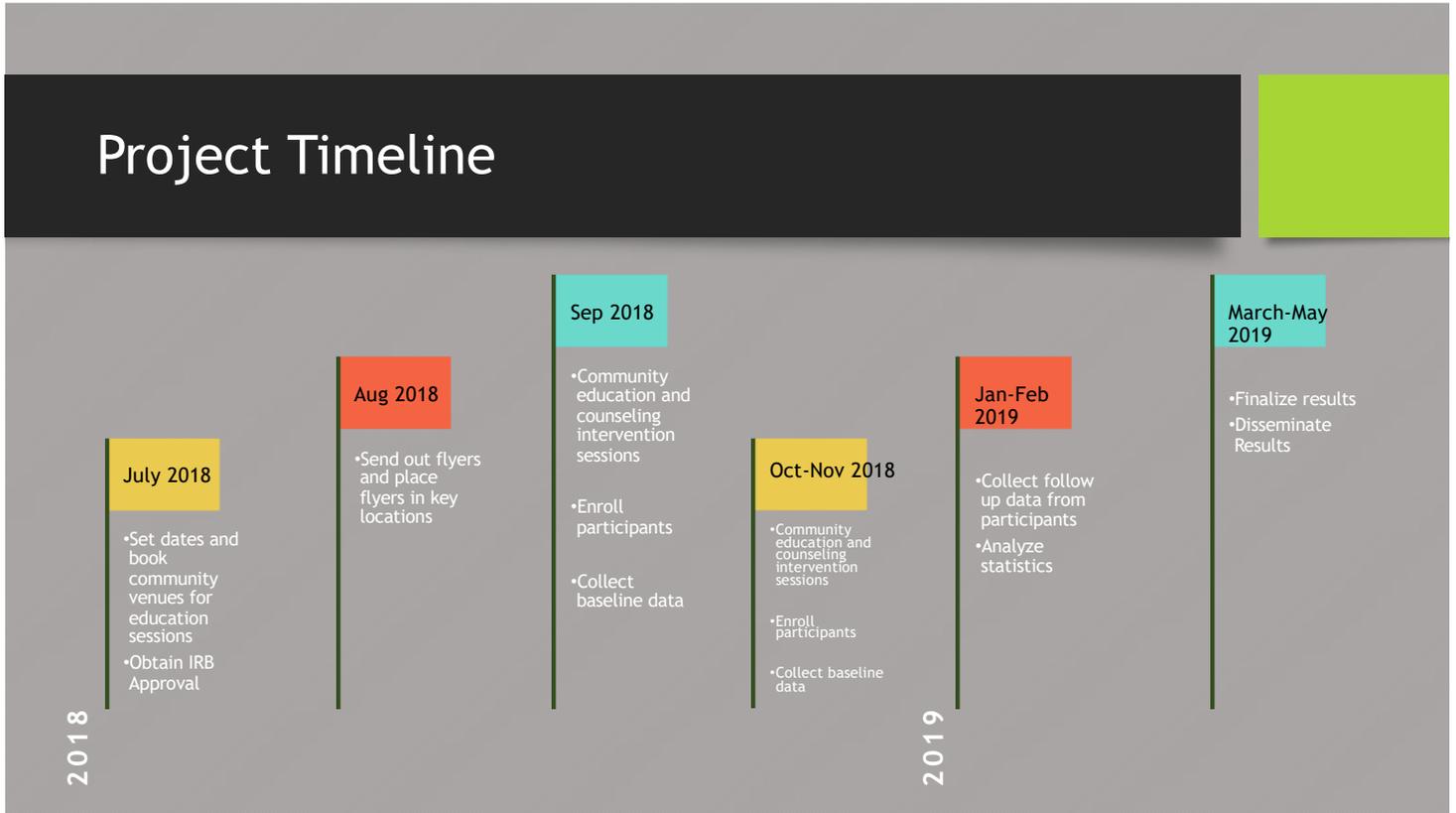
Some Flexibility:
 "It is OK if you have to change my prior decisions. But, there are some decisions that I never want you to change. These decisions are..."

No Flexibility:
 "Follow my wishes exactly, no matter what."

Appendix J
Intervention Flow Diagram



Appendix K
Timeline



Appendix L

Logic Model for DNP Project					
Student: Megan Gibbons FNP-BC, NP-C					
Inquiry, PICOTS: In healthy adults without terminal diagnosis (P) does an interactive webpage advanced directive counseling and education program (I) compared to current standards (C) improve legal documentation and completion rates (O) during a 3-month period (T) in Missouri (S)?					
Inputs	Intervention(s) Activities	Outputs Participation	Outcomes -- Impact		
			Short	Medium	Long
Evidence, sub-topics 1. Counseling 2. Knowledge 3. Palliative Care 4. Decision Making 5. Autonomy Major Facilitators or Contributors 1. Megan Gibbons Major Barriers or Challenges 1. Community Setting venue 2. Diverse population 3. Funding	EBP intervention which is supported by the evidence in the Input column (brief phrase) Comprehensive education and counseling intervention to improve knowledge regarding advanced care planning and improve advanced directive completion rates Major steps of the intervention (brief phrases) 1. Pre-intervention assessment 2. Education/counseling program 3. Provide community opportunity to complete/discuss advanced directives. This includes distribution of Missouri advanced directive forms 4. Post-intervention assessment 5. Follow up 2-3 months after session to evaluate if Advanced directive was discussed with friends/family and legally enacted	The participants (subjects) St. Louis Community Site Community Center/Church/Hospital Time Frame 4-6 months Consent or assent Needed Consent needed Other person(s) collecting data (yes,no) No Others directly involved in consent or data collection (yes/no) No	(Completed during DNP Project) Outcome(s) to be measured Primary: Increased number of legal advanced directive in place for patients Secondary, if applies: Increased knowledge of Advanced Directives, improved attitude score Measurement tool(s) 1. Advanced Directive Attitude Scale 2. Advanced Directive Knowledge Tool Statistical analysis to be used 1. Paired T-Test (pre-test, post-test) 2. Multiple regression- Consider how ADAS and Knowledge will affect completion rates	(after student DNP) Outcomes to be measured Improves discussion of care wishes with loved ones. Continued increase in patients locally and nationally with legally document advanced directives	(after student DNP) Outcomes that are potentials Program development to use in primary care setting

Rev. 7/09, 1/2015 http://www.uwex.edu/ces/lmcourse/interface/coop_M1_Overview.htm Logic-Model Worksheet content revisions by Lyla Lindholm for DNP Project. Not to be placed on web for public use. For UMKC DNP coursework only.

Appendix M
Advance Directive Engagement Survey

Contained in Private Domain

Appendix N

NONEXCLUSIVE LICENSE AGREEMENT

This Non-exclusive License Agreement is made and entered into this 10th day of August, 2018 ("Effective Date"), by and between **THE REGENTS OF THE UNIVERSITY OF CALIFORNIA**, a California constitutional corporation ("The Regents"), acting on behalf of the University of California San Francisco, and through the Office of Technology Management, University of California San Francisco, 600 16th Street, Suite S-272, San Francisco, California, 94143, and **CURATORS OF THE UNIVERSITY OF MISSOURI ON BEHALF OF UMKC SCHOOL OF NURSING AND HEALTH STUDIES**, 2464 Charlotte St., Kansas City, Missouri 64108, hereinafter called "Licensee";

WITNESSETH:

Whereas, The Regents is the proprietor of the content, including, without limitation, text, graphics and video, on the websites designated as www.prepareforyourcare.org and subdirectories thereof ("PREPARE");

Whereas, Licensee desires to obtain from The Regents, and The Regents desires to grant to Licensee, a license to use PREPARE;

NOW, THEREFORE, in consideration of the mutual covenants, conditions, and terms hereinafter set forth, and for other good and valuable consideration, the parties hereto hereby agree as follows:

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2. Licensee agrees to use PREPARE in compliance with all applicable statutes and regulations.
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Appendix O
Data Collection Template and Data Collection Survey

	A	B	C	D	E	F	G	H	I	J
1	Participant	Demographics		Gender	Age	Marital Status	Edu Level	Medical conditions	Ethnicity	Religion
2	1									
3	2									
4	3									
5	4									
6	5									
7	6									
8	7									
9	8									
10	9									
11	10									
12	11									
13	12									
14	13									
15	14									
16	15									
17	16									
18	17									
19	18									
20	19									

	A	B	C	D	E
1	Participant	Advanced directive at Start	Advanced directive at 3 month post intervention		
2	1				
3	2				
4	3				
5	4				
6	5				
7	6				
8	7				
9	8				
10	9				
11	10				
12	11				
13	12				
14	13				
15	14				
16	15				
17	16				
18	17				
19	18				
20	19				
21	20				
22	21				
23	22				
24	23				
25	24				

Survey Questions

Baseline data

- Do you currently have an advance directive, living will, or power of attorney for healthcare decisions? (select all that apply)
 - Advanced directive
 - Living Will
 - Power Attorney
 - None

After intervention

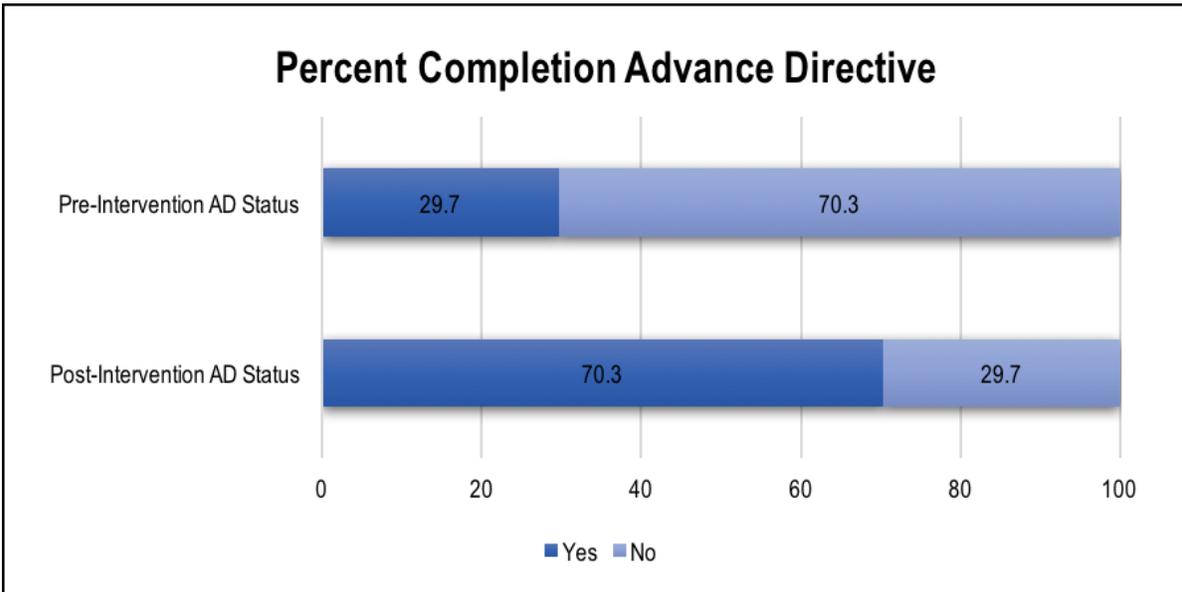
- As a result of this study do you now have a completed and notarized advanced directive which includes living will and power of attorney?
 - Yes
 - No
- If you do not have a current advanced directive, do you plan to complete one in the next 6 months?
 - Yes
 - No
- If you do not plan to complete an advanced directive, could you please share your thoughts on this decision?

Demographic Survey

- What is your age?
 - 21-24 years' old
 - 25-34 years' old
 - 35-44 years' old
 - 45-54 years' old
 - 55-64 years' old
 - 65-74 years' old
 - 75 years or older
- Ethnicity origin (or Race): Please specify your ethnicity.
 - White
 - Hispanic or Latino
 - Black or African American
 - Native American or American Indian
 - Asian / Pacific Islander
 - Other
 - Prefer not to state
- Education: What is the highest degree or level of school you have completed? *If currently enrolled, highest degree received.*
 - No schooling completed
 - Nursery school to 8th grade
 - Some high school, no diploma
 - High school graduate, diploma or the equivalent (for example: GED)
 - Some college credit, no degree
 - Trade/technical/vocational training
 - Associate degree
 - Bachelor's degree
 - Master's degree
 - Professional degree
 - Doctorate degree
- Marital Status: What is your marital status?
 - Single, never married
 - Married or domestic partnership
 - Widowed
 - Divorced
 - Separated
- What is your religious preference?
 - Roman catholic
 - an orthodox church such as the Greek|or Russian orthodox church
 - Jewish
 - Christian Scientist
 - Mormon
 - Seventh-Day Adventist
 - Protestant
 - Muslim
 - Other (please specify)

Appendix P
Statistical Analysis Table

Pre Intervention AD Status				Post Intervention AD Status				
		Frequency	Valid Percent			Frequency	Valid Percent	
Valid	yes	11	29.7	Valid	yes	26	70.3	
	no	26	70.3		Total	no	11	29.7
	Total	37	100.0			Total	37	100.0
Missing	System	3		Missing	System	3		
Total		40		Total		40		



		Frequency	Percent
Valid	Pre-Contemplation	13	35.1
	Contemplation	5	13.5
	Preparation	5	13.5
	Action	9	24.3
	Total	32	86.5
Missing	System	5	13.5
Total		37	100.0

AD Completion, Pre to Post ^a	
	Pre-Intervention AD Status & Post- Intervention AD Status
N	37
Exact Sig. (2-tailed)	.000061 ^b
a. McNemar Test	
b. Binomial distribution used.	

Appendix Q



July 25, 2018

UMKC Institutional Review Board
Primary Project Site IRB
UMKC DNP Student

UMKC IRB, Primary Project Site IRB, and DNP Student

This letter serves to provide documentation regarding Megan Gibbons' Doctor of Nursing Practice (DNP) Project proposal. Ms. Gibbons obtained approval for her project proposal, *Adult Community Counseling on Advanced Directives to Increase Completion Rate*, from the School of Nursing and Health Studies DNP faculty on July 25, 2018.

If we can provide further information, please feel free to contact us.

Sincerely,

A handwritten signature in black ink that reads "Dr. Cheri Barber". The signature is written in a cursive style.

Cheri Barber, DNP, RN, PPCNP-BC, FAANP
Clinical Assistant Professor
DNP Program Director
UMKC School of Nursing and Health Studies
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Lyla Lindholm, DNP, ACNS-BC
Clinical Assistant Professor
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