

END OF LIFE DISCUSSIONS IN THE COMMUNITY

End of Life Discussions in the Community

A doctoral project submitted in partial fulfillment of the requirements

for the Degree of Doctor of Nursing Practice

by

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Abstract

Background: Advance Care Planning (ACP) is a process of review and discussion between patients, family members, and healthcare providers that focus on goals of care rather than specific treatments. Advance Care Planning should be initiated and implemented by the health care provider before the patient is terminally ill or develops diminishing cognitive abilities.

Purpose: The PICOT question of this project is “In community dwelling residents age 50 or older, with a chronic medical condition, does having an ACP discussion with a healthcare provider increase the likelihood that a patient and /surrogate decision maker will be comfortable stating his or her ACP wishes and making an Advance Directive (AD) ?”

Method: The Stetler Model was used to guide implementation of the project. The Gunderson Lutheran “Respecting Choices Patient Centered Advance Care Planning (PC-ACP) was used to guide the discussion about advance care planning,

Results: Twenty two (22) patients were recruited from senior community buildings owned or managed by National Church Residences (NCR), and given the Health Care Directive form pre and post intervention to review possible changes in their decisions based on the intervention.

Conclusion: This Project promoted open discussions with patients, family members, and healthcare providers about patient wishes and preferences, before the patient became gravely ill or experienced diminished cognitive abilities. Though limited by a small sample size, the results showed a tendency for patients to want to limit life sustaining treatment if they became terminally ill or in a vegetative state. Surrogate decision

makers also were more confident that they would be able to advocate for their loved ones and had a better understanding of their wishes for end of life.

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Description of Problem

Many adult Americans desire to die at home and avoid life support if terminally ill, but more commonly, one in five Americans dies in or shortly after admission to the Intensive Care Unit (ICU). Approximately half of all United States (U.S.) deaths occur in a hospital with more than twenty percent of all U.S. health care dollars being spent on patients in the last year of their lives (Halpern, 2012). The emotional and financial cost of caring for terminally ill loved ones can be overwhelming, with 10-16% of families having to take out a loan or mortgage, spend all their savings, or obtain another job to cover medical costs. Seventy seven percent of caregivers report missing work due to their caregiving duties (Donley & Danis, 2011). More often, patients and loved ones express the desire to have involvement in decision making related to end of life care and to choose where and how to die, rather than just hope for a peaceful death. Organizations like Aging with Dignity, the Conversation Project, and many others encourage patients, family members, and health care providers to sit down and discuss end of life decisions in advance, before patients are unable to express their wishes for a peaceful death (Aging with Dignity”, 2012). This project explores end of life discussions, identifies a PICOT question, and describes the framework guiding the project. Also included is a review of the pertinent literature and appraisal of the evidence. Finally, it discusses implications for practice and develops an initial plan of action for implementation of advance care planning.

Prevalence of Problem

Even though medical technology has advanced dramatically since the 1970s, health care providers' willingness or ability to discuss the course of disease and its trajectory has not advanced (Lokker, 2012). If the patient is aware of the progression of disease and the prognosis or potential outcomes, this knowledge may allow health care providers to help patients evaluate their goals and avoid poorly considered decisions (Lokker, 2012). If patients are only approached near the time of their death to discuss their end of life wishes, then opportunities are lost to help patients be more fully involved in developing advance directives and choosing where and under what circumstances they wish to die. The One Slide is a quick outline of the most important questions that health care providers and patients need to discuss, and that family members need to ask of their loved ones. It provides a minimal script that broaches the subject to get patients, families, and health care providers talking about end of life care, (Appendix A, The One Slide). If at least these questions are asked, then a further discussion can be planned later to get more information or allow a patient to confer with their family.

The impact of not having communicated or not developed Advance Care Plan is enormous for the patient as well as the family. The economic impact can be substantial, with one study noting that 10-16% of families with a terminally ill family member have to take out a loan or mortgage, spend their savings, or get another job to cover costs of medical care. Patients can feel guilty about the financial toll their illness places on their loved ones and can feel helpless about the financial fallout that might occur after their death (Donley & Danis, 2011). Emotionally, the impact is more profound. Without Advance Care Planning, patients may die, not at home with their family and friends to comfort them, but in an

ambulance, the emergency room (ER), or in the Intensive Care Unit (ICU). Patients and families still pursue unrealistic treatments, desperately hoping for a cure, with the eventual death leaving surviving family members with guilt and regret (Murray & Jennings, 2005). Equally disconcerting, even with all the treatments and medications that are available to alleviate pain and suffering, is that many people still die in severe pain due to lack of provider training, unnecessary regulations that impede practice, and financial barriers that limit access to hospice and palliative care during the course of the illness and at the end of life (Murray & Jennings, 2005).

The SUPPORT Trial A landmark two year observational and two year controlled clinical trial published in 1995 sought to improve end of life decision making and decrease frequency of a painful and prolonged dying process. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) (JAMA, 1995) followed 9105 adults with one or more of 9 (nine) life-threatening illnesses with a 6 month mortality rate of 47%. Trained nurses met with patients, families, physicians, and hospital staff to elicit care preferences. The phase I observational trial noted deficiencies in communication, frequency of aggressive care, and characteristics of hospital death. Only 47% of physicians knew when patients wanted to avoid forego cardiopulmonary resuscitation (CPR), 47% of Do Not Resuscitate (DNR) orders were written within 2 (two) days of death, 38% of patients who died spent at least 10 days in intensive care, but more importantly, during the phase II intervention, there was no improvement in communication or promotion of a peaceful death with only 37% of control patients and 40% of intervention patients discussing CPR preferences (JAMA, 1995). The in-hospital death characterized in the SUPPORT trial demonstrated uncontrolled pain, prolonged suffering, and caregiver

distress. Significant confusion and moderate anxiety were present in 25% of patients near the end of their life (Collins, Parks, & Winter, 2006). Data from SUPPORT also reveals that surrogates who are asked to demonstrate “substituted judgement” to interpret how the patient, if able to understand circumstances, would make treatment decisions, was poor, with surrogate understanding of patient preferences only slightly better than chance (Collins, et al 2006). Later studies looking at surrogate inaccuracy demonstrated that access to a patient’s Advance Directives did not improve proxy accuracy. Other reasons for the discordance is that surrogates routinely underestimate patient preferences for less aggressive end of life care, their own values impact their decisions, and depression and anxiety are common in surrogates and may affect decision making accuracy (Collins, et al 2006). Even if patients have completed an Advance Directive, and it is available to the health care provider, and the surrogate decision makers are aware of what it states, many times it is not respected.

Several barriers affect health care providers’ willingness to discuss end of life care: lack of provider education, inadequate methods to provide information, lack of protocols for communication, reluctance to discuss death, difficulty discussing the unknown, projecting undesirable outcomes, asking patients to make decisions about an uncertain “future self”, lack of shared understanding of values among the patient, family, and health care provider (Waldrop, 2012). A multi-center trial with 53 patients and 43 physicians demonstrated that patients wanted providers to be honest about end of life issues and wanted their physician to play an integral role in discussions and expected outcomes. They also wanted information earlier in the course of their disease (Pfeiffer, Sidorov, Smith, Boero, Evans, Settle, et al, 1994).

Unfortunately, even if an Advanced Directive is available, it typically is not used since health care providers are unaware of its existence, or it addresses a hypothetical medical catastrophe that may not be relevant to the patient's particular situation, or it may speak to interventions like CPR that might help a healthy individual who has a sudden accident or heart attack, but would be of limited benefit to an elderly patient with advanced illness or frailty (Tuohey & Hodges, 2011). Many web sites and organizations have been developed over the last several years to encourage discussion with patients and decision makers about what a patient's end of life wishes are and how to discuss these with family and other loved ones (See Appendix B, Websites to help end of life discussions).

Significance of Problem

The Patient Self Determination Act (PSDA), signed in 1991, was a federal mandate allowing patients to accept or refuse treatment, and be given information about ADs on admission to a health care facility. Efforts to promote use of Advance Directives have experienced only limited success, with only 5-15% of patients having a completed Advance Directives (Waldrop, 2012). Advance Care planning is a process of review and discussion among patients, family members, and healthcare providers that focuses on goals of care rather than specific treatments. Advance Care Planning should be initiated by the health care provider well before the patient is terminally ill or develops diminishing cognitive abilities (Waldrop, 2012).

Forms that may be used to assist with Advance Care Planning include Living Wills: documents which explicitly state patient preferences, usually regarding life sustaining treatments such as renal dialysis, feeding tubes, antibiotics, mechanical ventilation, and pain control; Durable Power of Attorney for HealthCare (DPOAHC): a documents which names

a surrogate decision maker in the event the patient cannot speak for him or herself. Another document developed at the University of Oregon twenty years ago with is gaining broader support in several states, is the Physician Orders for Life Sustaining Care (POLST/MOLST). This is a medical order developed with the patient and health care provider, which follows patients throughout the health system and translates the patient or surrogate decision maker's precise wishes for end of life care into specific medical orders that pertain to the patients care. The goal of this form is to ensure shared and informed medical decisions. This document is implemented in part or whole in 30 states, with programs being developed in 26 more, including Ohio (Bomba, Kemp, & Black, 2012). Do Not Resuscitate (DNR): a document which states that if a person's heart or breathing ceases, that only comfort will be provided and attempts to restart the heart or breathing via CPR will not occur. (Dea Moore, 2007). Finally, Allow Natural Death (AND) was developed in 2000 by Reverend Chuck Meyer as an alternative to a traditional DNR, which to some people implies that no care whatsoever will be provided if the patient is dying. To some people, DNR orders are considered "passive orders...., which are a crisis response and not a plan to help a patient die comfortably" (Schlairet & Cohen, 2013). Allow Natural Death orders allow non- interference with a natural process but interventions to be provided or withheld are clearly discussed and documented, (Schlairet & Cohen, 2013). By using Allow Natural Death orders, health care providers can direct patients and surrogate decision makers in more detail to gain an understanding of natural death to help selectively refuse treatments that might prolong life and promote a peaceful death (Schlairet & Cohen, 2013).

The benefit to a written health care directive is the patient's ability to provide clear documentation of his/her intentions (Ward, 2009). The purpose of the discussion however,

should not be simply to get forms signed, but to discuss with patients and families their desires and goals regarding treatment, including benefits and risks of treatment, issues related to medically futile care, and withdrawing or withholding treatment (Dea Moore, 2007).

Purpose and Goal of Project

Purpose Statement

The purpose of this Evidence Based Practice (EBP) project was to determine if having a Advance Care Plan discussion with patients and surrogate decision makers using the Respecting Choices PC-Advance Care Planning format increases the likelihood that a patient is able to articulate his or her desires for end of life care to the decision maker and then to have them documented so that the decision maker and provider can understand and advocate for the patient's wishes regarding treatment and care.

PICOT Question

(P) Population of interest- patients 50+ years of age in a community living facility (independent or assisted living), with at least one comorbidity and their surrogate decision makers

(I)- Intervention of interest- discussion and education of end of life care with patient and decision maker using the Gunderson Lutheran Respecting Choices Patient Centered Advance Care Planning interview (PC-ACP).

(C)- Comparison group- patients who do not have an end of life discussion or an Advance Care Plan

(O)- Outcome- documentation of end of life discussion and preparing an Advance Directive (living will- durable power of health care, or DNR), modifications in answers

regarding end of life preferences by the subject after Respecting Choices PC-ACP interview compared to prior to interview and change in answers for comfort with role of surrogate decision maker after the Respecting Choices PC-ACP interview

(T)- Time- 60 days

Theoretical Frameworks

Glaser and Strauss- Levels of Awareness

In 1966, Glaser & Strauss discussed how patients in hospital settings became aware of their impending death and how clinicians tended to avoid discussing it with patients, hoping the patient would figure it out on his or her own. They developed four “awareness contexts” based on the awareness of the health care team, patient and family awareness of the patient’s status, and their recognition of each other’s awareness (Glaser & Strauss, 1966). Closed awareness: the patient is unaware of his terminal state but everyone else is aware. This may be due to the family and health care team belief that the patient might not be able to cope with full disclosure of the severity of the illness. Suspected awareness: The patient suspects what everyone else knows; this may be triggered if the health care team and the family have inconsistent communication and behavior. Mutual pretense awareness: Everyone knows the patient is dying but pretends otherwise. Open awareness: Everyone knows the patient is dying and acknowledges that fact (Glaser & Strauss, 1966). If a person and his family are in closed awareness, then it is unlikely that any discussions about end of life care will occur. Patients who are aware of the imminence of death are more likely to die peacefully and more likely to feel like life was worth living (See Appendix C, Levels of Awareness).

This model is crucial to Advance Care Planning and this project. If the patient and surrogate decision makers are not at the same level of awareness, then end of life discussions will not occur and the surrogate decision makers cannot advocate for the patient. Many times, the patient is aware of his increasing debility and severity of illness, but the surrogate decision maker is not, leading to lack of communication about the benefit or futility of continuing medical treatments related to the patient's quality of life goals.

Trajectories of Illness

One hundred years ago, most deaths were sudden, usually caused by accidents, infection, or complications from childbirth. In developed society, deaths are usually attributable to serious progressive illnesses (cardiovascular or pulmonary disease, or cancer), which limits a person's usual activities increasingly until death occurs. (Murray, Kendal, Boyd, & Sheikh, 2005). Three distinct illness trajectories have been developed, which are crucial to helping a patient and family prepare for end of life planning (see Appendix A). Progressive Chronic Illness: usually cancer, involved progressive predictable decline over weeks, months, years, with weight loss and increasing debility occurring in the last months before death. This generally provides time to anticipate palliative needs and provide end of life planning. Organ Failure: This trajectory covers patients with cardiovascular, pulmonary, or other chronic organ failure; this is characterized by long periods of chronic illness, with occasional, acute exacerbations requiring intensive treatment with possible hospitalization. Each exacerbation may result in death; if the patient survives the episode, there is a progressive deterioration overall, but the timing of death is not clear. There may be periods of acute deterioration, some recovery, and sudden (perhaps unexpected) death. Finally, there is Progressive Disability: This is characterized by either

brain failure related to dementia, or generalized fragility, where patients loses weight and functional capacity, then finally succumbs to a relatively minor event that would not affect a health person, but in conjunction with declining abilities may prove fatal to this patient. Death then occurs unexpectedly after a sudden illness or acute event.

Trajectories of illness are important to Advance Care Planning and this project since if a patient and Surrogate decision maker understand the disease process and likely course of illness, they are more able to anticipate end of life needs and possible time periods to consider, as well as what treatment options would help or hinder the patient's quality of life goals (See Appendix C, Trajectories of Illness).

The Stetler Model

The Stetler model will be used to guide this project and has five steps, preparation, validation, comparative evaluation/decision making, and translation/application. This model defines evidence as “information or facts that are systematically obtained” and this evidence can come from different sources and can vary in the degree it is systematically obtained (Ciliska, 2011). The Stetler model, (See Appendix D), is known as a practitioner oriented model because of its focus on critical thinking and ability to be used by an individual practitioner (Ciliska, 2011).

Steps to using the Stetler model are:

- 1) Preparation: define and affirm a priority need- search, sort and select sources of research and supplemental evidence, consider influential factors, affirm nature, degree, and priority of problem, and define purpose and outcomes per issue.
- 2) Validation: assess evidence by critiquing each study with a utilization focus in mind. Perform utilization focused critique and synopsis per source, synthesize findings, and evaluate common aspects per criteria.
- 3) Comparative evaluation/decision making: making decisions about use after synthesizing the data using a set of utilization criteria then deciding if and what to use based on the identified need. (Fit and qualifiers/ feasibility/substantiating evidence/current practice). State decisions re: use of findings per strength of overall evidence.
- 4) Translation/application: converting the findings into a type of change to be made, planning application, putting plan into action, and then enhancing adoption and implementation with evidence based change plan. Confirm type, level and method per details/qualifiers.
- 5) Evaluation: evaluation of plan in terms of degree of implementation and whether goals for using evidence were met. Evaluate dynamically, identify goals for each “use,” obtain evidence re: the implementation, approach, targeted practice or system changes, and the result/outcomes (Melnyk & Fineout-Overholt, 2011).

This model was applicable for the project since it is designed for a sole practitioner using critical thinking. This model can be used in a practice setting and allows for variation

in the context of an individual patient's preferences and circumstances (Ciliska, 2011), which are necessary when discussing end of life decisions with patients and loved ones.

Review of Literature

Search Strategies

Databases searched included OhioLink, Google Scholar, Ebsco, Proquest, and EJC. These databases were utilized because they represent a wide range of healthcare related journals. The literature search began in February, 2013 and was ongoing during the project. Key words for search included "End of Life" and "Primary care" and "Primary care " and "discussions, "Do Not Resuscitate," "advance directives," "patient preferences",, "protocols", "code status," "advance care planning", and "palliative care," POLST, trajectories of illness, trajectories of dying, ALLOW Natural Death, end of life guidelines, protocols and palliative care, Medical Directives, and health care directives.

Critical Appraisal and Evaluation of the Evidence

For this project, articles were reviewed for the following: time relevance (since 2000), primary care focus, tools to improve end of life discussion, and research articles or protocols and guidelines to implement end of life discussions in primary care. Research was excluded if it was published prior to 2000 unless it was a seminal document or it was not primary care based. Research was excluded if it singularly focused on emotional aspects related to dying or palliative care. One study (Schwartz, Wheeler, Hammes, Basque, Edmunds et al (2002) was evaluated using the AGREE too (See Appendix E Literature Synthesis).

Literature was searched from 2000-2014 looking at studies related to Advance Care Planning and Advance Directives. Terms used included "primary care" + "advance

directives/"end of life"/"DNR", POLST, Allow Natural Death (AND), /"protocols"/"treatment preferences"/"palliative care/medical directives/Advance care planning." The most successful research was obtained through OHIOLINK, though Cochrane database and EvidenceUpdate also provided data. Because of the landmark nature of the SUPPORT trial, it was included even though it was outside the desired time frame.

Articles Included: Any articles pertaining to completion of Advance Directives, barriers to completion, stability of end of life preferences over time, and emotional aspects to promote end of life discussions. Because discussing end of life care is so emotionally fraught, literature on factors to promote Advance Directives discussions was included as well as those focusing on Primary Care Provider's role in promoting discussion. Also included is research on Advance Directives that discussed whether surrogate decision makers could understand an AD from a loved one. Literature which focused on the AD process (not just the form) was also included.

Literature excluded: was written before 2000 unless seminal research (SUPPORT trial), theoretical articles that were not research based, articles linking AD with other topics such as organ donation, articles on palliative care that did not address AD completion, and any research solely discussing hospice, since hospice is a more type of end of life care, and not specifically related to completion of an Advance Directive.

After evaluating the available research, it is evident that promoting discussions regarding Advance Directives and its preparation remains problematic. However, the Respecting Choices Advance Care Planning program developed at Gunderson Lutheran Medical Center is showing great promise. An early study by Schwartz, Wheeler, Hammes, Basque, Edmunds et al (2002) using this program illustrates positive results in 61

ambulatory geriatric patients with the majority of patients/surrogate decision makers showing congruence in their understanding of patient goals of END OF LIFE treatment. However, this study is limited by the small sample size. Two studies by Kirchhoff, Hammes, Kehl, Briggs, and Brown (2010, 2012) also have shown success in improving patient end of life care with regards to their desired wishes in surrogate decision makers (2010), and in patients with specific medical diagnoses both using 313 patient/decision maker pairs. More recently, a retrospective study in 2014 looking at the use of Respecting Choices among 722 hospitalized patients looked at Advance Directives in minorities compared to white patients did find significant improvement in the use of Advance Directives among minorities, (25.8 & to 38.4%), though not in white patients, (35.9 % to 42.9%), with high consistency for all orders (74%-96%) (Pecanac, Repenshek, Tannenbaum, and Hammes, (2014).

Recommended Practice Change

End of life discussions are not always effective despite the use of multiple approaches. While much research identifies the need for end of life discussions, and desire of patients to have the conversation while still healthy, patients and family members do not have the discussion and health care providers often do not initiate the conversation. Even if the discussion does occur, the family is often unable or unwilling to advocate the patient's wishes to the health care providers, the patient is unable to advocate for himself, or the health care provider does not follow the advance directives.

Rationale from Literature

The Agency on Healthcare Research on Quality (AQHR) has published protocols and guidelines on AD in nursing homes, for disease management, and for patients with cancer,

but many of the interventions used in research only modestly increased the number of advance care planning discussions or preparation of Advance Directives. Most evidence is level 3 or 4, and only 4 random controlled studies (RCT) were found in the literature, likely due to the sensitive nature of the topic. Three of the studies, (Schwartz, 2002, Kirchhoff et al, 2010 and 2012), did find significant improvement in Advance Directive preferences being documented and followed using a training program Patient Centered- Advance Care Planning from Gunderson Lutheran Health system. Most review of literature focused on emotional aspects of end of life care, barriers to discussions both for patients and providers, and how patients and providers felt about having or not having a discussion about end of life care.

Studies by the Agency for Healthcare Research & Quality show that patients are willing to discuss end of life care but most patients have not participated in those discussions with their health care providers. Patients are more likely to accept or refuse treatments based on how invasive the treatment might be or how long the treatment might last. They are more likely to accept CPR vs. long term ventilation if they are in their current state of health. If they are given a hypothetical situation involving a stroke, fewer patients want either CPR or long term ventilation (Advance Care Planning, Preferences for Care at End of Life, 2003). They recommend that hypothetical scenarios be used to help patients identify their opinions on certain treatment patterns (Advance Care Planning, 2003). The following steps are recommended to encourage discussion about Advance Directives:

1. Initiate a guided discussion: use hypothetical scenarios related to a patient's particular situation and find out patient preferences under certain circumstances

2. Introduce the subject of Advance Care Planning and offer information: encourage patient to fill out both a Living Will and Durable Power of Attorney for Health Care.
3. Prepare and complete Advance Care Plan documents: standard language is often not specific enough to be helpful at directing care. If a patient does not want a ventilator, the provider should clarify if that is true under all, or only some, circumstances.
4. Review the patient preferences regularly and update documentation: remind the patient that documents can be revised at any time and the provider should note what preferences change, and what stays the same
5. Apply the patient's desires to actual circumstances: Patient's treatment was considered generally consistent with their preferences if those were clearly stated in an Advance Directives and the provider was aware the preferences. Even if a decision is needed for an unanticipated situation, providers and surrogate decision makers can make an educated guess based on knowledge about the patient's goals and thresholds for treatment (Advance Care Planning, 2003). Research has shown that patients are more likely to accept treatment for conditions they consider better than death, and refuse treatment for conditions they consider worse than death (Advance Care Planning, 2003). Options that are more invasive (mechanical ventilation or dialysis) may be less acceptable than less invasive treatments (CPR or antibiotics) (Advance Care Planning, 2003).

Very little research has been done on how to promote end of life discussion or completion of Advance Directives in healthy adults who live in community living

settings. Recent studies in 2010 and 2012, as well as an earlier study in 2002, have showed promise by presenting information more focused towards patients' end of life wishes and goals rather than simply educating about the need to fill out specific forms. None of the studies however, were done in a community setting to evaluate if the Respecting Choices Advance Care Planning Facilitator training would enhance discussion and decision making. In addition, the studies were done in Wisconsin, which has a wider acceptance for Advance Directives due to the work of Gunderson Lutheran in promoting Advance Directives, and a smaller minority population. Of note, the Agency for Healthcare Research & Quality innovation webpage (2013) discusses the use of the Respecting Choices training program and its effect on Advance Care Planning, not only in Wisconsin, but in Minnesota and Australia.

Implications for Practice

The Agency for Healthcare Research & Quality recommends that patients be asked about end of life preferences at regularly scheduled outpatient visits and when a provider could ask him or herself if they would be surprised if a patient had died in the next year, or within 6 months (Advance Care Planning, 2003). Patients should be screened at their initial visit and if they say they have an Advance Directive, it should be obtained and documented in the patient chart. The health care provider should then ask about and document the presence and type of advance directive. The health care provider should then make every effort to schedule an appointment at a later date to discuss the Advance Directive in detail and document the findings. The non-professional staff can print out and give any desired forms to the patient and answer simple questions. If needed, the questions can be routed to the provider through a telephone consult so the question can

be answered in a timely fashion. Existing patients should have their charts reviewed at least annually during their Medicare wellness visit or wellness visit by their private insurance carrier. Patients who only come in for ill visits should be asked about an Advance Directive and asked to provide one if available, or schedule an appointment to discuss.

Methods

Implementation

Initially this project was set for a family practice setting in Tallmadge, Ohio, and for the year prior to the study, attempts were made to educate the patient population on the need for Advance Care Plan during scheduled office visits. Patients were asked, “Who is the person who would be your medical decision maker if you could not speak for yourself?” or “have you discussed with them what you would want?” Patients were then offered information from the brochure “Conversations that Light the Way” (www.lucas-co-probate-ct.org/forms/MiscCourtForms/conversations.pdf) and the Ohio Living Will and Durable Power of Attorney-HealthCare if they were interested. Most patients admitted they had not considered an Advance Care Plan, though many were aware of its necessity. Numerous patients were grateful for the opportunity for assistance to have the discussion and document their wishes, or for the opportunity to discuss wishes of family members. However, several barriers affected the ability to proceed with this process. Elderly patients who came in for acute medical visits were not always interested in the discussion, and patients who came in for chronic medical visits already had numerous other issues to address. Family members of elderly patients were often suspicious as to why this question was being asked of their 98 year old mother when she just “came in for a cold.” Time

constraints were also a limiting factor as these discussions tended to take more than the allotted time. Asking patients to come back to have this discussion was problematic as many patients were on fixed incomes and thus could not afford another copay, did not have transportation and had to rely on others, or simply were not concerned. Even more challenging was the lack of administrative support. Though other physicians in the practice agreed that it was a necessary discussion, they were not willing to address the sensitive topic of advance care planning to their patients. Another concern was that the practice owner did not feel patients would be receptive a formal interview discussing advance care planning and that the project may have a negative impact on the practice. Fortunately, National Church Residences, whom the researcher had used for other clinical projects, recognized the need for this project and the benefits of advance care planning as a critical aspect of providing holistic care for its' residents, and graciously stepped forward to implement the project.

Respecting Choices Program

The Respecting Choices Patient Centered Advance Care Planning facilitator certification is a copyrighted training program developed by Gunderson Medical Foundation which includes several hours of online training and continued training onsite. The goal is to train interested persons in protocols to initiate discussions with patients and decision makers through a series of questions to help direct the process of Advance Care Plan by identifying decision makers, goals of treatment for the patient, and identifying any religious, personal, or cultural views that would affect treatment choices. The program acknowledges that the discussion is not a “static” one time discussion, but is fluid and needs to take place over time as the patient’s health changes. A key element is identifying the surrogate decision

maker and his/her willingness to advocate for the patient should it become necessary. (First Steps ACP facilitator training manual). Because this Patient Centered-Advance Care Plan is a structured interview technique, facilitators are encouraged to adhere the wording of the script. If a facilitator does not know an answer about the client's health care, likely course of disease, or possible outcomes they are instructed to help the client make a list of questions for his healthcare provider.

The Health Care Directive

The Health Care Directive (See Appendix L) was a tool initially developed by Linda Emanuel in 1989 (Emanuel & Emanuel, 1991), and modified in 2004, to help individuals develop a plan of care for which interventions (CPR, ventilator support, artificial nutrition, surgery, dialysis, blood transfusion or simple diagnostic testing) they would want if they had a medical emergency, and were unable to speak for themselves. These interventions were then graded on a scale of 1-3; with 1 being "comfort care only"; 2 being "attempt cure" and 3 being "prolong life".

There were six (6) scenarios listed:

1. Coma and no hope of recovery
2. Coma, with small chance recovery, moderate chance of some disability, and large chance no recovery
3. Non reversible brain injury and can't communicate or care for self and terminally ill
4. Non reversible brain injury, can't communicate or care for self and not terminally ill

5. Incurable chronic condition with physical or mental suffering and will eventually cause death, and a life threatening but potentially reversible condition
6. My usual state of health with a life threatening but potentially reversible condition

Agent Comfort Form

The Agent Comfort Form (See Appendix M) was developed by Delta Quest and asked six (6) questions on how comfortable an Agent (the surrogate decision maker) felt being a decision maker for an individual (the Principal). The answers were then scored on a range of 0-4 with 0 being not at all, 1 being a little bit, 2 being somewhat, 3 being quite a bit, and 4 being very much.

The questions were:

1. I feel comfortable being a decision maker
2. I am concerned I will not make decisions reflecting my Principal's wishes
3. I believe I understand my Principals preferences
4. I am not confident I will be able to make important medical decisions in a crisis.
5. I feel adequately informed about my Principal's wishes.
6. The responsibility I have for my Principal's health care decisions is overwhelming.

Project Setting/Population

The setting for this project was senior living communities in the Summit County area managed or owned by National Church Residences (NCR). Subjects were recruited by the Service Coordinators of the buildings using data from the Care Path documentation program used by National Church Residences. Residents had a Mini Mental Status Exam (MMSE) on file as these are done routinely on residents. The project population included any patient 50 and older who had Chronic Obstructive Pulmonary Disease (COPD), Atherosclerotic Heart

Disease (ASHD)/Congestive Heart Failure (CHF), or dementia. Patients and surrogate decision makers were approached and enrolled into the study as a pair. Residents and surrogate decision makers signed consent. The Health Care Directive Form, (see Appendix 11), was given to the patient and an Agent Comfort Form was given to the surrogate decision maker (also referred to as the Agent), (see Appendix 12), before the intervention to see if the patient and decision maker could articulate what the patient (the Principal) would want in terms of end of life care and how the surrogate felt about his/her competency in fulfilling this role. A structured interview was performed and the tools were completed again, after the intervention. Five buildings were used to recruit subjects with a total of nearly 400 potential subjects available for the project. A total of 22 subjects and SDMs completed the intervention and questionnaires.

Human Subject Protection

Human rights were protected by selecting persons who had a Mini Mental Status Score (MMSE) score 23 and above, and who could understand the consent form, sign and participate without undue distress. The surrogate decision maker also signed a consent form. The project was reviewed and approved by the University of Toledo (UT) Institutional Review Board (IRB).

Implementation Plan

The service coordinators distributed information sheets that described the project and who was eligible to participate. Residents who were interested in participating contacted the service coordinators. In addition, informational meetings were held in five buildings in Summit, Portage, and Stark Counties to inform potential participants of the purpose or the proposed project. Service coordinators assisted to contact and set up appointments to recruit

interested participants and surrogate decision makers. Service coordinators made sure there was a documented MMSE on file, and any resident who scored less than 23 was excluded from the study. The investigator contacted the residents to sign the consent and give the Health Care Directive and set up a time to consent the surrogate and give the ACF. The Service Coordinators assisted residents if they had questions about forms and helped collect the forms. The investigator interviewed the resident and surrogate decision maker using Respecting Choices protocol and had them complete a 2nd Health Care Directive and Agent Comfort Form.

Barriers and Facilitators

Initial barriers that required intervention included a lack of willing participants initially when they were not directly approached by the Service Coordinator and encouraged to participate in the study. Residents did not understand the project even after explanation; “I already have my will done”, or insisted that even though they had a decision maker, they would not have time to participate. Several residents reported they had no family or decision maker to help them. Retrieving completed paperwork was also problematic since SDMs were not always prompt in returning their forms. Another barrier was that the Health Care Directive was difficult at times for some residents to fill out, and the Agent Comfort Form had some confusing questions that required some time to answer. The time needed was overestimated and tended to be a barrier to potential subjects. Interviews were scheduled on weekends and evenings to accommodate schedules of decision makers. Service Coordinators who used a more direct approach of actively recruiting residents and explaining why the intervention was needed tended to be more successful at recruiting residents and decision makers. Cost remained an issue since there was no financial assistance and the tools from

Gunderson were purchased from the Respecting Choices Web site. Facilitators were the Service Coordinators, who understood the need for this intervention, and the NCR Corporate office in Columbus was very supportive of the project (See Appendix F, Barriers and Facilitators).

Implementation Process using Stetler Model

Validation. The researcher completed literature review searching key terms, and completed Patient Centered-Advance Care Plan Facilitator training through Gunderson Health systems. The researcher met with stakeholders to discuss roles, and the risks and benefits of project, and obtained permission from the authors to use Health Care Directive, and Agent Comfort Form in the study.

Comparative evaluation/decision making. The researcher finalized the tools for use in project and completed literature review for updated studies.

Translation/Application. The researcher met with National Church Residences marketing director and received permission from National Church Residences corporate office and obtained Institutional Review Board approval. The researcher met with Service Coordinators to review the information sheet and format of the tools to be used. The Service Coordinators distributed information letters, answered questions from residents, reviewed the computer program Care Guide to make sure resident had current MMSE on file to evaluate for cognitive deficits that would affect decision making ability (goal >23). The researcher obtained consent for willing patients and surrogate decision makers, gave the forms to the resident and decision maker, and scheduled interviews for patients and surrogate decision makers.

Evaluation. The researcher continually reviewed the protocols with the Service Coordinators and adjusted the subject recruitment method as well as the collection of completed tools, while simultaneously overcoming identified barriers. The recruitment method was modified towards the latter half of the project to increase Service Coordinator involvement in directly contacting potential subjects, and increasing the number of subjects recruited for participation.

Outcome Measures

Data was collected from the Demographic form, the Health Care Directive, and the Agent Comfort Form. The data was entered into SPSS 21 and results were compared before and after implementing the Respecting Choices interview with subjects and their surrogate decision makers.

Evaluation Process

The outcomes for the project evaluated if subjects and surrogate decision makers were both able to understand what the subject would want in terms of end of life care and then be able to openly discuss these wishes with each other. This project also evaluated how comfortable the surrogate decision maker was before and after the intervention with the role given to them. Data was collected by giving the subject the demographic form to complete and then giving them the Health Care Directive, and giving the surrogate decision maker the Agent Comfort Form pre- interview. These were completed and the Respecting Choices Patient Centered Advance Care Planning interview then proceeded. After the interview, the post Health Care Directive and Agent Comfort form were completed again. The subject was also provided with a Living Will and Durable Power of Attorney-Health Care with instructions to complete if desired. Subjects who expressed an interest in having a DNR

form completed were referred back to the Service Coordinator. The results of the scores from the Health Care Directive and Agent Comfort Forms pre and post interview were entered into the SPSS Statistics Program version 21.0 by the student investigator.

Descriptive data analysis was completed to analyze the data from the demographic form, the Health Care Directive, and Agent Comfort Form.

Outcomes of Project

Presentation of Findings

Thirty subjects and surrogate decision makers completed demographic form and Health Care Directive pre interview forms of the project, but only twenty two completed the pre and post Health Care Directive and the pre and post Agent Comfort Form. Tables listing demographic characteristics, Pre and Post Health Care Directive and Agent Comfort Form answers are listed in the Appendix section (16-18)

Demographics. The 22 subject ages ranged from 58-89, with most ranging from 63-73, 77% were female, most had a high school diploma (31%), while 18% had some high school, and 18% had some college. 86% were white, 77% were Christian, and 50% made <\$12,000. The most common diagnosis was heart disease (77%), and most subjects (63%) had no prior experience with end of life planning or hospice

Health Care Directive data: For all the scenarios, (See Table 2), most of the participants were able, after the intervention to identify which treatments were likely to prolong their suffering, versus reach their stated quality of life goals.

For scenario A (coma), the most startling changes occurred in CPR and diagnostic testing. Subjects choosing comfort care only (CCO) initially was 63%, which rose to 86% after the intervention, while attempt cure decreased 27% to 13%. One participant chose

prolong life prior to the intervention, but none did afterwards. Clients who chose CCO remained stable at 59% while attempt cure increased from 18% to 36%). Prolong life options decreased from 22% to 4.5% after the intervention. This indicates that once participants were able to understand the likely trajectory of their illness, they were better able to identify what treatments would not benefit them. Also, by focusing on an Open level of awareness (Glaser and Strauss, 1966), participants and surrogate decision makers both were able to ask questions of each other about how the other felt about the information they received.

For scenario B (brain injury), the biggest changes were in preference for ventilator support, surgery, and artificial nutrition. Prior to the intervention, (59%) wanted Comfort Care Only (CCO), while after the intervention, this rose to 86%. Similar results were found in surgery preference, where prior to the intervention, 54% wanted CCO, while after the intervention, this increased to 81%. Prolong life remained stable at (9%) pre and post intervention, while attempt cure option decreased from 36% to 9%. Artificial nutrition also showed a similar increase in the CCO option, with 59% requesting CCO prior to the intervention, while 81% opted for CCO after the interview. Attempt cure decreased from 31% to 13%. Prolong life also decreased from 9% to 4.5%. This scenario demonstrated that most subjects were able to understand that a severe brain injury would not improve and that interventions such as CPR, surgery, or artificial nutrition would not improve their condition and allow them to enjoy what they considered an acceptable quality of life.

For scenario C (brain injury-terminally ill), the results were less striking but consistent. For CPR, subjects prior to the intervention chose Comfort Care Only (CCO) 77% prior and 86%, after, but attempt cure decreased from 18% to 4.5% after the interview. For surgery,

CCO increased slightly from 72% to 86%, while attempt cure decreased from 22% to 4.5%. Interestingly, the prolong life option increased slightly from 4.5% to 9%. Again most subjects were able to identify that life prolonging treatments such as CPR for someone who was brain injured and terminally ill would not permit what they considered an acceptable quality of life.

For scenario D (brain injury-not terminally ill), for CPR and ventilator, results were striking: For CPR, Comfort Care Only CCO rose from 72% before the intervention, to 90% after, while attempt cure decreased from 9%, to 4.5%. Prolong life was chosen by 18% prior to the intervention, while only 45% after. For ventilator usage, CCO rose from 68% to 90%, while attempt cure decreased from 13% to 4.5% and prolong life decreased from 18% to 4.5%. Subjects were able to understand that CPR, and ventilator use would simply prolong a poor quality of life and not allow them to live at home.

For scenario E (chronic fatal illness + reversible life threatening), the change for ventilator support was most striking. Prior to intervention, Comfort Care Only (CCO) was 68% while after was 86%. Attempt cure decreased from 22% to 4.5%, while prolong life fell from 9% to 4.5%. Subjects verbalized understanding that using a ventilator to treat them a potentially fatal illness might help them in the short term, but that

For scenario F (current health + life threatening), for CPR and ventilator support the change in answers was evident. For CPR, Comfort Care Only (CCO) was chosen 18% prior to intervention, while 50% chose after the interview. Prolong life decreased from 45% to 13%. In summary, subjects preferred after the intervention to decline CPR, ventilator support, and a feeding tube, or to wish a trial only versus continuing futile treatment. Subjects were surprised to find out how unlikely CPR was to be successful in clients with

chronic medical problems, and were not willing to suffer the likely consequence of needing other medical interventions such a feeding tube or ventilator support afterwards if their family would then have to stop the intervention. Subjects and surrogate decision makers tended to be surprised by the notion that they could decide at any time during any intervention except CPR to place a time limit on how long they wanted to pursue a treatment depending on how successful the treatment was or how invasive or painful it might be. For instance, if a person was not able to be weaned off the ventilator and was unlikely to recover their previous level of function and the next option was a feeding tube, they could elect to stop both of those interventions if desired relating to their goals of comfort and happiness. Surrogate decision makers for the most part were involved in the interview and asked appropriate questions regarding what might be expected from certain interventions and how those interventions might affect the subjects stated quality of life goals.

Agent Comfort Form Data. The Agent Comfort Form data with the most noticeable change occurred in questions 1 “I feel comfortable exercising my role as Health Care Agent for my Principal”, and 4 “I am not confident that I will be able to make important medical decisions for my Principal in a medical crisis”. Participants who answered question prior to intervention chose not at all 4.5%, quite a bit 27%, very much 68%; while after the interview, they chose quite a bit 18%, and very much 81%. This confirmed what was noted with the participants in that when the surrogate decision maker understood the likely trajectory of their Principal’s chronic illness, and were able to openly discuss their fears and concerns, that they were more comfortable with their role. Also, transitioning to an open level of awareness allowed questions about quality of life and outcomes of possible intervention to be answered for both participants and decision makers.

For question 4, “I am not confident that I will be able to make important medical decisions for my Principal in a medical crisis” prior to intervention, not at all 68%, a little bit 13%, somewhat 4.5%, and quite a bit 9.1%. After the intervention, not at all 81%, a little bit was unchanged and very much was 4.5%. The other questions had smaller changes in score but leaned towards more confident and knowledgeable after the intervention.

Surrogate decision makers answered confidently before the intervention that their role was not stressful and they understood what their Principal wanted but afterwards many admitted that they had not understood exactly what their Principal wanted. Surrogate decision makers, during the interview, asked their Principals during the interview to clarify under what circumstances the Principal might want a certain intervention or how long the Principal would want for the intervention to continue before stopping the treatment. Overall, surrogate decision makers felt that even if their answers did not change after the interview, they appreciated the opportunity to sit down and have this discussion with their loved one, as it tended to be useful, as stated by some subjects: “just pull the plug if I am a vegetable.”

Relationship to PICOT question

The PICOT question was answered in that subjects and surrogate decision makers were able to articulate that they did not want to live as a “vegetable” but were not able to articulate in detail what that meant until they discussed what their quality of life goals would be and what was important to them. The outcomes portion regarding the number of subjects who returned an Advance Directive compared to other subjects in the building could not be answered. Due to the short duration of the study, many of the subjects who would have filled out an Advance Directive would have done so after their participation in

the study was complete and most likely would not have notified the Service Coordinator that they had completed the forms.

Most subjects and surrogate decision makers overestimated the effectiveness of CPR during the discussion. After discussion many subjects expressed that they did not want to be on ventilator or have a feeding tube for a non-reversible illness, but would be willing to have CPR or Attempt Cure if they had a chance to return to their current level of activity. They were able to identify and articulate that any attempt at cure be monitored and stopped if their condition did not improve or would require permanent disability. Most subjects and surrogate decision makers felt the interview technique would allow them to continue the discussion between themselves, other family members, and the subjects' Primary care provider. Many subjects requested information on DNR and were referred to their Service Coordinators for help in getting them completed. The researcher did answer the PICOT question, but was unable to recruit enough residents to allow full data analysis as to effectiveness of Respecting Choices interview technique in a larger group of subjects.

Economic Outcomes

The Cost Benefit Analysis of this project has enormous implications. As can be seen from Appendix O, an average hospital stay costs nearly \$2,000/day, while a Respecting Choices Patient Centered-Advance Care Planning certification program costs \$420. Every resident who is able to tell their decision maker they do not want prolonged life support, CPR, or other aggressive interventions to prolong a poor quality of life has the potential to save our health care system millions of dollars, not to mention saving the emotional trauma and guilt for the family (see Appendix N and O).

Discussion

Most of the previous research in Advance Care Plan using Respecting Choices has used participants recruited from hospital settings with dialysis units and cardiac rehabilitation units (Kirchhoff et al, 2012), or ambulatory clinics or physician practices (Schwartz et al, 2002; Kirchhoff et al, 2010), but none have targeted residents living in community living settings. This setting is crucial as these patients may have multiple medical issues that require comprehensive primary care provider visits that may not allow time to address end of life, many patients see multiple specialists who may not be coordinating care effectively, may require more complex home care needs due to multiple hospital stays, may lack surrogate decision makers who can advocate for them, or may have mental health issues that prevent them from articulating their wishes at the primary care visits. Residents may see their health care provider every three months or less frequently, and as has been identified in the literature, most primary care providers are not willing or able to initiate this discussion with their patients. Previous research also did not focus on the potential cost savings of the Patient Centered-Advance Care Planning interview. Other research has focused on using video images to help people with limited health literacy (Volandes et al 2008). Incorporating the strategy of video scenarios in community dwellers may be helpful to evaluate effectiveness of the intervention.

Limitations of Study

Limitations to study included small sample size, which may have been improved by more aggressive identification and contact of potential subjects by the Service Coordinator, who had a much closer relationship and better understanding of that resident's health related issues and social situation. Being approached by a stranger, even if introduced by the Service Coordinator may have been too overwhelming for some residents. Starting earlier in

the process with having Service Coordinators passing out brochures such as “Conversations that Light the Way” to the residents when they had their scheduled interactions, or offering end of life planning brochures or study information to family members in mailings or other informational formats may have opened up discussion and encouraged participants to take part in this study. Other limitations included confusion with Health Care Directive and Agent Comfort Form forms being too complicated for some participants to complete without assistance. Reviewing the tools and rewriting them in simpler terms may help address this issue for the next study.

Future Recommendations and Conclusions

Implications for future policy. Many of the most profound changes in health care (fathers in the delivery room, transparency in understanding health care costs, insurance payment for alternative health care, and open access to medical records), have come from public demand for such innovations. Policy makers have to empower the public by providing financial incentives for health care providers to educate the public on the need for Advance Care Planning. Currently, there is little reimbursement for Advance Care Planning in primary care, and none in home health care or other rehabilitation or nursing home settings. Home health services, nursing homes, and other settings provide a unique opportunity to help patients address these needs as often services are required on a long term basis (such as dialysis or home health), or recurrently for short periods (rehabilitation or nursing homes), where patients may develop trusting relationships with health care providers who are well aware of the likely prognosis of that client’s health condition. Health care payors also need to evaluate continued medical treatments that offer little or no benefit to terminally ill patients or patients with no hope of meaningful recovery. Policy makers need to also look at

funding for training for Advance Care Planning to help offset the cost for small health care organizations that may not be able to provide financial support for their staff to take Advance Care Plan training.

Implications for future practice. Organizations that care for the elderly need to empower their staff to have meaningful discussions with their residents about their end of life wishes in light of their view on quality of life. Nurses and social workers are prime candidates to be offered Patient Centered- Advance Care Planning Facilitator training and use that knowledge to initiate these discussions. The cost of Patient Centered Advance Care Planning training would be an initial barrier but as health care policy changes, this barrier should decrease. The Gunderson training does emphasize that the Patient Centered-Advance Care Planning interview technique is structured and scripted, but open discussion is encouraged between patients and surrogate decision makers and questions that may arise are to be written down and discussed with the patient's healthcare provider. All healthcare providers need to be educated starting early in their programs to view end of life or advance care planning not as an admission of possible failure on their part, but as part of a natural process in which all people need to participate. Health care providers including nurses and social workers need to work as a team to advocate Advance Care Planning participation. This would take the burden off the physician to initiate the discussion and create a pathway that all patients are offered during their care at any stage of their disease. Advance care plans needs to be communicated to all participants and reinforced intermittently as the patient's medical situation changes. Patients with limited education, mental health issues, or lack of a surrogate decision maker would require more one on one assistance using other

modalities. They might benefit from assistance using audio or video tools, or writing a letter to their health care provider stating their end of life wishes.

Residents living in senior communities are perfect candidates to start end of life discussions given they have access to supportive staff who are knowledgeable about how to broach the subject and provide guidance. The Respecting Choices Patient Centered-Advance Care Planning interview technique can be an invaluable tool for Service Coordinators who may have limited comfort and experience discussing end of life plans. The structured interview technique with optional brochures which discuss concepts such as feeding tubes, ventilator usage, and DNR, would provide residents and their surrogate decision makers with tools with which to discuss options with resident's primary care provider. Though the cost of \$400 for the Gunderson training would be difficult for Service Coordinators to purchase themselves, a large corporation such as National Church Residences could reimburse staff and encourage not only Service Coordinators to participate, but also their home health and nursing home staff including social workers, and nurses who are often uncomfortable bringing up and discussing these difficult issues without the healthcare provider leading the way. Residents who do not have surrogate decision makers need to participate in their end of life planning, using other brochures and techniques to document their wishes and discuss those wishes with their primary care provider. A living will can be modified with the addition of a letter written to the resident's primary care provider or loved one, stating their wishes and goals for care. At the very least, every resident should have the opportunity to understand options regarding DNR if desired so that this can be documented to allow a peaceful death in their residence. Residents should be offered this discussion sometime during the admission process, and yearly thereafter or as often as their condition

changes. It should be considered as part of the process every resident participates in, rather than as something that is only offered to residents who have imminent issues.

In conclusion, the Doctorally prepared Advance Practice Nurse is in an excellent position to promote Advance Care Planning in all aspects of health care. By fostering further research on a larger scale on the use of the Gunderson Advance Care Planning protocol in the community, advocating for policy change at the healthcare payor level, and encouraging interprofessional education and reimbursement. As leaders of organizations that provide care to the medically fragile and elderly, Doctorally prepared Advance Practice Nurses can promote end of life care that meets patient, family, and society needs by changing policy so that patients' die where and how they want, families have emotional closure and society does not have to bear such a financial burden providing futile and expensive care at end of life.

APPENDIX A

The One Slide


Can You and Your Loved Ones Answer These Questions?

1. On a scale of 1 to 5, where do you fall on this continuum?

(1) ————— (2) ————— (3) ————— (4) ————— (5)

Let me die without medical intervention *Don't give up on me no matter what, try any proven and unproven intervention possible*

2. If there were a choice, would you prefer to die at home, or in a hospital?
3. Could a loved one correctly describe how you'd like to be treated in the case of a terminal illness?
4. Is there someone you trust whom you've appointed to advocate on your behalf when the time is near?
5. Have you completed any of the following: written a living will, appointed a healthcare power of attorney, or completed an advanced directive?

 [engagewithgrace.org](http://www.engagewithgrace.org) The One Slide Project

Retrieved from <http://www.engagewithgrace.org/Download.aspx>

Appendix B

Websites to Assist in End of Life Decision Making

Conversations that Light the Way retrieved from <http://www.lucas-co-probate-ct.org/forms/MiscCourtForms/conversations.pdf>

Planning Ahead: Have you made a Plan retrieved from http://www.caringinfo.org/files/public/brochures/Conversations_booklet.pdf

Aging with Dignity retrieved from <https://fivewishesonline.agingwithdignity.org/>

End of Life Planning: Starting the Conversation retrieved from http://www.leadingage.org/End_of_Life_Planning_Starting_the_Conversation.aspx
<https://www.aftersteps.com/> (an electronic method to secure ones Advance Directives online)

End of Life Financial and Legal Planning retrieved from <http://www.caring.com/articles/health-directives-and-living-wills>

The Conversation Project retrieved from <http://theconversationproject.org/>
<http://www.considertheconversation.org/adoats>

Engage with Grace: the One Slide Project retrieved from <http://www.engagewithgrace.org/>

Hard Choices for Loving Families retrieved from http://www.hnehealth.nsw.gov.au/_data/assets/pdf_file/0016/54250/HardChoices.pdf

Handbook for Mortals: Guidance for People Facing Serious Illness retrieved from <http://www.growthhouse.org/mortals/mor0.html>

References

Making Health Care Decisions for Others: a Guide to Being a Health Care Proxy or

Surrogate retrieved from

<http://www.montefiore.org/documents/staffing/MakingHealthCareDecisionsforOthers.pdf>

Americans for Better Care of the Dying retrieved from <http://abcd-caring.org>

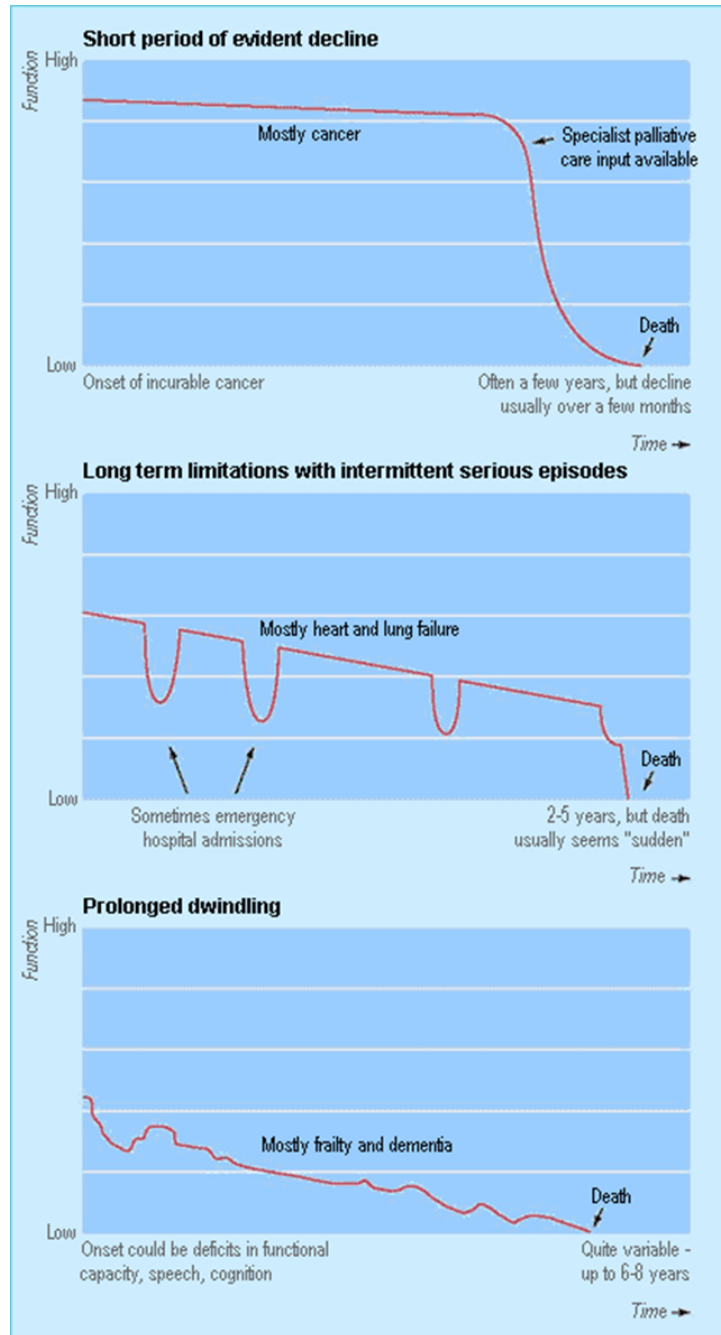
Talk Early, Talk Often retrieved from <http://www.talk-early-talk-often.com/>

Dying Matters: Let's Talk about it Retrieved from

http://dyingmatters.org/sites/default/files/BSA30_Full_Report.pdf

Appendix C

Trajectories of Illness

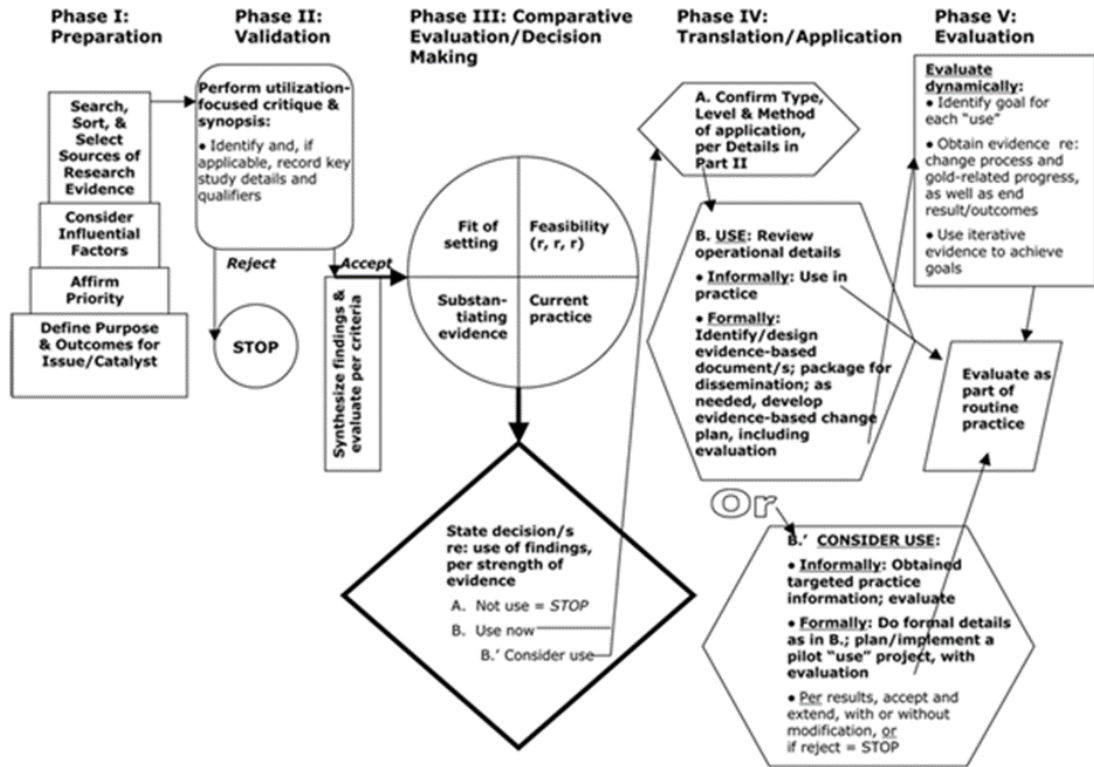


Illness Trajectories Retrieved from

http://www.google.com/imgres?imgurl=http://wildiris4.securesites.net/cms_prod/files/course/332/illness-

Appendix D

Stetler Model



Retrieved from http://www.ktdrr.org/ktlibrary/articles_pubs/ktmodels/#stetler

Appendix E

Level of Evidence

Level I	Level II	Level III	Level IV	Level V	Level VI	Level VII
Level I= systematic review or metaanalysis; Level II= Randomized control study (RCT) ; Level III= Controlled study without randomization; Level IV= case control or cohort studies; Level V= systematic review of qualitative or descriptive studies; Level VI= Qualitative or descriptive studies; Level VII= opinion or consensus.(Melnik & Fineout-Overholt, 2011).						
Author/year	N of participants	Study type	Intervention	Presence of AD/discussion-level of evidence		
Ramsaroop 2007	18 studies	Metanalysis	Multiple types	+AD/ (I)		
Ditto 2001	401	Pilot qualitative	Computer program	+ AD (IV)		
Tung 2011	574/146	RCT	Multimedia	+AD (II)		
Wissow 2004	2120	Quasi	Team approach	+AD (III)		
Green 2008	50/34	Qual	Computer	+AD (IV)		
Schwartz, 2002	61	RCT	ACP intervention	+ AD (II)		
Kirchhoff, 2010	313 pairs	RCT	ACP intervention	+ AD (II)		
Kirchhoff, 2012	313 pairs	RCT	ACP intervention	+ AD (II)		
JAMA 1995	9105 patients (2 phases)	Observation phase 1, RCT phase 2	ACP intervention (2 nd phase)	-AD (II)		
Radwany, 2014	80 patients	RCT pilot	ACP intervention/In house geriatric/palliative interdisciplinary team	+ AD/ (II)		

Appendix F

Level of Effectiveness

Implications for Practice	Reference	Level of Effectiveness
All patients > = 50 in primary care practice with a chronic medical condition will be screened for AD and have discussion with PCP about AD/ treatment preferences	Michigan Quality Improvement Consortium. Advance care planning. Southfield (MI): Michigan Quality Improvement Consortium; 2014 Jan. 1 p.	Not specifically stated

Retrieved from

<http://www.guideline.gov/content.aspx?id=47803&search=advance+care+planning+and+%22end+of+life+care%22>

Appendix G: Barriers and Facilitators to Project

Barriers	Facilitators
Time- Each discussion per protocol for Respecting choices program = 1.5 hours DNP student will do protocol on days off (Tues or weekends/evenings)	Discuss at conference with Gunderson team how can be modified to include all information in faster time frame More flexible time frame will need arranged to accommodate patient/SDM/DNP scheduling conflicts
Space- no extra space at NCR building beside common rooms and resident apartment	Can do in resident apartment
Staff opposition- Non-professional staff Too much work	Education on purpose and goals of program and benefits to patient/SDM to staff Service Coordinators (SCs) will be crucial to the success of this project to help identify and recruit patients
Patient/family resistance (touchy subject “why now?”, discomfort with subject)	Education on purpose and goals of treatment and how can help alleviate family stress and uncertainty and improve patient well-being that decisions are understood well in advance
Apprehension of Boss (concern about patient/family distress and may leave practice)	Share training principles from Gunderson Lutheran program (Respecting choices- ACP training) to improve understanding of protocol. Addressed by finding another site with a more supportive partner
Financial cost to practice-education program Not reimbursed by government	Reinforce overall savings to healthcare (most Medicare dollars spent last year of life), as well as adhere to upcoming quality indicator issues regarding re-hospitalization of medically fragile diagnoses

Appendix H

EBP Implementation table

DNP project END OF LIFE discussions in Primary Care	Implementation Table using Stetler Model	
Time	Activity	Key Stakeholders
<p><u>Preparation</u> Search, sort, select sources of research and supplemental evidence Consider influential factors Define purpose and outcomes</p>	<p>Finish Lit Review Obtain survey tool (either statement of treatment preferences or Healthcare Decision making form) Decide if presentation will be to groups or to individual patients/decision makers</p>	<p>Matt Kehlmeier –Director of Marketing- National Church Residences DNP student Patients who have no END OF LIFE planning/ Surrogate Decision makers (SDMs) Insurance/Medicare Payors</p>
<p><u>Validation</u> state strength of individual evidence and record key study details/qualifiers</p>	<p>Narrow focus of literature to specific studies with utilization of data in mind Meet with EPB mentor</p>	
<p><u>Comparative Evaluation/Decision Making</u> assess fit/qualifiers, feasibility/ substantiating evidence and current practice</p>	<p>Sign up for Gunderson Lutheran Program (respecting choices) and take online 6 contact hours and 7 hours live training in Lacrosse WI/Sandusky Ohio Get brochures from Gunderson website to review Finish evaluation of literature/critical analysis</p>	
<p><u>Translation/Application</u> Confirm type, level and method of application plan for direct use of instrument/teaching materials</p>	<p>Staff education for purpose/goal of project Show tools from ACP training program to be given out to patients Show HealthCare decision making tool and Agent Comfort form Have SCs pass out</p>	<p>DNP student, Service Coordinators</p>
		<p>DNP student and Service</p>

	<p>information letters and sign up residents who show interest in project, Make sure MMSE on file and 23 or above and meet criteria and can identify SDM w Pass out information letters to residents of building #1 and #2 (if needed)(goal get at least 50 participant pairs) Hang up posters at work seeking volunteers Have Service Coordinators pass out recruitment letter Copy brochures as needed about END OF LIFE decisions to pass out to patients/decision makers for study Secure room and plan times to meet with residents/decision makers Answer questions from patients/SDM</p>	<p>Coordinators</p>
	<p>Sign consent letters for participants/ do pre-intervention survey to assess patient/SDM understanding of AD and patient wishes currently Phone call to participants who did not respond to initial letter to clarify and Recruit more participants if needed</p>	<p>DNP student</p>
<p><u>Translation/Application (continued)</u> Week 1 Implementation</p>	<p>Schedule end of life discussions in resident apartment or other area of building per resident request Start program Ongoing Evaluation of procedure/recruitment</p>	<p>DNP student, SCs</p>
<p><u>Week 4 Evaluation</u></p>	<p>Finish program- do post</p>	<p>DNP student, SCs</p>

Evaluate dynamically, get evidence re: implementation, targeted practice or system change, end result	intervention survey to eval understanding and willingness to implement patient AD	
<u>Week 8 Evaluation (continued)</u>	Review data- meet with statistician Review successes and failures Update protocol for continuing use Ongoing evaluation of process with SCs, make adjustments as needed	DNP student/ statistician/SC, Instructor
Week 16 (dissemination)	Ongoing Evaluation/ develop tools for ongoing project continuation	DNP student, SCs, Director of Marketing

Appendix I

Literature Search/Table for Data Search

Date of search	Key word	Source	Hits/# reviewed	Used
4/4/2013	Advance Directives+ primary care	ebsco	326/15	10
2/6/13	Volandes, angelo	Google	1	1
2/6/13	End of life care	Ohio link	6094/15	3
2/9/13	“protocols” and advance directives	Ohio link	0	
2/9/13	Protocols and palliative care	Proquest	197/10	1
“	“protocols and “end of life care	Ohiolink	172/10	7-8
4/14/2013	“end of life care” and “primary care”	Ohiolink	144/50	5
4/14/2013	“DNR” and “primary care”	Ohiolink	2/2	1
“	“Advanced care planning” and “primary care”	Ohio link	30/30	2
“	“Advance directives” and”primary care	Ohio link	38/38	3
“	“palliative care” and “primary care”	Ohio link	268/50	3

4/16/2013	“treatment preferences” and “primary care”	Ohio link	73/25	2
4/18/2013	“Patient preferences” and END OF LIFE care	Ohio link	222/50	1
6/16/2013	Allow natural death (AND)	Ohiolink	12/12	2
“ “	AD and ambulatory care	Ebsco	13/12	0
“ “	END OF LIFE guidelines	Ebsco	2/2	0
6/16/2013	Improving END OF LIFE Care	Ebsco- Medline	113/113	2
“ “	AD and primary care	Ebsco	113/20	0
“ “	Allow natural death and advance care planning	Google scholar	1380/10	0
6/27/2014	Allow natural death	Ebsco	475/10	1
8/27/2013	Trajectory of illness	Ebsco	112/50	1
9/2/2013	Trajectory of death	Ejc	0	
“ “	Illness trajectory	Ebsco	943/5	0
“ “	Illness trajectory and Lynn (author)	Ebsco	11/11	0
6/6/2014	ACP and primary care	EBSCO	2/96	1
9/9/2014	ACP	Cochrane	4	1
9/9/2014	ACP and barriers	EvidenceUpdate	0	
9/9/2014	End of life and primary care	EvidenceUpdate	0	
9/9/2014	ACP and community	10	2	
1/23/2015	Respecting Choices	Ebsco	2	2

Appendix J

Rapid Critical Appraisal

Schwartz, Wheeler, et al (2002) Early intervention in Planning End of Life Care with Ambulatory Geriatric Patients- results of a Pilot Trial *Archives of Internal Medicine* 162: 1611-1618

1. Are the results of the study valid?
 - a. Were the subjects randomly assigned to the experimental and control groups **Yes** No Unsure
 - b. Was random assignment concealed from the individuals who were first enrolling subjects into the study Yes No **Unsure**
 - c. Were the subjects and providers blind to the study group? Yes **No** Unsure
 - d. Were there reasons given to explain why subjects did not complete the study? **Yes** No Unsure
 - e. Were the follow up assessments conducted long enough to fully study the effects of the intervention? **Yes** No Unsure
 - f. Were the subjects analyzed in the group to which they were assigned? **Yes** No Unsure
 - g. Was the control group appropriate? **Yes** No Unsure
 - h. Were the instruments used to measure the outcomes valid and reliable? **Yes** No Unsure
 - i. Were the subjects in each of the groups similar on demographic and baseline clinical variables? **Yes** No Unsure
2. What are the results?
 - a. How large is the intervention of treatment effect (NNT, NNH, effect size, level of significance)?
NNT was 62 per study arm. The small sample size of 61 was not large to document effect so results were reported using Effect Size (ES) using the formula of Cohen. ES of 0.20-0.40 is small, 0.41-0.79 is medium, ES of 0.80 or larger is significant. (Documented ES -0.43)
 - b. How precise is the treatment or intervention (CI)?
Change in tolerance of poor health status was 0.78, no CI was listed.
3. Will the results help me in caring for my patients? **Yes** No Unsure
 - a. Were all clinically important outcomes measured? **Yes** No Unsure
 - b. What are risks and benefits of treatment? Risk is emotional distress if patients or surrogate decision makers are not ready to have this discussion. Benefits are immense: patient can express wishes regarding END OF LIFE care, surrogate decision makers can understand and plan to advocate for loved ones, the healthcare system saves money by focusing resources on people who have treatable conditions rather than spending vast resources on fruitless treatment that only prolongs the dying process.
 - c. Is the treatment feasible in my clinical setting? **Yes** No Unsure

d. What are my patient/family's values and expectations for the outcomes that is trying to be prevented and the treatment itself? I hope that they feel empowered and at peace when they can have these important discussions with a provider and their loved ones.

(obtained from Student resource CD ROM. Melynk, B., & Fineout- Overholt, E. (2011). Evidence Based Practice in Nursing and Health Care: a Guide to Best Practice. Wolters Kluwer/Lippincott, Williams & Wilkins: Philadelphia, PA).

Appendix K: Literature Synthesis

Citation	Design/method	Sample/setting	Variable/Definition	Measurement	Data analysis	Findings	Appraisal	
Tierney, W. et al (2001), Effect of discussions about AD on patient satisfaction with primary care	Prospective cohort study enrolled in RCT of use of AD at office visits	Academic primary care IM practice affiliated with urban hospital N= 686 elderly pts, 87 pcp	DV – satisfaction score	Satisfaction	BIM and MOS-VSQ patient satisfaction scores	Strongest multivariable correlate with visit satisfaction was satisfaction at enrollment visit or previously discussing AD, also discussing AD at that visit borderline significance (p.075)	Strengths: encouraged pcps to discuss AD with patients Limits: might depend on pcp communication skills, setting might not be generalizable, could not assess exactly what occurred in ACP discussion No risk of harm, feasible for practice	
Ramsaroop, S.D. (2007), Completing an AD in primary care setting: what do we need for success?	Metanalysis of 18 studies looking at literature from 1991-2005 re: what modalities worked best for getting AD completion	18 studies met criteria for design (RCT)	DV AD #	#AD	Effect size calculated	Most successful intervention was direct patient-pcp interaction over mult visits.	Limitations: limited number of studies Strengths: reinforced need to use all modalities not just hand a brochure Feasible in practice	
Kirshhoff et al (2012) Effect of a Disease Specific Advance Care Planning Intervention on End of Life Care	Prospective Trial	313 pairs of patients and surrogates	DV AD followed	Preferences compared before intervention and at death	Kappa	PC-ACP intervention effective 74% patients got care they wanted	Strength: showed AD adherence can be shaped and advocated for, feasible with training	
Citation/	Conceptual framework	Design/Method	Sample/setting	Variable/Definition	Measurement	Data Analysis	Findings	Appraisal/Worth
Anderson, W.	None noted	Qualitative:	2 hospitals within	DV code status	#	Cohens Kappa	Code status	Limits: only

<p>et al (2010) Code status discussions between attending physicians and medical patients at hospital admission</p>		<p>Cross sectional observational study of conversations between attending physicians and patients about code status</p>	<p>a hospital system between 8/2008-3/2009- N=32 physicians and 171 patients</p>	<p>discussion in admission encounters using criteria of introduction of topic of code status, discussion of prognosis and patient values, informed consent, and physician recommendation</p>	<p>discussions</p>		<p>discussions lasted a minute, more frequently occurred in patients more likely to die in a year or have ICU admission but 66% of those patients did not have discussion</p>	<p>captured first discussion, may have been brief if doc was confirming previous discussion, specialists may have discussed with patient instead, unable to screen all patients Strengths: delineates guidelines that may help providers give more appropriate information to patient. Feasible: somewhat though not in hospital setting</p>
<p>Ditto,P.et al (2001) Advance Directives as Acts of Communication</p>		<p>RCT 1 of 5 experimental conditions to see if surrogate decision makers accurately predicted loved ones</p>	<p>401outpatients using 9 different illness scenarios- 189 of 2544 unwilling to participate, 75 year olds oversampled, 612 could not be followed d/t</p>	<p>DV- Correct S DM</p>	<p># correct AD</p>	<p>LPSQ</p>	<p>90% of patients were confident that surrogate decision makers understood their wishes</p>	<p>Strengths:proved that just having a AD did not help surrogate decision makers, Limitations: relied on hypothetical</p>

		preferences	death. 447 excluded for other reasons					scenarios, no pcp was involved in single session discussion, might need more intervention Feasible: yes need to develop better ways to communicate patient wishes to family
Green, M. & Levi, B. (2008), Development of an Interactive Computer Program for Advance Care Planning	Multi Attribute Utility Theory (MAUT)	Qualitative Pilot testing of computer program for ACP to emphasize process of AD using 6 step process	50 adults from IM practice, 34 adults from cancer treatment center	DV- RCP	ACP	Likert average user took 106 mins with program and rated 4.2/5 for improving knowledge and decision making and 8.5/10 for overall satisfaction with program and cancer patients rated it 8.5/10 overall (p<0.001)	Interactive program was helpful at giving patients scenarios to help plan their AD	Strengths: emphasizes that NOT making a decision is in fact a decision left to people who are not qualified to know what patient would want Limit: computers may be too hard to elderly, future forecasting may not be accurate Feasible: possibly
Volandes, A., et al (2007),		6 study sites (at 2 teaching	146 patients completed survey	V- hl	Hl score	Decisional Conflict scale and REALM	Race/education, health	Strengths: showed

<p>Improving Decision Making at the End of Life with Video Images</p>		<p>hospitals), between 12/2005-1/2007, before and after oral survey/video</p>				<p>(health literacy scale)/McNemars Test and ANOVA</p>	<p>status associate with level of uncertainty with 88% whites having health literacy 40% African Americans</p>	<p>education doesn't equal health literacy and that mult decision aides need to be used Limitations: did not include latinos, ? if more uncertainty d/t dx dementia chosen, did not analyze people who changed preferences Feasible: videos may helpful</p>
<p>Cantalejo, I. et al (2012) Stability over time in the Preferences of Older Persons for Life Sustaining Treatment</p>		<p>Longitudinal cohort study patients 65 and older over 18 months in primary care centers in Spain</p>	<p>Initial N=150 /65 failed to complete 18 months later N=85, 25 not found, 25 refused, 7 died, 2 terminally ill, 6 physical disability</p>	<p>DV treatment preferences over time</p>	<p>Change ACP</p>	<p>LPSQ-e and Family APGAR (Smilkstein,Ashworth, and Montano1982)- McNemers test paired student T test</p>	<p>Majority of patients who declined treatment in 5/6 LSPQ scenario did not change preference after 18 months Family APGAR average 8.7 no difference between 85 who completed 2 questionnaires and 65 who</p>	<p>Strengths: stability of preference for treatment/non treatment over time and less likely to change if had AD already Limits: small sample size, length of time between survey, may not be generalizable, Feasible: need to discuss over</p>

							only completed 1	time and include surrogates
Robinson, C. et al (2012), Awareness of DNR orders, what do patients know and want		Qualitative: Cross Sectional self administered survey to assess patient preference and understanding of DNR orders	429 consecutive patients >40 in 4 primary care offices, 90% survey completion between 3/2009-5/2009) N= 386	DV: understand DNR	DNR literacy	Cross tabulation and Chi square test	84% were aware of DNR and 86% wanted pcp to initiate discussion, , 56% said when healthy was time for talk	Strengths: people want to discuss with pcp and not stressful Limits: limited validation of tool, and given in office might have affected whom they wanted to discuss with
Rosnick, C. & Reynold, S. (2003) Thinking Ahead: Factors associated with Executing Advance directives	Anderson Model of Health care utilization (1974)	Cross-sectional community based data from Charlotte County Health Aging study	N=458 Patients 60-84 living in healthy population/excluded for missing information or AD	DV- # AD	AD factors	OR- Correlational analysis between DV and 43 IV- NEOFPI (Costa and McCrae 1992)	Six factors were related to having an AD, age, openness to experience, high income, # meds, high quality of life, and high control	Strengths: identified factors associated with having AD and to identify in patients with lower income Limitations: wealthy population (non representational) Feasible: no
Tung, E. et al (2011). Clinical		Retrospective analysis	Patients >60 assessed by generic disease	DV- #AD	#AD	2x2 table and Fisher exact test P value	44% said they read all information	Strengths: multimedial presentation

<p>Decision Support Technology to Increase Advance Care Planning in the Primary Care Setting</p>			<p>management program prior to pcp visit N= 574 intervention and 146 usual care (only 12.5% (72) patients returned survey</p>				<p>and 52% said it motivated them to complete Ads by at least 75%, 41/72 completed AD with 31/72 not. most common reason for not, " don't know what my wishes are"</p>	<p>shown useful addresses lack of time low health literacy and lack of privacy barriers Limitations: study group may not be representative , can't generalize to other cultural groups, do not reach folks with low vision or low literacy, low response rate Feasible: yes</p>
<p>Silveia,M. (2012) End of Life Care from the Perspective of Primary Care Providers</p>		<p>Qualitative - focus groups interviewed PCPS and clinical support staff</p>	<p>28 PCPs and 22 clinical support staff in internal medicine and family medicine clinics in Michigan</p>	<p>Explore factors affecting pcp's ability to care for dying patients</p>	<p>Type of barrier</p>	<p>Data analysis in iterative fashion using constant comparison to develop codes. entered into NVivo 7 Software</p>	<p>Ability to care for patients depends on continuity, flexible schedule, information sharing, coordination of care and ability to act</p>	<p>Strengths: same elements needed for PCP care also needed for end of life care Limitations: sample bias, ? generalizable, small size of focus groups, Feasible; yes, useful for primary care</p>
<p>Wissow, L. (2004), Promoting Advance</p>		<p>Prospective Quasi experimental</p>	<p>N= 2120 elderly patients in 5 suburban and urban health</p>	<p>DV- AD</p>	<p>#AD</p>	<p>Logistic regression models OR new AD at tx sites 22.3 % increase CI 95% CI,</p>	<p>3.5% (75/2120)patients made a new</p>	<p>Strengths: reinforced need team approach to</p>

<p>Directives among Elderly Primary Care Patients</p>			<p>centers in large managed care organization. 1 other site served as control (Int group N= 843), Control group N=1277</p>			<p>associated with community income</p>	<p>AD, more likely to be elderly</p>	<p>raise the subject but not taken into account by leadership to help productivity Limitations: not seen as institutional priority, not part of QI, economic status may not be generalizable Feasible: yes</p>
<p>Rhee, J., Zwar, N.& Kemp, L. (2013) Advance Care Planning and Interpersonal Relationships: a two way street</p>	<p>Straussian grounded theory and Clarkes Positional Maps (grounded theory methodology)</p>	<p>Qualitative with semi-structured interviews/ purposive sampling, face to face, open ended interviews</p>	<p>17 GPs in Australia between 2010 and 2011</p>	<p>DV- emotions re ACP</p>	<p>Types of emotions</p>	<p>Coding and analysis constant comparisons, flip flop, looking for negative cases and looking at language</p>	<p>Bidirectional relationships impacts of ACP on relationships, GPS desire to avoid conflict with family, utility of ACP</p>	<p>Strengths: reinforce need to tailor ACP for each patient, and role of medical home Limitations: participants own accounts, only included GPS interested in palliative care. Feasible: yes</p>
<p>Tung, E., & North, F. (2009) Advance Care Planning in the Primary Care Setting:</p>		<p>Qualitative survey of residents and staff physicians</p>	<p>Web based needs assessment of 144 pcps (completion rate 94 (65%) at Mayo Clinic about barriers to care (either patient or</p>	<p>DV- barriers to ACP</p>	<p>Type of barrier</p>	<p>Fisher Exact test to determine differences between staff and resident physician</p>	<p>System processes affected ACPs in primary care, providers feel they should</p>	<p>Strengths: identify barriers that need to be addressed, less patient and more setting</p>

<p>A comparison of Attending Staff and Resident Barriers</p>			<p>system)</p>				<p>lead discussion but not sure who else should</p>	<p>based Limitations: single institution, mult choice limited answers Feasible: definitely as issue in many practices</p>
<p>Volandes, A. et al (2008) Health Literacy not Race Predicts End of Life Preferences</p>		<p>Before and after verbal description and video</p>	<p>173 subjects (23 Disqualified d/t prior relationship with demented family N= 80 african americans/64 whites</p>	<p>DV: hl</p>	<p>Hl score</p>	<p>REALM measurement and Fisher exact test)</p>	<p>After video of demented person, most preferred comfort even in African American</p>	<p>Strengths: suggested not race but health literacy so alt methods of interaction are needed Limitations: not equal amount low literacy whites, small sample, preferences might change later Feasible: yes</p>
<p>Rodriguez, K. & Young, A. (2005). Perspectives of Elderly Veterans Regarding Communication with Medical</p>		<p>Qualitative: Cross sectional survey semi structured interviews from 4/2000-10/2002</p>	<p>Convenience sample of VA patients in outpatient setting over 60/ N=30 (61 declined)</p>	<p>Emotions about END OF LIFE</p>	<p>Types of emotions</p>	<p>Qualitative content analysis using ethnograph (Qualis Research Denver Colorado)</p>	<p>7 themes, focus on patient centered approach with open communication</p>	<p>Strength: focus on what patients actually want from pcp Limitations: small sample, single VA, lack of diversity Feasible: yes</p>

Providers about End of Life Care								
Carter, C. et al (2006) Physician Perspectives on END OF LIFE care: factors of race, specialty, and geography		Qualitative: open ended interviews	Convenience sampling- N= 40 23 pcps, 7 cardiologists, and 10 oncologists in rural and urban S.C. (69 consented to interview excluded d/t screening failures)	DV cultural issues/specialist issues	Emotions	Univariate frequencies/chi square and Fisher exact test, responses coded then verified	Cardiologists less likely to discuss END OF LIFE, providers felt blacks and whites differ in END OF LIFE preferences	Strengths: pointed out need to address cultural issues to make sure all benefit from END OF LIFE care Limits: small study, no black specialists participated Feasible yes
Schwartz (2002) early intervention in planning END OF LIFE care with ambulatory geriatric patients		ACP program	RCT N=61	DV congruence of understanding of END OF LIFE preferences	Congruence between patient and surrogates for END OF LIFE preferences	Beliefs and values questionnaire, visual analog, formula of Cohen	Intervention group 76% complete agreement vs 55% controls	Strengths: can educate family and patient to increase understanding. feasible with training
Kirchoff (2010) effect of a disease specific planning intervention on surrogate understanding of patient goals for future medical treatment		ACP program	Multi site RCT N= 313	DV understanding of patient goals	Clarification of patient goals for 4 disease states	kappa	Kappa scores showed 0.61-0.71 vs control 0.07-0.28	Strength with proper training family members and patients can understand and direct END OF LIFE goals for certain diseases Feasible with training

IM- internal medicine, pcp (patient care providers), ABIM- American Board of Internal Medicine, MOS-VSQ- Visit Specific Questionnaire for Medical Outcomes Study
RCT- Random control study, OR- odds ratio, LPSQ (Life Support Preferences/Predictions Questionnaire), REALM (Rapid Estimate of Adult Literacy in Medicine) tool, NEO-FFI (Neurotism, Extraversion, Openness, Personality Inventory), General Practitioner (GP), SDM (surrogate decision making), RCP (rational care plan), health literacy (hl), physician practices, ACP- Patient centered Advance Care Planning program through Gunderson Lutheran

Appendix L

Emanuel and Emanuel Health Care Directive

INTRODUCTION

As part of a person's right to self-determination, every adult may accept or refuse any recommended medical treatment. This is relatively easy when people are well and can speak. Unfortunately, during severe illness people are often unconscious or otherwise unable to communicate their wishes, at the very time when many critical decisions need to be made.

The Health Care Directive states your wishes regarding various types of medical treatment in several representative situations so your desires can be respected. It also lets you appoint someone to make medical decisions for you if you should become unable to make your own; this is a proxy decision-maker or durable power of attorney. It comes into effect only if you become incompetent (unable to make decisions or to express your wishes), and you can change it at any time until then. As long as you are competent, you should discuss your care directly with your healthcare provider.

COMPLETING THE FORM

You should, if possible, complete the form in the context of a discussion with your health care provider. Ideally, this should occur in the presence of your proxy decision-maker(s). This lets your healthcare provider and proxy decision-maker(s) know how you think about these decisions, and it provides you and your healthcare provider with the opportunity to give or clarify relevant personal or medical information. Many may wish to discuss the issues with a religious mentor.

The Health Care Directive contains six illness situations that involve incompetence. In each situation you consider possible interventions. The situations include two involving coma (A & B), two involving dementia (C & D) and two involving temporary inability to make decisions (E & F).

The interventions you may state preferences about are described briefly here; if you have further questions ask your Health Care Provider.

The goals of therapy can be chosen from those listed or stated in your own words.

Health Care Directive Instructions

Instructions: this form will give you the chance to consider your advance care wishes regarding types of life sustaining treatment. These types of life sustaining treatment are:

1. Cardiopulmonary Resuscitation (aimed at reviving a person who is on the point of dying, involves chest compressions, drugs, electric shocks and artificial breathing).
2. Mechanical Breathing (the use of a breathing machine called a Ventilator to help someone who cannot breathe on his own).
3. Artificial Nutrition and Hydration (food and fluids given by a feeding tube placed into the mouth or stomach).
4. Major Surgery (such as removing the Gall Bladder or part of the intestines).
5. Kidney Dialysis (machine hooked to a person and used to clean the blood when a person's kidneys have stopped working).
6. Chemotherapy (medications to fight cancer).
7. Antibiotics (to fight infection)
8. Simple Diagnostic tests (blood or urine testing)

9. Pain Medication even if indirectly would shorten my life

Consider your goals of health care treatment on a scale of 1-3 where:

1: Comfort Care Only-quality of life over long life- do not want intervention

2: Attempt Cure but Reevaluate Often- treatment trial, stop for no improvement

3. Prolong Life- Treat Everything - want intervention

Now considering the above treatments and your goals answer the following 6 scenarios.

SITUATION (A)

If, in the opinion of my physician and two consultants, I am in a coma or in a persistent vegetative state, and have no known hope of regaining awareness and higher mental functions no matter what is done, then my wishes, if medically reasonable, for this and any additional illness would be on a scale of 1-3:

CPR-	1	2	3
Mechanical Ventilation-	1	2	3
Surgery/Dialysis/Blood Transfusion-	1	2	3
Artificial Nutrition and Fluid-	1	2	3
Simple diagnostic tests/antibiotics-	1	2	3

SITUATION (B)

If, in the opinion of my physician and two consultants, I am in a coma, with a small and uncertain chance of regaining higher mental functions, and a greater chance of recovering with some residual damage, and a much greater chance of not recovering at all, then my wishes, if medically reasonable, for this and any additional illness would be :

CPR-	1	2	3
Mechanical Ventilation-	1	2	3
Surgery/Dialysis/Blood Transfusion-	1	2	3
Artificial Nutrition and Fluid-	1	2	3
Simple diagnostic tests/antibiotics	1	2	3

Situation (C)

If, in the opinion of my physician and two consultants, I have nonreversible brain damage which makes me unable to recognize people, or to speak meaningfully to people, or to live independently, and I also have a terminal illness, then my wishes, if medically reasonable, for this and any additional illness, would be:

CPR-	1	2	3
Mechanical Ventilation-	1	2	3
Surgery/Dialysis/Blood Transfusion-	1	2	3
Artificial Nutrition and Fluid-	1	2	3
Simple diagnostic tests/antibiotics	1	2	3

SITUATION (D)

If, in the opinion of my physician and two consultants, I have nonreversible brain damage which makes me unable to recognize people, or to speak meaningfully to people, or to live independently, but I have no terminal illness and I can live for a long time like this, then my wishes, if medically reasonable, for this and any additional illness, would be:

CPR-	1	2	3
Mechanical Ventilation-	1	2	3

Surgery/Dialysis/Blood Transfusion-	1	2	3
Artificial Nutrition and Fluid-	1	2	3
Simple diagnostic tests/antibiotics	1	2	3

SITUATION (E)

If, in the opinion of my physician and two consultants, I have an incurable chronic illness which involves mental disability or physical suffering and ultimately causes death, and in addition I have an illness that is immediately life threatening but reversible, and I am temporarily unable to make decisions, then my wishes, if medically reasonable, would be:

CPR-	1	2	3
Mechanical Ventilation-	1	2	3
Surgery/Dialysis/Blood Transfusion-	1	2	3
Artificial Nutrition and Fluid-	1	2	3
Simple diagnostic tests/antibiotics	1	2	3

SITUATION (F)

If I am in my current state of health, (describe briefly) and then have, in the opinion of my physician and two consultants, a life threatening but reversible illness, and I am temporarily unable to make decisions, then my wishes, if medically reasonable, would be:

CPR-	1	2	3
Mechanical Ventilation-	1	2	3
Surgery/Dialysis/Blood Transfusion-	1	2	3
Artificial Nutrition and Fluid-	1	2	3

Simple diagnostic tests/antibiotics	1	2	3
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Original: Emanuel LL, Emanuel EJ. The Medical Directive: a new comprehensive advance care document. JAMA. 1989;261(22):3288-3293. PMID: 2636851
Adapted with permission from the author- The Health Care Directive JAGS-DECEMBER 1991-VOL. 39, NO. 12

Appendix M

Agent Comfort Form

Directions: Please indicate how true each of the following statements is for you over the past week by circling one number per line

. Not at all	A little bit	Somewhat	Quite a bit	Very much
0	1	2	3	4

C1. I feel comfortable exercising my role as a Healthcare Proxy for my Principal.

0	1	2	3	4
---	---	---	---	---

C2. I am concerned that I will not make a decision that reflects my Principal's wishes if he/she is in a medical crisis.

0	1	2	3	4
---	---	---	---	---

C3. I believe that I understand my Principal's preferences regarding medical treatments in times of crisis.

0	1	2	3	4
---	---	---	---	---

C4. I am not confident that I will be able to make important medical decisions for my Principal in a medical crisis.

0	1	2	3	4
---	---	---	---	---

C5. I feel adequately informed about my Principal's health care preferences.

0	1	2	3	4
---	---	---	---	---

C6. The responsibility I have for my Principal's health care decisions is overwhelming.

0	1	2	3	4
---	---	---	---	---

Appendix N

Budget Estimate

Product	Details	Estimate Cost
PC-ACP first steps certification course	\$420	\$500.00
Patient literature/ Respecting Choices	<ul style="list-style-type: none"> • Making choices information card bundle of 100=\$30.00 • Making choices healthcare agent card bundle of 100=\$35 • Making choices information booklet bundle of 100= \$135 • Making choices wallet card bundle of 100 = \$12 • Making choices CPR card each \$3.10 (#75) • Making choices tube feeding cards \$3.10 (#75)= \$ 252.50 • Making choices help with breathing cards (\$3.10 (#75)= \$252.50 • Making choices planning guide bundle of 100= \$55 • total respecting choices literature \$1,159.50 	\$1200
Personnel Costs	<ul style="list-style-type: none"> • Student investigator NP 2 hours x PC –ACP facilitator interviews for 75 subjects/surrogate decision makers \$50/hour = \$7500 	
Travel cost (air fare domestic to LaCrosse Wisconsin from Akron Canton Airport	<ul style="list-style-type: none"> • Akron Canton to Lacrosse Wisconsin = \$534.50 	\$700
Miscellaneous stationery costs	<ul style="list-style-type: none"> • Consent forms • Medical Directive forms • Agent comfort forms • Packets for each subject/decision maker = 150 each (500 sheets of copy paper/pack) = \$6.49 = \$115 	\$200

Total Cost	• \$9729	\$10,000



Description	Quantity	Amount	Total
First Steps ACP Facilitator Certification		\$420.00	\$420.00

Appendix O

Cost/Benefit Analysis of PC-ACP

Benefit of PC-ACP intervention- cost of hospital stay/day for patient admitted with exacerbation of chronic medical problem in Ohio

- State/local government hospitals — \$1,943/day
- Non-profit hospitals — \$2,173/day
- For-profit hospitals — \$1,972/day

(from <http://www.beckershospitalreview.com/lists/average-cost-per-inpatient-day-across-50-states-in-2010.html>)

ROOM AND BOARD — PER DAY CHARGES

CHARGE: ICU \$4,295.00/day

(from http://medicalcenter.osu.edu/patientcare/patient_and_visitor_information/financial_information/hospital_fees/pages/index.aspx)

Cost Benefit Analysis: Cost of implementing PC-ACP in project: \$ 10,000

Cost savings 3 days ICU stay @\$4300/day for 2 patients: $\$12,900 \times 2 = \$25,800$

Cost savings 3 days hospital stay @ \$2,000/day for 2 patients = \$12,000

Cost savings \$2000 for inpatient hospital stay (2 patients at 3 days each) or \$15,800 for ICU stay for 2 patients.

Table 1: Demographics

Age

N=22

Range 89

Mean 73.1

Gender

	Frequency	Percent
Male	5	22.7
Female	17	77.3
Total	22	100.0

Marital Status

	Frequency	Percent
Never Married	2	9.1
Widowed	8	36.4
Divorced	9	0.9
Total	22	100.0

Education Level

	Frequency	Percent
Some High School	4	18.2
High School Diploma	7	31.8
GED	2	9.1
Trade/Vocational School	3	13.6
Some College	4	18.2
Bachelor's Degree	2	9.1

Total	22	100
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Ethnicity

	Frequency	Percent
White	19	86.4
African American	2	9.1
Native American	1	4.5
Total	22	100

Religion

	Frequency	Percent
Protestant/Christian	17	77.3
Catholic	4	18.2
Other	1	4.5
Total	22	100

Income

	Frequency	Percent
<\$12k	11	50.0
\$12,001-\$25,000	7	31.8
\$25,001-\$50,000	3	13.6
\$50,001-\$75,000	1	4.5
Total	22	100

Diagnosis

	Frequency	Percent
Heart Disease	17	77.3
Chronic Lung Disease	3	13.6
Dementia	2	9.1
Total	22	100

Previous Experience

	Frequency	Percent
None	14	63.6
Hospice	6	27.3
End of life Planning	2	9.1
Total	22	100

Table 2 Health Care Directive Tables

HCD A CPR Pre			HCD A CPR post		
	Frequency	Percent		Frequency	Percent
Comfort Care Only	14	63.6	Comfort Care Only	19	86.4
Attempt Cure	6	27.3	Attempt cure	3	13.6
Prolong Life	2	9.1			
Total	22	100.0	Total	22	100.0

HCD A vent pre			HCD A vent post		
	Frequency	Percent		Frequency	Percent
Comfort Care Only	17	77.3	Comfort Care Only	20	90.9
Attempt cure	5	22	Attempt cure	2	9.1
Total	22	100.0	Total	22	100.0

HCD A surg pre			HCD surg post		
	Frequency	Percent		Frequency	Percent
Comfort Care Only	17	77.3	Comfort Care	18	81.8%
Attempt cure	4	18.2	Attempt Cure	3	13.6
Prolong Life	1	4.5	Prolong Life	1	4.5
Total	22	100	Total	22	100.0

HCD A nut pre

	Frequency	Percent
Comfort Care Only	17	77.3
Attempt cure	4	18.2
Prolong life	1	4.5
Total	22	100

HCD A nut post

	Frequency	Percent
Comfort Care Only	16	72.7
Attempt cure	5	22.7
Prolong life	1	4.5
Total	22	100.0

HCD A dx pre

	Frequency	Percent
Comfort Care Only	13	59.1
Attempt cure	4	18.2
Prolong life	5	22.7
Total	22	100.0

HCD A dx post

	Frequency	Percent
Comfort Care Only	13	59.1
Attempt Cure	8	36.4
Prolong life	1	4.5
Total	22	100.0

HCD B CPR pre

	Frequency	Percent
Comfort Care Only	14	63.6
Attempt Cure	6	27.3
Prolong Life	2	9.1
Total	22	100.0

HCD B CPR post

	Frequency	Percent
Comfort Care Only	15	68.2
Attempt cure	6	27.3
Prolong life	1	4.5
Total	22	100.0

HCD B vent pre

	Frequency	Percent
Comfort Care Only	13	59.1
Attempt Cure	7	31.8
Prolong life	2	9.1
Total	22	100.0

HCD B vent post

	Frequency	Percent
Comfort Care Only	19	86.4
Attempt cure	3	13.6
Total	22	100
Attempt cure	2	9.1
Prolong life	2	9.1
Total	22	100

HCD B surg pre

	Frequency	Percent
Comfort Care Only	12	54.5
Attempt cure	8	36.4
Prolong Life	2	9.1
Total	22	100

HCD B surg post

	Frequency	Percent
Comfort Care Only	18	81.8

HCD B nut pre

	Frequency	Percent
Comfort Care Only	13	59.1
Attempt cure	7	31.8
Prolong Life	2	9.1
Total	22	100.0

HCD B nut post

	Frequency	Percent
Comfort Care Only	18	81.8
Attempt cure	3	13.6
Prolong life	1	4.5
Total	22	100.0

HCD B dx pre

	Frequency	Percent
Comfort Care Only	11	50.0
Attempt cure	7	31.8
Prolong Life	4	18.2
Total	22	100.0

HCD B dx post

	Frequency	Percent
Comfort care only	12	54.5
Attempt cure	8	36.4
Prolong Life	2	9.1
Total	22	100.0

HCD C CPR pre

	Frequency	Percent
Comfort Care Only	17	77.3
Attempt cure	4	18.2
Prolong life	1	4.5
Total	22	100.0

HCD C vent pre

	Frequency	Percent
Comfort Care Only	17	77.3
Attempt cure	4	18.2
Prolong life	1	4.5
Total	22	100

HCD C CPR post

	Frequency	Percent
Comfort Care Only	19	86.4
Attempt cure	2	9.1
Prolong life	1	4.5
Total	22	100.0

HCD C vent post

	Frequency	Percent
Comfort Care Only	20	90.9
Attempt cure	1	4.5
Prolong life	1	4.5
Total	22	100

HCD C surg pre

	Frequency	Percent
Comfort Care Only	16	72.7
Attempt cure	5	22.7
Prolong life	1	4.5
Total	22	100

HCD C surg post

	Frequency	Percent
Comfort Care only	19	86.4
Attempt cure	1	4.5
Prolong life	2	9.1
Total	22	100

HCD C nut pre

	Frequency	Percent
Comfort Care Only	16	72.7
Attempt cure	5	22.7
Prolong life	1	4.5
Total	22	100

HCD C nut post

	Frequency	Percent
Comfort Care Only	18	81.8
Attempt cure	2	9.1
Prolong life	2	9.1
Total	22	100

HCD C dx pre			HCD C dx post		
	Frequency	Percent		Frequency	Percent
Comfort Care only	14	63.6	Comfort Care Only	17	77.3
Attempt cure	5	22.7	Attempt cure	3	13.6
Prolong life	3	13.6	Prolong life	2	9.1
Total	22	100	Total	22	100

HCD D CPR pre

	Frequency	Percent
Comfort care only	16	72.7
Attempt cure	2	9.1
Prolong life	4	18.2
Total	22	100

HCD CPR post

	Frequency	Percent
Comfort care only	20	90.9
Attempt cure	1	4.5
Prolong life	1	4.5
Total	22	100

HCD D vent pre

	Frequency	Percent
Comfort Care Only	15	68.2
Attempt cure	3	13.6
Prolong life	4	18.2
Total	22	100

HCD D vent post

	Frequency	Percent
Comfort Care Only	20	90.9
Attempt cure	1	4.5
Prolong life	1	4.5
Total	22	100

HCD D surg pre

	Frequency	Percent
Comfort care only	15	68.2
Attempt cure	3	13.6
Prolong life	4	18.2
Total	22	100.0

HCD D surg post

	Frequency	Percent
Comfort Care only	19	86.4
Attempt cure	1	4.5
Prolong life	2	9.1
Total	22	100

HCD D nut pre

	Frequency	Percent
Comfort Care only	15	68.2
Attempt cure	3	13.6
Prolong life	4	18.2
Total	22	100

HCD D nut post

	Frequency	Percent
Comfort Care only	19	86.4
Attempt cure	1	4.5
Prolong life	2	9.1
Total	22	100

HCD D dx pre

	Frequency	Percent
Comfort care only	13	59.1
Attempt cure	5	22.7
Prolong Life	4	18.2
Total	22	100

HCD D dx post

	Frequency	Percent
Comfort care only	17	77.3
Attempt cure	3	13.6
Prolong life	2	9.1
Total	22	100

HCD E CPR pre

	Frequency	Percent
Comfort Care only	15	68.2
Attempt cure	5	22.7
Prolong life	2	9.1
Total	22	100

HCD E CPR post

	Frequency	Percent
Comfort Care only	19	86.4
Attempt cure	2	9.1
Prolong life	1	4.5
Total	22	100

HCD E vent pre

	Frequency	Percent
Comfort Care Only	15	68.2
Attempt Cure	5	22.7
Prolong Life	2	9.1
Total	22	100

HCD E vent post

	Frequency	Percent
Comfort Care Only	19	86.4
Attempt cure	2	9.1
Prolong life	1	4.5
Total	22	100

HCD E surg pre

	Frequency	Percent
Comfort care only	15	68.2
Attempt cure	5	22.7
Prolong life	2	9.1
Total	22	100

HCD E surg post

	Frequency	Percent
Comfort Care only	18	81.8
Attempt cure	2	9.1
Prolong life	2	9.1
Total	22	100

HCD E nut pre

	Frequency	Percent
Comfort care only	14	63.6
Attempt cure	6	27.3
Prolong life	2	9.1
Total	22	100

HCD E nut post

	Frequency	Percent
Comfort Care only	17	77.3
Attempt cure	3	13.6
Prolong life	2	9.1
Total	22	100

HCD E dx pre

	Frequency	Percent
Comfort care only	11	45.5
Attempt cure	9	40.9
Prolong life	3	13.6
Total	22	100

HCD E dx post

	Frequency	Percent
Comfort care only	14	63.6
Attempt cure	6	27.3
Prolong life	2	9.1
Total	22	100

HCD F CPR pre

	Frequency	Percent
Comfort Care only	4	18.2
Attempt cure	8	36.4
Prolong life	10	45.5
Total	22	100

HCD F CPR post

	Frequency	Percent
Comfort Care Only	11	50.0
Attempt cure	8	36.4
Prolong life	3	13.6
Total	22	100

HCD F vent pre

	Frequency	Percent
Comfort care only	6	27.3
Attempt cure	6	27.3
Prolong life	10	45.5
Total	22	100

HCD F vent post

	Frequency	Percent
Comfort care only	10	45.5
Attempt cure	10	45.5
Prolong life	2	9.1
Total	22	100

HCD F surg pre

	Frequency	Percent
Comfort Care Only	7	31.8
Attempt cure	5	22.7
Prolong life	10	45.5
Total	22	100

HCD F surg post

	Frequency	Percent
Comfort Care only	8	36.4
Attempt cure	9	40.9
Prolong life	5	22.7
Total	22	100

HCD F nut pre

	Frequency	Percent
Comfort Care Only	6	27.3
Attempt cure	6	27.3
Prolong life	10	45.5
Total	22	100

HCD F nut post

	Frequency	Percent
Comfort Care Only	9	40.9
Attempt cure	10	45.5
Prolong life	3	13.6
Total	22	100

HCD F dx pre

	Frequency	Percent
Comfort care only	4	18.2
Attempt cure	7	31.8
Prolong life	11	50.0
Total	22	100

HCD F dx post

	Frequency	Percent
Comfort care only	6	27.3
Attempt cure	10	45.5
Prolong life	6	27.3
Total	22	100

Table 3 Agent Comfort Form

ACF 1 pre

	Frequency	Percent
not at all	1	4.5
quite a bit	6	27.3
very much	15	68.2
Total	22	100

ACF 1 post

	Frequency	Percent
quite a bit	4	18.1
very much	18	81.9
Total	22	100

ACF 2 pre

	Frequency	Percent
not at all	16	72.7
a little bit	2	9.1
somewhat	3	13.6
very much	1	4.5
Total	22	100

ACF 2 post

	Frequency	Percent
not at all	16	72.7
a little bit	4	22.7
quite a bit	2	4.5
Total	22	100

ACF 3 pre

	Frequency	PercentValid
not at all	2	9.1
a little bit	2	9.1
somewhat	2	9.1
quite a bit	3	13.6
very much	13	59.1
Total	22	100

ACF 3 post

	Frequency	Percent
a little bit	2	9
quite a bit	6	27.3
very much	14	63.7
Total	22	100.0

ACF 4 pre

	Frequency	Percent
not at all	15	68.2
a little bit	3	13.6
somewhat	1	4.5
quite a bit	2	9.1
very much	1	4.5
Total	22	100

ACF 4 post

	Frequency	Percent
not at all	18	81.8
a little bit	3	13.6
very much	1	4.5
Total	22	100

ACF 5 pre

	Frequency	Percent
not at all	3	13.6
a little bit	2	9.1
somewhat	1	4.5
quite a bit	7	31.8
Very Much	4	9
Total	22	100

ACF 5 post

	Frequency	Percent
somewhat	3	13.6
quite a bit	4	18.2
very much	15	68.2
Total	22	100

ACF 6 pre

	Frequency	Percent
not at all	15	68.2
a little bit	4	18.2
somewhat	2	9.1
very much	1	4.5
Total	22	100

ACF 6 post

	Frequency	Percent
not at all	16	72.7
a little bit	3	13.6
somewhat	2	4.5
very much	1	4.5
Total	22	100

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