# USE OF THE 'PHYSICIAN ORDERS FOR LIFE SUSTAINING TREATMENT' FORM IN THE EMERGENCY DEPARTMENT SETTING: THE PROVIDERS' EXPERIENCE

By

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To the Faculty of Washington State University:

The members of the Committee appointed to examine the thesis of ALLISON RICHARDS find it satisfactory and recommend that it be accepted.

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# USE OF THE 'PHYSICIAN ORDERS FOR LIFE SUSTAINING TREATMENT' FORM IN THE EMERGENCY DEPARTMENT SETTING: THE PROVIDERS EXPERIENCE

#### Abstract

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Beginning in the early 1990s, leaders in long-term care and Emergency Medical Services in Oregon recognized a need to better communicate patient preferences about treatment near the end of life. In 1995, an Oregon Health & Science University task force developed a simple onepage form to facilitate clarification of a person's wishes regarding end of life treatment. The single page, double sided form titled Physician Orders for Life Sustaining Treatment (POLST) translates an individual's choices for his or her end of life health care treatment into provider orders and can be honored in all care settings. This qualitative study evaluated the experiences of emergency department providers with the POLST form. Understanding the experiences of providers in the emergency department setting is crucial to understanding ways to improve the use and effectiveness of the POLST form. Imogene King's Interacting Systems Theory was used as the framework for this study. The study sample consisted of five emergency department providers at four hospitals in Oregon and Washington. Data were collected by the researcher through individual interviews which were analyzed for categories and themes. This study found that a major barrier to POLST form compliance was the families of patients who had completed the form. The findings suggest that better education about the POLST form, for both the patients and their families, may improve the successful use of the form.

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## Chapter 1

# Introduction and Background

# Statement of the Problem

The Physician Orders for Life Sustaining Treatment (POLST) form is just over a decade old. Posted in a person's home, stored along with medical information, or carried in a purse or wallet, the POLST form should be given to emergency department (ED) providers or Emergency Medical Technicians (EMT's) when the first contact is made with the patient. POLST forms have been in use in Oregon since 1995 and in Washington since 2001. The POLST form, or a similar variation, is in use in 17 states and in development in several others. It is designated for use in emergency or urgent situations. While there are a small number of studies related to POLST forms in both Oregon and Washington and their adherence rates outside the hospital setting (Teno, Licks, Lynn, Wenger, Connors, & Phillips, 1997; Tilden, et al., 2000; Hickman, et al., 2004; Meyers, Moore, McGrory, Sparr & Ahem, 2004), there are none specific to the problem of treatment matching POLST orders, and none related to the emergency Department setting.

The author's interest in this subject stems from her experience as a hospital staff nurse. In this role, POLST forms were in clients' charts, yet some clients received care that the POLST orders specifically stated was unwanted. In many cases these clients were unable to verbalize their choices. A review of the list of studies related to POLST forms maintained by the Oregon Health & Science University Ethics Task Force at the polst.org website, and a literature search using PROQUEST and CINAHL did not reveal a study related to POLST use in the emergency department setting.

# Statement of the Purpose

Studies reveal that health care professionals may not know about and/or fail to honor advance directives (ADs) (Teno, Licks, Lynn, Wenger, Connors, & Phillips, 1997). Though the POLST form is different from ADs, there may be a similar failure on the part of ED providers, to honor POLST orders that were previously signed by others.

The Association of Washington Public Health Care Districts (2006) urges health care facilities to file the POLST as the first document in a patient's clinical record. The POLST should then be recognized as a set of provider orders to be implemented as any other provider orders would. In a non-institutional setting, such as a person's home, the POLST form should be posted in a prominent location so that emergency personnel can find and follow it.

The goals of this study were to describe factors that influence whether or not health care professionals working in an emergency department setting in Oregon or Washington provide care based on an individual's POLST form and the experiences that health care providers have had with POLST forms in the emergency setting. By understanding the attitudes and experiences of emergency department providers with the POLST form, at multiple locations, strategies for increasing the number of providers who honor the POLST may be developed.

#### Conceptual Framework

The interacting systems theory written by Imogene King (1971, 1981) serves as the framework for this study. King's theory is based on the concept that a person's perceptions of objects, persons, and events influence his or her behavior, social interaction, and health. The theory is composed of three interacting systems: personal systems, interpersonal systems, and social systems. The interpersonal system was the focus of this study, specifically the dyad relationship between provider and client.

The concepts associated with interpersonal systems are interaction, transaction, communication, role and stress. These are important concepts to analyze in relationship to end-of-life care, especially when a client is seeking emergency healthcare from a provider. "An individual's perceptions of self, of body image, of time and space influence the way he or she responds to persons, objects, and events in his or her life. As individuals grow and develop through the life span, experiences with changes in structure and function of their bodies over time influence their perceptions of self" (King, 1981, p. 19).

Based on King's theory, a provider's decisions regarding POLST forms would be directly influenced by one's life experiences. For example, the external stressors involved in emergency care, such as the pressure from the patient's family, may cause a healthcare provider to treat a client with medical interventions despite having a POLST form indicating that they do not want treatment. Individual perceptions and the way that providers respond to events in his or her life may similarly affect their choices about patient care. If a provider has a positive experience with his or her own family member's end of life decision making, then he/she may be more likely to follow the orders on another individual's form. Use of the interacting systems theory would predict that providers will determine what treatment actions to perform on a client based on the provider's prior experiences and personality.

Using the interacting systems theory, the following questions can be asked. What factors influence a providers implementation of the POLST form? What are the provider's views of POLST forms in the emergency setting? Are healthcare providers comfortable with following the POLST form directives? To answer any of these questions, it is first necessary to determine what providers' views regarding POLST are, what their experiences are, and what the providers themselves think are factors involved with POLST form decisions.

# Literature Review

Autonomy and comfort are both important factors in client treatment, especially in cases of terminal illness and end-of-life care. To ensure that these factors are addressed, the Patient Self Determination Act (PSDA) was created out of the Omnibus Budget Reconciliation Act. The PSDA, implemented in 1991, requires all healthcare facilities that receive federal funding to provide persons with written information about their rights to make end of life choices and to document on the patient's chart whether or not the individual chose to make directive choices (Federal Patient Self Determination Act, 1990).

Legally, under the PSDA, providers are required to ensure that the patient's advance directives are met and are not mandated to deliver care that conflicts with the advance directive. Providers are also not required to implement an advanced directive if it is a matter of conscience and State law allows the provider to conscientiously object. If the provider is unable to follow the directives because of personal views, they are required to provide a clear and concise statement of limitation concerning this. If a patient is incapacitated and unable to receive directive information at the time of admission or the start of care, the provider is required to provide information to the patient's family and then to the patient when they are able to receive it (Federal Patient Self Determination Act, 1990).

Beginning in the early 1990s, leaders in long-term care and the Emergency Medical System (EMS) in Oregon recognized a need to better communicate patient preferences about treatment near the end of life. They began meeting and developed a form called the Medical Treatment Cover Sheet which later became known as Physician Orders for Life Sustaining Treatment (POLST). Early on it was piloted in a few small settings around the state. The POLST form became widely available for use in Oregon in 1995. Also in 1995, a taskforce met

at the Center for Ethics in Healthcare at Oregon Health & Science University (OHSU) to address the issue of respecting advance directives during transfer from a nursing facility to a hospital setting. In 1998 a second group, the Regional Ethics Network of Eastern Washington (RENEW), began adaptation and development of the form for use in Washington State. The statewide use of the POLST form in Washington began in 2001. A more recent group, currently named the POLST Paradigm Task Force, is working toward implementing use of the POLST form at the national level. POLST or a form similar to it is now available in 17 states. To avoid confusion between forms in states with differing programs, the term POLST paradigm is used to describe POLST-related programs nationwide. The paradigm has one distinct purpose: to convert an individual's treatment choices into medical orders. An informed consent process based on communication with patients and families provides the basis for use of the form (POLST, 2006; Meyers, et al., 2004). The original OHSU task force developed a simple, onepage double-sided form that clarifies a person's wishes regarding end of life treatment and translates an individual's choices for his or her end-of-life health care treatment into provider orders that can be honored in all settings.

The POLST form is printed on brightly colored cardstock (pink in Oregon and green in Washington) to ensure identification and quick location on the front of a chart or at the individual's home (see figure 1). Although the form is printed in English, written information about the form can be obtained in both English and Spanish (OHSU, 2007). Over the past decade, several states have developed programs similar to POLST (see figure 2), some using a different name. Oregon, Washington, New York, West Virginia, and parts of Pennsylvania and Wisconsin currently have POLST programs that have been endorsed by the National POLST Paradigm Initiative Task Force. Nevada, Utah, Nebraska, Missouri, Michigan, New Hampshire,

Tennessee, North Carolina, Georgia, and Florida have programs currently in development (OHSU Center, 2005).

Despite recent attention to honoring the autonomy of individuals and end-of-life decisions the POLST is not yet available in all states (Werner, Carmel, & Ziedenberg, 2004; Tolle, Rosenfeld, Tilden, & Park, 1999; Tilden, Nelson, Dunn, Donius, and Tolle, 2000). Health care providers do not always honor the POLST which makes it less than 100% effective toward achieving its goal (Tolle, Tilden, Nelson, & Dunn, 1998).

The POLST is an easily accessible and succinct form that is useful when caring for people in emergency situations. It can provide immediate guidance for treatment and is focused on the individual's current health status. POLST provides orders in a brief and well-defined manner. This is in contrast to advance directives that are less focused, can have multiple sections for clients to write their preferences for treatment in very specific situations, and are designed for more long-term use (Hickman, Tolle, Smith & Carley, 2006).

The POLST form is an important advancement when considering changes that have occurred in society during the past century. Life expectancy has increased, more life prolonging technologies are available, family structures have changed, and there is an increased prevalence of chronic disease, increased co-morbidities, and frailty with advancing age. These all add to the complexity of care and the end-of-life decision-making process (The POLST Paradigm Task Force 2006).

As the healthcare system becomes more complex, the POLST form clarifies and can simplify treatment in urgent care situations for both the individual and healthcare providers. Having a valid and correctly completed POLST form allows people to make choices about the treatment their chronic illnesses will require. If an individual does not feel that placement on a

ventilator is desired, he or she should be free to make that decision. Having a POLST form allows the individuals themselves to make these choices in advance of an emergency situation that might render the individual unable to speak for him or herself.

As of 2004, over one million Oregon POLST forms had been distributed, targeted toward individuals who have a high potential for needing life-sustaining treatment decisions (Hickman, et al, 2004). According to the Washington State Medical Association, Washington distributes approximately 60,000 to 80,000 forms each year around the state (G. Short, personal communication, January 30, 2007). In Washington, the POLST form requires a signature from both the individual or legally designated surrogate decision maker and the health care provider. The provider may be a physician, nurse practitioner (NP), or physician's assistant (PA). In Oregon, the form requires the signature of a physician or NP and the client's signature is optional (T. Schmidt, personal communication, February 3, 2007).

Another important issue, related to surrogate decision making, is the changing definitions of what constitutes a family. The United States Census Bureau found in 2005, that more than 32% of households were non-family and only 51% of households are married couples (United States Census Bureau, 2006). The definition of family has evolved from blood relatives or marriage to people personally chosen by the individual (Alpers & Lo, 1999). In the event of conflict between legally defined relatives and the persons that the individual feels are his or her closest family, the POLST form allows for documentation in support of the client's wishes (POLST, 2006).

A focus of the POLST Paradigm task force is the signature process used to activate the POLST. Requiring a provider's signature on the form opens the door for discussion between patient and provider and also honors patient autonomy in health care decisions. Some states do

not require patient/surrogate signature on the POLST form while others only require the patient's signature. States also have varying laws regarding surrogates and their decision making authority. The POLST Paradigm Task Force is attempting to standardize the requirements at a national level and to achieve recognition and reciprocity of the form among states (POLST, 2006).

The front side of the form is used to document patient/provider signatures and decisions about the four key areas of medical management that the POLST covers. These are (a) resuscitation status, (b) medical interventions and transfer to a hospital, (c)antibiotic use, and, (d) short-term and long term options for artificial nutrition (Tilden, et al., 2000). The back side of the form has areas to provide documentation for persons involved in the POLST decision making process, supporting evidence for treatment choices from an individual's ADs, and space to document periodic review and update of the form (see figure 1).

There is a large body of literature published on advance directives and end-of-life treatment. The current literature that is available specifically on the POLST form is limited due to the short length of time that the POLST has been in use and the small percentage of states that use a POLST or POLST-type program.

There is qualitative research available about healthcare workers' attitudes toward end of life treatment. Hinkka, Kosunen, Metsanoja, Lammi, and Kellokumpu-Lehtinen (2002) studied 1182 health care providers using a terminal cancer patient scenario with alternatives to evaluate their readiness to withdraw or withhold treatment options. The researchers found that personal experience and training, life values, and attitudes toward terminal care markedly influence decision making in end-of-life situations. Werner, Carmel, and Ziedenberg (2004) found that nurses are more supportive of artificial nutrition at a person's end-of-life but are less willing to

use mechanical ventilation or CPR. In the qualitative study by Hinnka and colleagues (2002), it was stated that the presence of an Advance Directive caused physicians to be more likely to withhold treatment. This study, however, was conducted by providing the physician with a hypothetical situation and then analyzing responses to questions about it. It is not clear that these responses may be extrapolated and to know whether or not the real-life responses of the physicians would be similar.

Fried, Bradley, and Towle (2002) found that provider-patient communication is essential to what they termed a "good death" experience. Identifying and honoring patients' preferences is an essential component of quality end-of-life care. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) investigators (1995) found that physicians are largely unaware of end-of-life wishes even when clients have made their wishes known through advance directives. In this study of 638 seriously ill clients, only 25% had primary care physicians aware of their end-of-life wishes. During the course of this study the researchers documented deficits with the use of advance directives. A do-not-resuscitate (DNR) order was not written in about 50% of cases where the patient did not wish to be resuscitated. Only 23% of seriously ill and 11% of terminally ill patients even spoke with their provider about CPR wishes. The POLST form's signature requirements help to facilitate patient-provider communication and also increase application of individuals' preferences. Hawkins, Ditto, Danks, and Smucker (2005) found that health care surrogates were not proficient in predicting individuals' specific wishes for medical treatment and individuals needed more flexibility in conveying their preferences to others.

Rodriguez and Young (2005) developed four end-of-life care goals: extending the length of life, improving the quality of life, maintaining or improving specific biological functions, and

assisting the body for a temporary period of time. They found that the majority of clients did not wish to have life extended without hope of recovery but did want assistance for a short period of time if recovery was certain. Resnick and Andrews (2002) discovered that half of their study's subjects did not want any life sustaining treatment and were more likely to use measures to facilitate comfort than those that prolong life. Having a POLST in the individual's home or medical chart communicates his/her personal wishes in a clear, succinct manner. Further, the POLST can be updated with less complication and more frequency than the traditional directive because it consists of only a single page of specific orders.

Research has also shown the positive correlation between POLST forms and the management of clients using their own treatment choices. According to Tilden, Nelson, Dunn, Donius, & Tolle (2000) the POLST form can encourage respect for client preferences for end-of-life care ensuring a high quality of comfort care and non-abandonment of the client as he or she changes goals of treatment to palliative care from extension of life. The POLST form may play a positive role in the prevention of unwanted aggressive treatment at the end of life in the home and hospital setting, preventing providers from performing undesired life sustaining measures.

Studies have shown positive results with use of POLST in nursing homes in Oregon. Hickman and colleagues (2004) found that the majority of individuals with cardiopulmonaryspecific orders such as do not resuscitate (DNR) requested some other form of life-extending treatment, including treatment with antibiotics and artificial nutrition. The study also concluded that the POLST form was widely used in Oregon at nursing homes and had increased over the previous decade. There were 356 nursing home residents all older than age 65 evaluated in this study and the oldest old (age greater than 85 years) were more likely than the young old (age 65-74) to have orders on the POLST limiting the treatment in all four categories. Follow up studies

of POLST use in nursing homes in Washington State are currently underway (J.L. Meyers, personal communication, February 1, 2007).

Ninety percent of Americans say they want to die at home, but the SUPPORT studies found that four out of five die in a hospital or other healthcare facility (as cited in Garas, 2001; Teno et al., 1997). Oregon long term nursing facilities have a high rate of advance planning; 91% of nursing facility residents having DNR orders on their advance directive or POLST form. There is a section on the POLST form where the individual can designate when to be transferred to a hospital facility. During a statewide one year prospective study of 316 Oregon nursing facility residents, 91 persons died but only five did so in a hospital setting. Eighty-six residents died in the nursing home per their wishes on their POLST form. A sub-sample of residents also had POLST forms with a specific order of "transfer only if comfort measures fail" (Tolle, et al., 1999). This study suggests that a POLST form can have a positive impact on appropriate transfer of individuals to a hospital setting at end-of-life.

Outside of the hospital setting, the POLST form appears to have a high compliance rate. A study conducted by Schmidt and colleagues (2004) to evaluate Emergency Medical Technicians' (EMTs) experiences with POLST found that the form is effective in the prevention of unwanted treatment, hospitalization and cardiopulmonary resuscitation outside of the hospital, but clients' decisions about medical interventions were followed less frequently than those for CPR. This study found the POLST form an effective tool for EMTs to prevent unwanted treatments for clients and the clients often use the form to change treatment decisions. Ninetyone percent of the EMTs surveyed found that the POLST was useful in determining treatment for a pulseless and apneic client; 62% found the POLST to be helpful when the individual was breathing and had a pulse.

Individuals who have POLST forms at end-of-life have a good, but not perfect, chance of having their wishes for end of life care honored. A study was conducted to evaluate the end-of-life experience of 58 adults with POLST forms who were also enrolled in a Program for All-Inclusive Care for the Elderly (PACE) (Lee & Brummel-Smith, 2000). The researchers reviewed the subjects' charts over the final two weeks of their life. Ninety-one percent of the participants had their wishes for CPR interventions followed, 46% had their medication wishes followed, 86% of those who had infections had antibiotics given per their instructions, and 94% of the participants had their wishes for artificial nutrition honored. This study suggests that the POLST form improves the effectiveness of communicating patients' wishes for CPR and artificial nutrition. However, requests declining specific medical interventions are not followed as consistently. The factors explaining this phenomenon were not studied. Moreover, the literature does not include information about providers' views of the POLST form or attempt to understand why a provider would chose not to follow the wishes written on the form.

## **Research Questions**

- 1. What factors influence whether or not an ED health care provider honors the POLST?
- 2. What is the experience of ED health care providers with the clients and their families who seek to have a POLST honored?

## Definition of Terms

Advance Directives: Written instructions stating how persons wish their medical decisions to be made if they become unable to make decisions for themselves. Advance Directives are sometimes called living wills. As an adjunct or alternative to an Advance Directive, most states allow patients to appoint a person with durable power of attorney for healthcare authority

(DPAHC). The person with DPAHC authority can make health care decisions for an individual who no longer has decisional capacity to make decisions

Artificially Administered Nutrition: When a person can no longer eat food by mouth, nutrition can be given by artificial means including tube feedings. On a short-term basis, fluids and liquid nutrients can be given through a nasogastric tube. For long-term feeding, a gastric tube or jejunal tube can be inserted through a surgical procedure.

Cardiopulmonary Resuscitation or CPR: Attempts to restart breathing and heartbeat for a person who has stopped breathing or has no pulse. This may involve chest compressions, assisted breathing, defibrillation, or intubation.

Comfort Measures: Measures that promote comfort for patients and do not necessarily prolong life. With the POLST form, a person may choose to be transferred to the hospital only if his or her comfort could not be maintained in the current setting.

Life sustaining treatment: Treatment measures used to sustain or prolong life.

Mechanical ventilation/respiration: Mechanical assistance for respiration via a ventilator that is connected to an endotracheal tube.

Medical decision maker: State laws define that a designated surrogate or family member may serve as a representative of an individual and make decisions for a person who is unable to make decisions for him or herself.

Physician Orders for Life Sustaining Treatment (POLST) form. A one page double sided form printed on cardstock that was created in 1995, in Oregon, and revised in 1997, 1999, and 2000, that translates persons' wishes for end-of-life care into a set of physician/provider orders for medical treatment. The Washington State version was first distributed in 2001 and revised in 2004 and December 2006.

# Significance to Nursing

Physician Orders for Life Sustaining Treatment (POLST) forms have been in existence for 12 years in Oregon and six years in Washington. The POLST form provides a way to honor a client's autonomy in making end-of-life decisions. There are multiple ethical issues surrounding the use of POLST forms. Whether or not a provider can allow a person to die from a terminal illness without attempting to treat by all means possible (Feudntner, 2005), which person is considered the medical decision maker at end of life (Alpers & Lo, 1999), and the conflicts that arise when family members do not agree with the individual's POLST wishes or each other (Eisenberg & Kelso, 2002) are some of the more prominent issues seen in current research. All of these issues make new information about the use of the POLST significant to the healthcare field.

There is no study available about the course of Emergency Department treatment and the use of the POLST form. This study adds to the body of knowledge in this little-studied area of healthcare by exploring the experiences of ED providers. The results obtained in this study may be useful in educating healthcare providers about the use of POLST forms in the emergency setting. Nurses, nurse practitioners, physician's assistants and physicians in the emergency setting may benefit from this study by understanding the underlying issues as to whether the POLST form is honored.

#### Chapter 2

# Introduction

This chapter outlines the type of study design, setting for the study, population and sample studies, instrumentation, procedures for data collection, and data analysis techniques. The study focused on use of POLST forms by health care providers in the emergency setting. Human subjects considerations were addressed, including the risks and benefits to the participants.

# Type of Design

This study is a non-experimental descriptive inquiry. This qualitative study is designed to evaluate the experiences of healthcare providers with POLST forms. A qualitative format was suitable for the study because the experiences of the providers in this very personal situation would be difficult to capture using quantitative methods. Meyers (2000) states that the mutual goals of handling subjectivity, describing the intricacy of lived experience, and the value of holism and intuition are favorable to nursing and expressed in qualitative methodology. Research that attempts to understand difficult human experiences including pain, caring, powerlessness and comfort need to be qualitative in nature. Using descriptive inquiry, a study aimed at discovering an accurate portrayal of situations and/or frequency of occurrence of phenomena will help to uncover underlying themes and provide insight (Polit & Beck, 2004).

# Setting for Study

This study was conducted at four western Oregon and Washington hospitals. Conducting this study in multiple emergency departments, including both rural and urban settings, provided an opportunity to assess the experience of providers with the POLST at differing sites.

# Population and Sample

The sample consisted of five ED healthcare providers at four different sites in Oregon and Washington; four physicians and one nurse practitioner. The sample was selected based on willingness of facilities and providers to participate in the study. Inclusion criteria were an independent healthcare provider, specifically a physician, nurse practitioner or physician's assistant, currently practicing in the Emergency Department of an Oregon or Washington hospital. A purposive sample was used for data collection. A purposive sample is composed of respondents with similar attributes that may be able to provide insight to the phenomena being studied (Burns & Grove, 2005).

#### Instrumentation

The instrumentation for data collection in this study was a seven question interview guide developed by the investigator. The interview guide was based on King's interacting systems theory (Appendix A). The participants were asked to discuss their experiences with the use of POLST forms and to respond to open-ended questions regarding these experiences. The questions were administered in a sequence used to prevent bias, encourage openness, and be psychologically meaningful. Particular attention was paid to the possibility of questions influencing each other. Psychologically difficult questions were placed between questions that have less impact on the emotion of the participant.

Rigor was addressed based on its concepts of credibility, transferability, dependability and confirmability. Credibility was addressed through the researcher's purposeful selection of the study's subjects and ongoing verbal interviews with open-ended questions until saturation was reached. Individual interviews were used to ensure candor of the participant and to prevent any one member of the study group from dominating the conversation, as in a focus group type

setting. Evidence suggests that speaking around other members of the healthcare team may cause the providers to be less open and honest than they would be in one-on-one discussion (Burns & Grove, 2005).

Transferability was tested as the researcher determined in what settings outside of the original one this study may be useful. For example, this study information has the potential to be used in multiple states across the nation. The results of this study can be used by instructors, healthcare providers, other researchers, and the National POLST paradigm task force. Dependability was tested in this study as the researcher asked the same seven questions to multiple subjects to look for both corresponding themes and discrepancies (Burns & Grove, 2001).

One of the limitations to this study was the researcher's personal bias. The investigator is currently an ED nurse and past experiences with POLST forms were the motivation to conduct this research. However, because the questions are open-ended, there is less opportunity for personal bias to affect the outcomes of the study. None of the participants were known to the researcher, limiting the risk of bias and lack of full disclosure should the participant respond in a way that he or she believes the researcher prefers.

A second limitation was the small sample size with only five participants. Although participation information was sent to 20 hospitals, nine chose not to participate in the study, seven did not return the form, and only four consented to the study. The sample used was purposive rather than random and therefore may not representative of the entire population. Also, the study was conducted only in two western states. These factors limit transferability.

# Data Collection Procedure

The researcher submitted the research proposal to the Washington State University Institutional Review Board for review (WSU IRB). Data collection was initiated after receiving IRB approval. A letter seeking study participation of selected Oregon and Washington hospitals was sent to emergency department managers or designated individuals (Appendix B). A form to confirm participation was sent to each manager or designated individual and when returned kept on file (Appendix C). After agreeing to participate, each contact person was asked to distribute a recruitment letter to emergency department personnel who met inclusion criteria. The letter discussed the nature and purpose of the study, the significance and anticipated benefits, rigor, safety, the inclusion criteria, and the researcher's contact information (Appendix D). There was also a sample of the interview questions for the participants to review. The participants were informed of the possible uses of the results of the study for publication, presentation and comparison with future studies. A form was provided for the potential subject to mail to the researcher in an addressed and stamped envelope to indicate willingness to participate (Appendix E). Once an individual agreed to participate, he or she was contacted by telephone or e-mail to schedule an interview. Prior to data collection, informed consent was obtained from each potential participant (see Appendix F).

Interviews were conducted at the time of the subject's preference from a land-line phone. Close attention was paid to keeping appointments, avoiding conflicting schedules, and maintaining a suitable system of confidentiality during data collection (Polit & Beck, 2004).

The interview was approximately 15 minutes long and conducted one-on-one by telephone on a land line to avoid any breach of confidentiality. Interviews were audio-taped and transcribed by the researcher. The researcher was willing to honor at any time the participant's

request to withdraw from the study or the request to withdraw any statement from the final transcript upon completion. To protect confidentiality, audiotapes were destroyed after transcription to eliminate the ability to identify a participant by voice.

# Data Analysis

The analysis of this study occurred in stages as interviews were conducted. As themes emerged the researcher identified areas to probe in subsequent interviews to assure that the research questions were addressed. Emergent themes were determined as well as their frequency of occurrence. The data interpretation process began with an attempt to explain the findings within the context of Interacting Systems Theory, prior literature review, and the researcher's personal experiences (Polit & Beck, 2004).

# Human Subjects Considerations

Approval from the WSU IRB was obtained prior to beginning the study. The Animal/Human Subjects' Protocol developed by the National Institute of Health was followed and the online module was completed by the researcher prior to beginning this proposal (Appendix H).

Prior to beginning the interview, written consent was obtained and included an explanation of the purpose of the study, the benefits and risks, sample questions, procedures and a request for permission to audiotape and transcribe the interview. Verbal consent to audiotape the phone interviews was also obtained and recorded. The researcher was prepared to offer assistance for difficult feelings that may have been evoked during the interview process or to provide information for further assistance if needed once the interview was completed.

To protect confidentiality, the transcripts were stored on CD ROMs rather than on a computer. Coded transcripts and the CD ROMs were stored in a locked cabinet in the

researcher's home. A duplicate set was kept in the researchers password protected home safe. Only the researcher and her thesis committee members had access to the data.

Risks to the participants included emotional stress and loss of confidentiality. To avoid any repercussions for providers who chose not to follow the POLST form orders, the audiotapes were destroyed after transcription. The study had the potential to evoke emotions that the provider has about end-of-life and related to specific patients they have treated. Introspection, self-disclosure, fear of the unknown, fear of repercussions, and discomfort with strangers may also cause psychological or emotional distress (Polit & Beck, 2004). Identifying information such as particular patient information was changed to protect the identity of patients and participants. The verbal interview was conducted at the participant's convenience to limit the risk of privacy and monetary loss from loss of time at work. There was no foreseen physical risk to the participant in this study.

The benefits for the participants are the ability to enhance the treatment of patients who are seen in the emergency department with POLST forms. The participants may also have developed increased knowledge about themselves, comfort in being able to discuss their situations with the researcher, satisfaction that their information may provide help to others, and excitement of being part of a study (Polit & Beck, 2004). Health care providers and ED patients may benefit from this study. The study provides insight into the experience of providers with the POLST form in the emergency setting. With knowledge obtained from this study, healthcare providers may be able to deliver improved quality in end-of-life care.

Chapter 3

Use of the 'Physician Orders for Life Sustaining Treatment' Form in the Emergency Department Setting: The Providers' Experience

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#### Abstract

*Introduction*: Beginning in the early 1990s, leaders in long-term care and Emergency Medical Services in Oregon recognized a need to better communicate patient preferences about treatment near the end of life. In 1995, an Oregon Health & Science University task force developed a one-page form to facilitate clarification of a person's wishes regarding end of life treatment. The form, the Physician Orders for Life Sustaining Treatment (POLST) form translates an individual's choices for their end-of-life health care treatment into provider orders and can be honored in all care settings.

*Methods*: This qualitative study evaluated the experiences of emergency department providers with the POLST form. Imogene King's Interacting Systems Theory was used as the framework for this study. The study sample consisted of five emergency department providers at four hospitals in Oregon and Washington. Data were collected by the researcher through individual interviews. The experiences of providers were compared for underlying themes.

*Results*: The main barrier to POLST form compliance was the intervention of patients' families. This pilot study provides insight into some of the barriers that surround the use of the POLST form in the emergency setting. It also reveals the key element necessary to increase compliance with POLST form orders, i.e. education of the family.

*Discussion*: Understanding the experiences of providers in the emergency department setting is crucial to improving the use and effectiveness of the POLST form. The study implies that better education of both the patients and their families may improve the success of the form.

# Introduction

Autonomy and comfort are both important factors in client treatment, especially in cases of terminal illness and end-of-life care. To ensure that these factors are addressed, the Patient Self Determination Act (PSDA) was created out of the Omnibus Budget Reconciliation Act. The PSDA, implemented in 1991, requires all healthcare facilities that receive federal funding to provide persons with written information about their rights to make end of life choices and to document on the patient's chart whether or not the individual chose to make directive choices<sup>1</sup>.

Legally under the PSDA, providers are required to ensure that the patient's requirements are met and are not required to provide care that conflicts with the advance directive. Providers are also not required to withhold care based on the advanced directive if it is a matter of conscience. If the provider is unable to follow the directives because of personal views, they are required to provide a clear and concise statement of limitation concerning this. If a patient is unable to receive directive information at the time of admission, the provider is required to provide information to the patient's family and then to the patient when they are able to receive it<sup>2</sup>.

Beginning in the early 1990s, leaders in long-term care and Emergency Medical Services in Oregon recognized a need to better communicate patient preferences about treatment near the end-of-life. In 1995, an Oregon Health & Science University task force developed a simple, one-page form to facilitate clarification of a person's wishes regarding end of life treatment. The single page, double sided form known as the Physician Orders for Life Sustaining Treatment (POLST) form translates an individual's choices for his or her end of life health care treatment, into physician orders.

Honoring autonomy and providing comfort are both important factors in client treatment, especially in cases of terminal illness and end-of-life care. Beginning in the early 1990s, leaders in long-term care and the Emergency Medical System (EMS) in Oregon recognized a need to better communicate patient preferences about treatment near the end of life. They developed a form called the Medical Treatment Cover Sheet which later became known as Physician Orders for Life Sustaining Treatment (POLST).

The POLST form became widely available for use in Oregon in 1995. In 1998 a second group, the Regional Ethics Network of Eastern Washington (RENEW), began adaptation and development of the form for use in Washington State. The statewide use of the POLST form in Washington began in 2001. A more recent group, currently named the POLST Paradigm Task Force, is working toward implementing use of the POLST form at the national level as the POLST or similar form is now available only in 17 states (figure 1).

The POLST form is printed on brightly colored cardstock (pink in Oregon and green in Washington) to ensure identification and quick location on the front of a chart or at an individual's home. Although the form is printed in English, written information about the form can be obtained in both English and Spanish. Over the past decade, some states have developed programs that use a form similar to the POLST form. The POLST is an easily accessible and succinct form that is useful when caring for people in emergency situations. It provides immediate guidance for treatment and is focused on the individual's current health status. The POLST form provides orders in a brief and well-defined manner. This is in contrast to various types of advance directives that are less focused, can have multiple sections for clients to write their preferences for treatment in very specific situations, and are designed for long-term use<sup>3</sup>.

As of 2004, over one million Oregon POLST forms had been distributed, targeted toward individuals who have a high potential to need life-sustaining treatment decisions (1). According to the Washington State Medical Association, Washington distributes approximately 60,000 to 80,000 forms each year around the state<sup>4</sup>. In Washington, the POLST form requires a signature from both the individual or legally designated surrogate decision maker, and the health care provider. The provider may be a physician, nurse practitioner (NP), or physician's assistant (PA). In Oregon, the form requires the signature of a physician or NP and the individual's signature is optional<sup>5</sup>. There are four key areas of medical management that the POLST covers: (1) resuscitation status; (2) medical interventions and transfer to a hospital; (3) antibiotic use; and (4) short-term and long term options for artificial nutrition<sup>6</sup>.

Although the POLST form originated in 1995, there is limited research about its use in general and no research about its use in the emergency department setting. This article describes the experiences of emergency department providers with the POLST form. Understanding the experiences of providers in the emergency department setting is crucial to improving the use and effectiveness of the POLST form.

# Review of the Literature

There are numerous studies published on Advance Directives and end-of-life treatment. The literature that is available specifically on the POLST form is limited due to the short length of time that the form has been in existence and the small number of states that use a POLST or POLST-type form.

Hinkka, Kosunen, Metsanoja, Lammi, and Kellokumpu-Lehtinen<sup>7</sup> studied 1182 health care providers using a terminal cancer patient scenario with alternatives to evaluate their readiness to withdraw or withhold treatment options. The researchers found that personal

experience and training, life values, and attitudes toward terminal care markedly influence decision making in end-of-life situations. The presence of an Advance Directive caused physicians to be more likely to withhold treatment. This study, however, was conducted by providing the physician with a hypothetical situation and then analyzing responses to questions about it. These findings cannot be generalized to predict whether physicians would respond similarly to a real life situation.

Resnick and Andrews<sup>8</sup> discovered that half of their study's subjects did not want any life sustaining treatment and were more likely to use measures to facilitate comfort than those that prolong life. Having a POLST form in the house or on an individual's medical chart communicates his/her personal wishes in a clear, succinct manner. Further, the POLST form can be updated with less complication and more frequency than the traditional Advance Directive because it consists of only a single page of specific orders.

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)<sup>9, 10</sup> revealed that physicians are largely unaware of end-of-life wishes even when clients have completed an advance directive. In this study of 638 seriously ill clients, only 25% had primary care physicians aware of their end-of-life wishes. Researchers documented deficits with the use of advance directives. A do-not-resuscitate (DNR) order was not written in about 50% of cases in which the patient did not wish to be resuscitated. Only 23% of seriously ill and 11% of terminally ill patients even spoke with their provider about CPR wishes.

Studies have shown positive results with use of the POLST form in nursing homes in Oregon. Hickman and colleagues<sup>3</sup> found that the majority of individuals with cardiopulmonary-specific orders such as do not resuscitate (DNR) requested some other form of life-extending

treatment, including treatment with antibiotics and artificial nutrition. The study also concluded that the POLST form was widely used in Oregon nursing homes and use had increased over the previous decade. There were 356 nursing home residents all older than age 65 included in their study. The oldest old, age greater than 85 years, were more likely than the young old, ages 65-74, to have orders on the POLST limiting the treatment in all four categories. Follow up studies of POLST form use in nursing homes in Washington State are currently underway<sup>11</sup>.

In Oregon long term nursing facilities there is a high rate of advance planning with 91% of nursing facility residents having DNR orders on their Advance Directive or POLST form. During a statewide one year prospective study of 316 Oregon nursing facility residents, 91 persons died but only five did so in a hospital setting. Eighty-six residents died in the nursing home per their wishes on their POLST form. This is in contrast to the fact that while 90% of Americans say they want to die at home, the SUPPORT studies found that four out of five die in a hospital or other healthcare facility <sup>12, 13</sup>. A sub-sample of the Oregon nursing facility residents facility residents also had POLST forms with a specific order to transfer only if comfort measures fail <sup>14</sup>. This study suggests that a POLST form can have a positive impact on appropriate transfer of individuals to a hospital setting.

Outside of the hospital setting, there appears to be a high compliance rate with POLST form. A study conducted by Schmidt and colleagues<sup>15</sup> to evaluate Emergency Medical Technicians' (EMTs) experiences with POLST found that the form is effective in the prevention of unwanted treatment, hospitalization, and cardiopulmonary resuscitation outside of the hospital. The study found the POLST form was an effective tool for EMTs to prevent unwanted treatments for clients. Ninety-one percent of the EMTs surveyed reported that the POLST form

was useful in determining treatment for a pulseless and apneic client while 62% reported the POLST form was helpful when the individual was breathing and had a pulse.

Individuals who have POLST forms at the end-of-life have a good chance of having their wishes for end of life care honored. A study was conducted to evaluate the end-of-life experience of 58 adults with POLST forms who were also enrolled in a Program for All-Inclusive Care for the Elderly (PACE)<sup>16</sup>. The researchers reviewed the subjects' charts over the final two weeks of their life. Ninety-one percent of the participants had their wishes for CPR interventions followed, 46% had their medication wishes followed, 86% of those who had infections had antibiotics given per their instructions, and 94% of the participants had their wishes for artificial nutrition honored. This study suggests that the POLST form improves the effectiveness of communicating patients' wishes for CPR and artificial nutrition. Requests to not have specific medical interventions were not followed as consistently. The factors explaining this phenomenon were not studied. Meyers, et al.<sup>17</sup> also found that there was consistency between the residents' wishes, as expressed in interviews, and the POLST orders on their charts

There is a large body of evidence that a POLST form is well adhered to. A study conducted by Tolle et al.<sup>14</sup> suggests that introduction of the POLST form may have a positive impact on this phenomenon by providing a tool that can be transferred between facilities. The study also found that there was a universal respect for nursing home residents with regard to their CPR wished on the form. Schmidt, Hickman, Tolle and Brooks<sup>15</sup> found that the POLST form was effective in the prevention of unnecessary cardiopulmonary resuscitation (CPR) however the individual's wishes regarding other medical interventions were followed less often. Lee and Brummel-Smith<sup>16</sup> found similar results with the rate of initiation of CPR matching POLST form

designations 91% of the time. Medical interventions, however, only matched the POLST form orders 46% of the time.

There are no studies available that address providers' views of the POLST form or attempt to understand why a provider would chose not to follow the wishes written on the form. The goals of this study were to answer those questions, providing insight into the use of the POLST from the provider's point of view.

#### Methods

This qualitative study uses a non-experimental descriptive design to evaluate the experiences of emergency department (ED) healthcare providers with POLST forms. After approval from the Institutional Review Board, a purposive sample of ED healthcare providers was recruited at multiple sites in Oregon and Washington. Recruitment letters were sent to selected hospitals based on size and location and if the facility employed multiple types of providers in the ED. Once a facility agreed to participate a recruitment letter was sent to all ED providers who met inclusion criteria. Inclusion criteria were a healthcare provider, specifically a physician, nurse practitioner or physician's assistant, currently practicing in the emergency department of an Oregon or Washington hospital. A total of five providers participated, four physicians and one nurse practitioner.

Data collection utilized a seven question interview guide developed by the investigator based on King's interacting systems theory (Appendix A). After giving informed consent, participants were asked to discuss their specific experiences with the use of POLST forms and respond to open-ended questions regarding these experiences. Interviews were approximately 15 minutes long and conducted one-on-one by telephone on a land line to avoid any breach of

confidentiality. Interviews were audio-taped and transcribed by the researcher. Content analysis of the transcripts was conducted as well as the themes that emerged.

### Results

The number of times a POLST form was seen varied among providers in relation to the time worked in the emergency department. Two reported having seen the POLST form dozens of times, one had seen the form 20-30 times, one had seen the form at least once a week, and the last had seen the POLST upwards of 200 times. "[There have been] maybe 20 [to] 30 times where it has actually been clinically useful. Most people who come from Nursing Homes have a POLST of some sort."

The providers' experiences with using the POLST form differed. A provider from a large urban hospital felt that the POLST was helpful in simplifying the process of end-of-life care, making things more definitive. "It especially helps the family to be able to draw lines and set limits on care of people in end of life situations".

The respondents' experiences with families were mixed. "I think that [the families of patients with the POLST form] are better informed about palliative care decisions than the families without. There are situations at times when the families disagree with what the patient states on their POLST form". Another provider had similar experiences. "There are some people and families that I find that don't understand what they have defined, the implications of it, and have a lot of buyers remorse or hesitations with what it means and the finality of life and death issues". The form makes the wishes of the patient and family much clearer and in most cases the providers tried to honor the form and help the family to understand why they chose to do that. "I think that they [families] are better informed about palliative care decisions than the families without for the most part." Another respondent says "It is mixed, I think that for some,

it provides a relief. They feel that they do not have to make a tough decision when it is there". "I think when it seems like the doctor has taken time to explain what it means to the patient, then it is definitely worthwhile."

One respondent believed that families were always informed of the POLST form and did not ask for further interventions and were better informed about palliative care decisions. Another respondent thought the form offered relief to the family eliminating the need to make tough decisions. One provider cited that more problems occurred with patients who did not have POLST forms. "The family has not had much influence on [the patient's] treatment. They are usually aware of what the patient wants and agreeable with their decisions. When I do [communicate with] a family member [of] a patient who has a POLST, I can't remember a case when they were surprised by the wishes...the times we get families that are not in agreement are those patients who do not have POLST."

Unanimously, the respondents' experiences with the form had been positive. Moreover, the content of the form was important because it became part of the patient's orders and influenced the type of unit to which a patient was admitted.

Two of the respondents reported providing care the patient specified on the form that was not wanted, citing family intervention as the reason for this. One provider stated: "usually the family comes [with the patient] and they ask [for treatment beyond what is written on the POSLT". Another provided more care than was indicated on the POLST form because the family had either called an ambulance to bring the patient to the emergency department, prompting treatment not indicated on the POLST, or the family brought the patient to the hospital asking for care not indicated on the POLST.

Two providers felt that they had never provided care to a patient that was not indicated on the POLST form. "I would always, always, always follow the wishes of the patient if I had a POLST form at the bedside. Without [a POLST form], I am more likely to error towards the area of providing more rather than less treatment."

Several of the respondents specifically identified difficulties with families and the use of the POLST form stating that they felt that the families were a barrier to honoring the POLST. Another provider's experiences were mixed and although families were not perceived as a barrier to using the POLST form, families were sometimes not well informed about the POLST. "I wouldn't say they are a barrier. I would say that sometimes there wasn't enough conversation with them and the patient about why they wrote the POLST form the way that they did…I just think [the families] don't understand it. Sometimes they think it is going to stop [the patient's] getting the care they need."

All of the providers believed that the POLST form was easier to use than traditional advance directives because it makes clear what the patient wants in specific situations. "It is more detailed and leads people through a thought process of, 'what things do I need to have." Another added that, "it addresses the key issues of what people want." This provider went on to say that while an advance directive has its place in long term treatment, POLST are better for changing situations. "The language is much clearer…the POLST covers the necessary information in a more concise manner than the old advance directive, which [are] difficult to read."

When asked about what influenced their decision to follow the orders indicated on the POLST, respondents had a range of responses. Some offered no factors that influenced their decision while others mentioned prior experience and training, especially in ethics and policy

making. Highlighting the influence of clinical experience and why the POLST is honored, one provider commented: "I have worked...more than 30 years now so I have seen patients coded that didn't probably want to be."

The respondents all expressed satisfaction with use of the form in the emergency setting. Suggestions related to use of the POLST included the following. "Some iteration of the POLST form should be in use in all states. I think it is a necessity in our healthcare system." A wallet-sized card for ease of transfer was suggested by one respondent. "It would be nice if we could figure out some way that makes it easier for patients to carry it with them". This would allow a person traveling between states to have the POLST available. A 2007 wallet card is currently available for purchase by healthcare providers at the POLST website at OHSU's Center for Ethics in Healthcare for \$.50 a card<sup>17</sup>.

Education of families and providers about the POLST form was vital. During discussion of the POLST with patients and families, prior to completion, an explanation should be given about what is involved in care when a potentially life-ending experience occurs. "As an emergency department provider, I do not get a chance to sit and talk to families about the form. It would be worthwhile to sit down with the patient and family and discuss with them what to do in [specific] scenario[s]; make them think long and hard about each situation." Another agreed, stating, "I think when it seems like the doctor has taken time to explain what it means to the patient, then [POLST] is definitely worthwhile." Increasing provider awareness could also improve the use of the form. "I think that a lot of [providers] are not aware of its existence, and that is probably its one weakness."

## Discussion

The main barrier the study participants gave for not honoring POLST was family interventions. This is consistent with other findings that note the presence of family conflict in end-of-life decision making <sup>18, 19, 20, 21</sup>. Dubler<sup>22</sup> found that families are requesting treatment for patients, long after patients are able to speak for themselves, based on the families' moral and political right to life agenda. She sites four areas of conflict. Family wishes are not always consistent with the wisdom of medicine, law, and bioethics; appeals to patient wishes may not resolve difficult decisions about end of life; private decisions may be made public by appeals to the media, legislature, and congress; and legal and bioethical labels may encourage intellectual and emotional chaos.

The sponsoring organizations report that use of the POLST form has been increasing in Oregon and Washington. It is possible that some providers are not aware that the POLST is available, but respondents in this study offered only one reason for not honoring it. The findings of this study suggest that the problem of POLST forms not being honored in emergency departments might be remedied by including families, when appropriate, in discussion of POLST form directives and explaining to patients and families exactly what each area of the POLST form means. This is consistent with Jecker's<sup>23</sup> argument that patients and families are best considered as "a commons" in which the principles of autonomy and justice, and the virtues and responsibilities of intimate others, are considered.

The findings from this study indicate a need for further research and evaluation of the use of the POLST form in emergency departments. The POLST form could be studied from the perspective of both the patients and their families, including whom the patient chooses as his or her surrogate and also the types of discussions that occur between the provider, patient, and family.

A study could also be performed evaluating the course of emergency department care for a person with and without the POLST to compare treatment options and determine the effectiveness of POLST form use with regards to following the patient through their course of care.

A recommendation based on this study is to offer healthcare providers more education about the use of the POLST form and how to discuss with patients and families end-of-life options. It is clear that these discussions require considerable time, tact, compassion, and patience. Certainly, it would be better if these discussions occurred prior to an ED event, in an environment that was conducive to thoughtful consideration of the significance of end of life care choices. Focus group participants in a 2003 study in Washington State were consistent in their call for these discussions to occur in the offices of doctors and nurse practitioners. The POLST training materials available on the Washington State Medical Association website stress that providers initiate a discussion of POLST. Providers are encouraged to ask, "Would it surprise me if this person were to die in the next six months to a year<sup>24</sup>. In hospitals and nursing homes, nurses and social workers are often the facilitators of these discussions and the back side of the Washington State POLST form contains an area for that professional's signature. Crane, Whittink, and Doukas<sup>25</sup> propose that end of life discussion occur over time, particularly when the patients health status changes. Any ambiguity should be addressed by collaboration between the patient, provider, and family to review past stated values and preferences to endure accuracy of the decisions.

Another recommendation derived from this study is to offer patient and family education and resources on the POLST form. This could be accomplished by seminars, television and media advertisement. Patients should be taught that it is important to make end-of-life decisions

with one's family so the family will honor the patient's decisions. The findings of this study suggest that would prevent confusion, unwanted treatment at the end of life, and/or conflict between providers and family members. In a recent study about end of life health care planning conducted by Carr and Khudyoakov<sup>26</sup>, it was found that when discussing end of life care with patients, many strategies may be needed since personal resources and needs vary from person to person.

The findings from this study relate to the Patient Self Determination Act of 1991 in that the PSDA gives patients the right to participate in and direct their own healthcare. They have the right to accept or refuse treatment, the right to prepare an advance directive, and have information on the provider's policies that govern the utilization of these rights <sup>27</sup>. In order to assure full compliance with the PSDA, a POLST form should be made a requirement on the front of patients' charts, continue with them throughout a hospital stay, and transfer to other health care settings. The POLST form should be accepted in other states and be a document easily transported by the patient.

Changes to also consider are increasing the education of providers to require at least 8 contact hours of continuing education between license renewals that focus on the implementation of the POLST form with both patients and families. The requirement for community education should be expanded from written materials to involve televised community service announcements over multiple channels to attempt to reach a broader spectrum of people. Also, the PSDA directs that written information about advance directive be given to the family only if the patient is unable to receive the information<sup>2</sup>. This section should be changed to allow providers to distribute materials to the patient's families on admission regardless of the patient's health status.

Interventions made by the families of patients with POLST forms are complex.

Emergency department providers should be better educated about the rights and responsibilities that families may legitimately have in the decision making process. Do families indeed have the right to ask for changes in POLST decisions in the ED?

### Limitations

One of the limitations to this study was the researcher's personal bias. The investigator is currently an emergency department nurse and past experiences with POLST forms were the motivation to conduct this research. However, because the interview guide questions were openended, there was less opportunity for personal bias to affect the outcomes of the study. None of the participants were known to the researcher, limiting the risk of bias and lack of full disclosure should the participant respond in a way that he or she believes the researcher prefers.

A second limitation was the small sample size. There were five participants, from four emergency departments and the study was conducted in two western states. The sample used was purposive and therefore may not representative of other ED providers. All of these factors limit generalizability. However, given that use of the POLST form is strictly voluntary in these states, the data may offer a better reflection of other emergency department providers' experiences than the sample size might indicate.

A third limitation of this study was the researcher's novice status. The researcher did not ask the probing questions needed to have findings that are credible and well understood. This limitation should be addressed by conducting subsequent interviews based on the data already gathered, evoking more data from the responses.

Implications for Emergency Nurses

The POLST or similar form is recognized in 17 states. Emergency nurses should be aware of its use in these states and be alert to its adoption in other states over the next few years. For example, the Idaho legislature mandated use of a Physician Orders for Scope of Treatment form beginning on July 1, 2007. Nurses, as patient advocates, should educate both patients and families about the use of the POLST form and discuss each section of the POLST form. Attention to family involvement in the process of completing a POLST form can avoid having families attempt to inappropriately intervene when an emergency department provider acknowledges and honors the POLST form. Once complete, ED nurses can assist families in understanding the POLST form. Nurse practitioners who work in the emergency department may avoid inappropriate family intervention by initiating a discussion of the POLST form, and normalizing its use for families who are unfamiliar with it. ED nurses need to work with other providers, perhaps through the aforementioned televised community service announcements, to provide community education about the POLST form.

### Conclusion

POLST or POLST like forms are becoming more widely recognized in more than 17 states. Research in the states of Oregon, where it was developed, and Washington indicates the form has a positive effect on end of life care. The form provides clear directions for care, is more specific than various forms of advance directives, and is portable across all health care settings.

This pilot study reveals that emergency department providers in Oregon and Washington are aware that the POLST is available and cite family intervention as the main barrier to not honoring the form. The results of this study indicate that more education is needed for providers to involve clients' families in completion of the POLST form, and what the POLST form means

in emergency situations. Collaboration with the healthcare provider, the patient, and the family in completion of the POLST form may lead to universal acceptance of the POLST form in the emergency setting.

Changes to the PSDA to consider are increasing the education of providers, requiring at least 8 contact hours of continuing education between license renewals focusing on the implementation of POLST forms. This education should involve promoting direct discussion between the patients, providers, and families over time. The requirement for community education should be expanded from written materials to involve televised community service announcements to attempt to reach a broader spectrum of people.

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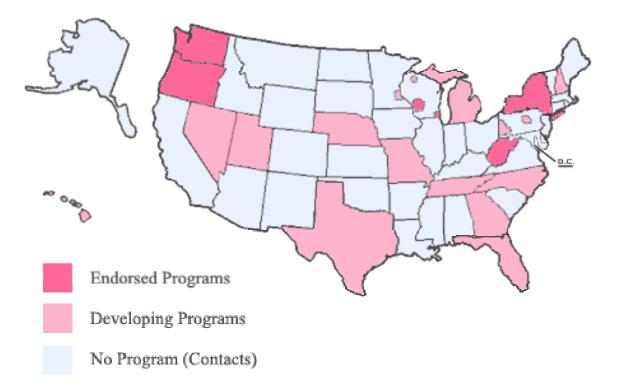
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Figure 1: Washington State POLST form Adapted from the Oregon Health Sciences University Center for Ethics in Healthcare.

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Figure 2: Adapted from POLST Paradigm Program by State, Oregon Health Sciences University Center for Ethics in Healthcare.



# Appendix A: Oral Interview Questions

- 1. Approximately how many times have you seen the POLST form in your practice?
- 2. What are your experiences with using the POLST form?
  - a. How does it influence your treatment of clients?
- 3. Have you ever provided care to a client for something that they have specified on the POLST form that they did not want?
  - a. If so, what were the circumstances around that decision?
- 4. What is your experience with the families of clients with POLST forms?
- 5. What is your opinion of the POLST form?
  - a. Is it easier/more difficult to use than an advance directive?
- 6. Are there other experiences with healthcare decision making that influence your use of the POLST form?
- 7. Is there anything else you wish to tell me about the POLST form and its use that I have not asked about?

# Appendix B: Facility Recruitment Letter

# WASHINGTON STATE UNIVERSITY INTERCOLLEGIATE COLLEGE OF NURSING

## Dear

I am a graduate nursing student at Washington State University. I am conducting a research study about the use of the Physician Orders for Life Sustaining Treatment (POLST) form in the emergency department. To evaluate the use of the POLST form I will be sampling emergency department healthcare providers at multiple sites in Oregon and Washington.

I am interested in interviewing physicians, nurse practitioners and physician's assistants who work in emergency departments. I am writing to ask if you would give me permission to recruit providers from your facility. Participation in the study will involve a telephone interview lasting approximately 30 minutes.

If you are willing to allow me to recruit study participants from your emergency department staff I would like to contact the providers by having you distribute a letter to them. This would assure no release of personal information without an individual's consent.

I would be happy to provide you with additional information regarding the study. I will follow up with a phone call in the next week or feel welcome to contact me by phone at 503-(503)440-0166 or e-mail ryan\_n\_alli@msn.com. You may also contact my thesis committee chairperson, Louise Kaplan, PhD, ARNP, for additional information at 360-546-9618 or by e-mail at kaplanla@wsu.edu.

Thank you very much for consideration of this request.

Sincerely,

Allison Richards, RN, BSN Graduate Student Washington State University

# Appendix C: Facility Consent Form



# POLST Study Participant Agreement Form

# Name:

□ I **agree** to take part in the POLST Study.

Please contact me via:

e-mail:

Telephone:

 $\Box$  I decline to take part in the POLST study.

Appendix D: ED Provider Recruitment Letter



I would appreciate your help in a study that I am conducting to evaluate emergency department physicians, nurse practitioners and physician assitants experiences with the Physician Orders for Life Sustaining Treatment (POLST) form. This study will also describe the factors influencing whether or not the POLST is followed in emergency department care. The understanding that will be obtained from this study may be used to assist healthcare providers to provide improved quality end-of-life care.

I am inviting your participation in the study. I would like to conduct an interview with you that should take approximately 30 minutes to complete and can be conducted in person or by telephone. Participation in the study is completely voluntary and you may choose not to answer any or all questions. Examples of questions include: 1)How many times have you seen the POLST in your practice? 2) What are your experiences with the POLST ? 3) How does the POLST influence your treatment of clients? You may choose not to answer any question or to stop at any time. Individual responses will be kept confidential and will only be made public in aggregate with the responses of other study participants.

Please respond by returning the enclosed form in the stamped addressed envelope. If you have any questions you would like answered before making a decision about your participation, please contact me by email at <u>ryan\_n\_alli@msn.com</u> or call Allison Richards at 503-440-0166. You may also contact my thesis committee chairperson, Louise Kaplan, PhD, ARNP, at 360-546-9618 or by e-mail at <u>kaplanla@wsu.edu</u>. I cannot assure the confidentiality of any information sent by e-mail.

Thank you for your consideration of this request!

Allison Richards, RN, BSN Graduate Nursing Student Washington State University Appendix E: Participant Agreement Form



# POLST Study Participant Agreement Form

Name:

□ I **agree** to take part in the POLST Study.

Please contact me via:

e-mail:

Telephone:

 $\Box$  I decline to take part in the POLST study.

WASHINGTON STATE UNIVERSITY Appendix F: Consent Form

WASHINGTON STATE UNIVERSITY CONSENT FORM

Qualitative Study: POLST forms in the Emergency Setting Researchers: Allison Richards, RN, BSN, FNP Student WSU Contact Information: 503-440-0166, ryan n alli@msn.com

# RESEARCHER'S STATEMENT

I am asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. You may ask questions about the purpose of the research, what I would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When I have answered all your questions, you can decide if you want to be in the study or not. This process is called 'informed consent.' I will give you a copy of this form for your records.

# PURPOSE AND BENEFITS

The Physician Orders for Life Sustaining Treatment (POLST) form translates an individual's choices for his or her end of life health care treatment into provider orders. Examining implementation of the use of the POLST form may be beneficial to healthcare providers and to individuals who are cared for in the emergency setting. The benefits for the participant will be the ability to enhance the treatment of patients who are seen in the emergency department with POLST forms. Healthcare providers may be able to provide improved quality end-of-life care with the understanding that will be obtained from this study. Society may benefit as a whole from this study as it provides insight into the experience of providers with the POLST form in the emergency setting.

## PROCEDURES

I am asking you to participate in an interview approximately 30 minutes in length. Examples of questions include: 1) How many times have you seen the POLST form in your practice? 2) What are your past experiences with the POLST form? 3) How does the POLST form influence your treatment of clients? You may choose not to answer any question or to stop at any time.

I would like to audiotape the interview so that I have an accurate record. The audiotapes will be transcribed and then destroyed. I, my thesis committee and select individuals involved in evaluating the rigor of the study will have access to the audiotapes. Each individual will sign a statement of confidentiality.

# RISKS, STRESS, OR DISCOMFORT

The risks to the participants include emotional stress and confidentiality. The study may potentially bring some emotions to the surface that the provider has about end-of-life and some emotions related to specific patients they have treated. The researcher is prepared to offer assistance for difficult feelings that may be evoked during the interview process or to provide information for further assistance if needed once the interview completes.

## OTHER INFORMATION

Interview data will be confidential. Any reports from the data will not link any information to an individual. Data may be reported in journal articles and presentations. It may be used to compare data collected in future studies. Data will be retained for seven years. You may refuse to participate or you may withdraw from the study at any time. If you have any questions about the study you may contact my thesis chairperson Louise Kaplan, PhD, ARNP, Assistant Professor at 360-546-9618 or at kaplanla@wsu.edu.

Allison Richards

Name of researcher

Signature of researcher

Date

Subject's statement

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have general questions about the research, I can ask one of the researchers listed above. If I have questions regarding my rights as a participant, I can call the WSU Institutional Review Board at (509)335-9661. This project has been reviewed and approved for human participation by the WSU IRB. I will receive a copy of this consent form.

Printed name of subject	Signature of subject	Date
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# Appendix G: Follow-up Script

My name is Allison Richards and I sent you a letter last week asking if you would participate in a study of emergency department providers and their experiences with the Physician Orders for Life Sustaining Treatment. I am [calling] [writing] at this time to ask if you are willing to participate in the study or if you have any questions about the study that you would like me to answer before making a decision to participate.

1. If the person consents to participate:

Thank you very much. I would like to set up a time and place to conduct the interview.

2. If the person declines to participate:

Thank you very much for your consideration.

3. If the person is undecided or has questions:

What specific questions can I answer or what additional information can I provide?

Appendix H: NIH Human Subject Protection Completion Certificate NIH Human Subject Protection Completion Certificate

This is to certify that **Allison Richards** has completed the **Human Participants Protection Education for Research Teams** online course, sponsored by the National Institutes of Health (NIH), on 01/15/2006.

This course included the following:

- key historical events and current issues that impact guidelines and legislation on human participant protection in research.
- ethical principles and guidelines that should assist in resolving the ethical issues inherent in the conduct of research with human participants.
- the use of key ethical principles and federal regulations to protect human participants at various stages in the research process.
- a description of guidelines for the protection of special populations in research.
- a definition of informed consent and components necessary for a valid consent.
- a description of the role of the IRB in the research process.
- the roles, responsibilities, and interactions of federal agencies, institutions, and researchers in conducting research with human participants.

National Institutes of Health