Evaluation of Patient Education to Facilitate Advance Directives Completion with Dialysis Patients

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EVALUATION OF PATIENT EDUCATION TO FACILITATE ADVANCE DIRECTIVES COMPLETION WITH DIALYSIS PATIENTS

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ABSTRACT

Completion of advance directives (ADs) is an important part of identifying a patient's treatment preferences. Lack of patient understanding regarding the scope and importance of advance directives is a common barrier to AD completion. This project reports on the effectiveness of a patient education intervention in facilitating patient understanding in an outpatient dialysis facility in rural Virginia. Thirty patients were selected by convenience sampling to participate in a 10-minute verbal presentation based on a brochure entitled "Advance Care Planning: Tips from the National Institute on Aging" and completed two short questionnaires, one before and one after the education session. Patients felt that the education was informative and helpful, and 73.3% of participants planned to complete an AD after the study. The implications of this study include a solution to overcome barriers and provide practical advice to clinicians for facilitating AD completion in the patient care of the dialysis population.

Keywords: End stage renal disease, hemodialysis, patient education, advance directives, advance care planning

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List of Abbreviations

ACP	advance care planning
AD	advance directive
ESRD	end stage renal disease
IRB	Institutional Review Board

SECTION ONE: INTRODUCTION

Dialysis-dependent end stage renal disease (ESRD) is a serious illness with a high disease burden, morbidity, and mortality that affects over 700,000 people in the United States (United States Renal Data System, 2017). Advance care planning (ACP) is the process of communication between patients’ family members and providers to clarify the patient’s values, goals, and preferences for care if they are seriously ill or dying (O’Hare et al., 2016). Completion of advance directives, while it does not replace advance care planning, is an important component of the advance care planning process and should reflect the outcomes of advance care planning discussions (Wasylynuk & Davison, 2016). However, patient understanding of the benefits and burdens of life-sustaining treatment is necessary for optimal advance care planning (Skar et al., 2014), and nurse-led patient education interventions can be a feasible and effective way of facilitating advance directives completion in a general population (Hilgeman et al., 2018; Hinderer & Lee, 2013; Sinclair et al., 2017). This project seeks to identify whether a patient education intervention can be an effective strategy in facilitating patient understanding and the completion of advance directives in an outpatient dialysis facility. The implications of this study include a solution to overcome barriers and provide practical advice to clinicians for integrating advance care planning into the patient care of the dialysis population.

Background

Since the passage of the Patient Self-Determination Act (PSDA) in 1990, federal law has required that facilities receiving Medicare or Medicaid funding must help educate patients regarding advance directives (PSDA of the Omnibus Budget Reconciliation Act of 1990, 1990). An advance directive (AD) is a legal document that allows patients to document their treatment preferences and designate a substitute decision-maker if the patients are unable to make their own health care decisions (Wasylynuk & Davison, 2016). While the completion of advance directives is not a substitute for the more detailed process of advance care planning, it is an important legal document of a patient’s treatment preferences.

Some of the barriers to advance directives completion is lack of patient education, not understanding advance directives, incomplete understanding of medical care, associated complications, and survival rates (Toraya, 2014; Hilgeman et al., 2018; Hinderer & Lee, 2014). Patient education is not only an effective first step towards raising patient awareness, but also helps close the gap in disparities regarding health literacy; previous literature indicates advance directives and video decision aids that have been developed to address the needs of patients with limited health literacy have been particularly useful in improving advance care planning and end-of-life decision-making outcomes in other medical disciplines (Eneanya et al., 2018; Hickman & Pinto, 2013).

Problem Statement

The University of Virginia dialysis center in Lynchburg is one of several outpatient dialysis facilities in central Virginia. Facility social workers review AD completion at least yearly with each patient, but few patients have completed ADs, suggesting patient resistance may be a barrier to AD completion. The baseline data indicate that only 29 of the 211 patients (13.7%) in outpatient hemodialysis have documented advance directives on file.

Purpose of the Project

The purpose of the project is to evaluate the effectiveness of a patient education session provided by the project leader to discuss the purpose and importance of ADs. Effectiveness will be measured by a pre-education survey, a post-education survey, and the percentage of documented advance directives completion in the facility’s electronic health record before and after the intervention.

Clinical Question

In outpatient adult dialysis patients, does the use of a one-on-one patient education session on advance care planning increase patient understanding of and interest in completing advance directives, as measured by a post-intervention patient survey, and increase the completion of advance directives as compared to current facility interventions?

SECTION TWO: LITERATURE REVIEW

Despite increasing evidence that interventions to facilitate ACP among patients with advanced kidney disease can lead to better preparations for end-of-life treatment decisions, significant barriers prevent serious illness conversations from taking place (Mandel, Bernacki, & Block, 2016). Current provision for integrating structured ACP into dialysis are inadequate and inconsistent, and few patients formalize their wishes as advance directives (Lim et al., 2016). Furthermore, the lack of patient education regarding the definition, process, and significance of advance care planning poses a barrier to effective conversations with the care provider regarding goals of treatment and care (Mandel, Bernacki, & Block, 2016).

Search Strategy

The search strategy was done using CINHAL Plus with full text, MEDLINE with full text, and the Cochrane database using the following keywords: patient education/health education/health literacy, advance directives/advance care planning/end-of-life care, and dialysis/hemodialysis/haemodialysis/chronic kidney disease/end stage renal disease. The parameters of the search included articles published in the English language within the last five years, from 2013 to 2018. The search yielded 45 results. Each abstract was appraised for relevance to search terms and study methodology. Relevant criteria included study location, patient-centeredness, and study methodology. Articles with study settings outside of the United States or the United Kingdom were excluded, due to cultural factors that limit generalizability. Articles that focused on provider education were excluded as not relevant, as the focus of the literature review was to explore patient-centered interventions. Articles on provider perspectives of patient interventions, however, were included. Practical guidelines for providers on the implementation process of advance care planning were excluded to focus the literature review on articles with a study methodology. Duplicates, abstracts, and expert opinions were also eliminated. Fifteen articles were chosen for the final review and included in the summary and synthesis table (Appendix A).

Critical Appraisal

The evidence was analyzed using a critical appraisal table and the Melnyk Levels of Evidence (Melnyk & Fineout-Overholt, 2011). The literature review is summarized in Appendix A. The literature review included a range of study methods, including two systematic reviews, one randomized control trial comparing an ACP intervention to usual care alone, one systematic realist review to identify implementation theories, one literature review of nephrology nurse perspectives on ACP, one pilot study, one mixed-methods study, and eight descriptive studies.

The higher-level research included in this literature review had weak or inconclusive results. The systematic integrative review by Luckett et al. (2014) to identify which measure had been used to conduct advance care planning had a low number and quality of studies, and the systematic review by Lim et al. (2016) included only two studies in their review. The randomized control trial by Song et al. (2015) indicated improvement and positive long-term effects of ACP among patients in outpatient dialysis.

Of the descriptive studies, two were thematic analyses: one thematic analysis of semi-structured interviews with doctors and nurses on a nephrology unit (Lazenby et al., 2017) and the other a systematic review and thematic synthesis of qualitative studies of patients' and caregivers' perspectives (Tong et al., 2014). Three were cross-sectional observational studies (Janssen et al., 2013; Eneanya et al., 2016; Eneanya et al., 2018), and one an observational study using cohort comparison of retrospective data (Kurella et al., 2017). The other two descriptive studies evaluated provider perspectives, one using semi-structured interviews (O'Hare et al., 2016) and the other using online surveys for data collection (Culp et al., 2016). The literature review also included provider perspectives and nursing involvement in advance care planning.

Synthesis

Overall, the literature review supports the benefits of ACP among the dialysis population and reveals a wide range of implementation strategies that can be used to help facilitate its implementation. There was overwhelming support demonstrating the lack of adequate advance care planning among dialysis patients, from both patient and provider perspectives (Culp et al., 2016; Lazenby et al., 2017; Tong et al., 2014; Haras et al., 2015; O'Hare et al., 2016; Janssen et al., 2013), even though interventions that facilitated advance care planning for patients on dialysis were demonstrated to have overall positive effects, including fewer intensive interventions and inpatient deaths (Kurella et al., 2017; Lim et al., 2016; Song et al., 2015).

Only one study measured a nursing-specific intervention: the implementation of an assessment tool to assist with addressing the symptom burden to raise renal nurses' awareness of the need to support and prepare the patient for end-of-life conversations (Smith & Wise, 2017).

The other measured interventions involved more interdisciplinary interventions (Song et al., 2015), and a renal-specific advanced communication training program for providers to improve ACP discussions (Bristowe et al., 2014). Most of the studies included were more descriptive studies with the goal of exploring perceptions, experiences, and preferences.

Five studies described the perspectives of care providers of dialysis patients, with three drawing samples from multiple disciplines (Culp et al., 2016; Tong et al., 2014; O'Hare et al., 2016) and two focusing on the dialysis nursing perspectives (Haras et al., 2015; Smith & Wise, 2017). Culp et al. (2016) discussed barriers to advance care planning among dialysis patients, as identified by dialysis care providers, citing a low awareness of available resources and lacking the guidance to help with decision-making in seriously ill patients. Strategies for implementation identified training for health care professionals and simple documentation processes (Lazenby et al., 2017). Both studies highlighted the benefits of nurse involvement and supported the nursing role in addressing the dimensions of advance care planning among dialysis patients (Smith & Wise, 2017; Haras et al., 2015).

There is also evidence for the role of organizational and systemic support (O'Hare et al., 2016). Patient education and awareness, while not the primary thrust of the interventions in the studies included, contributed to overall lack of support for advance care planning (Lazenby et al., 2017; Culp et al., 2016). Lack of patient education was identified as a barrier to effective advance care planning, as patients are more likely to become engaged once they understand how ACP can benefit them (Wasylynuk & Davison, 2016). Health literacy did affect patient knowledge of cardiopulmonary resuscitation in one study of dialysis patients (Eneanya et al., 2018), supporting evidence that both literacy and race contribute to the completion rate of advance directives (Waite et al., 2013).

In general, successful interventions were complex and involved multiple stages; multidisciplinary care teams are usually in an excellent position to integrate ACP into routine kidney care, and nurses can be a key player to facilitate these discussions. Lack of patient awareness and low health literacy also affect advance care planning; targeting these barriers with patient education through nursing involvement can be an effective strategy for facilitating advance directives completion.

Conceptual Framework

The project will utilize the revised Iowa Model of Evidence-Based Practice for the conceptual framework. The Iowa Model is a heuristic model developed by nurses to guide clinicians in evaluating and infusing research findings into patient care (Titler et al., 1994). Since its origin in 1994, the Iowa Model has been used in numerous academic settings and health care organizations as a pragmatic guide for the evidence-based practice process (Buckwalter et al., 2017). The concepts within the Iowa Model include identifying the trigger issue, forming a team, assembling the body of evidence, designing and piloting the practice change, and integrating the practice change (Buckwalter et al., 2017). The project leader obtained permission to use the Iowa Model (Appendix F).

Identify triggering issues and opportunities. Identifying the triggering issue includes an assessment of clinical or patient-identified issues (Buckwalter et al., 2017). The model identifies five focus areas for identifying triggering issues and opportunities: clinical or patient-identified issue; organization, state, or national initiative; data/new evidence; accrediting agency requirements/regulations; and philosophy of care (Buckwalter et al., 2017). The need for facilitation of AD completion among outpatient dialysis patients is reflected in several of these categories. The triggering issue was clinically identified, as evidenced by the baseline data collection, which demonstrated the low percentage of documented advance directives at the outpatient facility. The current process for completing ADs also presented an opportunity for change through patient education sessions. Current processes at the facility place the burden of initiating the discussion, providing patient education, and completing advance directives with patients on the social workers. There is currently no protocol for nursing staff involvement or patient education, which is an untapped potential resource for the current dialysis facility. Patient education on various topics is often provided by nursing staff during the patient's dialysis, but there is currently no education provided regarding ADs. These circumstances triggered the idea of an education session provided for patients while they are on dialysis to help facilitate further conversations with social workers, "priming" the patients, as it were, to be more likely to be interested in participating in the process of advance care planning.

State the question. The next step includes formally stating the question or purpose. Formally stating the purpose enables a more focused approach and better informs the next steps. The question of this project is reflected in the study's clinical question in PICO format. PICO elements include population or problem, intervention, comparison and outcome.

Decision Point 1: Is this topic a priority? Given the high rates of mortality and morbidity in the dialysis population, the topic of advance directives is also a priority for the facility to address. Organizationally, the low rate of AD completion is concerning for the dialysis facility manager, as its implementation is consistent with the organizational mission and vision for quality of patient care and evidence-based practice. Completion of advance directives is also a national initiative due to the passage of the Patient Self-Determination Act (PSDA) in 1990. It is also a topic of concern professionally within the field of nephrology, as clinical practice guidelines have recommended advance care planning as central tenets of dialysis care and chronic kidney disease management (Holley & Davison, 2015).

Form a team. Once the topic has passed the first decision point, the next step is to form an interdisciplinary team (Buckwalter et al., 2017). The activities of the team should include reviewing existing literature, obtaining baseline data, and engaging key stakeholders (Buckwalter et al., 2017). An effective team for this project includes the project leader, the DNP faculty advisor, the dialysis program director, the facility social workers, and the nephrologist provider. The project leader is guided by the DNP faculty advisor in the completion of the doctoral project. The clinical program director manages and oversees the dialysis clinic, and her support is crucial for the identification of resources, project feasibility, and dissemination of data. At this dialysis facility, the on-site social workers are the ones primarily responsible for assisting the patients in filing out advance directives and their approval and engagement is critical for the success of the project. Although it was not feasible for all providers to be on the team, they were all made aware of the project, and at least one provider was included, as they are the leaders for determining the direction of patient care. Although one meeting with all clinic providers was not feasible, the project leader was able to obtain a series of individual conversations with two of the nephrology providers at the clinic.

Assemble, appraise, and synthesize the body of knowledge. The next step includes the assembly of a body of evidence to support the practice change and aid in the development of an intervention. The body of evidence should be weighted for quality, quantity, consistency, and risk (Buckwalter et al., 2017). A systematic search of the literature is detailed in the literature review section and summarized in the summary and synthesis table in Appendix A.

Decision point 2: Is there sufficient evidence? Following the review and synthesis of the evidence, the second decision point is to determine whether there is sufficient evidence for a practice change. As evidenced in the literature review, there is overwhelming support for the use of advance care planning, the importance of advance care planning in outpatient dialysis patients, the importance of patient education and awareness, and the role of nursing staff in the provision of patient education to facilitate advance directive completion.

Design and pilot. As the integration of advance care planning is supported by the literature, the next step was to design and pilot the practice change. This step included collecting data, developing a plan, preparing materials, promoting adoption, and reporting post-pilot data (Buckwalter et al., 2017). The project design is based on the current processes and needs of the dialysis facility and developed with the collaboration of the interdisciplinary team. This step also includes the need to address necessary resources, constraints, and approvals. Resources included material resources and time needed for the project leader to provide the intervention education sessions. Constraints included the project leader’s timeline for project completion, and approvals included the approval of the dialysis manager, providers, social workers, and institutional review boards.

Is the change appropriate for adoption in practice? This step requires the scholarly evaluation of pilot data to determine if the practice change worked, or if the implementation plan was effective (Buckwalter et al., 2017). A statistical analysis of the collected data should be included for evaluation. If results are not as anticipated, the team should consider revising the implementation plan or considering alternatives (Buckwalter et al., 2017).

Integrate and sustain the practice change. If the plan was effective, steps should be taken to integrate and sustain the practice change. Key elements for integrating and sustaining change include identifying and engaging key personnel, such as building new teams and identifying new change champions (Buckwalter et al., 2017). Should the pilot practice be successful, the results should be shared with all nursing staff, and nursing staff should be educated on how to provide the education to patients using the education materials. A champion should be selected, and the intervention should be provided for all current dialysis patients. A protocol for ensuring that new dialysis patients receive the education will also need to be developed, and a champion nurse should be selected to ensure compliance.

Disseminate results. Dissemination of results includes strategic internal dissemination and sharing results externally (Buckwalter at al., 2017). Internally, the project results can be shared with staff at the dialysis facility, such as through staff meetings and posters. The project leader should also seek opportunities for additional ways to disseminate to the various dialysis clinics within the organization.

Summary

There is strong literature support for the benefits of advance care planning in the dialysis patient population and the literature indicates a variety of strategies to be effective, without consistent support of any one method in particular. The literature demonstrates patient education, interdisciplinary involvement, and patient-centered discussions to be effective individually, and this author has sought to integrate these three ways into a targeted intervention in the proposed project. Completion of advance directives and patient surveys will provide baseline data for measurement, with the hypothesis that targeted patient education can increase patient awareness and facilitate the completion of an advance directive, which will be completed under the supervision of the social worker, or the update of the patient code status, which will be completed by a nephrologist provider.

SECTION THREE: METHODOLOGY

Design

This project is an evidence-based practice project, utilizing a quasi-experimental approach to collect and analyze data, as guided by the Iowa Model. According to the Iowa Model, a pilot study is used to evaluate a practice change (Buckwalter et al., 2017). A quasi-experimental approach was used, as participants were not randomized (Geldsetzer & Fawzi, 2017).

Measurable Outcomes

The project measured patient understanding of ADs, code status, and their desire to complete advance directives together with a patient survey before and after the intervention. Advance directives' completion and code status change were tracked through a report in the facility electronic medical record (EMR). A chart review of the completion rate of advance directives or code statuses was completed before the intervention took place and four weeks after the intervention took place. Each participant also completed two different surveys, one before the patient education session, and one afterwards. Each survey was brief and consisted of either dichotomous yes/no responses or Likert-scale type responses. Results from the survey were recorded and analyzed for descriptive statistics.

Setting

The project was conducted in an outpatient dialysis clinic associated with a university hospital in central Virginia. The goal of the project not only to improve the dialysis center's compliance with national initiatives to integrate ACP into care, but also with the organizational initiatives to provide evidence-based, value-driven care (UVA Health System, 2018). The literature establishes ACP as an integral component of increasing patient quality of life and reducing health care costs among dialysis patients (Song et al., 2015), and the project's goal to bridge the gap between the standard of care for dialysis patients at the dialysis clinic and current practice aligns with the organization’s mission to provide quality and evidence-based patient care.

The organizational environment within the dialysis clinic is both collaborative and hierarchical. The clinic employs a variety of roles; the large interdisciplinary care team work together to provide all aspects of patient care. Nurses and dialysis technicians provide the most direct patient care. Dieticians, social workers, nurse educators, nurse managers, and administrative staff are also present on site. In this organization, addressing ADs fall under the responsibility of the social worker to review with the patient upon dialysis initiation as well as annually.

Key stakeholders within the organization for the project included the clinic director, the nurse manager, the social workers, and the nephrology providers. The project had the support of the clinic director and nurse manager, who both have nursing background experience with palliative care and are passionate about facilitating advance care planning within the dialysis population. A letter of support was obtained prior to project initiation and is provided in Appendix B.

Population

The setting provides a large sampling population which provided an ideal setting for conducting a pilot study. The setting dialysis clinic is a large dialysis clinic with 43 chairs and 205 patients. The population consists of adults over the age of 18. Patients at the clinic are generally of low socioeconomic status, and there is a large African American population. These patient demographics likely reflect the dialysis population, as African Americans constitute more than 35.3% of all patients in the U.S. receiving dialysis for kidney failure, as of 2013 (National Kidney Foundation, 2016).

Inclusion and Exclusion Criteria. Inclusion criteria included dialysis patients over the age of 18, patients with a diagnosis of ESRD on chronic in-center dialysis for at least three years at the study setting facility, patients who did not have documented ADs on file, and patients whose primary language is English and who are able to complete survey forms independently. Patient who had been on dialysis at least three years at the current facility ensured that patients were established patients at the facility and not new to dialysis. They had also had at least three chances to complete ADs, as social workers review AD completion with patients annually, per facility protocol. Exclusion criteria included patients with a known learning disability, patients who are cognitively impaired, patients who are pregnant, and patients with a known medical diagnosis of dementia. The study exclusion criteria sought to eliminate IRB-defined vulnerable populations and those who would not be able to a complete informed consent.

Sampling Method. The population for the project was achieved through a convenience sample of the current patients on hemodialysis at the site. A convenience sampling technique was the most feasible sampling method for the current project and its timeframe. All patients were first screened through a review of medical records to ensure they met the eligibility criteria. If the presence of cognitive impairment was unclear or uncertain in the medical record documentation, the project reviewed that patient’s case with their assigned social worker. The project leader approached the social worker with the following question: “Does this patient have a cognitive disability that would compromise his or her capacity to make a decision about study participation?” and received a yes or no answer. If any of the exclusion criteria were present, unclear, or unknown, the patient was considered ineligible and excluded from the study. Of the

211 dialysis patients at the facility at the time of the project initiation, 84 patients had been at the dialysis facility at least three years. Three years was defined as a dialysis start date of later than January 1, 2016. Further application of the inclusion and exclusion criteria, after confirmation from the social workers, eliminated 31 patients, leaving a remaining eligible population of 53 patients. These patients were approached by the project leader in the order of time that they dialyze (i.e. patients who dialyze on the first shift was approached to join the study first, then patients who dialyze on the second shift) until the goal sample size of 30 patients had been reached. A total of 50 patients were approached for informed consent, 15 of whom declined to participate in the study, and five who dropped out after giving consent but prior to the intervention stage.

Study Participants. Of the 30 participants, 37% (n = 11) were female and 63% (n = 19) were male. Eighty percent of the participants were African American (n = 24) and 20% (n = 8) were Caucasian. Participants' ages ranged from 27 to 85. The mean age was 60.2 with a standard deviation of 12.96. The number of years on dialysis at the current facility ranged from 3 to 15 with a mean of 6.43 and a standard deviation of 3.202. Half of the participants had been on dialysis at the facility for at least five years but more than three (n = 15) and 17% of the participants had been on dialysis at the facility for over 10 years (n = 5).

Ethical Considerations

Ethical considerations, such as beneficence, patient privacy, confidentiality, and informed consent were high priorities for the project. The project leader had completed the Collaborative Institutional Training Initiative Certificate for Social and Behavioral Researchers as well as the Biomedical and Health Science Researchers (Appendix C). The project was approved by the Liberty University Institutional Review Board and was deemed exempt by the dialysis clinic's organizational Institutional Review Board. Copies of the IRB approval letter and the exempt letter are provided in Appendixes D and E respectively.

Ethical considerations for the study include the protection of human subjects throughout the process of implementation. This includes the protection of patient privacy and confidentiality of sensitive medical information, as well as the determination of patient consent. The project leader provided verbal and written information regarding the purpose and scope of the project, and all patients signed a written consent form prior to study participation (Appendix I), as well as a confidentiality form for the use of medical records (Appendix J). Since the project leader is also an employee at the facility, the consent form included a statement that participation is voluntary, and that patient care and the nurse-patient relationship will not be impacted by participation in the study or the outcomes of the study. The dialysis facility’s policy for patient data confidentiality was followed when accessing patient data, and IRB-approved methods were followed for secure data storage.

Data Collection

Data collection occurred in four phases: baseline data collection, data collection to determine patient eligibility, data collection of participant demographic information and survey results after participant recruitment, and data collection four weeks after the patient intervention. All data were collected through the dialysis facility’s EMR and included a review of patient progress notes, the medical diagnosis list, and special reports. Special reports included a summarized report of AD completion and the code status of all facility patients, as well as a report summarizing the dialysis start dates of all facility patients.

Baseline Data Collection. Baseline data collection to determine the AD completion rate at the dialysis facility was necessary to determine the extent of the problem. The dialysis facility’s EMR was able to run a report of the code status and AD completion of each patient at the facility. This report indicated that only 13.7% of the patients at the dialysis facility had completed ADs. The project leader confirmed with the site social workers and office administrator that this report was up to date.

Patient Eligibility Determination. Next, the project leader began to review the medical charts for eligibility criteria. The project leader reviewed an EMR report that listed patients from their dialysis start date, or 84 patients. Each patient’s medical records in this list were reviewed for exclusion criteria. This was accomplished by reviewing their medical diagnosis, unique orders, and nursing and social worker progress notes from the past month. For example, a medical diagnosis of dementia in a patient’s diagnosis list excluded that patient from the study. Patients with social worker notes or nursing assessment notes that mentioned any cognitive disability or learning disability were also excluded. To further ensure that patients met eligibility criteria, patients whose notes were unclear or uncertain were confirmed with their assigned social worker at the facility. Only two patients at the facility did not have English as their primary language. None of the patients were under the age of 18, and none of the patients were pregnant. This process resulted in the elimination of 31 additional patients.

Participant Information and Results. Next, after patients were recruited to the study, the project leader completed another review of the medical records for participant age and ethnicity, code status, and years on dialysis. The project leader also collected all survey results after the patient education was completed. A final report of the AD completion rate and code status was collected four weeks after the intervention on the participating patients.

Tools

The project leader utilized two different patient surveys, a survey prior to the education session and a survey after the education session had been conducted. The survey questions were based on survey questions from an evaluation of advance directive video education for patients by Toraya (2014), with a few modifications. The project leader obtained permission from the author to reuse and modify these questions for the purposes of this project (Appendix G).

Pre-intervention Survey. The survey prior to the education session included six questions: 1) Have you discussed your health care wishes with family/loved ones in case you ever get seriously ill or injured and cannot communicate your wishes? 2) Have you discussed these wishes with your doctor? 3) Are you familiar with advance directives or living wills? 4) Have you completed an advance directive (living will)? 5) Do you feel that you understand the purpose of the advance directive (living will)? 6) Are you interested in completing an advance directive (living will)? Responses to questions 1, 2, 4, and 6 are dichotomous yes/no responses. Possible responses for questions 3 and 5 will include “yes”, “no”, or “somewhat”.

Post-intervention Survey. A post-intervention survey included the following four questions. First, has this education changed anything about your future health care wishes or about discussing your wishes with your family/loved ones and your doctor? Possible responses include “yes” and “no”. Second, do you plan to complete the advance directive form because of the education given? Possible responses include “yes” and “no”. Third, do you feel that you have enough information to start the process of discussing your wishes and completing the forms? Possible responses include “yes” and “no”. Fourth, how helpful was the education session to you? Responses to the last question was in the form of a Likert scale, ranked 1 through 5, with 1 rated as “not helpful” and 5 rated as “extremely helpful”.

Educational Information. For the education, the project leader presented a summary of the key points from the brochure “Advance Care Planning: Tips from the National Institute on Aging” provided by the National Institute of Aging (2018) via their website. This education is a free resource provided by the National Institute on Aging. This education resource was included in the systematic evaluation of advance care planning patient educational resources by Gazarian et al. (2018) and was recommended as helpful to increase patient awareness in the precontemplation/contemplation phase of change. Gazarian et al. (2018) analyzed the resource using the Patient Education Material Assessment Tool (PEMAT) to determine the understandability and actionability of the material, and the Flesh-Kincaid reading ease and grade level (Gazarian et al., 2018). The analysis found the resource to have an acceptable readability level, usability, and actionability (Gazarian et al., 2018). The information included in the brochure was summarized and presented in a 16-slide PowerPoint slide presentation for the patients. The PowerPoint slides were printed out and placed into a binder. The information included a summary of the definitions of advance care planning, living will, durable power of attorney, cardiopulmonary resuscitation, ventilator use, artificial nutrition and hydration, comfort care, and do-not-resuscitate orders. These points were chosen as they most closely reflected the common choices patients face while completing an AD form. As it is a public resource, permission was not required for the use of this information, according to a written confirmation by the National Institute on Aging Information Center (Appendix H).

Intervention

Project Development. The project implementation began with the identification of a triggering issue by the project leader, as guided by the Iowa Model (Buckwalter et al., 2017). As an employee of the dialysis clinic, the project leader had insight into the need for the improvement of the advance care planning process at the facility. This was confirmed by conversations with the clinic management team, especially the nursing manager. The nursing manager assisted the project leader in identifying key stakeholders, including the clinic social workers and the clinic nephrologist.

Intervention Development. Once the team was formed, the project leader proceeded to have a series of conversations with the clinic charge nurse, the nursing managers, the three clinic social workers, and two different providers to discuss perceived barriers and strategies for change. From these conversations, two main barriers emerged: lack of provider time and patient resistance. A lack of time to explain and educate the patients through the process posed a barrier to AD completion for the social workers. Physician providers also identified a lack of patient education as a barrier to having productive discussions about code status changes. Patient resistance identified included cultural barriers, as it was perceived that many African American patients were reluctant to address the subject, and lack of patient education. The social workers also felt that some of the newer dialysis patients felt overwhelmed by their condition and were not ready to discuss end-of-life issues.

The project idea underwent several design iterations after these conversations, and the project leader completed a literature review of the evidence to guide the development of a study intervention that would be feasible within the time constraints of the project timeline and yet still have clinical impact. This project guided the project intervention towards a more educational intervention that would be patient focused. Ideally, a patient-focused education would decrease patient resistance to AD completion and facilitate provider and social worker conversations, and potentially save time for them during their conversations. The tools for the intervention were identified through the literature review and were reviewed with the project chair and key stakeholders, and the project leader received verbal confirmation from all three social workers, two providers, the nurse manager, and the charge nurse. After finalizing the intervention idea, the project leader obtained a letter of approval from the dialysis clinic manager to conduct the study on the dialysis facility premises.

IRB Approval. IRB approval was required for this project by the dialysis clinic and Liberty University. After submission of the necessary documents, the project leader obtained an expedited review through Liberty University. Through the IRB process, the project leader developed a consent form and a written recruitment letter. The project leader also collaborated closely with the IRB liaison at the dialysis clinic organization. After submission of the necessary documents and completion of an online protocol builder, the project was approved as exempt from IRB review, although study participants would be required to read and sign confidentiality, use, and disclosure of health information forms. The project leader also obtained permission to access patient medical records and create reports for data collection. All chart reviews were completed within the dialysis facility, and all information of patient data for the purposes of the project were stored either on a facility encrypted computer or within a manager’s office, according to the IRB protocol.

Eliciting Participants. Next, the project leader began the process of data collection to identify eligible participants. This process is explained in detail under the “Data Collection” section of this manuscript. Once the project leader had identified a list of eligible patients, they were then grouped by the time that they dialyze for a more efficient recruitment method. The project leader then approached each patient either before, during, or after their dialysis for recruitment. The project leader provided the letter of recruitment and verbally explained the purpose and timeline of the project. The project leader provided participants who agreed to participate with a consent form and a confidentiality disclosure form (Appendixes I and J respectively). Patients were also given the choice to think about participating if they were uncertain, with follow-up the next week. All patients who agreed to participate signed both forms on the day of recruitment; one patient who required time to consider decided not to participate. A list of eligible patients, a list of recruited patients, and signed consent forms were kept in a secure location within the dialysis clinic per IRB protocol. The full recruitment process took two weeks' time, as not all eligible patients were present for every dialysis treatment, due to missed treatments or hospitalizations.

Baseline Data Collection. The project leader completed a chart review to collect the baseline AD completion rate and code status from selected participants. Other patient data collected included patient age, ethnicity, and time on dialysis. Participant names were coded with a unique identifier and all participant information was kept in a secure location within the dialysis facility.

Patient Education. After recruitment, the project leader approached each participant individually while they were on dialysis to provide the patient education session. The project leader first checked with the patient's nurse to ensure it would be an appropriate education session for the patient before approaching the patient for permission. Several patients who were not feeling well declined to participate and the project leader returned the following week. Patients who were agreeable to the education session at the time were given the question pre-education survey. After completion, the project leader presented the 10-minute presentation summarizing the brochure "Advance Care Planning: Tips from the National Institute on Aging", on the information provided by the National Institute on Aging (2018). The patients were also presented with a printed full version of the brochure for their reference. Any patient questions were answered by the project leader to the best or her ability or referred to the patient's social worker. After the education session, patients completed the post-education survey. Both surveys were collected and returned to the project leader after completion through the nursing staff. Survey responses were identified with a unique identification number. The patient education was provided to each of the 30 participants over a two-and-a-half-week time period.

Social Worker Notification and Final Data Collection. During and after the patient education, the project leader emailed each social worker with the names of study participants and a request to follow up for AD completion through the dialysis facility's encrypted email system. The project leader received email confirmation of email receipt. The project leader completed a final chart review three weeks after the intervention to assess the AD completion rate among the participants.

Timeline

The project conception began in November of 2018. Meetings with key stakeholders occurred throughout January of 2019. Liberty University IRB approval was obtained on April 2, 2019. The IRB approval through the dialysis organization was obtained by May 3, 2019. The baseline data collection for patient eligibility began on May 6, 2019. Patient recruitment began on May 9 and was concluded on May 24, 2019. Patient education began on June 3, 2019 and was concluded on June 19, 2019. A last chart review was completed on July 12, 2019.

Feasibility Analysis

The burden of the project fell primarily on the project leader. The project overall required minimal resources from the dialysis clinic and dialysis staff. The project leader did not utilize any work hours to complete the project, nor did it require any training of dialysis staff members. The data collection process utilized the facility's existing technological resources. The educational tools for preparing the project were free of charge and accessible via the internet. The only costs were the printing costs and the cost of purchasing office supplies by the project leader to organize the project tools and paperwork.

Data Analysis

The project leader analyzed the patient demographic data and survey responses using descriptive statistics. In addition, the project leader measured the association between survey responses and patients' age and the length of time a patient had been on dialysis at the current facility. All information was coded and entered into SPSS version 25.0.

Demographic Data. The demographic data measured include a patient's gender, age, ethnicity, years on dialysis at the current facility, and code status. All information was entered into SPSS version 20.0 with the following codes: gender was coded as 0 for "female" and 1 for "male", ethnicity was coded as 0 for "Caucasian" and 1 for "African American", and code status was coded as 0 for "full code" and 1 for "Do Not Resuscitate". Demographic information was entered into SPSS as separate variables and then analyzed, using descriptive statistics to determine frequency, mean, and range, as appropriate for the variable.

Survey Responses. Similarly, the responses to the survey questions were coded into SPSS. Questions with yes/no responses were coded as 0 for "no" and 1 for "yes". Questions with Likert-scale responses were coded as 0 for "no", 1 for "somewhat", and 2 for "yes". The question that asked participants to rank the helpfulness of the information provided from a scale of 1 to 5, with 1 being "not at all helpful" to 5 being "very helpful" were coded into SPSS from a scale of 1 to 5. Coded survey responses were then entered into SPSS and analyzed using descriptive statistics.

Correlation Between Demographic Data and Survey Responses. The project leader used linear regression and correlation to measure the association between patients' age and the length of time a patient had been on dialysis at the current facility with their responses for both pre- and post-education surveys. Correlation analysis was chosen as a straightforward way to measure the association between the two variables (Lind, Marchal, & Wathen, 2010). The percentage of "yes" responses was calculated for each "yes/no" survey response per age group and per years on dialysis. The mean response was calculated for survey questions with Likert-scale responses per age group and per years on dialysis. The coefficient of correlation, or Pearson's r, was chosen, as it measures the strength of the linear relationship between two variables, and statistical significance was defined at $p < 0.05$ (Lind, Marchal, & Wathen, 2010). The project leader anticipated that there would be a correlation between both a patient's age and the length of time they had been on dialysis with survey responses, especially familiarity with ADs and intent to complete the ADs.

AD Completion

The participant AD completion rate was entered into SPSS and analyzed using descriptive statistics. Participant code status was also analyzed using descriptive statistics in SPSS. The project leader anticipated an improvement in the percentage of participants who had completed ADs after the intervention. The project leader also anticipated an increased number of code status changes from full code to DNR.

SECTION FOUR: RESULTS

Pre-education Surveys

Most of the participants (63.3%) had discussed their future health care wishes with family and loved ones (n = 19) but few had discussed their wishes with their provider (30%, n = 9). Half of the participants said they were familiar with ADs (53.3%, n = 16), with 26.7% (n = 8) saying they were “somewhat” familiar and the rest, 20% (n = 6), saying they were not familiar at all with ADs. Around 63.3% of participants said they understood the purpose of ADs (n = 19), with 26.7% saying they “somewhat” understood the purpose of ADs (n = 8), and only 10% responding that they did not understand the purpose of ADs (n = 3). About 66.7% of participants said they wanted more information (n = 20). Responses to the pre-education surveys are summarized in Table 1.

Post-education Surveys

After the presentation, 66.7% (n = 20) responded that the education had changed something about their future health care wishes or about discussing their wishes with their family/loved ones or doctor. About 73.3% (n = 22) of participants planned to complete an AD because of the information provided. The majority of participants (86.7%) felt the video gave them enough information to start discussing their wishes and completing AD forms (n = 26). The average score when participants were asked to rank the helpfulness of the education was 4.43 on a scale of 1 to 5. Responses to the post-education surveys are summarized in Table 2.

Correlation Between Survey Responses and Demographic Data

The project leader used linear regression and correlation to measure the association between the length of time a patient had been on dialysis at the current facility with their responses for both pre- and post-education surveys. Statistical analysis did not find a statistically significant correlation between any of the survey responses with the number of years a participant had been on dialysis at the current facility. Results are summarized in Table 3.

Correlation Between Survey Responses and Age

Statistical analysis found one statistically significant correlation between a patient's age and their response to the first question of the post-education survey, with a *p* level at 0.043. Patients who were older were less likely to change their health care preferences or discuss their wishes with family or a doctor after the education session than younger patients. There was no other correlation between patient age or years on dialysis at the current facility and how patients responded to the survey questions, as all other survey responses did not indicate statistically significant correlation. Results are summarized in Table 4.

AD Completion and Code Status

Seven of the participants were moved to a different dialysis facility due to the dialysis clinic renovations soon after the intervention took place. A chart review of the remaining 23 participants three weeks after the intervention took place indicated no change in code status or AD completion rate among the study participants.

SECTION FIVE: DISCUSSION

Advance directive education sessions emphasizing the importance of discussions and AD forms were demonstrated to be helpful for outpatient dialysis patients and may help facilitate a patient's desire to complete the AD. Responses from the post-educational survey indicate that the educational session influenced patient decision-making, and an overwhelming majority of participants responded favorably to completing an AD because of the information provided. However, there was no change in the AD completion rate, which is likely due to a lack of appropriate social worker follow-up due to external factors. Overall, the project reflects the need for education and increased patient awareness regarding ADs and supports the role of patient education in the process of advance care planning.

Implication for Practice

Despite the lack of improvement in the AD completion rate or code status change after the intervention, participants in the study found the education to be helpful and responded positively to completing ADs. The process of patient education may be a low-cost solution to raise patient awareness of advance directives, stimulate patient interest in completing advance directives, and establish a useful patient education tool for dialysis staff. Overall, the project results have several clinical and organizational implications.

Clinical Implications. First, this project provides evidence that patient education may be an important step in the process of facilitating AD completion. The project led to an increased patient awareness of ADs among both patients and dialysis staff. Several participants requested to speak with their social worker after the educational intervention to complete ADs, and two requested copies of the dialysis organization's AD forms to take home to review with their family. One participant called his son immediately after the intervention to consult about having a code status change. One dialysis staff member approached the project leader to obtain online resources for filling out an AD for herself. Given these promising signs observed by the project leader, the project leader suspects that the lack of an improved AD completion rate is likely due to lack of follow-up among the social workers or other external factors, such as the dialysis facility renovation that began one week after the intervention concluded.

Organizational Implications. Organizationally, this project supports integrating patient education about ADs into current facility protocol to improve the AD completion rate at the dialysis facility. The dialysis facility that participated in the project has a low rate of AD completion, despite the current facility protocol to address AD completion by facility social workers as part of a mandatory annual review. Participants who were recruited to the study have been on dialysis at the facility setting at least three years, and yet have not completed ADs, suggesting patient resistance to AD completion. From the results of this project, it is suggested that a patient education session may play a key role in encouraging patient compliance with completing ADs at the current facility, as patients who are “primed” with baseline knowledge regarding ADs may be more receptive to further steps in the process of advance care planning when the subject is approached by a member of the health care team. Further studies should be conducted to measure the AD completion rate at the dialysis facility after the education session during a period more conducive to follow-up.

Strengths. Project strengths include the representative nature of the dialysis patient participant sample, which is thought to be very similar to other dialysis clinics in rural Virginia. Another strength is the feasibility of this intervention. The project design may be easily replicated in a broader setting, given the cost-effectiveness of a strategy using accessible online resources as a guide to provide patient education on ADs.

Limitations. The major confounding factor of this project was the lack of social worker follow-up. The dialysis facility began building renovations, which required a shut-down of parts of the facility. Current dialysis patients were temporarily moved to different dialysis facilities within the organization and the dialysis times of most of the current patients were changed to accommodate the renovations. This occurred right after the patient education sessions concluded. Seven patients went to different facilities and all the study participants’ dialysis times were changed. The renovations also created additional workload for the social workers, as they were displaced from their offices and there was chaos at the dialysis facility, since patient times were changed often to accommodate the progression of renovations.

The study limitations also include limitations of internal validity due to the small sample size and relative homogeneity of the sample ethnicity, as the participating patient population consisted primarily of African American patients. However, the sample size is representative of the dialysis clinics in the rural Virginian area. Convenience sampling may also include bias, as patients who agreed to participate in the study may be more likely to respond positively to the education. In addition, the project leader was also an employee at the dialysis facility, although the patients were informed during the consent that participation would not influence the quality of their care or their relationship with the project leader. Additional confounding variables include patient awareness and education on ADs from other sources. External validity effects include patients' subjective perceptions of ADs, personal experience with end-of-life care discussions, and lack of social worker follow-up due to clinic renovations.

Sustainability

The sustainability of the practice change was addressed through email communication with the social workers and dialysis clinic manager. It is promising that the social workers intend to follow up with the participants to the study, although a more structured approach is necessary for long-term sustainability. It is worthy to note that the dialysis facility has begun implementing AD education into the orientation for patients new to dialysis, and a new research project on advance care planning will be launched at the facility in the coming months. However, implementing a strategy to continue to re-address AD completion and raise awareness regarding AD and advance care planning is essential.

Feasibility. The material used in the education session was provided to the social workers and clinic manager to utilize as a continued educational tool. Although individual patient educational sessions require a time commitment the social workers may not have, the educational material can be shared by any qualified member of the dialysis health care team. For example, nurses, who spend the most time with the patients and are often the first to identify patients who would benefit from the education, are ideal candidates to provide the patient education.

Project Evaluation. The project was limited by the timing of the dialysis clinic's renovations, which created a huge barrier for the facility's social workers. It is possible that a longer time to allow for social worker follow-up could have produced more favorable results. Closer collaboration with the social workers by the project leader, more consistent reminders, and closer follow-up by the project leader may have improved follow-up, although the current building renovations would still have been a barrier.

Dissemination Plan

The dissemination plan includes sharing the study results with key stakeholders. Results of the study will be summarized into a poster presentation and presented at the dialysis clinic staff meeting. An email summary of the results will also be emailed to key stakeholders. The project leader also hopes to present the information to all dialysis managers of multiple dialysis clinics at a monthly leadership meeting, thus reaching all the dialysis clinics within the organization.

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List of Tables

Table 1. Responses to Pre-Education Survey

Question	*Yes*	*Somewhat*	*No*
1. Have you discussed your health care wishes with family/loved ones in case you ever get seriously ill or injured and cannot communicate your wishes?	63.3% n = 19	___	36.7% n = 11
2. Have you discussed these wishes with your doctor?	30% n = 9	___	70% n = 21
3. Are you familiar with advance directives (living wills)?	53.3% n = 16	26.7% n = 8	20% n = 6
4. Do you feel that you understand the purpose of advance directives (living will)?	63.3% n = 19	26.7% n = 8	10% n = 3
5. Would you like more information about advance directives?	66.7% n = 20	___	33.3% n = 10

Table 2. Responses to Post-Education Survey

Question	*Yes*	*No*
1. Has this education changed anything about your future health care wishes or about discussing your wishes with your family/loved ones and your doctor?	66.7% n = 20	33.3% n = 10
2. Do you plan to complete the advance directive (living will) forms because of the education provided?	73.3% n = 22	26.7% n = 8
3. Do you feel that you have enough information to start the process of discussing your wishes and completing the forms?	86.7% n = 26	13.3% n = 4
4. How helpful was the education to you?	Mean rank of 4.43 (from 1 – 5)	

Table 3. Correlation between Survey Items and Patient Age

Survey Questions	*Pearson's Correlation*	*Two-tailed significance*
Pre-Education Survey Questions		
1. Have you discussed your health care wishes with family/loved ones in case you ever get seriously ill or injured and cannot communicate your wishes?	-0.101	0.647
2. Have you discussed these wishes with your doctor?	0.362	0.09
3. Are you familiar with advance directives (living wills)?	-0.542	0.008
4. Do you feel that you understand the purpose of advance directives (living will)?	-0.408	0.053
5. Would you like more information about advance directives?	-0.066	0.766
Post-Education Survey Questions		
1. Has this education changed anything about your future health care wishes or about discussing your wishes with your family/loved ones and your doctor?	-0.426	0.043*
2. Do you plan to complete the advance directive (living will) forms because of the education provided?	-0.391	0.065
3. Do you feel that you have enough information to start the process of discussing your wishes and completing the forms?	-0.315	0.143
4. How helpful was the education to you?	0.14	0.525

*significant result

Table 4. Correlation between Survey Items and Years on Dialysis at Current Facility

Survey Questions	*Pearson's Correlation*	*Two-tailed significance*
Pre-Education Survey Questions		
1. Have you discussed your health care wishes with family/loved ones in case you ever get seriously ill or injured and cannot communicate your wishes?	-0.62	0.865
2. Have you discussed these wishes with your doctor?	-0.452	0.189
3. Are you familiar with advance directives (living wills)?	0.627	0.052
4. Do you feel that you understand the purpose of advance directives (living will)?	0.552	0.098
5. Would you like more information about advance directives?	-0.497	0.144
Post-Education Survey Questions		
1. Has this education changed anything about your future health care wishes or about discussing your wishes with your family/loved ones and your doctor?	0.058	0.874
2. Do you plan to complete the advance directive (living will) forms because of the education provided?	-0.158	0.663
3. Do you feel that you have enough information to start the process of discussing your wishes and completing the forms?	0.362	0.305
4. How helpful was the education to you?	0.124	0.732

Appendices

Appendix A

Evidence Table

Article Title, Author, etc. (Current APA Format)	**Study Purpose**	**Sample**	**Methods**	**Study Results**	**Level of Evidence**	**Study Limitations**	**Would Use as Evidence to Support a Change? (Yes or No) Provide Rationale.**
Lim, C.E.D., Ng, R.W.C., Cheng, N.C.L, Cigolini, M., Kwok C., & Brennan, F. (2016). Advance care planning for haemodialysis patients. *Cochrane Database of Systematic Reviews 2016*, 7. DOI: 10.1002/14651858.CD010737.pub2.	To compare ACP intervention with no form of advance care planning and its effect on hospital admissions and quality end-of-life care	Studies on people with ESRD undergoing hemodialysis, did not include people with clinically diagnosed mental illness	Systemic review of RCTs and quasi-RCTs	Patients were highly satisfied with quality of communication and greater levels of comfort; ACP discussion did not destroy hope, cause unnecessary discomfort or anxiety for patients	Level 1	Only two studies were included in the review due to poor study quality	Yes; provides background information on ACP in dialysis and reflects need for more research
Song, Mi-Kyung, RN, PhD, Ward, Sandra E., RN, PhD, Fine, J. P., ScD, Hanson, Laura C., MD, MPH, Lin, F., PhD, Hladik, G. A., MD, . . . Bridgman, Jessica C., RD, MPH. (2015). Advance care planning and end-of-life decision-making in dialysis: A randomized controlled trial targeting	To examine efficacy of ACP intervention on preparation for EOL decision-making for dialysis patients and surrogates	Outpatient dialysis centers in 8 counties in North Carolina	RCT comparing ACP intervention called SPIRIT to usual care alone with blinded outcomes	SPIRIT was superior to usual care alone in enhancing congruence in terms of goals of care, surrogate decision-making confidence, but effects decreased after 12 months	Level 2	Conducted in a single US region	Yes, study did show improvement in positive long-term effects of ACP

patients and their surrogates. *American Journal of Kidney Diseases, 66*(5), 813-822. doi:10.1053/j.ajkd.2015.05.018							
Lazenby, S., Edwards, A., Samuriwo, R., Riley, S., Murray, M. A., & Carson, S. A. (2017). End-of-life care decisions for haemodialysis patients: "We only tend to have that discussion with them when they start deteriorating." *Health Expectations, 20*(2), 260–273. https://doi.org/10.1111/hex.12454	To explore the experiences and perceptions of doctors and nurses in nephrology for involving hemodialysis patients in EOL decisions	20 doctors and nurses recruited through snowball sampling (7 attendings, 4 fellows, 4 residents, 5 senior RNs) from one nephrology unit in the UK	Thematic analysis of semi-structured interviews	Four themes emerged: uncertainties of prognosis, low use of advance care planning in practice, limitations of withdrawal practices, barriers to achieving better end-of-life care	Level 6	Data from one large nephrology unit limits generalizability	Yes; results support the need for advance care planning to be initiated early and increased patient awareness, education, and support after starting dialysis
O'Halloran, P., Noble, H., Norwood, K., Maxwell, P., Shields, J., Fogarty, D., … Brazil, K. (2018). Advance Care Planning with Patients Who Have End-Stage Kidney Disease: A Systematic Realist Review. *Journal of Pain and Symptom Management, 56*(5), 795–807.e18. https://doi-org.ezproxy.liberty.edu/10	To identify implementation theories of advance care planning in ESRD patients, factors that help or hinder implementation, and develop theory on how the	62 articles	Systematic realist review searching 7 electronic data bases, documents selected on their relevance for theory	Identified two intervention stages: training for health care professionals and the use of documentation and processes that are simple, individually tailored, culturally appropriate, and	Level 5	Intervention studies were few with small sample sizes	Yes. Results identify barriers and facilitators for ACP integration that support my proposed intervention

.1016/j.jpainsymman.2018.07.008	intervention may work		building using appropriate appraisal tool by two reviewers	involve surrogates			
Culp, S., Lupu, D., Arenella, C., Armistead, N., & Moss, A. H. (2016). Unmet Supportive Care Needs in U.S. Dialysis Centers and Lack of Knowledge of Available Resources to Address Them. *Journal of Pain & Symptom Management, 51*(4), 756–761.e2. https://doi.org/10.1016/j.jpainsymman.2015.11.017	To describe dialysis professionals' perceptions of the adequacy of supportive care in dialysis centers, barriers to providing it, suggestions for improving it, and familiarity with existing evidence-based resources for supportive care of dialysis patients	Convenience sample of 487 health care professionals (nephrologists, nurse practitioners/PAs, nurses, social workers, and dialysis center administrators)	Online survey of 16 questions; question format included multiple choice and ratings on five-point scales	4.5% of respondents believed they were doing an adequate job providing high-quality supportive and end-of-life care, low awareness of available resources, "guidance to help with decision-making in seriously ill patients" rated as top choice that could most improve supportive care in the dialysis center	Level 6	Lack of formal survey instrument development and use of convenience sample	Yes; results demonstrate significant room for improvement in multiple aspects of supportive care in dialysis centers
Eneanya, N. D., Wenger, J. B., Waite, K., Crittenden, S., Hazar, D. B., Volandes, A., & ...	To explore racial variability in EOL	AA and Caucasian patients with stage 4	Cross-sectional study between	Low rates of ACP and EOL discussions for patients with	Level 6	Conducted in a single US	No; low level of evidence, addresses pre-

Paasche-Orlow, M. K. (2016). Racial Disparities in End-of-Life Communication and Preferences among Chronic Kidney Disease Patients. *American Journal of Nephrology, 44*(1), 46-53. doi:10.1159/000447097	communication, care preferences, and ACP	or 5 CKD from 2 academic outpatient nephrology centers in Boston (152 patients total)	2013 and 2015	CKD with their nephrologists or other health care providers, no substantial racial differences in EOL utilization		region, limited diversity of cohort, pre-dialysis patients	dialysis patients only
Tong, A., Cheung, K. L., Nair, S. S., Kurella Tamura, M., Craig, J. C., & Winkelmayer, W. C. (2014). Thematic synthesis of qualitative studies on patient and caregiver perspectives on end-of-life care in CKD. *American Journal of Kidney Diseases: The Official Journal of The National Kidney Foundation, 63*(6), 913–927. https://doi.org/10.1053/j.ajkd.2013.11.017	To describe patients’ and caregivers’ perspectives on conservative treatment and end-of-life care in CKD	26 studies included for review	Systematic review and thematic synthesis of qualitative studies	Five themes: invasive suffering, personal vulnerability, relational responsibility, negotiating existential tensions, and preparedness	Level 5	Excluded non-English articles	Yes; results promote CKD management to encompass palliative care strategies that promote emotional resilience, sense of well-being, and self-value
Haras, M. S., Astroth, K. S., Woith, W. L., & Kossman, S. P. (2015). Exploring Advance Care Planning from the Nephrology Nurse	To explore the literature about advance care planning from the nephrology	20 research articles included	Two literature reviews conducted between September	Four structural and procedural dimensions found from thematic literature review: knowledge of	Level 5	Limited number of included studies	Yes; results identify structure and process components to increase

Perspective: A Literature Review. *Nephrology Nursing Journal*, *42*(1), 23–36. Retrieved from EBSCO.	nurse perspective		2010 and November 2013	advance care planning, organizational support for advance care planning, attitude towards advance care planning, and nurse comfort with discussions			nephrology nurse involvement in advance care planning
Luckett, T., Sellars, M., Tieman, J., Pollock, C. A., Silvester, W., Butow, P. N., . . . Clayton, J. M. (2014). Advance care planning for adults with CKD: A systematic integrative review. *American Journal of Kidney Diseases*, *63*(5), 761-770. doi:10.1053/j.ajkd.2013.12.007	To identify which measures have been used to conduct ACP	Adults with primary diagnosis of CKD	Systematic integrative review of qualitative, quantitative, or mixed methods	Unable to draw conclusions as most research on ACP in CKD is descriptive	Level 2	Low number and quality of studies	No; results inconclusive
O'Hare, A. M., Szarka, J., McFarland, L. V., Taylor, J. S., Sudore, R. L., Trivedi, R., & ... Vig, E. K. (2016). Provider Perspectives on Advance Care Planning for Patients with Kidney Disease: Whose Job Is It Anyway?. *Clinical Journal of The*	To describe perspectives on ACP of multidisciplinary providers who care for patients with advanced kidney disease	26 providers who care for patients with advanced kidney disease from different disciplines and	Qualitative study with semi-structured one on one interview and data analysis based on	Many challenges exist for interdisciplinary collaboration around ACP planning with a need for systematic efforts at organizational	Level 6	Small sample size	Yes; supports a systematic approach for addressing ACP

American Society Of Nephrology: CJASN, *11*(5), 855-866. doi:10.2215/CJN.11351015		specialties at the VA in Seattle, WA	grounded theory	levels to support teamwork			
Bristowe, K., Shepherd, K., Bryan, L., Brown, H., Carey, I., Matthews, B., & ... Murtagh, F. M. (2014). The development and piloting of the REnal specific Advanced Communication Training (REACT) programme to improve Advance Care Planning for renal patients. *Palliative Medicine*, *28*(4), 360-366. doi:10.1177/0269216313510342	To evaluate if a renal-specific advanced communication training program can improve ACP discussions for ESRD patients	2 large renal units in London teaching hospitals	Pilot pre-post survey	The program was associated with a non-significant increase in confidence in communicating about end-of-life issues	Level 4	Pilot study, not powered for assessing effect	No; results were not significant enough to improve provider confidence about communicating end of life issues
Kurella Tamura, M., Montez-Rath, M. E., Hall, Y. N., Katz, R., & O'Hare, A. M. (2017). Advance Directives and End-of-Life Care among Nursing Home Residents Receiving Maintenance Dialysis. *Clinical Journal of The American Society of Nephrology: CJASN*, *12*(3), 435–442.	To determine the content of advance directives of nursing home residents receiving dialysis versus patients with other serious illnesses, whether having advance	31,716 nursing home residents receiving dialysis and 30, 825 nursing home residents with other serious illnesses	Observational study using cohort comparison of retrospective data from 2006 – 2007 retrieved from the United	Treatment-limiting directives and surrogates were associated with fewer intensive interventions and inpatient deaths but were in place much less often than for nursing home residents	Level 4	Results limited to patients residing in a nursing home, lacked information on psychosocial	Yes; strong support for the benefits of advance directives among nursing home residents on dialysis

https://doi.org/10.2215/CJN.07510716	directives were associated with less intensive end-of-life care, and how often patients with ESRD received care consistent with their advance directives	during the year before death	States Renal Data System	with other serious illnesses		factors which may influence use of advance directive and patient experience near end of life	
Eneanya, N. D., Olaniran, K., Xu, D., Waite, K., Crittenden, S., Hazar, D. B., … Paasche-Orlow, M. K. (2018). Health Literacy Mediates Racial Disparities in Cardiopulmonary Resuscitation Knowledge among Chronic Kidney Disease Patients. *Journal of Health Care for the Poor & Underserved, 29*(3), 1069–1082. https://doi.org/10.1353/hpu.2018.0080	To investigate whether health literacy would mediate racial disparities in understanding CPR among black and white patients with advanced CKD	149 patients with advanced CKD with Stage 4 or 5 CKD from outpatient nephrology clinics	Cross-sectional study among dialysis patients using an interview assisted knowledge questionnaire	A higher proportion of black patients had limited health literacy, fewer advance directives, and lower knowledge of CPR compared with white patients. Health literacy was a significant predictor of CPR knowledge	Level 4	Questionnaire was not validated for CKD patients	Yes; results support tailored advance care planning conversations to account for cultural, educational, and social support differences to engage minority populations
Smith, V., & Wise, K. (2017). Evaluating nurses' action outcomes and exploring their	To evaluate nurses' action outcomes and explore their	54 patients who completed the POSS-S	Mixed-methods design using 2	Between 11% and 24% of patients had moderate to severe symptom	Level 6	Small sample sizes for retrospe	Yes; results support that regular tracking of

perspectives of implementing the POS-S (Renal) assessment tool for haemodialysis patients. *Renal Society of Australasia Journal, 13*(1), 14–21. Retrieved from EBSCO	perspectives on the implementation of an assessment tool to assist with addressing symptom burden, advance care planning, and quality end-of-life care	(Renal) tool. Focus group included 11 participants	year retrospective audit of patient symptom reporting followed by thematic analysis of focus groups with nurses	burden, more than half with corresponding progress note and nursing action; analysis of focus groups revealed increased confidence and willingness to take ownership to effect change within nursing rules		ctive chart audit and focus groups, and results not generalizable	symptom burden can help raise renal nurses' awareness of the need to support and prepare the patient for end-of-life conversations; also supports a nurse-led approach in driving change in practice
Janssen DJ, Spruit MA, Schols JM, van der Sande FM, Frenken LA, & Wouters EF. (2013). Insight into advance care planning for patients on dialysis. *Journal of Pain & Symptom Management, 45*(1), 104–113. https://doi.org/10.1016/j.jpainsymman.2012.01.010	To understand the preferences for life-sustaining treatments of outpatients on dialysis and to study the quality of patient-physician communication about end-of-life care and barriers and facilitators to	Convenience sample of 80 clinically stable dialysis patients in one academic and five general hospitals in the Netherlands in 2008 and 2009	Cross-sectional observational study, using several different questionnaires for patients and nephrologists, statistical analysis of using SPSS 18	Life-sustaining preferences were discussed with nephrologists by 30.3% of patients, quality of patient-physician communication about end-of-life care was rated poor	Level 4	Small convenience sample of dialysis patients, younger demographically, few were non Caucasian, questionnaires	Yes; results provide directions to facilitate the process of advance care planning for patients on dialysis

	this communication					used were not validate for patients in dialysis	

Appendix B

Site Letter of Support

UNIVERSITY of VIRGINIA
HEALTH SYSTEM

UVA Lynchburg Dialysis

March 28, 2019

Xuesi Liu BSN, RN
DNP Student
Liberty University
105 Hardwood Ct.
Forest, Va. 24551

Dear Xuesi Liu:

After careful review of your Evidence-Based Scholarly Project entitled "Evaluation of Advance Directive Patient Education for Dialysis Patients", I have decided to grant you permission to conduct your study at UVA Lynchburg Dialysis.

Check the following boxes, as applicable:

- ✓ The project leader has permission to access patient data through the facility's electronic health record for this project.
- ✓ The requested data WILL NOT BE STRIPPED of all identifying information before it is provided to the researcher.
- ✓ I am requesting a copy of the results upon study completion and/or publication.

Sincerely,

[redacted]

Kimberly Q. Campbell MHA, BSN, RN, CDN, NE-BC
Nurse Manager
UVA Lynchburg Dialysis

103 Clifton Street | Lynchburg, VA 24501-1460
434.455.7100 | Fax 434.528.2722

Appendix C

CITI Certifications

Completion Date 01-Jul-2017
Expiration Date 30-Jun-2020
Record ID 21175165

This is to certify that:

Xuesi Liu

Has completed the following CITI Program course:

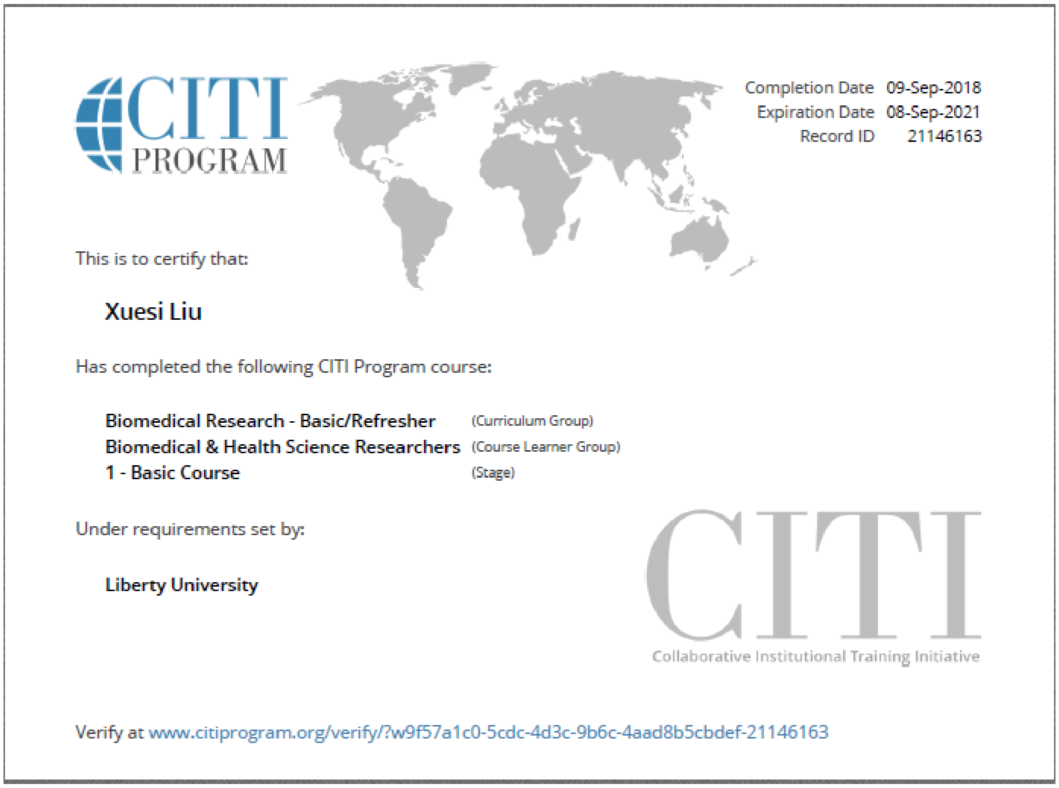
Social & Behavioral Research - Basic/Refresher	(Curriculum Group)
Social & Behavioral Researchers	(Course Learner Group)
1 - Basic Course	(Stage)

Under requirements set by:

Liberty University

Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?w7460047a-a4d5-4db6-a245-108228576522-21175165



Completion Date 09-Sep-2018
Expiration Date 08-Sep-2021
Record ID 21146163

This is to certify that:

Xuesi Liu

Has completed the following CITI Program course:

Biomedical Research - Basic/Refresher	(Curriculum Group)
Biomedical & Health Science Researchers	(Course Learner Group)
1 - Basic Course	(Stage)

Under requirements set by:

Liberty University

Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?w9f57a1c0-5cdc-4d3c-9b6c-4aad8b5cbdef-21146163

Appendix D

Liberty University IRB Approval Letter

LIBERTY UNIVERSITY.
INSTITUTIONAL REVIEW BOARD

April 2, 2019

Xuesi Liu
IRB Approval 3734.040219: Evaluation of Advance Directive Education with Dialysis Patients

Dear Xuesi Liu,

We are pleased to inform you that your study has been approved by the Liberty University IRB. This approval is extended to you for one year from the date provided above with your protocol number. If data collection proceeds past one year or if you make changes in the methodology as it pertains to human subjects, you must submit an appropriate update form to the IRB. The forms for these cases were attached to your approval email.

Your study falls under the expedited review category (45 CFR 46.110), which is applicable to specific, minimal risk studies and minor changes to approved studies for the following reason(s):

> 5. Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis). (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt.)
>
> 7. 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. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.)

Thank you for your cooperation with the IRB, and we wish you well with your research project.

Sincerely,

[redacted]

G. Michele Baker, MA, CIP
Administrative Chair of Institutional Research
Research Ethics Office

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UNIVERSITY.
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Appendix E

University of Virginia IRB Approval Letter

UNIVERSITY of VIRGINIA
OFFICE of the VICE PRESIDENT for RESEARCH
IRB for Health Sciences Research

IRB-HSR #/UVA Study Tracking#: 21530

Study Title: Evaluation of Advance Directive Education with Dialysis Patients

The University of Virginia IRB for Health Sciences Research confirms that this project meets the criteria of research which is exempt from federal regulations under 45CFR46.104(d)(1), 45CFR46.104(d)(2)(iii) and 45CFR46.104(d)(4)iii.

Per 45CFR46.110(b)(iii) the IRB conducted an expedited limited IRB review required by 45CFR46.111(a)(7) and determined that the study provides an adequate plan to protect the privacy of subjects and the confidentiality of their information.

FOR THE CHART REVIEW PORTION OF THE STUDY:

This study has been granted a waiver of HIPAA authorization under 45CFR 164.512(i)(2) via expedited review procedures for the main study. The following HIPAA identifiers will be collected: Name. The minimum necessary PHI to be collected includes: diagnosis, length of time on hemodialysis, age, code status, documentation of completed advance directives.

FOR THE SURVEY AND EDUCATION PORTION OF THE STUDY:

The IRB-HSR has granted a waiver of HIPAA Authorization via expedited review procedures via 45CFR 164.512(i)(2) to contact subjects by direct contact by a person who is not their health care provider. Direct contact may include phone, letter, direct email or approaching potential subjects while at UVA. Phone, letter or emails will be approved by the IRB-HSR prior to use. The following HIPAA identifiers may be collected: Name, medical record number, date of birth and contact information. The minimum necessary PHI to be collected includes only those items related to the inclusion/ exclusion criteria.

Written HIPAA Authorization will be obtained for the Survey and Educational portion of the study and is on file with this study. Also on file are the pre and post educational surveys.

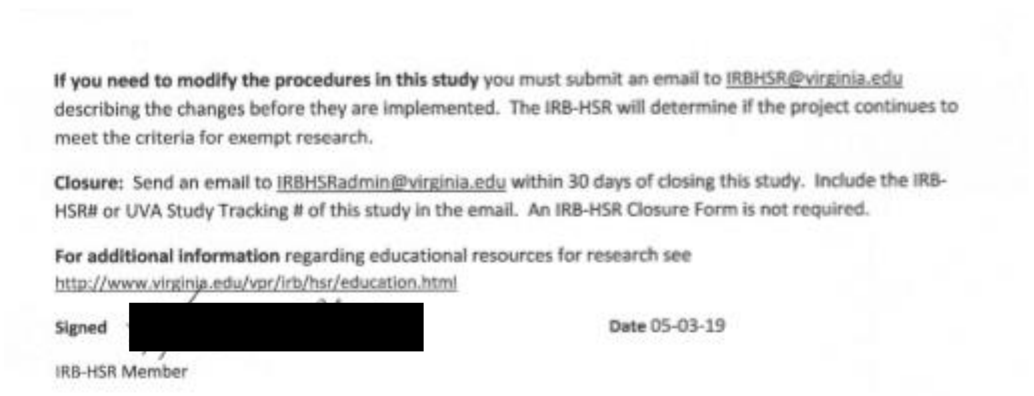
Any health information shared outside of UVA will be de-identified.

You are required to protect the data according to the enclosed Privacy Plan and the Data Security Plan.

Personnel Changes:

You must notify the IRB of any new personnel working on the study PRIOR to them beginning work.

Modifications:



If you need to modify the procedures in this study you must submit an email to IRBHSR@virginia.edu describing the changes before they are implemented. The IRB-HSR will determine if the project continues to meet the criteria for exempt research.

Closure: Send an email to IRBHSRadmin@virginia.edu within 30 days of closing this study. Include the IRB-HSR# or UVA Study Tracking # of this study in the email. An IRB-HSR Closure Form is not required.

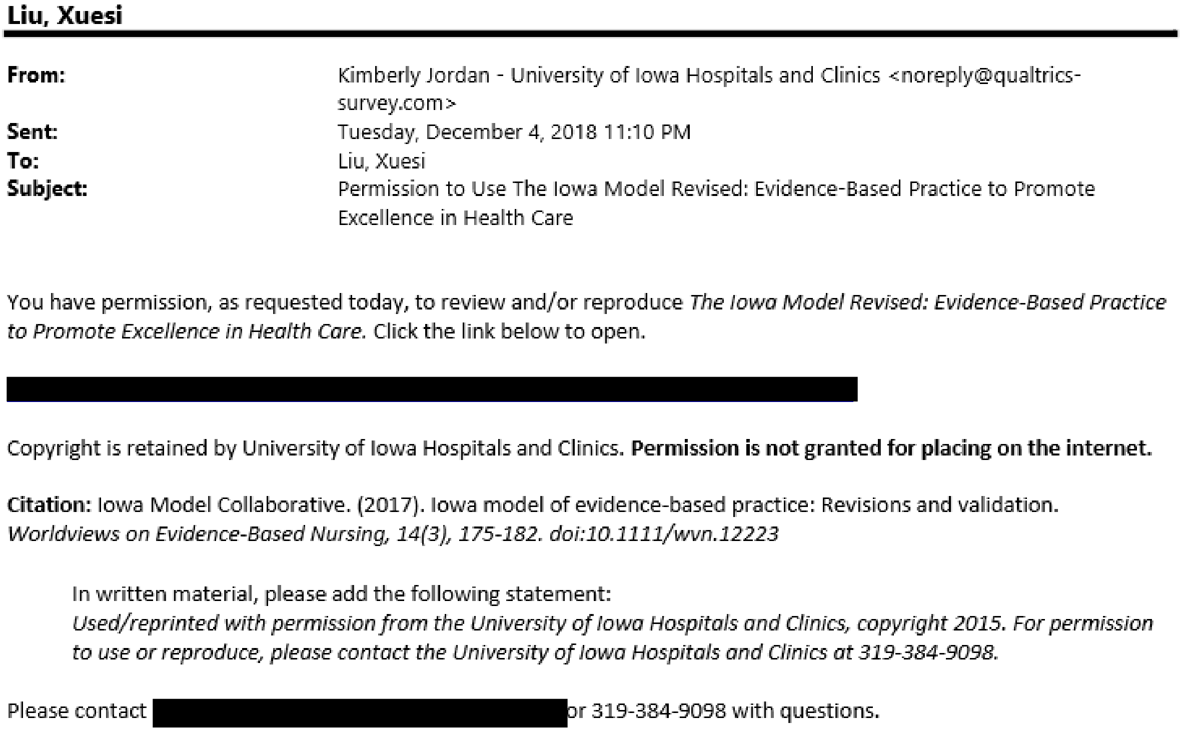
For additional information regarding educational resources for research see http://www.virginia.edu/vpr/irb/hsr/education.html

Signed [redacted] **Date** 05-03-19

IRB-HSR Member

Appendix F

Permission to use the Iowa Model



Liu, Xuesi

From: Kimberly Jordan - University of Iowa Hospitals and Clinics <noreply@qualtrics-survey.com>
Sent: Tuesday, December 4, 2018 11:10 PM
To: Liu, Xuesi
Subject: Permission to Use The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care

You have permission, as requested today, to review and/or reproduce *The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care.* Click the link below to open.

[redacted]

Copyright is retained by University of Iowa Hospitals and Clinics. **Permission is not granted for placing on the internet.**

Citation: Iowa Model Collaborative. (2017). Iowa model of evidence-based practice: Revisions and validation. *Worldviews on Evidence-Based Nursing, 14(3), 175-182. doi:10.1111/wvn.12223*

> In written material, please add the following statement:
> *Used/reprinted with permission from the University of Iowa Hospitals and Clinics, copyright 2015. For permission to use or reproduce, please contact the University of Iowa Hospitals and Clinics at 319-384-9098.*

Please contact [redacted] or 319-384-9098 with questions.

Appendix G

Permission to Use Survey Questionnaires

Liu, Xuesi

From: ctoraya@aol.com
Sent: Saturday, January 26, 2019 12:35 AM
To: Liu, Xuesi
Subject: Re: Request for permission to use survey questions

Cici,

You have my permission to use the survey questions similar to mine for your study. Good luck.

Best,
Cindy Toraya, MD, JD, MA

-----Original Message-----
From: Liu, Xuesi <xliu1@liberty.edu>
To: ctoraya@aol.com <ctoraya@aol.com>
Sent: Fri, Jan 25, 2019 10:02 am
Subject: Request for permission to use survey questions

Good morning Dr. Toraya,

My name is CiCi Liu, a RN at an outpatient dialysis facility in central Virginia and current graduate student in the Doctor of Nursing Practice program at Liberty University. I came upon your article "Evaluation of Advance Directives Video Education for Patients" while doing my literature review, and I am reaching out to request permission to use the survey questions included in your article.

For my graduate studies, I plan to be conducting a small quazi-experimental evidence-based study evaluating a nurse-provided education session on advance directives for patients in outpatient dialysis. I plan to be evaluating the education session similar to how you evaluated the video education, and would like to model both the pre and post survey questions after the survey questions you used in your study. I would be changing a few words to reflect my own education session, (i.e. exchanging the word "video" with "education session" and eliminating "durable power of attorney"), but the structure of the questions will remain the same.

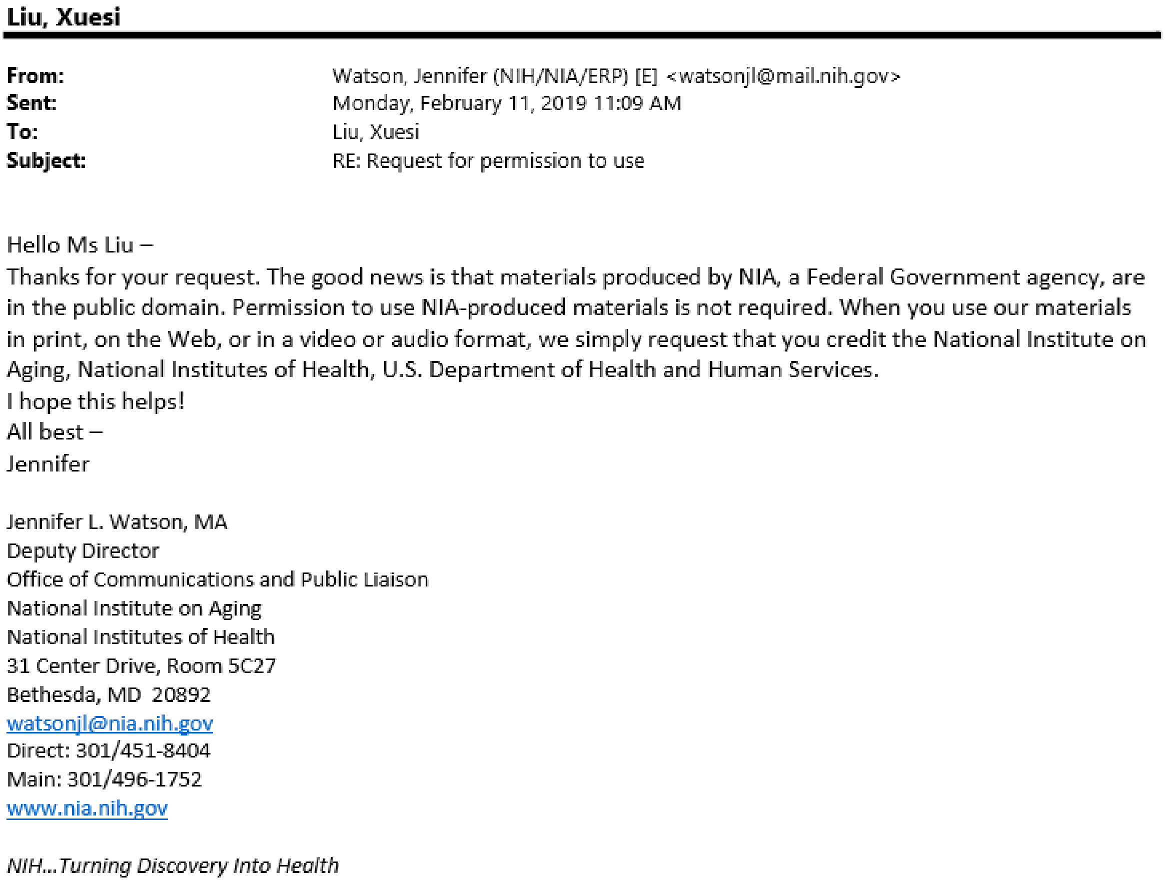
I'd like to have your official approval before moving forward with the IRB application process. Would you be willing to provide a written statement of approval through email or letter, or what would be the process to obtain a written permission to use your survey?

Thank you very much for your time,

CiCi Liu

Appendix H

Permission to Use “Advance Care Planning” Brochure



Liu, Xuesi

From: Watson, Jennifer (NIH/NIA/ERP) [E] <watsonjl@mail.nih.gov>
Sent: Monday, February 11, 2019 11:09 AM
To: Liu, Xuesi
Subject: RE: Request for permission to use

Hello Ms Liu –
Thanks for your request. The good news is that materials produced by NIA, a Federal Government agency, are in the public domain. Permission to use NIA-produced materials is not required. When you use our materials in print, on the Web, or in a video or audio format, we simply request that you credit the National Institute on Aging, National Institutes of Health, U.S. Department of Health and Human Services.
I hope this helps!
All best –
Jennifer

Jennifer L. Watson, MA
Deputy Director
Office of Communications and Public Liaison
National Institute on Aging
National Institutes of Health
31 Center Drive, Room 5C27
Bethesda, MD 20892
watsonjl@nia.nih.gov
Direct: 301/451-8404
Main: 301/496-1752
www.nia.nih.gov

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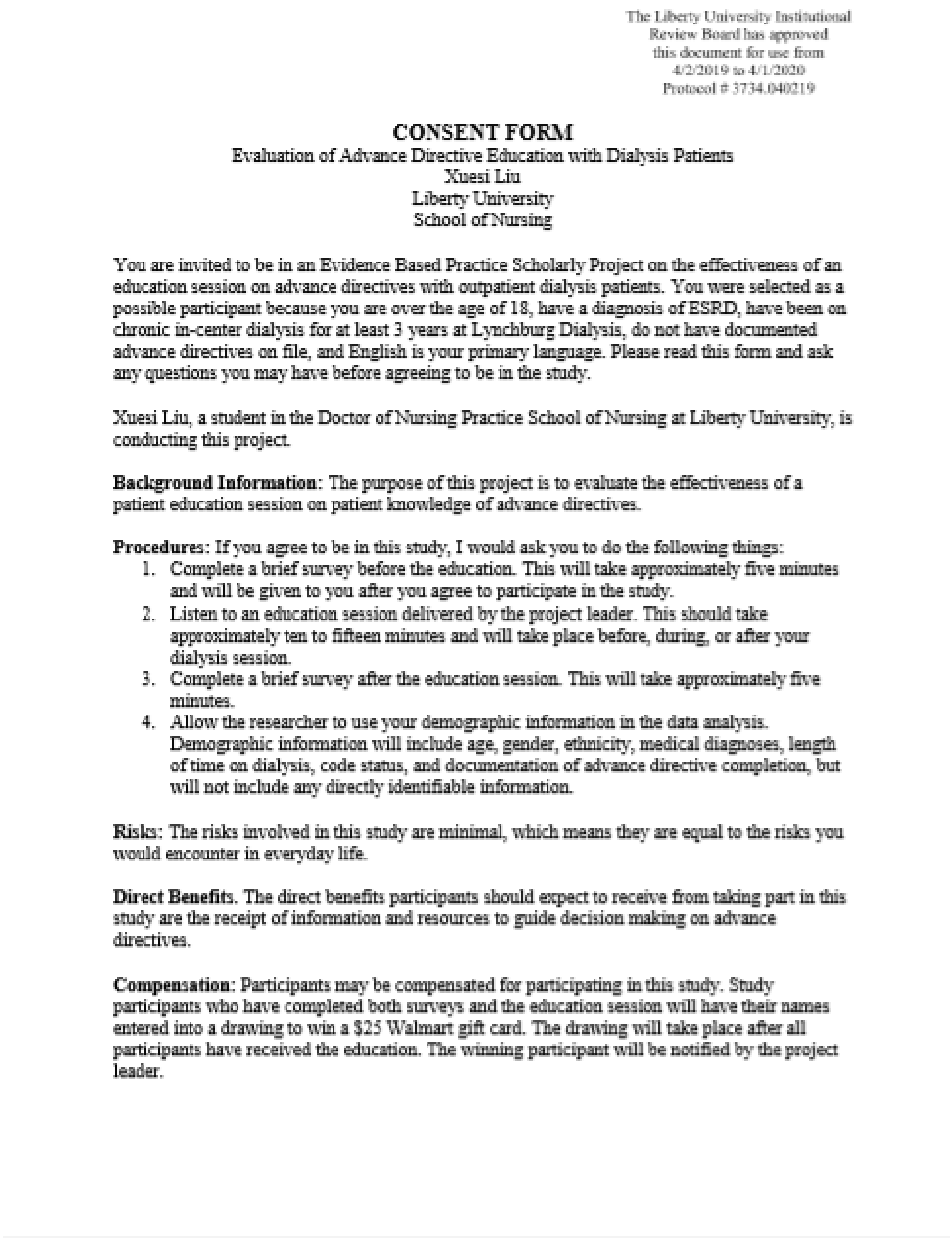
Appendix I

Participant Consent Form



The Liberty University Institutional
Review Board has approved
this document for use from
4/2/2019 to 4/1/2020
Protocol # 3734.040219

CONSENT FORM

Evaluation of Advance Directive Education with Dialysis Patients
Xuesi Liu
Liberty University
School of Nursing

You are invited to be in an Evidence Based Practice Scholarly Project on the effectiveness of an education session on advance directives with outpatient dialysis patients. You were selected as a possible participant because you are over the age of 18, have a diagnosis of ESRD, have been on chronic in-center dialysis for at least 3 years at Lynchburg Dialysis, do not have documented advance directives on file, and English is your primary language. Please read this form and ask any questions you may have before agreeing to be in the study.

Xuesi Liu, a student in the Doctor of Nursing Practice School of Nursing at Liberty University, is conducting this project.

Background Information: The purpose of this project is to evaluate the effectiveness of a patient education session on patient knowledge of advance directives.

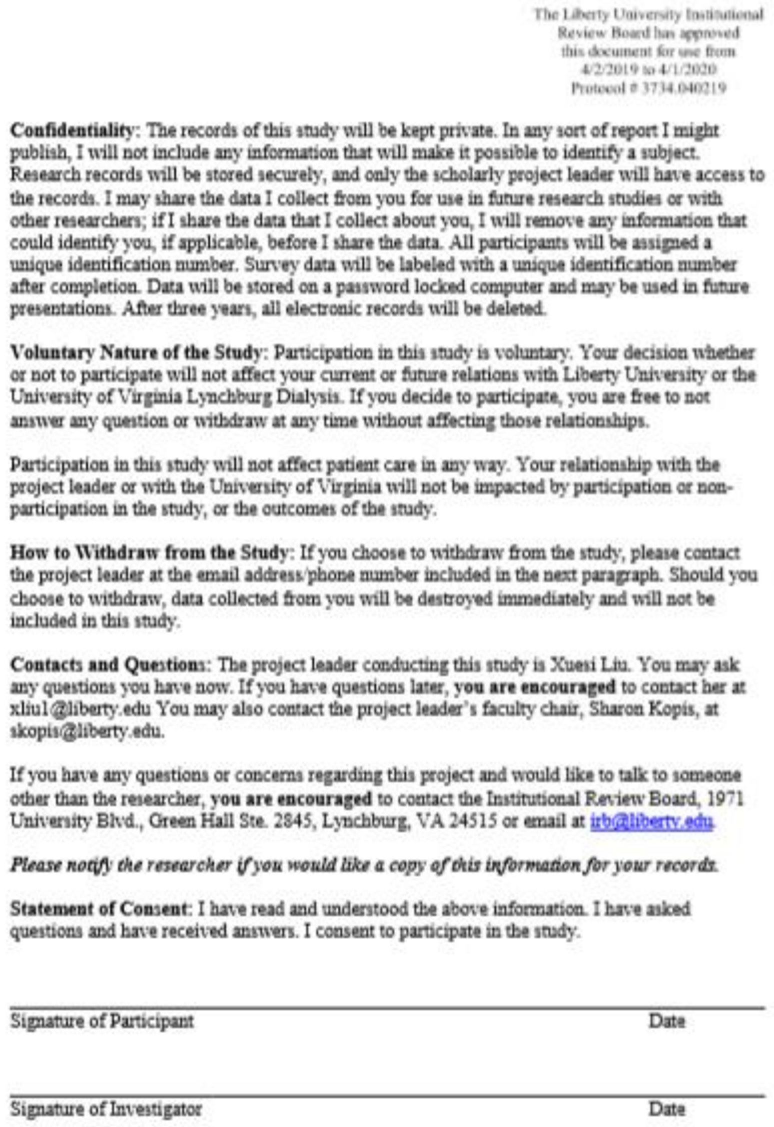
Procedures: If you agree to be in this study, I would ask you to do the following things:

1. Complete a brief survey before the education. This will take approximately five minutes and will be given to you after you agree to participate in the study.
2. Listen to an education session delivered by the project leader. This should take approximately ten to fifteen minutes and will take place before, during, or after your dialysis session.
3. Complete a brief survey after the education session. This will take approximately five minutes.
4. Allow the researcher to use your demographic information in the data analysis. Demographic information will include age, gender, ethnicity, medical diagnoses, length of time on dialysis, code status, and documentation of advance directive completion, but will not include any directly identifiable information.

Risks: The risks involved in this study are minimal, which means they are equal to the risks you would encounter in everyday life.

Direct Benefits. The direct benefits participants should expect to receive from taking part in this study are the receipt of information and resources to guide decision making on advance directives.

Compensation: Participants may be compensated for participating in this study. Study participants who have completed both surveys and the education session will have their names entered into a drawing to win a $25 Walmart gift card. The drawing will take place after all participants have received the education. The winning participant will be notified by the project leader.



The Liberty University Institutional
Review Board has approved
this document for use from
4/2/2019 to 4/1/2020
Protocol # 3734.040219

Confidentiality: The records of this study will be kept private. In any sort of report I might publish, I will not include any information that will make it possible to identify a subject. Research records will be stored securely, and only the scholarly project leader will have access to the records. I may share the data I collect from you for use in future research studies or with other researchers; if I share the data that I collect about you, I will remove any information that could identify you, if applicable, before I share the data. All participants will be assigned a unique identification number. Survey data will be labeled with a unique identification number after completion. Data will be stored on a password locked computer and may be used in future presentations. After three years, all electronic records will be deleted.

Voluntary Nature of the Study: Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with Liberty University or the University of Virginia Lynchburg Dialysis. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

Participation in this study will not affect patient care in any way. Your relationship with the project leader or with the University of Virginia will not be impacted by participation or non-participation in the study, or the outcomes of the study.

How to Withdraw from the Study: If you choose to withdraw from the study, please contact the project leader at the email address/phone number included in the next paragraph. Should you choose to withdraw, data collected from you will be destroyed immediately and will not be included in this study.

Contacts and Questions: The project leader conducting this study is Xuesi Liu. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact her at xliu1@liberty.edu You may also contact the project leader's faculty chair, Sharon Kopis, at skopis@liberty.edu.

If you have any questions or concerns regarding this project and would like to talk to someone other than the researcher, **you are encouraged** to contact the Institutional Review Board, 1971 University Blvd., Green Hall Ste. 2845, Lynchburg, VA 24515 or email at irb@liberty.edu.

Please notify the researcher if you would like a copy of this information for your records.

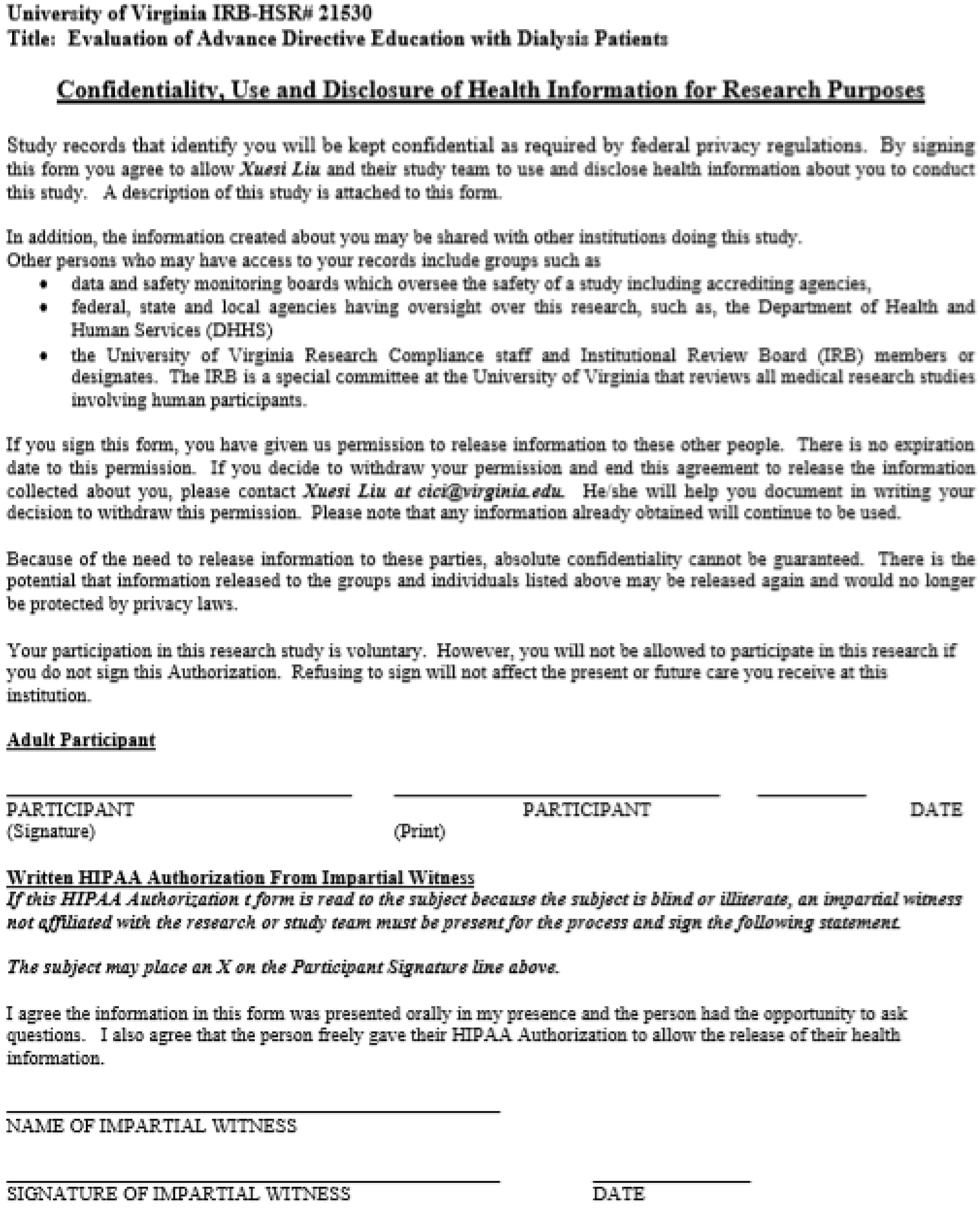
Statement of Consent: I have read and understood the above information. I have asked questions and have received answers. I consent to participate in the study.

Signature of Participant Date

Signature of Investigator Date

Appendix J

HIPAA Confidentiality Form



University of Virginia IRB-HSR# 21530
Title: Evaluation of Advance Directive Education with Dialysis Patients

Confidentiality, Use and Disclosure of Health Information for Research Purposes

Study records that identify you will be kept confidential as required by federal privacy regulations. By signing this form you agree to allow ***Xuesi Liu*** and their study team to use and disclose health information about you to conduct this study. A description of this study is attached to this form.

In addition, the information created about you may be shared with other institutions doing this study.
Other persons who may have access to your records include groups such as

- data and safety monitoring boards which oversee the safety of a study including accrediting agencies,
- federal, state and local agencies having oversight over this research, such as, the Department of Health and Human Services (DHHS)
- the University of Virginia Research Compliance staff and Institutional Review Board (IRB) members or designates. The IRB is a special committee at the University of Virginia that reviews all medical research studies involving human participants.

If you sign this form, you have given us permission to release information to these other people. There is no expiration date to this permission. If you decide to withdraw your permission and end this agreement to release the information collected about you, please contact ***Xuesi Liu at cici@virginia.edu.*** He/she will help you document in writing your decision to withdraw this permission. Please note that any information already obtained will continue to be used.

Because of the need to release information to these parties, absolute confidentiality cannot be guaranteed. There is the potential that information released to the groups and individuals listed above may be released again and would no longer be protected by privacy laws.

Your participation in this research study is voluntary. However, you will not be allowed to participate in this research if you do not sign this Authorization. Refusing to sign will not affect the present or future care you receive at this institution.

Adult Participant

______________________	______________________	________
PARTICIPANT (Signature)	PARTICIPANT (Print)	DATE

Written HIPAA Authorization From Impartial Witness
If this HIPAA Authorization t form is read to the subject because the subject is blind or illiterate, an impartial witness not affiliated with the research or study team must be present for the process and sign the following statement.

The subject may place an X on the Participant Signature line above.

I agree the information in this form was presented orally in my presence and the person had the opportunity to ask questions. I also agree that the person freely gave their HIPAA Authorization to allow the release of their health information.

____
NAME OF IMPARTIAL WITNESS

______________________________ ____________
SIGNATURE OF IMPARTIAL WITNESS DATE