Community Outreach Programs Aimed at Preparing Individuals for Serious Illness through Physician's Order for Life Sustaining Treatment (POLST) Form Education: A Pilot Study

By

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A Directed Scholarly Project Submitted to the
Department of Nursing
in the Graduate School of
Bradley University in
partial fulfillment of
the requirements for the
Degree of Doctor of Nursing Practice.

Peoria, Illinois

2019

Acknowledgements

I would like to thank all those who acted as driving forces behind and key players in the completion of this scholarly project. First of all, I'd like to thank all of the patients I've taken care of over the years. You taught me that participating in and witnessing one's passing is not something to fear. Rather, it is a beautiful gift that I have been truly blessed to bear witness to. The end of your stories were just as beautiful, if not more so, than the beginnings. Were it not for my project mentor, Dr. Artin Mahmoudi, I may not have realized how incredibly important end-of-life care planning is. He is a strong patient advocate who speaks honestly about hard truths when others cannot. I will forever be indebted to him for all the time and energy he has spent educating me and supporting my goals. Thank you to Dr. Sarah Silvest-Guerrero, my project Chairperson at Bradley University, for her ability to gently nudge and guide me, while honoring my unique vision. Finally, thank you to my wonderful family. Mom and Dad (I know you're watching), you taught me early that there was nothing I couldn't do. To my "Castle," thank you for loving me through and, at times, despite all of this. Thank you to my three amazing kids. Noey, you taught me more than anyone else ever could about quality over quantity and how to love while letting go. Mason, you have watched me study for one degree or another since you were three months old; you will be 13 by the time this paper is published. Thank you for standing by me through all of it and for being such a loving son. Matilyn, thank you for reinvigorating our lives with so much sunshine. Finally, thank you Bradley University for this amazing opportunity and Adventist Health (Tracy Joyce, Brian Forbes, and Edyta Morozinski) for supporting this project.

Abstract

Introduction: Nearly one quarter of all American adults have given little, if any, thought to their end-of-life wishes and even fewer have successfully captured those desires through legally acceptable forms of documentation. Yet, evidence tells us that despite the difficult content, patients actually want to have these discussions and feel empowered by them. *Objectives*: This study was designed to determine if community outreach events are an adequate way of improving patient education regarding end-of-life care planning and increasing the number of POLST forms within the participant population. *Methods*: A community-outreach pilot study was designed to create an opportunity for discussion about end-of-life care planning. 18-participants attended this event which showed the Netflix documentary, Extremis, and then provided medical document planning education. They filled out surveys before and after the event to assess their perceptions, preparedness, and satisfaction with the event. Descriptive statistics and t-tests were utilized to determine significance for the quantitative survey findings. *Results*: The study found that the community event was a strongly agreeable means of offering end-of-life care planning education, that it had the potential to change perceptions regarding death discussions and increased the number of POLST forms within the participation population. Conclusion: Outreach programs aimed at preparing individual's for serious illness proved a successful model for improving POLST form education and documentation and should be recommended to all communities.

Keywords: serious illness, POLST, physician's order for life sustaining treatment, end-of-life, advanced care planning, unforeseen illness

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11/21/2019

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Chapter I: Introduction

Life grants all of us only one absolute guarantee – a promise that we must all face death. While many of us take the time to contemplate and create birthing plans and expectations on how we want our children to enter this world, almost none of us put that same intention and purpose into planning how we choose to exit this world. We take such pride in controlling the narrative of the beginning of our individual life stories. Yet, either through fear or avoidance, we neglect to transcribe the final pages of our memoirs. As a result, we have very little control, if any, in how the end of our story will be told and remembered. In order to die well, we must talk about death during life.

Nearly one quarter of all American adults have given little, if any, thought to their end-of-life wishes; even fewer have captured those wishes through appropriate documentation (Institute of Medicine of the National Academies, 2015). Instead, we or our loved ones, end up in the hospital where the discussion is forced. At these times, we are unprepared and emotionally fragile. It is obvious that we are all missing a vital piece of our story - the narrative. But there is, in fact, a way to have intention, purpose, and control over the end of our lives. We simply need to have end-of-life discussions while we are mentally and emotionally equipped to do so.

As both a health care provider and consumer, I had a great desire to find a solution for this deficit in care. We've work so hard to prevent and cure illness but do not put in that same effort and energy into making time for valuable discussions about death. I've seen patients lingering on life-support, while we performed difficult and often painful medical treatments, knowing full well that not only is the prognosis grim, but that we may in fact be extending their

suffering as well. We might not be prolonging life, but rather prolonging death. It all could have been avoided if only we had a plan to follow which best honored the patient's own wishes.

Perhaps, with the right solution we could change practice, across America, so that no one suffers needlessly or spends their final days attached to lines, tubes, and machines, bereft of meaningful contact with their loved ones. Instead, we would follow patient wishes, which are well-known, documented, and easily accessible through the electronic medical record. It was my aim to do exactly that – to initiate a pilot study with the hope of impacting patient outcomes in my rural practice community as well as across the country. It was my intention and purpose to make a contribution to the healthcare system and more importantly, its consumers. Not only could such a project address end-of-life planning but when we can open up discussions for palliative approaches, we can also help patients maintain the highest quality of life for the longest possible period of time (Institute of Medicine of National Academies, 2015).

This project utilized a community outreach program, designed at educating healthcare consumers to engage in serious and thoughtful discussions about their end-of-life wishes. Successful completion of the program aimed to increase the number of POLST forms thereby paving the pathway for real and honest change within the medical industry. The project's intention was to ensure patients are no longer victimized by a loss of autonomy during their final stages of life, in serious illness, or unforeseen traumatic medical events.

Background and Significance

Sonora is a beautiful, rural community in Northern California with a large population of aging citizens who moved there to retire as part of the desire to "age in place" (Bullock, Goltvyanitsa, Shields, Garcia, & Lebray, 2015). With 10,000 people turning 65 every single day in the United States, the population of "aging" citizens is expected to continue to increase over

the next 20 years. With that increase comes a population where 33.3% have mobility issues like getting up and down stairs; concerns of loneliness and isolation abound; 27.3% are not even aware of what resources for health management exist for them, and 14% describe their own health as “poor” or even “very poor” (Bullock, et al., 2015). Most of them reported having at least one chronic health issue, if not multiple health problems, including 39.1% with arthritis, 15.7% with diabetes, and 15.0% with heart disease.

With all those problems, most of them reported not having enough time to speak with their physicians in a fulfilling way (Bullock, et al., 2015). More importantly, only 26% of Tuolumne County residents, over age 50, reported that they had a legal will and trust, advance directive for health care, or power of attorney in place. This indicates that as much as three-quarters of the aging population in Tuolumne County had no advanced care planning documentation within their electronic medical records. If passive reliance on patients and providers to initiate discussions about end-of-life care planning were the solution, then 75% of the population would not be missing these legal documents. Additional research also suggested there is a direct correlation between levels of education, and income, and having an advance directive, which demonstrated that education is needed in Sonora and Tuolumne County about end-of-life planning (Bullock, et al., 2015).

Census data suggested that there is a large portion of individuals living in Sonora who have health issues and aging concerns but not enough time to talk to or plan end-of-life care with their providers (United States Census, 2017). As a result, they end up at the only hospital close enough to serve them and in many circumstances do not have end-of-life wishes available for access by their medical providers through their electronic medical record. Their wishes may not be known and therefore may, in fact, have been disregarded. With 9.8% of Tuolumne County

residents over 50 years of age living below the poverty level, we can fully expect that the hospital will foot the bill for length of stays which exceed Medi-Cal and Medicare reimbursements (Bullock, et al., 2015; United States Census, 2017).

On a broader scale, prolonging death costs millions as people were kept alive artificially in expensive hospitals on medications and machines which were not going to improve their condition. In cases of serious medical illness, 20% of all health care costs in the US are spent on patients in critical care units. This accounts for as much as 1% of the entire gross national domestic product (Winters, 2013). The cost of just one day in a critical care unit can be well over $4,000. Yet, with all that money spent, as much as 68% of those patients still passed away during their treatment (Winters, 2013). One could argue then that many of these expensive treatments are futile and do nothing to improve one's quality of life.

Patients who know they are dying want to have a say in how that happens. When we are not prepared for death, we spend millions of dollars on artificial measures. Yet, studies show most physicians counsel families against this - what they describe as futile treatment. Cost savings ranging from $1,041 to $64,830, or as much as a 15% gross savings were found when acute care planning is utilized, showing a positive relationship between effectiveness and cost impact of advanced care planning (Kingler, Schmitten, & Marckmann, 2015). In addition, patients who have suffered through expensive medical treatments reported that they wish they never would have started them in the first place. As much as 61% of dialysis patients regretted their choice to start dialysis; 36.1% wanted to die at home with hospice, and sadly only 10% reported having end-of life discussions with their providers, reporting very little knowledge of their palliative care options (Davison, 2010). These are significant findings pointing to general unpreparedness in end-of-life planning and the health-care costs associated with it.

In 2016, California's End-of-Life Option Act passed, allowing patients diagnosed with terminal illness to request an aid in dying prescription from their provider (California Department of Public Health, 2017). Acts such as these, which have passed in other states, taught us that patients are not just concerned about dying but they are also about "wrongful life." People do not want to suffer through pain, disability, and debilitation; they do not want to become burdensome to their families. People with terminal illness want to be able to say when their right time is to go and to have some control over their end-of-life plan. Perhaps they want to die at home with their family around them. Perhaps they want to die in a hospital, so their family does not associate their home with death. Only they can tell us what they believe is best for them.

What does this tell us? It tells us that people who know death is coming are interested in planning the end of their lives. Studies have shown that patients want to be included in end-of-life discussions with their providers and/or families; they want to be heard (Detering, Hancock, & Reade, 2010). Patients lucky enough to have providers engaging in these discussions reported greater satisfaction with their provider and were more likely to rate them as excellent (Tierney, et al., 2001). So, the planning needs to begin now, while we are well and daring enough to talk about death with intention and purpose.

Needs Assessment

There is only one acute care hospital in a tri-county area. Therefore, the needs of Tuolumne County itself (where the hospital is located) mimic the needs of this hospital. With as much as 25% of a 55,000-person population being over 65 years of age (United States Census, 2017), one can presume that chronic medical conditions, comorbidities, illnesses, and end-of-life processes are a large part of the medical services rendered to said residents. The objective of this

project was to address those needs through end-of-life care planning and education so that the primary consumers of this tertiary care facility have their needs met and the financial impacts of unwarranted and undesired care reduced. The practitioners, providers, and administrators of the facility were key stakeholders in this project. On an even broader level, all medical health providers within the county were stakeholders; they are the providers of medical goods for consumption to all those within Tuolumne County.

In order to collect data on the needs of Tuolumne residents and the key stakeholders mentioned, county census data and a 2014 needs assessment survey from the Area 12 Agency on Aging were utilized. The costs of lengthy hospital stays and days in the ICU were also utilized to communicate financial impacts of critical care at the acute care facility. Finally, the revealing statistics about survival rates, despite expensive medical interventions, were communicated to these stakeholders. All factors combined, helped communicate the need for this project and the current gap in care – lack of planning.

SWOT analysis (see Appendix O), which helped identify organizational strengths, weaknesses, opportunities, and threats, showed that undertaking a project aimed at increasing the number of individuals who engage in end-of-life planning through POLST form preparation would be strongly supported. The needs of a project like this in the chosen community included addressing the specific needs associated with a largely "aging" population and the financial implications on primary stakeholders related to lengthy hospital stays with decreased survival rates. SWOT found when addressing those needs that this project had a planned evidence-based intervention with the potential to decrease the number of admissions, associated costs, and to minimize the decision-making burden on patients and their loved ones. In addition, the acute care facility has skilled inpatient providers and social workers already devoted to having these

discussions. The scientific tools were already been created and the personnel already prepared to help realize the goal of this project, alleviating the above-mentioned needs of the community.

The current state of care in Tuolumne County indicates that 71.0% of residents over 50 have Medicare and 12.9% have MediCal, indicating that most of the residents are on insurance plans heavily supported by taxpayer dollars (United States Census, 2017). Financially this means, at its current state, the acute care facility risks footing the bill for lengthy hospital stays and costly medical interventions. In addition, 26% of residents over 50 had no legal documents prepared to help express their wishes, including a will and trust, advance directive for health care, or a power of attorney (Bullock, et al., 2015). This indicated that POLST form documentation must also be lacking. Worthy of consideration was the fact that when a large portion of the population is "aging," the county and hospital find themselves in a unique situation, having to address chronic diseases and disabilities specifically associated with geriatric populations (Bullock, et al., 2015).

This project aimed to increase the number of residents who reported to have POLST form documents completed. Current literature identified that there is a direct correlation between level of education in persons who reported having an advance directive for health care (Bullock, et al., 2015). This finding clearly identified that the missing piece was a lack of education regarding end-of-life planning and medical documentation. Therefore, the project was created to provide an opportunity to educate healthcare consumers about their end-of-life care planning options. It addressed the need to have POLST form documentation. Without this documentation, there is not a valid means of conserving patient autonomy during times when patients cannot speak for themselves.

Tuolumne County and the acute care facility in Sonora are certainly not alone in this problem. It is not the only community in California, or the US affected by death. On a larger scale, as we all know, there is no one unaffected by death or serious illness. The medical industry is affected not just by the medical treatments we utilize to maintain life but also by all the policies and financial resources utilized during the death and dying process. The need to address end-of-life planning affects all persons living within Tuolumne County; the whole tri-county area served and impacts every single living individual alive today.

This project had the potential to reduce the financial burden felt by the acute care facility as it provided expensive critical care to patients who, if they could talk, may have felt they were being kept wrongfully alive. It also allowed patients and providers to engage in conversations about quality of life and death planning to continue the tradition of patient autonomy. It gave patients some control over the most difficult part of life - death. Everyone benefits from having a solution to the problem of unprepared end-of-life planning. The patient and family burden were eased of hasty decisions during times of fear and loss. Providers were relieved of having to "push" patients or families in one direction or the other and allowed to create treatment plans which support the patient's wishes. Insurance providers, hospitals, and taxpayers also benefit from reduced medical expenses when we remove expensive treatments that do not serve to promote quality of life.

Problem Statement

Nearly one quarter of all American adults have given little, if any, thought to their end-of-life wishes and even fewer have successfully captured those desires through legally acceptable forms of documentation (Institute of Medicine of the National Academies, 2015). Yet, the evidence tells us that despite the difficult content, patients want to have these discussions and

feel empowered by them (Gesme & Wiseman, 2011). Furthermore, they report less anxiety and distress when their providers are honest with them about their medical conditions (Gesme & Wiseman, 2011). When there is a gap in end-of-life care planning there will also be an increased cost associated with substantial ICU stays during terminal hospitalization in the United States (Mrad, Abourgergi, & Daly, 2018). The most profound finding in the literature is this – early palliation leads not just to improvements in quality of life, but patients receiving palliative care lived longer than those receiving aggressive interventions (Temel, et al., 2010).

Unprepared patients, families, and providers lead to regretful situations where decisions about life or death are made under haste, often while fearful or in pain. Without expressed or documented wishes, patient autonomy - the crux of medical ethics - is lost. This often results in medical interventions which oppose patient wishes. Every single one of us will die. Therefore, the need to address end-of-life planning is crucial. There is simply no excuse not to partake in intelligent and informed discussions with one's provider about what one envisions to be appropriate medical interventions and how one defines quality of life. Yet, there is a large void as this is simply not being done in Tuolumne County and many other communities across the United States. This deficit needed to be addressed through a proposed change in practice. The proposed community outreach event was designed to work not just in rural communities like Tuolumne, but in all communities and for all patient populations.

Project Aims

This project attempted to determine if an end-of-life planning community outreach program could increase the number of POLST forms documented in Tuolumne County. The number of POLST forms prior to the intervention, and then after the intervention, was measured. Secondary quantitative measures were also used to explore perceptions of end-of-life planning

and discussions about death prior to and after the intervention. These measurements were attainable within the year the project was planned, designed, implemented, and concluded and are universally relevant, as death affects every single one of us.

Evidence-based practice, effective scientific tools, driven practitioners, and a mission to inspire wholeness minimized project weaknesses and threats. The primary objective of this project was to increase the number of POLST forms among project participants. This measurement indicated whether or not the project was successful in closing the gap identified through analysis (education and planning). It was deemed realistic to see the results of such a community outreach project within a one-year time period. In absence of this intervention, the community would continue to suffer from lack of end-of-life care planning both emotionally and financially.

Clinical Question

Do patients who attend a community outreach program aimed at providing end-of-life care planning have a higher rate of POLST form completion after the intervention than they did prior to the event?

Congruence with Organizational Strategic Plan

The acute care facility where the project was held is a religious, non-profit body which values spiritual well-being as the foundation of care provided to those who are ill, based on the heritage of the Seventh-day Adventist religion (Adventist Health Sonora, 2018). As a corporate organization, it serves more than 80 communities on the West Coast and in Hawaii. The acute care facility tasked itself with “managing people’s health to make care more affordable” (Adventist Health Sonora, 2018). Therefore, finding cost effective ways to honor patient wishes is paramount this this vision. In 2016, there were 150,202 admissions, 685,296 emergency visits,

2,952,313 outpatient visits, 239,742 home care visits, and 2,283,341 clinic visits provided by the 35,000 team members employed by the acute care facility's corporation (Adventist Health Sonora, 2018). A person-centered business, like this acute care facility, cannot promote care of the "mental, physical, and spiritual wellness by inspiring health, wholeness, and hope" when the only focus is on curative intervention (Adventist Health Sonora, 2018). Peaceful passing must also be addressed which was the aim of this project, in congruence with the organizations strategic plan.

The acute care facility promotes and cherishes one of its efforts focused in Paradise, California where it opened a six-bed hospice facility providing care to as many as 104 patients in 2017. This hospice house is considered a continuum of Palliative Care services offered by the acute care facility's corporation which expresses that "listening to patients" can help "guide practice" through one of its core values, 'promoting hope' (Adventist Health, 2017/2018). Their dedication to programs such as this showed that they wanted to shed light on even the darkest times of life, not just provide lifesaving, curative interventions.

Furthermore, the corporation promotes community integration through all that it offers, stating that they "are committed to providing excellent healthcare throughout partnerships with our communities" (Adventist Health, 2017/2018). They supply millions of dollars to support this commitment by offering over $50 million in free and discounted care, $21.9 million in community health improvement, $21.7 million towards education and research, $139 million in aid to the elderly, and billions more. This indicated that they were willing to financially support programs aimed at improving all aspects of patient care (Adventist Health, 2017/2018).

It was clearly evident that a project aimed at helping communities would obtain buy-in from the acute care facility. There was also a projected financial benefit for the acute care

facility should the project prove successful. The corporation received $4,145,220,000 in net revenue from patient care and other sources of income in 2017. However, it also had to foot the bill for rendering patient care and providing patient services, not covered by insurance, in the amount of $3,910,573,000 (Adventist Health, 2017/2018). That's almost $4 billion dollars in uncovered costs. Imagine if a project like this could reduce costs of care not covered by insurance. Imagine if hospital bounce-back admissions (which are not covered by MediCal) were reduced through proper end-of-life care planning and adequate communication among patients and providers. As already evidenced, the acute care facility is a non-profit and donates it profits back to the communities it serves. With less incurred expenses, their ability to continue to do well and pass on the benefits is foreseen.

Finally, when considering the perspective of the acute care facility specifically, this project aligned with local goals as well. The project topic was in fact initially presented by the Director of the Intensive Care Unit (ICU) at the hospital. A project presented by the primary physician for critically ill patients in the community, carried a great deal of weight. The ICU Director expressed that end-of-life care planning suffers from a large gap. His support was a strong indicator that the project complied well with the mission, values, and strategic plan for the organization.

Synthesis of Evidence

Several databases and resources were used to find evidence to drive the objective of this project. Databases included Google Scholar, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, and NCBI, all accessed online through both the general Google browser and through the Bradley University Library. In addition, printed journals including the New England Journal of Medicine, Critical Care Nurse Journal, AJCC Magazine, and Mayo

Clinic Proceedings. These journals were either received personally on a monthly basis or were found in the Physician's Library at the acute care facility in Sonora where the project was conducted. Another synthesis tactic used was to follow the references listed in the articles which were found to be appropriate for selection of final review. The evidence was "followed" so-to-speak. Several of the articles researched were also found specifically at the discretion of project mentors who were engaged in providing supportive statistics for the project.

There were multiple keywords utilized through the various search engines listed. They included all of the following: advanced directives, chronic disease, death and dying, decision making, end-of-life care, advanced care planning, improved perception, planning, advance care planning, healthcare costs, patient satisfaction, primary care, lung cancer, palliative care, terminal illness, life-sustaining treatment, living will, patient preferences, physician-patient communication, geriatric palliative care, and POLST forms. However, the search began with more specific queries that could incorporate all the components of the project and related PICO statement. For example, one query was "the cost of life-support." Another query was "do POLST forms improve patient care." The focus of the search was to find quantitative studies which could provide direction for the project. However, patient perceptions about end-of-life planning, or qualitative analysis, was a crucial component as well. The evidence supported a few key concepts.

Patients prefer discussion. Patients prefer physicians who initiate end-of-life discussions and planning (Detering, Hancock, Reade & Silvester, 2010; Gesme & Wiseman, 2011; Tierney, et al., 2001; & Ho Yung, et al., 2004). Since providers are obligated to fulfill the crux of medical ethics, autonomy, it is vital that they understand they are not harming the patient by breaching difficult subject matter. Rather, they are performing a service their clients expect

and desire of them. However, in order to fulfill this patient-centered requirement, they still require ongoing training on POLST form legalities and how to have hard discussions (Alliant Quality, n.d.; Tierney, et al., 2001; Gibson & Crowe, 2018; Mills Garrett, Harris, Norburn, Patrick & Danis, 1993; Sellman, et al., 2017; & Mitchell, et al., 2018). There are tools already available to providers which may help them determine when it is time to initiate these discussions, such as the Frailty Index and Clinical Frailty Scale (Gibson & Crowe, 2018).

Furthermore, the discussions need to be informative, accurate, and detailed. The discussion should hinge responsibility on the provider to assure that the patient has reasonable expectations regarding medical interventions and outcomes. Only then will the options chosen on the POLST form be well-informed and concordant with current preferences (Hickman, Hammes, Torke, Sudore, & Sachs, 2017). Not only does this lead to improved patient autonomy but interprofessional empowerment as well. Nurses report that they want their patients to engage in these types of discussions with providers for proper palliative care integration (Wolcott Altaker, Howie-Esquivel, & Cataldo, 2018). In addition, family member experiences improve when the entire interdisciplinary team is empowered and on-board with patient wishes (Jones, Puntillo, Donesky, & McAdam, 2018).

Planning reduces healthcare costs. In addition, the evidence supports the concept that when end-of-life care planning occurs, healthcare costs are reduced (Klingler, Schmitten & Marckmann, 2015; & Mrad, Abougergi, & Daly, 2018; Emanuel, Faircough, Slutsman, & Emanuel, 2000). This is a key concept to help drive stakeholders toward active engagement. Not only is it the duty of the health care industry to provide autonomy but also to stay financially relevant and capable of offering services to all, regardless of their ability to pay. This cannot

occur if costs continue to rise while services are rendered which may not be appropriate when patient wishes are taken into consideration.

The literature supports that some patients wish they had never begun specific medical interventions in the first place. Money could be saved had these interventions been forgone, if only patients were well enough informed to make personal decisions. For example, 61% of dialysis patients in a 2008 Canadian study reported that they regretted their decision to ever start dialysis (Davison, 2010). Additionally, one must consider that other patient populations, like foreign language speakers may have undergone unwanted medical treatments simply because they did not understand their medical situation and treatment options (Barwiseet al., 2018).

Patients live longer. The evidence led to a most incredible finding regarding end-of-life planning, particularly when dealing with terminal illness and palliative care treatment options. Not only are costs reduced, but patients report a higher quality of life, and actually live longer than those receiving aggressive treatment options (Institute of Medicine of the National Academies, 2015; Temel, et al., 2010; & Torke, et al., 2018). Of note is an article found through PubMed with the keywords “POLST forms” and “geriatric populations” which indicated that a project such as the one proposed here can be both feasible and successful with higher fidelity when applied in a long-term care facility and appropriate protocols in place for adherence (Torke, et al., 2018).

Conceptual or Theoretical Framework

The Donabedian model was utilized to conceptualize the framework for this project. This health care model teaches that when improvements occur within the structure of care, patient outcomes also improve (Moore, Lavoie, Bourgeois, & Lapointe, 2015). In order to improve patient outcomes, there must be a sound structural foundation for the clinical processes to

function from (Moore, et al., 2015). With this healthcare model in mind, the project was designed to change the structure or foundation from which the hospital and related providers operate. If end-of-life care discussions occur prior to unforeseen medical events, the plan is already in place and can be easily followed. The clinical process could then be altered to first ask after existence of the POLST form and then simply to follow the guidance and instructions provided within it. Once the system has adequately responded to the documented patient wishes, outcomes will be improved.

There are three main components associated with the Donabedian model: structure, process, and outcomes (ACT Academy, 2018). These three components are well embedded within this project. The structure does not need to be recreated as it is simply the POLST form, already well known across healthcare communities in the US. The process, however, is what the project aimed to change. The project reflects how well the hospital system and the POLST form process work together to deliver the desired outcome of having an increased number of patients engaged in end-of-life care planning (ACT Academy, 2018). The project focused on the way care is delivered through what really is a primary intervention approach – discussion which takes place before the medical event occurs. The outcome of the change in process measured the success of not just the project but also its ability to affect healthcare within the chosen patient population (ACT Academy, 2018).

Through utilization of the Donabedian healthcare model the outcome measurements addressed first how the current state or current processes are affecting patient populations within Tuolumne County. Then, post-intervention, it measured whether the main objective was met and whether there was any variation in the documented findings (ACT Academy, 2018). If the objective was not met, the project measured whether there were variations among the processes

across all the different organizational components of the facility. Then, the project could suggest changes which could be made to the intervention process to achieve the desired impact (ACT Academy, 2018)? Finally, the model helped evaluate whether the outcome measured elicited a sustainable change for the organization. In other words, did the project successfully offer a change in process with measurable positive outcomes?

The project was developed and implemented in the small rural community of Tuolumne County, California with a specific focus on the only acute care facility in the region, and it's out-patient and clinic providers. The community project took place at the acute care facility. The process of the project involved several phases. First, perception surveys were given to project participants. Secondly, a community outreach group intervention was offered, concentrating on end-of-life care planning with persons immediately available to assist in POLST form documentation. Thirdly, perceptions of end-of-life care discussions and planning were surveyed post-intervention. The post-intervention survey also included a patient satisfaction survey to assess how participants viewed the event itself. The number of POLST forms within the subject population was tracked prior to and after the community outreach project. The main goal outcome was to determine if there were an increased number of POLST forms among the participant group. The secondary outcome was to improve patient perceptions regarding end-of-life planning through Likert scale analysis. The final measurement was to qualitatively evaluate whether offering community education sessions was a desirable way to learn about end-of-life care planning options.

Chapter II: Methodology

Project Design

This project was designed to be a pilot study. It was an experimental design aimed at examining the effect of POLST form education within a rural community. The implemented intervention implemented was the offering of a community outreach program designed to provide POLST form education and end-of-life care planning. The expected change and outcome was for the group of project participants to have an increased number of completed POLST forms after the intervention than they did previous to it – data derived from the pre-intervention survey (see Appendix B). The cause of that change was the community outreach intervention. Surveys were utilized to explore perceptions of end-of-life care planning both prior to and post-intervention. While quantitative measurements were the primary determinants of project success, participants were also offered an opportunity to share open-ended feelings and opinions about end-of-life planning and the community outreach project itself. Perception helps determine feasibility of future projects on a broader scale. This was an appropriate design as there is little research on direct interventions aimed at increased POLST form documentation across communities (Institute of Medicine of the National Academies, 2015). The results of this project can therefore serve as a starting point for generating a change in process. It was designed with the potential to identify methods for effective education on behalf of providers and patients alike.

Setting

The project took place at an acute care facility in Sonora with many out-patient clinics and providers, in the Northern California County of Tuolumne. The 55,000-person population is composed of over a quarter of person's 65-years or older (United States Census, 2017). Most of the population is Caucasian, many are living below the poverty level (9.8%), and 14% reported that their health is either poor or very poor (United States Census, 2017). The acute care facility

has a three-story hospital building with a new addition of a state-of-the art cancer center and out-patient rehabilitation clinic across the street. The intervention was held in the large conference room on the ground level of the main hospital, easily accessed by all community residents, with a bus stop and easy parking within walking distance. The acute care facility has an organizational culture which continually demonstrates that it is prepared to make whatever changes are necessary to support its local community members, as evidenced by its many community outreach programs (Adventist Health, 2017/2018).

Population

The participants included in this pilot study were chosen through a convenience sampling of all Tuolumne County residents. Marketing efforts were conducted in an attempt to reach all residents. Those with access to the local newspaper and those with internet access were reached through the upcoming events sections (see Appendix I). However, those without access to the newspaper or internet were able to see posted flyers (see Appendix J). Flyers were provided to several local agencies, including Area 12 Agency on Aging, Unit 6 & Unit 7 (long-term care facilities owned by the corporation), the local food bank, and the local Lions Club, Rotary Club, and Moose Lodge. In addition, the flyers were sent to all the primary care offices within three counties. The Director of the ICU, who initially suggested the project, also passed out flyers to his patients within his pulmonology clinic. Finally, local senior-living and care facilities were also provided with flyers. It was assumed that those who saw the outreach efforts and chose to attend the event already had some reason to want to invest their time in end-of-life care planning.

Persons of all types, ages, and backgrounds can suffer from a debilitating illness and want to express their option to discuss their end-of-life care. Therefore, the only exclusion criteria was that the participant must be 18-years of age or older. The project was essentially an open

invitation to participate with no expectation on the number of people who might attend. The project asked those who chose to participate to first fill out a pre-intervention survey either prior to arrival or at the event itself (see Appendix B) and an informed consent form (see Appendix G). In one regard, having such an open-ended convenience sampling method may make it difficult to generalize in other settings. However, from another viewpoint, an open-ended invitation for people of any type yielded a community-centered population to study, therefore making the project easily generalized in any setting, across the country. The literature has tended to focus on specific population types, like dialysis and oncologic patients, or the elderly (Detering et al., 2010; Gesme & Wiseman, 2011; & Davison, 2010). This project did not focus on any specific population type, or any subgroup based on diagnoses or treatments in a specific effort to broaden the current literature's scope of findings.

Tools or Instruments

There were two primary tools associated with the project. First, is the POLST form utilized in the State of California, which is readily available online, and is well recognized by local providers (see Appendix A). The POLST form functioned both as a tool and a means of measuring the outcome. The POLST form has four sections, sections A through D. Section A focuses on cardiopulmonary resuscitation (CPR) and allows for the patient to choose either resuscitation efforts or to allow natural death. Should a person choose the first option in section A (full resuscitation), then they must also choose option one in section B, which focuses on medical interventions. They must choose the option for full treatment. Section B allows for full treatment, selective treatment, or comfort-focused treatment. Section C focuses on artificially administered nutrition with three available options: long-term artificial nutrition, a trial period of nutrition, or no artificial means of nutrition. Finally, section D is where the legal aspects of the

form are taken care of. This section requires signature of the patient or legal representative, as well as the physician, nurse practitioner, or physician assistant that validates the patient's wishes. This tool, the POLST form, is available for free online and accessible to any for use.

The other tools utilized were a set of two separate Likert scale surveys produced specifically for this project. They were evaluation tools, created by the student, meant to measure the perceptions of the participants in the study and their feelings on planning for end-of-life care. The surveys asked questions about perceptions of end-of-life planning before and again after the intervention utilizing a Likert scale (See Appendix B). The second patient perception Likert scale survey was utilized only after the intervention and assessed the participants' perceptions of the event itself (See Appendix D). It too was created by the doctoral student specifically for this project utilizing several different resources. The project mentor and ICU Director at the acute care facility had created a similar Likert scale for his patients to assess their perceptions on death and spirituality. Many of the questions stemmed from his survey and were adjusted to remove bias. The layout for his survey was replicated for the project survey. In addition, the literature review offered many questions in their participant surveys which offered evidence-based guidance related to perceptions of death. In addition, the Center for Disease Control offered some tips for creating project surveys and those suggestions were followed in an attempt to create non-biased questions that were not double-barreled or negative (Center for Disease Control, 2018). Anytime one is dealing with opinions and perceptions, the tool becomes less reliable. Perception surveys require honest answers and those answers may change in different environments. This is because the pilot study, while it can be mimicked perfectly, will always have innumerable variances. Expected variances include providers and professionals

who can attend, the population subgroups in attendance, and how the group of participants function together as a group.

Project Plan

A pilot study guised as an educational program was implemented to provide end-of-life care planning. There were five main steps necessary to conduct the project. Those five steps included: event planning, creating and distributing marketing materials, hosting the intervention/event, data collection and analysis, and drawing conclusions while evaluating strengths and limitations. The scheduling timeline is set for a period of 15 weeks with some allowed for fluidity (See Appendix C). As California offered some unexpected external environmental events that could not possibly have been planned for, Appendix C shows the expected timeline as well as the actual timeline of project events.

The population of study was recruited from Amador, Calaveras, and Tuolumne counties in California. They were recruited through marketing efforts created by the doctoral student. Anyone with access to the two local newspapers – The Union Democrat and The Calaveras Enterprise - or the internet had access to the recruitment efforts. Also, those who were current residents of the local rehabilitation units, senior living facilities, or who utilized services at facilities like Area 12 Agency on Aging were able to view provided flyers.

The marketing efforts included an invitation to respond if there is an interest in attending. Interested persons were invited to either email (a private email account was created) or contact the doctoral student directly to express their interest. A form was created to ask questions of the potential participate to discover if the participant was available on the date of the event, could commit their attendance, had available transportation, had any disabilities which may require survey personalization, and how they preferred to receive documentation (See Appendix E). Due

to unforeseen external events, this form was never utilized and while participants were encouraged to RSVP, this was no longer a requirement of participation. The informed consent form and pre-intervention surveys were available at the check-in station outside of the conference room where the event was held. Participants were requested to submit both their informed consent form and pre-intervention survey prior to engaging in the intervention.

Project participants took part in the event by listening to presented material (See Appendix J). The project began with self-introduction of the project mentor, Dr. Artin Mahmoudi, who then also introduced the doctoral candidate. Introduction also included a thank you to project participants for being willing to not only partake in the doctoral project but also to take the important step in being prepared to discuss end-of-life care options. Patient anonymity was reaffirmed at this time as well. Participants for also once again reminded that their participation was voluntary, and they were free to leave at any time and they did not have to fill out any of the surveys if they chose not to.

The second part of the intervention was a visual presentation of materials and open-ended questioning. Forty minutes was set aside for this part of the project. There were two main parts of the presentation prior to open-ended questioning. The first was a 24-minute presentation of the Netflix documentary “Extremis.” Permission for the public viewing of this educational documentary was granted by Netflix (See Appendix F). The second part of the presentation was an open invitation to the room to ask questions and share thoughts after watching “Extremis.” The open-ended question used to lead the discussion was: “How did that movie make you feel?” Ample time was set aside to share feelings and ask questions, which were answered by either the doctoral student or the project mentor. The open-ended conversation was not be recorded for qualitative research purposes but simply served as a way to get participants actively engaged in

thinking and learning about end-of-life care planning options. While the open forum and lead to information about the participants an emotional response to the movie, this data was not collected for qualitative purposes. Qualitative data was collected through the post-intervention patient satisfaction survey (See Appendix D).

After presentation of the material had concluded, an open invitation was made to all interested participants by the doctoral student to partake in on-site end-of-life care planning. Blank POLST forms were made available to all participants. The project mentor and doctoral student answered questions regarding the form. Those participants who chose to fill out their POLST forms were allowed to do so with project team assistance. Participants were also reminded that they could take these forms to their primary care providers to discuss their wishes with them. They were informed that they could ask for an appointment for "advanced care planning." They were taught how to utilize these forms, by placing them inside their homes, on their refrigerators, for example, and asking their provider to ensure it goes into their electronic medical record.

After completion of the community outreach event, participants were asked to fill out the post-intervention survey (See Appendix B). Additionally, participants were asked to fill out a second survey which assessed their satisfaction with the event/intervention itself (See Appendix D). Finally, quantitative data collection began, directly measuring the number of POLST forms completed as the result of the project and the perception surveys, patient perceptions on end-of-life care planning, and whether or not the pilot study design was an appropriate means of communicating end-of-life planning information.

Outcomes. The success of the pilot study and community outreach program was measured with SMART objectives. The first objective was to increase the number of POLST

forms completed within the population sample. The number of POLST forms among the project participants was measured before and after the intervention (via the pre- and post-intervention surveys) and then compared within the fifteen-week project period with a goal of 50% improvement (See Appendix B). The second objective of the project was to determine if community outreach programs, such as this pilot study, are a reasonably effective way to engage persons in discussions and planning for end-of-life care. A Likert scale survey was used to assess people's overall opinion of the intervention, if they felt it was a good way to learn and talk about end-of-life care planning, and if they would recommend it to a loved one (See Appendix D). This helped determine if the intervention was relevant and can be replicated across communities. The third objective was to determine if perceptions about death and dying change as a direct result of the intervention. This, too, was measured and completed with the fifteen-week project time period through use of the patient satisfaction survey which utilized both Likert scale questions for quantitative analysis and an option for open-ended responses for qualitative analysis (See Appendix D).

Basic patient information was also collected, such as age, gender, and if there was a religious preference. This information was utilized to determine if one age group, sex group, or religious group tended to have thoughts different from others regarding end-of-life care planning. The pre- and post-intervention perception surveys included areas to fill out this information. This information was collected and compared utilizing data collection methods (below) and basic statistical analysis.

Data collection. Survey data was collected by the doctoral student. Only the consent form has a patient identifier. From the informed consent form the participants were assigned a randomized number. The randomized number was then used on all the interventional surveys so

that no identifying data was included. Patient privacy was respected throughout the entire project with the doctoral student being the only person with access to any private information. Reliability of the data was based on two factors only. The first factor was that project participants answer survey questions honestly. There is simply no way to guarantee honest responses, however the participants were asked to answer every question on the survey to offset this factor. The second factor was that the doctoral student did not make any transcription errors when moving data from paper survey responses to Microsoft Excel, which was utilized to collate findings. Potential transcription errors were minimized by having the second check of data during the transcription process by a Professor at a local university, Sacramento State (again there were no patient identifiers on the surveys).

The largest barrier to the data collection process was that some project participants did not turn in all their surveys. One participant arrived late and so didn't have time to fill out the pre-intervention survey. Therefore, there was no way to compare her pre- and post-intervention surveys. Two other participants were taken out of the intervention by nursing staff from the ICU to respond to a family need. They were only able to fill out the pre-intervention surveys and not the post-intervention or attendee satisfaction survey. This barrier was already planned for as part of the voluntary participation and informed consent process. Participants were always allowed to leave and/or participate at any time. This is an inherent risk in survey-type data. Data collection took place after the intervention. While participants will be asked to return their pre-intervention survey's prior to attendance at the event, responses will still be accepted at the beginning of the community event, itself. After the event, data collection can begin immediately on the pre-intervention surveys. The project aimed to have all data collected and available for analysis by the end of week 12 (See Appendix C).

Evaluation and sustainability plan. Once the pre- and post-intervention perception and patient satisfaction surveys had been collected and entered into an Excel spreadsheet, statistical analysis was performed to see if there was a statistically significant interventional result. The data was utilized to evaluate if the project/intervention led to an increased number of POLST forms. In addition, did perceptions about end-of-life planning change as a result of the intervention? While perceptions are typically qualitative, by utilizing a Likert scale, the data analysis was interpreted quantitatively. The patient satisfaction survey also led to quantitative evaluation. However, it also allowed for open-ended commenting on participant perceptions regarding the intervention. These comments could then be utilized to summarize the data analysis findings.

Since this was a pilot study, results would only be sustained if the study proved successful and led to others just like it, either within the same community, or across other communities. The specific participants of the pilot study who have not gotten their provider to sign their POLST form yet may regress and never fulfill this medical tool either due to neglect or preference. The only way to prevent regression in the aforementioned situation is to continue to follow-up with project participants and answer any lingering questions they may have.

Project timeline. The project itself was meant to occur over a fifteen-week period. There were five major steps that needed to occur to complete the preparatory, intervention, and review phases of the project. All these steps were scheduled utilizing a Gantt chart (See Appendix C). Literature review, creation of tools, data collection methods, and presentation materials were all gathered prior to the fifteen-week period, during the first and second semesters (30 weeks) as part of the Doctor of Nursing Practicum courses.

Data Analysis

The quantitative data was analyzed for statistical significance mostly using descriptive statistics. Analysis used to determine if there was a statistically significant difference in mean values (number of completed POLST forms) prior to intervention and after intervention was done with one-tailed and two-tailed tests. The pre-intervention survey included a question directing participants to state whether they already have a POLST form completed. They were then asked this same question after the intervention (See Appendix B). In addition, this analysis was displayed is such a way to describe the population and how the intervention affected different subtypes. For example, were men or women more responsive to the intervention? The variable of interest, a community outreach program, also required an analytical method, like descriptive statistics to determine effectiveness prior to pursuing replication in other communities.

Descriptive results were also utilized to describe the studied population and this data is summarized in the results section. Participant perceptions were addressed in two different ways. A Likert scale was utilized to rank perceptions of the intervention and the results are displayed in table format with simple frequencies and percentages noted. These findings are listed in the results section of the analysis. In addition, open ended statements from post-intervention participants are shared in the results section. An attempt to summarize common themes and findings, should they exist, is also reported by the doctoral student. The data was analyzed for direct comparison to the SMART objectives for overall conclusion by the doctoral student if the pilot study was deemed successful.

Institutional Review Board and/or Ethical Issues

Approval for the project was given by Bradley University's Committee of the Use of Human Subjects in Research (CUHSR). The doctoral candidate has completed the Human

Subjects in Research CITI Training in order to comply with aspects of the CUHSR. Informed consent was given and to all project participants (See Appendix G). Only one patient identifier was collected by the doctoral candidate for each participant – their name. Once the participant agreed to volunteer, their name was entered into a private (locked) Excel spreadsheet along with a corresponding randomized subject number and stored on the doctoral student's private, non-network, and password-protected computer. The informed consent form had a removable section at the bottom which provided their randomized participant number and all further data collected had that randomized number on it. This process ensured that the data collected, analyzed, and published is free of any patient identifiers. Personal information was not shared with anyone involved. While there is no way to keep study participants completely anonymous, as the project was an in-person event requiring personal attendance, their survey results were maintained anonymously. The perceptions and patient satisfaction surveys will never be attached to personal identifiers. The completed surveys will be kept only in the personal (locked) filing cabinet at the private office of the project mentor which is within the acute care facility.

Chapter III: Organizational Assessment and Cost Effectiveness Analysis

Organizational Assessment

The medical center which hosted the intervention event is based in Tuolumne County, California and is part of a larger corporation which spans the west coast of the United States from Hawaii to Washington. The corporation is a Seventh Day Adventist based non-profit organization. When they have net revenue, they put their finances back into the communities which they serve. The acute care facility promotes community engagement efforts stating that they "are committed to providing excellent healthcare throughout partnerships with our communities" (Adventist Health, 2017/2018). They supply millions of dollars every year in this

effort and they clearly demonstrate a willingness to partake in community events which have the potential to impact their communities. In addition, part of the corporation's vision is to task itself with "managing people's health to make care more affordable" (Adventist Health Sonora, 2018). As the literature review indicated, end-of-life planning can reduce the financial implications of unwanted or unwarranted medical care, both for the patient and their providers. Creating a pilot study with the potential to elicit financial change was embraced and the acute care facility was prepared for this welcomed change.

There are some barriers to this change. As with any provider in the medical field, there is a feeling that there just isn't enough time to sit down and have quality discussions with patients. Even if the pilot study can prove to local providers that their patients want to have discussions about end-of-life care, we still must find a way to fit these conversations into their complex workflows. In addition, some providers and patients may have an inherent fear of death and therefore breaching the subject can be quite a challenge to begin with. However, the acute care facility has some assets at its disposal to offset these barriers. The tools that provider's need in order to have these discussions already exist and there is no need to recreate the wheel and no additional expenditure of time. They simply need continued access to the POLST form. They may also feel differently once they learn there are ICD codes and ways to be reimbursed for the time, they spend with patients having these discussions as advanced care planning is a billable and reimbursable diagnosis code. In addition, the acute care facility prides itself on having motivated professionals who share a goal of enhancing the community through education. There is already an abundance of very skilled social workers and in-patient providers willing to help community members plan for unforeseen medical events and death. These professionals are well-skilled and quite adept at breaching subjects many find taboo.

Risks and/or Unintended Consequences. It is possible that by giving people the tools and power to make their own healthcare decisions, they may not frequent the hospital as much, which could lead to a reduction in revenue. The goal when we educate people about POLST forms and advanced healthcare directives is not only to have them think thoughtfully about them, but also to share their wishes and these forms with their loved ones. That is the best way to ensure their wishes are followed. As it stands now, with poor or no preparation, families, friends, and caregivers who witness a sudden change in medical health may panic and take the ill person to the emergency room or call 911. This may be in direct conflict with the person's personal wishes to die at home. So, the person can end up in the hospital, receiving billable medical interventions, which the hospital in turn is reimbursed for. However, this possible risk does not take into consideration the many caveats of billing insurance companies. If a patient develops a hospital acquired infection or ulcer during their stay, or if they are bouncing back to the hospital too soon, MediCal and Medicare may not pay for the extended part of the stay and the hospitals is left to foot the rest of the bill (Paddock, 2007).

Cost Factors

The cost for this scholarly project was low as it relied heavily on tools, settings, and methods for marketing already in place (See Appendix H). However, there were costs associated with the marketing campaign to enlist and invite participants. The expected cost was $290. The actual cost was $239.78. However, due to unforeseen external events $119.71 of costs was required to host the event a second time. Ideally, this would imply that the actual cost for this pilot study (had the environment not interfered) would have been only $120.07, approximately $170 less than expected. While during the first event there were beverages provided by the dietary program at the acute care facility, the doctoral student could not ask this again from the

facility a second time. Costs were therefore incurred for beverages and snacks at the second event. The surveys and marketing materials were created by the doctoral student and printed from a personal computer, only requiring the cost of paper, printer ink, envelopes, and stamps (See Appendix H). The cost of printing the flyers professionally and of running newspaper advertisements is also show in Appendix H. The greatest used asset was personal time spent creating the questionnaires, the community outreach content, and driving through counties to post and deliver flyer. The survey data also had to be populated, evaluated, and analyzed statistically, which required significant personal time. Overall, the project cost is feasible for other communities as much of it can utilize volunteer efforts and donations.

Chapter IV: Results

Analysis of Implementation Process

The implementation process proved to be much more challenging than originally anticipated for two main reasons. The approval process took longer than expected and the California environment offered an additional obstacle to timely completion. The initial phase of the project proposal approval from the IRB and the Committee on the Use of Human Subjects in Research (CUHSR) took approximately 18 weeks, 10 weeks longer than expected. The reason for the extended amount of time is that the acute care facility where the project was hosted, while part of a larger corporation, does not conduct research and therefore did not have an Institutional Review Board. The researcher had to contact the corporate office and find out how to proceed. Another hospital under the same corporate umbrella (though six hours away from the project facility) did has an IRB. So, the first step was establishing a memorandum of understanding (MOU) between the research facility at Glendale and the project site facility (see Appendix L). Once the MOU had been established, the project application was submitted via the online

website portal supported by the Glendale facility. Exempt status approval was granted on June 13, 2019 (See Appendix M). This was granted within a timely manner with only one request to make some minor modifications. The next step was to request project approval from the CUHSR. This proved to be a delay as well since the CUHSR application process had been modified and researchers within Bradley University's Doctoral Program had to resubmit their applications. However, exempt status approval was granted by the CUHSR on July 20, 2019 (see Appendix N). The researcher learned an important lesson that when creating new processes for rural institutions (like the site facility); adequate time should be planned for the approval process. It is best to begin making contacts as early in the project process and design phase as possible.

The second largest implementation process obstacle was dealing with unforeseen external factors related to California's environmental health. The pilot study intervention had been planned to take place on October 6th, 2019. Flyers had been published and distributed throughout three counties, sent to all primary care providers within that same radius; newspaper ads had been placed, and social media marketing conducted. However, on the morning of the 6th it was announced publicly that over 50% of the state of California was to have their power shut off preemptively by Pacific Gas & Electric (PG&E) due to expected high winds and low humidity in an effort to prevent wildfires. The exact time of the shut-off was not known. Quickly, the doctoral student contacted local newspapers, online news sources, and went back through the social media networks previously utilized to announce that despite the power shut-off the project intervention would still be held (albeit in the dark) at the acute care facility.

The project facility lost power at 3:00pm on October 6th. The gas stations ran out of gas in two counties; there were no generators available for purchase within 100 miles; there were no

restaurants or stores left open, and the emergency room had to defer patients. It was clear that the community was most concerned with and focused on the power shut off and securing the safety of their families. As a result, only two people showed up for the project event. Those people did partake in the intervention using the researcher's personal computer and back-up lighting. However, a population sample of two would not suffice for a doctoral study of this nature. So, the entire event had to be planned a second time, all with great hope that continued power shut offs and surrounding active wildfires would not threaten to dissuade participants from the second event. The researcher learned that even the best planning may not come to fruition, as there are always factors, we cannot foresee or plan for. Rapid regrouping and reorganization are a vital skill for any researcher, as is patience and resilience. The doctoral student was left with very little time after the second event to analyze data and draw conclusions as is shown in the project schedule (see Appendix C).

Modifications had to be made to the second event in order to complete all project tasks within the 15-week Bradley University semester deadline. The original intent of the project was to allow potential participants to RSVP and a participatory statement was created to gather more information about those perspective participants and ensure the project was respectful of any specific needs or disabilities they may have (see Appendix E). However, with little time to complete all phases of the second event, RSVP was no longer required. Some participants did contact the doctoral student by phone and their questions were answered verbally at that time. This also meant that the researcher was unable to direct mail both the pre-intervention survey and the Informed Consent form to the participants prior to their arrival at the event. Instead, a check-in table was set up outside the event room to gather both documents prior to beginning. The last adjustment required was no longer allowing the participants to take their post-

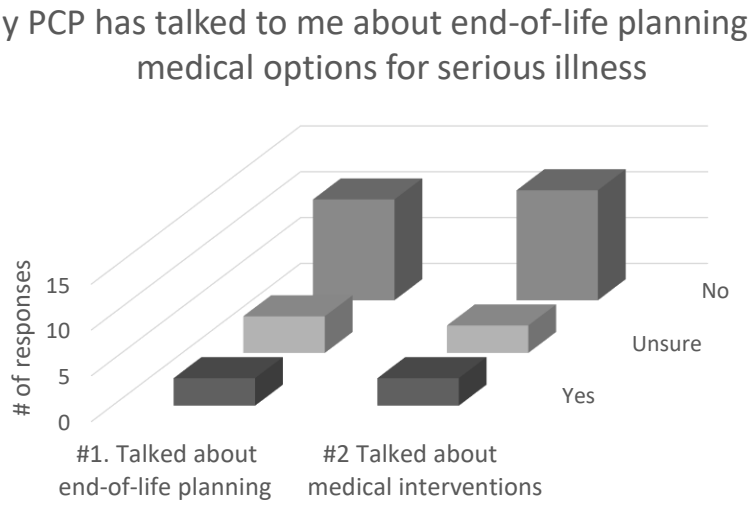
intervention and attendee satisfaction survey's home with them. Instead, they were asked to fill them out prior to leaving the event. This ensured that all data could be collected and analyzed in the new 10-day window. However, it did not allow time for the participants to take POLST forms home with them to discuss with their loved ones and/or primary care providers.

Analysis of Project Outcome Data

Characteristics of participants. There was a total of 22 participants between the first and second event. However, four of the participants were not included in the data analysis. One had to leave early and opted not to participate in the surveys; one arrived late and could not complete all of the survey's as the project was designed; two participants took park during most of the event but then were pulled away during the discussion phase by ICU staff from the project site facility. They had completed the informed consent and pre-intervention survey but left prior to completing the post-intervention and attendee satisfaction surveys. This left 18 participants. Of those 18 participants, seven were male (39%) and 11 were female (61%). The age range was between 43 and 73-years-of age, with a median participant age of 63, and an average age of 59.7. Ten of the 18 participants expressed that they did not consider themselves to be a religious person (56%), while the remaining 8 reported that they were religious (44%). The religions reported included: Catholic (4), Christian (2), Methodist, Buddhist, and "spiritual." The data collected from the 18 participants was analyzed from several different perspectives, the first of which was gathering general ideas from the participants prior to their participation in the project.

Section I results. The main reason this project was chosen by the doctoral student was because professional and personal experience, alongside the literature review findings, suggested that patients are not having conversations with their primary care providers about end-of-life care planning. Nor are they discussing options surrounding medical illness and interventions. Therefore, the first piece of data analyzed was to see how the participants answered questions one, two, five, and six on the pre-intervention survey (see Appendix P). The data found that the participants overwhelmingly disagreed with the two following statements: "my primary care provider has talked to me about end-of-life planning;" and "my primary care provider has talked about the medical options available to me if I get seriously ill" (see Figure 1). However, the data also suggested that the participants seemed to have a realistic understanding of CPR survival rates and expectations after being put on life support (see Figure 2).

Figure 1. The results of questions one and two from the pre-intervention survey show a trend that most participants have never talked to their providers about end-of-life planning or about the



medical options available to them if they get seriously ill.

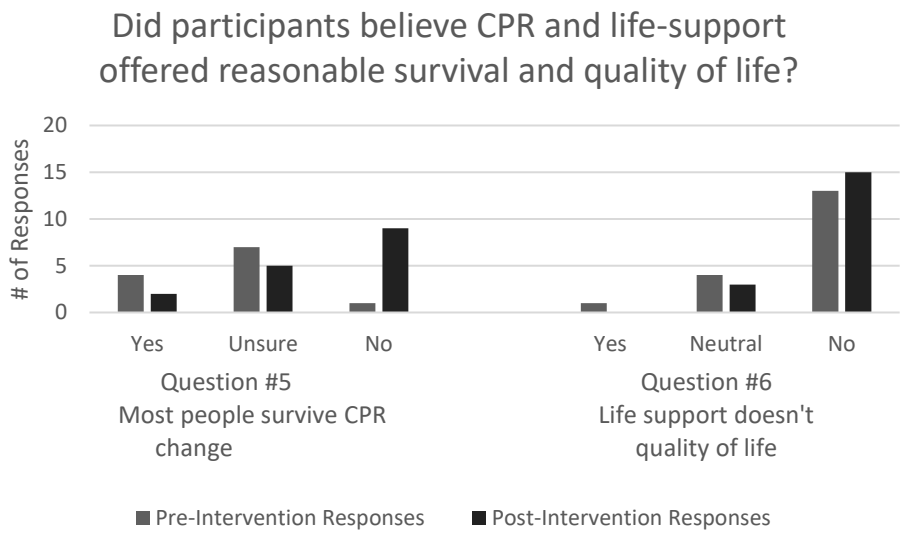


Figure 2. The results of questions five and six from the pre-intervention survey display that participants did seem to have an understanding that CPR survival rates are low, and that quality of life may change after being placed on life support. Their understanding of both these facts improved after the intervention.

Another important part of this initial analysis was assessing whether or not the participants were interested in talking to their primary care providers about end-of-life care and associated options. The data analysis found that the subjects strongly agreed as a group that they wanted their provider to be honest with them about the death and dying process (see Appendix Q). Additionally, they wanted to know the truth about their medical conditions and reasonable expectations of survival. In both lines of questioning, 100% of participants either strongly agreed or agreed with the statements listed on question numbers three and four in the pre-intervention survey.

Section II results. The second part of data analysis looked at whether or not the number of POLST forms among project participants increased after the project intervention. Data was collected from the pre-intervention survey to determine how many participants already had

POLST forms and then again after the event from the post-intervention survey to determine if this number had changed at all. There was a 100% increase in the number of POLST forms among project participants after the intervention (see Figure 3). Only two of the 18 participants (11%) had POLST forms prior to the event. This number increased to four or 22% post-intervention. The null hypothesis in this case is that there would be no difference between the two data sets (pre-intervention POLST forms and post-intervention POLST forms). The alternative hypothesis is that there is a difference between the two data sets. Alpha was set at 5% or 0.05 to determine statistical significance. Due to the low sample size (18) the 100% increase in POLST forms was not enough to conclude the finding as statistically significant in either a one-tailed or two-tailed t-test (see Appendix R). However, the hypothesized mean difference was 0.5 and the actual mean difference was 0.44 indicating that the alternative hypothesis may be easily supported in a larger sample size.

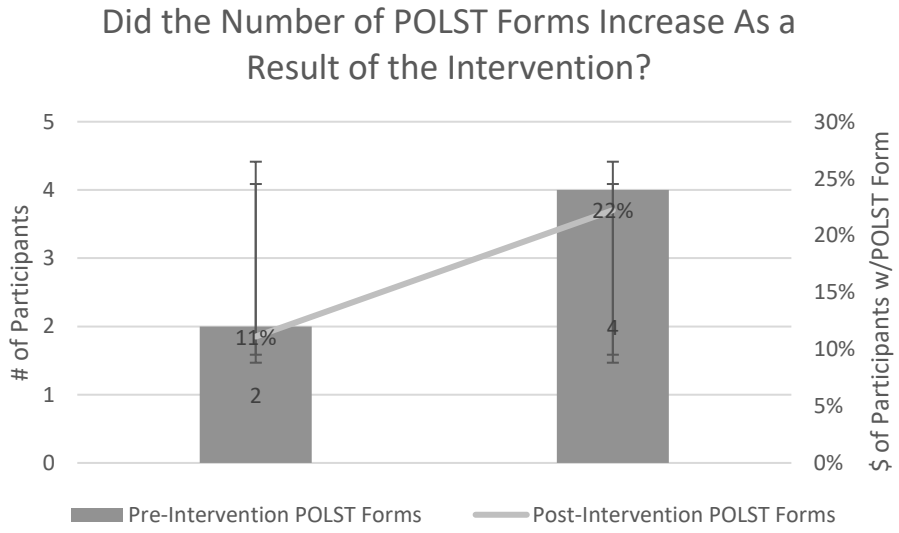


Figure 3. The number of POLST forms prior to the event was only two, which increased after the intervention to four POLST forms among the 18 participants for a 100% increase (11% to 22% of participants).

Section III results. Data was collected through the attendee satisfaction survey after the intervention to determine if participants believed this was a good model to follow for future endeavors in educating persons on end-of-life care planning. Eight separate questions were directed at determining if participants felt confident with the project design and if it was an effective way at providing education and addressing the topic of end-of-life care. Overwhelmingly the participants agreed that this model was one they felt positive about (see Figure 4). All eight questions were examined separately and then cumulatively.

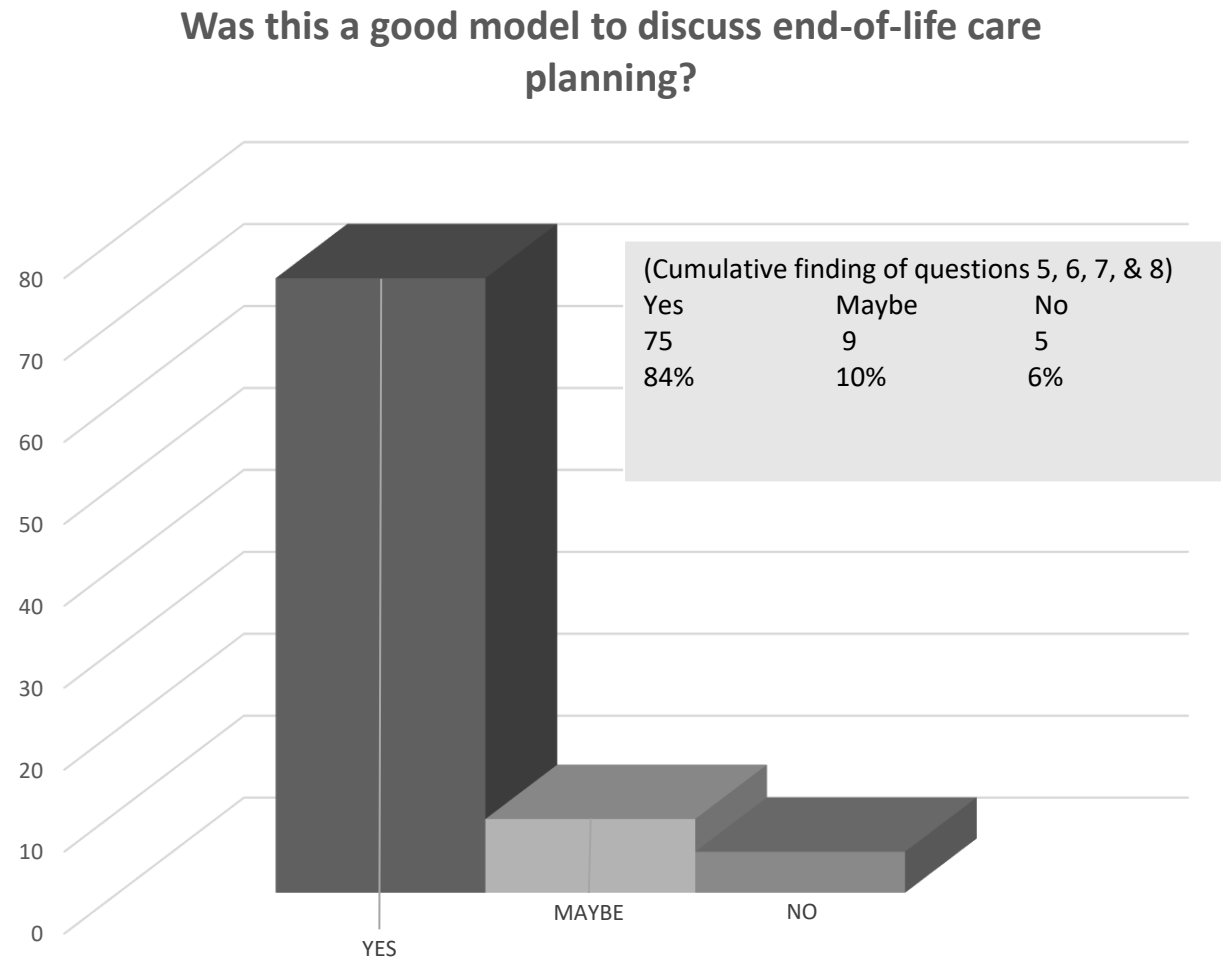


Figure 4. When questions five, six, seven, and eight were combined from the attendee satisfaction survey and analyzed cumulatively, the data showed that 84% of participants felt the pilot study was a good model for discussing end-of-life care.

Through descriptive statistical analysis, and upon evaluation of all attendee satisfaction surveys, it was discovered that 81.83% of the participants had a positive overall perception of the pilot study as a means of discussing end-of-life care planning; 11.28% were neutral in overall perception, and 13.04% had negative perceptions about the event (see Figure 5). Individual question analysis is summarized below (see Appendix S). 94.44% of participants would refer a friend or loved one to a similar event. 100% of participants reported that attending a community event was a good way to learn about the options available when planning end-of-life care. 100% were glad they attended the event. 88.89% reported they had a better understanding of end-of-life options and serious medical illnesses as a result of the event. 94% reported that all communities should offer end-of-life care planning events like this pilot study. Only 5.56% reported that they would rather learn this information in private directly from their primary care provider than at a community event. 44% of attendees reported that their opinion about what they wanted if they were to become seriously ill directly changed as a result of the event.

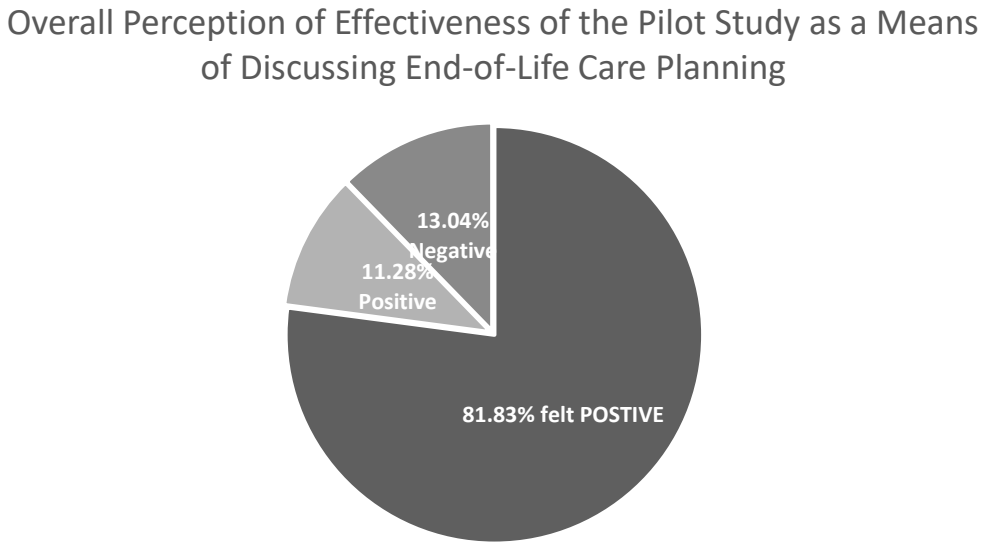


Figure 5. When all questions on the attendee satisfaction survey were analyzed cumulatively, the results indicated that 81.83% of participants found the pilot-study community intervention to be

an effective means of discussing end-of-life care planning. 11.28% were neutral and 13.04% felt had an overall negative perception of the event's effectiveness.

Section IV results. The project analyzed whether or not perceptions were changed regarding end-of-life care planning and fears surrounding discussions about death and dying by comparing the pre- and post-intervention surveys. The questions reviewed were numbers eight, nine, 15, 16, 17, 18, 19, and 20 as they all related to emotions, feelings, and perceptions (see Appendix S). One surprising result was discovered. 33% of participants were more fearful of talking about death with their loved ones after the intervention. However, when taking the Likert scale ratings into consideration what the data actually tells us is that none of the participants were fearful of talking about death with their loved ones prior to the intervention. After the event, two participants reported they now were fearful and one was neutral, whereas all the rest of the participants still expressed that they were not. So, while there was a change in perception, the mean perception still expressed that there was no fear discussing death with loved ones. There was a 12% increase in disagreement with the following statement, "I am scared of talking about dying with my primary care provider." Project participants felt that quality of life was more important than quantity of life both before and after the intervention with only an 8% increase in strength of agreement after the intervention. Similarly, they did not change their opinion that they were neutral about the idea of wanting a medical intervention if it had the potential to change their quality of life. Participants were 11% less likely to want to continue living if they became physically disabled after the intervention; 13% were less agreeable to continuing life after mental disability; 19% were less agreeable to continuing life if they could not eat; and 11% were less agreeable to continuing life if they could not stay in their own homes (see Appendix T).

Section V results. The doctoral student included a section on the attendee satisfaction survey, which was completed after participation in the project. This section allowed participants to share any personal feelings or thoughts about the community event they attended. Of the 18 participants, five utilized this section to write in personalized responses (0.28%). Most of the written responses were commendations to the doctoral student and the project mentor and said something to the effect of "thank you" or "good job." However, there were two comments worth noting as qualitative findings, particularly since they aligned so closely with the descriptive statistical analysis of the satisfaction survey findings. The first comment stated: "This is an event everyone should attend. Helping to take the fear and stigma out of these discussions is so worthwhile. Thanks for the information and the peace of mind it brings." The other was, "would be very beneficial to most elderly or retired populations." The Likert scale ratings mimicked these thoughts.

Chapter V: Discussion

Findings

The project used data analysis to determine if the three SMART objectives were met in a meaningful and significant way. The first and primary objective of the study was to increase the number of POLST forms among project participants as a result of the event. The goal was set at a 50% improvement. The number of POLST forms increased by 100%, surpassing the objective goal. However, as indicated in the results section, this 100% increase was not enough, considering the small sample size, to offer up statistical significance. The second objective of the project was to determine if a community outreach event was a reasonably effective way to engage persons in discussions on and planning for end-of-care. The attendee satisfaction survey utilized quantitative and qualitative measures to conclude that yes, the pilot study proved its

model was effective at achieving this goal. 100% of participants were glad they attended the event and cumulative findings of the survey demonstrated that 84% of participants ranked the model as a strongly agreeable way of discussing end-of-life care planning. The third SMART objective was to use analytical methods and Likert scales to determine if perceptions would change as a direct result of the intervention. The findings indicated that overall perceptions did change in the sense that people were less likely to want to continue living in the face of a new physical or mental disability, if they could no longer eat by mouth, or if they could not stay in their homes. Contrary to expectation the data also discovered that after the event participants became slightly more fearful to discuss death with their loved ones (although as a population they were not fearful at all of this, just slightly more so after the intervention). Overall, it was concluded that the pilot study was successful in meeting all of the outcomes. Therefore, the conclusion is made that the intervention was effective from the objective perspective.

While the project served only as a pilot study or jumping off point to illicit change in care delivery, it can profess to have changed clinical outcomes since the number of POLST forms did increase and perceptions were slightly redirected as a result of the project. Many participants personally addressed the doctoral student after the event and asked when the next event would be held so they could invite their family and friends to attend. Many others who were unable to attend because of schedule conflicts requested that the event be hosted at other locations or through live internet streaming. This suggests that the participatory desire was greater than the one-time population sample size, again recommending that the event was successful in creating a new model for care delivery for this community as it pertains to advanced care planning. The doctoral student can also attest that the personal expectations of the event were all met (aside

from aiming for a larger sample size), as participants were engaged, partook in thoughtful questioning and discussion, and reported satisfaction through survey responses.

Limitations or Deviations from Project Plan

The project itself suffered from one major set-back which created major time limitations and some deviations from the original project plan. As a result of the California power-shut offs and nearby wildfires, the event had to be hosted a second time. This cut the project timeline in half and did not allow for the participants to have personal time to thoughtfully respond to their surveys in the privacy of their own home. It also did not allow time for the participants to take their POLST forms home and discuss them with their loved ones and/or their primary providers and then later inform the doctoral student if they now had a completed form in their homes or electronic medical records. Originally the project plan allowed for these opportunities and likely would have changed the post-intervention outcomes. It perhaps may even have led to statistically significant findings related to the POLST form alternative hypothesis (POLST forms would increase in the population as a direct result of the independent variable – the intervention).

The sample size was also smaller than the doctoral student aimed for which may have contributed to lack of statistically significant findings. This may have been related to the power-shut off leaving less time for people to carefully consider their attendance. Another potential argument is that the event could have been marketed more effectively. Another factor worthy of consideration is that it is difficult to talk about death and end-of-life care planning, as the literature review demonstrated, and therefore the subject matter itself was a hindrance to achieving a large sample size.

Implications

Practice. The change suggested by this scholarly project is sustainable both within the small rural community where it launched the pilot study and across other communities as well. There is very little required of the hosting entity (particularly if no research data is being collected) other than to host a viewing party and guide questions and discussions about end-of-life care planning. This could easily be transferred to many different environments and settings. The project can be conducted in hospitals, town halls, private conference halls, or even in homes as best suits the population in question. In order to implement the project in other settings or communities' simple modifications can be made. For instance, rather than using a projector screen to show the Netflix documentary, it could be shown from a television or computer screen. Instead of utilizing a PowerPoint presentation to direct questioning and review key educational points, these could be written down and referred to on paper by the host. The event could be invitation only to reduce marketing expenses or could be open to any who care to attend. There are many implementation modifications which could be made to make this project transferrable for many different situations.

Future research. There are a great many opportunities for interdisciplinary collaboration related to this study. Since the pilot model is easily transferrable, it can be shared with providers in other subspecialties or locations so that they can provide the same intervention to their population of interest. In addition, the findings can be shared with area providers to show them that they will be doing their clients a favor by initiating honest discussions about end-of-life care and associated medical illnesses. The data indicated this is what patients want - truth and discussion from and with their providers. In addition, if the pilot study were to become a regular offering, case managers, social workers, mid-levels, and providers would all be able to

use this as a tool to help provide services to their patients. They could invite and encourage them to attend these events and then return to them for further directed discussion.

The data was able to offer some solid findings. However, there are still plenty of inquiries left to research for future scientific endeavors. For example, the project showed that participants were less likely to want to live if they became mentally or physically disabled, or if they could not eat by mouth, or were forced to leave their homes. Potential research could involve discovering what it is about these four things which make people not want to live in those ways. What are the emotions and/or fears surrounding these conclusions? Additionally, research should be done to conclude why more providers aren't having these discussions in the first place. Why did only 11% of the project's participants have POLST forms? What is holding providers back from having these discussions? Is it time, fear, inherent ideas about when it is appropriate to do so, or some other restrictive factor?

The doctoral student has several plans to disseminate the results of this scholarly project. First, the data will be shared with the acute care facility where the project was hosted, particularly since the participants are consumers of this facility. Their perceptions and opinions have the ability to shift culture and change practice for the providers within this organization. The doctoral student plans to offer a projector/PowerPoint presentation to key stakeholders at the facility. Secondly, the findings will be shared with the Glendale facility which facilitated the IRB approval process, as they are the research facility for the larger corporation. They too will be offered the same presentation.

Nursing. While this study did not evaluate the nursing profession directly, there were significant findings with the potential to impact nurses. Once nurses become aware of the data, they can better advocate for their patients. If aware that the study showed patients want to have

honest discussions with their providers and want to know realistic expectations about their medical illnesses, they can encourage providers to make time for these discussions. They can ensure that the education they provide includes realistic expectations and that they address some of the key concerns of project participants, namely mental and physical disability, eating by mouth, and remaining in their own homes. In consideration of the Advanced Practice Nursing (APN) profession, APNs should be encouraged to initiate discussions with their patients about end-of-life care planning, particularly focusing on POLST forms, regardless of gender, age, or religion. Their patients expect this of them, and they are fully equipped to take the lead in these discussions which are not restricted only to medical doctors. They should not fear embracing difficult subject matter because their patients are not scared to have these discussions. All nurses, in any industry, environment, or at any point in their career, should be taught to talk to both physicians and patients alike about planning. They are tasked with ensuring patient autonomy as the last buffer between patients and providers, patients and medications, and patients and medical interventions. They must ensure that whatever medication or intervention they are about to administer aligns with the patient's wishes. Just as nurses are trained to ask about allergies prior to administering a mediation, nurses should be trained to ask if patients are agreeable to the task the nurse is about to perform. Does this coincide with their wishes?

Health policy. Software programs utilized by inpatient and outpatient healthcare systems have begun to incorporate code status notifications at the very top of the toolbar, as a way of ensuring patient autonomy is respected and well-know. This indicates that the health care industry has recognized the importance of the topic of end-of-life care. While it's evident the recognition of importance is there, the application of end-of-life care discussions is still defunct. Therefore, not only must medical providers and institutions utilize technology to include data

about patient wishes in easily accessible ways, they must also offer pathways for patients to make informed decisions about their wishes. It is suggested that when a patient expresses curiosity about their code status, reports that they haven't discussed it yet, or are unsure what they want, this then should prompt a consultation from a provider, social worker, and/or palliative care nurse to visit this patient as quickly as possible. Should pilot studies like this one become common practice within communities, it would then be possible to refer patients like this to the next community event to become better educated on their options. Accepting that a patient is always a "full code" simply because they've never thought about it, perhaps is too young, or don't have legal documents in place, should no longer be accepted practice. The new software updates should be utilized to indicate those patients who require immediate referral to education programs so they can make decisions for themselves prior to having a medical intervention they may or may not want.

Chapter VI: Conclusion

Value of the Project

As introduced at the beginning of this study, not one of us will be spared from death. Yet research has continued to show that there is a deficit in planning for the end of our lives. This project created a model to address this deficit and was able to meet all its objectives. It is therefore the opinion of this researcher that the project was incredibly useful and provided valuable data about perceptions regarding death discussions, the expectations patients have of their providers, and how the medical industry can meet the challenge of providing valuable education to many. This model is easily transferrable across healthcare systems thereby lending to direct policy change. The researcher further suggests that any provider who attempts to embark on following this model will get incredible satisfaction from it. They will directly

contribute to improving the nation's health through primary prevention via education. They can play a role in sparing people from interventions they did not want or ensuring that they correctly advocate for them when they do. The model is simple and yet has the potential to change lives (and deaths), of which there is no greater purpose.

DNP Essentials

The doctoral student chose a project with the potential to illicit change and do real good for a rural community suffering from a lack of planning. The *DNP Essentials* offered professional tools for the researcher to follow to gain competency as a well-rounded scholar, researcher, and Advanced Practice Nurse (Moran, Burson, & Conrad, 2017). While all eight *DNP Essentials* were finely tuned by the doctoral student during this endeavor, there were a few which required skillful mastery. At the heart of this project was *DNP Essential V* - a desire to create a model for health care policy to better advocate for patients during the most important times in their lives (American Association of Colleges of Nursing, 2006). As part of this advocacy, the researcher focused on *DNP Essential VII* and creating a model that would improve the nation's health through population-focused education that would prevent undesired medical interventions (American Association of Colleges of Nursing, 2006). Prior to being in a position where the researcher could host the project event, ample research had to be conducted both to inform the project path but also to create a knowledgeable "expert" in the field of end-of-life care planning and medical documentation. This required *DNP Essential I*, scientific underpinnings for practice (American Association of Colleges of Nursing, 2006). Finally, in order for the researcher to be presented in front of a group of study participants and do so in a way which made them feel confident, respected, and in knowledgeable hands, the researcher had to master

the art of posing professionally as an Advanced Practice Nurse, as modeled by *DNP Essential VIII* (American Association of Colleges of Nursing, 2006).

Plan for Dissemination

The doctoral student plans to share the study findings with the acute care facility where the event was hosted, and also with the IRB facility in Glendale where the corporation as a whole conducts their research. Additionally, the doctoral student plans to share findings with the Intensivist who was featured in and produced the Netflix documentary, Extremis, since the video played a large role in the pilot study. The researcher expects that learning the documentary had future implications in outside communities would be valued information to receive. Finally, the doctoral student is considering putting together a public online live offering of the same event and the study findings post-graduation in response to the many requests to offer the event in other locations.

Attainment of Personal and Professional Goals

The doctoral student set both long-term and short-term goals both through the Bradley University four-year DNP/FNP program and through the completion of this scholarly project. As a critical care nurse, the researcher became frustrated and disheartened over time with the lack of education patients had regarding their end-of-life options. When deciding what project to move forward with, the researcher always knew that it needed to be a project with the potential to illicit real change, even if on a small scale. It needed to be something the researcher was passionate about so that professional growth could easily stay in stride with the drive to reach people on a powerful level. By attaining competency in all the *DNP Essentials* while working soulfully on this project, the researcher is now confident that the goal of creating real change has occurred. Even if that change was just for 18 people, the researcher now rests assured that those

18 people know how to advocate for themselves and what documents they need to have should they not be able to speak up. The researcher can confidently move forward, secure in the notion that the potential always exists to improve patient outcomes as a forever-vested patient advocate.

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Appendix A

California POLST Form

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B
(Effective 4/1/2017)*

First follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. **POLST complements an Advance Directive and is not intended to replace that document.**

Patient Last Name:	Date Form Prepared:
Patient First Name:	Patient Date of Birth:
Patient Middle Name:	Medical Record #: *(optional)*

A — CARDIOPULMONARY RESUSCITATION (CPR): *If patient has no pulse and is not breathing. If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.*

Check One

☐ **Attempt Resuscitation/CPR** (Selecting CPR in Section A **requires** selecting Full Treatment in Section B)

☐ **Do Not Attempt Resuscitation/DNR** (Allow Natural Death)

B — MEDICAL INTERVENTIONS: *If patient is found with a pulse and/or is breathing.*

Check One

☐ **Full Treatment – primary goal of prolonging life by all medically effective means.**
In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.

☐ ***Trial Period of Full Treatment.***

☐ **Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.**
In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.

☐ ***Request transfer to hospital only if comfort needs cannot be met in current location.***

☐ **Comfort-Focused Treatment – primary goal of maximizing comfort.**
Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. ***Request transfer to hospital only if comfort needs cannot be met in current location.***

Additional Orders: _____

C — ARTIFICIALLY ADMINISTERED NUTRITION: *Offer food by mouth if feasible and desired.*

Check One

☐ Long-term artificial nutrition, including feeding tubes. Additional Orders: _____

☐ Trial period of artificial nutrition, including feeding tubes. _____

☐ No artificial means of nutrition, including feeding tubes. _____

D — INFORMATION AND SIGNATURES:

Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker

☐ Advance Directive dated _____, available and reviewed →
☐ Advance Directive not available
☐ No Advance Directive

Health Care Agent if named in Advance Directive:
Name: _____
Phone: _____

Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)
My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.

Print Physician/NP/PA Name:	Physician/NP/PA Phone #:	Physician/PA License #, NP Cert. #:
Physician/NP/PA Signature: *(required)*		Date:

Signature of Patient or Legally Recognized Decisionmaker
I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Print Name:		Relationship: *(write self if patient)*
Signature: *(required)*	Date:	Your POLST may be added to a secure electronic registry to be accessible by health providers, as permitted by HIPAA.
Mailing Address (street/city/state/zip):	Phone Number:	

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

*Form versions with effective dates of 1/1/2009, 4/1/2011,10/1/2014 or 01/01/2016 are also valid

Appendix B

Pre- and Post-Intervention Perception Survey

My Age: ___

My sex (circle one only please): Male Female

I consider myself a religious person (circle one only please): Yes No

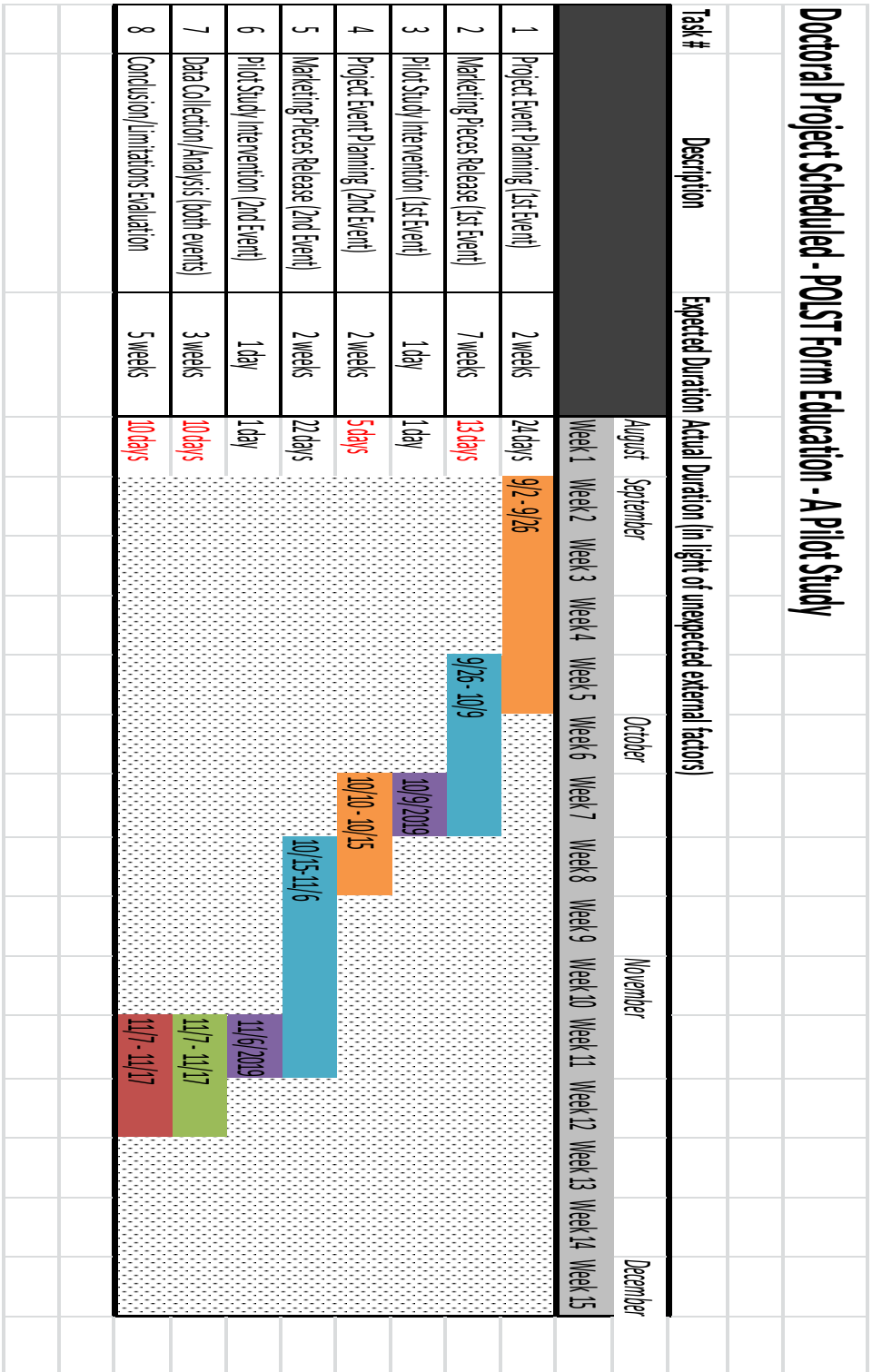
If answered yes to the above, the religion or belief system I most identify with is: _____

Answer these questions by placing an **X** in the appropriate box:

			Strongly agree	Agree	Neutral/NA	Disagree	Strongly disagree
1	My primary care provider has talked to me about end-of-life planning	1					
2	My primary care provider has talked about the medical options available to me if I get seriously ill.	2					
3	I would like my provider to be very honest with me about the death and dying process.	3					
4	I would like to know the truth about my medical conditions and reasonable expectations of survival	4					
5	I believe that most people who are resuscitated and receive CPR survive.	5					
6	I believe that if I were ever put on life support there is a good chance my life would be the same after as it was before.	6					
7	I trust my loved ones would make the right medical decisions for me if I was unable to.	7					
8	I am scared of talking about dying with my primary care provider	8					
9	I am scared of talking about death with my loved ones	9					
10	I believe that planning for end-of-life should wait until I'm diagnosed with an incurable illness or condition.	10					
11	I have a Physician's Order for Life Sustaining Treatment (POLST) form	11					
12	I have a will and testament	12					
13	I have an advanced directive	13					
14	My loved ones know what my wishes are if I were to get critically ill	14					
15	I believe that quality of life is more important than quantity of life.	15					
16	If my quality of life were to change as the result of a medical intervention, I would not want that intervention	16					
17	I want to continue living even if I become physically disabled	17					
18	I want to continue living even if I become mentally disabled	18					
19	I want to continue living even if I can no longer eat food by mouth	19					
19	I want to continue living even if I can no longer stay in my home	20					

Appendix C

Project Schedule



Appendix D

Attendee Satisfaction Survey (Post-Intervention)

My Age: ___

My sex (circle one only please): Male Female

I consider myself a religious person (circle one only please): Yes No

If answered yes to the above, the religion or belief system I most identify with is: _____

	Answer these questions by placing an **X** in the appropriate box:		Strongly agree	Agree	Neutral/NA	Disagree	Strongly disagree
1	I feel confident about my end-of-life care plan after attending the community event	1					
2	I would refer a friend or loved one to a similar event	2					
3	Attending a community event is a good way to learn about the options available when planning end-of-life care	3					
4	I would prefer to learn about my options in private with my primary care provider only	4					
5	I am glad I attended the event	5					
6	I have a better understanding of end-of-life options and serious medical illnesses because of the event	6					
7	My opinion about what I want if I become seriously ill has changed as a result of the community event	7					
8	I believe all communities should offer end-of-life care planning events like the one I attended	8					

If you would like to share any personal feelings or thoughts about the community event you attended, please feel free to do so, and utilize the space below:

Appendix E

Participatory Statement – Availability to Attend

Thank you for your wiliness to participate voluntarily in a local pilot study aimed at providing end-of-life care planning. In an effort to ensure that all project participants are available to complete all aspects of the project, I am requesting that you please complete the information below so that I can communicate with you throughout the process. Please keep in mind that your participation is voluntary and you may choose to stop at any time. By signing you indicate that you have transportation options available to get you to and from the community event on [insert date of event here] hosted at [insert address and location of event].

_____ _____

Signature of Voluntary Participant Date

My preferred method of communication for receiving surveys is (please check one):

_____ Email _____ Direct Mail My email or mailing address is:

_____

If you have difficulty with any of the following, please check which below:

____ Hard of Hearing ____ Vision Impaired ____ English is my Second Language

Please return this form along with your Participatory Statement as soon as possible, either by email or by direct mail. A pre-addressed and stamped envelope has been provided.

Lacey Neufeld, Doctor of Nursing Practice Candidate

[209.728.4334; polstplanning@gmail.com; Address: *omitted for professional publishing]

Appendix F

Netflix Documentary Permission for Public Showing

Extremis

Extremis is a verité documentary exploring the harrowing decisions that doctors, families and patients face in urgent end-of- life cases. With access to the intensive care unit of a public hospital, the film offers a uniquely intimate look at the intersection of science, faith and humanity.

DETAILS
Category:
Documentary

DISTRIBUTION
Global Original

PREMIERE DATE
9/13/2016

GRANT OF PERMISSION FOR EDUCATIONAL SCREENINGS

Netflix is proud to present original documentaries that speak to our users in a meaningful way. We know that many of you are as excited about these films as we are; and because of their informational aspects, you'd like to show them in an educational setting -- e.g., in the classroom, at the next meeting of your community group, with your book club, etc. Consequently, we will permit one-time educational screenings of any of the documentaries noted with this information, on the following terms:

- The documentary may only be accessed via the Netflix service, by a Netflix account holder. We don't sell DVDs, nor can we provide other ways for you to exhibit the film.
- The screening must be non-profit and non-commercial. That means you can't

Netflix.

We trust our users to respect these guidelines, which are intended to help you share and discuss our documentary content in your community.

To the extent your institution requires you to demonstrate that your have a license for your screening, please show them this page.

Press Contact Information

Jackie Berkowitz
jberkowitz@netflix.com

Maxine Pezim / Photo & Clip Requests
mpezim@netflix.com

Login or register for Press Assets

Appendix G

Informed Consent

BRADLEY UNIVERSITY
Information and Consent Form

Study Title:

Community Outreach Programs Aimed at Preparing Individuals for Serious Illness through Physician's Order for Life Sustaining Treatment (POLST) Form Education: A Pilot Study

Invitation to be part of a research study:

My name is Lacey Neufeld and I am a Doctoral Candidate at Bradley University. This event is a Bradley University Doctoral Student Project and is not affiliated with Adventist Health. I am conducting a local pilot study on end-of-life care planning and I'd like to invite you to participate. Your participation is voluntary and includes attending a local community event. Prior to attending the event I will send you an end-of-life survey to be completed and returned. There is minimal risk in participating and you can choose to stop at any time.

Key information regarding this study:

The purpose of this study is to collect data on end-of-life care planning in an effort to improve the quality of care patients receive from their medical providers. At the event you will view a 24-minute documentary on end-of-life care and discuss your thoughts, feelings, and concerns. There is a risk you may feel some sadness or stress when thinking about end-of-life planning. If this occurs, speak with your doctor, clergy, counselor, or a family member(s) to further discuss the issues. After viewing and discussing the documentary, you will be asked to complete a survey regarding end-of-life. A "Satisfaction Survey" will also be sent you to after the event.

Please take the time to read this entire form and ask questions before deciding to participate in this research project.

What is purpose of the Study?

The purpose of this study is to collect data on end-of-life care planning in an effort to improve the quality of care patients receive from their medical providers.

What will happen if you take part in this study?

If you agree to take part in this study, you will be asked to first sign this consent form and then complete a pre-intervention survey which will ask you questions about your perceptions regarding end-of-life care planning and talking about death. Then you will be requested to attend an in-person event at Adventist Health which will take approximately one hour of your time. At the event you will watch a brief video that poses questions about how we wish to live and to die. The forum will then be opened to questions. At the event you will be allowed the opportunity to talk about Physician's Order's for Life-Sustaining Treatment (POLST) forms and can even fill them out at the event if you choose. After the event, you will be requested to fill out two more surveys. The first survey will be the same survey you filled out prior to the event and the second will be one where you will be allowed to rate the event itself in order to determine if it is a reasonable way of reaching people to provide education about end-of-life care planning. All of your survey responses are completely anonymous, and you will not be linked to the data collected in any wall.

What are the risks of participating in the study?

There are no expected risks to you by participating in this research study. However, it is possible that talking about or considering end-of-life planning may be uncomfortable.

What are the benefits of participating in the study?

It is possible that you may not directly benefit through your participation in the study. However, they will help evaluate the effects of end-of-life care planning on perceptions of death. It will also help providers in your community better understand how to provide end-of-life care planning.

Are there any incentives for participating in the study?

There are not incentives offered for participating.

How will your information be protected?

We plan to publish the results of this study. To protect your privacy, we will not include any information that can directly identify you. Your survey results are completely anonymous and will not be linked to you in any way. We are collecting the data anonymously. There is no link between your name or other information that can directly identify you and the research record.

While your personal information will never be published, other people may need to see results of this research study including Adventist Health administration, providers, and staff, Bradley University, and those viewing completed research projects on The Doctoral of Nursing (DNP) Scholarly Project repository.

After the study, what will happen to the data collected?

We will keep your research data to use for future research**.** However, your name and other information that can directly identify you will be deleted from the information collected as part of the project.

AND

We may share your research data with other investigators without asking for your consent again, but it will not contain information that could directly identify you. The data will be published as part of the final research paper in the DNP Scholarly Project Repository which can be found online and accessed for free.

What are the costs?

There are no costs for participation in this study.

Your participation in the study is voluntary

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. You do not need to answer any question you do not want to answer. If you withdraw before the study is completed your previous involvement, including any previously answered survey questions will be removed from the included research.

Who should I call with questions or problems study?

If you have any questions about this study, please contact the researcher in charge of this study:

Student Principle Investigator: Lacey Neufeld, RN, BSN, CCRN, DNP/FNP Candidate
Phone: 209.728.4334
Email: lneufeld@mail.bradley.edu

Co-Principle Investigator: Dr. Sarah Silvest-Guerrero DNP MSN RN, Assistant Professor, Bradley University Department of Nursing.
Phone: 309.677.3886
Email: ssilvestguerrero@fsmail.bradley.edu

Who should I contact with questions about my rights as a research participant?

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the following:

Committee on the Use of Human Subjects in Research (CUHSR)
Bradley University
1501 W Bradley Avenue
Peoria, IL 61625
(309) 677-3877

Where can I get more information?

Additional information can be obtained from:
https://www.bradley.edu/academic/cio/osp/studies/cuhsr/

Your informed consent

You are voluntarily making a decision to participate in this study. Your signature means that you have read and understood the information presented and have decided to participate. Your signature also means that the information on this consent form has been fully explained to you and all your questions have been answered to your satisfaction. If you think of any additional questions during the study, you should contact the researcher(s).

I agree to participate in this study Date

_____ _____

Signature of Participant **[if appropriate, or legally authorized representative]**

_____

Printed Name

To be completed by doctoral student only:

Randomized Assigned Number for Subject/Participant:

_____

Appendix H

Project Budget

Community Outreach Program: A Pilot Study for POLST Form Education			
BUDGET			
Item	**Expected Cost**	**Actual Cost**	**Explanation of Associated Cost**
Creation of Marketing Materials	$0	$0.00	To be created by the Doctoral Candidate
Flyer Printer Costs (1st Event)	$50	$12.45	Printed flyers at Gateway Press for first event (#50)
Flyer Printer Costs (2nd Event)	$50	$47.14	Printing flyers, paying for newspaper announcements
Newspaper Advertisement Costs (1st Event)	$40	$25.00	Printing flyers, paying for newspaper announcements
Beverages Availabe at the Event (1st event)	$0		In-kind donation from event site hosts
Beverages/Food Available at the Event (2nd event)	$0	$72.57	Doctoral student purchased drinks and snacks
Direct Mailing Costs	$50	$16.92	Doctoral student sent flyers to every primary care office in 3 counties
Survey Costs	$50	$42.00	Printer Ink and Ream of paper purchased to print all surveys (#50)
POLST forms for event	$50	$23.70	Ordering of 50-75 blank POLST forms for subjects
Total Expected Cost	**$290**		
	Total Acutal Cost	**$239.78**	
	Difference	**$50.22**	
	2nd Event Costs	**$119.71**	

Appendix I

Newspaper Event Notice

Free Community Event: How to Plan for Unforeseen Medical Events

Wednesday, October 9, 2019
6:00pm – 7:00pm
Adventist Health Sonora Conference Room 1 & 2
1000 Greenley Road
Sonora, CA

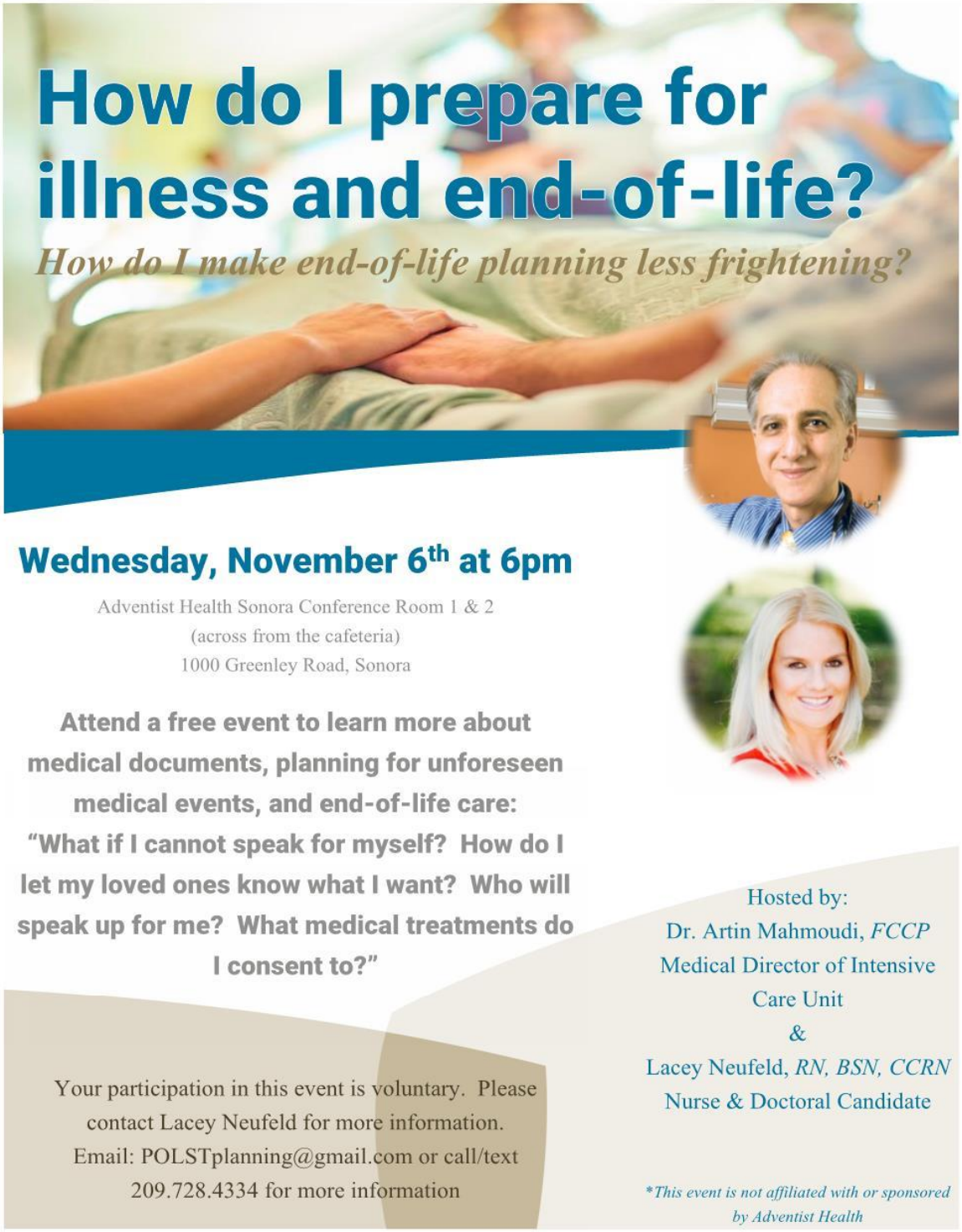
Attend a free event to learn more about medical documents and planning for unforeseen medical events and end-of-life care. This event is a Bradley University doctoral scholarly project aimed at offering free planning services to the local community. Agreement to participate in the event is required, so please contact the doctoral student at the email or phone provided.

Email POLSTplanning@gmail.com or call/text 209.728.4334 for more information

*This event is not affiliated with or sponsored by Adventist Health.

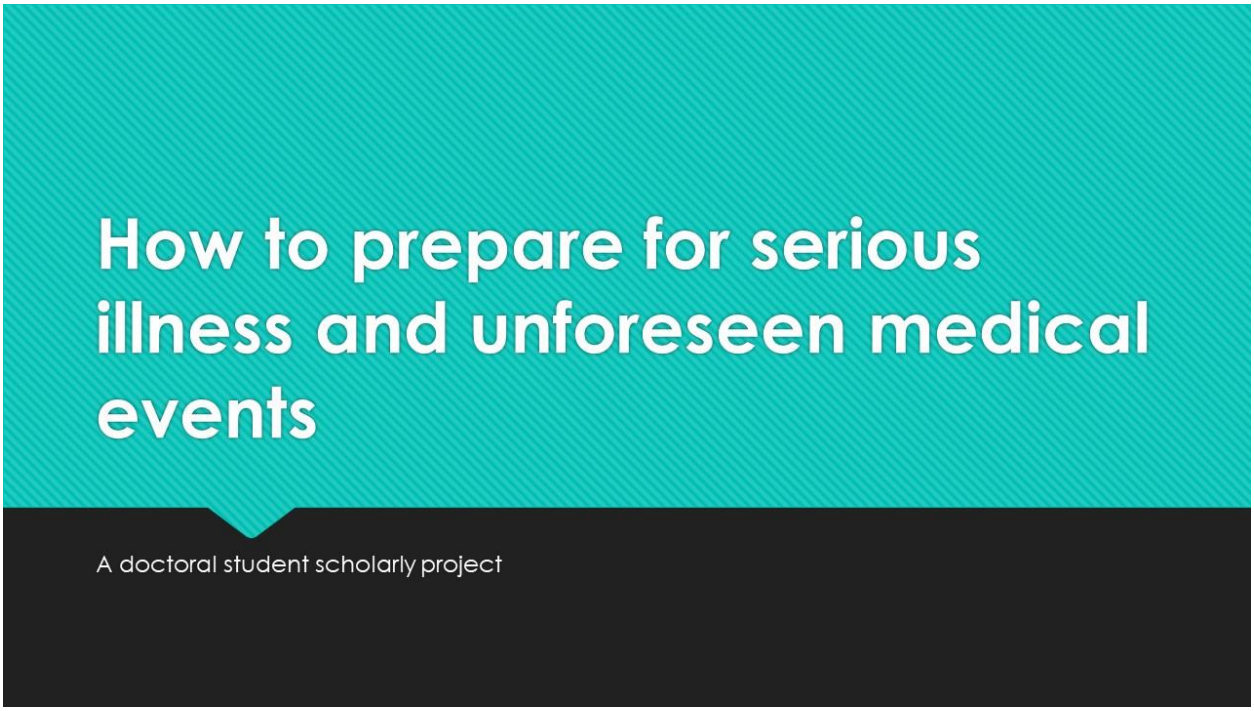
Appendix J

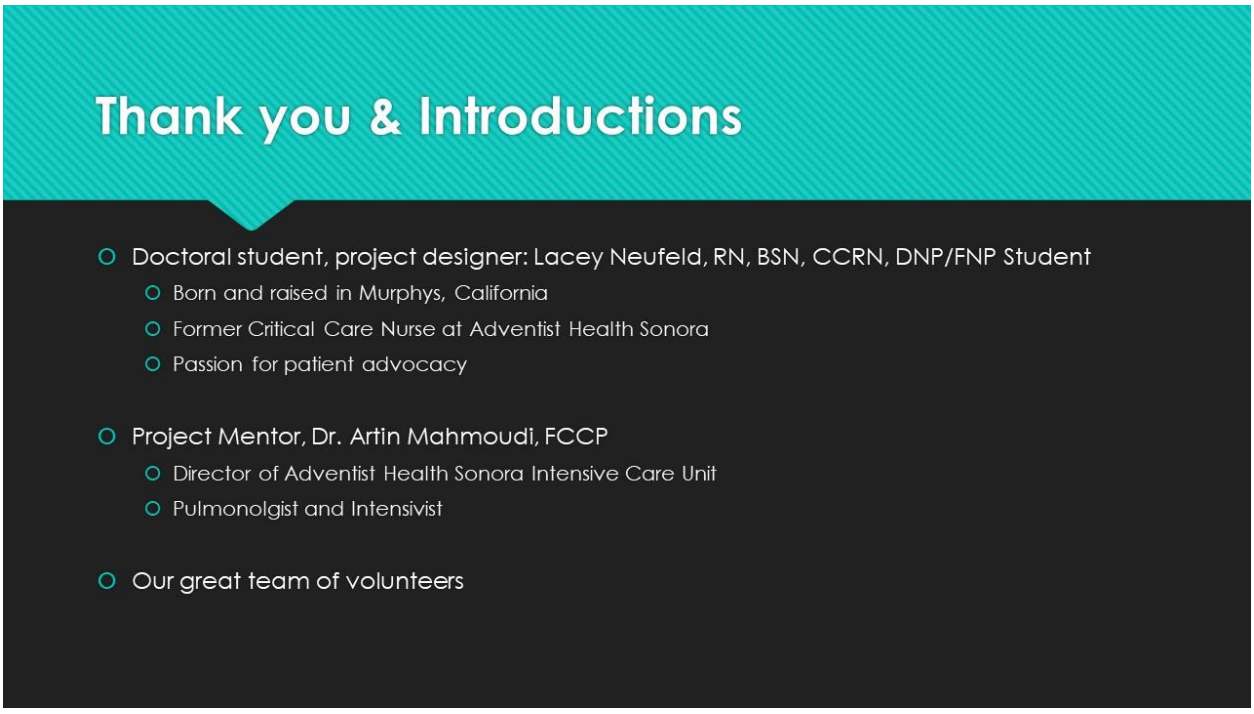
Event Flyer



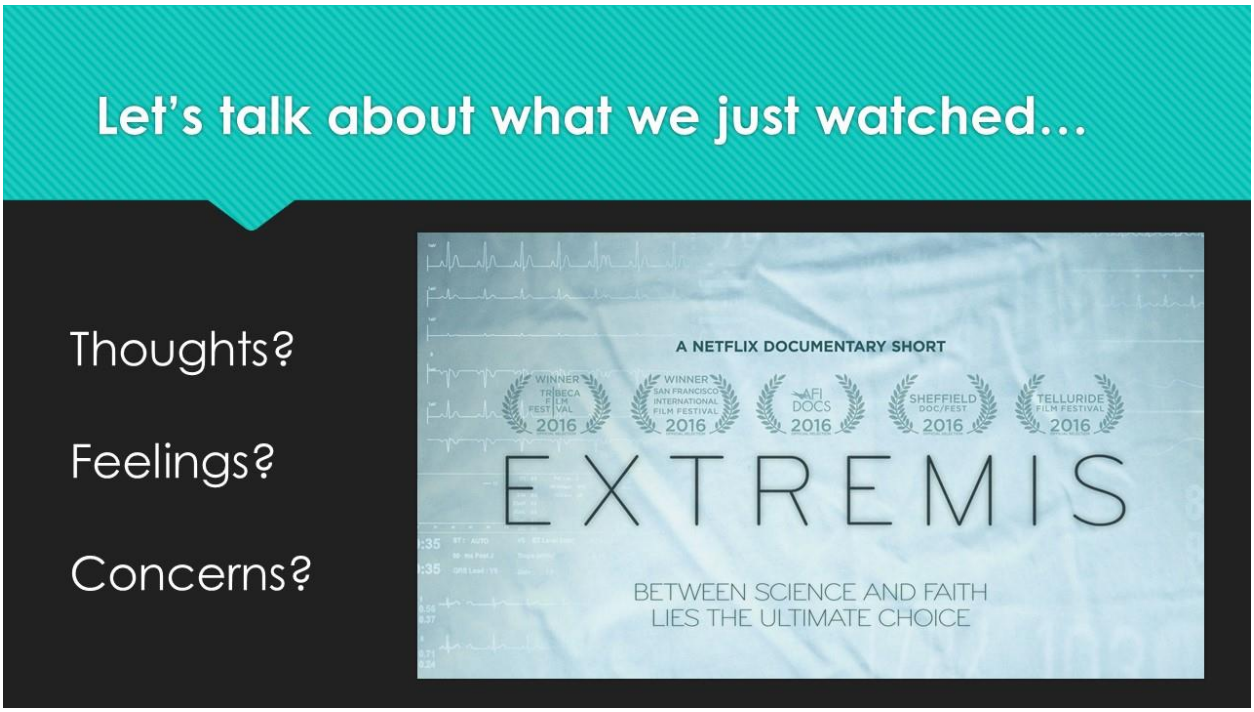
Appendix K

Project Presentation

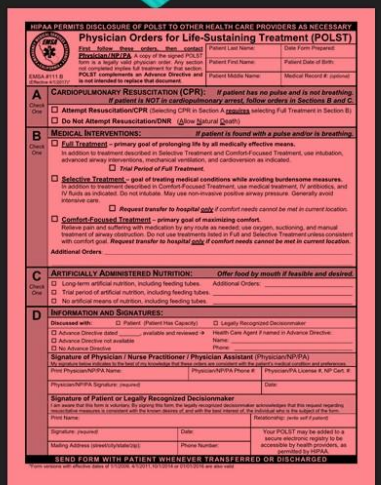





Extremis
A Netflix Documentary
Click to play


Let's talk about what we just watched...
Thoughts?
Feelings?
Concerns?
A NETFLIX DOCUMENTARY SHORT
WINNER TRIBECA FILM FESTIVAL 2016
WINNER SAN FRANCISCO INTERNATIONAL FILM FESTIVAL 2016
AFI DOCS 2016
SHEFFIELD DOC/FEST 2016
TELLURIDE FILM FESTIVAL 2016
EXTREMIS
BETWEEN SCIENCE AND FAITH
LIES THE ULTIMATE CHOICE

So, what options do we have?


HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

First, follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. POLST complements an Advance Directive and is not intended to replace that document.

Patient Last Name | Patient First Name | Patient Middle Name | Date Form Prepared | Patient Date of Birth | Medical Record # (optional)

EMSA #111 B (Effective 4/1/2011)

A CARDIOPULMONARY RESUSCITATION (CPR): *If patient has no pulse and is not breathing.* *If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.*

☐ Attempt Resuscitation/CPR (Selecting CPR in Section A requires selecting Full Treatment in Section B)

☐ Do Not Attempt Resuscitation/DNR (Allow Natural Death)

B MEDICAL INTERVENTIONS: *If patient is found with a pulse and/or is breathing.*

☐ Full Treatment – primary goal of prolonging life by all medically effective means.
In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.
☐ Trial Period of Full Treatment

☐ Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.
In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.
☐ Request transfer to hospital only if comfort needs cannot be met in current location.

☐ Comfort-Focused Treatment – primary goal of maximizing comfort.
Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. Request transfer to hospital only if comfort needs cannot be met in current location.

Additional Orders:

C ARTIFICIALLY ADMINISTERED NUTRITION: *Offer food by mouth if feasible and desired.*

☐ Long-term artificial nutrition, including feeding tubes. Additional Orders:
☐ Trial period of artificial nutrition, including feeding tubes.
☐ No artificial means of nutrition, including feeding tubes.

D INFORMATION AND SIGNATURES:

Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker

☐ Advance Directive dated _____, available and reviewed → Health Care Agent if named in Advance Directive: Name: Phone:
☐ Advance Directive not available
☐ No Advance Directive

Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)
My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.

Print Physician/NP/PA Name: | Physician/NP/PA Phone # | Physician/PA License #, NP Cert. #

Physician/NP/PA Signature (required) | Date:

Signature of Patient or Legally Recognized Decisionmaker
I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Print Name: | Relationship: (write self if patient)

Signature (required) | Date: | Your POLST may be added to a secure electronic registry to be accessible by health providers, as permitted by HIPAA.

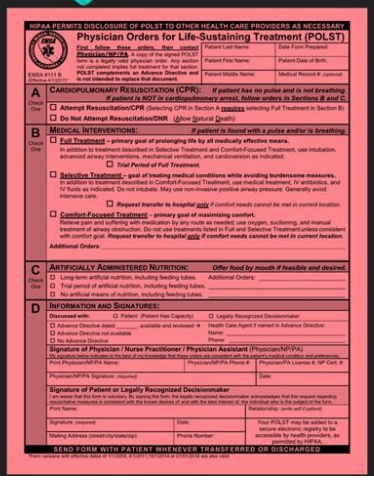
Mailing Address (street/city/state/zip) | Phone Number

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

Form versions with effective dates of 1/1/2008, 4/1/2011, 9/1/2014 or 01/01/2016 are also valid.

- Physician's Order for Life Sustaining Treatment (POLST)
- Advanced Directive
- Living Will and Trust

POLST FORM


HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

First, follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. POLST complements an Advance Directive and is not intended to replace that document.

Patient Last Name | Patient First Name | Patient Middle Name | Date Form Prepared | Patient Date of Birth | Medical Record # (optional)

EMSA #111 B (Effective 4/1/2011)

A CARDIOPULMONARY RESUSCITATION (CPR): *If patient has no pulse and is not breathing.* *If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.*

☐ Attempt Resuscitation/CPR (Selecting CPR in Section A requires selecting Full Treatment in Section B)

☐ Do Not Attempt Resuscitation/DNR (Allow Natural Death)

B MEDICAL INTERVENTIONS: *If patient is found with a pulse and/or is breathing.*

☐ Full Treatment – primary goal of prolonging life by all medically effective means.
In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.
☐ Trial Period of Full Treatment

☐ Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.
In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.
☐ Request transfer to hospital only if comfort needs cannot be met in current location.

☐ Comfort-Focused Treatment – primary goal of maximizing comfort.
Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. Request transfer to hospital only if comfort needs cannot be met in current location.

Additional Orders:

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☐ Long-term artificial nutrition, including feeding tubes. Additional Orders:
☐ Trial period of artificial nutrition, including feeding tubes.
☐ No artificial means of nutrition, including feeding tubes.

D INFORMATION AND SIGNATURES:

Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker

☐ Advance Directive dated _____, available and reviewed → Health Care Agent if named in Advance Directive: Name: Phone:
☐ Advance Directive not available
☐ No Advance Directive

Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)
My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.

Print Physician/NP/PA Name: | Physician/NP/PA Phone # | Physician/PA License #, NP Cert. #

Physician/NP/PA Signature (required) | Date:

Signature of Patient or Legally Recognized Decisionmaker
I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Print Name: | Relationship: (write self if patient)

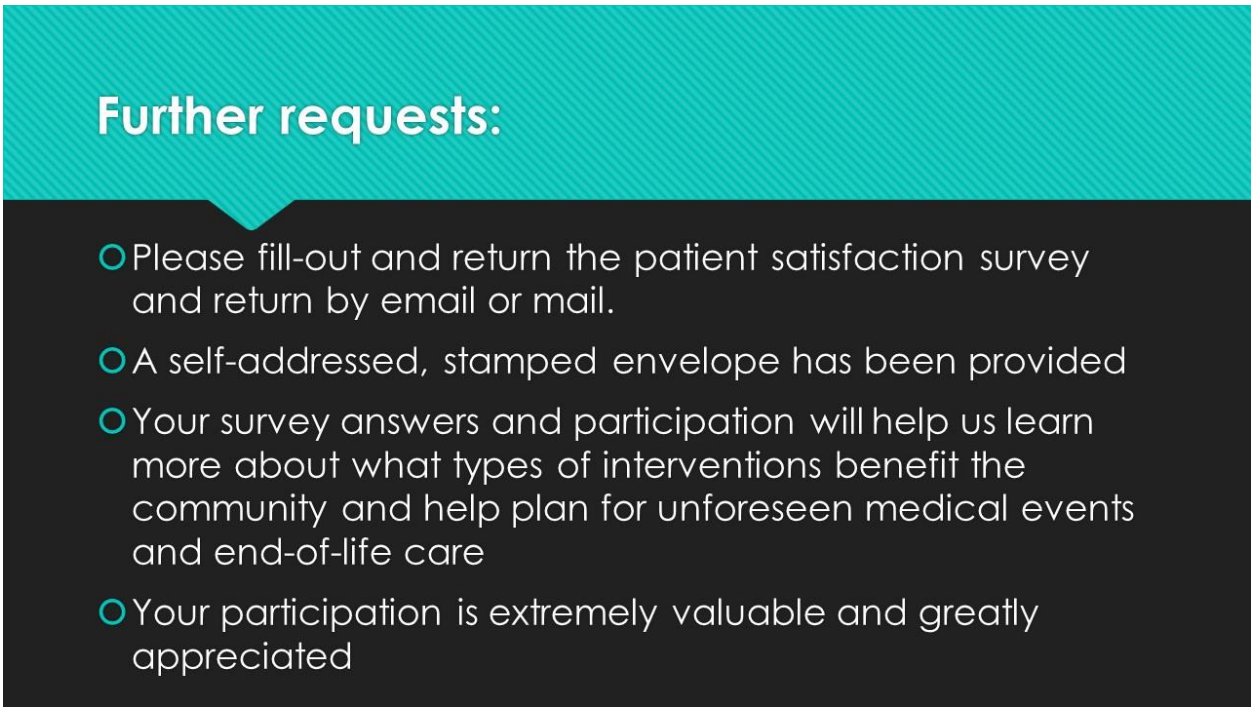
Signature (required) | Date: | Your POLST may be added to a secure electronic registry to be accessible by health providers, as permitted by HIPAA.

Mailing Address (street/city/state/zip) | Phone Number

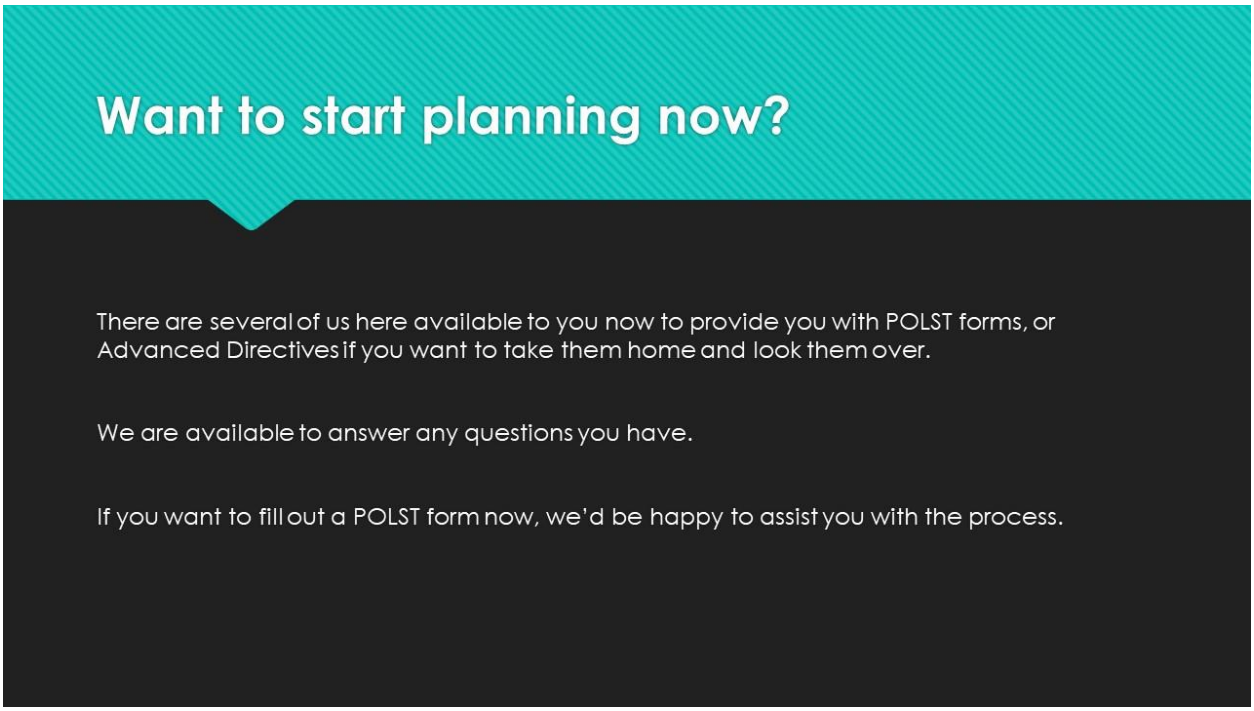
SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

Form versions with effective dates of 1/1/2008, 4/1/2011, 9/1/2014 or 01/01/2016 are also valid.

- What is this form for?
- How do I get one?
- If I have one, what should I do with it?


Further requests:
Please fill-out and return the patient satisfaction survey and return by email or mail.
A self-addressed, stamped envelope has been provided
Your survey answers and participation will help us learn more about what types of interventions benefit the community and help plan for unforeseen medical events and end-of-life care
Your participation is extremely valuable and greatly appreciated


Questions?


Want to start planning now?
There are several of us here available to you now to provide you with POLST forms, or Advanced Directives if you want to take them home and look them over.
We are available to answer any questions you have.
If you want to fill out a POLST form now, we'd be happy to assist you with the process.

Appendix L

Memorandum of Understanding (MOU)

AdventistHealth
Glendale

MEMORANDUM OF UNDERSTANDING BETWEEN

ADVENTIST HEALTH GLENDALE AND ADVENTIST HEALTH SONORA

FOR INSTIUTIONAL REVIEW BOARD REVIEW OF HUMAN SUBJECTS RESEARCH

RE: Community Outreach Programs Aimed at Preparing Individuals for Serious Illness through Physician's Order for Life Sustaining Treatment (POLST) Formed Education: A Pilot Study
Investigator: Lacey Neufeld

Adventist Health Glendale Federal Wide Assurance Number: FWA 00008164

Purpose: The purpose of this Memorandum of Understanding (MOU) is to set forth an agreement between Adventist Health Sonora to rely on Adventist Health Glendale's IRB for review, approval, or determination of exemption, for the above-mentioned humanitarian use device.

Human Subjects Research: The definition of human subject research is that set forth in federal regulations describing humans, research, clinical investigation and other closely related terms promulgated by the Office of Human Subject Protections for Human Subject Research at 45 CFR §46.102, and the Food & Drug Administration regulations of Clinical Investigations at 21 CFR §50.3, §312.3 and §812.3, and as required by California law.

Compliance with Federal and State Laws: Initial review, continuing review or a determination of exemption of human subject research under this MOU will be conducted in accordance with all applicable federal and state statutes and regulations and AHGL IRB policies governing the protection of human subjects in research.

Procedures: The AHGL IRB will be responsible for review and ongoing oversight of the study and AH Sonora will submit the following information to AHGL IRB for review: initial application, annual/continuing review reports; all subsequent changes to the approved version of the informed consent; revisions to the protocol or investigator's brochure; all significant adverse events and/or unanticipated problems; and any new information that would impact a subject's decision to continue participation in the study.

The AHGL IRB will have available to AH Sonora all approved documents and correspondence provided through the AHGL IRB electronic iMedRIS system, email or mail.

The undersigned officials have read and agreed to the terms above and this reliance will remain in effect unless or until revoked or superseded by a revised Memorandum of Understanding.

7-22-19

Greg McCulloch, CFO
Adventist Health Sonora

Date

7-2-19

Alice Issai, President and CEO
Adventist Health Glendale

Date

Appendix M

Institutional Review Board Project Approval

Adventist Health
Glendale

June 13, 2019

Lacey Neufeld
1000 Greenley Road
Sonora, CA 95370

RE: 2019-56: Community Outreach Programs Aimed at Preparing Individuals for Serious Illness through Physician's Order for Life Sustaining Treatment (POLST) Form Education: A Pilot Study

Dear Ms. Neufeld:

The above-referenced human subject's research project was presented for Exempt Review on June 13, 2019 and the following action(s) were taken:

Reason for Review: Exempt Review 45 CFR 46.101(b)

IRB Action(s): Research Certified as Exempt
Exempt Category 2

Additional Requirements:
1. All data must be stored on the Adventist Health computer system.
2. No personal devices may be used to contact participants or store information.
3. Please submit the contact email and phone number you will be using.
4. **Submit revised documents as identified in the iMedRIS system prior to the start of the study.**

Expiration Date: Exempt studies have no expiration date and do not require continuing review.
Required: Submit a "Study Closeout Report" when the study is completed.
Required: Submit a copy of your publication and/or findings at the time of study closure.

Certification of Exemption is effective for the life of the study. However, any modifications must be submitted to the IRB for prospective review prior to implementation. In some circumstances, changes to the project may disqualify it from exempt status. An amendment may *not* be used to revise the project dates, a complete "NEW" application must be submitted.

Adventist Health is committed to protecting the privacy and security of PHI and our commitment to the HIPAA Privacy Rule is an extension of our mission, vision, and values. The following Adventist Health policies must be abided by and are available in "Lucidoc" for your review:

- **Use and Disclosure of Protected Health Information in Research (Policy AD-10-015-S):** The purpose of this policy is to provide procedures regarding the ***use and disclosure of protected health information*** (PHI) for research so as to comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA), and more specifically the Privacy Rule.
    - **Other Sites:** Office of Human Research Protections: Coded Private Information or Specimens Use in Research

RE: 2019-65 June 13, 2019

- **Confidentiality of Protected Health Information (Policy AD-10-002-S)**: It is the policy of Adventist Health to ***maintain confidentiality*** for patients and employees at all times and under all circumstances to include the protection of PHI.
    - **Protecting PHI.** Appropriate levels of protection of confidentiality must be afforded to all: (1) printed PHI, (2) telephone calls concerning PHI, (3) conversations concerning PHI, (4) faxed PHI, copied PHI (5) computerized PHI, including PHI stored/transmitted on devices such as smartphones, tablets, and flash drives and (6) PHI on whiteboards viewable from public areas.
- **Compliance with Minimum Necessary Requirements; Role Based Access (Policy AD-10-003-S):** Compliance with the HIPAA Privacy Rule requires an understanding and analysis of the following elements: who is using or disclosing PHI; to whom the PHI is being disclosed; why the information is being used or disclosed, and, what information is involved, and how much information is needed to accomplish the purpose.
- **De-Identification of Protected Health Information (AD-10-014-S):** The purpose of this policy is to describe the process by which ***individually identifiable health information is rendered de-identified*** so as to comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA), and more specifically the Privacy Rule.
- **HIPAA Guide for Research Investigators**: Please review to ensure that your use of Adventist Health PHI (e.g., medical records, databases) complies with the Privacy Rule as Adventist Health must protect the privacy of PHI used or released for research. The HIPAA waiver is authorized as it was found that:

    1. The use or disclosure of protected health information involves no more than a minimal risk to the privacy of individuals, based on, at least, the presence of the following elements:
        - an adequate ***plan to protect the identifiers*** from improper use and disclosure;
        - an adequate ***plan to destroy the identifiers*** at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers or such retention is otherwise required by law; and
        - adequate ***written assurances that the protected health information will not be reused or disclosed to any other person or entity***, except as required by law, for authorized oversight of the research project, or for other research for which the use or disclosure of protected health information would be permitted by this subpart;
    2. The research could not practicably be conducted without the waiver or alteration; and
    3. The research could not practicably be conducted without access to and use of the protected health information.

Please immediately report any suspected or known privacy incidents or breach of information to the IRB.

The Research Compliance Specialist may be contacted at 818 409-8522 if you have any questions regarding the review of your research.

Sincerely,

Simon Keushkerian, M.D.
IRB Chairman, AHGL IRB

Part 14B: IRB Expedited Review Letter

Appendix N

CUHSR Project Approval

BRADLEY University

DATE: 20 July 2019

TO: Lacey Neufeld, Sarah Silvest-Guerrero
FROM: Bradley University Committee on the Use of Human Subjects in Research

STUDY TITLE: Community outreach programs aimed at preparing individuals for serious illness through physician orders for life-sustaining treatment POLST form education: A pilot study
CUHSR #: 49-19
SUBMISSION TYPE: Initial Review

ACTION: Approved
APPROVAL DATE: 20 July 2019
REVIEW TYPE: Exempt

Thank you for the opportunity to review the above referenced proposal. The Bradley University Committee on the Use of Human Subject in Research has determined the proposal to be EXEMPT from IRB FULL REVIEW according to federal regulations

The study has been found to be exempt pursuant to 45 CFR 46.104(d) 2i, 2ii [Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording). The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects; 2ii Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation]

Please submit a final status report when the study is completed. A form can be found on our website at https://www.bradley.edu/academic/cio/osp/studies/cuhsr/forms/. Please retain research records for three years from the conclusion of your study. Be aware that some professional standards may require the retention of records for longer than three years. If this study is regulated by the HIPAA privacy rule, retain the research records for at least 6 years.

Be aware that any future changes to the protocol must first be approved by the Committee on the Use of Human Subjects in Research (CUHSR) prior to implementation and that substantial changes may result in the need for further review. These changes include the addition of study personnel. Please submit a Request for Minor Modification of a Current Protocol form found at the CUHSR website at https://www.bradley.edu/academic/cio/osp/studies/cuhsr/forms/ should a need for a change arise. A list of the types of modifications can be found on this form.

While no untoward effects are anticipated, should they arise, please report any untoward effects to CUHSR immediately.

This email will serve as your written notice that the study is approved unless a more formal letter is needed. You can request a formal letter from the CUHSR secretary in the Office of Sponsored Programs.

Committee on the Use of Human Subjects in Research – 100 Kauffman
1501 W Bradley Ave.
Peoria, IL 61625

Appendix O

SWOT Analysis

Objective:
To conduct a community outreach program aimed at increasing the number of POLST and/or Advanced Directive forms documented in that community.

Internal Factors	
Strengths (+)	Weaknesses (-)
• Strong stakeholder buy-in • Planned intervention is evidence based • Christian-based non-profit with a mission to inspire wholeness and hope • The scientific tools have already been created and proven effective • Motivated professionals who similar goals to enhance their community through education • Community population is proportionately geriatric heavy • Skilled inpatient providers and social workers already devoted to having these discussions	• Lack of time noted by providers to have valuable discussions. • Fear of having discussions about death • Not all community providers can access the acute care facilities system medical records (may not have access to uploaded advanced care planning forms) • Need follow-up and support from providers at every level of patient interaction – not all are easy to reach and educate. • Inability to charge insurance for the time spent on these discussions

External Factors

Opportunities (+)	Threats (-)
• Greater patient autonomy in during unforeseen traumatic medical events or serious illness • Reduced number of readmissions • Decreased inpatient and skilled nursing hospital costs • Reduced burden on surrogate decision makers • Reduced burden on providers and physicians • Increased support from palliative and hospice personnel	• Lack of funding • Inability to contact patients in rural areas • Poor turnout • Poor marketing opportunities for outreach program • No incentive to participate • Providers don't have time to participate in extracurricular educational opportunities

Evaluation of Objective:
Evidenced-based practice, effective scientific tools, driven practitioners and a mission to inspire wholeness will minimize weaknesses and threats to help achieve an increased number of POLST and/or Advanced Directive forms catalogued within the electronic medical record of community patients.

Appendix P

Section I Results – How Well Educated Were Participants Prior to the Intervention

SMART OBJECTIVE - Did Perceptions Change as a Result of the Intervention

WERE THE PARTICIPANTS WELL EDUCATED PRIOR TO THE EVENT?

1. My primary care provider has talked to me about end-of-life planning

Sex	Status	Age	Question #1	Numerical Equivalent
Male	No	66	Strongly Disagree	1
Female	Yes	64	Strongly Agree	5
Male	No	70	Neutral	3
Female	Yes	55	Strongly Disagree	1
Male	No	71	Strongly Agree	5
Female	Yes	63	Neutral	3
Female	No	63	Neutral	3
Female	No	72	Neutral	3
Male	Yes	57	Strongly Disagree	1
Female	Yes	43	Strongly Agree	5
Female	Yes	73	Strongly Disagree	1
Female	Yes	70	Strongly Disagree	1
Female	No	46	Strongly Disagree	1
Male	No	47	Strongly Disagree	1
Female	Yes	63	Strongly Disagree	1
Male	No	44	Strongly Disagree	1
Female	No	46	Strongly Disagree	1
Female	No	63	Strongly Disagree	1

	N	18
Disagree	Mean	2.11
	STd. Dev.	1.57
	S.E.	0.37

2. My primary care provider has talked about the medical options available to me if I get seriously ill

Sex	Status	Age	Question #2	Numerical Equivalent
Male	No	66	Strongly Disagree	1
Female	Yes	64	Strongly Agree	5
Male	No	70	Neutral	3
Female	Yes	55	Strongly Disagree	1
Male	No	71	Neutral	3
Female	Yes	63	Strongly Agree	5
Female	No	63	Strongly Disagree	1
Female	No	72	Neutral	3
Male	Yes	57	Strongly Disagree	1
Female	Yes	43	Strongly Agree	5
Female	Yes	73	Strongly Disagree	1
Female	Yes	70	Strongly Disagree	1
Female	No	46	Strongly Disagree	1
Male	No	47	Strongly Disagree	1
Female	Yes	63	Strongly Disagree	1
Male	No	44	Strongly Disagree	1
Female	No	46	Strongly Disagree	1
Female	No	63	Strongly Disagree	1

	N	18
Disagree	Mean	2.00
	STd. Dev.	1.57
	S.E.	0.37

Key

Likert Scale	Numerical Equivalent
Strongly Agree	5
Agree	4
Neutral	3
Disagree	2
Strongly Disagree	1

PRE-INTERVENTION **POST-INTERVENTION**

5. I believe that most people who are resuscitated and receive CPR survive.

Sex	Status	Age	5	Numerical Equivalent	5	Numerical Equivalent
Male	No	66	Agree	4	Agree	4
Female	Yes	64	Neutral	3	Strongly Agree	5
Male	No	70	Disagree	2	Disagree	2
Female	Yes	55	Agree	4	Strongly Disagree	1
Male	No	71	Disagree	2	Disagree	2
Female	Yes	63	Neutral	3	Disagree	2
Female	No	63	Strongly Disagree	1	Strongly Disagree	1
Female	No	72	Disagree	2		
Male	Yes	57	Agree	4	Disagree	2
Female	Yes	43	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	73	Neutral	3	Neutral	3
Female	Yes	70	Neutral	3	Neutral	3
Female	No	46	Disagree	2	Strongly Disagree	1
Male	No	47	Neutral	3	Neutral	3
Female	Yes	63	Neutral	3	Strongly Disagree	1
Male	No	44	Strongly Disagree	1	Strongly Disagree	1
Female	No	46	Agree	4	Neutral	3
Female	No	63	Neutral	3	Neutral	3

	N	18	N	17
Not sure or don't believe	Mean	2.67	Mean	2.24
	STd. Dev.	1.03	STd. Dev.	1.20
	S.E.	0.24	S.E.	0.29
			Percent Change	-16%

PRE-INTERVENTION **POST-INTERVENTON**

6. I believe that if I were ever put on life support there is a good chance my life would be the same after as it was before.

Sex	Status	Age	Question 6	Numerical Equivalent	6	Numerical Equivalent
Male	No	66	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	64	Neutral	5	Neutral	3
Male	No	70	Strongly Disagree	3	Strongly Disagree	1
Female	Yes	55	Disagree	1	Strongly Disagree	1
Male	No	71	Disagree	3	Strongly Disagree	1
Female	Yes	63	Strongly Disagree	5	Strongly Disagree	1
Female	No	63	Strongly Disagree	1	Strongly Disagree	1
Female	No	72	Strongly Disagree	3	Strongly Disagree	1
Male	Yes	57	Disagree	1	Disagree	2
Female	Yes	43	Disagree	5	Disagree	2
Female	Yes	73	Strongly Disagree	1	Disagree	2
Female	Yes	70	Strongly Disagree	1	Disagree	2
Female	No	46	Neutral	1	Disagree	2
Male	No	47	Disagree	1	Strongly Disagree	1
Female	Yes	63	Disagree	1	Strongly Disagree	1
Male	No	44	Neutral	1	Neutral	3
Female	No	46	Agree	1	Disagree	2
Female	No	63	Neutral	1	Neutral	3

	N	18	N	18
They tend not to believe this	Mean	2.00	Mean	1.67
	STd. Dev.	1.57	STd. Dev.	0.77
	S.E.	0.37	S.E.	0.18
			Percent Change	-17%

Appendix Q

Section I Results – Did Participants Want to Talk About and Prepare for End-of-life Care?

Do people want to talk about and prepare for end-of-life care?

3. I would like my provider to be very honest with me about the death and dying process.

Sex	Status	Age	3	Numerical Equivalent
Male	No	66	Strongly Agree	5
Female	Yes	64	Strongly Agree	5
Male	No	70	Strongly Agree	5
Female	Yes	55	Agree	4
Male	No	71	Strongly Agree	5
Female	Yes	63	Strongly Agree	5
Female	No	63	Strongly Agree	5
Female	No	72	Strongly Agree	5
Male	Yes	57	Strongly Agree	5
Female	Yes	43	Strongly Agree	5
Female	Yes	73	Strongly Agree	5
Female	Yes	70	Agree	4
Female	No	46	Strongly Agree	5
Male	No	47	Strongly Agree	5
Female	Yes	63	Strongly Agree	5
Male	No	44	Strongly Agree	5
Female	No	46	Strongly Agree	5
Female	No	63	Strongly Agree	5

	N	18
Strongly Agree	Mean	4.89
	STd. Dev.	0.32
	S.E.	0.08

4. I would like to know the truth about my medical conditions and reasonable expectations of survival?

Sex	Status	Age	4	Numerical Equivalent
Male	No	66	Agree	4
Female	Yes	64	Strongly Agree	5
Male	No	70	Strongly Agree	5
Female	Yes	55	Strongly Agree	5
Male	No	71	Strongly Agree	5
Female	Yes	63	Strongly Agree	5
Female	No	63	Agree	4
Female	No	72	Strongly Agree	5
Male	Yes	57	Strongly Agree	5
Female	Yes	43	Strongly Agree	5
Female	Yes	73	Strongly Agree	5
Female	Yes	70	Agree	4
Female	No	46	Strongly Agree	5
Male	No	47	Strongly Agree	5
Female	Yes	63	Strongly Agree	5
Male	No	44	Strongly Agree	5
Female	No	46	Strongly Agree	5
Female	No	63	Strongly Agree	5

	N	18
Agree/Strongly Agree	Mean	4.83
	STd. Dev.	0.38
	S.E.	0.09

Key

Likert Scale	Numerical Equivaler
Strongly Agree	5
Agree	4
Neutral	3
Disagree	2
Strongly Disagree	1

Appendix R

Section II Results – Did the Number of POLST Forms Increase?

Did the number of POLST forms increase?

Pre	Post
Strongly Agree	Strongly Disagree
Strongly Agree	Strongly Disagree
Strongly Disagree	Strongly Disagree
Strongly Disagree	Strongly Agree
Strongly Disagree	Strongly Agree
Strongly Disagree	Strongly Disagree
Strongly Disagree	Strongly Disagree
Strongly Disagree	Strongly Disagree
Strongly Disagree	Strongly Disagree
Strongly Disagree	Strongly Disagree
Strongly Disagree	Strongly Disagree
Strongly Disagree	Strongly Agree
Strongly Disagree	Strongly Disagree
Strongly Disagree	Strongly Disagree
Strongly Disagree	Strongly Disagree
Strongly Disagree	Strongly Agree
Strongly Disagree	Strongly Disagree
Strongly Disagree	Strongly Disagree
Strongly Disagree	Strongly Disagree
2	4
11%	22%
% Increase	**100%**

Key

Likert Scale	Numerical Equivalen
Strongly Agree	5
Agree	4
Neutral	3
Disagree	2
Strongly Disagree	1

Statistics	Pre	Post	Differe
	5	1	4
	5	1	4
	1	1	0
	1	5	-4
	1	5	-4
	1	1	0
	1	1	0
	1	1	0
	1	1	0
	1	1	0
	1	5	-4
	1	1	0
	1	1	0
	1	1	0
	1	5	-4
	1	1	0
	1	1	0
	1	1	0
N	**18**	**18**	0
Mean	**1.44**	**1.89**	-0.44444
STd. Dev.	**1.29**	**1.71**	-0.41765
S.E.	**0.30**	**0.40**	-0.09844

t-Test: Paired Two Sample for Means

	Variable 1	*Variable 2*
Mean	1.444444444	1.888888889
Variance	1.673202614	2.928104575
Observations	18	18
Variance between groups (Sd)	0.408289113	
t-score	1.088566866	
df	34	
Hypothesized Mean Difference	0.5	
P(T<=t) one-tail	0.1	
P(T<=t) two-tail	0.2	

Appendix S

Section III Results – Attendee Satisfaction

ATTENDEE SATISFACTION SURVEY (POST-INTERVENTION)

1. I feel confident about my end-of-life care plan after attending the community event

	Strongly Agree		Agree		Neutral		Disagree		Total Count of 1	Total Question #01
Row Labels	Count of 1	Question #01	Count of 1	Question #01	Count of 1	Question #01	Count of 1	Question #01		
Female	5	41.67%	5	41.67%	1	8.33%	1	8.33%	12	100.00%
Male	2	33.33%	2	33.33%	2	33.33%		0.00%	6	100.00%
Grand Total	**7**	**38.89%**	**7**	**38.89%**	**3**	**16.67%**	**1**	**5.56%**	**18**	**100.00%**
		Total Population	14	77.78%	3	16.67%	1	5.56%		

2. I would refer a friend or loved on to a similar event.

	Strongly Agree		Agree		Neutral		Total Count otal Question #	
Row Labels	Count of 2	Question #02	Count of 2	Question #02	Count of 2	Question #02		
Female	7	58.33%	4	33.33%	1	8.33%	12	100.00%
Male	4	66.67%	2	33.33%		0.00%	6	100.00%
Grand Total	**11**	**61.11%**	**6**	**33.33%**	**1**	**5.56%**	**18**	**100.00%**
		Total Population	17	94.44%	1	5.56%		

3. Attending a community event is a good way to learn about the options available when planning end-of-life care

	Strongly Agree		Agree		Total Count otal Question #	
Row Labels	Count of 3	Question #03	Count of 3	Question #03		
Female	9	75.00%	3	25.00%	12	100.00%
Male	4	66.67%	2	33.33%	6	100.00%
Grand Total	**13**	**72.22%**	**5**	**27.78%**	**18**	**100.00%**
		Total Population	18	100.00%		

4. I would prefer to learn about my options in private with my primary care provider only

	Agree		Neutral		Disagree		Strongly Disagree		(blank)		Total Count of 4	otal Question #0
Row Labels	Count of 4	Question #04	Count of 4	Question #04	Count of 4	Question #04	Count of 4	Question #04	Count of 4	Question #04		
Female		0.00%	4	33.33%	3	25.00%	5	41.67%		0.00%	12	100.00%
Male	1	20.00%	2	40.00%	1	20.00%	1	20.00%		0.00%	5	100.00%
Grand Total	**1**	**5.88%**	**6**	**35.29%**	**4**	**23.53%**	**6**	**35.29%**		**0.00%**	**17**	**100.00%**
Total Population	1	5.56%	6	0.33%			10	55.56%				

5. I am glad I attended the event

	Strongly Agree		Agree		Total Count otal Question #	
Row Labels	Count of 5	Question #05	Count of 5	Question #05		
Female	10	83.33%	2	16.67%	12	100.00%
Male	5	83.33%	1	16.67%	6	100.00%
Grand Total	**15**	**83.33%**	**3**	**16.67%**	**18**	**100.00%**
		Total Population	18	100.00%		

6. I have a better understanding of end-of-life options and serious medical illnesses because of the event

	Strongly Agree		Agree		Neutral		Total Count otal Question #	
Row Labels	Count of 6	Question #06	Count of 6	Question #06	Count of 6	Question #06		
Female	9	75.00%	2	16.67%	1	8.33%	12	100.00%
Male	3	50.00%	2	33.33%	1	16.67%	6	100.00%
Grand Total	**12**	**66.67%**	**4**	**22.22%**	**2**	**11.11%**	**18**	**100.00%**
		Total Population	16	88.89%	2	11.11%		

7. My opinion about what I want if I become seriously ill has changed as a result of the community event

	Strongly Agree		Agree		Neutral		Disagree		Strongly Disagree		Total Question #07	Total Count of 7
Row Labels	Question #07	Count of 7	Question #	Count of 7	Question #	Count of 7	Question #	Count of 7	Question #07	Count of 7		
Female	3	25.00%	2	16.67%	4	33.33%	1	8.33%	2	16.67%	12	100.00%
Male	2	33.33%	1	16.67%	1	16.67%	1	16.67%	1	16.67%	6	100.00%
Grand Total	**5**	**27.78%**	**3**	**16.67%**	**5**	**27.78%**	**2**	**11.11%**	**3**	**16.67%**	**18**	**100.00%**
		Total Population	8	44%	5	28%			5	28%		

8. I believe all communities should offer end-of-life care planning events like the one I attended

	Strongly Agree		Agree		Neutral		(blank)		Total Count of 8	Total Question #08
Row Labels	Count of 8	Question #08	Count of 8	Question #08	Count of 8	Question #08	Count of 8	Question #08		
Female	9	81.82%	2	18.18%		0.00%		0.00%	11	100.00%
Male	4	66.67%	1	16.67%	1	16.67%		0.00%	6	100.00%
Grand Total	**13**	**76.47%**	**3**	**17.65%**	**1**	**5.88%**		**0.00%**	**17**	**100.00%**
		Total Population	16	94%	1	6%				

Appendix T

Section IV Results – Did Perceptions Regarding End-of-Life Change

Did Participant Perceptions Change as a Result of the Intervention?

PRE-INTERVENTION / POST-INTERVENTION

8. I am scared of talking about dying with my primary care provider

Sex	Status	Age	Question #8	Numerical Equivalent	Question #8	Numerical Equivalent
Male	No	66	Disagree	2	Disagree	2
Female	Yes	64	Strongly Disagree	1	Strongly Disagree	1
Male	No	70	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	55	Disagree	2	Strongly Disagree	1
Male	No	71	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	63	Neutral	3	Strongly Disagree	1
Female	No	63	Strongly Disagree	1	Strongly Disagree	1
Female	No	72	Strongly Disagree	1	Strongly Disagree	1
Male	Yes	57	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	43	Disagree	2	Strongly Disagree	2
Female	Yes	73	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	70	Disagree	2	Disagree	2
Female	No	46	Disagree	2	Disagree	2
Male	No	47	Disagree	2	Strongly Disagree	2
Female	Yes	63	Strongly Disagree	1	Strongly Disagree	1
Male	No	44	Strongly Disagree	1	Strongly Disagree	1
Female	No	46	Strongly Disagree	1	Strongly Disagree	1
Female	No	63	Strongly Disagree	1	Strongly Disagree	1
			N	18	N	18
			Mean	1.44	Mean	1.28
			STd. Dev.	0.62	STd. Dev.	0.46
			S.E.	0.15	S.E.	0.11

*Participants are even less fearful of talking about dying with PCP

Percent Change: -12%

17. I want to continue living even if I become physically disabled

Sex	Status	Age	Question #17	Numerical Equivalent	Question #17	Numerical Equivalent
Male	No	66	Disagree	2	Neutral	3
Female	Yes	64	Strongly Disagree	1	Strongly Disagree	1
Male	No	70	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	55	Neutral	3	Strongly Disagree	1
Male	No	71	Neutral	3	Neutral	3
Female	Yes	63	Neutral	3	Neutral	3
Female	No	63	Agree	4	Neutral	3
Female	No	72	Agree	4		
Male	Yes	57	Neutral	3	Disagree	2
Female	Yes	43	Agree	4	Agree	4
Female	Yes	73	Neutral	3	Neutral	3
Female	Yes	70	Agree	4	Agree	4
Female	No	46	Strongly Agree	5	Agree	4
Male	No	47	Strongly Agree	5	Strongly Agree	5
Female	Yes	63	Strongly Disagree	1	Strongly Disagree	1
Male	No	44	Strongly Agree	5	Strongly Agree	5
Female	No	46	Strongly Disagree	1	Strongly Disagree	1
Female	No	63	Neutral	4	Neutral	3
			N	18	N	17
			Mean	3.11	Mean	2.76
			STd. Dev.	1.41	STd. Dev.	1.39
			S.E.	0.33	S.E.	0.34

*Participants are less agreeable to continuing life after physical disability

Percent Change: -11%

PRE-INTERVENTION / POST-INTERVENTION

9. I am scared of talking about death with my loved ones

Sex	Status	Age	Question #9	Numerical Equivalent	Question #9	Numerical Equivalent
Male	No	66	Strongly Disagree	1	Disagree	2
Female	Yes	64	Strongly Disagree	1	Strongly Disagree	1
Male	No	70	Disagree	2	Disagree	2
Female	Yes	55	Disagree	2	Strongly Disagree	1
Male	No	71	Strongly Disagree	1	Strongly Agree	5
Female	Yes	63	Disagree	2	Neutral	3
Female	No	63	Strongly Disagree	1	Strongly Disagree	1
Female	No	72	Strongly Disagree	1	Strongly Disagree	1
Male	Yes	57	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	43	Strongly Disagree	1	Strongly Agree	5
Female	Yes	73	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	70	Disagree	2	Disagree	2
Female	No	46	Disagree	2	Disagree	2
Male	No	47	Disagree	2	Strongly Disagree	1
Female	Yes	63	Strongly Disagree	1	Strongly Disagree	1
Male	No	44	Strongly Disagree	1	Strongly Disagree	1
Female	No	46	Strongly Disagree	1	Strongly Disagree	1
Female	No	63	Strongly Disagree	1	Strongly Disagree	1
			N	18	N	18
			Mean	1.33	Mean	1.78
			STd. Dev.	0.49	STd. Dev.	1.31
			S.E.	0.11	S.E.	0.31

*Participants were more fearful of talking about death w/loved ones

Percent Change: 33%

18. I want to continue living even if I become mentally disabled

Sex	Status	Age	Question #18	Numerical Equivalent	Question #18	Numerical Equivalent
Male	No	66	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	64	Strongly Disagree	1	Strongly Disagree	1
Male	No	70	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	55	Neutral	3	Strongly Disagree	1
Male	No	71	Disagree	2	Disagree	2
Female	Yes	63	Strongly Disagree	1	Disagree	2
Female	No	63	Disagree	2	Strongly Disagree	1
Female	No	72	Disagree	2	Disagree	2
Male	Yes	57	Neutral	3	Disagree	2
Female	Yes	43	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	73	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	70	Disagree	2	Strongly Disagree	1
Female	No	46	Agree	4	Agree	4
Male	No	47	Strongly Agree	5	Agree	4
Female	Yes	63	Strongly Disagree	1	Strongly Disagree	1
Male	No	44	Agree	4	Agree	4
Female	No	46	Strongly Disagree	1	Strongly Disagree	1
Female	No	63	Neutral	3	Neutral	3
			N	18	N	18
			Mean	2.11	Mean	1.83
			STd. Dev.	1.28	STd. Dev.	1.15
			S.E.	0.30	S.E.	0.27

*Participants are less agreeable to continuing life after mental disability

Percent Change: -13%

PRE-INTERVENTION | POST-INTERVENTION

15. I believe that quality of life is more important than quantity of life.

Sex	Status	Age	Question #15	Numerical Equivalent	Question #15	Numerical Equivalent
Male	No	66	Strongly Agree	5	Agree	4
Female	Yes	64	Strongly Agree	5	Strongly Agree	5
Male	No	70	Strongly Agree	5	Strongly Agree	5
Female	Yes	55	Agree	4	Strongly Agree	5
Male	No	71	Agree	4	Agree	4
Female	Yes	63	Agree	4	Agree	4
Female	No	63	Strongly Agree	5	Strongly Disagree	1
Female	No	72	Strongly Agree	5	Strongly Agree	5
Male	Yes	57	Strongly Agree	5	Strongly Agree	5
Female	Yes	43	Strongly Agree	5	Strongly Agree	5
Female	Yes	73	Strongly Agree	5	Strongly Agree	5
Female	Yes	70	Agree	4	Agree	4
Female	No	46	Strongly Agree	5	Agree	4
Male	No	47	Strongly Agree	5	Strongly Agree	5
Female	Yes	63	Strongly Agree	5	Strongly Agree	5
Male	No	44	Strongly Agree	5	Agree	4
Female	No	46	Strongly Agree	5	Strongly Agree	5
Female	No	63	Agree	4	Neutral	3

N	18	N	18
Mean	4.72	Mean	4.33
STd. Dev.	0.46	STd. Dev.	1.03
S.E.	0.11	S.E.	0.24

*There was almost no change in notions of quality versus quantity

Percent Change -8%

PRE-INTERVENTION | POST-INTERVENTION

19. I want to continue living even if I can no longer eat food by mouth

Sex	Status	Age	Question #19	Numerical Equivalent	Question #19	Numerical Equivalent
Male	No	66	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	64	Strongly Disagree	1	Strongly Disagree	1
Male	No	70	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	55	Strongly Disagree	1	Strongly Disagree	1
Male	No	71	Disagree	2	Strongly Disagree	1
Female	Yes	63	Neutral	3	Disagree	2
Female	No	63	Neutral	3	Disagree	2
Female	No	72	Strongly Disagree	1	Strongly Disagree	1
Male	Yes	57	Neutral	3	Disagree	2
Female	Yes	43	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	73	Neutral	3	Strongly Disagree	1
Female	Yes	70	Disagree	2	Strongly Disagree	1
Female	No	46	Disagree	2	Disagree	2
Male	No	47	Disagree	2	Disagree	2
Female	Yes	63	Strongly Disagree	1	Strongly Disagree	1
Male	No	44	Strongly Agree	5	Strongly Agree	5
Female	No	46	Strongly Disagree	1	Strongly Disagree	1
Female	No	63	Neutral	3	Neutral	3

N	18	N	18
Mean	2.00	Mean	1.61
STd. Dev.	1.14	STd. Dev.	1.04
S.E.	0.27	S.E.	0.24

*Participants are less agreeable to continuing life if they cannot eat

Percent Change -19%

PRE-INTERVENTION | POST-INTERVENTION

16. If my quality of life were to change as the result of a medical intervention, I would not want that intervention

Sex	Status	Age	Question #16	Numerical Equivalent	Question #16	Numerical Equivalent
Male	No	66	Strongly Agree	5	Disagree	2
Female	Yes	64	Agree	4	Agree	4
Male	No	70	Strongly Disagree	5	Strongly Disagree	1
Female	Yes	55	Neutral	3	Strongly Agree	5
Male	No	71	Neutral	3	Agree	4
Female	Yes	63	Neutral	3	Agree	4
Female	No	63	Disagree	2	Agree	4
Female	No	72	Strongly Disagree	1	Agree	4
Male	Yes	57	Agree	4	Agree	4
Female	Yes	43	Neutral	3	Agree	4
Female	Yes	73	Neutral	3	Disagree	2
Female	Yes	70	Disagree	2	Strongly Disagree	1
Female	No	46	Disagree	2	Disagree	2
Male	No	47	Disagree	2	Disagree	2
Female	Yes	63	Neutral	3	Strongly Agree	5
Male	No	44	Neutral	3	Neutral	3
Female	No	46	Agree	4	Agree	4
Female	No	63	Neutral	3	Neutral	3

N	18	N	18
Mean	3.06	Mean	3.22
STd. Dev.	1.06	STd. Dev.	1.26
S.E.	0.25	S.E.	0.30

*There was almost no change in desire to have life-changing interventions

Percent Change 5%

PRE-INTERVENTION | POST-INTERVENTION

20. I want to continue living even if I can no longer stay in my home

Sex	Status	Age	Question #20	Numerical Equivalent	Question #20	Numerical Equivalent
Male	No	66	Neutral	3	Neutral	3
Female	Yes	64	Strongly Disagree	1	Strongly Disagree	1
Male	No	70	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	55	Disagree	2	Strongly Disagree	1
Male	No	71	Agree	4	Neutral	3
Female	Yes	63	Neutral	3	Neutral	3
Female	No	63	Disagree	2	Disagree	2
Female	No	72	Neutral	3	Neutral	3
Male	Yes	57	Neutral	3	Disagree	2
Female	Yes	43	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	73	Strongly Disagree	1	Strongly Disagree	1
Female	Yes	70	Agree	4	Agree	4
Female	No	46	Agree	4	Agree	4
Male	No	47	Disagree	2	Disagree	2
Female	Yes	63	Neutral	3	Strongly Disagree	1
Male	No	44	Strongly Agree	5	Strongly Agree	5
Female	No	46	Strongly Disagree	1	Strongly Disagree	1
Female	No	63	Neutral	3	Neutral	3

N	18	N	18
Mean	2.56	Mean	2.28
STd. Dev.	1.25	STd. Dev.	1.27
S.E.	0.29	S.E.	0.30

*Participants are less agreeable to continuing life if they cannot stay at home

Percent Change -11%

Key

Likert Scale	Numerical Equivalent
Strongly Agree	5
Agree	4
Neutral	3
Disagree	2
Strongly Disagree	1