

Advance Care Planning in Faith Communities: A Quality Improvement Project

Lorie Shobe Hacker

Touro University, Nevada

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DNP Project Chair: Dr. Jessica Grimm

DNP Project Member(s): Dr. Catie Chung

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Advance Care Planning in Faith Communities: A Quality Improvement Project

Advance care planning (ACP) is an important aspect of care for adults. Effective screening and prevention are key to determine individual treatment preferences to improve quality of life (National Committee for Quality Assurance [NCQA], 2018). ACP improves patient outcomes by increasing clinician understanding of patient wishes, reducing hospitalizations and aggressive care at the end of life, increasing use of hospice programs, and increasing patient satisfaction with care provided (Detering & Silveira, 2018, p. 3). Ninety-two percent of people indicate that having a conversation regarding end of life care is important, however only 32% have had this conversation (The Conversation Project, 2020). Faith communities play an important role in shaping social issues and values surrounding end of life care and can help to overcome barriers to health promotion in many cultures. This quality improvement project will target faith communities through the creation of an ACP Training Tool (ACPTT) in the faith community nursing program of an Indiana hospital. This ACPTT will guide faith community nursing (FCN) practice in conducting ACP interventions in their individual community-based faith groups (Sun et al., 2017).

Background

ACP has been promoted since the first living will was proposed in 1967 with a focus on common and constitutional law requirements regarding patient treatment without consent. Since the 1970's advance directives have been used as legal tools to formally communicate one's wishes regarding end of life care (Sabatino, 2010, p. 212). Through the technological evolution of medical care in the 1970's questions arose regarding difficulty distinguishing life-saving interventions from interventions that prolong suffering and death. Many began to question why

medical providers would need immunity when the law already presumed immunity and that providers would respect their patient's wishes (Sabatino, 2010, p. 213).

Today, advance care planning is defined as discussion between the patient and others about future care with the goal being to ensure patients receive medical care that is "...consistent with their values, goals and preferences" (Detering & Silveira, 2018, p. 1) . ACP conversations may lead to the completion of advance directives (AD) such as health care surrogate (HCS) documents, living wills (LW) and other actionable documents such as a do-not-resuscitate (DNR) order (Detering & Silveira, 2018, p. 2). An HCS is also known as a health care proxy or durable power of attorney for health care and serves as a legal document that authorizes medical decision making on the patient's behalf if the patient no longer has capacity (Detering & Silveira, 2018, p. 8). The LW is a summary of the patient's treatment preferences for future medical care and provide the HCS and clinical team a general sense of the treatment preferences (Detering & Silveira, 2018, p. 9). Actionable orders for treatment preferences include the DNR which specifies the patient or HCS wishes regarding cardiopulmonary resuscitation (CPR). In some states the Physicians Orders for Life Sustaining Treatment (POLST/POST) is legislatively established and is considered a highly effective way to communicate treatment preferences. The POST is portable across the continuum of health care settings such as home, skilled nursing facilities (SNF) and acute care settings (The Indiana POST Program, 2019). The Center for Medicare and Medicaid Services (CMS) published billing codes for ACP on January 1, 2016 and provided direction for implementation by physicians and nonphysician providers who serve under the order of the treating physician in a face to face encounter (Center for Medicare and Medicaid Services [CMS], 2016). Engaging community health workers in the dissemination of education regarding ACP has proven an effective way to increase knowledge and awareness of

ACP which leads to increase completion of AD (Litzelman, Cottingham, Griffin, Inui, & Ivy, 2016, p. 641).

FCNs are uniquely positioned to bridge the gap with ACP as faith communities welcome the integration of faith and health through outreach programs such as ACP (Rastas, 2014).

Problem Statement

Seventy percent of Indiana residents do not have advance directives ("Biospace," 2019). Exposure to ACP information and outreach is known to significantly increase completion of advance directives (Splendore & Grant, 2017). A faith community is defined as a group of people who share a set of religious beliefs (Longman, 2020) and this FCN program is defined as a nurse led program in parishes, churches, or congregations across the central Indiana region. Faith communities can partner with health care organizations and this partnership is an effective way to reach the community for health promotion and increase completion of ACP (Kotecki, 2002, p. 61). Exposure to ACP information and outreach is known to significantly increase completion of advance directives (Splendore & Grant, 2017). One hospital in central Indiana has an FCN program that engages a group of FCN's across the region. There has been support and education to FCN's in this program regarding ACP with discussion and presentations, however no formal training exists for FCN implementation. Health care professionals are often uncomfortable speaking with patients and families about advance care planning and 87% report hesitation to implementation until illness become severe (Booth & Lehna, 2016). This FCN program does not currently have a tool to guide the FCN in conducting ACP education, outreach, and AD completion.

Purpose Statement

The development of an ACPTT will engage faith communities in ACP by equipping FCN's with education, tools and resources that will be sustainable for future implementation at this project site. The aim of this project is to increase ACP knowledge and self-efficacy, to increase ACP outreach and completion of AD in targeted faith communities by 25% by the fall of 2020.

Project Question

Does providing an ACPTT to FCN's increase outreach and education of ACP in faith communities compared to those with FCN's with no training guide?

Project Objectives

In the timeframe of the DNP project, the following objectives will be addressed:

1. An ACPTT will be created for implementation at the project site by Fall 2020.
2. Faith community nurses will demonstrate a 25% increase in knowledge and self-efficacy of ACP and AD by the Fall 2020 from pre-intervention- *Advance Care Planning Engagement 34-point survey* to post intervention (The Regents of the University of California, 2013).
3. Faith community nurse's will demonstrate a 25% increase in ACP outreach activities in their faith communities by the Fall 2020 from pre-intervention to post intervention.
4. Faith community members will complete 25% more AD post intervention compared to pre-intervention by the Fall 2020.

Search Terms

The literature review consisted of utilization of several databases including CINAHL Plus with Full Text, PubMed, Jay Sexter Library Inter-Library Loan Services, EBSCO and

Google Scholar using the PICO question; How does FCN engagement in ACP education and outreach increase ACP engagement among faith communities? The elements of the PICO question were used to form search terms. Initial search terms included advance care planning, end of life planning, advance directives, patient outcomes, quality of care, faith communities and faith community nurses. Initial results for this search revealed zero results likely due to the search terms being too narrow and therefore the search terms were refined to include search terms in themes for the project. Three themes for search terms evolved including ACP impact on patient outcomes, FCN's impact on patient outcomes through health promotion such as ACP, and community health and faith community education impact on patient outcomes. Each of the three themes had inclusion criteria of articles published in peer reviewed journals between 2015 to 2020 and full text article availability in the English language. The search terms ACP or end of life (EOL) planning OR AD and patient outcomes OR quality of care and education resulted in 10 articles. The second theme search terms utilized were FCN or parish nursing and health education or health promotion and resulted in two articles. The third theme included search terms; community health education, faith communities, patient outcomes or quality of care and ACP and resulted in 26 articles. Exclusion criteria for all results included articles related to pediatrics, post-acute care setting, oncology, and hospital-based initiatives.

Review of Literature

The review of the literature included the evaluation of each article found from the three themes of the search terms and assessment of the level of evidence using the American Association of Critical Care Nurses (AACCN) system (Peterson et al., 2014). The themes that emerged from the literature review are as follows, ACP's positive impact on patient outcomes, FCN health promotion through ACP and community health and faith community education and

health promotion. Articles included in the literature review range in the level of evidence from qualitative studies and integrative reviews (Level C), peer-reviewed professional reviews and clinical recommendations (Level D) and articles that contained expert opinions (Level E) (Peterson et al., 2014, table 2). High level of data supported by meta-analysis of multiple controlled studies specific for this topic were not found.

Impact of Advance Care Planning on Patient Outcomes

ACP is important because it empowers patients and their families, reduces burdens on others to make decisions, prevents unwanted treatments and unnecessary hospital admissions (Merlane & Armstrong, 2020) and has a positive impact on quality at EOL (Kastbom, Milberg, & Karlsson, 2019). Merlane and Armstrong published a peer reviewed journal article whose level of evidence would be Level E, of expert opinion and demonstrates the importance of advance care planning and the role of the nurse in ACP (2020). Kastbom, et al. utilized a latent qualitative content analysis design and the methods used interviews with inclusion criteria that demonstrated the effectiveness of ACP in nursing homes (2019). ACP should be implemented in every care setting. Providing patient and family centered care will improve care quality, patient, and family satisfaction as well as cost containment (Novelli & Banarjee, 2017). One scoping review found that ACP is complex and can be widely defined. Some of these definitions include facilitated discussions, training, and completion of advance directives. In this review, patient outcomes for all ACP interventions were positive and show overall benefit for patients, surrogates, and clinicians as well. Additionally, the definition of ACP reflects a shift from advance directives documentation to an “ongoing, individualized support and preparation for communication and in-the moment decision making” (McMahan, Tellez, & Sudore, 2020, p. 2). ACP efforts should continue as a process over the life span with the ideal implementation to

begin early in adulthood to be re-visited as circumstances and health issues change over time (National Institute of Health [NIH], 2015). This project will translate this evidence into practice with the culmination of an ACPTT.

Faith Community Nursing and Health Promotion

The FCN is uniquely positioned to address the gaps in care in the community and to assist healthcare systems to reduce the number of hospital readmissions by increasing the use of preventive medical and social services, increased adherence to treatment regimens and by providing support for community members to thrive in their own homes (Schroepfer, 2016). The American Nurses Association (ANA) includes specific scope and standards of practice for the FCN that include the assistance of faith community members with life transitions for adults with chronic illness and specific direction to assess social determinants of health to develop targeted health promotion activities (Health Ministries Association, 2017). Additionally, the FCN can access populations that may be difficult to reach due to socioeconomic disparities and decreased access to primary care (Schroepfer, 2016). Health care systems have routinely partnered with faith community nurses to reach the vulnerable and provide supportive holistic care. FCN's integrate mental, physical and spiritual health which lead to connections with fellow church members, this intimacy leads to more thorough congregational needs assessment and health promotion and members perceive the FCN as a positive, beneficial trusted healthcare resource (Lind & Chase, 2014). The integration of faith and health creates an ideal setting for the FCN to be an educator and motivator of health in the community (Gotwals, 2018). Kimbrel and Powers (2016) developed a pilot study to determine if FCN's could address ACP. The authors recruited and surveyed volunteers in a protestant church community who engaged in Caring Conversations curriculum. The results revealed statistically significant improvements in knowledge of ACP

post intervention among the 42 subjects (Kimbrell & Powers, 2016). The FCN role is naturally adaptable in a variety of settings to include home or church which is based on the needs of the members. Gotwals study design was quasi-experimental and a correlational study using a convenience sample of FCN's that were randomly assigned to experimental groups to examine the relationship of the FCN's perceived knowledge with a posttest about health promotion (2018). Collaboration with home health partners provide the FCN with resources for members as many FCN's assist older adult membership. FCN's provide supportive services including education and one survey indicated that outreach on average occurred to over 35 individuals per month (Wordsworth, Moore, & Woodhouse, 2016). The FCN scope and standards include quality improvement programs which involve guiding conversations about care decisions such as ACP as well as serving as a health care advocate by defining medical terminology and assistance with interpretation of medical language for treatments and modalities (Health Ministries Association, 2017, p. 13). Transitional care interventions include anticipatory guidance and community health promotion included in ACP and the FCN Transitional Care Model include interventions by the FCN to assist in post discharge care which includes holistic assessment and educational outreach such as ACP (Westberg Institute for Faith Community Nursing, 2018). Faith community members who engage with FCN outreach efforts resulted in increases in completion of advance directives and can be an effective way to increase the rates of discussions related to ACP (Medvene et al., 2003). Integrating health promotion activities such as ACP increase health-promoting behaviors by recipients of FCN outreach and efforts and reiterate the important role that FCNs play in the facilitation of health promotion interventions across the lifespan (Callaghan, 2015, p. 18).

Community Health Education and Faith Communities

The impact of community health education in faith communities on patient outcomes is illustrated by the Mississippi State Department of Health initiative to improve health outcomes by collaborating with community health partners such as churches and faith communities and has a coalition with 25 churches called the Delta Alliance for Congregational Health (DACH). This includes a health and wellness ministry team that promotes health among the churches and has demonstrated positive changes regarding meal services and a heart healthy diet and reached over 5,000 Delta residents (Centers for Disease Control and Prevention [CDC], n.d.). A community and faith-based prostate cancer screening program in a minority population demonstrated an increase in knowledge and screening post health promotion and outreach in Virginia (Howard et al., 2018). This study demonstrates support for health promotion at the community level. This study used a pre-test/post-test survey design and sampled 438 Black men and created a community advisory board to assist in the implementation of a two-hour community/faith-based health outreach that increased prostate screenings among those who participated (Howard et al., 2018, p. 62).

Barriers

There are many barriers to implementation of ACP which include lack of awareness or lack of perceived need (Conroy, Fade, Fraser, & Schiff, 2009) . Among faith communities, fear, denial, and fatalism citing “God’s Will” are some examples of barriers as well as cultural implications. For example, African Americans may demonstrate a mistrust of the health care system and concern for who will receive care based on income status (West & Hollis, 2012, p. 134). In some Asian American faith communities, it is considered taboo to discuss death and dying and some believe that these discussions may even hasten death (Sun et al., 2017, p. 382).

One study evaluated the views of 30 churches in various Christian denominations and found that other factors that are barriers to health promotion in faith communities include perceived irrelevance, a general mistrust of the community and concerns for conversion agendas (Ayton, Manderson, & Smith, 2017). Methods for this study included interviews of five directors of church-affiliated groups and leaders among the 30 churches identified (Ayton, Manderson, & Smith, 2017, p. 52). Another barrier is the limitations to the role of the FCN because most of the FCN positions are un-paid and are only implemented in those faith communities where leadership and an FCN have common interest to engage in an FCN program (Wordsworth, Moore, & Woodhouse, 2016). Controversy regarding the role of ACP and EOL care remain including a disconnect between law and ethics which have propelled community members and the medical community to often engage in futile acts of care resulting in prolonged suffering citing lack of communication and understanding of the Patient Self-Determination Act. Solutions to this include continued education and communication regarding goals of care and advance care planning (Duke, Yarbrough, & Pang, 2009).

Significance of Evidence

The literature review provides ample evidence of the support and need for ACP in the community setting and the positive impact on patient outcomes, cost avoidance by health systems by empowering patient autonomy and preventing futile care that is not desired by the patient and the family (Detering & Silveira, 2018). The community setting and specifically the faith community is often underserved, and the FCN is uniquely positioned to provide effective, culturally relevant ACP education and outreach that will result in an increase in ACP engagement and AD completion in this FCN Indiana program (Lind & Chase, 2014).

Theoretical Framework

The project will utilize the practical, robust implementation and sustainability model (PRISM) to guide the project implementation process (National Institutes of Health [NIH], n.d.) and reference to the theoretical model of faith community nursing (Ziebarth, 2014) as a basis for the ACPTT development.

PRISM is an implementation model that was developed by Feldstein & Glasgow (2008) for the purpose of providing infrastructure with a practical model for translating research into practice that builds on prior models of quality improvement work. This culminated in a tool that researchers may use that integrate leveling of organizational workers to bridge the gap between research and nursing clinical practice in a sustainable manner. The model contains four major domains with a subset of elements within each domain. Success of implementation and sustainability of an intervention or program increases with the use of three to four PRISM domains and at least one elemental subset of each (Feldstein & Glasgow, 2008). The successful implementation of research to nursing practice has a profound impact on the profession and patient outcomes that are directly impacted by expediency to solve problems in the profession with an evidence-based approach (Hall & Roussel, 2017).

Historical Development of the Theory

The PRISM model was developed in 2006 out of the need to translate research into practice and although scant literature exists for implementation there is little evidence to support the use or benefit of any specific implementation science strategy (Feldstein & Glasgow, 2008). PRISM utilizes key elements from the diffusion of innovation theory, the chronic care model, the model for improvement and the RE-AIM model that guided the theory development by

providing principles for adoption of new behaviors, the need to leverage community support, an infrastructure for sharing best practices, and an emphasis on public health. Sharing best practices and a quick implementation of evidence to nursing practice is a key component of improving patient outcomes. The result was a model (National Institutes of Health [NIH], n.d., Appendix A) that included four major domains; program or intervention, external environment, infrastructure and recipients with numerous elements within each domain (Feldstein & Glasgow, 2008, p. 230).

Applicability of Theory to Current Practice

The PRISM model is applicable to nursing as it provides a practical framework for not only the quick dissemination of research into practice which can improve patient outcomes but also helps to provide a foundation for sustainability for future clinical practice (Feldstein & Glasgow, 2008). The model details the importance of the organizational, staff and patient perspectives for a given program with an assessment of organizational readiness so that barriers can be ascertained and addressed which will increase the likelihood of acceptance and integration of the innovation into practice (Feldstein & Glasgow, 2008). Consideration to payor sources and the regulatory environment in nursing are examples of factors identified in the external environment domain that impact the implementation of innovation from research as well as performance data and adaptability of procedures or protocols that shape the domain of future implementation and sustainability. The final domain, recipients, include aspects of nursing such as organizational health and culture, staffing and incentives and patient knowledge and beliefs that impact the implementation of an innovation from research (Feldstein & Glasgow, 2008). Each of the PRISM domains has the opportunity to directly hinder or support the translation of research to clinical innovation that impact the profession of nursing and specifically the implementation and sustainability of this project.

Major Tenets

Program or Intervention

The first domain includes evaluation of the organization and patient perspectives. Organizational assessment of readiness, evaluation of the strength of evidence for the proposed strategy and target clinical area, consideration to address identified barriers, program ease of use and perceived usefulness, adaptability to locality, trialability, reversibility and observability are elements important to consider during the development and implementation phase of a project. Careful attention to these elements in this domain will help to ensure acceptance into general practice (Feldstein & Glasgow, 2008, p. 230).

External Environment

The domain of the external environment includes powerful “...predictors of success and therefore are key to implementation and maintenance” (Feldstein & Glasgow, 2008, p. 237). This element may include market forces, reimbursement and payors, regulatory bodies, and reporting authorities. Community resource availability such as national repositories of patient education may assist in making complex health interventions more affordable (Feldstein & Glasgow, 2008).

Infrastructure

This domain provides emphasis on building the project with sustainability in mind at the start. Elements of communication and relationships between senior level managers and front-line workers are important. Partnerships that facilitate translation of research to practice have high value and include recommendations for; a dedicated implementation team, routine performance measurement and data sharing, protocols or procedures that can be adapted for specific locations

and implementation training that includes support and a venue for sharing best practices (Feldstein & Glasgow, 2008).

Recipients

The final domain of PRISM includes recipients which are organizations and patients. Each recipient has defined characteristics that affect their ability to incorporate innovation and change behaviors. For the organization, three levels were identified: top management, middle managers, and front-line teams. Other organizational characteristics include financial and structural health, staff history, culture, and morale. Management support for an innovation should include communication of goals across all three levels and efforts to involve key leaders for strategic communication should be robust (Feldstein & Glasgow, 2008). Patient characteristics include “age, gender, socioeconomic status, health literacy, native language and culture” (Feldstein & Glasgow, 2008, p. 236). Other considerations of this domain include the patient (client) population with pre-existing conditions that impact access to the innovation, and their experience of social support, knowledge, beliefs, and perception of outcomes (Feldstein & Glasgow, 2008).

Theory Application to the DNP Project

The PRISM theory will be a useful framework for the development of the project as the application of each of the domains provide a method for conducting implementation of the ACPTT and sustainability for the project site. The first domain provides tools to assess the organizational and patient perspective (Feldstein & Glasgow, 2008). Assessment of the FCN program will need to include evaluation of readiness of the project site, appraisal of the strength of evidence for ACP in this environment, consideration of the barriers such as minimal resources for the primarily volunteer FCN group with special attention to the cost, adaptability and

usability of the ACPTT. The ACPTT will need to be developed with the patient perspective in mind so that it provides adaptability among faith community needs and yet remain client centered to promote ACP.

The external environment domain will include evaluation of community resources such as ACP educational modalities and regulatory bodies such as the legislation related to ACP in the state of Indiana (Feldstein & Glasgow, 2008). Additional external environments will include FCN state, national and international groups that will help shape and inform the tool such as incorporation of the theoretical model of faith community nursing (Ziebarth, 2014, Appendix B) to guide FCN practice as well as individual faith community groups.

Implementation and sustainability infrastructure is the third domain that will provide direction to the development of a dedicated project team, inclusion of training for the ACPTT that is portable and adaptable, the development of metrics to evaluate performance data such as FCN implementation of the tool and a robust communication system to assist with training and support (Feldstein & Glasgow, 2008).

The final domain, recipients, will include evaluation of the FCN program's organizational health and culture and identification of the organizational levels, FCN program director, FCN program facilitator and the FCN as the front-line staff to ensure communication across levels (Feldstein & Glasgow, 2008). Consideration of the front-line FCN as primarily volunteer will be an important consideration with the development of the ACPTT so that time burdens for implementation may be eliminated or reduced. The patient characteristics to be considered for the project are perceptions of end-of-life, cultural and religious beliefs, and health literacy. Inclusion of these elements will be important during the development of the ACPTT. The FCN role in increased social support for the ACP project will increase likelihood of patient

receptiveness and will help with ACP implementation and AD completion and help to ensure future sustainability of the project (Feldstein & Glasgow, 2008).

Theoretical Model of Faith Community Nursing in ACPTT Development

The theoretical model of faith community nursing was developed in 2014 by Deborah Ziebarth and provides a framework for faith community nursing as "...a method of healthcare delivery that is centered in a relationship between the nurse and client... that occurs in an iterative motion over time when the client seeks or is targeted for wholistic health care" (Ziebarth, 2014, p. 1831). The essential attributes include faith integrating which is continuous and "health promoting, disease managing, coordinating, empowering and accessing health care" that occur with intentionality in a variety of settings including the "...faith community, home, health institution and other community settings with fluidity as part of a community, national, or global health initiative" (Ziebarth, 2014, p. 1831). The model provides a visual representation of the attributes with the nurse and client relationship as central and faith integration as a continuous attribute (Ziebarth, 2014, Appendix B). This model will provide structure for the ACPTT development as it will target the FCN and faith community member (client) relationship and will provide tools for the FCN to implement over time with faith integration as a continuous component. The ACPTT will provide the FCN with a structure that will help to empower clients, to coordinate health care by promoting the discussion of ACP and the completion of AD. This model will provide a conceptual framework to build the ACPTT to incorporate those elements that are integral to faith community nursing and unique to the faith community setting.

Project Design

Setting

The setting for the project is a central Indiana FCN program that is sponsored by a local hospital system. The site employs one half time program facilitator and one program manager. The staff include 18 active and 5 inactive professional non-paid FCN's. This represents approximately 23 faith community groups in the region. The documentation system at the site is an informal process and includes intermittent paper charting determined by individual FCN practice. Monthly reporting on the community benefits inventory for social accountability (CBISA) form and is submitted to the facilitator to document FCN activity.

Population of Interest

The direct population of interest includes FCN's at the practice site. The indirect population of interest include members of the faith community which are also known as healthcare consumers. Healthcare consumers are defined as "the person, client, family, group, community or population who is the focus of attention and to whom the registered nurse is providing services as sanctioned by state regulatory bodies" (Health Ministries Association, 2017, p. 87). Inclusion criteria would be voluntary participation for each FCN at the site. FCN's that are not affiliated with the practice site will be excluded from data collection.

Stakeholders

The key stakeholders for the project include the program manager, program facilitator, professional non-paid FCN's, faith community members and leadership, professional organizations such as the Westberg Institute, Faith Community Nurses International, and the Health Ministries Association, spiritual care providers such as chaplains, clergy and pastors and community-based collaborative partners such as the accountable care organizations, primary and specialty care providers and community resources such as palliative care services.

Permission for this quality improvement project was granted by the program leadership for collaboration and implementation of the project at the site. (See Appendix C). The specific role of the program manager will be as an advisor and consultant to the program facilitator who will provide direct leadership and collaboration for the implementation of the project. The project facilitator will be instrumental in communication within the group and to coordinate the quarterly meetings during which the dissemination of the ACPTT will take place. The facilitator will also be responsible for collating the CBISA reports monthly from the FCN's. The professional organizations provide foundational structure for resources for FCN practice as well as programs and tools such as the scope and standards published by the American Nurses Association that guides FCN specialty practice (Health Ministries Association, 2017). The ACPTT will be made available to the Westberg Institute for inclusion in the core curriculum which guides foundational FCN training (Westberg Institute, 2020). The Faith Community Nurses International organization will receive updates regarding the project for inclusion and the dissemination among the research committee. Spiritual care providers are important collaborators to facilitate the development of the ACPTT to ensure that the spiritual aspects of the tool are supported and guide practical implementation ideas for facilitation of the ACPTT within the faith communities. Community resources such as medical providers, the accountable care organizations and local palliative care teams will be referral sources for the FCN's to direct members for additional support within the medical community.

Interventions

Interventions for this quality improvement project include the development of a robust, adaptable and portable ACPTT (see Appendix D) for use among the FCN's at the site, modification of the CBISA report (see Appendix E) to include ACP outreach and AD completion

tracking, ACPTT delivery and education (see Appendix F) to the non-paid professional FCN's at the practice site, and pre and post intervention data collection and analysis.

The ACPTT will provide foundational information regarding the importance of ACP and AD completion, implications for whole person care, and provide a variety of methods and resources for planning outreach activities within faith communities.

ACP outreach and AD completion data were not previously collected at the site, so a modification to the current CBISA template was completed. Pre intervention survey data will be collected from the voluntary FCN participants, prior to introduction and education of the ACPTT during the fall FCN meeting. Post intervention survey data of AD knowledge and self-efficacy will be collected immediately after the intervention and CBISA data will be collected 5 weeks after the intervention for analysis.

Tools

The tools selected for data collection include the CBISA monthly report (Appendix E) and the Advance Care Planning Engagement 34 Item Survey (Appendix G). The ACPTT (Appendix D) will be disseminated in the fall 2020 using a demonstration and Socratic technique for educating the FCN's regarding the use of the tool (Appendix F).

CBISA Monthly Report

Evaluative metrics for objective three, which is the FCN's will demonstrate a 25% increase in ACP outreach activities, and objective four, completion of 25% more AD post intervention compared to pre-intervention will be captured using the CBISA report which provides the number of ACP outreach activities and the number of AD completed by each FCN on a monthly basis (see Appendix E). The number of ACP outreach activities and AD completion will be compared pre and post intervention based on the frequency of events. The

CBISA monthly report (Appendix E) is a pre-existing tool that has been developed by the practice site and amended by the project lead to include the number of ACP outreach activities and AD completion which were not previously tracked. The CBISA tool was adapted by the project lead and program facilitator and reviewed and approved for context relevance by the project team and stakeholders.

The data will be collected from the CBISA tool and entered into a data file excel spread sheet (see Appendix H). The total number of ACP outreach activities will be calculated the month prior to intervention and the month following the intervention to determine the percentage of change of ACP outreach or AD completion, if any.

Advance Care Planning Engagement 34 Item Survey

The evaluation of objective two, which is a demonstration of a 25% increase in FCN knowledge and self-efficacy of ACP and AD will be measured using the ACP Engagement 34 Item Survey (see Appendix G). This survey is culturally vetted and validated and measures the complex process of ACP including knowledge and self-efficacy of ACP and AD. This survey was developed and validated by Prepare for Your Care and is made available for use on the prepareforyourcare.org site (The Regents of the University of California, 2013). “The survey is based on social cognitive and behavior change theories and focuses on four behavior change constructs (i.e., knowledge, contemplation, self-efficacy, and readiness within four ACP domains” (The Regents of the University of California, 2013, p. 3). Sudore et al., (2013) evaluated the reliability and validity of this tool by field testing and comparing survey data from an older cohort to a comparison sample of a younger cohort. The results from validation testing demonstrated that the survey has “good internal consistency (Process Measures Cronbach’s alpha, 0.94) and test-retest reliability (Process Measures intraclass correlation, 0.70; Action

Measures 0.87)” with both process and action measures scores “higher in the older than younger group, $p < .001$ ” (Sudore et al., 2013, p. 1). Permission is provided from the PREPARE website for use of unaltered materials given appropriate credit to PREPARE and the www.prepareforyourcare.org site (see Appendix I).

The survey, which is estimated to take approximately 20 minutes, will be administered prior to receipt of the ACPTT dissemination and education and then again after the education is presented. Each respondent’s data will be collected and entered into the data entry file (Appendix H) pre and post intervention in preparation for analysis.

ACPTT Educational PowerPoint

The ACPTT will be delivered to the FCN group with a high-level overview of the tool’s purpose and use. A PowerPoint (Appendix F) will provide structure to the overview and includes bulleted slides to use with the Socratic method as the primary learning strategy. This method is often used for the guided discovery for adult learners (Overholser, 2018). The visual and kinesthetic demonstration and Socratic guided discovery of the ACPTT will appeal to a wide range of learning styles (Prithishkumar & Michael, 2014). This guided discovery will give the FCN’s an opportunity to begin to develop a practical use and implementation plan. The tool was developed by the project lead and program facilitator and reviewed and approved for context relevance by the project team and stakeholders.

Study of Interventions and Data Collection

Data Collection

The CBISA report, which includes the number of ACP outreach and AD completion activities, was collected one month prior to and four weeks after the intervention. This

aggregated CBISA data of ACP outreach and AD completion was obtained from the program facilitator.

The pre-intervention advance care planning engagement survey was distributed in person and via email to the participants immediately prior to the delivery of the ACPTT education. The paper forms were collected in person, and electronic surveys from the virtual participants were collected via email. After the education of the ACPTT was delivered, the post intervention advance care planning engagement survey was provided to the participants and collected.

The data collected from the CBISA reports and the advance care planning engagement survey was entered into the excel data file in preparation for analysis and kept in a password protected and secure cloud base drive.

Ethics and Human Subjects Protection

Ethical treatment and protection of human subjects in research is an integral component of high-quality translational quality improvement (Robinson Bailey, n.d.). The project intervention and study design were reviewed by the Touro University Nevada project team and does not meet the definition of research. This project does not require review by the Institutional Review Board from the university or practice site.

The privacy of the voluntary participants in this quality improvement project will be protected with the assignment of participant identification numbers that removes identifiable information from the data. Each participant will be assigned an identification number that will be stored electronically with a secure password separate from the data file.

Plan for Analysis

CBISA Data

Analysis of the CBISA data includes a comparison of frequency of ACP outreach and AD completion pre and post intervention. The frequency was calculated using the total percent change calculation. The percent change between the pre and post-intervention data was calculated by taking the original values of ACP outreach and AD completion individually and deducting the difference (post-intervention) and dividing this value by the original amount and multiplying by 100 to get the percentage change.

Advance Care Planning Engagement Survey Data

The excel data file for the Q1-Q34 pre and post variables was analyzed using paired t test calculations. The calculations were performed using the IBM SPSS software. The paired t test was selected due to the need to analyze pre and post intervention data from the same group of people on two different occasions. Assumptions for parametric t tests such as paired t testing include the use of a continuous scale (the Likert scale), that scores are obtained from a random sample of the population that has a normal distribution, the observations are independent of one another, and samples are obtained from populations of equal variances. Additionally, the difference between the two scores for each subject should be normally distributed (Pallant, 2013).

The data was screened by checking for errors for each variable for scores out of range. Errors that were identified were found and corrected if needed. The test was conducted using one set of participants. The two variables were time (pre and post) and one continuous variable selected from the advance care planning survey variables (Q1-Q34). Each variable has a further grouping based of either knowledge or self-efficacy as identified by the code book. The IBM SPSS procedure for the paired sample t test was followed.

Analysis of Results

The data collected included pre- and post-intervention responses from eight FCN's. Survey data includes the 34 question ACP Engagement Survey that measured ACP knowledge and self-efficacy. The CBISA data was collected pre- and post-intervention and measured the frequency of ACP outreach and AD completion. The data was entered into an excel data file with variables named for each of the 34 survey questions delineated by pre- and post- intervention (ex: Q1pre and Q1post), and CBISA data (ex: ACPpre and ACPpost). The data set was uploaded to the IBM SPSS software (Pallant, 2013) and evaluated for errors. Procedures were followed for checking for categorical and continuous variables. No out of range variables were identified.

The paired t-test was conducted via SPSS software to compare the mean scores for the FCN group at two different time intervals (pre- and post-intervention) for the ACP engagement survey of knowledge and self-efficacy. A frequencies measure was used to calculate a percentage change for the ACP outreach and AD completion using Microsoft Excel.

Results

ACP Engagement Survey: Knowledge and Self-Efficacy Results

A paired-samples t-test was conducted to evaluate the impact of the ACPTT intervention on the FCN scores for knowledge (Q1-Q2) and self-efficacy (Q3-Q34) (see Appendix J). Improvements to ACP knowledge (Q1 and Q2) and self-efficacy (Q3, Q8, Q10-Q17, Q19, Q22-Q34) were demonstrated. There was no statistically significant difference in the Sig. (2-tailed) scores from Q1-Q34 pre to post intervention overall (range of $p = .080$ to $p = 1$) (see Figure 1). The positive mean change for knowledge (Q1 and Q2) was $-.063$ and -0.38 respectively (see Figure 2). The average mean for the positive changes for the self-efficacy scores (Q3, Q8, Q10-Q17, Q19, Q22- Q34) ranged from -0.13 (Q8) to -1 (Q27) (see Figure 3).

		Paired Samples Test								
		Paired Differences					t	df	Sig. (2-tailed)	
		Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference					
					Lower	Upper				
Pair 1	Q1pre - Q1Post	-.625	.916	.324	-1.391	.141	-1.930	7	.095	
Pair 2	Q2pre - Q2Post	-.375	.744	.263	-.997	.247	-1.426	7	.197	
Pair 3	Q3pre - Q3post	-.375	.518	.183	-.808	.058	-2.049	7	.080	
Pair 4	Q4pre - Q4post	.000	.535	.189	-.447	.447	.000	7	1.000	
Pair 5	Q5pre - Q5post	.000	.926	.327	-.774	.774	.000	7	1.000	
Pair 6	Q6pre - Q6post	.125	.641	.227	-.411	.661	.552	7	.598	
Pair 7	Q7pre - Q7post	.000	1.069	.378	-.894	.894	.000	7	1.000	
Pair 8	Q8pre - Q8post	-.125	1.356	.479	-1.259	1.009	-.261	7	.802	
Pair 9	Q9pre - Q9post	.125	.641	.227	-.411	.661	.552	7	.598	
Pair 10	Q10pre - Q10post	-.375	1.506	.532	-1.634	.884	-.704	7	.504	
Pair 11	Q11pre - Q11post	-.250	.707	.250	-.841	.341	-1.000	7	.351	
Pair 12	Q12pre - Q12post	-.500	1.309	.463	-1.595	.595	-1.080	7	.316	
Pair 13	Q13pre - Q13post	-.500	1.195	.423	-1.499	.499	-1.183	7	.275	
Pair 14	Q14pre - Q14post	-.500	1.690	.598	-1.913	.913	-.837	7	.430	
Pair 15	Q15pre - Q15post	-.667	1.366	.558	-2.100	.767	-1.195	5	.286	
Pair 16	Q16pre - Q16post	-.500	1.604	.567	-1.841	.841	-.882	7	.407	
Pair 17	Q17pre - Q17post	-.750	1.753	.620	-2.215	.715	-1.210	7	.265	
Pair 18	Q18pre - Q18post	.000	1.690	.598	-1.413	1.413	.000	7	1.000	
Pair 19	Q19pre - Q19post	-.125	.991	.350	-.954	.704	-.357	7	.732	
Pair 20	Q20pre - Q20post	.000	1.069	.378	-.894	.894	.000	7	1.000	
Pair 21	Q21pre - Q21post	.125	1.126	.398	-.816	1.066	.314	7	.763	
Pair 22	Q22pre - Q22post	-.250	1.753	.620	-1.715	1.215	-.403	7	.699	
Pair 23	Q23pre - Q23post	-.375	1.598	.565	-1.711	.961	-.664	7	.528	
Pair 24	Q24pre - Q24post	-.500	1.927	.681	-2.111	1.111	-.734	7	.487	
Pair 25	Q25pre - Q25post	-.500	1.927	.681	-2.111	1.111	-.734	7	.487	
Pair 26	Q26pre - Q26post	-.500	1.690	.598	-1.913	.913	-.837	7	.430	
Pair 27	Q27pre - Q27post	-1.000	1.633	.617	-2.510	.510	-1.620	6	.156	
Pair 28	Q28pre - Q28post	-.857	1.773	.670	-2.497	.782	-1.279	6	.248	
Pair 29	Q29pre - Q29post	-.714	1.496	.565	-2.098	.669	-1.263	6	.253	
Pair 30	Q30pre - Q30post	-.571	1.902	.719	-2.331	1.188	-.795	6	.457	
Pair 31	Q31pre - Q31post	-.857	2.193	.829	-2.885	1.171	-1.034	6	.341	
Pair 32	Q32pre - Q32post	-.429	1.902	.719	-2.188	1.331	-.596	6	.573	
Pair 33	Q33pre - Q33post	-.125	.835	.295	-.823	.573	-.424	7	.685	
Pair 34	Q34pre - Q34post	-.625	2.326	.822	-2.570	1.320	-.760	7	.472	

Figure 1. Paired Samples Test: Knowledge and Self-Efficacy

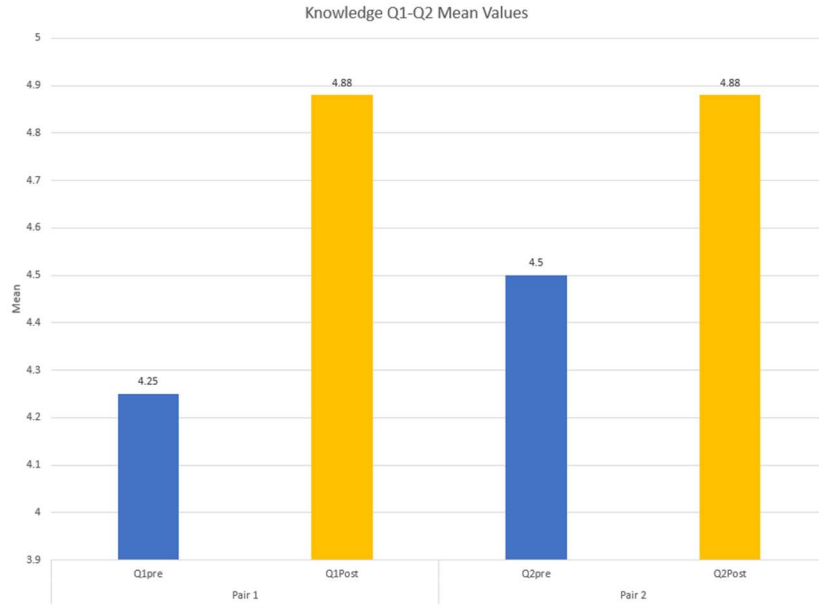


Figure 2. Knowledge Q1-Q2 Mean Values

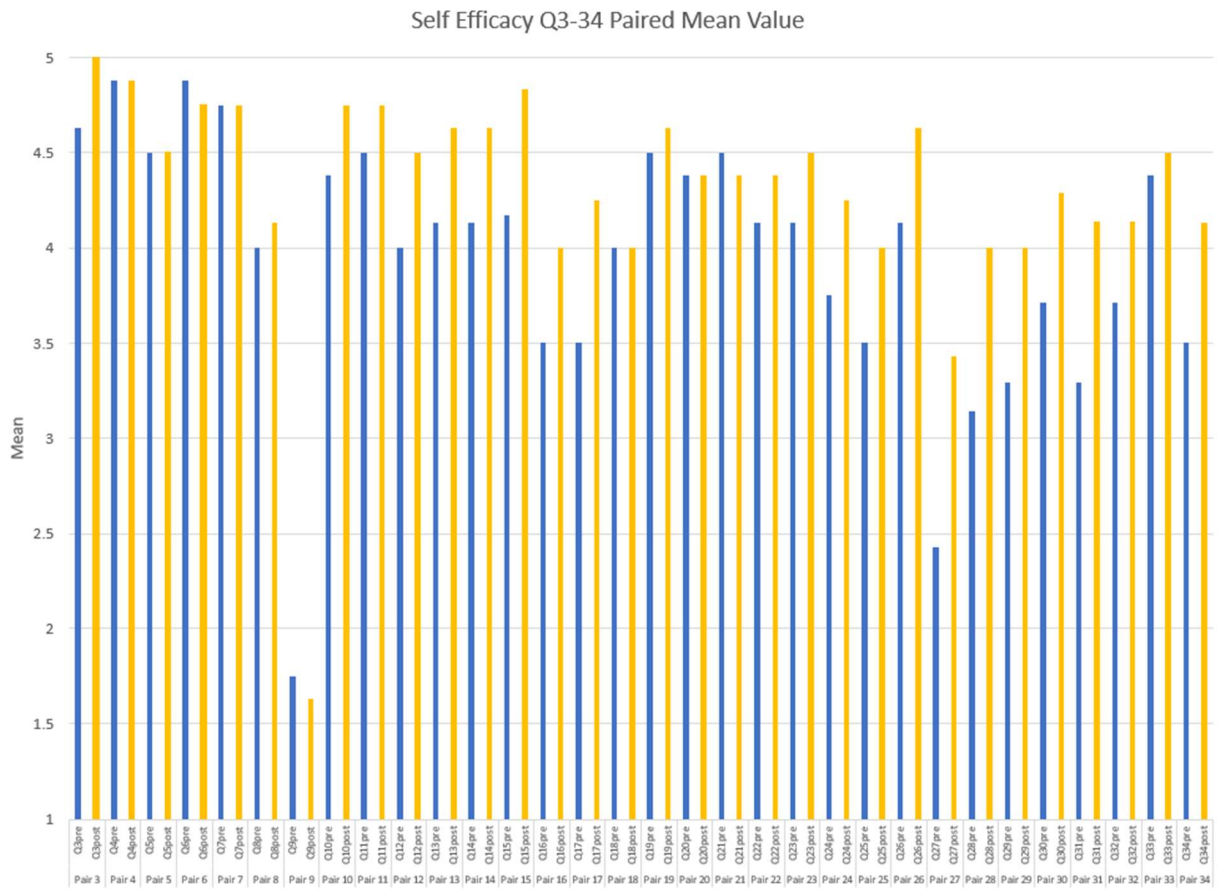


Figure 3. Self-Efficacy Q3-Q34 Paired Mean Value

CBISA Data: ACP Outreach and AD Completion Results

The CBISA reports prior to the ACPTT intervention revealed that only one out of the eighteen churches affiliated with the FCN program conducted ACP outreach activities. This resulted in the completion of one AD. The total number of congregants that received ACP outreach prior to the intervention was 30.

After the ACPTT intervention was completed three churches engaged in ACP activities and reached 1,690 individuals, resulting in the completion of one AD (see figure 4). There were no measurable differences in the completion of AD pre (1) and post intervention (1).

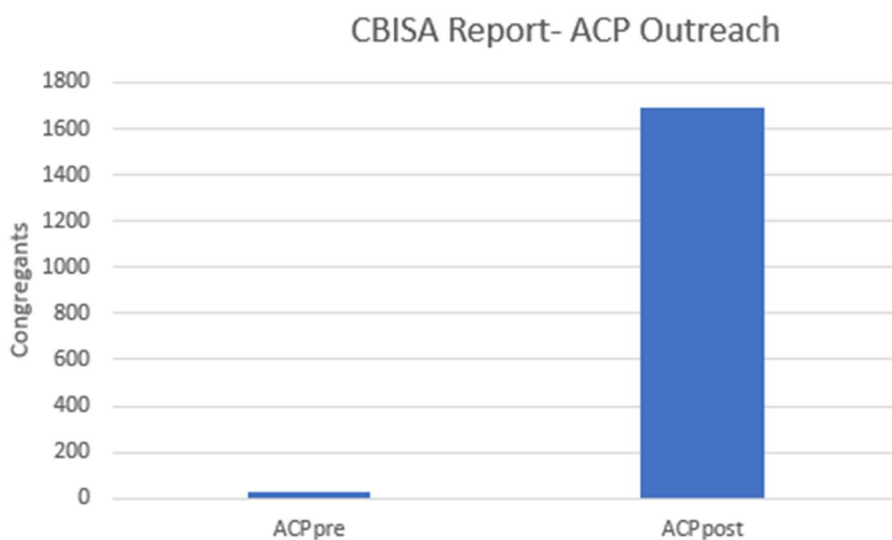


Figure 4. CBISA ACP Outreach Number of Congregants reached: Pre and Post Intervention

Analysis

The results revealed improvements to knowledge, self-efficacy, and ACP outreach after the ACPTT was distributed to the FCN group. Although, due to the small sample size (N=8) statistical significance was not demonstrated, the results demonstrate clinical significance (Sylvia & Terhaar, 2018).

The survey questions that measure knowledge (Q1 and Q2) revealed an average of 11% increase post intervention. The self-efficacy questions had an average of a 14% increase.

Notably, a 41% increase was found for Q27, which described *how much they have thought about talking with their medical decision maker about how much flexibility they would give them*. A 27% increase was demonstrated for Q28 which described *how **confident** they were that today they could talk with their doctor about how much flexibility they would give to the medical decision maker*. There was a 26% increase for Q31 which referenced *how **ready** they were to talk to their doctor about how much flexibility they would want to give their decision maker*.

Advance directive (AD) completion revealed no change from pre to post intervention. An explanation of this could be due to the continuous nature of ACP. This is a process that evolves over time that involves education, thoughtful reflection, and conversations with family and health care providers. The post intervention data was collected just 4 weeks after the intervention and may not have provided adequate time to demonstrate this continuous process resulting in the completion of AD forms. Additional ramifications include the timing of the intervention over the Thanksgiving holiday and during the COVID-19 pandemic. New restrictions and barriers to typical FCN practice such as health outreach efforts in the group settings has been ongoing.

The impact of improvement of knowledge (11%) and self-efficacy (14%) were below the stated objectives of 25% for this project. The pre intervention scoring on average ranged moderate (3) to high (5) which illustrates that the baseline knowledge and self-efficacy of this group was high leaving a small margin for measurable improvements in these areas.

Although these changes are not statistically significant (Sig. 2-tailed $Q1_{pre}-Q1_{post} = 0.095$, and $Q2_{pre}-Q2_{Post} = 0.197$), the clinical significance is important to consider. Clinical significance is revealed and have implications for FCN practice. Measurable increases in ACP outreach activities among faith communities support the continuous efforts of ACP and helping communities achieve goal concordant care. Clinical significance reflects the impact on clinical

practice (Ranganathan, Pramesh, & Buyse, 2015). Clear and measurable improvements to ACP outreach efforts were demonstrated among the group. The clinical significance of the impact of education and receipt of the ACPTT to the FCN's resulted in an increase in the number of churches conducting outreach activities. The increase in outreach efforts resulting in an increase in the number of congregants that received ACP education. The literature supports that engaging communities in the dissemination of education regarding ACP has proven to be an effective way to increase knowledge and awareness of ACP which leads to increase completion of AD and the move closer to goal concordant care (Litzelman, Cottingham, Griffin, Inui, & Ivy, 2016).

Discussion

The purpose of this project was to evaluate the impact of providing an ACPTT to FCN's on outreach and education of ACP in faith communities compared to those with FCN's and no training guide. Evaluation of the project objectives included the development and dissemination of an ACPTT, demonstration of an 11% increase in knowledge and 14% increase in self-efficacy of ACP and AD, a 5,553% increase in ACP outreach activities, and no change in AD completion post intervention compared to pre-intervention from October to December 2020. Demonstrative increases in knowledge and self-efficacy resulted in a significant increase in ACP outreach activities among faith communities.

The ACP process is reflective of ongoing conversations and communication regarding future medical care (McMahan, Tellez, & Sudore, 2020). The FCN's engagement within the community underscore the potential access to vulnerable and often underserved members of society. Through the practice of whole person care FCN's fostered continued conversations for members with ACP outreach activities to aide communities to move closer to goal concordant care. These professional unpaid nurses planted seeds to over 1,690 congregants over

approximately six-week period regarding the value of ACP as part of health promotion programs. This was accomplished despite the barriers of a pandemic and social distancing policies that prohibited many in person gatherings common to FCN practice. The integration of faith and health created an ideal setting for the FCN to be an educator and trusted motivator of health in the community (Gotwals, 2018) during a time of an unprecedented viral pandemic. Equipping FCN's with tools to increase knowledge and self-efficacy provided a foundation for ACP outreach and eased facilitation of what otherwise may have been a difficult and complex endeavor.

Significance

Most Indiana residents do not have advance directives ("Biospace," 2019) despite most consumers expressing a desire to do so (The Conversation Project, 2020). Exposure to ACP information and outreach is known to significantly increase completion of advance directives (Splendore & Grant, 2017). The evidence of the support and need for ACP in the community setting is clear. Positive impacts include patient outcomes, cost avoidance by health systems, empowered patients, patient autonomy and the prevention of futile treatment resulting in goal concordant care (Detering & Silveira, 2018). The community setting and specifically the faith community is often underserved, and the FCN is uniquely positioned to provide effective, culturally relevant ACP education and outreach that resulted in a significant increase in ACP engagement demonstrated by this project (Lind & Chase, 2014). Equipping the FCN with an evidence-based tool increased engagement in ACP outreach activities among faith communities. Outcomes that are important for communities and especially those suffering from chronic or serious illnesses include ACP and goal concordant care (Murali et al., 2020). Goal concordant care has been described as a key priority by the National Academy of Medicine and is considered

a key quality measure by health care systems. Some have described goal concordant care as a type of high-quality communication and evaluate whether specific medical interventions were goal concordant. Broadly defined, goal concordant care is treatments provided that match a patient stated or documented goals (Halpern, 2019). Providing community-based nurses with tools to promote ACP outreach and education provides a foundation for clients to have conversations with others about future medical care. This project has demonstrated a clinically significant impact on faith communities as an integral part of achieving goal concordant care.

Implications for Nursing

The theoretical model of faith community nursing guides the application of whole person care with an emphasis on the nurse client relationship that occurs over time (Ziebarth, 2014). The implication of this quality improvement project on nursing reiterates the importance of faith integration and whole person care. This care fosters a trusting relationship between a congregant and the FCN that occurs in part due to this intimate relationship. Subsequently, the ACP process emphasizes fostering conversations about what matters most and future medical care between the patient or client and others. FCN's bridge the gap between intention and desire to have these discussions. The fruition of these efforts culminates in small steps toward goal concordant care. Nursing as a profession can be informed by this project to prioritize whole person care regarding the topic of mortality, death and dying and the anticipation of future medical care through ACP conversations.

Nursing history is rich with examples of the application of whole person care. One example that can be drawn from is Hildegard of Bingen, who was a medieval healer and Benedictine Nun in the 11th century. Hildegard emphasized the early understanding of whole person care by considering body, mind and spiritual aspects known to early medicine with the

addition of environmental implications such as art, music, and nature. Hildegard is often viewed as one of the early founders of nursing and medicine. She understood how whole person care was central to the notion of healing. Modern-day nurses can inform their practice by considering Hildegard's work when formulating plans of care for clients, families, and communities (Fordham University, 1995). Nurses can use the essential attributes of faith community nursing to include faith integration while conducting continuous health promoting endeavors such as ACP in a variety of settings (Ziebarth, 2014).

Like Hildegard, the nursing profession has a rich narrative of health promotion, disease prevention, and care for communities of faith. Equipping nurses with relevant, and current evidence-based tools that facilitate health education and health promotion activities increase not only targeted activities such as ACP, but also increases the nurse's knowledge base and how nurses personally related to the materials through self-efficacy. The essence of whole person care creates buy in that comes from self-efficacy. This cultivates health promotion activities and increases the possibilities of improving community health, through empowered patients seeking goal concordant care. FCN's play an integral role in community health. Through the facilitation of relationship building and trust the FCN can respond to the needs of the faith community that is unique to FCN practice. This trusting relationship is beyond the reach of traditional healthcare systems that may be devoid of the personal connection integral to these intimate conversations. Healthcare often operates in silos which further disconnects traditional healthcare providers from the concepts of whole person care. This profoundly influences the nature of support provided when discussing future medical care. Empowering nurses with accurate information to facilitate conversations, integral to high-quality care, can and should be revisited over time. This further permits gradual adjustments for congregants and their families to take control and process the

notion of goal concordant care while reflecting on what matters most for them and their families (Walshe, 2020).

The importance of the nursing role in the facilitation of ACP has been highlighted during the COVID-19 pandemic of 2020. Overbaugh (2020) emphasized that improving nurse knowledge of ACP and subsequent reflection on their own values and preferences are important first steps. The ACPTT serves as a vehicle to improve knowledge and self-efficacy for the FCN. Secondly, nurses should consider the implications of ACP and AD at strategic moments during a patient healthcare experience such as during admission or when knowledge deficits regarding health care surrogacy or future medical care are identified. Equipping nurses at large to advocate for goal concordant care by asking questions such as what matters most can be facilitated from the trusted and therapeutic relationships inherent in the act of caregiving (Overbaugh, 2020). Faith communities are often intimately involved in life events such as birth, illness, and death. This creates a natural role for the FCN to use the power of intention to facilitate advancements in the ACP conversation. By identifying congregants who have a new medical diagnosis, are experiencing life transitions and events, or who are contemplating plans, the FCN can gently walk beside these members and provide support, education, and guidance that is palliative in nature.

Limitations

Translational research projects attempt to articulate specific targets and objectives that focus on the adoption of best practices. Evaluation is measured on whether the project meets metrics using a flexible approach that conveys relationships between program elements and outcomes (Rubio et al., 2011). The aim of this project was to determine what impact providing an ACPTT to FCN's in the community setting would have on knowledge, self-efficacy, and

implementation of ACP and AD completion. Project evaluation revealed limitations in the overall design and implementation. Limitations included the small sample size, implementation during a pandemic with face to face restrictions, a largely non-paid professional nursing workforce, and a relatively short time for the FCN to implement the project over the winter holiday season.

Data Collection

The data collection procedures required flexibility to include in-person and electronic methods. The original procedures had planned to conduct the surveys in person; however, due to the restrictions on the face to face gatherings as well as the personal comfort of the FCN group members, adaptations were made. The project was presented in person and via Zoom, with data collection occurring in-person and via email.

Small Sample Size and Non-Paid Professional Group

The targeted FCN group consisted of approximately 18 non-paid professional FCN's in total. This project included 8 participants representing 44% of the total. Small sample sizes can impact statistical analysis and significance by decreasing statistical power (Deziel, 2018). The small group and subsequent sample size are directly impacted by the volunteer nature of this program. Volunteer engagement and retention are concerning for many administrators as the workforce demographic is changing. The majority of the FCN's in this program are retired, and of those that are still working have limited time to devote to FCN activities. Additional challenges with the engagement of a volunteer workforce include finding registered nurses who are interested in taking additional training specific to FCN practice. Often volunteer dominant programs are not provided with infrastructure and support from administration and leadership

that would support additional volunteer recruitment and training (Rogers, Rogers, & Boyd, 2013).

Timing of the Implementation

The project was implemented during an unprecedented pandemic that resulted in sweeping changes to FCN practice. These changes included limited or no access for face to face interactions among the faith community members and increasing use of technological interactions. ACP is a process that evolves over time through the intimate, thoughtful interactions of whole person care. The limitations to the art of prayerful presence, and non-verbal communication inherent to empathic expression were limited at best.

Implementation of the project over a 4-week period that coincided with national holidays was also a limitation to the project. Given the evolving nature of ACP, it is likely that the evidence of the interventions may not be demonstrated for some time to come (Halpern, 2019). Additionally, due to the non-paid professional nature of the FCN role in this group, implementing new projects over a busy holiday season may not be a priority while balancing other family and work responsibilities.

Dissemination

The implication of the dissemination of the project results will help inform and shape nursing practice. The target population will be those who engage in community health, faith community/parish nursing, and palliative care. The goal of dissemination will be to generate interest about FCN practice that may support growth and expansion, to provide a framework for ACP interventions for community health nurses among faith communities, and to support community members to achieve goal concordant care (Reavy, 2016).

Opportunities for project dissemination include acceptance for a podium presentation at the Westberg Institute Symposium at the Caring for the Human Spirit Conference in April 2021. Additionally, at this conference, the project will be presented during a panel discussion by the Faith Community Nurses International Research committee. The Indiana Center for Parish Nursing, Bay Care Faith Community Nursing Program, Faith Community Nurses International, Community Hospital Network, Franciscan Health, and Marian University has also extended invitations to share the ACPTT and project results. The project manuscript will be submitted for publication to the Journal of Hospice and Palliative Nursing in the spring 2021.

Project Sustainability

The ACPTT was designed to be adaptable and portable. It is available electronically through the FCN practice site shared website and has been disseminated in electronic and booklet form. The project was designed using the PRISM implementation model to promote sustainability. The PRISM models build on prior models of quality improvement work. This model emphasizes that sustainability will be more successful when three or more domains have been included. This project has included all four domains. The program (ACPTT) was developed from the organizational and patient perspective and included a review of the external environment of the FCN and faith community. A dedicated team at the practice site (the program facilitator and FCN member) has been established to conduct the training and revisions. The recipients of the project include numerous organizations which will direct FCN's client/patient engagement at the practice site and beyond (Feldstein & Glasgow, 2008). The tool can be updated over time to reflect emerging science related to ACP as well as changes to FCN practice by the program site facilitator. The tool will be included DNP Project Repository and in the Faith Community Nurses International toolkit for new FCN practice that will be disseminated via a

website. Consideration for the inclusion of the tool in the national FCN foundations training is being explored.

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Appendix A

Prism Model

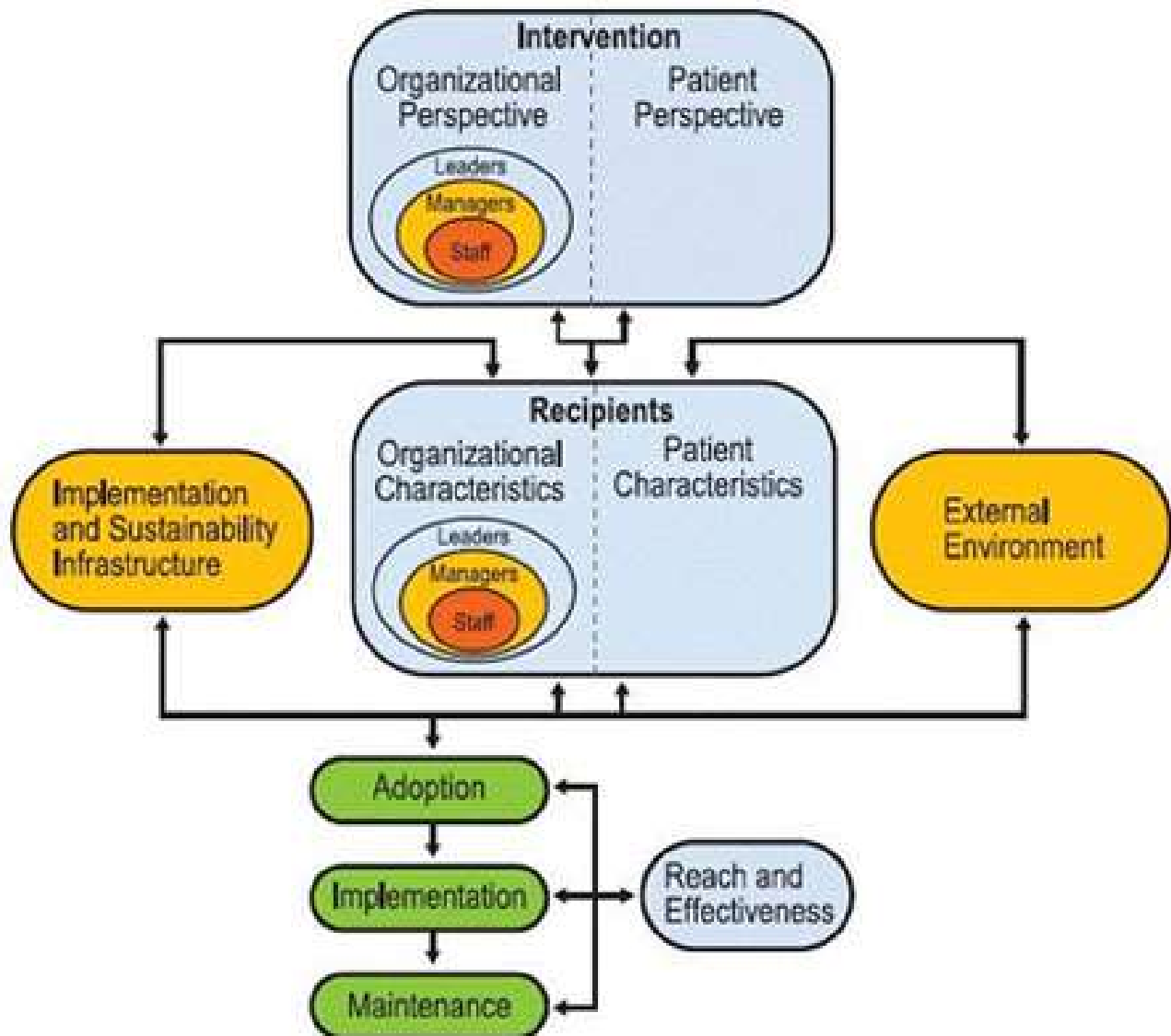


Figure 4. PRISM model: NIH, n.d.

Appendix B

New Conceptual Model: Faith Community Nursing

New Conceptual Model: Faith Community Nursing (FCN)
 A Method of Wholistic Health Care Delivery (Ziebarth, 2014)

Old Conceptual Model: Parish Nursing
 (Solari Twadell, et al, 1991)

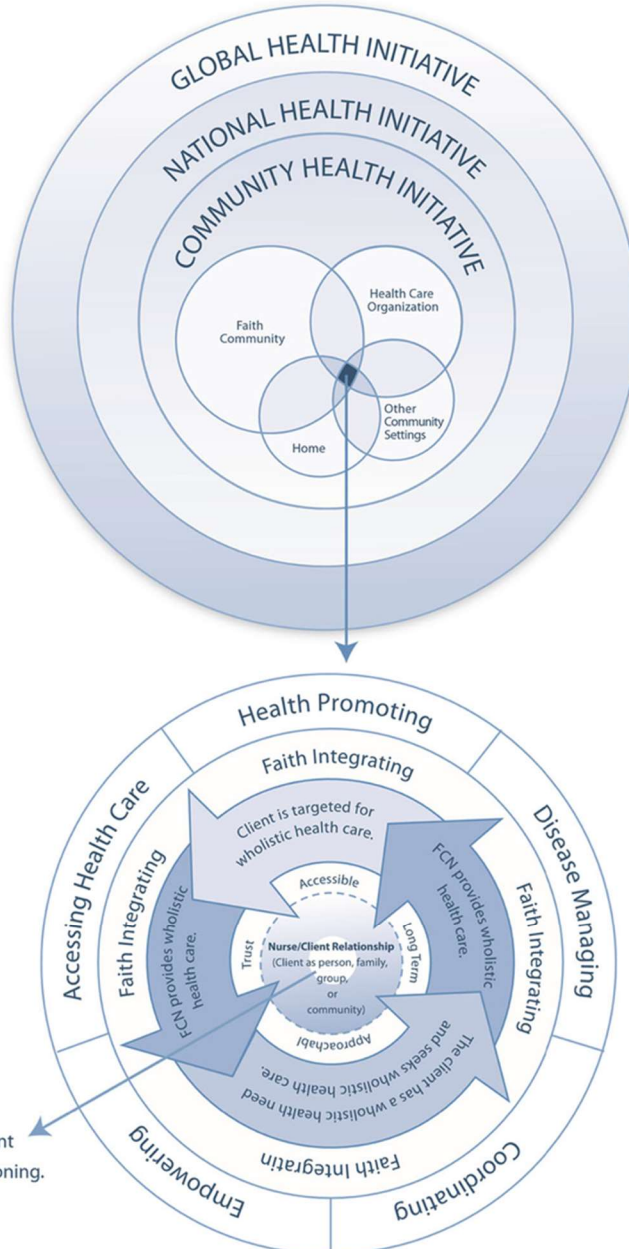
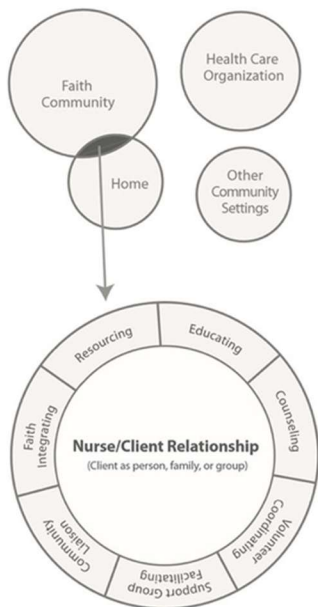





Figure 5. Theoretical Model of Faith Community Nursing: D. Ziebarth, 2014

Appendix C

Project Site Permission

RE: DNP Project

 Gaddis Jan <Jan.Erlenbaugh-Gaddis@franciscanalliance.org>
To:  Lorie Hacker
Cc:  Smiley Christa

[Reply](#) [Reply All](#) [Forward](#) [...](#)

Tue 3/31/2020 3:03 PM

Yes Lorie, Franciscan Health Parish Nurse program in Central Indiana is willing to work with you on your DNP advance care planning project with faith community nursing and congregations.
Thank you for inviting us to participate.
Peace and all good, Jan

Jan Gaddis, BSN, RN-BC
Faith Community Nurse
Franciscan Health - Indianapolis
Palliative Care Outpatient Services
317-528-6298

From: Lorie Hacker <lorie.hacker@gmail.com>

Appendix D

Advance Care Planning Training Tool (ACPTT)

**Advance Care Planning
Training Tool
for the Faith Community Nurse**

Lorie Hacker MSN, NP-C, RN, CNE

The purpose of this tool is increase advance care planning outreach and advance directive completion in faith communities by equipping the faith community nurse with resources.

Prayer for the Faith Community Nurse

Dear God,

Send your Holy Spirit into my heart today and hear my prayer for health and healing.

Use my hands as if they were yours to touch and help heal others.

Use my ears as if they were yours to listen to those in pain, loss, or indecision.

Use my heart as if it was yours to love and accept those that are different from us, lonely, and afraid.

Use my arms as if they were yours to embrace those who need reassurance and security.

Use my soft voice as if it was yours to pray and provide comfort.

Use my gentle spirit as if it was yours to bring your Holy presence into those who need you close.

Give me your strength and ability to work through you and give of myself for others in need.

Amen.



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2020

Acknowledgements

This training tool is a product of many hours of collaboration and prayer. A special thank you to Touro University Nevada Doctor of Nursing Practice Program, Franciscan Health Indianapolis and the Faith Community Nursing Program for guiding the development.

To Jan Gaddis for being a model of what it means to be a faith community nurse, being instrumental in the development of this tool and for being open to let go and let God take us on a journey.

My prayer is that many will find this tool useful for the integration of whole person care among faith communities, and that many people of faith will begin advance care planning conversations with their families and friends.

Additional recognition and heartfelt thank you to Pat Tadel with Respecting Choices, Faith Community Nurses International, the Westberg Institute for Faith Community Nursing, and The Conversation Project for paving the way for evidence based training in advance care planning.

To my husband and family, thank you for supporting me, my academic pursuits and my faith journey. I love you.

Lorie Hacker MSN, NP-C, RN, CNE



How can a Faith Community Nurse Use this Tool?

This tool is designed to provide quick access to evidence-based practice, resources and outreach materials for advance care planning outreach in faith communities. Options for use include *basic quick start*, *steady start*, and *advanced start*. These levels determine how involved the advance care planning outreach will be.

Implementation can be completed for any faith community regardless of time and talent commitment. Additional resources for cultural and ethnic considerations, faith community leadership, and COVID-19 information are included.

Ninety-two percent of people indicate that having a conversation regarding end of life care is important, however, only 32% have had this conversation (The Conversation Project, 2020)

Why is advance care planning important to faith communities?

Advance care planning (ACP) is an important aspect of care for adults. Effective screening and prevention are key to determine individual treatment preferences to improve quality of life (National Committee for Quality Assurance [NCQA], 2018).

Consider how much time you have to spend on this project?

Select one of the following options and follow the detailed instructions for ACP outreach and implementation for each start level.

Little Time ⇒ BASIC QUICK START

More Time ⇒ STEADY START

More Interest ⇒ ADVANCED START



Respecting Choices – Person Centered Care

Faith communities play an important role in shaping social issues and values surrounding end of life

ACP improves patient outcomes by increasing clinician understanding of patient wishes, reducing hospitalizations and aggressive care at the end of life, increasing use of hospice programs and increasing patient satisfaction with care provided (Detering & Silveira, 2018, p.3). Ninety-two percent of people indicate that having a conversation regarding end of life care is important, however only 32% have had this conversation (The Conversation Project, 2020).

Seventy percent of Indiana residents do not have advance directives (Biospace, 2019). Exposure to advance care planning information and outreach is known to significantly increase completion of advance directives (Splendor & Grant, 2017).

A faith community which is defined as a group of people who share a set of religious beliefs (Longman, 2020) play an important role in shaping social issues and values surrounding end of life care and can help to overcome barriers to health promotion in many cultures.

Health care professionals are often uncomfortable speaking with patients and families about advance care planning and 87% report hesitation to implementation until illness become severe (Booth & Lehna, 2016). Faith community nursing (FCN) is uniquely positioned to address the gaps in care in the community and to assist healthcare systems to reduce the number of hospital readmissions by increasing the use of preventive medical and social services, increase adherence to treatment regimens and by providing support for community members to thrive in their own homes (Schroepfer, 2016). Faith communities can partner with health care organizations and this partnership is an effective way to reach the community for health promotion and increase completion of ACP (Kotecki, 2002, p. 61). Exposure to ACP information and outreach is known to significantly increase completion of advance directives (Splendor & Grant, 2017).

Changing Lives

VIDEO LINK- INTER-VIEWS

Watch:

Extremis- 24 min

(Netflix)

Witness the challenging emotions that accompany end-of-life decisions as doctors, patients and families in a hospital intensive care unit face harrowing choices.

Being Mortal-54 min

(Frontline)

<https://>

www.youtube.com/watch?v=IQh13Jb7vMg

Advance Care Planning

Advance care planning is defined as discussion between the patient and others about future care with the goal being to ensure patients receive medical care that is "consistent with their values, goals and preferences" (Detering & Silveira, 2018, p. 1). ACP conversations may lead to the completion of advance directives such as health care surrogate documents, living wills and other actionable documents such as a do-not-resuscitate (DNR) order (Detering & Silveira, 2018, p. 2). A health care surrogate is also known as a health care proxy or durable power of attorney for health care and serves as a legal document that authorizes medical decision making on the patient's behalf if the patient no longer has capacity (Detering & Silveira, 2018, p. 8). The living will is a summary of the patient's treatment preferences for future medical care and provide the healthcare surrogate and clinical team a general sense of the treatment preferences (Detering & Silveira, 2018, p. 9).

What is the Evidence?

ACP empowers patients and their families, reduces burdens on others to make decisions, prevents unwanted treatments and unnecessary hospital admissions (Merlane & Armstrong, 2020) and has a positive impact on quality at EOL (Kastbom, Milberg, & Karlsson, 2019). Merlane and Armstrong published a peer reviewed journal article and demonstrates the importance of advance care planning and the role of the nurse in ACP (2020). Kastbom, et al. demonstrated the effectiveness of ACP in nursing homes (2019). ACP should

be implemented in every care setting and by providing patient and family centered care this will improve care quality, patient and family satisfaction and cost containment (Novelli & Banarjee, 2017). ACP efforts should continue as a process over the life span with the ideal implementation to begin early in adulthood to be re-visited as circumstances and health issues change over time (National Institute of Health [NIH], 2015).

Faith Community Nursing & Health Promotion

The FCN is uniquely positioned to address the gaps in care in the community and to assist healthcare systems to reduce the number of hospital readmissions by increasing the use of preventive medical and social services, increased adherence to treatment regimens and by providing support for community members to thrive in their own homes (Schroepfer, 2016). The American Nurses Association (ANA) includes specific scope and standards of practice for the FCN that include the assistance of faith community members with life transitions for adults with chronic illness and specific direction to assess social determinants of health to develop targeted health promotion activities (Health Ministries Association, 2017). Additionally, the FCN can access populations that may be difficult to reach due to socioeconomic disparities and decreased access to primary care (Schroepfer, 2016). Health care systems have routinely partnered with faith community nurses to reach the vulnerable and provide supportive holistic care. FCN's integrate mental, physical and spiritual health which lead to connections with fellow church members, this intimacy leads to more thorough congregational needs assessment and health promotion & members perceive the FCN as a positive, beneficial trusted healthcare resource (Lind & Chase, 2014).

Faith Community Nursing...continued

The integration of faith and health creates an ideal setting for the FCN to be an educator and motivator of health in the community (Gotwals, 2018). The FCN role is naturally adaptable in a variety of settings to include home or church which is based on the needs of the members. Collaboration with home health partners provide the FCN with resources for members as many FCN's assist older adult membership. FCN's provide supportive services including education (Wordsworth, Moore, & Woodhouse, 2016). Integrating health promotion activities such as ACP increase health-promoting behaviors by recipients of FCN outreach and efforts and reiterate the important role that FCNs play in the facilitation of health promotion interventions across the lifespan (Callaghan, 2015, p. 18).



Transitional care interventions include anticipatory guidance and community health promotion include ACP by the Faith Community Nurse (Westberg Institute for Faith Community Nursing, 2018).

Community Health Education & Faith Communities

The impact of community health education in faith communities on patient outcomes is illustrated by the Mississippi State Department of Health initiative to improve health outcomes by collaborating with community health partners such as churches and faith communities and has a coalition with 25 churches called the Delta Alliance for Congregational Health (DACH).

This includes a health and wellness ministry team that promotes health among the churches and has demonstrated positive changes regarding meal services and a heart healthy diet and reached over 5,000 Delta residents (Centers for Disease

Control and Prevention [CDC], n.d.). A community and faith-based prostate cancer screening program in a minority population demonstrated an increase in knowledge and screening post health promotion and outreach in Virginia (Howard et al., 2018). This study demonstrates support for health promotion at the community level.



Faith Community Nursing Model

The theoretical model of faith community nursing was developed in 2014 by Deborah Ziebarth and provides a framework for faith community nursing as "...a method of healthcare delivery that is centered in a relationship between the nurse and client... that occurs in an iterative motion over time when the client seeks or is targeted for wholistic health care" (Ziebarth, 2014, p. 1831). The model provides a visual representation of the attributes with the nurse and client relationship as central and faith integration as a continuous attribute.

Faith Community Nursing Scope & Standards

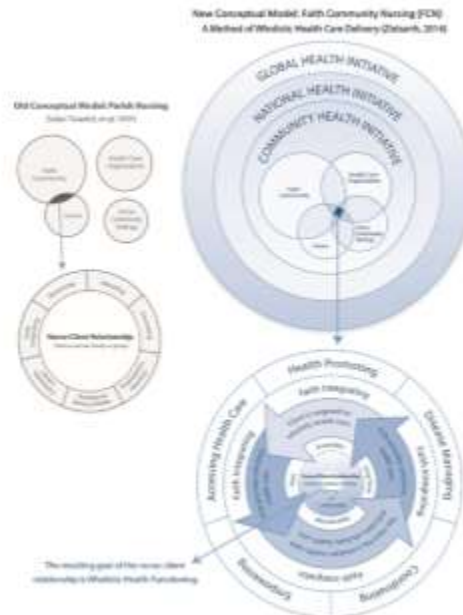
The FCN scope and standards include quality improvement programs which involve guiding conversations about care decisions such as ACP as well as serving as a health care advocate by defining medical terminology and assistance with interpreting medical language for treatments and modalities (Health Ministries Association, 2017, p. 13). Transitional care interventions include anticipatory guidance and community health promotion included in ACP and the FCN Transitional Care Model include interventions by the FCN to assist



in post discharge care which includes holistic assessment and educational outreach such as ACP

(Westberg Institute for Faith Community Nursing, 2018). To order a copy of the standards visit <https://www.nursingworld.org/nurses-books/faith-community-nursing-scope-and-standards-of-practice-3rd-edition/>

New Conceptual Model: Faith Community Nursing (FCN) A Method of Wholistic Health Care Delivery



Basic Quick Start Guide

Ready to get started, but don't have much time? Start here!

Step 1: Pray

Watch the following videos:

<https://youtu.be/eLIYsEU9E1c> 1:58 min

<https://www.christushealth.org/about/advance-care-planning> 3:48 min

Step 2:

Meet with leadership and select a video announcement, bulletin insert or email from the options below. Go!



Improve quality of life & outcomes ~~~ Preserve Dignity & Autonomy

Video, Email and Bulletin Announcements for a Quick Start

- <https://youtu.be/EdLOPlwEgFE>- The Conversation Project PSA 3:58 min
- <https://youtu.be/ITXv-20ULwQ> Who will speak for you? 2:02 min
- <https://youtu.be/owH-os9I19I> The Conversation Project: An Overview 4:32 min

Have you had the conversation? Advance care planning is an important part of preparing for future medical care. Having a conversation can make all the difference. Consider the following questions. What is most important to you as you think about how you want to live at the end of your life? What do you value most?



What loved ones do you want to talk to? Have you designated a health care surrogate? Find out more about advance care planning by talking with your healthcare provider and by visiting www.theconversationproject.org.

LEARN MORE

Suggested Reading

Gawande, A. (2014). *Being mortal*. New York, New York: Metropolitan Books.

Suggested Training

Do you feel prepared to have ACP conversations with individuals and their families? Do you want to learn more about how to help people make informed future healthcare choices? **Respecting Choices® (RC) has the tools to help you.** The Basic Concepts in Advance Care Planning module is an affordable online curriculum that teaches time-tested ways of preparing people to facilitate meaningful and effective ACP conversations. To learn more & enroll, visit: <https://respectingchoices.org/types-of-curriculum-and-certification/online-curriculum/>

Steady Start Guide

Have about an hour? This guide will help you get started!

Step 1: Pray

Watch the following videos:

<https://youtu.be/eLIYsEUGe1c>
1:58 min

<https://www.christushealth.org/about/advance-care-planning> 3:48 min

<https://youtu.be/eLIYsEUGe1c>
1:58 min

Step 2:

Meet with leadership, consider hosting a table with educational information, bulletin, email and

video announcements.

Step 3:



Learn more about advance care planning. Increase your knowledge so you can answer questions and appropriately refer. Select from the LEARN MORE Options to the left.

Step 4:

Select a video announcement and bulletin insert from the options below.

Step 5:

Gather your educational materials from the RESOURCES section & Go!

Video, Email and Bulletin Announcements for a Steady Start

<https://youtu.be/EdLOPIWegFE>- The Conversation Project PSA 3:58 min

<https://youtu.be/ITxv-20ULWQ> Who will speak for you? 2:02 min

<https://youtu.be/owH-os9l19I> The Conversation Project: An Overview 4:32 min

Have you had the conversation? Advance care planning is an important part of preparing for future medical care. Having a conversation can make all the difference. Consider the following questions. What is most important to you as you think about how you want to live at the end of your life? What do you value most? What loved ones do you want to talk to? Have you designated a health care surrogate? Find out more about advance care planning by talking with your healthcare provider and by visiting www.theconversationproject.org.



The Conversation Project

The Conversation Starter Kit is a useful tool to help you have the conversation with a family member, friend, or other loved one about your – or their – wishes regarding end-of-life care. It is available in several languages. **All of the Starter Kits are available to download and print for free.**

Visit: <https://theconversationproject.org/starter-kits/>



Your Conversation Starter Kit

When it comes to end-of-life care, talking matters.



Improve quality of life & outcomes ~ Preserve Dignity & Autonomy

Health Fair & Table Strategies

National Healthcare Decisions Day in April

This is a great time to conduct advance care planning outreach on an annual basis.

1. Plan your event.
2. Publish announcements in the weekly bulletin, newsletters or emails.
3. Obtain health care surrogate forms and 5 Wishes documents for the table. Order your free conversation starter kits.
4. The day of the event-
 - A. Set up your table with educational materials
 - B. Be open, friendly, ready to answer simple questions, educate and direct members to their health care providers for in-depth conversations

www.theconversationproject.org

LEARN MORE

Suggested Reading

Gawande, A. (2014). *Being mortal*. New York, New York: Metropolitan Books.

Suggested Training

Do you feel prepared to have ACP conversations with individuals and their families? Do you want to learn more about how to help people make informed future healthcare choices?

Respecting Choices® (RC) has the tools to help you. The Basic Concepts in Advance Care Planning and First Steps ACP Facilitation Training are an affordable online curriculum that teaches time-tested ways of preparing people to facilitate meaningful and effective ACP conversations. To learn more & enroll, visit: <https://respectingchoices.org/types-of-curriculum>

Advance Start Guide

If you have more interest, start here!

Step 1: Pray

Watch the following videos:
<https://youtu.be/eLIYsEU9E1c> 1:58 min
<https://www.christushhealth.org/about/advance-care-planning> 3:48 min

Step 2:

Meet with leadership, consider hosting a table with educational information, bulletin, video, and email announcements. How can you meet with your membership?

Step 3:



Learn more about advance care planning. Select from the LEARN MORE Options to the left. Consider becoming certified as a Respecting Choices ACP Facilitator.

Step 4:

Plan your event and select a video announcement and bulletin insert from the options below. Consider your audience and how to meet 1:1

Step 5: Gather your educational materials from the RESOURCES section & Go!

Video, Email and Bulletin Announcements for a Advance Start

- <https://youtu.be/EdLOPlwEgFE>- The Conversation Project PSA 3:58 min
- <https://youtu.be/iTxv-2OUlwQ> Who will speak for you? 2:02 min
- <https://youtu.be/owH-os9I19I> The Conversation Project: An Overview 4:32

Have you had the conversation? Advance care planning is an important part of preparing for future medical care. Having a conversation can make all the difference. Consider the following questions. What is most important to you as you think about how you want to live at the end of your life? What do you value most? What loved ones do you want to talk to? Have you designated a health care surrogate? Find out more about advance care planning by talking with your healthcare provider and by visiting



www.theconversationproject.org

The Conversation Project

The Conversation Starter Kit is a useful tool to help you have the conversation with a family member, friend, or other loved one about your – or their – wishes regarding end-of-life care. It is available in several languages. **All of the Starter Kits are available to download and print for free.** <https://theconversationproject.org/starter-kits/>



Your Conversation Starter Kit

When it comes to end-of-life care, talking matters.

H Institute for Healthcare Improvement **the conversation project**

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Improve quality of life & outcomes ~ Preserve Dignity & Autonomy

Health Fair & Table Strategies

National Healthcare Decisions Day in April

This is a great time to conduct advance care planning outreach on an annual basis.

1. Plan your event.
2. Publish announcements in the weekly bulletin and newsletters.
3. Obtain health care surrogate forms and 5 Wishes documents for the table. Order your free conversation starter kits.
4. The day of the event-
 - A. Set up your table with educational materials www.theconversationproject.org
 - B. Be open, friendly, ready to answer questions, assist with completion of advance directives such as healthcare surrogate forms, educate and direct members to their health care providers for in-depth conversations.

Examples for HOSTING & Organizing Events

Ideas from churches using tools from the www.theconversationproject.org

Thoughtful Endings

the conversation project
in boulder county

A five-part education and discussion series on end-of-life-planning
Longmont congregations will host the sessions on Sundays, 2:00 – 4:00 p.m. at the churches below. All are welcome. Drop in for one or all of the sessions. \$5 suggested donation. Refreshments will be provided. Coordinated by The Conversation Project in Boulder County.

Sept 22
Health Care Decision-Making
United Church of Christ, 1500 9th Ave, Longmont
Fostering meaningful and effective conversations with those who will be making decisions for you. Practical tools for exploring values and choosing a decision-maker.

Sept 29
Practical Planning
Westview Presbyterian Church, 1500 Hover Street, Longmont
Financial and non-medical planning that will ensure that your "house is in order"

Oct 6
Aging Solo
Central Presbyterian Church, 402 Kimbark Street, Longmont
Suggestions will be offered on how to find support with decision-making in a faith community and in the general community.

Oct 13
Medical Aid-in-Dying
St. Stephens Episcopal Church, 1303 S. Bross Lane, Longmont
Learn about the Colorado End of Life Options Act. Followed by a panel discussion of faith perspectives.

Oct 20
Your Body After Death
Bethlehems Lutheran & Light of Christ Churches, 1000 15th Ave, Longmont
Information will be provided on organ and whole body donation, traditional, green burial, cremation and other options.

Details on presentations at www.TheConversationProjectInBoulder.org

The Conversation Project

St. John the Evangelist RC Church, Howard County, Maryland

They established a new ministry for their 3,000-member congregation, called "Your Gift of Peace."

- Priests preached at three Masses (two in English, one in Spanish) about the importance of having the conversation.
- They hold Conversation Starter Kit Workshops three times a year.
- They trained lay Pastoral Associates to share the Conversation Starter Kit with other congregants.
- They developed a library of materials pertaining to end-of-life decision making, spirituality, and care.
- They held panels featuring health care providers on topics such as hospice, palliative care, and what happens in the ICU.

Bethel AME Church, Boston, Massachusetts

Their "Planning Ahead" ministry infuses the conversation about end-of-life wishes throughout the congregation with preaching and multimedia messaging.

They regularly offer a three-part program to small cohorts to:

- Lead people through the Conversation Starter Kit.
- Review advance care planning documents.
- Celebrate congregants who complete documents and have the conversation with their doctor.

First Church Bedford, Massachusetts, Unitarian Universalist

They offered a variety of programs to meet people at their interest level.

- They preached on the importance of having crucial, intimate conversations sooner rather than later.
- They hosted Death Over Dinner events.
- They held Conversation Starter Kit Workshops.
- They used the improv "True Story Theater" company to dramatically interpret people's stories and feelings about a "good death" or a "hard death" — having or not having had the conversation.
- They convened panels on legal and medical implications, home funerals, and green burials.

Host a Bible study

A Christian's guide to end of life decisions.

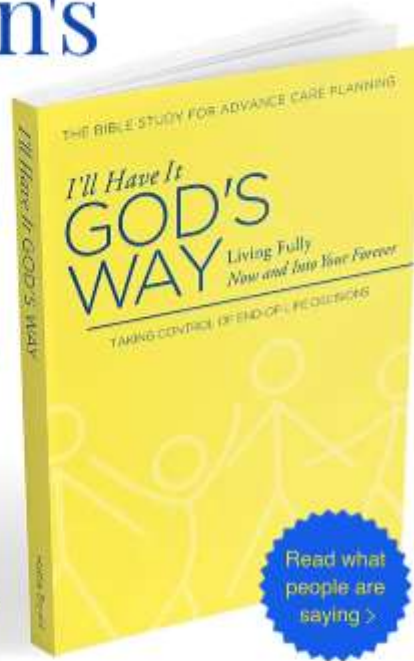
What every Christian needs to know about engaging with modern medicine in the face of serious illness or frailty.

Forms didn't work for Hattie's mom and they're not working today. Use the tool to lift a burden off of yourself and your family. Create the ultimate gift for family, friends, pastors and physicians.

[Learn More](#)

[Buy Now](#)

Amazon | Barnes & Noble | Christian Book | Walmart



Author Hattie Bryant
<https://www.illhavetogods way.com/>

Health Care Representative

The Health Care Representative form is a legal document. The person that you name will be contacted by your physician and/or hospital health care team to guide your health care if and when you are unable to do so.

YOU SHOULD CHOOSE A PERSON WHO MEETS THE FOLLOWING CRITERIA:

- Is 18 years old or older
- Is not your doctor or a part of your medical care team
- Is willing and able to discuss medical care issues with you
- Can be trusted to make decisions that adhere to your wishes and values
- Can be trusted to be your advocate if there are disagreements about your care

A health care representative is someone you designate to make medical decisions for you in the event that you are not able to. A family member such as a spouse, parent, or child is usually designated as a health care representative.

Ideally, you will have discussed your preferences with the person you ask to be your health care representative so they will know how to best honor your wishes.

YOU MAY REMOVE OR CHANGE YOUR DESIGNATED HEALTH CARE REPRESENTATIVE AT ANY TIME.

- Choosing a person to act as your representative is important. Your provider does not necessarily think anything bad will happen to you in the near future but not all situations can be anticipated.
- Our hope is that everyone over the age of 20 will assign a health care representative.

AFTER COMPLETING THE FORM ON THE REVERSE SIDE, PLEASE GIVE TO A MEMBER OF YOUR TREATMENT TEAM.

Additional answers and help for health care representatives are available through calling:

Franciscan Health Indianapolis
Spiritual Care
(317) 528-3560

Franciscan Health Mooresville
Spiritual Care
(317) 834-5883

Franciscan Health Carmel
Spiritual Care
(317) 528-3560

Palliative Care
Inpatient: (317) 528-8930
Outpatient: (317) 528-6298

Continuing Christ's Ministry
in our Franciscan Tradition



FranciscanHealth.org

WHO'S GOT YOUR BACK?

YOUR HEALTH CARE REPRESENTATIVE



This form is available through the Franciscan Health Faith Community Nursing Program



Appointment of Health Care Representative

I, _____, voluntarily appoint the following person as my health care representative. My representative is authorized to act for me in all matters of health care in accordance with IC 16-36-1 and IC 30-5 et. seq., except as otherwise specified below.

Appointed Health Care Representative	Street Address
Telephone Number	City
Social Security Number <i>(not required)</i>	State and Zip Code

I authorize my health care representative to make decisions in my best interest concerning consent to treatment and the withdrawal or withholding of health care. If at any time, based on my previously expressed preferences and the diagnosis and prognosis, my health care representative is satisfied that certain health care is or would be excessively burdensome, then my health care representative may express my will that such health care would be withheld or withdrawn and may consent on my behalf that any or all health care be discontinued or not instituted, even if death may result.

My health care representative must try to discuss this decision with me. However, if I am unable to communicate, my health care representative may make such a decision for me, after consultation with my physician(s) and other relevant health care givers. To the extent appropriate, my health care representative may also discuss this decision with my family and others, to the extent they are available.

This appointment is to be exercised in good faith and in my best interest subject to the following terms and conditions:

This appointment becomes effective and remains effective if I am incapable of consenting to my own health care. I do authorize my health care representative hereby appointed to delegate decision-making power to another.

Dated this _____ day of _____, year of _____.

Signature	Street Address
Print Full Legal Name	City, County & State of Residence
Date of Birth	Social Security Number <i>(not required)</i>

I declare that I am an adult at least eighteen (18) years of age and that at the request of the above named individual making the appointment, I witnessed the signing of this document by the Appointee on the date noted above.

Witness Signature	Street Address
Witness (Please Print Full Legal Name)	City, County & State of Residence
Telephone Number	

(Place patient information label here)



Health Care Proxy



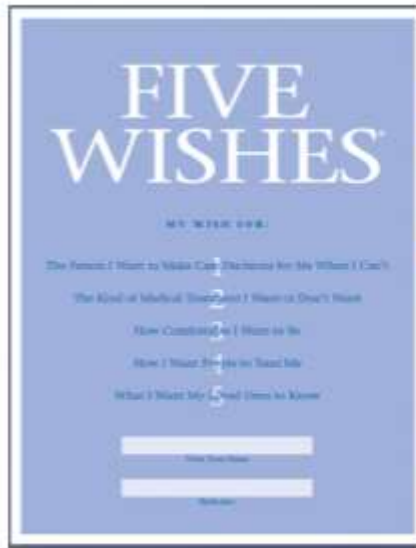
Who Will Speak For You?

How to choose and be a health care proxy



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Download this free printable brochure: <https://theconversationproject.org/wp-content/uploads/2017/03/ConversationProject-ProxyKit-English.pdf>



Five Wishes- More than just a document, this is a complete approach to discussing and documenting care and comfort choices. <https://fivewishes.org/>

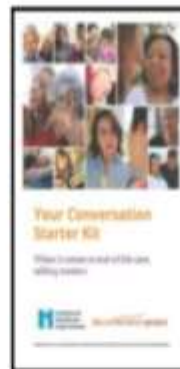
Additional Advance Directive Forms are available at the Indiana Advance Directives Resource Center <https://www.in.gov/isdh/25880.htm>

Conversation Starter Kit

Talking with your loved ones openly and honestly, before a medical crisis happens, gives everyone a shared understanding about what matters most to you at the end of life. You can use this Starter Kit whether you are getting ready to tell someone else what you want, or you want to help someone else get ready to share their wishes.

Languages:

- Coming Soon: Arabic
- Chinese
- English
- French
- German
- Haitian Creole
- Hebrew
- Hindi
- Japanese
- Korean
- Portuguese
- Russian
- Spanish
- Vietnamese



Audio version: Ellen Goodman reads The Conversation Starter Kit (English)

Co-branded version: For organizations planning to distribute the Conversation Starter Kit, we have a version to which you can add your logo and local contact information. Available for purchase [here](#).



Information for Clergy, Leadership & Healthcare Ministers

Share the following information for those in pastoral care and leadership

Watch: Talking matters in faith communities.
<https://theconversationproject.org/faith> 3:05 min

Download and review the *Getting Started Guide for Congregations*
<https://theconversationproject.org/wp-content/uploads/2018/03/ConversationProject-CommunityKit-Congregations-English.pdf>

Review the Five Wishes for faith communities
<https://fivewishes.org/five-wishes/communities/five-wishes-in-your-community/faith-and-community-organizations>

*“So, teach us to number our days, that we may present to You a heart of wisdom”
 ~ Psalm 90:12*

“For me, to live is Christ and to die is gain.” ~ Phil 1:21

“Nevertheless, I must go on my way today and tomorrow and the day following, for it cannot be that a prophet should perish away from Jerusalem” Luke 13:13

20

Biblical References

- “Whether we live or die, do all to honor the Lord”- Romans 14:8
- “Lord, make me to know my end and what is the extent of my days; Let me know how transient I am” – Psalm 39:4
- “So, teach us to number our days, that we may present to You a heart of wisdom”- Psalm 90:12
- “In those days Hezekiah became mortally ill. And Isaiah the prophet the son of Amoz came to him and said to him, “Thus says the Lord, ‘Set your house in order, for you shall die and not live.’” – 2 Kings 20:1
- “For here we do not have a lasting city, but we are seeking the city which is to come.” – Hebrews 13:14

Tools and Strategies for ACP Outreach



Go Wish Cards- a fun sorting card game to help you easily start a comfortable conversation
https://codaalliance.org/wp-content/cache/page_enhanced/codaalliance.org/go-wish/index.html

Hello- a game about living and dying, what matters most- <https://commonpractice.com/>

Prepare- Step-by-step program with video stories to help you have a voice, talk with your doctors and families- <https://prepareforyourcare.org/index.php/welcome>

Cultural Considerations

Culture Group	Beliefs, Traditions & Practices
African American	Care for loved ones at home, large extended families, use direct eye contact, church is a vibrant part of the community, may view hospice as “giving up”, openly express emotions, distrust of the medical establishment, healthcare disparities,
Asian (Chinese, Japanese, Korean, Vietnamese)	Importance of family, respect for elders, care for elders at home, may not seek services, male hierarchy, may suffer in silence, wide range of spiritual practices (Buddhism, Christianity, Confucianism, Taoism), great respect for the body
Hispanic/Latino	Family is paramount, accept Western medicine and may also observe folk remedy, spiritual healers, nodding out of respect, not necessarily understanding, matriarchal family structure, low use of hospice, thought of morphine as equal to euthanasia, Roman Catholic, Protestant Christian, talking about death may make it happen, elders rarely attend bereavement groups

(VITAS Healthcare, 2016)

What is Hospice Care?

Hospice care is a Medicare A benefit that provides a program of care and support for those with a terminal diagnosis and have a life expectancy of 6 months or less. Hospice care focuses on comfort care, not on curing an illness with a team of professionals that provide whole person care. Hospice care is typically provided at home but can be provided where ever the patient resides (Department of Health & Human Services, n.d.).

What is Palliative Care?

Palliative care is specialized curative treatment with a goal of medical care that focuses on the improving or maintaining quality relief of symptoms, goals of care of life (Get Palliative Care, 2020). discussions, and advance care planning. Palliative care is appropriate at any age and at any stage of illness. Palliative care can be provided alongside

To locate palliative care providers in your area go to www.getpalliativecare.org and search by zip code.

Locate a Hospice Provider

To locate hospice service providers in your area go to <https://www.nhpco.org/find-a-care-provider/> and search by name or location.



Barriers to Advance Care Planning

Lack of awareness
Fear, denial and fatalism
Mistrust of the healthcare system
Taboo
Concern for conversion agendas
Disconnect between law & ethics that propel futile care

(Ayton, [Manderson](#) & Smith, 2017) (Sun et al., 2017) (West & Hollis, 2012), Conroy, Fode, Fraser & Schiff, 2009)



Medical engagement of futile acts of care result in prolonged suffering and a lack of understanding of the Patient Self-Determination Act (Duke, [Yarbrough](#), & Pang, 2009).

Solutions to these barriers include ***continued education and communication*** regarding goals of care and advance care planning (Duke, Yarbrough, & Pang 2009).

COVID-19 Resources

Being Prepared in the Time of COVID-19

Three Things You Can Do Now

This is a challenging time. There are many things that are out of our control. But there are some things we can do to help us be prepared — both for ourselves and the people we care about. Here are three important things each of us can do, right now, to be prepared.

1 Pick your person to be your health care decision maker

Choose a health care decision maker (often known as a proxy, agent, or health care power of attorney) — a person who will make medical decisions for you if you become too sick to make them for yourself.

- Here's a simple [guide](#) to help you choose a health care decision maker.

Have a talk with your health care decision maker to make sure they know what matters most to you.

- Make a plan to talk with your decision maker as soon as possible. Phone calls or video chats are good if you don't live with that person.

Fill out an official form naming your health care decision maker. Give one copy of the filled-in form to your decision maker and one copy to your health care team.

- Get a free health care decision maker form here or download a form for free from your state attorney general website.
- In a time of social distancing, you may not be able to create an official legal document. That's okay! Writing it down is still better than nothing!

2 Talk about what matters most to you

Talk with your important people and decision maker about what matters most.

- The [Conversation Starter Kit](#) can help you get ready to talk to others about what matters most.
- If you have already completed the Conversation Starter Kit or have an Advance Directive, review it with your loved ones to see if you want to make any changes or updates.

After you talk to your loved ones about what matters, talk to your health care team.

- Call your primary care provider or specialist to set up a televisit to talk about this. Knowing what matters to you helps your care team provide better care that's right for you.

 **AARC** *the national association of*
ambulatory care

YOU SHOULD KNOW

- First and foremost, do everything you can to stay personally safe and protect others!
- Follow the CDC recommendations for social distancing: Stay home. Clean your hands often. Avoid close contact. Cover coughs and sneezes.
- Most people who get COVID-19 get a mild or moderate illness and don't need to go to the hospital.
- Those who do get a severe case of COVID-19 are mostly people who are older or have other medical problems.
- Some people, especially those who are young and healthy, will get better with routine hospital care. But many, especially those who are older and sicker, are not likely to survive even with a ventilator (breathing machine).
- Those who survive may be left with disabilities, both from damaged lungs and deconditioning after intensive care. Despite weeks or months in the hospital or rehabilitating in a nursing facility, survivors may not regain enough strength or function to return home.
- People who do not want intensive care should receive comfort care. Comfort care may be possible at home or in a nursing facility, especially with the care and support of hospice.
- Many hospitals are overcrowded and are not allowing visitors, so if you can, bring a smartphone, laptop or tablet to help communicate with your important people. In certain parts of the country, access to hospital or intensive care may become limited in the coming weeks.

3 Think about what you would want if you became seriously ill with COVID-19

People who are older or have chronic medical conditions are more likely to become very sick if they get COVID-19. Some will recover with hospital care, but even with ventilator support many will die. Think about what you would want if you became very sick at this time:

What would be most important to you? (Examples: Being comfortable. Trying all possible treatments.)

What are you most worried about? (Examples: Being alone. Being in pain. Being a burden.)

What is helping you through this difficult time? (Examples: My friends. My faith. My cat.)

If you became very sick with COVID-19, would you prefer to stay where you live or go to the hospital?

If you chose to go to the hospital, would you want to receive intensive care in the hospital?

When you speak with your health care provider, ask if completing a [POLST/MOLST](#) form would be appropriate so others know what treatments to use or avoid if you become very sick.

List any other questions or concerns you want to bring up with your friend/family/provider:

COVID-19 Resources

Respecting Choices®
PERSON-CENTERED CARE

NEWSLETTER SIGNUP PROGRAMS LAST VISIT EMAIL DONATE

COVID-19 Resources
How Can We Help You?
Programs and Services
Curriculum and Certification
Research and Reports
Online Store
National Courses and Events
About Us
Contact Us

Resources for having Proactive Planning Conversations in the context of COVID-19.

Name	Description	For Use By	End recipient
Proactive Care Planning for COVID-19	Conversation guide to print and use when having an ACP conversation with a patient.	Any clinician having ACP Conversations	Patient
Proactive Care Planning with HC Agents for COVID-19	Conversation guide to print and use when having an ACP conversation with the healthcare agent of a non-decisional patient.	Any clinician having ACP Conversations	Healthcare Agent
Medical Preferences and Treatment Options	1-page document - patient/agent to read along during the conversation. For Use in Conversation Only	Any clinician having ACP Conversations	Patient or Healthcare Agent
Scheduling Proactive Care Planning for COVID-19	Abbreviated 2-page document for use by any team members to call and schedule time a for clinician to have conversation with an individual.	Any staff proactively contacting individuals to schedule conversations	Patient
Scheduling HC Agents to Proactive Care Planning for COVID-19	Abbreviated 2-page document for use by any team member to call and schedule time for clinician to have conversation with the Healthcare Agent of individual	Any member of team who are proactively contacting Healthcare Agent of high-risk individuals to have ACP conversations	Healthcare Agent
Recorded Webinar: How to have a respectful care planning conversation.	25-minute video walk through the use of the Proactive Care Planning for COVID-19 conversation guide and tools in this section.	Clinicians who will facilitate ACP conversations	Clinicians

ACP Materials to Share with Patients and Healthcare Agents

Name	Description	For Use By	End recipient
Proactive Care Planning for COVID-19 for Individuals	The importance of knowing treatment preferences before a medical crisis	Individuals and their agents/loved ones	Individuals and their families
Proactive Care Planning for COVID-19 for Healthcare Agents	The importance of knowing treatment preferences before a medical crisis	Healthcare Agent of individuals	Healthcare Agent of individuals

<https://respectingchoices.org/covid-19-resources/#planning-conversations>

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Appendix E

Community Benefits Inventory for Social Accountability (CBISA) Template

Date: _____

Parish Nurse/Faith Community Nurse Contact #: _____

Contact e-mail: _____

Church/Congregation/Communi _____

Address: _____

Phone: _____

Pastor: _____



HEALTH SERVICES: Include BIP and other screenings provided by your Health

Date	Name of Event	Number of People Served	Number of Hours
Total		0	0

EDUCATION AND SUPPORT SERVICES:

Date	Name of Event	Number of People Served	Number of Hours
Total		0	0

	Number visited/served/reached	Number of hours	# Referrals/Resources
Home visits			
Church visits			
Hospital visits			
ECF visits			
Phone calls/visits			
Prayer services			
Support groups			
Newsletter			
Church Bulletins			
Bulletin Boards			
Other			
ACP Outreach			
AD Completion			
Totals:	0	0	0

CONTINUING EDUCATION/PERSONAL DEVELOPMENT:

Narrative: Please add antidotal, compelling stories, testimonials, and best practice for FCN

Appendix F

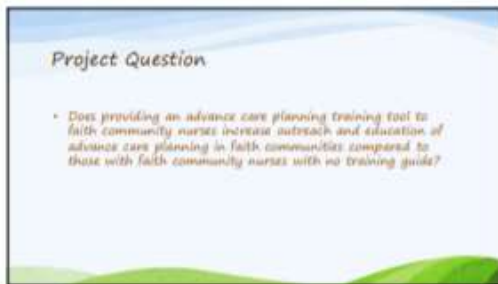
ACPTT Education



1



2



3



4



5



6



7



8



9



10



11



12



13



14



15



16



17

Appendix G

Advance Care Planning Engagement 34 Item Survey

Version: May 2020

**Advance Care Planning
Engagement Survey**

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General Instructions for Use

The Advance Care Planning (ACP) Engagement Survey has been validated and used in several ACP studies.

The ACP Engagement Survey was developed, culturally vetted, and validated to measure the complex process of ACP. The Survey is based on Social Cognitive and Behavior Change theories and focuses on four behavior change constructs (i.e., knowledge, contemplation, self-efficacy, and readiness) within four ACP domains (i.e., surrogate decision makers, values and quality of life, flexibility in surrogate decision making, and asking doctors questions).

Several versions of the survey have been validated, including the original 82-item version (takes approximately 50 minutes to administer) and a 55-item, 34-item, 15-item, 9-item, and 4-item version.

Analysis concerning the validation of the shorter versions of the survey in English and Spanish found that shorter versions were able to detect changes comparable with the 82-item version and can be useful for efficiently and effectively measuring ACP engagement in research and clinical settings (see reference #4).

The choice of which Survey version to use will depend on overall data collection burden, available resources, and the desire to look at Survey subscales or specific Survey domains.

References:

- (1) [Development and validation of a questionnaire to detect behavior change in multiple advance care planning behaviors](#). Sudore RL, Stewart AL, Knight SJ, McMahan RD, Feuz M, Miao Y, Barnes DE. PLoS One. 2013 Sep 5;8(9):e72465. doi: 10.1371/journal.pone.0072465. eCollection 2013. PMID: 24039772
- (2) [Measuring engagement in advance care planning: a cross-sectional multicentre feasibility study](#). Howard M, Bonham AJ, Heyland DK, Sudore R, Fassbender K, Robinson CA, McKenzie M, Elston D, You JJ. BMJ Open. 2016 Jun 23;6(6):e010375. doi: 10.1136/bmjopen-2015-010375. PMID:27338877
- (3) [Measuring Advance Care Planning: Optimizing the Advance Care Planning Engagement Survey](#). Sudore RL, Heyland DK, Barnes DE, Howard M, Fassbender K, Robinson CA, Boscardin J, You JJ. J Pain Symptom Manage. 2017 Apr;53(4):669-681.e8. doi: 10.1016/j.jpainsymman.2016.10.367. Epub 2016 Dec 29. PMID: 28042072
- (4) [Brief English and Spanish Survey Detects Change in Response to Advance Care Planning Interventions](#). Shi Y, Barnes DE, Boscardin J, You JJ, Heyland DK, Volow AM, Howard M, Sudore RL. J Pain Symptom Manage. 2019 Dec;58(6):1068-1074.e5. doi: 10.1016/j.jpainsymman.2019.09.004. Epub 2019 Sep 18. PMID: PMC6878141

Version: May 2020

SCORING FOR THE FULL 82-ITEM ACP ENGAGEMENT SURVEY VERSION:

The 82-item version of the survey has both Behavior Change Process measures and Action measures. Please see Table 1: Original ACP Engagement Survey and Questions Retained in Progressively Shorter Versions After Item Reduction. This table provides the text of the questions and the response options are listed in the footnote. The table also lists the item as either in the Process or Action domain, and lists sub-domains.

- **The Behavior Change Process items** use a 5-point Likert response option. The Behavior Change Process score is reported as an overall average 5-point Likert score.
 - The Behavior Change Process measure includes validated sub-scales of:
 - Knowledge ("How much do you know...")
 - Contemplation ("How much have you thought about...")
 - Self-efficacy ("How confident are you...")
 - Readiness ("How ready are you...")
- These sub-scales can be reported separately using average 5-point Likert scales.
- **The Action items** use a dichotomous response option of yes or no. There are 25 items. Therefore, the Action score is reported on a 0 to 25-point scale.
 - The Action Score measure includes validated sub-domains of:
 - Medical decisions makers
 - Quality of life and health situations
 - Flexibility for the medical decision makers
 - Asking medical providers questions.

***See below for scoring shorter versions of the survey, and additional potential analyses of the Readiness questions.** For example, shorter versions do not include the Action measures, but can still be used to report yes/no for specific ACP behaviors using readiness response items.

SCORING FOR SHORTER SURVEY VERSIONS (55, 34, 15, 9, AND 4-ITEM):

All shorter versions of the survey use items only from the Behavior Change Process measure. All items use 5-point Likert response options. We suggest you continue to analyze and report these shorter versions on an overall average 5-point Likert scale. This is how we reported these scales in our randomized trials and subsequent studies.

Subscale/subdomains have not yet been validated for the shorter versions. If you are interested in sub-scale analyses, we recommend using the full 82-item version.

After extensive analysis, the Action items were dropped (see references 3 and 4 above). Redundancy between Action items (yes/no) and corresponding Readiness items (five-point Likert scale with "5" indicating "I have already done it") was high (mean 96.1%, SD 5.9%). However, specific ACP behaviors can still be analyzed and reported as yes/no by using the readiness response items of the Behavior Change Process measures (see below).

ADDITIONAL POTENTIAL ANALYSIS OF THE READINESS QUESTIONS:

Each version of the Survey contains Readiness questions. The 4-item version is exclusively made up of Readiness items. The Likert response options for the Readiness questions were adapted from Fried et al. and were expanded for use for all ACP behaviors and sub-domains in the ACP Engagement Survey.

[Stages of change for the component behaviors of advance care planning.](#) Fried TR, Redding CA, Robbins ML, Paiva A, O'Leary JR, Iannone L. J Am Geriatr Soc. 2010 Dec;58(12):2329-36. doi: 10.1111/j.1532-5415.2010.03184. PMID: 21143441

These response options allow the Readiness items to be reported as an average 5-point Likert score, to be dichotomized into a yes or no action item for each ACP behavior (e.g., "I have already done it"), and to categorize participants into behavior change stages for each ACP Behavior.

The Readiness response options:	Behavior Change Stage	Dichotomize yes/no completed the action
I have never thought about it.	Pre-contemplation	No
I have thought about it, but I am not ready to do it.	Pre-contemplation	No
I am thinking about doing it in the next 6 months.	Contemplation	No
I am definitely planning to do it in the next 30 days.	Preparation	No
I have already done it.	Action	Yes
Timing (when completed) questions (see below)	Maintenance (see below)	

We typically report the percentage of participants who have moved out of pre-contemplation to higher behavior change stages. See the following reference. It is possible to also report the percentage of individuals who moved into any higher stage from baseline, for example, from pre-contemplation to preparation and/or from preparation to action.

[A novel website to prepare diverse older adults for decision making and advance care planning: a pilot study.](#) Sudore RL, Knight SJ, McMahan RD, Feuz M, Farrell D, Miao Y, Barnes DE. J Pain Symptom Manage. 2014 Apr;47(4):674-86. doi: 10.1016/j.jpainsymman.2013.05.023. Epub 2013 Aug 21. PMID: 23972574

OPTIONAL: Timing question to categorize the "Maintenance" behavior stage

It is possible to separate out the Action behavior stage into both an "Action" and "Maintenance" stage by asking about the timing of these ACP actions. If the participant completed the ACP behavior within 6 months they are considered in the "Action" stage, and if they completed the ACP behavior greater than 6 months ago, they are considered in the "Maintenance" stage for that behavior.

Here is one example:

How ready are you to sign official papers naming a person or group of people to make medical decisions for you?

<input type="checkbox"/>	I have never thought about it.
<input type="checkbox"/>	I have thought about it, but I am not ready to do it.
<input type="checkbox"/>	I am thinking about doing it in the next 6 months.
<input type="checkbox"/>	I am definitely planning to do it in the next 30 days.
<input checked="" type="checkbox"/>	I have already done it.

OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?"

- Less than 6 months ago (→Action stage)
- More than 6 months ago (→Maintenance stage)

These optional timing questions are marked in blue in the following surveys. The timing questions are not included in the average 5-point Likert scores. They are only asked to be able to further delineate Action into both Action and Maintenance stages, if that is desired for your analysis.

CLINICALLY MEANINGFUL EFFECT SIZES

In prior studies, we used mixed-effects linear regression with fixed effects for time (baseline, 1 week, 3 months, 6 months, and 12 months) to interpret changes in ACP engagement scores. Mixed-effects models enabled inclusion of all available data in intention-to-treat analyses while accounting for within-individual correlation over time. We calculated effect sizes using standard, clinically meaningful thresholds (ie, small, 0.20-0.49; medium, 0.50-0.79; and large, ≥ 0.80).

Cohen J. *Statistical Power Analysis for the Behavioral Sciences*. 2nd ed. Hillsdale, NJ: Lawrence Erlbaum Associates; 1988.

Furthermore, we include part of the discussion section of our survey validation paper to help put the effect sizes into perspective:

"This study allowed us to quantify a clinically meaningful change in ACP Engagement Survey score based on effect sizes using standard thresholds (Cohen, 1988). Small effect sizes (0.20-0.49) were associated with mean change scores of approximately 0.2 to 0.3 points. Moderate effect sizes (0.50-0.79) were associated with mean change scores of approximately 0.4 to 0.5 points. Large effect sizes (≥ 0.80) were associated with mean change scores of ≥ 0.6 points. Therefore, the smallest clinically meaningful change in response to an ACP intervention would be approximately 0.2 points, and is an evidence that patients are moving along the behavior change pathway – from pre-contemplation, to contemplation, to preparation, to action. Larger changes of 0.6 or greater likely reflect ACP actions that are farther down the behavior change pathway. For example, in a prior validation study of the Survey in 559 respondents in two countries, a score changes of 1.0 was associated with having completed a prior advance directive."

See the published randomized trials for additional information regarding how we discussed effect sizes in our methods and results:

- (1) [Effect of the PREPARE Website vs an Easy-to-Read Advance Directive on Advance Care Planning Documentation and Engagement Among Veterans: A Randomized Clinical Trial.](#)
Sudore RL, Boscardin J, Feuz MA, McMahan RD, Katen MT, Barnes DE.
JAMA Intern Med. 2017 Aug 1;177(8):1102-1109. doi: 10.1001/jamainternmed.2017.1607. PMID: 28520838
- (2) [Engaging Diverse English- and Spanish-Speaking Older Adults in Advance Care Planning: The PREPARE Randomized Clinical Trial.](#)
Sudore RL, Schillinger D, Katen MT, Shi Y, Boscardin WJ, Osua S, Barnes DE.
JAMA Intern Med. 2018 Dec 1;178(12):1616-1625. doi: 10.1001/jamainternmed.2018.4657. PMID: PMC6342283.

MISSING DATA:

In prior studies, response items 8 (not sure) and 9 (refused) were considered missing data. No individual ACP Engagement Survey question was missing greater than 10%; therefore, we used a mean imputation approach. All available data were included to create an average 5-point Likert score.

- (1) [Effect of the PREPARE Website vs an Easy-to-Read Advance Directive on Advance Care Planning Documentation and Engagement Among Veterans: A Randomized Clinical Trial.](#)
Sudore RL, Boscardin J, Feuz MA, McMahan RD, Katen MT, Barnes DE.
JAMA Intern Med. 2017 Aug 1;177(8):1102-1109. doi: 10.1001/jamainternmed.2017.1607. PMID: 28520838
- (2) [Engaging Diverse English- and Spanish-Speaking Older Adults in Advance Care Planning: The PREPARE Randomized Clinical Trial.](#)
Sudore RL, Schillinger D, Katen MT, Shi Y, Boscardin WJ, Osua S, Barnes DE.
JAMA Intern Med. 2018 Dec 1;178(12):1616-1625. doi: 10.1001/jamainternmed.2018.4657. PMID: PMC6342283.

Table 1: Original ACP Engagement Survey and Questions Retained in Progressively Shorter Versions After Item Reduction
 Table is published here:

[Measuring Advance Care Planning: Optimizing the Advance Care Planning Engagement Survey.](#)

Sudore RL, Heyland DK, Barnes DE, Howard M, Fassbender K, Robinson CA, Boscardin J, You JJ.

J Pain Symptom Manage. 2017 Apr;53(4):669-681.e8. doi: 10.1016/j.jpainsymman.2016.10.367. Epub 2016 Dec 29. PMID: 28042072

Question # ^a	Sub-Scale	Type	Original 82-item Questionnaire	Versions				
				55 items	34 items	15 items	9 items	4 items
DOMAIN: MEDICAL DECISION MAKER								
1	Knowledge ^b	Process	How well informed are you about who can be a medical decision maker?	X				
2	Knowledge	Process	How well informed are you about what makes someone a good medical decision maker?	X	X			
3	Knowledge	Process	How well informed are you about the types of decisions that a medical decision maker may have to make for you in the future?	X	X			
4	Contemplation ^c	Process	How much have you thought about who your medical decision maker should be?	X	X			
5	Contemplation	Process	How much have you thought about asking someone to be your medical decision maker?	X				
6	Contemplation	Process	How much have you thought about talking with your doctors about who you want your medical decision maker to be?	X				
7	Contemplation	Process	How much have you thought about talking with your other family and friends about who you want your medical decision maker to be?	X				
8	Self- Efficacy ^d	Process	How confident are you that today you could ask someone to be your medical decision maker?	X	X	X	X	
9	Self- Efficacy	Process	How confident are you that today you could talk with your doctor about who you want your medical decision maker to be?	X	X			
10	Self- Efficacy	Process	How confident are you that today you could talk with your other family and friends about who you want your medical decision maker to be?	X	X			
11 ^a	Decision	Action	Have you already decided who you want your medical decision maker to be?					
12 ^a	Readiness ^e	Process	How ready are you to decide who you want your medical decision maker to be?					
13 ^a	Action ^f	Action	Have you already formally asked someone to be your medical decision maker?					
14	Readiness	Process	How ready are you to formally ask someone to be your medical decision maker?	X	X	X	X	

15 ^a	Action	Action	Have you talked with your doctor about who you want your medical decision maker to be?					
16	Readiness	Process	How ready are you to talk with your doctor about who you want your medical decision maker to be?	X	X	X	X	
17 ^a	Action	Action	Have you already talked to your other family and friends about who you want your medical decision maker to be?					
18	Readiness	Process	How ready are you to talk to your other family and friends about who you want your medical decision maker to be?	X	X			
19 ^a	Action	Action	Have you signed official papers naming a person or group of people to make medical decisions for you?					
20	Readiness	Process	How ready are you to sign official papers naming a person or group of people to make medical decisions for you?	X	X	X	X	X
DOMAIN: QUALITY OF LIFE – HEALTH SITUATIONS								
21	Contemplation	Process	How much have you thought about whether or not certain health situations would make your life not worth living?	X				
22	Contemplation	Process	How much have you thought about talking with your medical decision maker about whether or not certain health situations would make your life not worth living?	X				
23	Contemplation	Process	How much have you thought about talking with your doctor about whether or not certain health situations would make your life not worth living?	X				
24	Contemplation	Process	How much have you thought about talking with your other family and friends about whether or not certain health situations would make your life not worth living?	X				
25	Self- Efficacy	Process	How confident are you that today you could talk with your medical decision maker about whether or not certain health situations would make your life not worth living?	X	X			
26	Self- Efficacy	Process	How confident are you that today you could talk with your doctor about whether or not certain health situations would make your life not worth living?	X	X			
27	Self- Efficacy	Process	How confident are you that today you could talk with your other family and friends about whether or not certain health situations would make your life not worth living?	X	X			
28 ^a	Decision	Action	Have you already decided whether or not certain health situations would make your life not worth living?					
29	Readiness	Process	How ready are you to decide whether or not certain health situations would make your life not worth living?	X	X			
30 ^a	Action	Action	Have you talked with your decision maker about whether or not certain health situations would make your life not worth living?					

Version: May 2020

31	Readiness	Process	How ready are you to talk to your decision maker about whether or not certain health situations would make your life not worth living?	X	X			
32 ^a	Action	Action	Have you talked with your doctor about whether or not certain health situations would make your life not worth living?					
33	Readiness	Process	How ready are you to talk to your doctor about whether or not certain health situations would make your life not worth living?	X	X			
34 ^a	Action	Action	Have you talked with your other family and friends about whether or not certain health situations would make your life not worth living?					
35	Readiness	Process	How ready are you to talk to your other family and friends about whether or not certain health situations would make your life not worth living?	X	X			
36 ^a	Action	Action	Have you signed official papers to put your wishes in writing about whether or not certain health situations would make your life not worth living? These forms are sometimes called an advance directive or living will.					
37	Readiness	Process	How ready are you to sign official papers putting your wishes in writing about whether or not certain health situations would make your life not worth living?	X				
DOMAIN: QUALITY OF LIFE – MEDICAL CARE AT THE END OF LIFE								
38	Contemplation	Process	How much have you thought about the care you would want if you were very sick or near the end of life?	X				
39	Contemplation	Process	How much have you thought about talking with your medical decision maker about the care you would want if you were very sick or near the end of life?	X				
40	Contemplation	Process	How much have you thought about talking with your doctors about the care you would want if you were very sick or near the end of life?	X				
41	Contemplation	Process	How much have you thought about talking with your other family and friends about the care you would want if you were very sick or near the end of life?	X	X			
42	Self- Efficacy	Process	How confident are you that today you could talk with your medical decision maker about the care you would want if you were very sick or near the end of life?	X	X	X	X	
43	Self- Efficacy	Process	How confident are you that today you could talk with your doctor about the care you would want if you were very sick or near the end of life?	X	X	X	X	
44	Self- Efficacy	Process	How confident are you that today you could talk with your other family and friends about the care you would want if you were very sick or near the end of life?	X	X			
45 ^a	Decision	Action	Have you already decided on the medical care you would want if you were very sick or near the end of life?					

34 Item Version

Measuring Advance Care Planning: Optimizing the Advance Care Planning Engagement Survey.
Sudore RL, Heyland DK, Barnes DE, Howard M, Fassbender K, Robinson CA, Boscardin J, You JJ.
J Pain Symptom Manage. 2017 Apr;53(4):669-681.e8. doi: 10.1016/j.jpainsymman.2016.10.367. Epub
2016 Dec 29. PMID: 28042072

PREPARATION ENGAGEMENT SURVEY

Introduction **We will ask about your experiences and opinions. We may ask about things that you have already done, or have not thought about at all. Just answer as honestly as you can.**

Over the next few sections we will be asking you about 4 topics:

- 1. Medical decision makers, or surrogates**
- 2. Deciding what matters most in life**
- 3. Flexibility for a medical decision maker**
- 4. Asking doctors questions**

1. Medical Decision Makers

This set of questions ask about medical decision makers. A medical decision maker is a family member or friend who can make decisions for you if you were to become too sick to make your own decisions.

Remember, please give us your honest opinions and there are no right or wrong answers.

KNOWLEDGE (1 – DM)

These two questions ask about how well informed you are about medical decision makers. You can use the red answers. *[Read options.]*

How well informed are you about.....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
1. What makes someone a good medical decision maker? <small>(PE_s1_k2)</small>		1	2	3	4	5	8 / 9
2. The types of decisions that a medical decision maker may have to make for you in the future? <small>(PE_s1_k3)</small>		1	2	3	4	5	8 / 9

THOUGHT ABOUT IT (1 – DM)

The next question asks about how much you have thought about any of the following. You can use the green answers. *[Read options.]*

How much have you thought about...	Green	Never	Once or twice	A few times	Several times	A lot	Not sure/ Ref.
3. Who your medical decision maker should be? <small>(PE_s1_t1)</small>		1	2	3	4	5	8 / 9

SELF-EFFICACY (1 – DM)

These questions ask about how confident you are to actually talk to someone about who you choose as your decision maker. You can use the red answers. *[Read options.]*

How confident are you that today you could....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
4. Ask someone to be your medical decision maker? <small>(PE_s1_se1)</small>		1	2	3	4	5	8 / 9
5. Talk with your doctors about who you want your medical decision maker to be? <small>(PE_s1_se2)</small>		1	2	3	4	5	8 / 9
6. Talk with your OTHER family and friends about who you want your medical decision maker to be? <small>(PE_s1_se3)</small>		1	2	3	4	5	8 / 9

READINESS (1 – DM)

The following questions are about how ready you are to talk to others about who you want your medical decision maker to be and to put this information in writing.

<p>7. How ready are you to formally ask someone to be your medical decision maker? (PE_S1_ASKDM_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> >6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>8. How ready are you to talk with your DOCTOR about who you want your medical decision maker to be? (PE_S1_TELLDR_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it over the next few visits</p> <p>4 <input type="checkbox"/> I am definitely planning to do it at the next visit</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> >6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

Now I am going to ask some questions about talking to other family and friends. "Other family and friends" are people who may be in your life and have opinions about your medical care, but not who you may choose as your medical decision maker.

<p>9. How ready are you to talk with your OTHER FAMILY and FRIENDS about who you want your medical decision maker to be? Remember this would be someone other than your medical decision maker. (PE_S4_DM)</p> <p>1 <input type="checkbox"/> Yes, we had a very detailed discussion</p> <p>2 <input type="checkbox"/> Yes, but we just had a general discussion</p> <p>3 <input type="checkbox"/> No, because I assume my family and friends know who I want</p> <p>4 <input type="checkbox"/> No, not yet</p> <p>5 <input type="checkbox"/> No, because I don't want my family and friends involved in my medical care**</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> >6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

<p>10. How ready are you to SIGN OFFICIAL PAPERS naming a person or group of people to make medical decisions for you? (PE_S1_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> >6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

2. What Matters Most in Life

Now we want to talk about how some people feel about their quality of life. For instance, how they want to live, and how they do not want to live. Some people think that all health situations or experiences, such as being in a coma or not being able to get out of bed, are worth living through. Other people think that some health situations or experiences would make their life not worth living.

Please give us your honest opinions. There are no right or wrong answers.

SELF-EFFICACY (2 – HEALTH SITUATIONS)

The next three questions ask about how confident you are to actually talk to someone about your medical wishes. You can use the red answers. *[Read options.]*

How confident are you that today you could....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/Ref.
11. Talk with your decision maker about whether or not certain health situations would make your life not worth living? (PE_S2A_SE1)		1	2	3	4	5	8 / 9
12. Talk with your doctors about whether or not certain health situations would make your life not worth living? (PE_S2A_SE2)		1	2	3	4	5	8 / 9
13. Talk with your OTHER family and friends about whether or not certain health situations would make your life not worth living? (PE_S2A_SE3)		1	2	3	4	5	8 / 9

READINESS (2 – HEALTH SITUATIONS)

The following questions are about how ready you are to decide and talk about health situations. Again, health situations can be such things as being in a coma, or not being able to get out of bed.

14. How ready are you to decide whether or not certain health situations would make your life not worth living? (PE_S2A_SIT_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA 8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

[If they haven't already done it, say "I know you haven't decided about certain health situations, but ..."]

15. How ready are you to talk to your DECISION MAKER about whether or not certain health situations would make your life not worth living? (PE_S2A_TELLOM_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA 8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

<p>16. How ready are you to talk to your DOCTOR about whether or not certain health situations would make your life not worth living? (PE_S2A_TELLING_RDV)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next few visits</p> <p>4 <input type="checkbox"/> I am definitely planning to do it at the next visit</p> <p>5 <input type="checkbox"/> I have already done it</p>		<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>		<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> >6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

Now I am going to ask you some questions about talking to other family and friends who would not be your decision maker.

<p>17. How ready are you to talk to your OTHER FAMILY and FRIENDS about whether OR NOT certain health situations would make your life not worth living? (PE_S4_SIT_RDV)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>		<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>		<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> >6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

We are switching topics now. The previous questions were about how people would or would not want to live.

The following questions are about specific medical treatments that people may or may never want if they were very sick or at the end of their life. For instance, some people know they would want to be on a breathing machine. Other people know they would never want to be on a breathing machine. Please give us your honest opinions to the following questions about medical treatments. There are no right or wrong answers.

THOUGHT ABOUT IT (2B – CARE AT EOL)

The following question asks about how much you have thought about your medical wishes. You can use the green answers. [Read options.]

How much have you thought about...	Green	Never	Once or twice	A few times	Several times	A lot	Not sure/Ref.
18. Talking with your OTHER family and friends about the care you would want if you were very sick or near the end of life? (PE_S2B_T4)		1	2	3	4	5	8 / 9

SELF-EFFICACY (2B – CARE AT EOL)

The next three questions ask about how confident you are to actually talk to someone about your medical wishes. You can use the red answers. [Read options.]

How confident are you that today you could....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/Ref.
19. Talk with your decision maker about the care you would want if you were very sick or near the end of life? (PE_S2B_SE1)		1	2	3	4	5	8 / 9
20. Talk with your doctors about the care you would want if you were very sick or near the end of life? (PE_S2B_SE2)		1	2	3	4	5	8 / 9
21. Talk with your OTHER family and friends about the care you would want if you were very sick or near the end of life? (PE_S2B_SE3)		1	2	3	4	5	8 / 9

READINESS (2B – CARE AT EOL)

The following questions are about how ready you are to decide and talk about the care you would want if you were very sick or near the end of life.

22. How ready are you to decide on the medical care you would want if you were very sick or near the end of life? (PE_S2_CARE_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA 8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

[If they haven't already done it, say "I know you haven't decided about certain health situations, but ...]

<p>23. How ready are you to talk to your DECISION MAKER about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELLDM_READY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> >6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>24. How ready are you to talk to your DOCTOR about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELDR_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next few visits</p> <p>4 <input type="checkbox"/> I am definitely planning to do it at the next visit</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> >6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

Now I am going to ask you some questions about talking to other family and friends, so not who you would have as your decision maker.

<p>25. How ready are you to talk to your OTHER FAMILY and FRIENDS about the kind of medical care you would want if you were very sick or near the end of life? (PE_S4_CARE_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> >6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

<p>26. How ready are you to SIGN OFFICIAL PAPERS putting your wishes about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> >6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

3. Flexibility

Now we are going to talk about **flexibility in decision making**. Flexibility means that your decision maker can work with your doctor and change your prior medical decisions, if it is best for you at that time. Patients can decide to give or not give flexibility.

THOUGHT ABOUT IT (3 – FLEXIBILITY)

These questions ask about **how much you have thought** about flexibility. You can use the green answers. [Read options.]

How much have you thought about...	Green	Never	Once or twice	A few times	Several times	A lot	Not sure/ Ref.
27. Talking with your medical decision maker about how much flexibility you want to give them? (PE_S3_T2)		1	2	3	4	5	8 / 9

SELF-EFFICACY (3 – FLEXIBILITY)

These questions ask about **how confident you are** to talk to someone **about flexibility**. You can use the red answers. [Read options.]

How confident are you that today you could....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
28. Talk with your DOCTOR about how much flexibility you want to give your medical decision maker? (PE_S3_SE2)		1	2	3	4	5	8 / 9
29. Talk with your OTHER family and friends about how much flexibility you want to give your medical decision maker? (PE_S3_SE3)		1	2	3	4	5	8 / 9

READINESS (3 – FLEXIBILITY)

The following questions are about how ready you are to talk to others about how much flexibility you want to give your medical decision maker and to put this information in writing.

<p>30. How ready are you to talk to your DECISION MAKER about how much flexibility you want to give them? (PE_S3_TELDDM_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S3_DECDM_WHEN)</p> <p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> >6 months ago</p> <p>99 <input type="checkbox"/> NA</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>31. How ready are you to talk to your DOCTOR about how much flexibility you want to give your decision maker? (PE_S3_TELDDM_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next few visits</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next visit</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
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32. How ready are you to SIGN OFFICIAL PAPERS to put your wishes in writing about how much flexibility to give your decision maker? (PE_S3_PAPER_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused	
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

4. Asking Your Doctor Questions

Now we are going to talk about asking doctors questions.

SELF-EFFICACY	(5 – ASK DR)					
How confident are you that today you could...	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/Ref.
33. Ask the right questions of your doctor to help make good medical decisions? (PE_S5_SE1)	1	2	3	4	5	8 / 9

READINESS	(5 – ASK DR)	
34. How ready are you to ask your doctor questions to help you make a good medical decision? (PE_S5_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused	
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

Appendix I

Advance Care Planning Engagement Survey Site Permission

WAYS TO USE PREPARE MATERIALS WITHOUT A LICENSE:

- Using PREPARE materials
- Listing PREPARE as a resource

Using PREPARE Materials (PREPARE Pamphlet, Advance Directives, Question Guide, Toolkit for Group Movie Events)

As long as you download these materials directly from the PREPARE website and print them unaltered, you can freely use them and hand them out to individuals. They cannot be uploaded as a PDF or placed on another website; included within another organization's printed or online booklet, workbook, or toolkit; or altered in any way.

Listing PREPARE as a Resource

It is OK to provide the www.prepareforyourcare.org link on your website or materials as a resource to individual patients or people. If you do provide a link to PREPARE or any of the PREPARE materials, **you must use the main www.prepareforyourcare.org website link**. Information about the advance directives and written material are right on the home page.

PLEASE use this description of the PREPARE program:

"PREPARE for Your Care is an online resource that helps people learn about and prepare for medical decision making. This evidenced-based tool features video stories in English and Spanish and guides users as they explore their wishes and learn how to discuss them with family, friends, and medical providers. The website also offers PREPARE written pamphlets as well as a Toolkit to help put on a

Appendix J:**Paired Samples- ACP Engagement Survey Pre and Post**

		Paired Samples Statistics			
		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	Q1pre	4.25	8	.707	.250
	Q1Post	4.88	8	.354	.125
Pair 2	Q2pre	4.50	8	.535	.189
	Q2Post	4.88	8	.354	.125
Pair 3	Q3pre	4.63	8	.518	.183
	Q3post	5.00	8	.000	.000
Pair 4	Q4pre	4.88	8	.354	.125
	Q4post	4.88	8	.354	.125
Pair 5	Q5pre	4.50	8	.535	.189
	Q5post	4.50	8	.535	.189
Pair 6	Q6pre	4.88	8	.354	.125
	Q6post	4.75	8	.463	.164
Pair 7	Q7pre	4.75	8	.707	.250
	Q7post	4.75	8	.707	.250
Pair 8	Q8pre	4.00	8	1.069	.378
	Q8post	4.13	8	.835	.295
Pair 9	Q9pre	1.75	8	.463	.164
	Q9post	1.63	8	.518	.183
Pair 10	Q10pre	4.38	8	1.188	.420
	Q10post	4.75	8	.707	.250
Pair 11	Q11pre	4.50	8	.535	.189
	Q11post	4.75	8	.463	.164
Pair 12	Q12pre	4.00	8	1.309	.463
	Q12post	4.50	8	.535	.189
Pair 13	Q13pre	4.13	8	.641	.227
	Q13post	4.63	8	.744	.263
Pair 14	Q14pre	4.13	8	1.246	.441
	Q14post	4.63	8	.744	.263
Pair 15	Q15pre	4.17	6	1.169	.477
	Q15post	4.83	6	.408	.167
Pair 16	Q16pre	3.50	8	1.195	.423
	Q16post	4.00	8	.926	.327

Pair 17	Q17pre	3.50	8	1.512	.535
	Q17post	4.25	8	1.035	.366
Pair 18	Q18pre	4.00	8	.756	.267
	Q18post	4.00	8	1.069	.378
Pair 19	Q19pre	4.50	8	.756	.267
	Q19post	4.63	8	.518	.183
Pair 20	Q20pre	4.38	8	.744	.263
	Q20post	4.38	8	.518	.183
Pair 21	Q21pre	4.50	8	.756	.267
	Q21post	4.38	8	.518	.183
Pair 22	Q22pre	4.13	8	1.246	.441
	Q22post	4.38	8	.916	.324
Pair 23	Q23pre	4.13	8	1.246	.441
	Q23post	4.50	8	.756	.267
Pair 24	Q24pre	3.75	8	1.165	.412
	Q24post	4.25	8	.886	.313
Pair 25	Q25pre	3.50	8	1.414	.500
	Q25post	4.00	8	1.195	.423
Pair 26	Q26pre	4.13	8	1.246	.441
	Q26post	4.63	8	.744	.263
Pair 27	Q27pre	2.43	7	1.397	.528
	Q27post	3.43	7	.535	.202
Pair 28	Q28pre	3.14	7	1.069	.404
	Q28post	4.00	7	.816	.309
Pair 29	Q29pre	3.29	7	.756	.286
	Q29post	4.00	7	.816	.309
Pair 30	Q30pre	3.71	7	1.496	.565
	Q30post	4.29	7	.756	.286
Pair 31	Q31pre	3.29	7	1.496	.565
	Q31post	4.14	7	.900	.340
Pair 32	Q32pre	3.71	7	1.496	.565
	Q32post	4.14	7	.900	.340
Pair 33	Q33pre	4.38	8	.518	.183
	Q33post	4.50	8	.535	.189
Pair 34	Q34pre	3.50	8	1.414	.500
	Q34post	4.13	8	.991	.350