A Nurse Practitioner-Led Group Advance Care Planning Program in an Independent and Assisted living Community

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A Nurse Practitioner-Led Group Advance Care Planning Program in an Independent and Assisted living Community

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Abstract

It has been well documented that the majority of people want to spend their last days in the comfort of their own homes, free of pain, and off any dependent machine. However, the majority of people have not documented these wishes or talked with their family or provider about end of life care (Hamel, Wu, & Brodie, 2017). The Patient Self Determination Act (PSDA), which took effect on December 1, 1991, was enacted to raise awareness and promote discussions between patients and providers about end of life (EOL) healthcare decisions. The primary care nurse practitioner is in a prime position to initiate advance care planning (ACP) interventions with patients and their loved ones to help ensure they receive the care that is most consistent with their goals, preferences, and values. As our aging population continues to grow, so will the demand for healthcare services; therein making the case to develop innovative and efficient initiatives to increase public awareness, empower community members, and advocate for patient’s rights to take control of their health care wishes.

A Community-Based Advanced Care Planning Program was developed in collaboration with facility staff, a partnering provider group, and University of San Francisco faculty and integrated into a retirement community. A pre-/post-survey design was used to evaluate this intervention. Survey data were analyzed by way of comparative means and tested for level of significance using a paired t-test. Results of this intervention indicate that participants had significantly increased in all outcome measures including knowledge of ACP processes and ACP documents. Participants also demonstrated a significant increased level of confidence and expressed that on average, they were more likely to designate a durable power of attorney for health care and discuss their goals of care with their family and provider after the intervention.
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Background & Significance
The Patient Self Determination Act (PSDA), which took effect on December 1, 1991, was enacted to raise awareness and promote discussions between patients and providers about end of life (EOL) healthcare decisions (Koch, 1992). The majority of people want to spend their last days in the comfort of their own homes, free of pain, and off any dependent machines. Now, more than 28 years since the PSDA was signed into law, only one-third of adults have an advance directive (Yadev et al., 2017). Based on these findings, it is evident that patients are not asking their providers about getting their wishes documented, and not all providers are initiating the conversation. In 2013, the CDC reported two out of three adults aged 65 and older have multiple chronic health conditions; that the number of older adults is expected to double in the next 25 years; and older adults are responsible for 66% of health care costs (CDC, 2013). Without appropriate advance care planning documentation, individuals are at greater risk of receiving unwanted healthcare interventions at EOL (Detering et al. 2010). On the other hand, when a plan is in place, providers, patients, their families, and the health care system experience better outcomes (Weathers et. al., 2016).

Innovative and efficient initiatives that aim to increase public awareness, empower community members, and advocate for patient’s rights to collaborate with their health care team and develop a personalized treatment plan are needed. ACP includes informing individuals of their right to decide and document what treatments they receive; discussing individuals’ goals, values, and preferences for end of life (EOL) care; supporting the designation of a health care power of attorney (HCPOA); and completion of ACP documentation. ACP documentation includes advance directives (AD) and state authorized portable orders (SAPO) for life-sustaining treatments, such as a Physician Order for Life Sustaining Treatment (POLST). The primary care nurse practitioner is in a prime position to initiate advance care planning (ACP) interventions.
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with patients and their loved ones to help ensure care is consistent with their wishes. A life-threatening event can happen at any time, emphasizing the importance of having the conversation and documenting health care wishes early in adulthood, but even more importantly in older age when a health crisis is more likely to occur.

Problem Description

This project took place in a continuous care retirement community in Oakland, California. This community offers independent, assisted and skilled nursing living. All residents are encouraged to have an advance directive in their charts. However, after speaking with key clinical and administrative staff, it was found that many of the residents have incomplete or no ACP documentation, or have not shared their ACP records with staff. Staff believed the residents would greatly benefit from receiving additional information about advance care planning and life-sustaining-treatments. The intervention for this DNP project is an innovative approach, designed to overcome several barriers and reach as many community members as possible.

Multiple barriers hinder the ACP process, including lack of information about ACP, limited health literacy, the belief that the practitioner or family member will know what is best or wanted, the belief that the conversation about EOL care should be started by someone else, provider time constraints, and lack of preparation for discussion. In addition, race, socioeconomic status, and cultural and religious beliefs all affect beliefs about EOL (Volandes et al., 2008; Weekes, 2012). Without appropriate ACP documents and discussions, individuals are at greater risk of receiving unwanted healthcare interventions during a health crisis (Detering et al. 2010). On the other hand, when a plan is in place, providers, patients, their families, and the health care system experience better outcomes (Weathers et. al., 2016).
Available knowledge

Methods

**Search strategy:** A comprehensive literature review of ACP interventions and their personal and economic impact was conducted in the process of developing this project. The evidence was reviewed between February 2019 and May 2019. The search for literature was accomplished with the use of electronic databases through the University of San Francisco’s online library and included searches on CINAHL Complete, PubMed, DynaMed, and Cochrane. Additional background data were obtained from governmental and non-governmental reports and periodicals. More than 200 titles and 63 abstracts were reviewed, from which 6 full-text articles were selected to include in this paper.

Key words and phrases included the following: *advance care planning, advance directives, goals of care, nurse practitioner, primary care, group visit, impact, advance care planning intervention, and elderly.*

**Inclusion criteria:** The articles selected for this review were peer-reviewed, published in English language, and published between 2014 and 2019. Additionally, they must have evaluated personal impact of advance directives, economic impact of advance directives, cost effectiveness of advance care planning intervention, or focused on providing a community based advance care planning intervention.

**Exclusion criteria:** Non-peer-reviewed articles published prior to 2014 written in a language other than English, or did not focus on effectiveness or impact of advance directives.

**Appraisal of evidence:** The articles reviewed in this paper were reviewed and tested for level and quality of evidence using the Johns Hopkins Nursing Evidence-Based Research
Appraisal Tools (Dearholt & Dang, 2012). A summary of the articles with appraisal of evidence level and quality are included in Appendix C.

What Works

In a systematic-review by Weathers et. al. (2016), nine interventions were reviewed, which evaluated the impact that advance care planning (ACP) has on specific outcome measures. The authors distinguished outcomes in two categories. The first category examined specific ACP outcomes, including documentation of health care wishes, documentation of a selected durable power of attorney, and completion of a standardized advance care directive (ACD). The second category examined patient and family outcomes, including knowledge of EOL preferences, understanding of individual EOL preferences, and if the care was delivered in congruence with EOL wishes. The first category will be presented in terms of what works, and the second category will be discussed later under the impact of ACP on patients and caregivers.

All selected studies were from randomized controlled trials published in English, used an ACP intervention, and included a population of older adults (>65 years old). A total of nine studied were selected for the review and included a population of 3,646 older adults from a variety of settings and geographic regions. Similarly, the interventions of each study also varied; however, the overarching goal to have individual’s health care decisions known by the health care proxy was universal.

Four of the nine studies evaluated outcomes from the first category, ACP outcomes. Three of the interventions focused on direct face-to-face discussions with patients and their families and/or proxies about ACP, whereas the other study used indirect patient education by providing a printed pamphlet and a 20-minute video on ACDs. Three studies found that the ACP
interventions resulted in an increase in documented EOL care wishes; one found an increase in documented HCPOA, and one reported an increase in the number of completed ACD.

In a separate systematic review by Solis, Mancera, and Shen (2018), the authors reviewed nine RCT and one pilot study, which focused on interventions to improve ACP in the primary care setting. The studies used a single or combination approach of patient education, provider education, computer generated triggers, and/or a multidisciplinary approach. In six of the studies, each method had some level of success in influencing the occurrence of ACP conversations and documentation; however, three studies showed there was no significant improvement in ACP actions when the intervention did not include a discussion with a practitioner. Of significant mentioning, it was found that the best results occurred when a combination approach was used, including both patient and/or proxy education and discussion with a health care provider.

Since the above mentioned systematic reviews were published, new innovative strategies that support the implementation of single or combined approaches have emerged, including but not limited to the following interventions: Group-visits; community-based ACP workshops; interactive web-based ACP aids (Appendix D) such as PREPARE, MyDirectives, and Making Your Wishes Known; communication-priming tools provided prior to office visits; and the use of communication/documentation tools (Curtis et al., 2018; Splendor & Grant, 2018; Lum et al., 2017; Sudore, Boscardin, Feuz, McMahan, Katen, & Barnes, 2017; Flowers & Howe, 2015; Green, Schubart, Whitehead, Farace, Lehman, & Levi, 2015).

For example, in a two-year project at the University of Colorado Hospital, which included implementation of a two-session group-visit intervention at three primary care clinics, Lum et al. (2017) reported a significant increase in the completion rate of ACP documentation among the participants. A total of 118 participants attended at least one of two group-visits,
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which were facilitated by a physician and a social worker. At the three-month follow-up, documentation of a health care proxy increased from 39% to 81%, and 89% \( p < 0.001 \) at twelve months. Additionally, completion of ACP documentation including an ACD and/or MDPOA increased from 20% to 57% at three months post intervention, and 67% \( p < 0.001 \) at 12 months.

Likewise, Splendore & Grant (2018) report similar effectiveness of a nurse practitioner led community-based ACP intervention. This intervention included a ninety-minute session conducted in two separate workshops. Forty participants attended the workshop, of which thirty-one did not have an ACD pre-intervention. Completion of ACD increased from 17% to 55% at the one-month follow-up. However, unlike the previously mentioned intervention, this was conducted in a community setting without any clinic affiliation, which placed the responsibility of discussing and disseminating the ACD on the participants. At the one-month follow-up, one of the participants who completed their ACD shared a copy with their HCPOA and their PCP; six discussed it with their HCPOA, and one discussed it with their PCP. Although this particular intervention has several limitations, the fact that there was nearly a 50% increase in completed ACDs post intervention further strengthens the notion that ACP interventions that systematically provide information and resources to consumers work.

**Impact of Advance Care Planning**

**Provider Impact**

Escher, Perenger, Rudaz, Dayer, and Perrier (2014) conducted a randomized control trial in an effort to quantify the impact that ACDs and HCPOA have on medical providers decisions. The researchers used cross-sectional mail surveys that included randomized vignettes with specific hypothetical medical situations, which demanded difficult medical decisions. The three
vignettes were designed to evaluate the impact of a written ACD (formal/informal vs. a proxy), compared to having neither of the two. In all three vignettes, the documented preferences and/or the opinions of the proxy were against invasive medical intervention. The outcome variable was based on the degree of difficulty to make the decision to either carry out or withhold a specific intervention using a Likert scale (1-very easy to 5-very difficult).

Each vignette was analyzed independently. Of the 1,962 providers who were mailed the surveys, a total of 853 providers responded to all or some of the vignettes. In all the vignettes, the option to forgo intervention was significantly easier with established EOL wishes either documented or communicated via health care proxy ($p < 0.001$). However, the decision was more difficult when the preferences were written on an informal document ($p < 0.037$). Moreover, the combination of both the written ACD and the presence of the health care proxy vs either alone had the greatest impact on providers’ decision-making being in congruence with the patient’s preferences ($p < 0.001$). Escher et al. (2014) provide clear and sound evidence that providers can be positively impacted by the presence of ACD and health proxies when faced with difficult clinical situations. However, the true impact is unknown, given that this was based on hypothetical vignettes rather than in a clinical setting. Additional research shows that patient and caregiver outcomes can be improved when ACP documentation is completed prior to a life-threatening event (Weathers et al., 2016).

**Patient and Caregiver Impact**

In the systematic review by Weathers et al. (2016), which was previously mentioned in terms of what works (ACP outcomes), five of the nine studies reviewed measured the impact advance care planning (ACP) had on patient and family outcomes. This second category of outcome measures include the following: Quality of care, healthcare utilization, and symptom
management at the end of life (EOL). In this category, one study found that patient knowledge of ACDs was increased. Two studies reported that patients were more likely to receive care that was aligned with their wishes when their EOL preferences were documented. Two studies revealed decreased levels of stress, anxiety, and depression among family members after the death of their loved one. Another study found that there was less distress and decisional conflict among caregivers when patient wishes were documented and discussed. Lastly, one study reported a significant decrease in healthcare utilization, including less hospitalizations and use of health resources.

This systematic review highlighted the impact that advance care planning can have on the individual patient, the patient’s family, and on the healthcare system. When EOL wishes are known and followed, better outcomes are achieved for all those involved in the patients’ care. Although this review reported that less health care resources were used in one study, the potential economic impact was not discussed. With better outcomes and less healthcare utilization, significant cost savings should be an expected benefit.

**Economic Impact**

In a systematic review, conducted by Klinger, Schmitten, and Marckmann (2016), seven studies were examined to evaluate if ACP did in fact reduce health care costs near the EOL. The studies varied in study design, population, setting, and geographic location. Additionally, the ACP interventions and the manner in which cost implications were evaluated in each study also varied, making it difficult to make clear conclusions regarding cost effectiveness.

Although there were multiple differences among the studies reviewed, cost savings were achieved in six of the seven studies, ranging from 1,041 US dollars to 64,830 US dollars per patient. Much of this variation can be associated with the patient populations examined, the study
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period, and cost measurement of each study. Cost savings were measured by comparing the cost of care (inpatient/outpatient) before and after an ACP intervention, or by comparing costs between an intervention group and a control group. Cost savings were achieved when the costs of health care (inpatient/outpatient) were decreased post intervention, or were less in the intervention group compared to the control group.

Another major finding revealed that the cost of ACP interventions were relatively small, ranging from 6% - 15% of the cost savings. Additional research is needed to better evaluate the economic impact of ACP interventions using standardized metrics across different settings to improve the fidelity of outcomes. With the current evidence to support ACP interventions and the availability of ACP tools and decision-aids, providers have the foundation to increase ACP practices in various settings.

Summary of Evidence

The evidence in this review shows that there are numerous interventions that can be implemented to improve ACP actions; however, a consensus which identifies any specific best practice(s) is void. Each intervention had some degree of success, as demonstrated by an increased incidence of completed ACP documentation; designation of HCPOA/proxy/surrogate decision maker and/or the positive impact of advance care planning on providers, patients, their families, and health care costs. When health care wishes are known, documented, and discussed, patients are more likely to receive care that is aligned with their preferences. Additionally, patients, their families, and health care personnel experience less stress and anxiety at EOL. Lastly, with less unwanted care delivered, significant cost savings associated with decreased hospitalizations and use of hospital resources can be expected. Although there is a substantial amount of literature to support the implementation of ACP programs into integrated health
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systems, private outpatient settings, and in the community, there are significant voids in research that examine implementation strategies and the economic impact of ACP interventions across different settings. More research in these areas will provide valuable information which should be used to develop guidelines for ACP interventions across clinical settings.

**Rationale**

**PICOT Question**

Among residents of an independent and assisted living facility in Oakland, California, how will implementing a community-based-group ACP program, compared to standard practice affect the residents’ current knowledge and understanding of ACP processes, and their confidence and likelihood of sharing their goals of care with their provider and or family?

**Conceptual Framework**

This project was developed using concepts from several existing models including the person-and-family-centered care model, group visit model, and ACP behavior change model (Institute for Healthcare Improvement [IHI], 2019; Parikh, M., Rajendran, I., D’Amico, S., Luo, M., and Gardiner, P., 2019; Fried, T., Bullock, K., Iaonne, L., and O’Leary, J., 2009). The focus of the person-and-family centered care model, developed by the Institute for healthcare improvement, includes the following key elements:

- To engage and include individuals and families in the design of programs.
- To ensure that the preferences and wishes of each person are respected.
- And to ensure communities are supported to stay healthy by collaborating with partners on programs designed to improve engagement, and shared decision making.
The Patient-and Family-Centered care Organizational Self-Assessment tool was also used to assess the organization’s performance in relation to specific components of the model prior to implementation (Appendix E).

The group visit model is different, due to the fact that there is not one standardized model for this type of visit. However, there are several key themes that this type of medical visit share, including the following:

- The visit is conducted by a provider/interdisciplinary team with billing privileges;
- Multiple individuals who have the same needs are seen at one shared time;
- An element of one-on-one care is provided either during the visit or arranged for a later time; and .
- Integrates a portion of medical practice such as vitals, medication management, and or patient education.

Group visits have been suggested to aid in improved outcomes due to multiple factors, such as experiential learning, social interaction, and the increased length of time dedicated to the visit.

The last framework mentioned, ACP as a health behavior, is described as a phenomenon that characterizes four themes that contribute to ACP behavior including the following:

- “Variable readiness to participate in ACP
- The wide range of perceived benefits and barriers to ACP
- The Process used by participants to engage in ACP and self-efficacy
- Experiences with loved ones on ACP as an expression of susceptibility” (Fried et al., 2009, p.4).

ACP behavior is used in this project as a way to identify and understand the different stages of ACP behavior in each member of the group in order to provide the appropriate level of support.
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Specific Aims

The project aim is to implement an educational intervention at an independent and assisted living community to: (1) increase residents’ knowledge and understanding of advance care planning processes and specific life sustaining treatments: and (2) increase their confidence with their goals of care such that they are more likely to discuss their wishes with a provider and/or family.

Methods

Context

The educational intervention was delivered to residents at a large community living center (CLC) that offers independent, assisted, skilled, and memory care accommodations. This CLC offers a variety of educational, entertainment, and social programs on a regularly scheduled basis, providing a great platform to seamlessly integrate this program into the normal routine of the organization. The project was initially designed to be conducted in a single 2-hour session, which reflects the common length of other group visits (Parikh, M., 2019); however, stakeholders advised that the presentation be either divided into two sessions or shortened to one 1-hr. session. Therefore, the intervention was divided into two 1-hr interactive educational presentations.

The first presentation included a PowerPoint presentation that introduced the concepts of ACP, ACP documents, and the importance of GOC discussions; a short Netflix documentary, *Extremis*, depicting the difficulty of decision-making for end-of-life care; and a facilitated discussion. Each participant received a folder including informational handouts on life-sustaining treatments, and a self-reflection exercise (Appendix M), which was intended to be reviewed prior to attending the second presentation. The second presentation included a review of the
information presented in the first presentation, an in-depth overview of specific life sustaining treatments (CPR, tube-feeding, mechanical ventilation, and dialysis), and a facilitated discussion on discussing GOC. Additionally, residents were encouraged to sign-up for individual follow-up time to review/update/complete ACP documents, discuss and document goals of care, and facilitate care coordination with their outside provider if needed.

The key stakeholders include the following: community residents and their families; nursing, social work, and other support staff; the Director of Wellness and Assisted Living; the Health and Services Administrator; the Director of Nursing; partnering providers; and University of San Francisco faculty, who continue to provide support and input throughout the development of this project. All of the stakeholders mentioned above have expressed a need for improved ACP education in this community and have enthusiastically approved the implementation of this project (see letter of support in Appendix B). The Director of Wellness and Assisted Living and Health and Services Administrator are the primary stakeholders who have the greatest influence for change and improvement in this site and have taken steps to coordinate and integrate this program.

**Intervention**

**Gap analysis:** ACP discussions with all adults are recommended to be part of standard practice in primary care; however, multiple barriers to having these conversations continue to persist (Institute of Medicine, 2014). Nationally, only one-third of adults have an advance directive (Yadev et al., 2017). Although residents in the assisted and independent living are encouraged to have appropriate ACP documentation in place, either prior to or shortly after they are integrated into the community, many of their documents are incomplete, unclear, or missing.
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Prior to this project, an ACP education intervention did not exist within the organizational program. See Appendix F for table of gap analysis.

**Timeline/Communication:** The timeframe from project proposal to completion, including the final presentation spans from January 2019 through October 2019. To start, the general concept was first proposed to faculty, at which time a review of current evidence was conducted and manuscript was written and revised. Next steps included writing the prospectus, meeting with stakeholders to perform a needs assessment and propose the intervention, confirming site location and dates for the intervention, developing the educational presentation and sharing with primary stakeholders prior to implementation. After the content of the intervention was approved, the presentation was delivered to the residents, at which time a pre-/post-evaluation was completed by the participants. After the final presentation, residents were provided the opportunity to schedule individual appointments for further discussion and assistance with the ACP process, up to 2 months after the presentation. The data collected from the evaluations was organized in a summary of data table, reviewed and analyzed (Appendix N). The complete breakdown of the project time-line can be found in the GANTT chart and communication matrix located in Appendices G and H, respectively.

**Strengths/Weaknesses/Opportunities/Threats Analysis:** In the process of developing this project and assessing the current environment around this topic, Internal and external advantages and challenges were analyzed using the strengths, weaknesses, opportunities, and threats (SWOT) model. The SWOT analysis was largely positive which contributed to the overall success of the program. This initiative has the potential to have a profound impact on the organization, the residents, and their families. Specific strengths include the following elements: Project alignment with organizational mission and values; seamless integration of
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intervention into established organizational program; enhanced relationship with partnering provider group; an established ACP educational presentation which can be continued after the DNP student completes the project, and increased understanding of ACP process among residents and staff. Potential weaknesses of the initiative include limited attendance at the educational intervention; residents may lack trust in the organization and be unwilling to share ACP documents; potential loss of participants due to drop-out; and difficulty with accurately measuring the impact of the intervention given that not all participants will complete the pre-/post evaluation forms.

The opportunities associated with this intervention include: increased revenue, as the training may be implemented as a medical group visit and partnering providers may have increased referrals for ACP appointments; the intervention may serve as a model which can be implemented at other neighboring facilities; increased community awareness of ACP processes; and the potential for decreased health care costs associated with cost savings from lower health care utilization, assuming that residents will choose less invasive treatment options for EOL care. Threats to sustainability may be attributed to the current political climate, as budget cuts to Medicare and MediCal are continually under review. Another perceived threat is that as greater attention is directed towards having ACP discussions with all adults in primary care, the need for this program may diminish. Please see Appendix I for SWOT table.

**Budget:** The cost of this intervention was minimal as the program was integrated into the normal routine of the organization. The only additional costs associated with the intervention are related to the materials (folders, printing the informational handouts and evaluations), which amounted to $36, and personal time (volunteered 180 hrs, including the two 1-hr presentations) and transportation cost for the DNP student ($100). A budget sheet is included in Appendix J. If
the program continues, and the presentation is delivered by a nurse practitioner, potential costs would include the cost of materials as well as the agreed upon reimbursement rate for the presenter.

**Cost Analysis:** Medicare reimburses nurse practitioners (NP) at 85 percent of physician reimbursement rates (Department of Health and Human Services, 2016). Physician are reimbursed for ACP visits at a rate of $86.00 ($73.10 for NP) for the initial 30 minutes and $75.00 ($63.75 for NP) for each subsequent 30 minutes (Coalition for compassionate care of California, 2019). The average salary for a nurse practitioner in Oakland California, ranges from $120,000 - $140,000 in the outpatient setting, which equates to $57.00 - $67.00 per hour Given that this is a 2-hour presentation, with and additional 1 hour for set-up and breakdown time, the nurse practitioner could receive reimbursement for 3 hours, totaling up to $200 per session. If the organization decides to bill for this service, at least 3 residents would need to attend each session to break even (See break-even analysis in appendix J).

**Study of the Intervention**

**Design/Analysis:** To assess the impact of this intervention a pre-/post-survey design was used to evaluate the specific outcomes. At the start of the presentation, residents were asked to complete a pre-survey to assess a baseline knowledge of ACP information and processes (fill in, yes/no), confidence level with discussing goals of care with a provider and family/loved ones (Likert scale), and how likely/ready they are to discuss their goals of care with their provider and or family/loved ones (Likert scale). The post-intervention survey contains the same knowledge and confidence questions, with the addition of questions to assess if the intervention met the objectives, and two open-response question where attendees can describe what they liked most
and any recommendations to improve the presentation. Lastly, the number of residents that requested individual follow-up was recorded.

The pre-/post-survey data was used to calculate and compare mean scores on knowledge and confidence responses. Additionally, a t-test was conducted to assess statistical significance. Success of the intervention was determined when the mean score for each area (knowledge/confidence) of the post-survey exceeded the mean score of the pre-survey, and had a p-value of \( \leq 0.05 \). Ideally, the mean score for Likert-scale questions will be greater than three (on a scale of 1-5) post intervention, indicating a positive level of confidence and likeliness/readiness to initiate ACP processes, including completing/updating ADs and or POLST, and/or discussing goals of care with a provider and/or family/loved ones.

**Ethical Consideration:** This project promotes patient advocacy and increases access to ACP information and resources, giving individuals the knowledge and tools to decide what care is most consistent with their personal goals, values, and preferences. The overall intent of this project is consistent with The American Nurses Association (ANA) Center for Ethics and Human Rights position on the importance of establishing goals of care with patients, encouraging shared decision making, and promoting ACP conversations (ANA, 2016).

Privacy and individuals’ well-being were considered in this intervention, given the private nature of the topic. Residents were asked to be respectful of each other’s personal beliefs and values, and not to share any specific information with anyone outside of the group without their consent. The surveys were completed anonymously and do not have any open fields to provide personal-identifiable information. Attendees were asked to voluntarily complete the evaluations.
This project was determined to be an evidence-based quality improvement (QI) project by the University of San Francisco School of Nursing and Health Professions department and meets federal guidelines for non-research. Please see Appendix A for DNP Statement of Non-research and checklist.

**Results**

The two-part group ACP presentation was completed on September 13th and 27th, 2019. A total of 30 residents attended either one or both of the sessions. 20 residents attended the first presentation, and 18 attended the second presentation. 8 residents attended both presentations. Of the 20 residents who attended the first presentation, 14 completed the pre-survey questionnaire, a 70% response rate. Two residents who were visually impaired received assistance with completing the survey by a wellness nurse. Of the 18 residents who attended the second presentation, 13 residents completed both the pre-survey and post-survey questionnaires (including the 8 residents who previously completed the pre-survey in the first presentation).

Pre-survey responses for the residents who only attended session one was used to compare mean scores; however, they were not used in the paired-\(t\)-test, which evaluated statistical significance of pre-/post-survey results. For the 8 residents who attended both presentations, the mean pre-survey score for the knowledge questions increased from 1.25 to 5.25. For this same group, the mean score for confidence questions increased from 1.25 to 6.88. For the 13/18 residents who attended and completed the post survey after the second presentation the mean score for knowledge questions increased from 1.15 to 5.38; and the mean score for confidence questions increased from 1.31 to 6.38. A paired t-test was conducted to test for statistical significance using pre and post intervention survey data. Each t-test resulted with a \(p\)-value < 0.001, indicating statistical significance. Please see Appendix N for summary of pre-
/post data analysis tables/graph. After the final presentation, only three residents requested individual follow-up. Three follow-up consultations were initially requested; however, only two were completed over the following week, each lasting about 20 minutes per visit. The third resident later expressed that he/she no longer needed additional assistance.

Qualitative data was also collected on the post-survey, with one yes/no question and two open-response questions. Residence were asked whether or not they believed they gained additional knowledge and understanding of the processes and benefits of ACP (yes/no). Residents were also asked to describe what they liked most and how the presentation could be improved. One hundred percent of respondents answered yes to the first question. Responses to the last question were as follows:

- “Gives you everything you need to know.”
- “Good information about procedures.”
- “Information about ACP documents and treatments.”

Only two residents provided a written response to the last question (What suggestions or recommendations do you have for ways we can improve this service?), which stated, “Have people bring their documents… Require documents to be in place within 1 year of residency;” “presentation is too fast.”

**Discussion**

**Summary**

The primary stakeholders and the host organization’s commitment to providing a patient-centered environment was instrumental in the successful implementation of this project. The
A GROUP ADVANCE CARE PLANNING PROGRAM

project aims for this intervention were all achieved. This intervention was successfully integrated into the routine of the host organization and was well received by all of the participants. A total of 38 residents attended one or both of the presentations. A total of 27 pre-evaluations and 13 post evaluations were received, which can partially be attributed to the drop-out rate of 19 residents between the first and second presentation; however, 10 residents who did not attend the first presentation, were able to attend the second session; and 8 residents attended both presentations. Despite the significant drop-out rate, every resident that attended the second presentation and completed the post evaluation expressed that they gained additional knowledge and understanding of ACP processes. Additionally, mean scores for knowledge and confidence questions significantly increased ($p$-value $\leq 0.001$) for the residents that attended both presentations as well as for residents who only attended the second presentation. Further success, dissemination, and expansion of this intervention is highly achievable based on the lessons learned and expanded interests from this project.

Stakeholders expressed a need for additional training for nursing and social work staff, who could benefit from further education on ACP processes, and life sustaining treatments. Additionally, DNP faculty expressed a need for FNP-student training on ACP and discussing GOC. Nurse practitioners in primary care and other specialties are in prime positions to initiate ACP actions and implement evidence-based ACP interventions in their practice. There is ample evidence to support ACP interventions in the community, and the efficacy and benefits of medical group visits.

Interpretation

This DNP project used evidence-based information and modalities to develop, implement and evaluate specific health education on ACP for the residents of an independent and assisted
living community. Similar to other publications that have focused on improving ACP practices, this intervention successfully increased access to advance care planning information and resources (Weathers et al., 2016). Also of note, like other ACP interventions that have been studied, this project is relatively low cost (Klinger, et al., 2016). As a result of attending this presentation, the participant demonstrated an increase in knowledge and confidence with ACP process and discussing their GOC with their provider and or family members. The residents expressed that the presentation was thorough and provided valuable information that would help them document and discuss their health care wishes. Stakeholders, including the host organization’s staff and DNP faculty have also expressed a need for additional training, which will contribute to the ongoing success of this project.

The potential impact of this project, as well as the possibility of further dissemination and expansion can be profound on our health care system. By understanding what patients’ goals of care are, providers will have a better understanding of how to manage their care and educate them on how specific treatments/interventions can help meet their goals. It would also be reasonable to expect significant cost savings by avoiding the unnecessary use of emergency and acute care services, as well as unwanted health care interventions. Further investigation and literature review is needed to identify gaps in training for all health care providers related to ACP and discussing GOC with patients and their loved ones.

Limitations

This is a difficult topic to present due to the nature of the content, which is focused on end-of-life care and is often avoided by patients and health care providers. The majority of medical group visits are 90 mins. – 2 hrs., reflecting the time needed to deliver this presentation. The time constraint of a 1 hour session resulted in the need to divide the 2- hour training into two
1-hour presentations. This consequently resulted in the unanticipated drop-out rate of 19 residents who did not return for the second presentation. However, the pre-survey results for all of the residents who attended either one or both of the presentation was significantly lower than the post-survey findings, indicating a need for ACP interventions like this in the community. To avoid the problem of potentially losing participants due to drop-out, this intervention may be better in a single session, rather than divided into two separate presentations in the future.

A significant limitation with this intervention and other like-interventions, is that there is no standardized evaluation/survey with proven validity/reliability to evaluate knowledge and confidence of ACP processes or life sustaining treatments. The evaluations created for this project were developed using information from the literature reviewed. Another limitation is the small sample size of survey data, limiting the generalizability of the findings. Observed barriers to participants completing the surveys included physical disabilities/limitations making it difficult to read the questions and or provide written responses; and personal preference. To overcome some of these barriers, it may be beneficial to have additional support staff or volunteers to assist residents with disabilities to complete the surveys. The results are also influenced due to convenience sampling. The time allotted for this presentation was integrated into the organizations regularly scheduled “wellness class.” Lastly, the impact this intervention has on actual future care received is beyond the scope of this project.

Conclusion

Although the majority of people believe that it is important to document and discuss their healthcare wishes with their loved ones and their health care providers, few have actually taken steps to take control of their EOL care. The finding of this DNP project, despite the limitations, strongly suggests there is a lack of community awareness about ACP processes. The results also
support further implementation of evidence-based quality improvement projects to improve ACP practices. Nurses have been recognized as the most trusted professional and have an excellent reputation for their compassion, communication skills, and holistic approach to caring. Nurse practitioners in primary care and other specialties are in prime positions to initiate ACP actions and implement evidence-based ACP interventions in their practice. This DNP project adds to the body of literature to support ACP interventions in the community, and the efficacy and benefits of medical group visits.

During the development of this intervention; new possibilities arose, presenting an opportunity to expand this project, including inter-and intradisciplinary training on ACP. This intervention can remain intact and serve as a model for dissemination in other like-facilities or reorganized to meet different setting’s needs. There is also an opportunity to expand on this model by adding it into the billing infrastructure as a medical-group visit and becoming a source of revenue through Medicare and Medicaid reimbursements. Although there is potential for revenue and cost savings across the health care system, the emphasis of this intervention focused on increasing access to ACP information and resources and promoting individuals to take appropriate ACP actions in order to ensure their goals and preferences are known and respected.

Other Information

Funding

This DNP project did not depend on or receive any external funding to report. The costs for materials, transportation costs, and time spent on this project was fully paid for and volunteered by the student.
References


Institute of Medicine. (2014). *Dying in America: Improving quality and honoring*


A GROUP ADVANCE CARE PLANNING PROGRAM

*Nurse Practitioners, 29(9), 535–542. https://doi.org/10.1002/2327-6924.12467


https://doi.org/10.1377/hlthaff.2017.0175
Appendix A

DNP Statement of Non-Research Determination Form

Student Name: Alexander V Bustos

Title of Project: Advance care planning education in the community to promote and improve patient-provider goals of care discussions.

Brief Description of Project: For this project, I will be using evidence-based material to develop an educational presentation for residents of independent and assisted living facilities in Oakland, Ca.

A) Aim Statement: The project aim is to improve community residents’ knowledge of advance care planning tools and specific life sustain treatments; and increase the residents confidence and likelihood of discussing their goals of care with their provider by implementing and evaluating an educational intervention in at least 1 assisted living facilities by October, 2019.

B) Description of Intervention: This will be a 2 hour interactive session, divided into two parts, and will include video, PowerPoint presentation, facilitated discussions, informational handout, and a self-reflection exercise. There will be a pre/post survey to
A GROUP ADVANCE CARE PLANNING PROGRAM

evaluate the effectiveness of the intervention.

C) How will this intervention change practice? By education the residents of the independent and assisted living facilities, the resident’s providers will be able to better direct care focused on the patient’s goals of care; and complete POLST orders that are consistent with the patient’s goals of care.

D) Outcome measurements: After receiving the educational presentation, residents will report improved understanding of the ACP process, specific life sustaining treatments; improved confidence in discussing their goals of care with their provider and/or family; and will report that they will be more likely to discuss their goals of care with their provider.

To qualify as an Evidence-based Change in Practice Project, rather than a Research Project, the criteria outlined in federal guidelines will be used: (http://answers.hhs.gov/ohrp/categories/1569)

X This project meets the guidelines for an Evidence-based Change in Practice Project as outlined in the Project Checklist (attached). Student may proceed with implementation.

EVIDENCE-BASED CHANGE OF PRACTICE PROJECT CHECKLIST *
Instructions: Answer YES or NO to each of the following statements:

<table>
<thead>
<tr>
<th>Project Title:</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance care planning education in the community to promote and improve patient-provider goals of care discussions.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The aim of the project is to improve the process or delivery of care with established/accepted standards, or to implement evidence-based change. There is no intention of using the data for research purposes.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>The specific aim is to improve performance on a specific service or program and is a part of usual care. ALL participants will receive standard of care.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>The project is NOT designed to follow a research design, e.g., hypothesis testing or group comparison, randomization, control groups, prospective comparison groups, cross-sectional, case control). The project does NOT follow a protocol that overrides clinical decision-making.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>The project involves implementation of established and tested quality standards and/or systematic monitoring, assessment or evaluation of the organization to ensure that existing quality standards are being met. The project does NOT develop paradigms or untested methods or new untested standards.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>The project involves implementation of care practices and interventions that are consensus-based or evidence-based. The project does NOT seek to test an intervention that is beyond current science and experience.</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>
The project is conducted by staff where the project will take place and involves staff who are working at an agency that has an agreement with USF SONHP.  

<table>
<thead>
<tr>
<th>X</th>
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</thead>
</table>

The project has NO funding from federal agencies or research-focused organizations and is not receiving funding for implementation research.  

<table>
<thead>
<tr>
<th>X</th>
</tr>
</thead>
</table>

The agency or clinical practice unit agrees that this is a project that will be implemented to improve the process or delivery of care, i.e., not a personal research project that is dependent upon the voluntary participation of colleagues, students and/ or patients.  

<table>
<thead>
<tr>
<th>X</th>
</tr>
</thead>
</table>

If there is an intent to, or possibility of publishing your work, you and supervising faculty and the agency oversight committee are comfortable with the following statement in your methods section: “This project was undertaken as an Evidence-based change of practice project at X hospital or agency and as such was not formally supervised by the Institutional Review Board.”  

<table>
<thead>
<tr>
<th>X</th>
</tr>
</thead>
</table>

**ANSWER KEY:** If the answer to ALL of these items is yes, the project can be considered an Evidence-based activity that does NOT meet the definition of research. **IRB review is not required. Keep a copy of this checklist in your files.** If the answer to ANY of these questions is NO, you must submit for IRB approval.  

*Adapted with permission of Elizabeth L. Hohmann, MD, Director and Chair, Partners Human Research Committee, Partners Health System, Boston, MA.*

**STUDENT NAME:** Alexander V. Bustos  
**Signature of Student:** Alexander V. Bustos  
**DATE:** 5/18/2019

**SUPERVISING FACULTY MEMBER (CHAIR) NAME:** Karen Van Leuven  
**Signature of Supervising Faculty Member (Chair):**  
**DATE:**
Appendix B
Letter of Support
08/12/2019

To whom it may concern:

We here at the Piedmont Gardens, a Human Good Community, enthusiastically support the work of Alexander Bustos for his DNP Scholarly project, titled: A Nurse Practitioner-Led Group Advance Care Planning Intervention. The project contributes tremendous value congruent with the mission and values of the Piedmont Gardens Community.

Advance care planning is an important, yet challenging topic that is often dismissed or under-addressed. Mr. Bustos will be addressing this by conducting the approved intervention, which will be a 2-part presentation for our community residents, held at the Piedmont Gardens. This intervention promotes an increase in knowledge and resources regarding advance care planning processes, and life sustaining treatments which can help our residents decide and discuss the care that will be most meaningful to them.

We look forward to seeing the positive impact of Mr. Bustos’ project throughout our community.

Sincerely,

Zinnia Koch | BSN RN
Director of Wellness & Assisted Living
Piedmont Gardens

Appendix C
Summary and Appraisal of Evidence
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Sample</th>
<th>Findings</th>
<th>Evidence : level and Quality</th>
</tr>
</thead>
</table>
| Weathers et al. (2016)| Systematic Review of RCTs without Meta-analysis | - 9 RCTs  
- 3,646 older adults (<65 y/o) from a variety of settings and geographic regions; primarily in the USA.  
- Various ACP interventions were implemented and evaluated using specific outcome measures, which were categorized into 2 sections (ACP outcomes) and (impact outcomes).  
- 6 of the studies were in the US  
- 1 from Australia  
- 1 form Canada  
- 1 from the UK.  
Settings included:  
- 2 nursing homes  
- 2 acute medical units  
- 2 primary care clinics  
- 2 medical offices  
- 1 pre-operative clinic  
- 1 Veteran Affairs Medical Center. | -Three studies showed increased documentation of EOL preferences  
-One study showed increased documentation of selected surrogate decision maker/HCPOA  
-One study showed increased completion of standard ACD documentation and/or official HCPOA.  
-Two studies reported health care wishes were more likely followed when they were documented.  
-Two studies revealed decreased levels of stress, anxiety, and depression among family members.  
-One study found that there was less distress and decisional conflict among care givers.  
-One study reported a significant decrease in healthcare utilization. | Level: I  
Quality: B |
| Solis et al. (2018).  | Systematic Review of combination of RCTs and Quasi-experimental studies | - 9 RCTs  
- 2 Prospective quasi-experimental studies | -Six studies showed an increased incidence of ACP conversations and documentation;  
-Three studies showed no change in ACP | Level: II  
Grade: B |
<table>
<thead>
<tr>
<th>Study Description</th>
<th>Experimental Study</th>
<th>Meta-Analysis</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>A GROUP ADVANCE CARE PLANNING PROGRAM</td>
<td>- 1 Retrospective quasi-experimental study - 19,932 older adults (average age &gt; 60 y/o) - From primary care settings in a variety of geographic locations. - A variety of ACP interventions specifically measured the completion of ACP actions including ACP communication with PCP and completed ACP documentation (ACD/HCPOA).</td>
<td>- The best results occurred when a combination approach was used, which included both patient and/or proxy and discussion with a health care provider.</td>
<td></td>
</tr>
<tr>
<td>Lum et al. (2017)</td>
<td>Prospective Quasi-experimental Study</td>
<td>- 118 participants from 3 primary care clinics of the University of Colorado Hospital</td>
<td>-Documentation of a surrogate decision maker increased from 39% to 89% at the 12 months post intervention. -Completion of standard ACD and/or HCPOA increased from 20% to 67% at 12 months post intervention.</td>
</tr>
<tr>
<td>Splendor &amp; Grant (2018)</td>
<td>Organizationa l Experience: Program Evaluation</td>
<td>-40 participants in a rural community-based setting outside of Pittsburgh, Pennsylvania attended 90 minute ACP workshop.</td>
<td>-Completion of standard ACD increased from 17% to 55% one-month post-intervention. -Six participants discussed their ACD with the HCPOA. - One participant shared a copy of the ACD with the HCPOA.</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Findings</td>
<td></td>
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<tr>
<td>-------------------------------------------</td>
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<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Escher et al. (2014)</td>
<td>RCT</td>
<td>- Zero participants discussed or shared their ACD with a PCP one month post-intervention.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Decision making was easiest when EOL wishes were documented and HCPOA was present.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Decision making was more difficult when health care wishes were written on an informal document vs a ACD, and HCPOA was not present; however, decisions about treatment did not vary.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- There was moderate improvement in decision making when either health care wishes were formally documented or a HCPOA was present.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- 4 RCTs</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- 1 Prospective cohort study</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- 1 Retrospective cohort study</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- 1 Observational Study/Organizationa l Experience: Program Evaluation</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>- 6 studies were conducted in the US – 1 in Canada.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- 3 were in hospitals, - 1 was in a nursing 3- were in home care settings.</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>- Cost savings were reported in six of the seven studies reviewed.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Cost savings ranged from 1,041 USD, to 64,830 USD per patient.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Cost of ACP intervention ranged between 6% - 15% of coast savings associated with cost of care.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix D  
Summary of Web-Based ACP Aids  
PREPARE, MyDirectives, and Making Your Wishes Known

<table>
<thead>
<tr>
<th>ACP-Aid</th>
<th>Web-Address</th>
<th>Summary of intervention</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>PREPARE for your care</td>
<td><a href="https://prepareforyourcare.org/advance-directive">https://prepareforyourcare.org/advance-directive</a></td>
<td>Allows individuals to select a state authorized ACD form available in English and Spanish for most states. Includes video stories, examples, and tutorials to aid individuals through the ACP processes, including completing an ACD. Provides the option of completing ACD electronically which allows individuals to save their answers and work on it over time, and update a previously completed ACD any time. The completed ACD can be printed and shared accordingly. Or individuals can print a blank form to be completed by hand. The form is 15 pages, and uses language that is easy to read and understand.</td>
<td>Free</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>---</td>
</tr>
<tr>
<td>MyDirectives</td>
<td><a href="https://mydirectives.com/en/">https://mydirectives.com/en/</a></td>
<td>Provided a cloud platform where individuals can create a customizable Universal Advance Digital Directive (uADD) Platform can be accessed from any computer or mobile device with internet access. Personal uADD is saved in the cloud and can be updated at any time. A MyDirectives mobile app is available through the Apple App-Store, which offers additional features such as the ability to record audio and videos.</td>
<td>Free for individual consumers and health care providers. Insurances and health care organizations pay to store patient ACD on AdVault cloud.</td>
</tr>
</tbody>
</table>
-User’s uADD is accessible even when phone is locked.

Once completed either on the website or through the mobile app, ACDs are downloadable, printable, and can be shared electronically through a secure link.

Making Your Wishes Known

https://www.makingyourwishesknown.com/default.aspx

This is an online-decision aid created to guide individuals through the ACP process and create an ACD.

This aid includes audio and video tutorials and examples common situations.

The aid also includes videos easy to understand explanations of different life sustaining treatments (dialysis, CPR, tube-feeding, intubations), palliative care, hospice care, and several medical conditions (stroke, coma, dementia, and terminal illness)

After working through the program, a completed ACD is generated in PDF format, which can be printed and shared.

Appendix E
Patient- and Family-Centered Care Organizational Self-Assessment Tool

<table>
<thead>
<tr>
<th>Domain</th>
<th>Element</th>
<th>Low</th>
<th>Medium</th>
<th>High</th>
<th>Do not know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leadership / Operations</td>
<td>Clear statement of commitment to PFCC and PF partnerships</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Explicit expectation, accountability, measurement of PFCC</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>PF inclusion in policy, procedure, program, guideline development, Governing Board activities</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Mission, Vision, Values</td>
<td>PFCC included in mission, vision, and/or core values</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-----------------------------------------------------</td>
<td>---</td>
<td>---</td>
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<td>---</td>
</tr>
<tr>
<td></td>
<td>PF-friendly Patient Bill of Rights and Responsibilities</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Advisors</td>
<td>PF serve on hospital committees</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>PF participate in quality and safety rounds</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Patient and family advisory councils</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Quality Improvement</td>
<td>PF voice informs strategic/operational aims/goals</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>PF active participants on task forces, QI teams</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>PF interviewed as part of walk-rounds</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>PF participate in quality, safety, and risk meetings</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>PF part of team attending IHI, NPSF, and other meetings</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Personnel</td>
<td>Expectation for collaboration with PF in job descriptions and PAS</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>PF participate on interview teams, search committees</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>PF welcome new staff at new employee orientation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Staff/physicians prepared for and supported in PFCC practice</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Environment and Design</td>
<td>PF participate fully in all clinical design projects</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Environment supports patient and family presence and participation as well as interdisciplinary collaboration</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Domain</th>
<th>Element</th>
<th>Low</th>
<th>Medium</th>
<th>High</th>
<th>Do not know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information / Education</td>
<td>Web portals provide specific resources for PF</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Clinician email access from PF is encouraged and safe</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>PF serve as educators/faculty for clinicians and other staff</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>PF access to/encouraged to use resource rooms</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Diversity and Disparities</td>
<td>Careful collection and measurement by race, ethnicity, language</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>PF provided timely access to interpreter services</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Navigator programs for minority and underserved patients</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Educational materials at appropriate literacy levels</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Charting and Documentation</td>
<td>PF have full and easy access to paper/electronic record</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Patient and family are able to chart</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
## Appendix F - Gap Analysis

<table>
<thead>
<tr>
<th>Objective</th>
<th>Current standing</th>
<th>Deficiency</th>
<th>Action Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Include ACP as routine component of health care for all residents</td>
<td>Encourage residents to have ACP documentation</td>
<td>Missing, unclear, or incomplete ACP documentation in resident records.</td>
<td>Communicate need for ACP among all adults, especially older adults who are at greater risk for a health crisis.</td>
</tr>
<tr>
<td>Increase awareness of ACP processes</td>
<td>Discuss need for ACP documentation at intake.</td>
<td>No ACP education for residents</td>
<td>Develop and integrate ACP education intervention into existing program</td>
</tr>
<tr>
<td>Ensure individual’s health care goals and</td>
<td>Encourage residents to have ACP</td>
<td>Missing, unclear, or incomplete ACP</td>
<td>Educate residents on necessary ACP processes, and discuss</td>
</tr>
<tr>
<td>wishes are respected and honored</td>
<td>ACP documentation</td>
<td>documentation in resident records</td>
<td>how to communicate goals of care</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>-------------------</td>
<td>-----------------------------------</td>
<td>----------------------------------</td>
</tr>
</tbody>
</table>


**Appendix G – GANTT Chart**
Appendix H – Communication Matrix
A GROUP ADVANCE CARE PLANNING PROGRAM

<table>
<thead>
<tr>
<th>COMMUNICATION</th>
<th>PURPOSE</th>
<th>MEDIUM</th>
<th>FREQUENCY</th>
<th>AUDIENCE</th>
<th>OWNER</th>
<th>DELIVERABLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kickoff Meeting</td>
<td>Introduce project. Perform gap analysis. Review objectives and goals.</td>
<td>In person / Face-to-face</td>
<td>Once</td>
<td>Primary Stakeholders (DNP faculty, Health and Service administrator, Director of Wellness.)</td>
<td>DNP Student (Project manager)</td>
<td>Agenda</td>
</tr>
<tr>
<td>Project Team Meetings</td>
<td>Review status of project</td>
<td>Face-to-face or e-mail</td>
<td>Weekly</td>
<td>Project team</td>
<td>Project manager</td>
<td>Agenda</td>
</tr>
<tr>
<td>Technical &amp; Implementation Meetings</td>
<td>Discuss, review technical &amp; implementation issues, potential obstacles, and solutions.</td>
<td>In person / Face-to-face, or e-mail</td>
<td>As needed</td>
<td>Project Team, may include information technology (IT) and other facility staff.</td>
<td>Project manager, director of Wellness</td>
<td>Agenda. Action Plan</td>
</tr>
<tr>
<td>Project Status Meetings</td>
<td>Update DNP faculty on project status, keep open line of communication with project team and stakeholders.</td>
<td>In person / Face-to-face, and / or e-mail.</td>
<td>Monthly</td>
<td>DNP faculty, Stakeholders</td>
<td>Project manager</td>
<td>Agenda</td>
</tr>
<tr>
<td>Project Implementation Meeting</td>
<td>Review social marketing materials, deliver flyers, and confirm site, location, and time.</td>
<td>In person face / to face and Email</td>
<td>Monthly and as needed.</td>
<td>Project manager Stakeholders</td>
<td>Project manager; Director of Wellness</td>
<td>Flyers, Project schedule</td>
</tr>
</tbody>
</table>

*Communication Matrix table adapted from Team Gantt. (TeamGantt, 2019). Retrieved from https://www.teamgantt.com/communication-matrix-template.*

**Appendix I – SWOT Analysis**

<table>
<thead>
<tr>
<th>Strengths (internal)</th>
<th>Weaknesses (internal)</th>
</tr>
</thead>
</table>
A GROUP ADVANCE CARE PLANNING PROGRAM

- Convenient access to ACP education for residents, staff, and families.
- Seamless integration of intervention into current organizational structure.
- Advance directives are clearly formatted and easy to read.
- Project is aligned with organizations mission and values.
- Minimal extra costs for organization, which only includes the cost of printed materials.
- There is no cost for residents, staff, or family members to attend, unless copay required for ACP group visit.
- May be continued after DNP student completed project.
- Increased understanding of ACP process for attendees and those they share resources with.
- Enhanced relationship with collaborating provider group which DNP student is working with.

- Residents may not attend the presentation.
- May be subject to drop-out, since presentation is divided into two parts.
- Residents may lack trust in organization to keep documents and may not share to be kept in records.
- Difficulty with accurately measuring the impact of the intervention given that not all participants will complete the pre-/post evaluation forms.

<table>
<thead>
<tr>
<th>Opportunities (external)</th>
<th>Threats (external)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased revenue, as the training may be implemented as a medical group visit.</td>
<td>Decreased need for program due to improved ACP practices in primary care.</td>
</tr>
<tr>
<td>Partnering providers may have increased referrals for ACP appointments</td>
<td>Threat of sustainability due to current political climate which poses reduced funding for Medicare and Medical programs.</td>
</tr>
<tr>
<td>May serve as a model which can be implemented at other neighboring facilities</td>
<td></td>
</tr>
<tr>
<td>Increased community awareness of ACP processes.</td>
<td></td>
</tr>
<tr>
<td>Nurse practitioners and Physician Assistants may now sign POLST orders</td>
<td></td>
</tr>
<tr>
<td>Decreased health care costs associated with cost savings from lower health care utilization.</td>
<td></td>
</tr>
</tbody>
</table>

Appendix J - Budget Sheet & Break-Even Analysis

**Cost of intervention**
<table>
<thead>
<tr>
<th>Action</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reimbursement for NP per patient</td>
<td>$73.10</td>
</tr>
<tr>
<td>Investment per presentation</td>
<td>$210.00 (Additional $10.00 estimated for cost of printed materials)</td>
</tr>
<tr>
<td>Break even analysis per presentation</td>
<td>$210.00 / $73.10 = 2.87 (rounded up to 3 whole patients).</td>
</tr>
</tbody>
</table>

*Investment per presentation is based on an hourly rate and cost of printed materials. Salary information was retrieved from Salary.com, which included job title and location.

**Appendix-K Pre/Post Survey**

**Pre-Intervention Survey**

1) What does DPOA stand for?
A GROUP ADVANCE CARE PLANNING PROGRAM

2) If I do not choose a medical decision maker, the medical provider will do what is best for me.
   True   False

3) If I write down my wishes, I do not need a medical decision maker.
   True   False

4) Palliative care is focused on providing comfort at the end of life.
   True   False

5) What does LST stand for?
   _______________________________________________________

6) I have experience with making end-of-life health care decisions for a loved one.
   Yes   No

7) I am confident that my loved ones and health care provider know my health care wishes.
   1   2   3   4   5

8) I am ready to ask someone to be my health care decision maker:
   (1 = Have not thought about it; 3= Have thought about it, but have not talked about it; 5 = absolutely ready; Have talked about it and already have a DPOA)
   1   2   3   4   5

9) I feel confident about talking to my provider about my health care wishes.
   (1 = not confident; 3 = moderately confident; 5 = very confident)
   1   2   3   4   5

10) Who should be part of your Goals of Care conversation?
   •
   •
   •
   •

   Post-Intervention Survey

1) What does DPOA stand for?
   _______________________________________________________

2) If I do not choose a medical decision maker, the medical provider will do what is best for me.
   True       False

3) If I write down my wishes, I do not need a medical decision maker.
   True       False

4) Palliative care is focused on providing comfort at the end of life.
   True       False

5) What does LST stand for?

__________________________________________________________________

6) As a result of attending this presentation I am more likely to discuss my goals of care with my medical decision maker/family/loved ones.
   (1 = not likely 3 = neutral; 5 = Very likely
   1    2    3    4    5

7) As a result of attending this presentation I am more likely to ask someone to be my health care decision maker:
   (1 = Not likely; 2 = Minimally; 3 = Neutral; 4 = Moderately  5 = Very likely)
   1    2    3    4    5

8) As a result of attending this presentation I feel more confident about talking to my provider about my health care wishes.
   (1 = Not confident; 2 = Minimally; 3 = Neutral; 4 = Moderately5 = Very confident)
   1    2    3    4    5

9) As a result of attending this presentation I am more likely to discuss my goals of care with a provider.
   (1 = Not likely; 2 = Minimally; 3 = Neutral; 4 = Moderately  5 = Very likely)
   1    2    3    4    5

10) Did this presentation enhance your knowledge and understanding of the processes and benefits of advance care planning?
    Yes       No
Who should be part of your Goals of Care conversation?

- 
- 
- 

Please describe what you liked most about this presentation.

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

What suggestions/recommendations do you have for ways we can improve this service?

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

Appendix L - Summary of Data

Pre-Intervention Survey: Summary of Data Table

- **Presentation #1**: 14 of 20 (1-14) participants completed the pre-survey
- **Presentation #2**: 13 of 18 (15-27) participants completed the pre-survey
- **Presentation #2**: 8 of 8 (15-22) participants who also attended Presentation 1 completed the post survey

<table>
<thead>
<tr>
<th>Survey</th>
<th>Q 1</th>
<th>Q 2</th>
<th>Q 3</th>
<th>Q 4</th>
<th>Q 5</th>
<th>Q 10</th>
<th>Q 7</th>
<th>Q 8</th>
<th>Q 9</th>
</tr>
</thead>
</table>

Knowledge Questions: 6 Questions
- Q 1: 1 point; Q 2: 1 point; Q 3: 1 point; Q 4: 1 point; Q 5: 1 point; Q 10: up to 2 points

Confidence Questions: 3 Questions
- Q 7: 1 point for >3 or 2 points for >4 on Likert scale; Q 8: 1 point for >3 or 2 points for >4 on Likert scale; Q 9: 1 point for >3 or 2 points for >4 on Likert scale.

Post-Intervention Survey: Summary of Data Table
*Post-surveys were only given to those who attended presentation # 2. Of the 18 participants who attended presentation #2, 10 did not attend the first presentation, and 8 attended both presentation #1 and presentation #2.
- 13 of 18 participants returned post-surveys.
- Post-Survey data for the participants that attended both presentations are numbers 1-8 in the summary table below.
Knowledge Questions: 6 Questions
- Q 1: 1 point; Q 2: 1 point; Q 3: 1 point; Q 4: 1 point; Q 5: 1 point; Q 11: up to 2 points

Confidence Questions: 4 Questions
- Q 6: 1 point for >3 or 2 points for >4 on Likert scale; Q 7: 1 point for >3 or 2 points for >4 on Likert scale; Q 8: 1 point for >3 or 2 points for >4 on Likert scale; Q 9: 1 point for >3 or 2 points for >4 on Likert scale.

Qualitative Questions: 3 Questions
- Q 10: Residents were asked whether or not they believed they gained additional knowledge and understanding of the processes and benefits of ACP.
- Q 12: Residents were asked to describe what they liked most about the presentation.
- Q 13: Residents were asked to describe how the presentation could be improved.

Analysis
I conducted a paired t-test to test for statistical significance using pre and post intervention survey data. I independently tested knowledge and confidence pre and post survey data for the participants that attended both presentations (n = 8/30) as well as the group as a whole who only attended presentation #2 (n = 13/18).
- Each t-test resulted with a p-value ≤ 0.001

I also compared pre and post mean scores for knowledge and confidence questions for each group (Group 1 = participated in presentation #1 and #2; Group 2 = Attended only presentation #2.
- Group 1: The mean Pre-survey score for knowledge questions was 1.25
  - Knowledge improved by 4 points or 320%
- Group 1: The mean Post-survey score for knowledge questions was 5.25
  - Knowledge improved by 4 points or 320%
- Group 2: The mean Pre-survey score for knowledge questions was 1.15
- Group 2: The mean Post-survey score for knowledge questions was 5.38
  - Knowledge improved by 4.23 points or 367%

- Group 1: The mean Pre-survey score for confidence questions was 1.25
  - Confidence increased by 5.63 points or 450%
- Group 2: The mean Pre-survey score for confidence questions was 1.31
- Group 2: The mean Post-survey score for confidence questions was 6.38
- Confidence increased by 5.07 points or 370% 

**Qualitative Data**

- **Q 10**: 100% of participants who completed the post survey ($n = 13$) answered Yes.
- **Q 12**: A few responses included the following remarks:
  - “Gives you everything you need to know.”
  - “Good information about procedures.”
  - “Information about ACP documents and treatments.”
- **Q 13**: One person wrote, “Have people bring their documents... Require documents to be in place within 1 year of residency.” One other person wrote, “presentation is too fast.”
*This graph illustrates the difference of sum scores for each question of the pre and post survey questionnaires. Note one through six are knowledge questions, and seven through 10 are confidence questions. There is no comparison for question 10, because this is a new item on the post survey.

Appendix M – Handouts on LSTs and Self-Reflection Exercise
What is important to you as you think about the future?

Different people want different things. What matters to you should guide decisions about your treatment. Talk with your health care team about what is important and what you want to accomplish. Your health care team can help you decide which treatments and services would best help you reach your health care goals.

What are goals of care?

Goals of care are what you would like to achieve through your health care.

Here are some examples:

- Easing symptoms to make you feel more comfortable
- Staying or becoming independent
- Curing an illness, or improving quality of life when cure is not possible
- Prolonging your life
- Supporting loved ones or caregivers
- Meeting a specific personal goal – like attending a wedding or taking a trip

What should I talk about with my health care team?

- Your medical condition – what it is and how it might change
- What is important to you – in your life, and about your health care
- Your health care goals – what you want your health care to accomplish or avoid
- Which services and treatments would likely help you reach your goals, and which ones would or would not be acceptable to you
- Your health care surrogate – the person you want to make health care if decisions for you if you could no longer make decisions for yourself.

Who should be part of the conversation?

---

1

Who should be part of the conversation?
A GROUP ADVANCE CARE PLANNING PROGRAM

- You
- Your health care provider or team
- Your health care surrogate
- Any other people you want to include

**What can I do to get ready for a conversation about my health care goals?**

- Think about what is important to you
- Think about your goals for your health care
- Invite your health care decision maker – and others, if you would like – to be there with you for the conversation
- Bring your advance directive, if you have one, when you meet with your health care provider or team

2
A GROUP ADVANCE CARE PLANNING PROGRAM

A message for people who make health care decisions for someone who is too sick to make decisions on their own

When a person is too sick to make decisions, the health care team relies on someone close to that person to help them understand what the person would want. If you are responsible for making health care decisions for someone else, your job is to tell the health care team *what that person would say* about their goals and the type of care they would accept. You should make decisions that match that person’s *values, beliefs, and preferences*. If you don’t know what those are, you should make decisions that are in that person’s *best interests*.

**How do I know what the person who is ill would decide?**

Think about what you know about them. What would they say is important to them now? What did they say about other people who were in similar situations? What did they say they would want, or what they would want to avoid? They might have completed an advance directive or life-sustaining treatment plan sometime in the past. Those documents can help you understand what their goals and preferences would be now.

Making health care decisions for others, even when you know what they want, can be stressful. The health care team can help you by providing information and support.
Information About Life-Sustaining Treatments

What are life-sustaining treatments?

Life-sustaining treatments are treatments that might help you live longer when you would be expected to die otherwise. Examples of these treatments are feeding tubes, mechanical ventilation, dialysis, and cardiopulmonary resuscitation (CPR).

Life-sustaining treatments might or might not work to help you live longer. Whether they are likely to work depends on your medical problems. They do not cure disease or chronic illness. Sometimes they are used for a short time to get a person through a health crisis, like when a chronic illness suddenly gets worse or while a person is being treated for a sudden serious illness. They can help some people with certain medical conditions live for a long time. Sometimes they cause complications or discomfort.

Decisions about life-sustaining treatments

Some people would want life-sustaining treatments, and others would not. Some people might want one life-sustaining treatment but not others.

Decisions about life-sustaining treatments should be made based on your goals and your preferences.

Your health care team can give you more information about life-sustaining treatments. Talk with them about how these treatments relate to your health care goals.

Feeding Tubes
What is a feeding tube?

A feeding tube carries liquid nutrition, fluids, and medications directly into your stomach or intestines.

One kind of feeding tube goes into the nose, down through the throat, and into the stomach. It is about one-eighth of an inch in diameter.

Another kind of feeding tube goes through your skin into your stomach or intestines. Putting in the tube requires a minor procedure or surgery.

When might a feeding tube be considered?

A feeding tube might be considered if you:

- Can’t eat enough to meet your body’s need for nutrition
- Can’t eat safely due to swallowing problems

These problems might happen if you are very sick, have brain damage, or have a health problem that affects your nerves and muscles. If you are expected to recover the ability to eat and swallow, a feeding tube might be considered for a short time. If you are not expected to recover the ability to eat and swallow, a permanent feeding tube might be considered.

Sometimes people who have trouble eating on their own (for example, someone with dementia or muscle weakness) can get more nutrition when someone helps feed them. In those cases, a feeding tube might not be needed.

If you have a severe illness that cannot be cured and gets worse over time, getting weaker and not being able to eat enough on your own can be a sign that you are getting closer to dying. Some diseases, in the very late stages, cause your organs to stop processing food and water normally. In those cases, a feeding tube might not help you feel better or live longer.
Benefits and Risks

What are some possible benefits of a feeding tube?

Depending on your condition, a feeding tube might prolong your life.

When your swallowing problem is expected to get better, having a feeding tube for a short time can help improve your nutrition. For example, a short-term feeding tube might help if you are recovering from a surgery or receiving a treatment that makes your throat very sore.

Long-term feeding tubes can help if your swallowing problem is caused by damage to your nerves or muscles.

You do not need to be in a hospital to receive fluid and nutrition through a feeding tube.

With some swallowing problems, there is a danger that food or fluids could go “down the wrong pipe” and go into your lungs. It is not clear that feeding tubes help reduce this risk.

What are some possible risks of a feeding tube?

Feeding tubes can cause bleeding, infection, skin irritation, leaking around the tube, nausea, vomiting, and diarrhea.

The tube can get blocked or fall out, and need to be replaced in a hospital.

You might find the tube to be uncomfortable.

You might inhale fluid into your lungs with a feeding tube. This could cause pneumonia.

Depending on your condition, the feeding tube may not help you feel better, gain weight, become stronger, or live longer. There is no evidence that feeding tubes help people live longer when they are in the last stages of a severe and incurable illness such as dementia or cancer.
What to Expect

What if I have trouble eating or swallowing and I have a feeding tube?

If you are awake and aware of what’s going on, having a tube down your nose and throat can be somewhat uncomfortable. It is usually not painful, and many people get used to it over time.

Having a tube that is placed through your stomach wall is not usually painful, and you can hide it under your clothes.

It is harder to get around when liquid is flowing through the feeding tube.

If you get confused, you might pull on the feeding tube. To prevent this from happening, you might be given medication to make you sleepy, you might have cloth wrapped around your mid-section to keep the tube in place, or you might have your hands covered or restrained.

You would receive care to help you be as comfortable as possible.
What to Expect

What if I have trouble eating or swallowing and I do not have a feeding tube?

Sometimes people who have trouble eating enough on their own can get more nutrition when someone helps them eat. You might continue to take in your favorite food and drinks, with help if needed, as long as you wanted to eat and were able to do so.

You would receive care to help you be as comfortable as possible. Without fluids or nutrition at all, some people might feel hungry or thirsty at first and others may not. You might be given ice chips and mouth swabs to keep your lips moist. The amount of time a person can survive without food depends on their health, body weight, and whether or not they are taking in fluids. Some people who are not eating at all but are taking sips of water have been known to live up to 20-40 days. Some people who are eating small amounts and drinking fluids might live for years. Without any fluid people might die within days to weeks.

In the last stages of severe, incurable illness, when death is near and a person is no longer taking in food or water by mouth, families often worry that the person will “starve to death.” In fact, for people with those medical problems, no longer taking in food and water is a natural, non-painful part of the dying process. In this case, the person is not dying because they have stopped eating, rather they have stopped eating because they are in the dying process.
Information for Patients and Families About

Dialysis

What is dialysis?

Dialysis filters a person's blood to remove waste products when their kidneys can no longer do the job. Dialysis is a type of life-sustaining treatment.

There are two main types of long-term dialysis.

**Hemodialysis** is the more common type of dialysis. In hemodialysis, your blood flows through a tube outside of your body into a filter to remove waste products. A needle is inserted into one of the blood vessels, usually in your arm. The needle is attached to a tube that carries a steady flow of your blood into the filter. After the blood is filtered of waste products, it returns to your body through a second needle that is inserted into another blood vessel. Each session lasts about four hours and must be repeated at least three times a week.

In **peritoneal dialysis**, your blood is cleaned when waste products pass out of the blood vessels of your intestines into clean fluid that is flushed in and out of your belly. Clean fluid from a bag flows through a tube that goes through the skin of your belly into a space inside, around your intestines. The fluid stays there for several hours, and waste products from the blood pass into it. The fluid containing waste products then drains out through the tube and is thrown away. This process is repeated several times a day, or each night while you are sleeping.
When Might Dialysis Be Considered?

In many people with long standing kidney disease, the problems slowly get worse over time. Dialysis would be considered when your kidneys could no longer remove enough waste products from the blood to keep you feeling well, and a kidney transplant was not available. You might feel sick to your stomach, tired, and weak. You could have little appetite and might have swelling. You might also have difficulty breathing or thinking clearly. Dialysis might help to partly relieve these symptoms.

Kidney problems may also come on quickly. If a severe illness causes the kidneys to fail or suddenly get worse, dialysis might be considered to help clean the blood during that time. Sometimes the kidneys start working again after the severe illness has passed. Other times, the kidneys don’t start working normally again, and long-term dialysis may be needed after the severe illness has passed. The kidneys are more likely to begin working again if the person's overall recovery from the sudden illness is good.
Benefits and Risks

What are some possible benefits of dialysis?

Dialysis may prolong your life, depending on your other health problems.

Dialysis may help you feel better. You may feel less sick to your stomach, tired, or weak. You may have less swelling. Your appetite may get better. You may have fewer problems breathing or thinking clearly.

Unless you have other health problems that would prevent you from being active, you may be able to go back to work and participate in activities that you enjoy.

If you are eligible for a kidney transplant, dialysis can keep you alive while you wait for a donor.

What are some possible risks of dialysis? You may feel dizzy, tired, or have cramping after dialysis. Access to your blood vessels (for hemodialysis) or the tube into your abdomen (for peritoneal dialysis) may get blocked. This can cause discomfort, and you may need a procedure to fix the problem. You may be more likely to get infections, and suffer from heart disease and other medical problems. As a result, you may need to come into the hospital more often and stay longer. These problems can also increase the risk of death.

For people with some medical problems, dialysis does not help them live longer or feel better.
What to Expect

What if my kidneys fail and I have dialysis?

You may choose dialysis when your kidneys can no longer remove enough waste products from the blood to keep you feeling well.

If your kidneys fail quickly, a tube will be placed into one of your blood vessels. The tube carries a steady flow of your blood through a filter to clean it. This may be done daily or as needed until your kidneys get better. If your kidneys do not get better, you and your health care team will discuss whether long-term dialysis will help.

For long-term dialysis, you would need surgery to prepare the blood vessels in your arms (for hemodialysis), or surgery to have a tube placed into your belly (for peritoneal dialysis).

Most people receive long-term hemodialysis in a hospital or in a dialysis center, usually three times each week. You may be able to have hemodialysis at home if you have a trained helper. During each hemodialysis session, you would sit next to a machine that removes waste products from your blood. Each session lasts about four hours.

Peritoneal dialysis is usually given at home, and may also be given while a person is at work or traveling away from home. To have peritoneal dialysis, you must be able to do it yourself or have someone who can help you. Peritoneal dialysis is repeated several times a day, or each night while you are sleeping.
What to Expect

More about what to expect with dialysis...

If you receive dialysis, you would have to be careful about the types of food you eat. You would need to limit the amount of salt and certain other foods that you eat, and how much water you drink.

Medicines may be needed to control blood pressure, treat anemia, and prevent bone and heart disease.

You would have to adjust your schedule to allow time for dialysis.

Dialysis is not as good as healthy kidneys at filtering your blood. As a result, you may not feel well.

Most people receiving long-term dialysis have a shorter than normal life span.
What to Expect

What if my kidneys fail and I do not have dialysis?

Most people can live for some time with kidneys that are only partly working. When the kidneys are not working properly, waste products slowly build up in the bloodstream. This might make you feel sick to your stomach, tired, and weak. You might have little appetite and have swelling. You will receive care to help you be as comfortable as possible.

When a person’s kidneys become very weak, death may occur within days to weeks. Death from kidney failure usually involves feeling less and less awake and may result eventually in coma. You will be given treatments to manage discomfort from pain or fluid build-up to help you be comfortable.

Your health care team can tell you if you are at risk for kidney failure. Talk with them about treatment options that support your goals and preferences.
Mechanical Ventilation

What is mechanical ventilation?

Mechanical ventilation helps you breathe when you can't breathe on your own. It doesn't fix the problem that causes you to have trouble breathing. Being able to breathe on your own again depends on whether the problem that causes your breathing trouble improves.

There are two types of mechanical ventilation.

**Non-invasive mechanical ventilation** helps you breathe by pushing air through a mask that is placed over your nose and mouth. Straps keep the mask in place. A machine pushes air and oxygen through the mask, and the pressure of the air helps you breathe. One type of non-invasive mechanical ventilation is called **CPAP** (continuous positive airway pressure) and another is called **BiPAP** (bi-level positive airway pressure).

**Invasive mechanical ventilation** uses a machine to push air and oxygen into your lungs through a tube in your windpipe. The machine is often called a **ventilator**. The tube goes through your mouth or nose, or through an opening that has been made in your throat, through your windpipe to your lungs. The tube is about as big around as a dime.
When Might Mechanical Ventilation Be Considered?

**CPAP or BiPAP** might be considered if you need some help breathing.

A **ventilator** might be considered if your breathing problems are more severe. A ventilator is used to breathe for you when you can’t breathe on your own.

Mechanical ventilation might be considered if you have:

- New or long-term severe lung problems
- Brain damage
- An injury to your spinal cord
- Severe weakness of the muscles in your chest

You might need mechanical ventilation for a few hours, a few days, or the rest of your life, depending on your condition. At first, it might be hard to predict how long you would need it.
Benefits and Risks

What are some possible benefits of CPAP, BiPAP, and a ventilator?
They might make it easier for you to breathe. They might help you breathe while you recover from a serious illness. They might prolong your life, depending on your condition. People with some conditions live for years using mechanical ventilation.

What are some possible risks of CPAP and BiPAP?
You may have a dry nose and sore throat. You may have a runny nose, congestion, and sneezing. You may get nosebleeds. It may irritate your eyes and the skin on your face. You may have abdominal bloating that causes discomfort or nausea.

What are some possible risks of a ventilator?
A ventilator places a person at high risk for infections. You might find a ventilator to be uncomfortable. You might try to pull the tube. To prevent this from happening, you might be given medicine to make you sleepy or your hands might be restrained.

Some people who need a ventilator do not recover to be as healthy as before.

You would need a lot of help. Most people on a ventilator need to be monitored in an intensive care unit or similar setting. Some people can be cared for in a nursing home or in their own home if they have care from professionals for monitoring and maintenance.
What to Expect

What if my breathing problems get worse and I use CPAP or BiPap?

You would wear a mask over your nose, or over both your nose and mouth. Straps would keep the mask in place. The mask would be connected to a tube and a small machine that would push air into the mask.

You could remove the mask if needed.

You would be able to eat and talk.

What if my breathing problems get worse and I do not use CPAP or BiPAP?

If you choose not to use CPAP or BiPAP, you would receive care to keep you as comfortable as possible. You would be offered medications to help you relax so that you do not feel like you have to struggle for breath or feel any discomfort.
What to Expect

What if my breathing problems become severe and I use a ventilator?

A tube would be placed in your windpipe through your nose or mouth and connected to the ventilator. The ventilator would push air through the tube into your lungs. You would receive care to keep you as comfortable as possible.

You might find a ventilator to be uncomfortable. You might need to take medication to make you sleepy or have your hands restrained if you try to pull on the tube.

If you need the ventilator for more than about two weeks, you would need a short surgery to place a hole in your neck where the breathing tube would be placed in your windpipe. This hole in your neck is called a tracheostomy.

You generally cannot talk, eat or drink while on a ventilator, and nutrition will be provided through a feeding tube. In some cases, people who are on a ventilator for a long time can be fitted with tubes to allow them to eat and speak.

Some people who are on a ventilator for a long time can get around in a special wheelchair.

If you need a ventilator for a long time, you might be able to go to a nursing home or your own home. You would need professional care for monitoring and maintenance.
What to Expect

What if my breathing problems become severe and I do not use a ventilator?

You would receive care to keep you as comfortable as possible. You would be given medicines to help you relax or sleep. This would help you feel comfortable and not feel like you have to struggle for breath.

If your lungs fail completely and you have decided not to use a ventilator, you would probably die within minutes or hours.

If you are on a ventilator and decide to stop, you might die within minutes, although you might live for several hours. Sometimes a person unexpectedly survives for several days or even longer.

Your health care team can tell you if you are at risk for serious breathing problems. Talk with them about treatment options that support your goals and preferences.
What is CPR? CPR stands for cardiopulmonary resuscitation. It is sometimes used in an emergency when someone’s heart has stopped beating adequately. Cardiac arrest is another term for when the heart stops beating. If you are in cardiac arrest, blood stops flowing through your body. This means that oxygen cannot get to your brain. Your brain can survive without oxygen for only about five minutes. After that point, you would have permanent brain damage.

CPR can help blood and oxygen flow to your brain while medical staff try to get your heart to beat normally again. This may help prevent brain damage.

- Someone pushing on your chest with their hands (chest compressions)
- Artificial breathing. This might mean that someone breathes from their mouth into yours (mouth-to-mouth), or uses a small bag attached to a mask
- Someone giving you medications to stimulate your heart
- A machine giving you one or more quick electrical shocks to your chest
- Someone putting a tube into your windpipe to help air reach your lungs
When might CPR be used?

You would only get CPR if your heart stopped beating (cardiac arrest). Cardiac arrest can be expected or unexpected. It is a normal part of the dying process. Cardiac arrest could happen unexpectedly because of a sudden severe illness or injury, or due to a heart problem that the person may or may not know about.

Health care staff would automatically do CPR if you went into cardiac arrest, unless you have a Do Not Attempt Resuscitation (DNAR) order. A DNAR order tells health care staff not to do CPR if you go into cardiac arrest. In some places, this order is called a Do Not Resuscitate (DNR) order.

You have a choice about whether or not you would get CPR when your heart stops beating. Your choice about CPR does not affect the care you will receive or your decisions about other treatments.
Benefits and Risks

What are some possible benefits of CPR?

CPR can save lives, especially when given to a young, relatively healthy person right after their heart stops. In some cases, CPR may return the person to the same health they were in before their heart stopped. This is more likely if the person does not have serious health problems, and if CPR is started quickly after their heart stops.

CPR might or might not work to re-start your heart. It is more likely to work if you are relatively healthy before a cardiac arrest. The chances of surviving are a little better if CPR is started quickly after the heart stops and if you receive CPR in the hospital. About one in six people who get CPR while in the hospital survives their hospital stay, and five in six people die. Survival chances for you may be more or less, depending on your health problems.

What are some possible risks of CPR?

CPR often does not work to re-start the heart, especially when given to someone who has more than one illness or a very serious disease.

If you survive after CPR, you may have a sore chest or broken ribs because of the chest compressions. You may have a collapsed lung.

If you do not get enough blood to your vital organs during cardiac arrest and you survive after CPR, you might have serious problems afterward. You might be dependent on others to care for you, have brain damage, or need a breathing machine.
What to Expect

What if my heart stops?

If you have a cardiac arrest, you would lose consciousness and pass out quickly. Once you passed out, you would not feel anything.

If you do not receive CPR, or if CPR does not work to restart your heart, you would die. If CPR works to restart your heart but you do not start breathing on your own, you would be put on a breathing machine (ventilator), unless you have a doctor’s order stating that you do not want to be on a breathing machine. If CPR works to restart your heart, you would receive medical care to treat any problems caused by CPR. Some possible risks of CPR are listed on the page before.

Your health care team can tell you if you are at increased risk for cardiopulmonary arrest. Talk with them about treatment options that support your goals and preferences.
Tell Us What Matters to You

Talk with people you trust and with your health care team about what is important to you, and what you want to accomplish through your health care. Based on your priorities, your health care team can help you decide which services and treatments would – and would not – be likely to help you reach your goals.

Personal Reflection
(check all the answers that apply)

1. Who died in your first personal experience with death?
   - Grandparent/great-grandparent
   - Parent
   - Brother or sister
   - A child
   - Other family member
   - Friend or acquaintance
   - Stranger or a public figure
   - Animal or pet

2. When you were a child, how was death or dying talked about in your family?
   - Openly
   - With some sense of discomfort
   - As though it were a taboo subject
   - Do not recall any discussion

3. What does death mean to you?
   - The end; the final process of life
   - The beginning of a life after death; a transition, a new beginning
   - A kind of endless sleep; rest and peace
   - End of this life, but survival of the spirit
   - Other (specify):

4. What about your own death concerns you most?
   - I could no longer have any experiences.
   - I am afraid of what might happen to my body after death.
   - I am uncertain about what might happen to me if there is a life after death.
   - I could no longer provide for my family.
   - It would cause grief to my family and friends.
   - There would be some things left undone.
   - I have no concerns about my death.
   - Other (specify):

5. What about the process of dying concerns you most?
   - It would be long and painful.
   - Being a financial burden to my family
   - Causing my family to suffer
   - Being dependent on others to care for me
   - Losing control of my mind and body
   - I am not concerned about the process of dying.
   - Other (specify):

(Continued on back)
6. How large a role has religion played in your attitude toward death?
- A very significant role
- Influential, but not a major role
- A relatively minor role
- No role at all

7. If you were told that you had a limited time to live, how would you want to spend your time until you died?
- I would pursue personal pleasures (travel, adventure, chocolate).
- I would prefer being alone: reading, thinking, or praying.
- I would shift from my own needs to a concern for others (family, friends).
- I would try to tie up loose ends.
- I would try to do one important thing.
- I would make little or no changes.
- Other (specify):

8. If or when you are married or have a long-term partner, would you prefer to outlive your spouse/partner?
- Yes, I would prefer to die second and outlive my spouse/partner.
- No, I would rather die first and have my spouse/partner outlive me.
- It doesn’t matter to me.
- This question doesn’t apply to me.

9. If you had a choice, what kind of death would you prefer?
- Sudden, unexpected death
- Quiet, dignified death
- Death in the line of duty
- Death after a great achievement
- There is no “appropriate” kind of death.
- Other (specify):

10. What is one thing you would want to say to someone special before you die?

The Center for Healthcare Decisions developed this questionnaire, based in part on Edwin Schneidman’s “You and Death: An Exercise.” For more information, contact the Center for Healthcare Decisions at (916) 851-2828.