ADVANCE DIRECTIVES AND POLST:
PERSPECTIVES FROM THE PUBLIC

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by
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Fall 2012
ADVANCE DIRECTIVES AND POLST:
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by

Evelyn Wiebe-Anderson

Fall 2012

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ABSTRACT

ADVANCE DIRECTIVES AND POLST:

PERSPECTIVES FROM THE PUBLIC

by

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The purpose of the study was to gain an understanding of participant experiences with Advance Directives (ADs) and Physician Orders for Life Sustaining Treatment (POLST). This was a qualitative descriptive study that explored participant reflections on the process of filling out ADs and POLST. After a public presentation on the topic, telephone calls were made to participants to determine how the new information was utilized and/or shared. The target population included individuals from the public in a rural Northern California county. The analyzed data were the spoken words of 17 participants. Four themes were identified: Communicating choices, rationalizing indecision, clarifying a difficult topic and increased confidence. Completing ADs or POLST was an empowering experience for some of the participants. Others gained a sense of relief by identifying end of life care choices for themselves or family members. Reasons for not completing the documents were also identified.
CHAPTER I

INTRODUCTION

Dying is a part of life. Advance planning for end of life care, whether it is one’s own or that of loved ones is an integral part of addressing the worries and concerns that are a part of dying. Advance Directives for health care (ADs) and Physician Orders for Life Sustaining Treatment (POLST), are a small but important portion of the process of advanced care planning. This study, *Advance Directives and POLST: Perspectives from the Public*, explored participant understanding of ADs and POLST, and individual motivations and barriers to completing ADs or POLST.

The Patient Self Determination Act of 1991 mandated that health care providers delivering care to recipients of Medicare and Medicaid provide these patients with written information regarding their legal rights to participate in medical decisions, including refusing or accepting treatment. The completion of ADs formalizes those treatment wishes (Maxfield, Pohl, & Colling, 2003).

Patients in the unpredictable circumstances of acute or chronic illness, their family and friends often ask questions that provide opportunities for nurses to discuss death and dying with them. Nurses need to be prepared for this discussion. Episodes of disease onset and exacerbation are ideal opportunities for nurses to initiate conversations about end of life care choices. Typically, these conversations do not happen unless initiated by health care professionals (Hammes & Briggs, 2007).
In the event an individual is unable to make decisions about medical treatment, ADs designate someone to make decisions for him or her. This designated person is referred to as a health care decision maker. ADs are legal documents that state a person’s choices about medical treatment and, more importantly, designate someone to make decisions regarding medical treatment for the individual should he or she become incapacitated or unable to make independent decisions (California Medical Association, 2003). POLST functions like ADs but is accessible to emergency medical personnel and is an appropriate document for individuals during end of life (California POLST Coalition, 2008).

Coustasse, Quiroz, and Lurie (2008) emphasized a team approach in care giving at the end of life that includes patient and family education about ADs. Nurses are an integral part of the team and often the primary educators of the public when it comes to end of life care choices. Coustasse et al. also recommended culturally sensitive outreach education that includes teaching people to make informed, rational decisions before the event of a medical crisis. This study supports this philosophy of educating the public about these choices and how to communicate them to the health care team. This study was preceded by a public teaching presentation: Advance Directives for Health Care, POLST and understanding end of life care (Appendix A). The goal was to educate a cross section of a community in rural northern California about POLST and ADs and thereby assist people to make informed decisions about end of life care and dying.
Background

Current advanced medical treatments provide a myriad of choices for individuals attempting to prolong or save life. Normative treatment in a medical crisis situation consists of heroic measures, unless otherwise specified. This creates a dilemma when medical advances in treatments and life support are used regardless of appropriateness or compassion (Coustasse et al., 2008). POLST are orders on a specific document developed to avoid unnecessary or painful medical interventions in the end of life environment. POLST is based on the belief that individuals have the right to make their own health care decisions and provides a mechanism for assuring that a patient’s decisions regarding end of life treatment are honored in all settings, especially emergency situations (Sattler, 2008).

Public Perceptions

Public perceptions about survivability of cardio-pulmonary resuscitation (CPR) are very different from actual rates of survival after CPR. Adams and Snedden (2006) analyzed responses from 100 randomly selected patients, aged 70 years or older to compare perceptions of survivability against actual statistics of survival after CPR. They found 81% of respondents believed they had a 50% chance or better of surviving CPR and leaving the hospital and 23% believed their chance was 90% or better. Nava, Santoro, Grassi, and Hill (2008) found similar results in their research with 63% of respondents expecting a survival rate of greater than 40%. The actual survival to discharge rates are closer to 10% (Adams & Snedden, 2006). Both studies revealed that respondents obtained healthcare information primarily from television. In a study with
similar results, Nava et al. (2008) found patients with chronic obstructive pulmonary disease greatly overestimated their chance of surviving CPR. The authors suggested patients should be made aware that media is a major source of both information and misinformation.

A person’s sense of dying and what it means to accept death are imbedded in deeply held beliefs often influenced by the media. Although the fear of death has probably not changed over the centuries, the sense of what is survivable has changed. More than twenty years ago, Stevens (1986) stated: “CPR (cardiopulmonary resuscitation) is now the rule rather than the exception and death is often viewed as the ultimate failure in modern medicine, rather than the final event of the natural life process” (p. 207). Since then, little has changed in both public attitude and that of the medical community. Kyba (2002) stated “advances in medical technology during the past three decades altered the scenarios of our dying. It is now possible to prolong life, with the frightening reality that we also can extend death” (p.141).

In today’s health care arena, respecting and carrying out the end of life choices of an individual necessitates discussions about these choices before overwhelming circumstances and medical crisis treatments dictate the end of life care. While most medical professionals are familiar with end of life scenarios, the lay public is not. The intent of the educational teaching project was to help clarify common assumptions and misconceptions about end of life care, and give validity to the mystery of dying. Lending grace and meaning to dying can add grace and meaning to living.
Problem Statement

The percentages of patients who complete AD forms remain low despite efforts of most healthcare facilities to encourage all patients to complete ADs. In a study of ADs done by Salmond and David (2005), 14% of participants had filled out ADs before the study and 26% completed ADs after filling out the questionnaire and discussing ADs with the researchers. The researchers suggested the methods of disseminating information on ADs were either inadequate or cultural barriers defeated the purpose of ADs.

The county where this study took place, like much of the United States is faced with a growing number of senior citizens in proportion to the rest of the population (U.S. Census Bureau, 2011). Much of the Baby Boomer generation, born between 1943 and 1960, is reaching retirement age. As this population set ages, they face a growing number of health concerns and potential chronic illnesses. In addition, Baby Boomers are increasingly caring for parents who are becoming incapacitated or approaching the end of life. As each generation contends with personal and familial health concerns, an understanding of end of life care is increasingly important.

In order for a health care client to comprehend end of life care options and outcomes, clear and open communication between the healthcare provider and client is essential at a time when such communication is meaningful and not compromised by a medical crisis. In order for nurses and other healthcare providers to understand the wishes of an individual at the end of life or in a life threatening situation, previous documentation of the individual’s wishes are needed (Roessel, 2007). Every area of
nursing practice, at some point includes the event of death and nurses are the ones most likely to care for dying patients.

Relevance of the Study to Nursing

Patient education is a critical part of most nursing roles. The goal of teaching patients is to direct the patient toward better understanding of his or her disease process and to facilitate autonomy in decision making. Dobalian (2006) emphasized the necessity of public educational efforts of completing ADs among healthy persons. Completed ADs and POLST documents allow nurses and other healthcare professionals to honor client treatment wishes at end of life. Nurses can help create a patient population that is better educated about documenting end of life care wishes by educating the public before they become patients. This study began with a public education effort: Advance Directives for Health Care, POLST and understanding end of life care. The intent of this study was to explore individual responses to completing or not completing ADs and/or POLST after participants attended the community education presentation on the topic.

The initiation of a POLST program in Oregon in 2002 revealed that 92% of nursing home residents had completed POLST forms in their charts. These results are from a sub-sample study done by Hickman, Tolle, Brummel-Smith, and Carley (2004) of seven facilities in Oregon. In this study, 88% of residents chose a DNR (do not resuscitate) and comfort care or limited intervention options. Of the 22% who chose the CPR option, 47% had preferences for less than the highest level of treatment. When it came to honoring the stated wishes, another chart review study conducted by Meyers, Moore, McGrory, Sparr, and Ahern (2004) in Washington revealed resident treatment
wishes were honored 90% of the time and POLST forms were 100% congruent with ADs.

It is clear that both documents, the POLST and ADs are vital to guiding compassionate end of life care. Every adult could benefit from having completed ADs to assist in mitigating an unforeseeable, adverse event. POLST is recommended for individuals with advanced chronic or terminal illnesses or anyone interested in further defining end of life care wishes (California POLST Coalition, 2008). An increased use of these documents will assist nurses and other healthcare professionals to give appropriate, compassionate care at end of life. Before an individual is physically or mentally incapacitated by illness, a clear understanding of treatment options available at end of life can help the individual make decisions consistent with his or her own life values. This is advance care planning.

Current trends in healthcare reform are seeing a shift from the hospital to the community with an emphasis on prevention and coordinated care (Domrose, 2010). Rather than waiting for an individual to become a patient, completing ADs or POLST allows individuals to document end of life care choices while still capable of making these choices. Because nurses play a significant role in end of life care they are the ones most likely to be in a position to introduce clients to POLST and ADs. The caring aspect of this nursing role allows patients to freely express both positive and negative feelings about the dying process (Rice & Denise, 2007).
Theoretical Underpinnings of the Study

In the Western or allopathic practice of medicine there is a mechanistic view that emphasizes control and predictability in illness. In Western society, value is placed on internal and external control, personal resourcefulness and self-efficacy (Mishel, 1990). These values leave little room for a holistic view of health that includes death as a natural process. Western society also holds the common belief that outcomes logically follow specific acts. For example, both practitioners and patients in the allopathic system have the expectation that causes of illness can be determined with certainty and illness can be controlled. Only hard, scientific, objective data are seen as valid. Despite this emphasis on control and predictability, outcomes are not always as anticipated and such results may be viewed as treatment “failure.” Recognizing this bias, Mishel (1990) updated her “Uncertainty in Illness Theory” to include chronic illness. Uncertainty during chronic illness has the potential to disrupt a person’s sense of control. Traditional orientation toward stability and adaptation does not allow for the conceptualization of growth and change in uncertain circumstances (1990). For those with end of life health concerns and chronic illness, uncertainty becomes a part of reality. Among her assertions, Mishel explained that uncertainty can prompt coping efforts with the intent of reducing the uncertainty and the accompanying emotional discomfort. Long term uncertainty can result in personal growth (1990, p. 257). When uncertainty cannot be reduced, coping strategies are employed to manage the emotional response. As uncertainty endures, an individual can move from the negative experience of “loss of control” to a new perspective and uncertainty is accepted as a natural part of the rhythm of life (1990, p. 260). The Uncertainty in Illness Theory underpins this study: Advance Directives and
POLST: Perspectives from the public. This study and the initial teaching effort provided a platform for discussion of the potentially negative experience of end of life.

Mishel (1990) emphasized a chronically ill patient’s need to shift from mechanistic thinking to probabilistic thinking. As uncertainty becomes part of the individual’s self-perception, he/she can learn the multiple possibilities, alternatives and choices. Mishel stated, “The new view of life allows the evaluation of uncertainty to be changed from danger to opportunity” (1990, p. 260).

Health care providers, and nurses in particular, can assist individuals and families in a more graceful transition to finding new perspectives in the uncertainty of chronic illness and end of life. Teaching about POLST and ADs is part of this process. Social support systems including educational efforts have a direct impact on uncertainty and can reduce the resulting emotional stress. Mishel (1999) explained how important it is for a patient to have support resources and health care providers to help him/her change uncertainty from a negative experience to a probabilistic understanding of uncertainty as a natural part of reality (1990, pp. 160-161). Earlier studies (Mishel & Braden, 1988) using the Mishel Uncertainty in Illness Theory (before it was updated) also elucidate the importance of having clear, thoughtful and caring information from health care providers in order to learn to cope with uncertainty.

Purpose of the Study

This study sought to determine participant understanding of ADs and POLST for health care, and to explore individual motivations and barriers to having completed ADs or POLST. The initial teaching presentation target audience was a cross section of
competent adults in a rural northern California county. This was accomplished through telephone interviews two to six months after the presentation.

Research Question

The purpose of the telephone calls was to allow participants to talk about their experiences with ADs and/or POLST. The question that drove the interviews was: After attending the presentation on Advance Directives and POLST did that initiate conversations for you with others about the topic? The goal of this study was to understand participant perceptions of ADs and POLST after they had attended the teaching presentation.

Definition of Terms

**Advance Directives**

Advance Directives (ADs) describe a person’s choices about medical treatment and name someone to make decisions about medical treatment in the event that this person is unable to make these decisions by him or herself. Together, these identified choices form one legal document. The person filling out the ADs forms is sometimes referred to as the principal. The principal selects a person to honor his/her wishes as stated in the ADs, make healthcare decisions and take durable power of attorney for the principal. This only occurs when the principal becomes incapacitated (California Medical Association, 2003).

**POLST**

POLST (Physician Orders for Life Sustaining Treatment) is a document intended to facilitate effective communication between health care professionals and
patients. The single page, bright pink POLST form is easily recognizable and travels with
the patient from home to hospital and skilled nursing facilities. In the institutional setting
it is kept in the patient chart. In states where the program is fully endorsed, emergency
medical personnel are trained to recognize and utilize the form. In effect, the POLST
converts end of life treatment preferences into physician orders.

Qualifications of Study Investigator

The qualifications of this project’s investigator include 27 years of experience
working with geriatric clients in the capacity of a registered and public health nurse, a
Certified Parish Nurse and a nursing instructor for the past seven years. In her current
role as case manager in a home health agency, the presentation of ADs to patients is
required when the patients are admitted to the services of the home health agency. The
experiences of the investigator provide the knowledge base necessary to answer questions
that may arise during presentation and discussion of ADs and POLST.

Most of the investigator’s work experience has been in rural Northern
California, which provided a unique understanding of local agency services and how the
agencies network together. These agencies included Hospice, various physician’s offices
and clinics, five skilled nursing facilities, several assisted care facilities for the elderly,
three home health agencies, area agencies on aging and senior resource centers.

Once or twice annually over the past ten years a workshop titled “Preparing
for the End of Life” has been coordinated and presented by this project investigator in
churches and community settings. These workshops include an explanation of ADs and
presentations by Hospice and a Funeral Consumers’ Alliance. The project investigator
attended monthly End-of-Life Project meetings in 2009 and currently interacts regularly with many of its members who are all health care providers. This group was one of several around California that contributed feedback toward the finalization of the POLST form for California. The group has since disbanded as the goals were met when the POLST form was finalized.

The project investigator attended a two day seminar in March of 2008 titled “Respecting Choices: Advance Healthcare Planning” presented by Catholic Healthcare West. Respecting Choices is a course for facilitators designed to promote, expedite, and assist individuals and small groups in advance care planning and ADs. The seminar also provided instruction on staff education and the development and management of advance care planning and ADs systems and practices. The purpose of attending the seminar was for the project investigator to augment knowledge and resources related to this project.

Currently the project investigator is a graduate student of CSU Chico, School of Nursing and has completed master’s course work in the areas of nursing research and theory.

Transitional Statements

With ongoing advances in medicine and medical technology, and a population that is increasing in age, the use of ADs and POLST is becoming ever more essential. ADs and POLST promote autonomy in decision making by allowing expression for personal values in end of life care choices. ADs also reduce the burden on family and healthcare providers by making patient wishes known and decreasing health care costs (Salmond & David, 2005).
This study required an initial teaching presentation about ADs and POLST to individuals in the community. These individuals were still capable of making independent adult choices regarding end of life care. The goal of the study was to understand public perceptions of ADs and POLST. Chapter I will cover a more in depth literature review of the topic.
CHAPTER II

LITERATURE REVIEW

Advance Directives and POLST are vital documents that allow clinicians to honor patient treatment wishes during end of life care. The literature review is organized around the following areas: why people may or may not utilize ADs, information pertaining to healthcare provider perspectives, and research on POLST. Much of the POLST research supports the utility of the document by identifying its immediate availability to healthcare providers. A review of the related literature about ethical concerns, palliative care and Hospice has been included to shed light on common end of life care concerns and questions that arise when completing ADs or POLST.

The search strategy for terms and concepts used in this literature review included Boolean phrases relating to DNR, end of life, Advance Directives, POLST and palliative care. The primary data bases accessed were CINAHL and PubMed. In addition the references of the utilized journal articles provided leads to related concepts with relevant information. Seminar presentations also provided useful information.

Usefulness of Advance Directives

ADs have been an important tool to assist patients in defining end of life care wishes. A retrospective study done by Teno, Gruneir, Schwartz, Nanda, and Wetle (2007) examined the role of ADs ten years after the Patient Self-Determination Act of 1991. The
sample was taken from representative data from adult, non-traumatic deaths. The researchers interviewed family members of 1,587 of the decedents between nine and fifteen months after death. The independent variable being studied was whether the decedent had completed ADs. Perceptions of quality of end of life care were measured. Quantitative data strongly supported the need for ADs, revealing that those with ADs were less likely to make use of heroic measures to prolong life and less likely to die in a hospital. Patients with ADs had a 17% chance of having a feeding tube in the last month of life whereas that percentage increased to 27% when no ADs were in place. Decedents who had not completed ADs were more likely to have had family members who had concerns about inadequate physician communication.

In a similar study Degenholtz, Rhee, and Arnold (2004) examined the association between living wills and the place of death. Living wills were explained as being a type of AD. The study, believed to be the first of its kind at that time, represented 1,590,892 community dwelling seniors who did not die suddenly or unexpectedly. The study did not delineate between those who received hospice or home health services or those who may have been recently hospitalized. The researchers found that decedents, including skilled nursing facility clients, who had ADs were less likely to die in a hospital. This implies that the deaths occurred with limited heroic intervention. The authors stressed the importance of physicians discussing preference for location of death with patients during the advance care planning process.

In a study of 106 outpatient psychiatric clients in medical crisis, Srebnik and Russo (2007) found that for those with ADs, the directives were followed 67% of the time. Instructions for medications, pre-emergency interventions, non-hospital alternatives
and personal care issues were followed by health care providers in most of the cases. The instructions for contacting identified surrogate decision makers were followed somewhat less but the overall adherence to instructions of the ADs were consistent. The researchers recommended clients identify surrogate decision makers that can be actively involved during a crisis. Although this was a small study with a narrowly defined subject population, it further emphasizes the need for teaching the public the value of naming an agent.

### Reasons for Underutilization of Advance Directives

Barriers to completing ADs or POLST were discussed by Johnson, Zhao, Newby and Granger (2012) in research that measured patient understanding of the Patient Self Determination Act of 1991 by asking newly admitted patients if they had ADs. The authors found patients younger than 65 and African American patients were less likely to have ADs than older patients and White patients. Alternately, patient understanding of ADs was not a significant factor in completion of the documents. However, their findings did reveal initiating a discussion by nurses about ADs facilitated thoughtful communication between patients and the health care decision makers about end of life care choices.

In a nationally representative survey of ADs for 5,899 residents in 815 nursing facilities Dobalian (2006) studied the independent variables of gender, race, income, education and diagnosis of residents to understand how those variables influenced ADs completion. This was a retrospective study using data collected from the 1996 Agency for Healthcare Research and Quality and the National Center for Health Statistics. The
author defined do-not-resuscitate orders, feeding/medication/other treatment restrictions and living wills, all as ADs. This study found that racial and ethnic minorities and lower-middle income to poverty level households were significantly less likely to have ADs than were whites and those who had incomes above 400% of poverty level. Education level was not found to influence completion of ADs. Given the ten year time span between data and publication of the article, there is a possibility for variation in more current statistics. The author identified a need for further research to clarify whether the reasons for this disparity were a result of inadequate education regarding ADs or differing cultural beliefs and family influences. Dobalian also stressed that most individuals interact with family and friends more than healthcare providers and therefore the family or friends are significant in the decision making process. This highlights the need for public education of end of life care choices.

In reflecting on healthcare providers’ perception of the usefulness of ADs, Bergman-Evans, Kuhnel, McNitt, and Myers (2008) found that healthcare providers understood ADs to be effective in reducing family stress of decedents. The study reviewed completed surveys of 412 respondents or, 63% of the total number of surveys distributed. The survey asked respondents about their perceived usefulness of ADs. The demographic data collected in the survey also included ethnicity, professional background, education, gender and age. No significant differences were found between groups based on profession but the authors did not delineate if other variables affected respondents’ views. Respondents were asked when discussions about ADs should happen. Seventy-five percent indicated that the conversation should take place on the initial admission to a health care facility, but that challenges exist in the process used for
completing and utilizing ADs. The researchers stated that ADs need to be in a check-off format that propels healthcare practitioners to have advance planning discussions with clients. The researchers also stressed that it is unacceptable for clinicians to fail to have this conversation.

Perkins (2007) conducted a literature review that identified common problems encountered in executing ADs. The problems included inaccessibility of the ADs in the event of a crisis, poor understanding by the health care agent of the disease process, or the principal’s choices and physician non-adherence. Perkins discussed a hypothetical but common scenario when a patient with repeated aspiration pneumonia had chosen to forgo heroic measures in the event of a return of his pneumonia. In the scenario a family member revoked the patient’s DNR choice. Even in the best of circumstances, Perkins explained problems of executing the ADs can arise.

Salmond and David (2005) described reasons for patients not having completed ADs included, reports of no prior knowledge, deferring to family for decision making, procrastination and being uncomfortable making decisions about life support treatments. A convenience sample of 80 patients was used in this descriptive correlational study. The sample taken from a single hospital presented a limitation. Although 82% of the participants in the study reported they had received information on ADs, fewer than half understood what they were. Surprisingly, although all participants had received information on ADs on admission to the hospital, a quarter of respondents later reported they had never heard of ADs. The researchers suggested that the current strategy of disseminating ADs does not effectively facilitate patient understanding. They also commented that discomfort played a role in postponing completing ADs. This is in
keeping with Mishel’s (1990) Theory of Uncertainty and elucidates the fear people may have with the uncertainty of addressing advance planning for end of life care. The respondents who claimed they had never heard of ADs revealed the importance of informing the public about ADs before the stress of hospitalization minimizes learning potential.

**Physicians Orders for Life Sustaining Treatment (POLST)**

POLST was originally designed to overcome the disadvantages identified by ADs (Hickman, Sabatino, Moss, & Wehrle Nester, 2008). A POLST document is readily recognized by emergency responders and health care professionals. Violation of patient wishes for non-heroic measures can also be avoided with a POLST. Meir and Beresford (2009) explained how POLST can convert patient preferences into portable medical orders that help ensure those preferences are honored and appropriate palliative care is administered. Meir and Beresford provided quotes from informal interviews with health care providers that supported the use of POLST. The authors stressed that POLST should be reviewed periodically and changed if needed, to be congruent with patient values and preferences.

Resnick, Foster, and Hickman (2009) studied POLST use in 1174 nursing homes across the U.S. It was purportedly the first nationally representative study of its kind. This research found that utilization of a POLST program was the most common end of life program among skilled nursing facilities. The researchers also found that facilities providing education to staff members on end of life concerns, such as hospice, pain management and dementia were more likely to participate in an end of life program. The
authors speculated that specialized training for staff in end of life care is more likely to result in increased patient autonomy and improved quality of life during the end of life. The authors also acknowledged that the questions asked during the survey offered a limited number of responses, which may not have been reflective of additional information about end of life programs offered in nursing homes. Despite these limitations, this study identified a growing trend in using POLST.

In one of the first studies of its kind, Schmidt, Hickman, Tolle, & Brooks, (2004) found first responders to a medical crisis were often without directives when it came to honoring end of life care wishes. ADs were often inaccessible and pre-hospital DNR orders did not necessarily accompany patients to the hospital. These documents also do not normally provide instructions about choices for additional heroic measures. POLST was designed not only for the hospital setting but for emergency medical field work as well. Although no document is a perfect solution to identifying patient wishes, POLST has been found to be more effective than ADs and pre-hospital DNR orders (2004). The researchers studied Oregon emergency medical technicians’ (EMT) and paramedics’ attitudes toward the POLST form. The researchers analyzed 558 surveys, (a 55% response rate). Other variables examined were gender, years of experience and educational level. The POLST form was found to influence treatment decisions and change the treatment plans according to patient wishes in 45% of the cases (2004). Most of the changes resulted in limitations of heroic procedures. Findings identified whether or not the POLST was used and the extent to which the document was accurately completed. Although the study represented only a small number of emergency medical responders, the results show POLST is widely used in Oregon and it influenced treatment
decisions. Ninety three percent of respondents agreed the POLST was useful in directing treatment options.

Hickman et al. (2008) also conducted interviews with state emergency medical services and long-term care expert informants. No sample size was identified but presumably every state was included because the authors referred to “an independent legal review of each state’s law to validate [informant’s] responses” (p. 120). The lack of inclusion of sample size presented a limitation to a thorough review of the reported study. The participants in the study were individuals who understood the state laws pertaining to the services they rendered. Hickman et al. reported on the limitations presented by state laws in utilizing POLST. These included identifying surrogate decision makers, witnessing requirements, and medical preconditions of the patients to whom the POLST applied. An example of an identified limitation based on law in twelve states is the requirement to have one or two witnesses for such documents as is needed with the pre-hospital DNR. If the POLST document contained a DNR order, those states would then have to include witness signatures in order for the POLST to be valid. Another identified limitation presented by state law was the requirement for the patient to have a “terminal illness” before he or she could have a POLST. The authors were concerned that the limiting factors presented by some states’ laws significantly curtailed the use of POLST. This study outlined some of the arguments against using POLST in some states. Fortunately, California does not have the same limiting laws. The Teaching ADs in the Community presentation took place in California and presentation of the POLST document was included.
In a retrospective review by Hammes, Rooney, Gundrum, Hickman and Hager (2012) treatments during the last 30 days of life were studied to determine the use and utility of POLST. The results showed treatment wishes of decedents had been honored 96% of the time. In the cases where treatment wishes varied from those identified on the POLST, the authors explained how the health care decision makers had chosen less aggressive treatments for the decedents when they learned aggressive treatment would not alter the natural course of a terminal illness.

Costs and Ethics

Cost of care during end of life was a concern raised by Fonk, Davidoff, Lutzow, Chesley and Mathiowetz (2012). These researchers studied the impact of ADs on the cost of end of life care. The data used came from recipients of a Medicare based plan in Wisconsin. The study found higher costs were accrued during end of life for those of minority status and these patients were also less likely to have ADs. However, they also noted that sicker patients with multiple co-morbidities were more likely to have ADs in place. The researchers called into question the validity of ADs as a cost saving measure and suggested further research to identify the influences of social and economic status on ADs.

Although dated, the following study was included because it provides useful information for clinicians for discussing end of life care with patients. Calam and Andrew (2000) reviewed 103 patient charts in a study of prognosis-after-resuscitation (PAR). The researchers found that 40% of the patients were unlikely to survive to discharge if CPR was initiated. This figure was based on patients’ PAR scores. PAR score was determined
by the presence of one or more of the following factors: metastatic cancer, sepsis, dependent functional status, non-metastatic cancer, pneumonia, and age greater than seventy. Admission with a myocardial infarction has a small positive effect on survivability to discharge. Cognitive level of patients and DNR status were also compared. The researchers explained how obtaining a PAR score could assist physicians in discussing end of life care choices with patients.

Lazaruk (2006) called into question the use of CPR and other heroic measures on frail, elderly patients. The author used a case example and her own experience as a member of a cardiac arrest team to advocate for the use of evidence-base-practice when determining if CPR is appropriate. Lazaruk stated,

We are not thinking about the future and the quality of life left to [patients] . . .. In many cases by performing CPR, [when evidence indicates it will be futile] we are actually causing significant harm to these patients and bringing about a lesser quality of life. (pp. 22, 24)

Lazaruk’s (2006) assertion that CPR may cause more harm than good is supported by Storch (2006) who states that performing CPR when technology does not fit medical and human need is moral negligence. Storch (2006) stated “Using any type of technology inappropriately means that something else that could be beneficial cannot be used” (p. 24). The author stressed nurses should advocate for the interests of all their patients and help them find appropriate care. This included providing palliative care or referrals to Hospice in end of life situations.

Johnson and Romanello (2005) explained how the silent generation (born 1925-1942) may have difficulty adjusting to technological advances. While the authors were referring primarily to nursing faculty in this age group, this statement may apply to
the general population. Patients in this age group are often overwhelmed by technological advances. Coustasse et al. (2008) described the dilemmas of modern life sustaining treatments and technology. Modern treatment options for life sustaining care are sometimes chosen because they exist. Some of these life-sustaining options can prolong suffering rather than provide compassionate care. These treatment options are a part of traditional modern medicine and conform to standard practice. People in the silent generation may choose such options for themselves or their loved ones because of an emphasis on tradition and conformity.

In a reflective piece, Davey (2001) discussed CPR and non-malfeasance explaining that treatments resulting in harm should only be taken if they achieve a “greater good” for the patient (p. 261). Many nurses were concerned about the injuries caused by CPR performed on frail, elderly victims. These injuries included broken ribs and sternum, collapsed lung, ruptured pericardial sac, skin burns and permanent brain damage from hypoxia (2001). The author expressed concern that there were perhaps too few patients choosing DNR or that the DNR decisions came too late.

Although dated, the following two research articles were included because of the frequency to which they were referenced by other researchers cited in this review and the quintessential statements that are relevant to this study. Hilberman, Kutner, Parsons, and Murphy (1997) reflected on the ethics of two cases. They explained how stress in a medical crisis prevented patients from making reasonable choices for declining or accepting CPR. The authors concluded that CPR is “not an appropriate response to death which occurs as a consequence of advanced age or illness” (p. 361). This is a sentiment shared by Marik and Craft (1997) who stated CPR on critically ill patients may restore
cardiac function but it prolongs the dying process. In this retrospective study, the researchers concluded that the 13% of patients who survived CPR and also survived until discharge were previously healthy patients without end stage conditions. They stated a belief that it is inappropriate and in poor medical judgment to attempt CPR on patients with terminal illnesses.

Patient and family perspectives of CPR and DNR were explored by Eliott and Olver (2008). In this qualitative study, the researchers interviewed 28 cancer patients in the final phase of their illness and likely to die within three months. Half of the patients had family members present during the interview. The researchers described how a common assumption of the choice between DNR and CPR is a choice between life and death and how this assumption causes ethical dilemmas for patients and family members. Eliott and Olver stressed using non-malfeasance and beneficence principles to ensure clinicians have knowledge of the choices presented and thus be able to minimize the moral dilemmas patients face. The authors also emphasized the need for teaching patients in the advance stages of cancer about the limitations of CPR and that there are other ways to show patients their lives have value and meaning.

Coustasse (2008) examined cost of end of life care in continuous renal replacement (CRRT) therapy. Of the 117 patients who underwent CRRT in the study, 71.8% expired in the hospital. The study also revealed that patients 65 years and older had a higher probability of not surviving if CRRT was used. This study was included here because CRRT is considered a heroic measure, particularly in light of end of life care. Contemplation of heroic measures is part of the process when individuals complete ADs or POLST. Coustasse expressed concern for the limited ethical consideration during end
of life in light of the additional human and material burden of CRRT. Cost of heroic measures is another factor that may be an ethical concern.

Payne, Laporte, Deber and Coyte (2007) analyzed research on severity of illness and morbidity in relation to health care expenditures on an aging population. They noted that morbidity appeared to have been reduced in all ages. Health care costs for patients further from death rose but costs near the time of death remained stable. The authors suggested more research is needed to explore the relationship between morbidity and health care expenditures. They also noted that “decision makers may wish to ensure that the costs of these services are justified by improvements in future life expectancy, quality of life, and/or future system costs” (2007, p. 250).

Palliative Care and Hospice

Palliative care is a growing specialty in health care. The focus of palliative care is to reduce the severity of symptoms of an illness rather than to provide a cure. In palliative care, symptom management becomes the focus rather than intent to prolong life (Haydar, Lowe, Kahveci, Weatherford, & Finucane, 2004). These researchers studied the correlation between DNR orders, congestive heart failure, and dementia in a review of medical records of 142 patients. Although the intent of treatment was to palliate disease rather than lengthen life, the authors noted that symptom management at times prolonged life. The example used was high-volume diuresis for patients with congestive heart failure. This treatment ameliorated respiratory distress but also resulted in patients living longer. The authors stressed that clinicians need to be sensitive to patient clinical needs
during end of life care. Teaching about ADs in the community should include explanation of the differences and similarities between compassionate care and heroic measures.

Hospice is recognized for expertise in palliative care. The team approach used by Hospice focuses on helping patients to be comfortable by addressing issues causing physical or emotional pain and suffering (National Hospice and Palliative Care Organization, 2007).

The following qualitative study by Braun and Zir (2001) although dated, was included because of the unique insight provided about socio-emotional and spiritual concerns being addressed in ADs. The researchers identified descriptive themes from end of life discussions in church related focus groups. These themes were based on what participants defined as a good death. These included not having the end of life artificially prolonged, a minimum of pain and suffering, having family close by, conflict resolution involving forgiveness and saying goodbye, and addressing the spiritual concerns of the dying individual. The spiritual concerns varied according to the person’s belief system but desire for blessings or religious rituals at the end of life were common themes that arose. The researchers found that church communities had an impact on improving end of life care and that education of clergy was an important step in guiding congregations. The authors listed five roles a church should take to help congregants prepare for a good death: counseling or classes, facilitation of conflict resolution, clarifying church theology, administration of appropriate rituals, and providing outreach to those facing death.

Sensitivity to human spiritual concerns during the end of life is an aspect of health care often provided by experienced clinicians. As a physician, Byok (2007) has
written and spoken extensively about the ethics of end of life care and advocated for greater compassion and use of Hospice and palliative care. He stated:

The confrontation with death lays bare the spiritual core of the human condition. Human spirituality arises in response to the awe-inspiring and terrifying mystery of life and the universe. We reflexively seek to make meaning of our experience in the world and make or strengthen our connections to others. (p. 437)

Substantiation of the Need for the Study

Recent attention in the mainstream press has also focused on the concerns of end of life care and the related legal issues. The Chicago Tribune addressed ADs in an article by Graham (2010). This report showed variation in expert opinions. One expert stressed the need to move away from a legal model of ADs and toward a social model that facilitates conversations about values and another supported the legal model as a starting point for conversations. In a summary opinion the author stated medical experts should be teaching doctors how to have ADs conversations with patients that allow doctors to honor patient wishes (2010).

In a Newsweek article, Raymond (2007) delineated what the caregiver needs to do in order to be effective in his/her role. The author addressed ADs, the health care power of attorney document, finances, housing, appropriate level of care and family dynamics. She also stressed the importance of talking about spiritual beliefs.

Carefully defined guidelines of a loved one who may need end of life care help family and caregivers understand his or her wishes. The process of filling out AD forms helps an individual to initiate a conversation with family and caregivers on the topics of end of life that many find uncomfortable such as cost of care, and CPR versus natural death. In studying the patient’s perspective Davison (2006) determined that
patients with end stage renal disease required more information and an earlier introduction to ADs with information tailored to the individual patient. Family involvement was integral for most patients.

The themes of dignity, spirituality, and family relations in ADs are consistent with this writer’s own experiences with clients of diverse cultures. Rather than assuming low completion rates of ADs are due to lack of perceived utility, it is the educational approach in some instances that may be deficient. Hammes and Briggs (2007) promoted the education of health care practitioners in the area of advance care planning. Their book, *Respecting Choices*, outlines effective educational strategies for healthcare providers to use on clientele. The authors explain how respecting individual rights to self-determination entails more than understanding goals, choices and the reasons for the choices. Nurses need to help patients understand risks and benefits of interventions, the right to refuse treatments and available alternatives.

. . . an important part of the advance care planning discussion can create an environment of shared decision making between the patient, family and health professional. If initiated early, while patients are capable, these conversations can provide needed information . . .. (Hammes & Briggs, 2007, p.1.8)

**Transitional Statements**

Documenting choices for end of life care is imperative for facilitating patient autonomy. A wealth of information on ADs and related information is available to the public and yet the completion of ADs remains low. The financial and emotional burden of heroic measures is another concern individuals may want to consider when completing ADs. Patients in critical care settings without ADs present a treatment conundrum to healthcare providers in the event of a life-threatening crisis. Even though ADs use is up
to 71% for community dwelling elders, concerns remain regarding how we as a society care for our frail, older, dying persons. ADs or POLST and previous identification of power of attorney for health care decisions would help alleviate these ethical quandaries.

This literature review demonstrated a need for an improvement in the way ADs and POLST are presented to the public. Socio-emotional and spiritual concerns must also be included in advance planning for end of life care. For many individuals, faith communities play an active role in end of life care. Churches and clergy can help overcome some of the barriers to completing ADs by providing knowledgeable discourse and information about available resources. Although some people may never be able to overcome the initial hesitation for advance planning for end of life, an improved effort to educate the public, including patients, healthcare providers, and clergy about POLST and ADs may help an increased number of people to directly confront the uncertainty of their own future. The next chapter will explain the research methodology and how participants were contacted and interviewed after participating in the community education presentation: Advance Directives for Health Care, POLST and understanding end of life care.
CHAPTER III

RESEARCH METHODOLOGY

Advance directives for health care (ADs) and Physician Orders for Life Sustaining Treatment (POLST), are a small but important portion of the process of advanced care planning for end of life care. This study explored individual responses to completing or not completing ADs and/or POLST after participants attended a community education presentation on the topic. Completing ADs or POLST enables individuals to explore difficult concepts in end of life care and accept or decline potential treatments during end of life. The purpose of the study was to gather data from participant statements and after analysis, gain an understanding of participant experiences.

This was a qualitative descriptive study. Sandelowski (2000) explained how qualitative descriptive studies present information in everyday language. Researchers stay close to the information retrieved from participants and use less interpretation and more interpretive description. This means a small number of participants enable an investigator to clarify meaning and analyze the spoken words obtained from participants without expanding on interpretation. In this study, the data analyzed were the spoken words of 17 participants. During the community education presentation participants were introduced to ADs and POLST and the history and utility of the documents. Heroic measures outlined in the POLST document were also described.
After the presentation, telephone calls to participants were used to determine how the new information was utilized and/or shared. Reasons for not completing ADs or POLST were identified. These calls also provided an opportunity for participants to further explore concerns and the nature of ADs or POLST.

Theoretical Underpinnings

Mishel’s (1990) Uncertainty in Illness Theory provided a theoretical underpinning for this study. Chronic illness and end of life concerns have the potential to disrupt a person’s sense of control. Traditional orientation toward stability and adaptation does not allow for the conceptualization of growth and change in uncertain circumstances (1990). Among her assertions, Mishel explained that uncertainty can prompt coping efforts with the intent of reducing the uncertainty and the accompanying emotional discomfort. Long term uncertainty can result in personal growth. As uncertainty endures, an individual can move from the negative experience of “loss of control” to a new perspective and uncertainty is accepted as a natural part of the rhythm of life (1990, p. 260). Findings from this study will be viewed in part from the context of Mishel’s Uncertainty in Illness Theory.

Sample Access

The target population included individuals from the public in a rural Northern California county. Participants who attended the community education presentation on ADs were recruited using a flyer distributed via means of an open invitational announcement posted in a monthly church newsletter and to a women’s group that
communicated the announcement to each other via email (Appendix A). The presentation is described in Appendices B, C, and D.

Sampling Process

The sample for this study came from the 23 participants who attended the community education presentations. Purposeful sampling was used. Sandelowski (2000) explained how the goal of purposeful sampling is to obtain cases that provide rich, in depth information. Adequate sample size is determined when there is enough data to provide insight into a phenomenon (Burns & Grove, 2005). In this study the phenomena were the reported experiences of the participants relating to ADs. The data came from participants who responded to follow-up telephone calls after the presentation. Not all who participated in the ADs educational presentation were available for follow-up telephone calls so the sample size diminished from the original number attending the presentations. At least two attempts were made by the investigator to contact each ADs workshop participant. Messages were left if possible. The final responding participant group size was 17 who agreed to the interview. The other ADs workshop participants did not respond.

The telephone interviews transpired between two months and six months after the workshop. Initially with each telephone call, the investigator introduced herself and explained the purpose of the call then asked permission to record the conversation. The stated purpose of the telephone call was to discover participant experiences with ADs and/or POLST. The participants were informed some of the statements would be utilized to further understand new revelations or barriers regarding the topic and that this call was
part of the process for fulfilling research requirements. Participants were also informed some of the quotes they provided could be used in publications or conference presentations or for a thesis. When permission was granted by the participant to record the telephone conversation, the investigator began the recording using a digital phone recording device. The question used to initiate the conversation with participants was: After attending the presentation in June, did that initiate conversations for you with others about Advance Directives or POLST?

Sample Characteristics

Participants were from a church and a senior women’s group. The church group represented 13 men and women aged approximately 45 to 65. All of the individuals in this group identified themselves as white or Caucasian. The number of participants in the senior women’s group was ten individuals aged 67 to 90. The racial/ethnic profile of this group included eight people who identified themselves as white, and one person who identified herself as [Hoopa] Indian. One individual declined to state her race or ethnic identity.

Ethical Considerations and Human Subjects Protection

Before proceeding with this study the investigator sought institutional approval from the CSU, Chico Human Subjects in Research Committee (HSRC). The basic principles of research, beneficence and autonomy, are required for any research involving human subjects (Speziale & Carpenter 2007). In supporting the principle of autonomy participation was voluntary and the investigator offered the respondents an
opportunity to decline participating in the conversation at any time if they felt uncomfortable or distressed by the topic. In supporting the principle of beneficence participants were informed there was no direct benefit to them but there was potential benefit to people like them in the future.

After obtaining permission from the participant to record the conversation, the investigator explained that confidentiality would be maintained and no identifying information would be used in the written description of the study. Recording proceeded only after participants verbally consented to be recorded.

Data obtained for this study including the recorded conversations, transcriptions and any identifying information such as telephone numbers collected from participants will be stored for five years in a secure locked location, accessible only to the investigator and the investigator’s committee on request. Individual statements will also be available to the participants in accordance with the United States Department of Health and Human Services (2006). After five years, the data from this study will be destroyed by means of shredding.

Data Collection

Data collection in qualitative research utilizes the field as the setting. The field is the natural arena where individuals live and where the research takes place and participants are the decision makers regarding what information is revealed to the researcher (Speziale & Carpenter, 2007). A telephone conversation between the investigator and the participant in the participant’s home (the natural setting) was utilized for data collection in this study. The investigator was not in control of the setting (the
participant’s home) and the participant was the one who guided the conversation after the initial question. This type of data collection technique was a minimally structured open-ended individual interview (Sandelowski, 2000).

A digital voice telephone recorder was used to record the conversations initiated by the investigator, who also transcribed them. Throughout the transcription document the investigator’s statements are prefaced with “I” for investigator and the participant’s responses are prefaced with “P.” The conversations were transcribed in the order they were recorded. Each respondent’s conversation was given initials (unrelated to the participant’s initials) for ease of tracking the statements and to maintain anonymity. The normal silent pauses and vocalized pauses that people made in the conversations were left out to facilitate ease of reading. Personal names as well as colloquialisms have been removed for the purpose of confidentiality and brevity. The investigator’s first question was written at the beginning of the first conversation, but thereafter, each transcribed conversation began with “First question.”

Data Analysis

The statements utilized for data in this study were made by each participant about ADs using his or her own everyday language. The analysis was both reflective and interactive. The interviews with the investigator allowed participants to state opinions, ask questions and describe personal experiences with ADs. Sandelowski (2000) described this as a dynamic process where data collection occurs simultaneously with data analysis. The collection and analysis shape each other.
This study used the first five steps outlined by Barroso (2010) to move from participant descriptions to themes. These steps are described below:

1. Thorough reading and sensitive presence with the entire transcription of the participant’s description.
2. Identification of shifts in participant thought, resulting in division of the transcription into thought segments.
3. Specification of the significant phrases in each thought segment, using the participant’s words.
4. Distillation of each significant phrase to express the central meaning of the segment in the researcher’s words.
5. Grouping together of segments that contain similar central meanings for each participant. (p. 105)

The investigator followed the steps outlined by Barroso (2010) by first listening to each participant’s statements from the telephone conversations three to four times during transcription. The transcriptions were later reviewed with the assistance of the thesis committee. Prior to moving forward with data analysis and many times during the analysis process the investigator solicited feedback from the thesis committee to ensure the process was consistent and correct as indicated by a member of the thesis committee who is an expert on qualitative analysis.

Transcription statements were first isolated into thought segments. These were isolated comments that defined single ideas. The thought segments were studied to identify central meanings. These were further organized into clusters of similar ideas or theme categories so the central meanings could be explained (Barroso, 2010).

Sandelowski (2000) explained how qualitative description uses participant statements with low inference. Low inference implies the reported statements are authentic even though different researchers may emphasize different statements. The recorded statements utilized by the investigator were not changed in any way. The descriptions of
the statements were not abstract. Rather, the investigator was charged with knowing the facts of the phenomenon in this study and ADs and how they were utilized by health care personnel and the public. Analysis of data (participant statements) allowed for a description of patterns in an effort to understand the data.

Process to Establish Rigor

Rigor is the process of establishing trustworthiness. The terms defined by Lincoln and Guba (1985) to establish trustworthiness are credibility, transferability, dependability, and confirmability (p. 219).

Lincoln and Guba (1985) described two steps for establishing credibility: first the inquiry should be carried out in a way in which the findings can be considered probable and secondly the findings should be credible or believable to the participants (p. 296). The digital voice recordings of the interviews for this study can be accessed to ascertain the accuracy of transcription of participant statements. Speziale and Carpenter (2007) state: “The goal of rigor in qualitative research is to accurately represent study participants’ experiences” (p. 49).

After themes were developed four participants were selected to be called a second time. This process is called member checking (Lincoln & Guba, 1985). Due to the sensitive nature of ADs for some participants, not all participants were called a second time. These specific four were selected because the investigator was very sure they would be willing to discuss the subject again. Three answered the phone calls. These three participants were able to recognize and confirm their experiences described by the
investigator by verifying the accuracy of their recorded statements and the authenticity of the investigator’s analysis. The findings were credible or believable to the participants.

Transferability can be described as applicability. According to Lincoln and Guba (1985), generalizations found from a naturalistic study are applicable to the population from which the sample was obtained (p. 297). Speziale and Carpenter (2007) state: “Transferability refers to the probability that the study findings have meaning to others in similar situations” (p. 49). The findings of this study could be applied to a population in a similar rural area in which this study was conducted.

Once credibility is established, the study can be considered dependable (Speziale & Carpenter, 2007). Dependability relies on prolonged engagement with the participants, persistent observation and peer debriefing (Lincoln & Guba, 1985). Fairness in representation and establishing an audit trail was the concern of the investigator of this study in an effort to establish dependability. Digital voice recordings of the interviews for this study can be accessed to ascertain participant statement accuracy. Peer debriefing is the process whereby enough information is provided to establish an audit trail so another researcher conducting a similar study would reach similar conclusions (Speziale & Carpenter, 2007). Additionally, peer debriefing for this study occurred through the review of the findings by the investigator’s thesis committee.

Confirmability is the investigator’s objective analysis and auditing of the data (Lincoln & Guba, 1985, p. 219). The audit trail as described by Lincoln and Guba included: 1) raw data, 2) data reduction and analysis, 3) data reconstruction and synthesis, 4) process notes, and 5) materials relating to intentions (p. 319). For this study, the raw data were the digital voice recordings of the interviews. The reduction and analysis
included organizing participant statements into thought segments. The reconstruction and synthesis was the process of separating the thought segments into themes and the process notes were the steps that established credibility and dependability in member checking. Step 5, materials relating to intentions, is reflected in the project proposal. Adherence to these five steps established confirmability for this study.

Transitional Statement

In summary, Chapter III described how the qualitative descriptive process was utilized for data analysis in this study. This chapter also described how the sample was obtained, how data collection occurred, how the human subjects were protected from harm, and how credibility, transferability, dependability, and confirmability were established. In Chapter IV, the findings of the study will be presented.
CHAPTER IV

STUDY FINDINGS

The purpose of the study was to explore participant understanding of Advance Directives for health care (ADs) and Physician Orders for Life Sustaining Treatment (POLST). Participants reflected on their understanding and involvement with ADs and POLST. The responses of the participants varied. Each reported experience regarding completing or not completing ADs and/or POLST was shaped by participant background, culture and prior experience with end of life care. Four themes were identified based on defining statements made by respondents: Communicating Choices, Rationalizing Indecision, Clarifying a Difficult Topic, and Increased Confidence.

Communicating Choices

Finalizing ADs involves completing three tasks associated with the document. The first task is to explore and define personal choices regarding life-sustaining or life-prolonging measures. This process enables individuals to have conversations with loved ones regarding these choices and to make sure the choices are communicated and documented in the ADs. Secondly, the document needs to be legalized. This can be done by having two witnesses sign in acknowledgement of the principal’s signature, or a notary public or attorney can provide authentication. The third task in finalizing ADs is to make sure loved ones and healthcare providers have a copy. In the instance of a POLST,
a doctor’s signature is required and the original document is retained with the patient. These three tasks or steps are all part of the process that allows for effective communication between the individual, the family and the healthcare providers regarding end of life care choices.

Respondents (not identified by their actual initials) were able to verbalize updating their ADs or making sure family and healthcare providers had access to the documents. As stated by this respondent:

*Let’s see, I already had an advance directive, but . . . it made me be more aware of the importance and to be sure that it is updated periodically. And, the POLST, I had that in place too but after going through my experience with my good friend . . . . I looked at mine, and I made sure my doctors had a copy and [the local] hospital has a copy.* (MF)

Accessibility to ADs (such as the POLST) by emergency response personnel also became clear to the same respondent:

*I’ve had an advance directive for years. What I wasn’t totally aware of, is the importance of having it really accessible.* (MF)

Many respondents reflected on how completing ADs enabled them to communicate personal choices with loved ones regarding end of life treatment. The most common statements of this nature involved conversations with significant others:

*My husband and I were able to do it right away after your presentation.* (CF)

*It prompted me to get mine started so that I can have that same projection that my husband has.* (CE)

*I talked to my wife and I talked to my father about it and it gave me a chance to get him involved and subsequently he had his POLST filled out.* (EB)

*I talked about the content and what our wishes would be. We talked with our families and [discussed] our philosophies and so forth, about it and how valuable it is and how important it is.* (LW)
Another respondent also recognized the importance of review:

... but then we realized that it was a good idea to take it out and look it over and go over it. It was kind of a refresher course and that was good. (CE)

The following respondent’s statement indicated a desire to spare family members from the hardship of difficult choices by having completed ADs:

I talked to my daughter... and we spent at least the whole morning... going over my papers... And that got me to finally get my doctor to sign it... and so I just feel so much better about having these in order because I’ve seen what happens. And you did a wonderful warning about how confused it can be for emergency people and so on, to deal with the situation without any kind of directives... you take it for granted that it is going to be hard to talk about it. But you still need to talk about it. (AS)

Although she was not facing a terminal illness, the previous respondent recognized the importance of being prepared for such an event. Her statement reflected a desire to have her daughter as well as her doctor involved in the discussion. She verbalized the difficulty of discussing end of life care but also sought to spare her loved ones from unnecessary hardships by having completed ADs.

The following participant’s statement was similar in nature and also indicated a desire to spare family members from the hardship of difficult choices by sharing personal choices of limited heroic measures at the end of life:

I mainly discussed... the reasons for not having extended facilities turned on so that we would just be laying there without any hope of recovery and keeping family less disturbed about all of it. I think it’s a good thing to have all the extra life supports not working on somebody that’s facing their mortality. (CE)

Completing ADs provided an opportunity for some respondents to have conversations they may not have had otherwise:

I’ve been married for 30 years and I thought I would know his answers but was surprised that he [my husband] answered differently than I thought he would. (CF)
From a personal point of view it inspired me to talk to my wife about it. And have that conversation with her in depth . . . [about] end of life issues, advance directives, other kinds of end of life issues. (EB)

Participants were able to articulate the importance of communicating choices in their ADs. Topics that were discussed included the importance of communicating choices with family members, the importance of reviewing and updating ADs, how the intent of ADs was to spare family members from hard choices including the choice for no heroism, and the importance of making sure health care personnel had copies.

Rationalizing Indecision

Reasons expressed by respondents for not completing ADs after the presentation were varied. Only four respondents expressed reasons for not completing ADs. One simply deferred the task because of a habit of procrastinating:

I am a horrible procrastinator. It’s like yes, I’m going to do it, I’m going to do it and then I forget to do it for a long, long time. So I have not completed it yet. (CH)

Due to the difficult nature of the conversation about end of life care, some respondents reflected on indecision because loved ones lived too far away, preventing face to face conversations and the completion of ADs:

It’s really hard for me in a phone conversation from three-thousand miles away to be telling her what she should or should not be doing. I’m so torn because I feel like I should be there with her, I’m her eldest daughter but I’m not in a financial position to be there. (FD)

[My wife] lives six hours away and when we can get together that is not one of the things that come up. (CH)

One respondent was able to fill out the ADs form but verbalized inability to complete the process because she was not sure who she should have sign and witness it:
I have to have somebody who’s not a family member. . . . I could have [my friend] do it, I have all these girlfriends who want to do it. (MF)

Discomfort in discussing end of life care was expressed by one respondent:

I just am not in a place to relate to it . . . and [my husband] is absolutely resistant about going there. (FD)

Participant’s rationalization of indecision for completing ADs was expressed in different ways. These included simple procrastination, physical distance from loved ones, uncertainty about how to finalize the document, and personal discomfort about the topic of end of life care.

Clarifying a Difficult Topic

The ADs educational workshop and the follow up telephone calls allowed participants to explore difficult concepts in familiar and comfortable settings. A discussion about ADs also provided an avenue for some people to talk about other related areas of concern such as chronic illnesses, financial planning at the end of life and funeral planning. In some instances, respondents were able to provide guidance to family members who were bewildered or uncomfortable with the topic of end of life care:

. . . when I spoke with my mom on Friday, she sounded like she had a great sense of relief, she sounded like she was glad we were addressing all of this. (FD)

Personal reflections on the difficulties of facing serious illness were well articulated in this statement by one respondent who was able to express confidence in the choices stated in her ADs.

It opened up a general conversation about how to deal with the things that people tend to not want to talk about . . . Psychologically, it made me think about things . . . and allowed me to open things up in my mind, it makes me think about what I would prefer and why and I think it was good to make me know that I can be informed and not just have to take it for granted that people know what I want but
that I can be certain. I can know what I want to do and give other people information about why they may or may not want to do something. It made me feel more confident about the subject... (RW)

The choices indicated in ADs or POLST can also reduce the burden of the disputes by designating a decision maker. The following respondent’s statement was reflective of the awareness that such conflict could arise in his family and how he wanted to ascertain his father’s treatment wishes were honored:

[My wife and I] talked about differences that other family members might have in their attitudes about end of life decisions and about the religious reasons for holding those decisions. It really came home about how important that POLST was and Dad said he would be sure and talk to everybody in the family about it and know what his decisions were. (EB)

Gaining clarity for the difficult topic of ADs was expressed. One participant revealed how addressing the topic with her mother provided a sense of relief. Another articulated how competing ADs helped her gain confidence in sharing personal choices with family and health care personnel. One participant revealed how ADs supported his religious beliefs regarding end of life care.

Increased Confidence

Rather than waiting for an individual to become a patient, ADs can be empowering for those still capable of making these choices. The following participant was able to articulate how hospitalization and emergency care can be overwhelming but how having ADs gave her confidence.

Because sometimes when you go to the hospital, you feel like everybody knows the answers except you. It made me feel more confident, that this is . . . no, this is my body and this is what I want to do and that’s how it is. (RW)
Her statement was reflective of how ADs lend autonomy in decision making during difficult times.

One of the objectives of the initial teaching presentation was for informed participants to engage others in a discussion of ADs. The following statements from participants reveal increased confidence in discussing ADs with non-participants:

_I tell people . . . that is a very good place to start with talking about what people are very uncomfortable talking about. Well, they need to start talking about it somewhere and this is a very good place to start._ (MC)

_I’ve had conversations with several others. The information I got . . . was very helpful._ (LW)

_I feel more equipped now to have that conversation with parishioners . . . I feel a little bit more prepared to do that._ (CH)

_So I’m glad I have a tenant. We keep an eye on each other’s health and she and I have also talked about it and she has some stuff going on. So I did spread the word to her._ (MF)

The following respondent was inspired to take direct action:

_I was able to go over to my neighbors and get them to do it to . . . It turns out they had the forms and they had been planning to do it for years but they just never got around to it. So we were able to do it with them that afternoon and [my husband] and I could be the witnesses for them._ (SB)

Participants were able to express increased confidence in the topic after having completed their own ADs. Five participants described a willingness to discuss ADs or end of life care with people other than family members. One participant further articulated ownership in her personal end of life care choices when communicating these choices to health care personnel.
Transitional Statement

The data collected for this study were statements made by participants during telephone interviews about personal experiences and understanding of ADs and POLST. The statements revealed rich detail in the varied responses. Four themes arose from the data. These were: Communicating Choices, Rationalizing Indecision, Clarifying a Difficult Topic, and Increased Confidence. The next chapter will focus on a discussion of the findings and implication for practice and education.
CHAPTER V

DISCUSSION AND REFLECTION ON

THE FINDINGS

The findings for this study will be presented as themes and discussed in the context of current literature and nursing practice. Themes will also be discussed in light of Mishel’s (1990) Uncertainty in Illness Theory. The themes that emerged in this study were: Communicating choices, Rationalizing indecision, Clarifying a difficult topic, and Increased confidence. The assumption was made in the introduction that dying is a part of life and ADs can assist in advance care planning during the end of life. This is congruent with Mishel’s assertions that chronic illness and end of life concerns have the potential to disrupt a person’s sense of control but that as uncertainty endures, an individual can move from the negative experience of “loss of control” to a new perspective and uncertainty is accepted as a natural part of the rhythm of life (1990, p. 260). Ultimately, ADs are about communication. All four themes in this study address different aspects of communication.

Communicating Choices

In this study, participant perspectives on ADs and POLST were explored. Participants were able to share the importance of communicating choices to loved ones and healthcare providers regarding end of life care through the use of ADs. The literature
that supports the use of ADs is focused primarily on clinician perspectives. Studies by Degenholtz et al. (2004) and Srebnik and Russo (2007) found ADs were likely to be followed and clinician adherence to instructions in ADs was consistent. These studies revealed how ADs helped direct clinicians to support client autonomy and requests for non-heroic measures such as palliative care at home. Hammes and Briggs (2007) explained how discussion about ADs between clinicians and patients created a supportive environment of shared decision-making. Patients were able to make their own decisions based on the information offered by healthcare providers. The cited research and the findings of this thesis study show the importance of communicating choices for end of life care.

Participants in this study who completed ADs or POLST commented on the value of the communication provided by the documents. One participant, after witnessing the suffering of a friend during the end of his life, made it clear her ADs were important to her because she did not want to risk suffering through similar heroic interventions. This perspective is noted in a study of adult, non-traumatic deaths by Teno et al. (2007). Teno et al. noted that patients without ADs were more likely to have had heroic measures such as feeding tubes and ventilators implemented during end of life care. Also, family members of decedents without ADs were more likely to be concerned about inadequate physician communication (Teno et al., 2007). Johnson et al. (2012) noted that patients and families were more capable of having discussions about ADs after a medical crisis when patient conditions were stabilized. They also explained that even when patients chose to not complete ADs, a clinician led discussion with patients and family members about the topic revealed valuable information about end of life wishes. This is consistent
with the results of this thesis study where participants revealed how the discussion with loved ones about end of life care was important to them.

Rationalizing Indecision

Procrastination, physical distance from loved ones, uncertainty about how to finalize ADs and personal discomfort about the topic of end of life were among the reasons described by participants in this study for not completing ADs. These results are very similar to the barriers to completing ADs described by Salmond and David (2005). Salmond and David reported reasons patients did not complete ADs. These included no prior knowledge, deferring to family for decision making, procrastination, and being uncomfortable making decisions about life support treatments. The participants in this thesis study did not report lack of previous knowledge about ADs but three concerns: deferring to family, procrastination, and discomfort with the topic are consistent with Salmond and David’s study.

One of the participants in this study who expressed personal discomfort with the topic of end of life care stated she “was not in a place to relate to it.” This view was reflected in research by Eliott and Olver (2008) who revealed how the choice between CPR and DNR was seen as a choice between life and death for patients rather than a treatment choice with palliative care options. This insight by Eliott and Olver may explain the participant’s response.

Distance from loved ones was another factor limiting completion of ADs for two of the participants in this study. To date no specific research has been identified to provide understanding or solutions to this problem. However, the cultural phenomenon of
deferring to family members to make decisions in a crisis was one of the reasons noted by Salmond and David (2005) for not using ADs. The participant who was not comfortable with the topic of end of life revealed her mother lived across the country. Another noted he lived six hours away from his wife for most of the month. Both of these participants might have responded differently to the question that drove the interviews if they had been living closer to the family members mentioned.

Although some participants in this thesis study were reticent to complete ADs they did express a desire to have communication about the topic with family members. One participant had filled out her ADs but was uncertain about who should witness the document in order to finalize it. Addressing the uncertainty about how to complete ADs is part of the conversation clinicians can have with clients to facilitate completion of ADs. Research reveals gaps in client knowledge can be addressed by their health care providers (Degenholz et al., 2004; Eliott & Olver, 2008; Resnick et al., 2009). Revelation of participant statements of confidence and empowerment in this thesis study could potentially address the discomfort felt by people who resist completing ADs.

Clarifying a Difficult Topic

The literature associated with clarity in ADs primarily supported the use of POLST as an alternate and more effective form of ADs (Hickman et al., 2008). In related research (Meir & Beresford, 2009; Meyers et al., 2004; Schmidt et al., 2004), clinician accessibility and congruence with patient treatment wishes were cited as the primary reasons for implementing POLST. The congruence is important because it indicates patient wishes were honored. This literature supports the findings in this thesis study that
revealed how participants gained a sense of confidence in personal choices defined in ADs or POLST. As previously mentioned, research by Eliott and Olver (2008) explains some of the resistance to completing the documents has to do with a misunderstanding of the difference between CPR and DNR. Both ADs and POLST allow for choices of heroic measures as well as choices for palliative care although POLST is more specific and definitive. Participants in this study shared their decisions with family and health care personnel by using one or both of the documents. One of the participants revealed how the conversation “opened up . . . how to deal with the things that people tend to not want to talk about . . .. I can know what I want to do and give other people information.” This statement is akin to the environment of shared decision-making described by Hammes and Briggs (2007). Hammes and Briggs (2007) explained the importance of including family members and clinicians in end of life care discussions to validate respect for individual rights and self-determination.

Another participant shared how POLST supported personal religious beliefs regarding end of life care. This understanding is supported by Byok (2007) who states terminal illness of a loved one can bring to light the ‘silent’ topic of religious persuasions regarding end of life care treatments. Without the principal’s autonomous decisions indicated in ADs, bitter disagreements between family members can arise about the use or nonuse of heroic measures (2007).

Increased Confidence

Increased confidence was a strong theme that arose during this study. Participants were able to share their ownership in decisions stated in ADs or POLST and
confidence in the necessity of the process of completing the documents. This finding is supported by Hickman et al (2008) and Resnick et al. (2009) who identified a growing trend in patient use of POLST. This may be because POLST clearly and succinctly defines choices for end of life care treatment options.

Some participants in this study revealed how the process of completing ADs or POLST was empowering for them. Others described confidence in how they had completed the documents. Some participants were also able to share their willingness to discuss ADs or end of life care with people other than family members. Jeong, Higgins and McMillan (2009) described how decision making for ADs occurred in an environment that included the social support of the individual as well as family members and clinicians. The external social support was especially important for patients who did not have involved family members (Jeong et al., 2009). One of the participants in this thesis study demonstrated this concept by helping her neighbors complete their ADs.

The sense of confidence and empowerment revealed by the participants in this study involved overcoming the sometimes emotionally difficult task of talking about silent or hidden topics regarding end of life. Ufema (2006) states: “The sharing is intimate and sacred.” (p. 2). She uses the following terms to explain the feelings patients encounter when discussing end of life care and ADs: hope and hopelessness, anger and guilt, fear, and pain. Adults at end of life must confront these feelings compounded by a loss of independence. Part of the process of maintaining independence involves completing ADs.

Clarity in communication about end of life care treatment decisions and a sense of empowerment regarding those decisions supports the use of ADs or POLST.
Participant rationalization for indecision also underscores the importance of having the conversation with individuals and groups in the public sphere. The use of ADs and POLST do not predict outcomes of illnesses but allow individuals to explore the nature of uncertainty regarding end of life care.

Implications for Practice

Communication regarding ADs and POLST was an area identified in this study and the literature as needing more attention by clinicians. When clarification about the topic is needed for a patient, the responses provided by participants in this study could provide examples and inspiration for patients in similar circumstances. For example, participant statements about being confident in their decision making may be appropriate to share when encouraging clients to complete the documents and when having end of life care discussions with family members.

Uncertainty about how to proceed can be addressed with clinician assistance and reference to the utility of the document. Procrastination and pure discomfort with the topic are more difficult to address. One of the barriers for a patient with chronic illness to developing a new, positive orientation toward uncertainty is health care providers who insist on a mechanistic approach to treatment where causes of illness can always be identified and treatments have predictable and desired outcomes (Mishel, 1990). Prolonged uncertainty in this worldview can cause increasing emotional distress. Mishel (1990) explains how nurses can alleviate this distress by helping patients consider alternative choices and possibilities. Promoting uncertainty as a natural part of life also increases acceptance of a variety of possible outcomes of disease and treatment. Attentive
listening is required when nurses and other health care providers discuss ADs with patients. The goal is to honor individual end of life choices. This discussion teaches patients to move from mechanistic thinking to probabilistic thinking, allowing for new ways of thinking and an acceptance of uncertainty.

Nurses and other clinicians can promote the documents by explaining the intent is to honor patient wishes. Perhaps the most important response to hesitancy about the document is to assure patients, regardless of the choices they make, that suffering will be addressed in the most medically appropriate way including transport to the hospital if wanted or needed. Nurses can increase confidence in the use of ADs and POLST by revealing how the documents were empowering to others. For example, a nurse might share some of the participant responses in this study that made definitive statements about how ADs and POLST provided a sense of relief or confidence in the personal choices defined for end of life care.

Implications for Education

The implications of this study for education focus on the public, nursing students and practicing clinicians. Public education regarding ADs and POLST can be addressed in the manner this study began—with community education about the topic. Participant feedback in this study could be used to augment the presentation.

Teaching nursing students about ADs and POLST can follow a similar format. Encouraging students to fill out their own ADs exposes them to some of the same questions their patients may encounter. Gaberson and Oermann (2007) recommend discussions between nursing faculty and students include an exchange of ideas with the
teacher asking open-ended questions. After students complete ADs, teacher led discussions can include questions about what assumptions were held before the completion of ADs and what students found that surprised them about the process or their responses. Although students may not personally value the utility of the document, completing their own ADs provides an opportunity to help them understand patient experiences with ADs. This study’s results about participant procrastination and discomfort can also provide insight for students when teaching patients about ADs or POLST.

Although individuals who work in the health care industry may be familiar with ADs and POLST, this does not preclude their advocating the use of the documents for patients. Experienced nurses are more likely than novice nurses to advocate for patient needs at end of life (Thacker, 2008). Advocacy also includes assisting patients in completing ADs or POLST. The public perspectives presented in this study could be included when teaching new nurses and other clinicians about the topic. This study’s results have the potential of influencing willingness of clinicians to assist patients in filling out the documents.

Implications for Research

The participants in this study represented a small rural community in northern California with a population that was mostly White. Further research in communities with different demographics is needed to explore public experiences with ADs and POLST. Investigations into why individuals in differing communities choose to complete ADs or POLST could assist in tailoring teaching presentations on the topic.
New research could also explore clinician responses to filling out their own ADs and POLST. Where the lay public may not be familiar with the topic, most clinicians have been exposed to the utility of the documents. Despite this assumption, it is not known what influences clinicians to complete their own ADs and what percentage of clinicians have ADs or POLST when compared to the public. The literature search did not reveal research about how clinician knowledge of outcomes from heroic measures influenced rates of completing their own ADs. This is an area of research that could potentially answer the question of clinician completion rates or explore influences that provide inspiration to do so.

Limitations of the Study

This study had the potential to be biased because of the nature of the small community where the study took place. Some of the participants frequented public institutions such as schools, churches, and health care facilities where the investigator also spent time. The responses by participants were potentially influenced by this acquaintance relationship. The open-ended questions asked by the investigator and the effort to establish beneficence and autonomy were designed to limit this bias.

The small community where this study took place had a population that is a majority White. The participants represented a comparable demographic but a more accurate representation of the northern California rural area would also have had five percent of the sample be individuals whose primary ethnicity was Hispanic (US Census Bureau, 2011). The small sample size of 17 in the study also had the potential to limit findings.
Conclusion

This study provided insights from the public about Advance Directives (ADs) and Physician Orders for Life Sustaining Treatment (POLST). The participants were representatives of their rural northern California community. The themes identified revealed both confidence and discomfort with ADs and POLST. The results added to the existing body of research knowledge on the topic. With the understanding that the uncertainty that surrounds the dying process is a part of life, participants were able to explore their experiences with completing ADs or POLST. The results also supported the need for more public presentations on ADs and POLST by recounting barriers to completing the documents but also revealing how participants felt personally empowered by completing their own ADs or POLST.

In the reconceptualization of the Uncertainty in Illness Theory, Mishel (1990) explains how the influences that assist a chronically ill person to form a new orientation toward the disease process are prior life experience, physiological status, social resources and health care providers (p. 260). Probabilistic thinking, where uncertainty is viewed as a natural part of life, allows for personal growth and an environment of trust if the patient’s support system, family, and clinicians operate within this paradigm. Uncertainty can be viewed as opportunity with multiple outcomes arising from a variety of choices. A majority of the participants in this study were able to articulate how they completed their own ADs or POLST or how they assisted a friend or family member in doing so. Their confidence came not from knowing outcomes of future illnesses but in taking ownership in the process of creating a personal support system and honoring uncertainty.
REFERENCES
REFERENCES


Aging Gracefully in an Era of Anxiety

A free three part series by Evelyn Wiebe-Anderson RN
Home Health Nurse and CR Nursing Instructor

Part III:

WHO WILL SPEAK FOR YOU?

Toward the end of our lives, most of us will be in need of someone who can care for us as well as speak for us when we can no longer speak for ourselves. How will you make sure your needs and wishes are met?

Advance Directives for Health Care, POLST and understanding end of life care

Sunday, May 15, 2011
1:30 to 3:00 pm
Church of the Joyful Healer

This workshop is free and open to the public
POWER POINT PRESENTATION OUTLINE

WHO WILL SPEAK FOR YOU?

Aging Gracefully in an Era of Anxiety
Part 3 of the 3 part series

by Evelyn Wiebe-Anderson RN
Home Health Nurse and CR Nursing Instructor

What are Advance Directives for Health Care?

Toward the end of our lives, most of us will be in need of someone who can care for us as well as speak for us when we can no longer speak for ourselves. How will you make sure your needs and wishes are met?

Test your Knowledge (this is completely voluntary)

Why Advance Directives?

Documentation of preferences for end of life care does not give certainty to chronic illness and end of life but can assist individuals and families in finding new perspectives and ownership in the process of decision making during difficult times

Why now?

- Presentation of videos
- Heroic Measures

CPR

- Intubation and mechanical ventilation
- Artificial hydration and nutrition
- Emergency transport

The “D” Words

- Medically confusing terminology: DNR, full code, CPR, life sustaining, etc.
- The D words: death, dying, died…..
- Why is this important?
• Addressing Suffering
• DNR does not mean “Do Not Treat”
• People are often afraid their own or a loved one’s suffering will not be addressed because of the negative terminology.
• The real question is often about the extent of suffering and how pain and distress will be addressed

The Forms

• Advance Directives for Health Care Decisions
• Pre-hospital DNR form, in hospital DNR orders
• POLST (blank forms are available)

Resources

• Social workers in the clinic and hospitals
• Home Health Services
• Hospice
• Senior Resource Center
• Your family
• You
Invitation and Consent to Participate in:

Advance Directives for Health Care, POLST and understanding end of life care

A workshop conducted by Evelyn Wiebe-Anderson

I am a registered nurse and currently a graduate student at CSU Chico. I work as a home health nurse and a nursing instructor.

This community education effort is part of my Master's project. This educational project seeks to educate individuals about advance directives for health care and POLST (Physicians Orders for Life Sustaining Treatment) while individuals are capable of making these choices and before they become ill. The educational workshop takes about one and a half hours.

There is potential for discomfort given the nature of the subject matter regarding end of life concerns and participants are free to leave at any time.

Completing a pre and posttest is requested of participants but completely voluntary. Participants may attend the workshop without taking the pre or posttest. No identifying information is being collected and your participation in taking the pre/posttest is your consent to participate. The tests help to identify strengths and weaknesses of the teaching project.

Objectives of the Project:

- Delineating the difficult concepts with regard to end of life care.
- Defining the differences between Advance Directives (ADs); the pre-hospital, DNR (do not resuscitate) forms and POLST (Physicians Orders for Life Sustaining Treatment).
• Describing when POLST is appropriate.
• Who should have ADs.
• Identifying the end of life care information and resources available.

Should you have question about any of the above please feel free to contact me at any time during the presentation, or if you prefer, contact me by phone: 826-1599 or by email: evnwal@suddenlink.net

Thank you!
Evelyn Wiebe-Anderson
APPENDIX D
A review of the DVD: “POLST at work: Honoring your treatment wishes” used for Teaching ADs in the community.

The DVD begins with healthcare providers’ brief perspectives on POLST as it pertains to end of life care and emergency situations. A physician speaks about the choices that POLST provides and explains how a POLST shows that individuals have thought about what choices are available to them at end of life.

A Hospice nurse’s perspective tells how hard it is for patients to talk about death initially but as their conditions progress there is greater acceptance of the disease process. She explains how the POLST helps facilitate the conversation about dying.

The sections of the POLST are reviewed one by one with narration and filming of the section. Clinicians explain why the choices are provided with further explanation of the options. For example, tube feeding is explained along with what alternatives might also be investigated.

The sections of the POLST are as follows:

1. Cardiopulmonary resuscitation
2. Medical interventions
3. Artificially administered nutrition
4. Signatures and summary of medical condition

One nurse’s comment states, “Comfort measures are never optional.” Clinicians repeatedly stress how the POLST is a document that allows health care providers to honor patient wishes and preserve dignity.

An example vignette of how POLST might work with a patient at home on Hospice services is provided. In this scenario, the patient is cared for by his wife at home. He falls and sustains a hip injury. The narration describes how the wife calls 911 for help. When the EMTs arrive, she shows them the POLST and they transfer the patient with the POLST to the hospital for stabilization. The narration explains the progression of his care and how the POLST document is utilized by all of the health care providers along the way. Eventually the patient returns home and the POLST accompanies him home.

The vignette is an important part of the DVD in teaching about POLST to lay people in the community.

One of the physicians commenting in the DVD explains that many patients have thought about end of life and many doctors have thought about end of life care for
their patients; but only 10% to 15% have actually initiated the conversation about dying and end of life care. He explains the reason for this is that both physicians and patients are waiting for the other party to initiate the conversation. He uses this information to advocate for utilizing POLST.

The DVD: “POLST at work: Honoring your treatment wishes” lasts 11 minutes. It can be viewed at [http://www.youtube.com/watch?v=8-cqZVW7M1M](http://www.youtube.com/watch?v=8-cqZVW7M1M).
Presentation Evaluation

Instructions: Please take a moment to complete this evaluation of the presentation in which you just participated. I want to provide effective teaching and value your opinion. Your comments will be used to make ongoing improvements in the presentation. Please refer to the rating scale provided below. Thank you for your participation.

Date: _________________

Location of presentation: _________________________

Reason for attending: _____________________________________________________

1---------------------------------2--------------------3-------------------4-------------------5
Strongly Disagree           Disagree                Neutral                Agree           Strongly Agree
(circle one)

1. The presentation met its stated objectives. 1 2 3 4 5

2. Overall this presentation met my expectations. 1 2 3 4 5

3. The content was relevant to my life and extended my knowledge. 1 2 3 4 5

4. The method of presentation (group discussions, videos, scenarios) enhanced my learning experience. 1 2 3 4 5

5. The audiovisual materials (posters, PowerPoint slides, case discussions Videos) enhanced the presentation. 1 2 3 4 5

6. The program resource materials (outlines and handouts) were useful. 1 2 3 4 5

7. The environment (room) was conducive to learning. 1 2 3 4 5

8. There were adequate and appropriate physical facilities for the program. 1 2 3 4 5

9. I would recommend this program to people like me. 1 2 3 4 5
10. The presenter presented the material with knowledge and clarity.  1  2  3  4  5

11. The presenter provided adequate and helpful feedback.  1  2  3  4  5

Please use this space to make additional comments:

Were there any specific strengths or weaknesses of the program that you would like to comment on?

(Optional)
If you would like feedback on your comments, please fill out the following:

Name______________________________________

Address ____________________________________

Phone _____________________________________

Signature (required if any action is being requested)

______________________________________

Please submit your comments to the presenter, or if you prefer, you can mail this form to:

Evelyn Wiebe-Anderson
3605 Heindon Road
Arcata, CA 95521

Thank you for your participation!