

**A CRITICAL LOOK AT THE PHYSICIAN ORDERS FOR LIFE-
SUSTAINING TREATMENT (POLST): WHAT ARE ITS WEAKNESSES?**

by

Jason W. Manne

B.S., State University of New York, 1975

J.D. University of Pittsburgh, 1979

M.H.A./M.B.A. University of Pittsburgh, 2003

Submitted to the Graduate Faculty of

The Center for Bioethics and Health Law in partial fulfillment

of the requirements for the degree of Master of Arts

University of Pittsburgh

2007

UNIVERSITY OF PITTSBURGH
THE CENTER FOR BIOETHICS AND HEALTH LAW

This thesis was presented

by

Jason W. Manne

It was defended on

November 18, 2007

and approved by

Michael DeVita, M.D., Center for Bioethics and Health Law

Mark Wicclair, Ph.D., Center for Bioethics and Health Law

Thesis Director, Alan Meisel, J.D., Center for Bioethics and Health Law

Copyright © by Jason W. Manne

2007

A CRITICAL LOOK AT THE PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST): WHAT ARE ITS WEAKNESSES?

Jason W. Manne, J.D., M.H.A., M.B.A.

University of Pittsburgh, 2007

The Physician Orders for Life-Sustaining Treatment (POLST) is a novel end of life advance planning tool that is being authorized for use in many jurisdictions. In form, the POLST is similar to medical order sets that are routinely completed by doctors in hospitals and nursing homes to specify or limit life-sustaining treatments for patients who are near the end of their lives. However, the POLST is completed by a physician before the onset of a medical crisis, and can be used by patients to control end of life medical treatment like an instruction directive or prehospital Do-Not-Resuscitate (DNR) order.

The POLST has some of the same weaknesses associated with instruction directives and DNR orders. There is a risk with the POLST that life-sustaining medical treatments will be forgone when the patient would have wanted them had he or she been able to communicate. A POLST may be incorrectly viewed by doctors as a general signal for limited treatment. There can be a lack of clarity regarding what specific procedures are covered by the POLST. It is unclear whether a physician may sign a POLST for a patient unilaterally, and whether a patient or surrogate may override the form without a physician's concurrence. The POLST has some unique weaknesses resulting from the requirement that it be transferable between treatment settings, and the fact it can co-exist with a conflicting instruction directive.

All of the research studies that have been done on the POLST have significant methodological weaknesses. It is not reasonable to conclude from these studies that the POLST is more effective than instruction directives and prehospital DNR forms in allowing patients to

control their end of life medical care. While the POLST is a useful addition to the tools that patients can use to control their end of life care, people may be led to believe that this advance planning device is more useful than it really is.

TABLE OF CONTENTS

INTRODUCTION.....	1
1.0 CHAPTER ONE - BACKGROUND TO DEVELOPMENT OF THE POLST.....	6
1.1 THE PROBLEM OF TECHNOLOGY AND DEATH	6
1.2 ADVANCE DIRECTIVES AS A RESPONSE TO THE PROBLEM.....	8
1.3 PRECEDENT AUTONOMY AND THE MORAL BASIS FOR ADVANCE DIRECTIVES	11
1.4 INSTRUCTION DIRECTIVES HAVE LIMITED EFFECTIVENESS	16
1.5 THE EMERGENCE OF PREHOSPITAL DNR ORDERS	19
1.6 THE POLST IMPROVEMENT	21
2.0 CHAPTER TWO - THE POLST’S WEAKNESSES	29
2.1 WEAKNESSES SIMILAR TO INSTRUCTION DIRECTIVES	30
2.1.1 The Risk in Making Decisions Outside of Medical Context	30
2.1.2 The Potential for Poor Disclosure and Understanding of Options.....	32
2.1.3 Changed Treatment Preferences	36
2.2 WEAKNESSES SIMILAR TO DNR ORDERS	39
2.2.1 Signal of Limited Treatment.....	40
2.2.2 Lack of Specificity Regarding Covered Medical Procedures	41
2.2.3 Unilateral Decisions by Physicians	42
2.2.4 Lack of Ability to Revoke Immediately	43
2.2.5 The Problem of Surrogate Completion.....	44
2.2.6 Problems Associated with Being a Binding Medical Order.....	46
2.3 WEAKNESSES UNIQUE TO THE POLST	48
2.3.1 Transferability Between Treatment Settings	49
2.3.2 Conflict with Advance Directives	51

3.0	CHAPTER 3 - WEAKNESSES IN POLST RESEARCH	53
3.1	WHAT POLST RESEARCH SHOULD BE ABLE TO SHOW	54
3.2	SUMMARY OF THE POLST RESEARCH STUDIES.....	56
3.2.1	Before and after survey by Dunn et al. (1996).....	56
3.2.2	Single cohort longitudinal study by Tolle et al. (1998)	58
3.2.3	Retrospective chart review by Lee et al. (2000)	60
3.2.4	Telephone survey and onsite review by Hickman, Tolle et al. (2004)	63
3.2.5	Interviews and chart reviews by Meyers et al. (2004)	64
3.2.6	Written survey of Oregon EMTs by Schmidt et al. (2004).	66
3.3	CONCLUSIONS ABOUT THE POLST RESEARCH	68
4.0	CHAPTER FOUR - CONCLUSION	70
	APPENDIX	77
	BIBLIOGRAPHY	80

INTRODUCTION

This thesis examines a health care planning device known as the POLST. The acronym “POLST” stands for Physician Orders for Life-Sustaining Treatment, and as suggested by its name, the POLST consists of a set of medical orders signed by a physician that direct the provision or withholding of specified life-sustaining medical treatments for a particular patient. In form, the POLST is similar to medical order sets that are routinely completed by doctors in hospitals and nursing homes to specify or limit life-sustaining treatments for patients who are near the end of their lives.^{1, 2} However, the POLST differs from a conventional critical care medical order set in that it is completed by a physician before the onset of a medical crisis and is based upon treatment preferences specified by the patient or a representative in advance. Moreover, unlike other end of life medical orders written in hospitals or nursing homes, a POLST may be kept at home by a patient and it is transferable between treatment settings. The POLST was developed in Oregon, and a copy of the June 2007 version of Oregon’s form is included in this thesis at Appendix A.

The POLST was created to enable patients to control the provision of life-sustaining medical treatment when they become unable to make decisions, and this feature makes the form

¹ A medical order is an order of a specifically identified medical practitioner lawfully acting within the scope of his license for a specifically identified patient’s health care needs. See e.g. Kentucky Revised Statutes, 315.010 (2006).

² A POLST order may be signed by a physician assistant or nurse practitioner where state licensing laws permit. However, for convenience, this thesis shall refer to a POLST being signed by a “doctor” or “physician.”

similar to an instructive directive or living will.³ The President’s Council on Bioethics [President’s Council] has characterized the POLST as “novel form of instruction directive” (President’s Council, 2005, p. 76). However, the POLST does not qualify as an instruction directive under state laws.⁴ The POLST is also similar to a prehospital Do-Not-Resuscitate (DNR) order that is authorized by statute or regulation in almost all states to govern care provided by emergency medical services (EMS) personnel.⁵ However, the POLST contains more comprehensive instructions than does a prehospital DNR order, and unlike a prehospital DNR order, it is intended for use in institutional settings. As of October 2007, the POLST form is in use in 19 states (Oregon Health and Science University [OHSU], 2007).⁶ Thirty-three states either have a POLST program, are developing a program, or have identified a contact for a POLST program. *Ibid.*

This thesis asks whether the POLST is really a substantial improvement over instruction directives and prehospital DNR forms. I explore and analyze whether there are weaknesses associated with use of the POLST that are similar to those associated with instruction directives and DNR forms. I also explore whether the POLST has certain unique weaknesses. Finally, I point out methodological weaknesses in the published research regarding the POLST, and

³ The terms “instruction directive” and “living will” are synonymous.

⁴ A POLST will usually not meet the requirements of state law necessary to be an instruction directive because a POLST form is not completed with the legal formalities (e.g. witnessing and notarization) that are often required for a document to be classified as an instruction directive under state law. Additionally, many instructive directive statutes require that a patient be terminally ill or permanently unconscious before an instruction directive takes effect (Meisel & Cerminara, 2007). By contrast, a POLST is effective when signed by a doctor regardless of the condition of the patient.

⁵ The term “out of hospital DNR order” is sometimes used to refer to these documents.

⁶ The nineteen states are: Oregon, Washington, Nevada, Utah, Nebraska, Missouri, Tennessee, North Carolina, Georgia, Florida, West Virginia, Hawaii, New York, New Hampshire, Michigan, Texas, Louisiana, Pennsylvania and Wisconsin (OHSU, 2007). The POLST has not been adopted statewide in Pennsylvania and Wisconsin, but is used in certain programs within those states. *Ibid.* In Pennsylvania, the legislature recently directed the state health department to study the POLST. See 20 Pa.C.S. §5488 (Added by Act 2006-169). Additionally, a state-appointed task force has recommended adoption of the POLST (Task Force for Quality at the End of Life, 2006).

question whether that research can be reasonably said to show that the POLST is any more effective than instruction directives or prehospital DNR forms in translating patient end of life treatment preferences into action.

Chapter 1 discusses the background circumstances that led to development of the POLST. The majority of deaths in the United States occur in hospitals, and these deaths often follow technologically supported efforts to maintain life that ultimately cause the dying process to be extended and unpleasant (Mularski, Heine, Osborne, Ganzini, & Curtis, 2005). Death need not occur in this manner. It is generally accepted that individuals have a right to determine the kind of medical care they will receive near the end of their lives, and people can use instruction directives to exercise their right of self-determination to limit or reject burdensome medical care. However, many studies have found that instruction directives often do not fulfill this goal because they seldom affect the medical care that patients actually receive (Ditto & Hawkins, 2005). The POLST was specifically designed to overcome the weaknesses inherent in instruction directives that cause them to be ineffective, and several studies suggest that the POLST does make a difference in how medical care is delivered (Meyers, Moore, McGrory, Sparr, & Ahern, 2004). The POLST is designed to achieve this result by building upon the model of the prehospital DNR order, and expanding it into a medical order set that is effective across treatment settings and provides immediately actionable instructions to medical personnel relative to a variety of life-sustaining treatments.

Chapter 2 discusses some of the weaknesses of the POLST. As is the case with instruction directives, there is a risk with the POLST that life-sustaining medical treatments will be forgone when the patient would have wanted them had he or she been able to communicate. Like a DNR order, a POLST that directs the withholding of certain specific life-sustaining

treatments may be incorrectly viewed by doctors as a general signal for limited treatment. There can be a lack of clarity regarding what specific procedures are covered by the POLST. It is unclear whether a physician may sign a POLST for a patient unilaterally and whether a patient or surrogate can override the form without a physician's concurrence. Finally, because it is a binding medical order set, the POLST is likely to be acted upon immediately, without pause for deliberation or consultation, and may cause the withholding or withdrawal of life-sustaining treatments in circumstances where the patient did not intend the instructions to apply.

Chapter 3 analyzes the research studies that have been published in the literature relative to the effectiveness of the POLST. I show that all of these studies have significant methodological weaknesses. I argue that it is not reasonable to conclude from these limited studies that the POLST is necessarily more effective than instruction directives and prehospital DNR forms in allowing patients to control their end of life medical care.

Chapter 4 explains my conclusion that while the POLST is a useful addition to the legal tools that patients can use to control their end of life care, only a narrow class of patients should be offered the form because of its potential to allow death to occur in circumstances where the patient might have desired treatment. The POLST is appropriate for those patients who are clearly close to the end of their lives and have strong and fixed feelings about their end of life care. The POLST is not appropriate for individuals whose end of life treatment preferences are more complicated and might vary depending upon the facts. The POLST is also usually inappropriate for individuals with stable medical conditions and many years of life expectancy. Moreover, proper use of the POLST requires that it be embedded into carefully developed process that involves training medical personnel in the form's use, screening patients for appropriateness, explaining patient treatment options in a clear and unbiased fashion, and

eliciting stable patient preferences. I observe that studies of the POLST's use in Oregon raise some caution flags about the potential for abuse. As was the case with living wills, I conclude that the POLST is being oversold to the public and policymakers, with the result that people may be led to believe that this new planning device is more useful than it really is.

The POLST form that I discuss in this thesis is the Oregon form copyrighted in June 2007 by the Oregon Health and Science University. This form is described on the POLST.ORG web site and is the model for forms used by other states (OHSU, 2007). Modifications to this POLST form by other states will not be analyzed.

1.0 CHAPTER ONE - BACKGROUND TO DEVELOPMENT OF THE POLST

1.1 THE PROBLEM OF TECHNOLOGY AND DEATH

“Over the past century, dying has become increasingly institutionalized. In the early 1900s, most people died at home, but by the middle of the 20th century, the majority of deaths in industrialized nations occurred in health care institutions” (Teno, et al. 2007). Moreover, end of life care is increasingly provided using sophisticated life-sustaining technology. Approximately one quarter of all deaths in the United States -- more than half a million deaths per year -- follow ICU therapy during the final hospitalization (Angus et al. 2004).

Technology has made the line between living and dying increasingly unclear. Most medical treatment holds the possibility of providing at least some benefit in almost every terminal illness (Callahan, 2000). Life-sustaining technology available in a modern ICU, such as mechanical ventilators and defibrillators, can often be employed by doctors to postpone a patient’s inevitable death for days or weeks. Only about 25% of ICU deaths occur following the unexpected cessation of a heartbeat or respiration. Instead, most ICU deaths occur after a decision to withhold or withdraw some form of life-sustaining treatment (Szalados, 2007; Angus, et al. 2004). As observed by Chaiten and Arnold (2001), in many institutions, “more patients die in the ICU than anywhere else in the hospital, making the management of death a more common task for ICU staff than restoring health.”

Death in an ICU is often uncomfortable. “Studies have documented a high prevalence of symptoms such as pain, dyspnea⁷, agitation, anxiety, depression, confusion, and fatigue among ICU and hospitalized patients, which may portend poor quality dying” (Mularski et al., 2005). A large study of the end of life decision making in hospitals found that more than one third of dying patients spent at least ten days in an ICU, and 46% received mechanical ventilation within three days of death (The SUPPORT Investigators, 1995). In this same study, “families reported that half of the patients who were able to communicate in their last few days spent most of the time in moderate or severe pain.” A more recent study by Teno, Clarridge et al. (2007) reported that dying hospitalized patients did not receive enough help with pain 19.3% of the time. Whether the more recent study actually indicates an improvement in care from that measured in the SUPPORT study is unclear given differences between the two studies. Regardless of the exact percentage, it is fair to say that a substantial number of people who die in hospitals today are uncomfortable in their last hours.

Many patients “when provided a choice, prefer a less intensive treatment plan than a technologically supported institutionalized plan just prior to death” (Heyland, Rocker, O’Callaghan, Dodek, & Cook, 2003). In a country where nine of ten persons say they would like to die at home, the fact that nearly one quarter will instead die in an ICU is a matter of concern (Angus et al. 2004). In many cases, life-sustaining treatments only prolong the dying process. Reducing unwanted, unnecessary, and futile interventions at the end of life can realign the intensity of care with patient preferences (Bomba & Vermilyea, 2006).

⁷ Dyspnea means difficult or labored breathing.

For at least the past thirty years, society has sought an effective method of allowing patients to control the kind of medical care they receive at the end of life.⁸ Out of these efforts came advance directives, prehospital DNR orders, and now the POLST.

1.2 ADVANCE DIRECTIVES AS A RESPONSE TO THE PROBLEM

Advance directives have been advocated by many ethicists, legal scholars, and medical organizations as a means of enhancing patient control over end of life decisions, and as a way to avoid a prolonged and unpleasant technologically supported dying process in the hospital. This legal tool to direct end of life medical care came into existence in the late 1960s, when people began to worry that new life-sustaining medical technology might keep them alive too long in an undignified state that they did not desire and might be burdensome to their loved ones (President's Council, 2005, p. 53-54). The long and highly publicized court fight over withdrawing a respirator from Karen Ann Quinlan, a young woman in a persistent vegetative state, also drew the attention of the public and policymakers. California became the first state to enact an advance directive statute in 1976, and today all states have such laws (Meisel & Cerminara, 2007, §7.01(A)). The federal government also supported the use of advance directives with the enactment of the Patient Self-Determination Act in 1990. Among other things, that law requires hospitals, nursing facilities, and certain other health care organizations receiving Medicare and Medicaid funds to inform patients of their rights under state law to

⁸ California enacted the first law to allowing patients to decide about life sustaining medical procedures in 1976. An early version of the living will was described in 1969 in an article by Luis Kutner in the Indiana Law Journal. (President's Council, 2005, p. 59).

execute advance directives and to have policies respecting the implementation of such directives.⁹

Advance directives can be classified as either proxy directives or instruction directives, and the two forms can be combined in a single document. In a proxy directive, an individual designates a surrogate to make health care decisions on his or her behalf. A health care power-of-attorney is a common form of proxy directive. In an instruction directive (often called a “living will” in its written form), the individual usually specifies circumstances under which a treating physician is to limit the provision of life-sustaining treatment (President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research [President’s Commission], 1982, p. 156)¹⁰. Instruction directives can be very specific, or generally “describe a person’s attitude toward a particular state of affairs” (p. 157).

Instruction directives are justified on both practical and moral grounds. From a practical standpoint, instruction directives can avoid the need for judicial intervention in medical decision making for incompetent patients, provide an assurance of civil and criminal immunity to providers when they carry out patient wishes to limit treatment, and reduce medical costs by limiting care that has little benefit (Meisel & Cerminara, ¶7.01(C)). Treatment preferences contained in instruction directives can shift the emotional burden of deciding whether to limit treatment for a patient away from family members, thus reducing both the possibility of family conflict and the likelihood that family members will experience guilt, resentment, self-doubt and anxiety (Wicclair, 1993). The desire not to be a burden to family is a common reason for signing an instruction directive (Duke, Thompson, and Hastie, 2007).

⁹ See 42 U.S.C. §§1395cc(f) and 1396a(a)(57).

¹⁰ In this thesis I refer to reports issued by both a President’s Commission and a President’s Council. The Commission was mandated by Congress and operated independently from January 1980 through March 1983. The Council was created in 2001 by executive order.

Instruction directives are morally justified as being “intended to effectuate the patient’s own choice, thereby honoring self-determination even when individuals no longer possess the capacity for self-determination” (Meisel & Cerminara, 2007, ¶7.01(C)). They “provide an opportunity for people to express and give effect to their personal ideas about how they would like their lives to end” (President’s Council, 2005, p. 68). This moral justification for instruction directives makes sense only if the treatment preferences expressed in the document are consistent with what the patient would want when an instruction directive is applied weeks, months, or years after the directive is written. This raises the question of whether we should assume a person who has expressed certain preferences relative to medical treatment when an instruction directive was signed would necessarily still hold those preferences later in time when that person has become unable to communicate or unable to decide.¹¹ Indeed, as I shall discuss later on, empirical research strongly suggests that treatment preferences change with time and disability, and many people who adamantly insist that they do not want certain kinds of medical treatment will change their minds when they confront the choice to refuse such treatments.

At the theoretical level, one reason why we allow an individual’s prior choices to control his or her current treatment at a time when the individual is mentally incapacitated is that we honor a concept called precedent autonomy (Davis, 2002, p. 115). A detailed analysis of precedent autonomy is beyond the scope of this thesis, but a brief discussion is in order since the moral legitimacy of following instructions given by an incapacitated person prior to such incapacity depends in large part upon the acceptance of this principle. The moral legitimacy of the POLST form is likewise based largely upon principles of precedent autonomy.

¹¹ It is nonsensical to refer to the contemporaneous treatment preferences of persons who lack all decisional capacity since, by definition, they have none. In such cases, it might be appropriate to inquire whether the treatment preferences of the individual might have changed before the individual lost all decisional capacity.

1.3 PRECEDENT AUTONOMY AND THE MORAL BASIS FOR ADVANCE DIRECTIVES

Ronald Dworkin's argument supporting precedent autonomy is often cited in the bioethics literature as the moral basis for allowing individuals to use instruction directives to control medical care they may receive in future when they are not competent to decide for themselves. In his book Life's Dominion, Dworkin (1993) argued that precedent autonomy has moral force because it is an extension of an integrity based view of autonomy that "encourages and protects people's general capacity to live their lives out of a distinctive sense of their own character, a sense of what is important to and for them" (p. 224). People have an interest in having their life "display a steady, self-defining commitment to a vision of character or achievement" and that their life as a whole be seen as an integral creative narrative (p. 205). The value of autonomy, according to Dworkin, "derives from the capacity it protects; the capacity to express one's own character—values, commitments, convictions, and critical as well as experiential interests—in the life one leads" (p. 224). Dworkin labeled the interests that people have in preserving a coherent narrative structure in their lives as "critical interests." It is our critical interests that "explain why many of us care how the final chapter of our lives turns out" (Dresser, 1995). Dworkin concluded that "a competent person's right to autonomy requires that his past decisions be respected even if they contradict the desires" he has at a later point when he is incapacitated (Dworkin, 1994, p. 228). In other words, to honor the narrative of a person's life, we must honor the individual's earlier choices (Dresser, 1995).

The concerns of Buchanan and Brock (1990) are often cited by those who oppose always giving moral priority to expressions of precedent autonomy found in instruction directives. There is always the practical issue of whether a person who signed an instruction directive was competent, adequately informed, and acted in a truly voluntary manner. Even if one accepts Dworkin's position on precedent autonomy, the treatment instructions contained in an instruction directive will not be morally binding if the patient did not act autonomously because of lack of complete information or subtle coercion. This is a real concern. As noted by Dresser (1995), "people complete advance directives in private, perhaps often with relatives, physicians, or attorneys, but often with little understanding of the meaning or implications of their decisions."

Even if an instruction directive reflects the autonomous decision of a patient regarding future medical treatment, Buchanan and Brock (1990) point out that there are significant differences between a contemporaneous decision regarding medical treatment and one expressed in an instruction directive that may warrant giving the latter less moral weight. Therapeutic options and patient prognosis may change after an instruction directive is signed. The patient's actual medical condition may be different from the one he or she contemplated when the directive was signed. The patient's preferences for treatment may change in ways that were not anticipated by the patient when the directive was signed. Indeed, on this last point, the research literature appears to show the existence of what some have called a "disability paradox," where individuals who once held very negative beliefs about living a certain way decide that life is indeed worth living even in very burdensome circumstances (Hertogh, deBoer, Dröes, & Eefsting, 2007). It can also be argued that psychological changes in an incapacitated person can be so profound that earlier choices lack moral authority to control what happens in the present

(Dresser, 1995; Buchanan & Brock, 1990).¹² Finally, informal safeguards that restrain imprudent or unreasonable contemporaneous choices, such as counter-arguments by family members, are not present when an instruction directive is applied.

The weight we should give to precedent autonomy, and the respect we should give to the treatment preferences an incapacitated person previously expressed through an instruction directive, remains disputed in the bioethics community (Levine, 2006). Always honoring a patient's precedent autonomy is controversial because "when health care professionals honor advance directives that call for life-sustaining treatment to be forgone, patients die" (Wicclair, 1993, p. 45). Dresser (1994) contends that although "precedent autonomy clearly is important to many of the philosophers, legal academics, and policy makers writing on this subject," it does not appear to be very important to the public. She argues that people often prefer to have loving family members decide their medical treatment if they become incapacitated.

Moreover, honoring precedent autonomy expressed in the form of an instruction directive can sometimes lead to morally uncomfortable consequences. This is especially true where it appears that the patient's medical situation was not anticipated. An iatrogenic cardiac arrest is one example of an unanticipated medical situation where honoring patient instructions to withhold care is morally problematic for many doctors. Casarett, Stocking, and Siegler (1999) report that 69% of surveyed physicians in an urban community teaching hospital said they would refuse to honor a patient requested DNR order when the patient arrested due to physician error.

¹² The argument that changes in the brain may result in a different "person" than the one who signed an advance directive is based upon the contention there is a psychological discontinuity between the person who signed the directive and the existing patient (Buchanan & Brock, 1990). This position asserts that damage to the brain resulting from conditions such as Alzheimer's disease may be so significant that the moral actor who issued an advance directive no longer exists and therefore an advance directive has no moral authority to direct the experiential interests of the individual who remains. *Ibid.* A complete treatment of the psychological discontinuity argument is beyond the scope of this thesis.

Another difficult situation is presented when an instruction directive requires the withdrawal or withholding of treatment for an incapacitated individual who appears to be in no discomfort. The example of the now pleasantly demented patient who develops an easily treatable illness, but who previously signed an instruction directive refusing treatment, is often cited as an example when applying precedent autonomy may be inappropriate (Buchanan & Brock, 1990, p. 108). Dworkin (1993) used the example of a pleasantly demented patient named “Margo,”¹³ and concluded that an instruction directive by this patient declining medical treatment for other illnesses should be enforced. He argued that we should enforce Margo’s instruction directive because if we refuse to do what she wanted when she was competent, “that would not be compassionate towards the whole person who tragically became demented.” (p. 232). Many disagree with this conclusion.

The President’s Council (2005) takes a position contrary to that of Dworkin in Margo-type cases and argues that in cases of dementia we should not overvalue precedent autonomy. Instead, the Council argues that we should focus on the present welfare of the patient in making treatment decisions. Illustrating the deep divide on the weight that should be given to precedent autonomy in such cases, one President’s Council member wrote a stinging dissent stating that the “clear message from this report is, if you feel strongly about not living in a decerebrate state, you better kill yourself while you have control over your fate” (p. 229).

Although the scope of precedent autonomy remains debatable as an ethical matter, it is essentially settled as a matter of law that competent individuals have a right to control future treatment when they become incapacitated (President’s Council, 2005, p. 60). However, this

¹³ Margo’s case is described by Andrew Firlík in a column titled “A Piece of My Mind. Margo’s Logic,” published in the *Journal of the American Medical Association*. See Firlík, A (1991) *JAMA*, 265: 191.

right is not absolute and may be regulated by the state. In Cruzan,¹⁴ a majority of the United Supreme Court upheld a Missouri statute requiring clear and convincing evidence of a patient's wishes before allowing a surrogate decision maker to terminate life-sustaining treatment. In Glucksberg,¹⁵ the Supreme Court held that terminally ill individuals do not have a right to a commit suicide and it follows from that court decision that an advance directive requesting euthanasia will not be honored. A number of state statutes place restrictions on the extent to which patients can exercise precedent autonomy to control the medical treatment they receive when they become incapacitated.

One significant area where the law often does not give effect to precedent autonomy is with respect to revocation of non-treatment instructions contained in an advance directive. Following the recommendation of National Conference of Commissioners on Uniform State laws in their proposed Uniform Rights of the Terminally Ill Act, many state statutes provide that an advance directive may be revoked by a patient without regard to his or her mental state (Meisel & Cerminara, 2007, ¶7.08(A)). In these jurisdictions, an incapacitated individual need only muster the ability to communicate a present desire for treatment in order to overrule a prior advance directive to the contrary. As to why many states have such a rule, it may be that it just “generally seems wrong” to withhold treatment when “a patient, no matter how confused, asks that treatment be continued” (President’s Commission, 1983, p. 152). Even in the case of cognitively impaired persons, it is arguably contrary to respect for persons to disregard their contemporaneously expressed preferences (Wicclair, 1993, p. 185). Like most things in bioethics, honoring precedent autonomy is not an absolute imperative.

¹⁴ Cruzan v. Director, Missouri Department of Health, 497 U.S. 261, 110 S.Ct. 2841 (1990).

¹⁵ Washington v. Glucksberg, 521 U.S. 702, 117 S.Ct. 2302 (1997).

1.4 INSTRUCTION DIRECTIVES HAVE LIMITED EFFECTIVENESS

Notwithstanding their widespread support by ethicists, lawyers, and others, the value of instruction directives in guiding medical treatment that is received near the end of life remains in dispute (Teno, Gruneir, et al., 2007).

Most studies of advance directives do not differentiate between instruction directives and proxy directives and almost all of these studies have found that advance directives have little effect on what happens in the hospital and ICU. For example, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) reviewed the care received by 618 patients with advance directives (i.e. proxy directives, instruction directives, and combined forms) and found that such directives “were irrelevant to decision-making” for end of life hospital care (Teno et al. 1994). Similarly, Kish Wallace, Martin, Shaw, and Price (2001) examined the records of 135 matched pairs of critically ill cancer patients admitted to the ICU of a comprehensive cancer center with and without advance directives. They found that “there were no differences regarding the frequency with which life-supporting interventions were initiated with and without advance directives.” According to Ditto and Hawkins (2005), the “institutionalization of advance directives in American law and medical practice....stands in stark contrast to a growing body of research challenging their effectiveness in producing specific improvements in end of life medical care.”

Still, a conclusion that instruction directives are ineffective is not warranted. Teno, Gruneir et al. (2007) found that patients with an advance directive (i.e. a proxy directive or an instruction directive) were significantly less likely to die in an ICU and that such directives were “associated with less use of life-sustaining treatment, greater use of hospice and less likelihood of terminal hospitalization.” Degenholtz, Rhee and Arnold (2004) specifically studied

instruction directives and found that they “are associated with a lower probability of in-hospital death for people older than 70 years of age, after adjustment for health status and other factors.” Both of these recent studies attempted to address the fact that many prior studies of the effectiveness of advance directives involved patients who were already hospitalized. Thus, the current state of the literature suggests that instruction directives have limited effect in determining what care a patient receives in a hospital or ICU, but they may have greater influence in determining whether an individual is taken to a hospital in the first place.

Instruction directives suffer from the unsolvable problem of trying to direct specific medical care that will be provided in a nursing home, hospital, or ICU under unknown future circumstances. If an instruction directive is drafted broadly, then it must be interpreted by doctors and the family, and the steps to be taken under it are often unclear. If the directive is drafted narrowly, then the range of circumstances to which it applies is likewise narrow or “its length and complexity would have to be increased” (President’s Commission, 1982, p. 157). Regardless of its breadth, instruction directives can only address “a limited range of medical situations that occur frequently enough to be of general concern to people” (p. 158). The President’s Commission concluded that instruction directives have “limited use in providing effective self determination” (p. 157).

Even if an instruction directive is sufficiently specific to provide meaningful direction for a patient’s particular medical condition, there are numerous procedural obstacles to its implementation. Ditto and Hawkins (2005) set forth a series of distinct hurdles that must be overcome before a patient’s wishes will be honored through an instruction directive. First, the patient must complete the directive. This alone can be a significant barrier since it has been estimated that only 15-20% of Americans complete advance directives (Lee, Brummel-Smith,

Meyer, Drew & London, 2000). The completion rate may be much higher among people near death, since Teno, Clarridge et al. (2007) found an advance directive (living will or proxy directive) completion rate of 70.7% for decedents in a survey of deaths that occurred in 22 states. It should be noted that the high advance directive completion rates found by Teno, Clarridge et al are an outlier in the literature. Assuming the advance directive completion rates found by Teno, Clarridge et al. are correct, there are still three out of ten individuals who have left no written instructions to guide treatment at the end of life.

Assuming the patient completes an instructive directive, there are the other barriers to compliance with patient treatment preferences identified by Ditto and Hawkins (2005). The wishes expressed in the instruction directive must be authentic, that is to say they must accurately predict what the patient will actually want when the time to apply the directive arrives. Surrogates responsible for the patient must know of the existence of the advance directive so it can be retrieved and presented to the patient's physician. Next, the persons responsible for the patient must be able to interpret and apply what is written in the directive to the patient's current condition. The patient's surrogate must be willing to allow the doctor to implement of the instruction directive.¹⁶ Finally, the physician must be willing to honor the directive.

It is clear that instruction directives often do not cause doctors to implement end of life treatment preferences expressed by patients. As a result, many patients who want to control their

¹⁶ Ditto and Hawkins (2005) include surrogate consent to implementation of an instruction directive as a step in its implementation. A surrogate need not be involved with implementation of an instruction directive but, as a practical matter, it is usually a spouse or child who produces the directive. Also, a physician will likely hesitate before implementing an instruction directive to withdraw or withholding treatment over the strenuous objections of a designated surrogate decision maker.

care at the end of life are unable to do so. This had led to a search for other legal devices that a patient can use to provide instructions that will direct his or her end of life medical care.¹⁷

1.5 THE EMERGENCE OF PREHOSPITAL DNR ORDERS

Another form of advance planning document that patients can use to provide instructions regarding the end of life medical care they will receive if they become incapacitated is the prehospital DNR order. State statutes authorizing prehospital DNR orders were enacted to address the situation of EMS personnel called in response to a medical crisis suffered by a patient who does not desire resuscitation. Often these individuals have a terminal condition and hope to die peacefully at home, but when they unexpectedly suffer respiratory distress or are in obvious pain, a spouse or other person calls 9-1-1 and EMS personnel are dispatched. If the patient then arrests, EMS personnel are confronted with the decision whether to resuscitate. Since EMS personnel usually operate under strict protocols set up by a governing body that favor resuscitation, the patient will often be resuscitated contrary to his or her wishes (Iserson, 1989). One purpose of the prehospital DNR order is to avoid “emotionally stressful, obviously inappropriate, and unwanted resuscitative efforts in the terminal patient” (Byock, 1989).

The prehospital DNR order “was created to allow individuals to provide an advance directive to emergency medical technicians (EMTs) regarding their desire for or against resuscitative treatment, thus becoming one of the last areas of medicine to do so” (Hall, 1997).

¹⁷ I do not discuss proxy directives in this section because such directives are not used to guide specific future medical treatments. Instead, an individual uses a proxy directive to designate someone else makes medical judgments on his behalf. (President’s Council, 2005). By contrast, instruction directives, prehospital DNR forms, and the POLST all share the characteristic of containing specific treatment instructions to be applied in the future. Although hybrid documents combining instructions with a proxy directive are often used, a POLST does not contain a proxy directive and is not similar to such a device.

Hall (1997) states that this form of DNR order “attempts to remedy the shortcomings other advance directives present in prehospital decision making by providing a simple and rapid means of identifying those individuals who do not wish to be resuscitated.” Typically, a bracelet, necklace, or card is provided to the patient (Adams, 1993).

State laws authorizing prehospital DNR orders are a relatively recent development. As of 1989, Iserson reported “no jurisdiction currently has a formal provision for generalized prehospital DNR orders.” By 1999, at least 42 jurisdictions had a law or regulation providing for such orders (Feder, Matheny, Loveless, & Rea, 2006). By 2005, the number of jurisdictions allowing prehospital DNR orders had grown to 44 (American Medical Association, 2005). However, notwithstanding its wide endorsement by state legislatures, the prehospital DNR form does not appear to be widely used. A survey of Washington State physicians found that many doctors were unaware that prehospital DNR orders existed (Silveria, Buell, & Deyo, 2003).

Data on the utilization of prehospital DNR forms, and compliance with DNR instructions is minimal (American Medical Association, 2005). One study by Lerner, Billittier, and Hallinan (2002) reported that one quarter of surveyed physicians in New York said that their prehospital DNR orders had been ignored at least once, but this may be explained by the fact that less than half of responding physicians used the official state form. In theory, prehospital DNR forms should be more effective than conventional instruction directives in limiting unwanted resuscitation at the end of life because several of the barriers to compliance with patient preferences that exist with respect to instruction directives are addressed by the prehospital DNR form. There is no need to search for a document since a DNR bracelet or necklace usually makes the patient’s desire for a DNR order evident. Issues of interpretation common to instruction directives are lessened with prehospital DNR orders because the form refers to

specific medical procedures, and implementation of the order is not contingent upon a doctor being on scene to make a needed diagnosis or prognosis prior to implementation. Most importantly, state laws or regulations authorize EMS personnel to honor the DNR form without further physician instructions.

Although the prehospital DNR form promises to allow patients increased control over their end of life medical care, the limitations inherent in this advance-planning tool preclude it from having much of an effect on the medical care most people receive near the end of their lives. The form is usually limited to addressing resuscitation procedures only -- it says nothing about the other common medical procedures that people must often endure near the end of their lives. As with many hospital DNR documents, it can sometimes remain unclear just what the order means in particular circumstances (Iseron, 2002). There may remain uncertainty as to whether EMS personnel should perform intubation, ventilation, or cardioversion when the patient has not arrested (Lerner et al. 2002). The form is also intended primarily as a guide for EMS personnel. It does not direct care that a patient receives in a hospital emergency room or ICU.

The POLST addresses most of these deficiencies. It is to that new end of life planning device we now turn.

1.6 THE POLST IMPROVEMENT

In 1991, a multidisciplinary task force consisting of Oregon healthcare providers and organizations came together to address the problem of unwanted intensive medical interventions and unwanted transfers to hospitals (Tolle & Tilden, 2002). The goal of the task force was to

develop a way for patients to express their end of life treatment preferences through a form that would be respected by medical personnel across treatment settings. Ibid. The result was a brightly colored POLST form that “converts patient and surrogate preferences for a variety of life-sustaining treatments into medical orders” (Hickman, Tolle, Brummel-Smith, & Carley, 2004). One purpose of the POLST form is to “prevent hospitalization during the dying process if the participant wants to receive comfort care at home” (Lee, Brummel-Smith, Meyer, Drew & London, 2000).

Initially, the POLST was suggested for use by a broad spectrum of the population and not just the terminally ill. Until late 2006, the official POLST.ORG web site said that any person with a “serious health condition” could consider using the form (OHSU, 2006). However, the POLST’s designers changed their recommendations regarding use of the form in 2006 and the POLST.ORG web site now states that the form “is most appropriate for seriously ill persons with life limiting, also called terminal, illnesses” (OHSU, 2007). The revised web site goes on to say that “to determine whether a POLST form should be encouraged, clinicians should ask themselves, ‘Would I be surprised if this person died in the next year?’ If the answer is ‘No, I would not be surprised,’ then a POLST form is appropriate.” Ibid. The revised web site also now states that “[u]nless it is the patient’s preference, use of the POLST form is not appropriate to limit treatment for persons with stable medical or functionally disabling problems who have many years of life expectancy.” Ibid.

POLST task force members have described the document as “one example of a progressive AD [advance directive],” a category which includes do-not-hospitalize orders and has a direct effect on treatment (Hickman, Hammes, & Tolle, 2004). The President’s Council (2005) calls the POLST a “novel form of instruction directive” (p. 76). It is difficult to classify

the POLST because while it has many of the characteristics of an instruction directive, it is not an instruction directive under state laws due to the lack of legal formalities generally required for instruction directives such as, for example, having the signatures of witnesses.

Instead, the POLST is a set of medical orders. A medical order is an order of a specifically identified medical practitioner lawfully acting within the scope of his or her license for a specifically identified patient's health care needs.¹⁸ As a medical order set, a POLST must be followed by nurses and other medical professionals unless countermanded. Additionally, because the POLST has the characteristic of being transferable across treatment settings, it differs from a conventional critical care medical order set. Ordinarily, medical orders governing life-sustaining treatments can be written only by physicians who have privileges where the patient is currently receiving care.

The POLST provides specific treatment instructions with respect to four items: (1) cardio-pulmonary resuscitation (CPR); (2) the level of medical intervention (ranging from comfort care at home to intensive hospital treatments); (3) antibiotic use; and (4) feeding tubes and IV fluids (long term or short term) (Lee et al., 2000). However, the POLST involves more than just a form. The designers of the POLST also crafted a set of requirements and processes to govern how the form is used. These requirements and processes are referred to as the POLST paradigm. The core criteria for the POLST paradigm are established by a National POLST Paradigm Initiative Task Force, and are listed on the POLST.ORG web site as follows:

1. The form constitutes a set of medical orders
2. The process includes training of health care professionals across the continuum of care about the goals of the program as well as the creation and use of the form

¹⁸ The definition is taken from Kentucky Revised Statutes, §315.010 (2007).

3. Use of the form is recommended for persons who have advanced chronic progressive illness, those who might die in the next year or anyone wishing to further define their preferences of care¹⁹
4. The form requires a valid Physician (Nurse Practitioner or Physician Assistant accepted depending upon program) signature and date of signature
5. The form may be used either to limit medical interventions or to clarify a request for all medically indicated treatments including resuscitation
6. The form provides explicit direction about resuscitation status if the patient is pulseless and apneic
7. The form also includes directions about other types of intervention that the patient may or may not want. For example, decisions about transport, ICU care, antibiotics, artificial nutrition, etc.
8. The form accompanies the patient, and is transferable and applicable across care settings (i.e. Long term care, EMS, hospital)
9. The form is uniquely identifiable, standardized, uniform color within a state/region
10. There is a plan for ongoing monitoring of the program and its implementation

(OHSU, 2007).

There are optional elements of the POLST paradigm as well. These optional elements involve whether to require a patient signature on the form, the role of surrogates, whether the POLST form will replace a separate out-of-hospital DNR form, and whether a state will recognize forms completed in other states. Ibid. In late Fall 2006, the National POLST Paradigm Initiative Task Force clarified the paradigm to say that it “strongly recommends” that the patient or a representative sign the form. Ibid.

¹⁹ As noted *supra*, the National POLST Paradigm Initiative Task Force has clarified this paragraph to make clear that unless it is the patient’s preference, a POLST is not appropriate for individuals with stable medical or functionally disabling problems who have many years of life expectancy (OHSU, 2007).

The POLST form contains boxes for both withholding and providing various forms of life-sustaining treatment covered by the form. Full treatment can be requested via a POLST. However, it seems most people use the POLST to limit medical care. A survey of POLST forms in seven Oregon nursing facilities found that 88% of POLST forms had the DNR box checked (Hickman, Tolle et al. 2004). A smaller study of 54 patients in one site of the Program for All-Inclusive Care for the Elderly (PACE) similarly found that 93% of the forms specified DNR (Lee et al., 2000). These findings are consistent with what researchers have found regarding how people use advance directives. Teno et al. (1997) found that patients “rarely employed ADs [advance directives] to encourage the use of life-sustaining treatment.” Dr. Alvin Moss of the West Virginia Center for End of Life Care said some people have joked that the POLST should be called Physician Orders Against Life-Sustaining Treatment “because most of the time people are completing the form because there’s one or more life-sustaining treatments they don’t want” (Rotstein, 2007). A POLST is probably unnecessary for a person who desires all medically indicated life-sustaining treatment, because full treatment is ordinarily the medical default position, even without a specific request from the patient.

Under the POLST paradigm, a POLST form should not be prepared for a patient without a conversation with a healthcare professional regarding the patient’s preferences (OHSU, 2007). However, the conversation need not be with the patient. The POLST paradigm recognizes that surrogates can provide instructions and the POLST.ORG web site says, “a health care professional can complete the POLST Paradigm form based on family members' understanding of their loved one’s wishes.” Ibid Additionally, the healthcare professional who has the conversation with the patient, a surrogate, or a family member need not be the physician who signs the POLST. Ibid. Indeed, in Oregon, it is reported that social workers complete the

POLST for a physician's signature at 40% of the nursing homes that use the form (Lorenz 2004). The POLST form contains a space for the name and identifying information of the healthcare professional completing the form, but completion of that information is optional. Likewise, the signature of the patient or surrogate is optional although, as noted above, the National POLST Paradigm Initiative Task Force now strongly recommends that state programs require a patient or surrogate signature (OHSU, 2007). The only signature that is required on the form is that of a physician.

A POLST does not replace conventional advance directives and may co-exist with them. The POLST.ORG web site says, "even if you have an advance directive, the POLST paradigm form is recommended" (OHSU, 2007). The issue of conflicts between a POLST and an advance directive will be discussed *infra*.

In theory, the POLST should be much more effective in translating patient treatment preferences into action in the ICU and elsewhere because it eliminates many of the barriers to completion and implementation of an advance directive. Two barriers to completion of advance directives are the legalistic process required to complete them and confusion about the role of health care professionals in explaining them (Duke, Thompson, & Hastie, 2007). The POLST is simple to fill out and must be explained to the patient by a physician or other medical professional. The POLST also overcomes the problem of treatment instructions contained in advance directives not being included in the patient's medical record. The POLST paradigm requires that the form be a medical order set that is part of the patient's medical record.

Several studies suggest that physicians and other medical personnel generally honor the medical orders on the POLST form. Tolle, Tilden, Nelson and Dunn (1998) followed 180 persons who had a POLST form in eight Oregon long-term care facilities. Of the 38 patients

who died, 95% died in the nursing home consistent with the instructions indicated on the POLST form. Lee et al. (2000) conducted a chart review of the care received by 54 participants at an Oregon site of the national Program of All-Inclusive Care for the Elderly who had a POLST in the medical record and died between January 1, 1997 and December 31, 1997. The authors found that compliance with POLST instructions relative to CPR was 91%, and for feeding tubes was 94%. Medical compliance with instructions relative to antibiotic administration and IV-fluids was 86% and 84%, respectively. Only with respect to level of care instructions was there significant non-compliance with POLST orders. Care was less intensive than indicated on the POLST form in 33% of the cases and was more invasive in 20% of the cases. Meyers, Moore, McGrory, Sparr and Ahern (2004) similarly conducted a chart review of care received by 21 residents in four Washington State nursing homes who had POLST forms. This study found that medical care was congruent with the instructions on the POLST form in 19 of the 21 cases. Finally, Schmidt, Hickman, Tolle and Brooks (2004) surveyed 572 Oregon EMTs regarding their experience with the POLST. The investigators found that 403 had seen one or more patients with a POLST. In nearly half of these situations, the EMTs changed their standard treatment plan based on the form.

Based on the foregoing research the POLST is often described in the literature as being effective. For example, a comment by Farber, Shaw, Mero and Maloney (2006) in the *Annals of Internal Medicine* asserts that “research has demonstrated [the POLST’s] effectiveness in helping patients have their preferences for end of life care honored, even when emergency medical services (EMS) are concerned.” Bomba and Vermilyea (2006) likewise assert that “a decade of research in Oregon has proved that the POLST program more accurately conveys end of life preferences that are more likely to be followed by medical professionals than traditional advance

directives alone.” The President’s Council (2005) similarly declares that the POLST “has shown high rates of compliance and effectiveness” (p. 76). What is not discussed in the literature is whether the POLST has weaknesses. It is to that issue that I now turn.

2.0 CHAPTER TWO - THE POLST'S WEAKNESSES

The POLST suffers from some of the same weaknesses and disadvantages that are associated with conventional instruction directives. As is the case with instruction directives, there is a risk with the POLST that life-sustaining medical treatments will be forgone in circumstances the patient did not contemplate, or when the patient would have wanted them had he or she been able to communicate. This risk is unavoidable whenever an individual tries to control his or her medical treatment outside of the context of a specific medical crisis. Additionally, a POLST may fail to communicate a patient's authentic treatment preferences much in the same way that an instruction directive can fail as an act of communication.

The POLST also has some of the weaknesses associated with DNR orders. Like a DNR order, the POLST may be perceived by physicians as a signal for limited treatment in general, and not just as a refusal of particular medical procedures. Both forms are medical orders kept in a patient's medical chart after hospitalization or admission to a medical facility, and this limits a patient's ability to revoke or change the form unilaterally. Both forms can be completed based upon the instructions of surrogates who may do a poor job in predicting patient treatment preferences. Finally, the medical order status of both forms may deter nurses and emergency medical personnel from exercising their own professional judgment.

The POLST also has unique weaknesses. The POLST paradigm eliminates important safeguards of the institutional credentialing and privileging systems. The fact that a POLST may

co-exist with conventional instruction directives gives rise to the possibility of a conflict between end of life instructions contained in different documents.

2.1 WEAKNESSES SIMILAR TO INSTRUCTION DIRECTIVES

The POLST has some of the same weaknesses that have been documented in the literature with respect to instruction directives. As discussed in more detail below, these weaknesses arise from the difficulty in making sound medical decisions in advance and outside of a medical context, the possibility that the form may not correctly reflect the patient's treatment preferences, and the possibility that patient preferences will change over time without the form being updated.

2.1.1 The Risk in Making Decisions Outside of Medical Context

Like an instruction directive, the POLST attempts to control how life-sustaining medical care is delivered outside of the context of a particular medical crisis. However, any attempt to control the delivery of medical care to a patient before it is needed is inherently problematic. There is “an inherent tension between ensuring that dying patients have a means of expressing their wishes about treatment termination before they are overcome by incompetence and ensuring that people do not make binding choices about treatment on the basis of hypothetical rather than real facts about their illness and dying process” (President's Commission, 1983, p. 143).

The fundamental problem is that one cannot know in advance the particulars of the medical crisis that one will face. As observed by the President's Council (2005):

There are, to begin with, simply too many possible future situations that the patient must try to imagine, each with its unique combination of burdens, benefits, and risks, making the notion of "informed consent" long in advance of treatment a highly questionable one. And those patients who are tempted to reject certain kinds of future medical intervention (on the ground that they "wouldn't want to live like that") may not understand how short-term use of some of the same interventions could restore them to basic or even normal function. (p. 73)

Fagerlin and Schneider (2004) argue that instruction directives are primarily useful for people "whose medical situation is plain, whose crisis is imminent, whose preferences are specific strong and delineable, and who have special reasons to prescribe their care." The same is true for the POLST.

There is clearly a danger of causing a death that is not desired by the patient when medical orders refusing CPR and other forms of life-sustaining treatment are written for people who are relatively healthy with years to live. Prior to the Fall of 2006, the recommended use of the POLST was not narrowly tailored and the POLST.ORG web site suggested that any person with a "serious health condition" could consider using the form (OHSU, 2006). This liberal eligibility criterion caused some Oregon hospitals to mandate use of the POLST form regardless of patient health status. Tolle and Tilden (2002) reported that "some hospitals now mandate the completion of a POLST form at discharge for patients transferred to long-term care facilities, other institutional settings, or home hospice" (p. 314)(emphasis added). A number of Oregon nursing homes were found to be filling out the form for virtually all patients in the facility. Hickman, Tolle et al. (2004) surveyed POLST forms in seven facilities in 2002 and found 92% of the patients had such forms, and 88% of these forms had the DNR boxes checked. However, since 44% of Oregon nursing facility patients were healthy enough to be discharged to their

homes in 2002, one must question why so many patients in the surveyed facilities had POLST forms with DNR boxes checked (Office of Oregon Health Policy and Research, 2002). These numbers certainly raise a question as to whether large numbers of relatively healthy individuals were using the POLST to reject life-sustaining treatments and, if so, why?

The POLST's designers appear to have recognized that the form was being offered to some people inappropriately. The POLST.ORG web site was revised in late 2006 to state that the form "is most appropriate for seriously ill persons with life limiting, also called terminal, illnesses" (OHSU, 2007). The revised web site also now states that "[u]nless it is the patient's preference, use of the POLST form is not appropriate to limit treatment for persons with stable medical or functionally disabling problems who have many years of life expectancy." *Ibid.* This change should result in the POLST form being offered less often to patients who are not near the end of their lives. Still, even with respect to terminally ill patients, there remains the possibility that a POLST will be applied in unintended circumstances. No individual can know the medical future with absolute certainty, and as is the case with instruction directives, use of the POLST carries with it the possibility that the form will be applied in unintended circumstances.

2.1.2 The Potential for Poor Disclosure and Understanding of Options

A second weakness common to both the POLST form and conventional instruction directives is the possibility that what is written on the form may not reflect authentic patient treatment preferences. If a patient lacks decisional capacity, if treatment options are not correctly explained, if a patient does not understand them fully, or if a patient is steered in a certain

direction, then the patient preferences indicated on the POLST form are not authentic because they are not truly reflective of an informed choice of treatments by the patient.

As is the case with conventional instructions directives, patients must have decisional capacity in order to articulate meaningful preferences that are reflected in a POLST. A person is said to have decision making capacity relative to medical decisions if he or she has “sufficiently stable and developed personal values and goals, an ability to communicate and understand information adequately, and an ability to reason and deliberate sufficiently well about the choices” (President’s Commission, 1983, p. 45). When a patient does not possess these characteristics, then the ability to make decisions is limited, and he or she “needs to be protected against the adverse consequences of a flawed choice” (President’s Commission, p. 44). Determining whether a patient has capacity to forego life-sustaining treatment should ordinarily be made the same way that capacity is determined for other significant decisions regarding medical care (President’s Commission, p. 45). Judgments of capacity are usually based on an informal evaluation of the patient’s general mental state and his or her ability to understand and make the decision at hand (Buchanan & Brock, 1990). When questions arise, a formal medical evaluation of capacity may be requested. A medical determination of capacity involves obtaining a detailed medical history from the patient, a collateral history from the family, and a focused physical examination that includes cognitive, function, and mood screens (Bomba & Vermilyea, 2006). Although some sort of patient capacity assessment should occur before a POLST is completed based upon a patient’s stated treatment preferences, the POLST paradigm does not explicitly require one.

Additionally, because it is a medical order set intended for use by medical professionals, the POLST contains technical medical jargon that is not easily understood by patients.

Treatment modalities such as “intubation” and “cardioversion” that are listed on the form must be thoroughly explained before patients can knowingly say whether or not they want them. The patient must also understand the explanation. In the living will context, this often does not happen. For example, Thorevska et al. (2004) found that many “patients with living wills did not fully understand them and had end of life wishes that were not reflected fully in their documents.” Unless the form is carefully explained, it is likely that similar confusion occurs with the POLST.

Individuals assisting patients in expressing their preferences on a POLST must be careful to communicate that knowledge in a way that allows the patient to exercise bona fide self-determination in choosing treatment options. Wording used in describing a medical treatment is often crucial. Like other types of medical judgments, “decisions about life-sustaining treatment can be dramatically affected by small changes in the way questions are framed” (Ditto & Hawkins, 2005). As observed by Fagerlin and Schneider (2004), “an ocean of evidence affirms that answers are shaped by the way questions are asked. Preferences about treatment are influenced by factors like whether success or failure rates are used, the level of detail employed, and whether long-term or short-term consequences are explained first.” Similarly, the President’s Commission (1982) stated:

It is well known that the way information is presented can powerfully affect the recipient’s response to it. The tone of voice and other aspects of the practitioner’s manner of presentation can indicate whether a risk of a particular kind with a particular incidence should be considered serious. Information can be emphasized or played down without altering the content. And it can be framed in a way that affects the listener – for example, “this procedure succeeds most of the time” verses “this procedure has a 40 percent failure rate.” Health care

professionals should, therefore, present information in a form that fosters understanding. (p. 67).

Finally, there is the risk that patients may be pressured into authorizing a POLST and expressing treatment preferences when they really have no such preferences. Many people lack preferences regarding specific medical procedures and would rather leave end of life decisions to family members when the time comes. Others would simply prefer not to deal with the issue at all. The psychological assumptions behind advance directives were explored as part of the Advance Directives, Values Assessment, and Communication Enhancement (ADVANCE) project. One ADVANCE study surveyed 337 community dwelling patients with a mean age of nearly 73 years. “When interviewers asked patients how they wanted decisions made for them, most expressed a preference for having several people talk and then one person (presumably the surrogate decision maker) make the final decision alone” (Hawkins, Ditto, Danks, & Smucker, 2005). Very few of the patients wanted a document like the POLST that provides strict directions regarding treatment. *Ibid.* As observed by the President’s Council (2005), some people are simply “content to delegate decisions to family members” and see documents like the POLST as “putting too much emphasis on self-determination rather than solidarity” or as “implying that disabled persons are better off untreated” (p. 72). Before a patient asked to indicate his or her preferences relative to the medical treatments covered by a POLST form, it is necessary to make sure that the patient is comfortable making those decisions in the first place.

The risk that what is written on the POLST form may not reflect what the patient truly desires can be minimized if individuals assisting in the POLST process are carefully trained in communication skills. The POLST paradigm is supposed to involve more than the mere completion of a form. Implemented correctly, the POLST paradigm is a “comprehensive,

systems-based approach to ensure advance care planning and end of life decision making” (Bomba & Vermilyea, 2006). The POLST paradigm explicitly requires “training of health care providers across the continuum of care about the goals of the program as well as the creation and use of the form” (OHSU, 2007). However, the extent to which training occurs varies by state and treatment setting, and the details of this training are left to individual state programs. There is no requirement in the POLST paradigm that individuals in hospitals and nursing homes who help patients fill out the form be trained on the POLST as a job requirement. There is also no requirement that doctors be trained on use of the POLST before they can sign one. Since the POLST is embedded within a set of requirements and processes for its proper use, one cannot assume that physicians will understand how to use the form correctly merely by virtue of being doctors.

Incomplete and inaccurate explanation of treatment options, failure by the patient to understand those options, as well as the use of language that either intentionally or unintentionally shapes patient preferences, can cause treatment preferences expressed in a POLST to be non-authentic. The possibility that inauthentic treatment preferences are expressed in the document is a weakness that the POLST shares with conventional instruction directives.

2.1.3 Changed Treatment Preferences

A third weakness that the POLST shares with instruction directives is a vulnerability to changed patient treatment preferences. Like an instruction directive, a POLST cannot express the real-time autonomous preferences of an incapacitated patient because it is impossible to know the wishes of a person who cannot express them. (Emanuel, 1995) Instead, we are required to apply

previously articulated patient treatment preferences expressed through the written document. This approach makes sense if we accept the concept of precedent autonomy, but is questionable if there is reason to suspect that a patient's previously expressed treatment preferences changed before the individual became incapacitated or non-communicative.

Ditto and Hawkins (2005) observe that a “number of studies have found preferences for life-sustaining treatment in response to hypothetical end of life scenarios to be only moderately stable over time.” Several studies suggest that overall, the proportion of people with stable preferences over a one or two year time period is around 75% (Ditto et al. 2003). However, there is considerable variation within subgroups. Several studies suggest “declining health status is associated with a greater willingness to bear the burdens of therapy” (Fried et al. 2006). Danis, Garrett, Harris and Patrick (1994) found that while treatment preferences are extremely stable among relatively healthy people, patients who suffered an accident or who were hospitalized were more likely to change their choices to elect more treatment. It appears that preference construction may be highly dependent upon context. If a patient's medical condition is unstable, the patient's treatment preferences may also be unstable (Ditto & Hawkins, 2005). In general, it seems that people are more prepared to accept treatment once they become sick than their prior statements would indicate (Callahan, 2000, p. 50).

Most studies of stability of preferences involved community dwelling elderly, but there is some research involving hospitalized patients as well. Rosenfeld et al. (1996) specifically examined the stability of preferences among seriously ill hospitalized patients over a period of two months. Using data from the SUPPORT project, the investigators examined treatment preferences for CPR versus DNR among more than 2000 patients. After two months, preference stability was 80%, with 135 patients (8.5%) changing to favor CPR. Ditto, Jacobson, Smucker,

Danks, and Fagerlin (2006) also studied stability of preferences among elderly hospitalized patients. They found high rates of preference stability (93%) among people refusing CPR and artificial nutrition and hydration. However, preference stability was much lower for refusals of gall bladder surgery (82%) and antibiotics (75%).

Many people who think they would never want to live with medical supports such as feeding tubes change their minds when the time comes. When questioned, individuals will often “express themselves positively on their quality of life, notwithstanding the fact that their actual existence strongly contrasts with formerly held standards: their affirmation of life seem almost ‘out of character’” (Hertogh, et al., 2007). People with chronic illness and disability often emotionally adapt to their conditions and experience relatively high levels of mood and quality of life (Ubel, Lowenstein, Schwartz, & Smith, 2005). This effect has been dubbed the “disability paradox.” (Kutner, et al, 2003). Thus, for example, a study of attitudes and perceptions held by 66 hospice patients found that quality of life was preserved and a positive outlook prevailed. Ibid. This effect is both typical and widespread (Hertogh, et al.).

Because people’s treatment preferences change, both with the passage of time and with changes in their medical condition, it is important that written treatment instructions be updated regularly to insure that they actually reflect a patient’s current desires. However, the POLST paradigm contains no procedure to insure such updating. As is the case with many instruction directives, a POLST does not automatically expire. Instructions on the reverse of the form provide that it “should” be updated periodically, upon a transfer, or when there is a change in the patient’s health status, but there is no requirement for a periodic review. If a patient lives at home and keeps the POLST form on the refrigerator door as recommended by a brochure posted on the POLST.ORG web site, then the form is not likely to be updated prior to the onset of a

medical crisis. The form may not reflect the patient's most recent treatment preferences, even if it correctly reflected those preferences at the time of execution, as the result of changed preferences.

The likelihood of patient treatment preferences being inconsistent with what is reflected on the POLST form should be minimized if physicians follow the new POLST paradigm recommendation to limit the form's use to patients who are likely to die within a year or if the form is updated periodically. Still, terminal patients can sometimes live much longer than expected, and preferences can change with changes in a person's physical condition over short time periods. If POLST forms are not frequently updated, they remain vulnerable to changing patient treatment preferences in the same manner as do conventional instruction directives.

2.2 WEAKNESSES SIMILAR TO DNR ORDERS

During the past thirty years, DNR orders have become "part of the ritual of death in our society, so commonplace that nearly all physicians have written one, or have been ordered to adhere to one, at some point in their career" (Burns, Edwards, Johnson, Cassem, & Truog, 2003). The pre-printed POLST form contains a DNR order, along with other medical orders to withhold or limit treatment. DNR orders have certain inherent weaknesses that may be shared by the POLST.

2.2.1 Signal of Limited Treatment

A number of studies suggest that “clinicians often interpret a DNR order to be consistent with a broader decrease in the intensity of care to be provided to these patients” (Burns et al., 2003). Patients in hospitals and long-term care facilities with DNR orders receive fewer life-prolonging procedures, even after controlling for age, functional status, and severity of illness (Beach & Morrison, 2002). However, by agreeing to a DNR order, a patient does not agree to have other treatments withheld. More than thirty years ago, the President’s Commission (1983) cautioned that “any DNR policy should ensure that the order not to resuscitate has no implications for any other treatment decision.” (p. 251).

“DNR orders focus on what will not be done for the patient, as opposed to what should be done for the patient” (Burns et al., 2003). The POLST, by contrast, allows the patient to direct that certain care be provided, and mandates that comfort care always be provided. Still, the POLST is most often used by patients to refuse rather than request the listed life-sustaining treatments (Lee et al., 2000; Rotstein, 2007). There is some evidence in the literature that the POLST is viewed by doctors as a general signal for limited treatment in the same manner as a DNR order. Dunn et al. (1996) found that 34% of surveyed providers said they would withhold treatment in circumstances that were found to be inappropriate when a predecessor to the POLST form was examined. Lee et al. (2000) found that care was less invasive than requested in 33% of reviewed cases that used a POLST.

There is a potential for physicians to view the POLST as a signal that the patient wants to withhold other non-specified treatments in the same way that doctors sometimes misinterpret a DNR order. This is a weakness.

2.2.2 Lack of Specificity Regarding Covered Medical Procedures

Like a DNR order, the POLST contains language that attempts to address specific medical procedures. However, also like many DNR orders, the POLST may not be sufficiently specific to provide meaningful instructions in certain situations.

If a patient is not breathing and has no pulse, then the POLST form is clear as to what should be done. Section “A” of the POLST form has two boxes for such a situation: one indicates “attempt resuscitation” and the other for DNR. However, what happens if the patient stops breathing and still has a detectable pulse? In that case, section “A” does not apply and the doctor must look to section “B” of the POLST form for guidance. That section of the POLST form contains boxes for comfort measures only, limited medical intervention, or full treatment. However, what do these terms mean in terms of actual medical procedures performed by doctors at the bedside?

Some examples of each type of care are provided on the POLST form, but the list is not exhaustive. In particular cases, it can be far from clear what medical procedures fall into each category. Is needle thoracentesis to relieve breathing discomfort for a patient near death a comfort measure, limited intervention, or a procedure associated with full treatment?²⁰ Even the general classification of procedures can be unclear. Bi-level positive airway pressure (BIPAP) is an example of an intervention about which clarification has been required (University of Pittsburgh Institute on Aging, 2007).

²⁰ Needle thoracentesis is the introduction of a needle or catheter into the lung in order to release trapped air or remove fluid.

In the context of DNR orders, even physicians on the same clinical team often disagree about which specific procedures are covered by the order (Truog, R., Waisel, D, and Burns, J., 1999). The POLST suffers from the same lack of clarity.

2.2.3 Unilateral Decisions by Physicians

“From the earliest days of CPR, few issues have been more contentious than whether a physician may determine, without patient or surrogate consent, that CPR is not indicated” (Burns, et al. 2003). Many hospitals allow unilateral DNR orders to be entered by physicians based upon considerations of futility. Ibid.

A POLST is not supposed to be signed by a doctor unilaterally, but the structure of the form contains no safeguards against unilateral action. Although a patient or surrogate signature is recommended, one is not required under the POLST paradigm (OHSU, 2007). There are boxes on the form to indicate by category (e.g. patient, parent of minor, etc) the person with whom discussions have been held, but the form does not require that the name of that person be listed or even that one of the boxes be checked.

Whether a POLST can be completed unilaterally when a doctor believes care is futile is unclear. A brochure entitled “The National POLST Paradigm Initiative” posted on the POLST.ORG web site categorically states that the POLST “cannot be filled out or changed unless there is a conversation with either the patient or their surrogate decision-maker (for those unable to make their own medical decisions)” (OHSU, 2007b). On the other hand, New York is listed on the POLST.ORG web site as having an officially endorsed program, even though that state’s procedures allow unilateral execution of the form to direct withholding of CPR for futility

under specified circumstances (Excellus, 2007). Additionally, the signature box for the 2007 version of the Oregon POLST form states that a physician's signature indicates that "the orders are consistent with the patient's preferences, **if known**." This language did not appear in prior versions of this form and implies that a POLST can be signed by a doctor even if the patient's preferences are not known.

The unilateral withholding of care by physicians on grounds of futility is controversial because physicians and laypeople can differ on whether care is "futile" under particular circumstances. Futility judgments are "entirely susceptible to subjective interpretation" (Biegler, 2003). The structure of the POLST form makes it possible for physicians to sign it unilaterally, and the POLST paradigm contains no clear guidelines specifying when doctors may do so. The possibility of unilateral execution in inappropriate circumstances is therefore a weakness that the POLST shares with DNR orders.

2.2.4 Lack of Ability to Revoke Immediately

Another weakness that the POLST shares with DNR orders is an inability on the part of the patient to revoke the order in an inpatient setting.²¹ Like a DNR order, the POLST is a binding physician's medical order that is kept in the patient's hospital or nursing home chart. As a rule, a patient cannot change the medical orders written in a chart and often cannot even access the chart. Instead, the patient must ask a physician to change the orders. This means that a patient's request to change a POLST form will not be implemented until arrangements can be made to

²¹ In an outpatient setting, the patient is usually in possession of the POLST form and can simply rip it up if revocation is desired.

have a physician make the change. In the interim, the patient is at risk of having the order implemented contrary to his or her desires.

Some programs that have implemented the POLST paradigm explicitly state that a POLST may be revoked orally by the patient at any time. In Pennsylvania, the University of Pittsburgh Institute on Aging has published a fact sheet stating that a POLST may be orally revoked by a patient in the same manner as an advance directive (University of Pittsburgh Institute on Aging, 2007). However, not all programs are so explicit, and the POLST paradigm itself is silent on the issue. This is a weakness.

2.2.5 The Problem of Surrogate Completion

Another weakness that the POLST form shares with DNR orders is the fact that both forms often rely upon surrogates to obtain information about patient preferences. Empirical research shows that surrogates are not very good at predicting end of life treatment preferences for patients. Since the moral justification for honoring surrogate instructions is often the assumption that they are likely to reflect a patient's own treatment preferences, this inaccuracy is a source of concern.²²

The POLST paradigm unambiguously contemplates completion of the form based upon the instructions of individuals other than the patient when an individual is incapacitated. The POLST.ORG web site says, "Family members may be able to speak on behalf of a loved one A health care professional can complete the POLST Paradigm form based on family members'

²² In some instances, a surrogate will make a decision for a patient based upon the best interests of the patient rather than what he or she believes the patient would want (i.e., a substituted judgment standard). A discussion of when it is appropriate to use a best interests standard rather than a substituted judgment standard is beyond the scope of this thesis.

understanding of their loved one's wishes" (OHSU, 2007). In the list of requirements for an endorsed POLST program, the web site states: "Ideally, a surrogate should be able to make decisions about treatment choices for a patient without decision making capacity, but states have varying laws regarding surrogates and decision making." Ibid.

More than a dozen studies have tried to measure how accurately surrogates predict patient treatment choices. Shalowitz, Garret-Mayer, and Wendler (2006) conducted a systematic review of these studies and found that overall, surrogates predicted patient treatment preferences with only 68% accuracy. Accuracy of predictions relative to CPR was 69%, for intubation was 70%, and for artificial nutrition and hydration was 69%. Significantly, these authors also found surrogate accuracy was not improved by prior discussions with the patient of treatment preferences. Study results are mixed as to whether surrogates tend to err by providing interventions that patients do not want or by withholding interventions that patients do want. Overall, it seems that surrogates "fail to predict patients' end of life treatment preferences accurately in one third of all cases" (Shalowitz, Garret-Mayer, & Wendler, 2006).

Surrogate decision making for incapacitated patients is firmly embedded into our legal and ethical framework surrounding medical care. Challenging the assumptions behind and rationale for surrogate decision making is beyond the scope of this thesis. My purpose here is to identify weaknesses that the POLST shares with DNR orders. It is therefore appropriate to observe that surrogates often do not accurately state a patient's treatment preferences, and therefore relying upon surrogates to accurately indicate such preferences is a weakness shared by the POLST with other medical orders that are based upon the instructions of surrogates.

2.2.6 Problems Associated with Being a Binding Medical Order

The fact the POLST form is a medical order set capable of immediate implementation is probably crucial to its effectiveness. Conventional instruction directives must be translated into medical orders and if “orders have not been written in advance of a life-threatening situation, emergency medical interventions and transfers to the hospital may occur before the advance directives can be translated into medical orders” (Hickman, Tolle, et al. 2004). The POLST eliminates this problem by being “immediately actionable without further interpretation” (Hickman, Hammes, et al., 2004). However, the immediate actionability of the POLST it is also a weakness because the form might “well be *too effective*, too easy to act on quickly...” (President’s Council, 2005, p. 76). In some cases, treatment may be withdrawn or withheld in circumstances not intended by the patient.

The POLST medical order set contains a DNR order box, and like a conventional DNR order, a POLST with the DNR box checked may not be intended as a literal proscription of particular types of medical care, but rather as a more general statement of patient goals. As observed by Casarett and Ross (1997), “patients are often motivated to request a DNR order because of their goals, but their request is documented in terms of procedures.”

As is the case with conventional instruction directives, sometimes it may be morally justified to disregard instructions that a patient provided in advance of a medical crisis through a POLST. “Such a decision would most often rest on a finding that the patient did not adequately envision and consider the particular situation within which the actual medical decision must be made” (President’s Commission, 1983, p. 137). The “primary obligation of caregivers is to serve the well-being of the patient.... This means paying attention to an advance instruction

directive if one exists, but not following its orders, *regardless of all other circumstances*” (President’s Council 2005, p. 194)(emphasis in original).

DNR orders, like other patient instructions, “are often framed with implicit assumptions about the conditions in which the directive will be applied” (Brock, 1991). One must wonder whether a patient who rejected use of a procedure such as mechanical ventilation “really meant to turn down short-term use of a mechanical ventilator that would restore him to his current state of health” (Teno et al. 1997). Indeed, it is arguably morally obligatory to ignore patient instructions embodied in a POLST form when they are patently inconsistent with the patient’s goals. Brock gives the example of a situation where a patient declines CPR because he envisions a circumstance where his overall condition has so deteriorated that that he is virtually certain not to survive the attempt. However, should the patient’s cardiac arrest be caused by a reaction to a drug, and in circumstances where CPR is highly likely to succeed and leave the patient unimpaired, it would seem morally obligatory to provide CPR notwithstanding what is on the form.

In fact, some physicians say they will override DNR orders when they appear inappropriate. A survey by Cassarett, Stocking, and Siegler (1999) of 285 hospital residents, internists, family practitioners, and OB/GYNs showed that 69% would override a DNR order when a patient arrested due to a physician’s error. An attending physician has discretion to countermand a DNR order when appropriate. Presumably, this same discretion will be exercised by doctors to countermand a POLST order when appropriate.

While a physician has the authority to override another doctor’s medical orders, the situation with respect to nurses and emergency services personnel is somewhat different. These medical professionals are normally expected to follow physicians’ orders and they fail to do so at

their own professional and legal peril. Thus, for example, Benjamin and Curtis (1992) state that so long “as a physician’s order is within the wide range of acceptable practice, and time is pressing, the nurse should obey the order even if she would prefer another course of action, and she should discuss the matter with the physician later.” EMTs may be even more restricted. When outside of the direct command of a physician, these providers are normally governed by standardized protocols. If the protocol says that a POLST must be honored, the EMT is legally required to follow the form. In Oregon, state regulations governing emergency medical services state that EMTs “shall request and honor life-sustaining treatment orders executed by a physician, nurse practitioner, or physician’s assistant if available”²³ Indeed the POLST form itself is designed to deter hesitation on the part of nurses and EMTs by specifically directing: “First follow these orders, then contact the physician, NP, or PA.”

The fact that a POLST can be used to translate a patient’s treatment preferences into immediately actionable medical orders is a source of the form’s potential effectiveness. However, the POLST’s status as a medical order means that some medical professionals will follow the form even when it appears inappropriate to do so. This is a weakness.

2.3 WEAKNESSES UNIQUE TO THE POLST

In addition to having weaknesses similar to those associated with instruction directives, there are features that are unique to the POLST that may cause the form to be applied so as to cause the withholding or withdrawal of life-sustaining treatment in circumstances that are not intended by

²³ OAR 847-035-0030(6)(2007).

patient. These unique features are: (1) the transferability of the POLST between treatment settings without regard to credentialing and privileging requirements; and (2) the possibility of conflict between the POLST form and conventional advance directives.

2.3.1 Transferability Between Treatment Settings

One perceived barrier to the effective use of instruction directives is that they “are not valid in health care institutions until they take the form of physician orders” and “many institutions honor only their own specific ‘no code’ forms” (Meyers et al., 2004). The POLST paradigm overcomes this barrier by mandating that the POLST form be a medical order set that is transferable between treatment settings. However, in order to make the POLST form transferable with the patient, the law must require hospitals to honor medical orders written by physicians who are not credentialed within the institution nor privileged to write end of life medical orders. This circumvention of credentialing and privileging procedures enhances the risk that a POLST may be implemented contrary to the intentions of the patient, and it may limit the ability of critical care physicians to provide the most appropriate care.

“Credentialing and privileging are the most direct means for an organization to insure that patients receive quality care from skilled practitioners” (Payne, 1999, p. 8). Hospitals are required to have credentialing and privileging processes by the Joint Committee on Accreditation of Healthcare Organizations. Credentialing refers to the process of ensuring that “any health care practitioner who wishes to provide patient care services within a hospital or other health care facility is qualified and competent to exercise the clinical privileges that have been granted to the individual” (Gassiot, Searcy, & Giles, 2007, p. 139). The credentialing process includes making sure a physician has graduated from medical school, possesses a valid state license, and

has the training, experience, and background that has been claimed. Privileging is the process of delineating what procedures a practitioner may perform or what patients he or she may treat. (Gassiot et al, 2007, p. 215). The goal of the privileging process is to identify a practitioner's competency level and then authorize him or her to practice only within that competency level (Gassiot et al., 2007, p. 217-218).

Both credentialing and privileging processes are necessary because “we know there are practitioners who overstate or falsify their credentials, who may be competent but who have behavior or health problems that affects their competency, or...who simply attempt to provide care or perform procedures for which they are not adequately trained or do not possess current experience” (Gassiot et al., 2007, p. 140).

The requirement that a POLST be transferable between treatment settings means that institutional credentialing requirements are swept aside and hospital medical personnel must honor the POLST without any assurance that the signature on the form is that of a competent and licensed physician. Credentialing requirements are informally enforced within hospitals by the fact that doctors and nurses practicing within an institution gain familiarity with each other's names, and they use their own institution's recognizable forms. It is easy to check when a doctor is on the hospital's medical staff. However, the POLST paradigm requires hospitals to honor any doctor's signature on a statewide POLST form. As a practical matter, there is no way for hospital personnel to know whether a signature on a form is valid, and this increases the possibility that persons who are not licensed physicians will sign the form and their improper action will go undetected. Moreover, hospitals are required by the POLST paradigm to follow the instructions of doctors to whom they would refuse to grant medical staff status due to disciplinary problems, demonstrated incompetence, or other practice-related issues.

Privileging issues are more complex because most hospitals in the United States use an open model of critical care that allows any physician with hospital admitting privileges, including primary care doctors, to write end of life medical orders that will be honored in an ICU (Hass, 2005). However, approximately 22% of hospitals have a closed system where the admission and care of critically ill patients is controlled by board certified intensive care specialists. Ibid. Closed ICUs are associated with better patient outcomes (Treggiari et al. 2007). The POLST can interfere with good patient care in a closed ICU because transferability between treatment settings is required by the POLST paradigm, and the National POLST Paradigm Initiative Task force recommends that a POLST be automatically followed until “a review [of the patient’s values and condition] is completed by the accepting health care professionals” (OHSU, 2007a). Requiring automatic compliance with the orders of physicians who may not be skilled in providing critical care is inconsistent with the goals and model of a closed ICU.

Credentialing and privileging procedures do not guarantee good patient care, but they are considered important safeguards. These safeguards are swept aside by the POLST paradigm.

2.3.2 Conflict with Advance Directives

Another weakness that is unique to the POLST is that it is allowed to co-exist with advance directives. The POLST.ORG web site states, “[e]ven if you have an advance directive, the POLST Paradigm form is recommended” (OHSU, 2007). If an advance directive contains treatment instructions that are different from those indicated on the POLST form, a conflict is created that may thwart the effectiveness of both documents.

Depending upon state law, treatment instructions contained in advance directives may be legally binding upon physicians. Thus, for example, Pennsylvania's recently enacted end of life statute says that when a living will is operative, a physician "**shall** act in accordance with its provisions..."²⁴ The University of Pittsburgh Institute on Aging (2007) attempted to address the possibility of a conflict between a POLST form and a living will. It concluded that a higher level of care must be provided until more information is known about why the documents conflict. However, from an operational standpoint in a health care institution, medical orders like the POLST that are contained in the chart will ordinarily control over a living will. If the two documents conflict, then it is likely that the medical orders will be followed even though from a legal standpoint Pennsylvania state law currently says that the living must take precedence.

²⁴ 20 Pa.C.S. §5443(b)(2007).

3.0 CHAPTER 3 - WEAKNESSES IN POLST RESEARCH

It is often reported in the literature that the POLST form is effective in translating patient preferences relative to end of life medical care into action. For example, a comment by Farber et al (2006) in the *Annals of Internal Medicine* asserts that “research has demonstrated [the POLST’s] effectiveness in helping patients have their preferences for end of life care honored, even when emergency medical services (EMS) are contacted.” Similarly, Bomba and Vermilyea (2006) assert that a “decade of research in Oregon has proved that the POLST program more accurately conveys end of life preferences that are more likely to be followed by medical professionals than traditional advance directives alone.” The President’s Counsel (2005) says that the POLST “has shown high rates of compliance and effectiveness.” (76).

In this chapter of my thesis, I question these assertions. There are six published research studies involving the POLST and no published article has examined the quality of these studies. I review the methodology of these studies and give my opinions regarding their validity as quantitative research. This chapter does not attempt to address difficult philosophical questions of what it means to “prove” something scientifically, or whether valid knowledge can be obtained through means other than quantitative research studies (e.g. through qualitative studies or experientially). This chapter merely demonstrates that the existing POLST studies have gaps and weaknesses, and to the extent “good” quantitative research regarding the POLST is desirable, such research is lacking.

3.1 WHAT POLST RESEARCH SHOULD BE ABLE TO SHOW

Research on the POLST should show us that the form is effective in translating patient preferences into action at the bedside. Quantitative research studies are an appropriate way to obtain this evidence. Quantitative research is an attempt to gather information in an objective manner, often involving groups and experiments, where the method of gathering data is strictly prescribed and the resulting data is subjected to a statistical analysis (Martella, Nelson, & Merchand-Martella, 1999, p. 561).

Good quantitative research has both internal and external validity. A study that is designed in such a way that one can be confident that the observed effects are due to the intervention being examined, rather than resulting from something else, is said to be internally valid (Shortell & Richardson, 1978, p. 38). A study has good external validity if its results can be generalized to other situations. Ibid.

Hypothesis testing is commonly used in quantitative research as the basis of study design (Martella, Nelson, & Merchand-Martella, 1999, p 5). Greenhalgh (2001) suggests that the hypothesis being tested should be clear in any quantitative research paper. In order to show that the POLST is effective, at least four hypotheses can be suggested for testing.

First, we should test the hypothesis that the treatment instructions contained in the POLST form accurately reflect authentic patient treatment preferences in a very high percentage of cases. The moral justification for using the POLST relies upon the truth of this hypothesis, and therefore research supporting it would seem to be crucial.

Second, we want to test the hypothesis that doctors and other medical providers comply with the instructions on the POLST form in a high percentage of cases and, importantly, that it is the POLST form and not some other intervention or factor that is causing that compliance. This

too is important. If it is some other intervention that is used in conjunction with the POLST that is prompting doctors to follow the instructions on the POLST form (e.g. family conferences), then the POLST will be ineffective when that other intervention is not present.

Third, we should test the hypothesis that the POLST form is better than living wills and prehospital DNR forms in causing medical providers to honor a patient's written treatment instructions. If our legal and medical institutions are going to spend time and money creating new processes and procedures to accommodate the POLST, then we ought to have some assurance that the POLST works better than what we already have.

Finally, we want to test the hypothesis that the POLST works across treatment settings and among diverse populations. If the POLST is only effective in nursing homes, or if its effectiveness is limited to certain racial, ethnic, or cultural groups, then its utility is limited.

The difficulty of generating quantitative research evidence on each of these points would seem to vary. With respect to the first item, it would seem reasonably straightforward to determine whether the POLST form accurately captures authentic patient treatment preferences by identifying and interviewing a random sample of competent patients who have the POLST form in their medical record. On the other hand, showing that it is the POLST form, and not some other factor, that causes doctors and other medical professionals to honor what is written on the POLST form can be very complex, since determining whether a particular health intervention causes certain results (i.e. internal validity) requires studies that protect against biases and potential confounding variables. Showing that the POLST is more effective than living wills or prehospital DNR forms probably requires comparison studies. Finally, in order to be assured that research findings are generalizable across treatment settings and among diverse

populations (i.e external validity), we would want to see how the form is used in hospitals, nursing homes, and by EMS personnel in several locations across the country.

In the next section of this thesis, I review each of the published POLST studies. I show that the only research evidence supporting the assertion that the POLST accurately captures patient treatment preferences is the opinions of medical providers and interviews with two patients and five surrogates. I show that the research evidence that purports to show that medical professionals follow instructions on the POLST form is tainted by problems including non-representative study subjects and the presence of family conferences as a confounding intervention. I show that there have been no comparison studies evaluating the effectiveness of the POLST versus living wills and prehospital DNR forms. Finally, I show that that the existing POLST research is not generalizable because all of the studies were conducted in an area of the country that has had a prolonged debate about end of life care (i.e. Oregon and Washington State), and none of the studies involved the form's use in hospitals or among diverse populations.

3.2 SUMMARY OF THE POLST RESEARCH STUDIES

3.2.1 Before and after survey by Dunn et al. (1996)

Dunn et al. (1996) reported on a study of a predecessor document to the POLST called the Medical Treatment Coversheet (MTC) that was conducted in Oregon. The stated objective of the study was to describe the development, initial evaluation, and plans for implementation of the MTC form. The study includes the results of the initial evaluation and contains conclusions.

The study involved two stages. The first stage used focus groups and a committee of emergency physicians and paramedics to evaluate the form. The focus groups were composed of

28 physicians and 5 long-term care nurses who evaluated the form and suggested changes. In the second stage of the study, a group of 87 physicians, paramedics, and long-term care nurses were provided with a modified MTC form and three different clinical scenarios. They were asked what they would do both before and after exposure to the form. “Ideal” responses were determined by an expert panel. The authors do not explain how the 87 participants were selected.

The results of the survey showed that post-MTC decisions were more appropriate than pre-MTC decisions across all scenarios and clinician groups with one exception. Advanced EMS treatments were inappropriately withheld by 34% of all providers after MTC exposure. The authors attribute this problem to lack of education and training about the document. Dunn et al. (1996) conclude that the MTC form is a “safe and effective instrument that would prevent unwarranted treatments and ensure that medically indicated treatments desired by the patient are provided.”

This study provides very limited evidence to support the four POLST hypotheses identified above. The form that was evaluated in the study was not a POLST form but a predecessor document called the MTC form. There was no attempt to evaluate whether the MTC form accurately reflected patient preferences. There was no attempt to test whether the MTC form was more effective than a living will or a prehospital DNR order.

The study explored whether physicians, nurses, and EMTs would change their behavior following exposure to the MTC form but the study has a number of weaknesses. The authors do not explain how they selected the study participants, so we have no assurance that the 87 participants were representative of medical providers in Oregon or elsewhere. The fact a survey design was used means that the responses reflect only what participants say they would do under

a limited set of hypothetical facts and the responses may not predict real-world behavior in a variety of clinical contexts.

The authors' conclusion that the MTC document ensures that medically indicated treatments desired by the patient are provided is clearly unwarranted. As noted above, there was no attempt to measure whether the MTC form accurately reflected patient preferences. Moreover, a substantial number (34%) of providers made decisions to inappropriately withhold life-sustaining treatments following exposure to the MTC.

3.2.2 Single cohort longitudinal study by Tolle et al. (1998)

The purpose of the study by Tolle et al. (1998) was to examine how frequently the DNR and comfort measures only orders on the POLST form were respected or ignored. The authors followed the care received by 180 residents of eight adult long-term care facilities in Oregon in which the POLST form had been in use for more than one year. One characteristic of all of these nursing homes was the very high percentage of residents having DNR orders. The mean number of patients in the selected nursing homes with DNR orders was 91%. Subjects for the study were selected based upon whether they had a POLST form in their medical record that indicated both DNR and that the patient should be transferred to a hospital only if comfort measures fail. Data for the study was obtained from patient records and other staff reports.

Of the 180 patients who were followed, 24 patients were hospitalized and 38 patients died. The hospitalizations were evaluated independently by two physicians to judge whether the transfers occurred as the result of failed comfort care. There was a 92% agreement between the raters on the reason for transfer. Raters disagreed on two cases but consensus was reached on

those cases after consulting a third physician. The medical records for the 38 patients who died were reviewed to determine the care received in the month prior to death.

The study found that 85% of hospitalized patients were transferred because of failed comfort care and in 15% of the hospitalizations (n=4) the transfer was to extend life. Only two of the 38 deaths occurred in the hospital, with the deaths of the remaining patients occurring in the original nursing home. Family conferences were held shortly before death in 67% of cases.

The authors observe that the frequency of death outside of acute care in the POLST study population, including the low rate of hospital and ICU days, was much lower than national data reported in the literature. Tolle et al. concede that Oregon has very low rates of in-hospital death, but note that the rates in their study are lower than previously reported. They acknowledge that nursing homes in their study probably had a culture attuned to advance planning because they were among the first adopters of the POLST. They also acknowledge that Oregon may be different from the rest of the country in terms of racial demographics and the population's knowledge and education about end of life issues resulting from the debate in that state about legalizing assisted suicide.

This study provides no evidence on whether the POLST form accurately reflects authentic patient preferences. There was no attempt to test whether the POLST was more effective than a living will or a prehospital DNR order. The study seeks to generate evidence on the effectiveness of the POLST only with respect to the DNR and do-not-transfer orders on the form. The other medical orders on the POLST form were not examined. The form was only examined in the context of nursing homes. Hospital care and EMS services were not studied.

The design of this study makes it difficult to draw inferences that can be generalized from the results. The authors acknowledge that the nursing homes selected to participate in this study

had extraordinarily high rates of DNR orders to start with, and were probably attuned to advance planning and end of life care. Oregon is also a unique environment as explained above. Medical staff in the studied facilities might have behaved similarly in the presence of conventional instruction directives or prehospital DNR orders. With respect to the patients who died, the presence of family conferences shortly before death in 67% of the cases is a confounding variable. We cannot tell from the study if it was the POLST, or the family conferences, that guided medical action. The number of cases where the POLST was implemented (24 hospitalizations and 38 deaths) is too small to generate statistically meaningful results even apart from the issue of whether the sample was representative.

3.2.3 Retrospective chart review by Lee et al. (2000)

Lee et al. (2000) conducted a retrospective chart review for 54 patients who died during 1997 with a POLST form in their medical record at an Oregon site of the national Program of All-Inclusive Care for the Elderly (PACE). The objective of the study was to evaluate whether treatments received in the final two weeks of life were consistent with instructions documented in the POLST form.

PACE participants are eligible for long-term care paid by Medicaid, but most continue to live in the community. PACE participants receive comprehensive interdisciplinary care. The selected PACE site considered end of life planning a priority for all participants and a POLST is completed in most cases. POLST forms are completed based on patient preferences if the patient has decisional capacity. In other cases, surrogates are consulted. Family conferences are convened whenever a patient's health status changes but the POLST may not be updated before urgent decisions are needed.

Of the 57 patients who died in 1997, 98% had a POLST in their record. The POLST form specifies treatment instructions relative to: (1) CPR; (2) level of care; (3) antibiotics; and (4) feeding tubes and IV fluids. The results of the study showed that 50 patients (93%) of the study participants had forms specifying DNR and four patients (7%) requested CPR. Care was consistent with the POLST form in 91% of the cases. Three patients received CPR even though they specified DNR and two patients did not receive CPR even though they wanted it.

With respect to level of care, study participants varied in the level of care specified on the POLST form, with 24% requesting comfort measures, 33% requesting limited interventions, 33% requesting advanced interventions, and 9% requesting full treatment. Care was consistent with the POLST instructions in 46% of the cases. Care was less invasive in 33% of cases and more invasive in 20% of the case.

For antibiotic administration, there were 28 patients for whom antibiotics were indicated. There was 86% compliance with POLST instructions relative to antibiotics, and in the remaining 14% of cases care was less invasive than requested. With respect to feeding tubes, 37 study participants were not eating sufficient calories to sustain life in the last two weeks of life. Of these patients, 34 had specified instructions regarding feeding tubes and care matched POLST form instructions in 32 (94%) of the cases.

For IV fluids, 41 participants stopped drinking adequate fluids by mouth in the two weeks prior to death. Three of these patients had not specified POLST instructions relative to IV fluids. For the remaining 38 patients, care complied with POLST instruction in 32 (84%) of cases. Five patients received more intensive IV therapy than requested and one patient received less.

Overall, the authors found that 39% of participants had POLST form instructions followed in all cases. Compliance rates with instructions on the POLST form were very high with respect to CPR (91%), antibiotics (86%), IV fluids (84%), and feeding tubes (94%). However, compliance with level of care instructions was only 46%. Lee et al. (2000) conclude that the POLST form “shows promise as a tool for promoting patients’ preferences” but caution that “there is substantial room for improvement in the level of medical intervention category...”

Like prior studies, this one by Lee et al. (2000) did not explore whether what was written on the POLST form accurately reflected patient treatment preferences. Also, like the prior studies, the one by Lee et al. does not compare compliance rates for the POLST form with those for living wills and, where applicable, prehospital DNR forms. This study also does not examine how the POLST form is used in hospitals.²⁵

Unlike the prior studies, this one examines the effectiveness of all of the interventions listed on the POLST form. However, the presence of family conferences is a confounding factor that makes it impossible to determine whether it was the POLST form, or the family conferences, that animated provider behavior. It is also difficult to generalize from this study. The authors selected a study site that was highly attuned to end of life planning and it is possible that similar results might have been obtained by use of a conventional instruction directive or, where applicable, a prehospital DNR form. The PACE study site was a small closed care system and the authors acknowledge that providers in that setting might have been more comfortable relying upon POLST orders than might be the case in a more anonymous setting. As with the prior studies, this one was conducted in Oregon.

²⁵ Six patients in this study by Lee et. al. (2000) died in a hospital.

3.2.4 Telephone survey and onsite review by Hickman, Tolle et al. (2004)

Hickman, Tolle et al. (2004) conducted a statewide telephone survey of Oregon nursing facilities between June and December 2002 followed by an onsite review of 467 medical charts at seven nursing homes. The objective of the study was to assess statewide use of the POLST form, and explore patterns of orders documented on the POLST form for Oregon nursing facility residents aged 65 and older.

In the telephone survey, a research assistant requested permission to speak with the individual responsible for the completion of advance planning documents in each facility. Facility employees were asked a variety of questions about use of the POLST form in their facility. For the onsite reviews, a semi-random stratified sampling procedure was used to identify seven nine Oregon nursing facilities that self-identified as using the POLST form for more than 50% of residents. Two facilities declined to participate so two alternate facilities were selected. The onsite reviews collected data including the presence or absence of a POLST form from each resident's chart, the location of the form, how the form was being used (i.e. to limit or request treatment) and typical problems in completing the form.

The telephone survey showed that 82% of surveyed Oregon nursing facilities used the POLST form for at least some of their patients. On average, these facilities reported that 86% of residents had completed POLST forms. The percentage of Oregon nursing facilities that reported use of the POLST form for more than half of their residents was 71%. A large majority (87%) of responding facilities also report that they believe the POLST form reliably expresses resident wishes.

The onsite review showed that 71% of the POLST forms had patient or surrogate signatures and 89% contained information showing with whom the orders contained in the

POLST form were discussed. Five percent of the forms were missing a physician or nurse practitioner signature. DNR orders were indicated on 88% of the POLST forms. Medical intervention limits were indicated on 89% of the forms. Antibiotic limits were indicated on 42% of POLST forms. Limits on artificial nutrition and hydration were indicated on 87% of forms. Of the forms with DNR boxes checked, 77% indicated that more than the lowest level of care should be provided in at least one other treatment category. Of the POLST forms with the resuscitate boxes checked, 47% had less than the highest level of treatment indicated in at least one category of care.

This study contains data on the reported use of the POLST in Oregon nursing facilities, and shows how the POLST form was filled out in seven Oregon nursing homes. It does not provide any evidence to support the four POLST hypotheses identified previously. The study inquires into whether the POLST form reliably reflects patient preferences but only the opinions of surveyed facility staff were obtained on this issue. There is no reason to believe these opinions are reliable. The study did not examine whether physicians comply with instructions contained on the POLST form. The study did not examine whether the POLST is any more effective than an instruction directive or a prehospital DNR form in directing medical treatment. There was no attempt to study the use of the POLST in hospitals, in the community, or by persons under age 65.

3.2.5 Interviews and chart reviews by Meyers et al. (2004)

Meyers et al. (2004) reviewed 21 medical charts and conducted 7 interviews to determine the extent to which POLST forms were being used in a two-county pilot area and whether POLST

forms accurately reflected patient preferences. The authors also explored the experiences of nursing home staff, residents, and legal surrogates in using the form.

The authors invited 25 nursing homes that sent representatives to POLST training to participate in the study. Six facilities agreed to participate in the study, but since no POLST forms were in use in two of the facilities only four nursing homes were ultimately involved. Twenty-one POLST forms were in use in the four nursing homes.

Project staff conducted medical chart reviews for each of the 21 residents with POLST forms. Project staff also interviewed two residents who had POLST forms along with the legal surrogates of five patients deemed incompetent. Nursing home contacts were also interviewed to gather information about training, policies, procedures and problems associated with the POLST form.

The study results showed that the two interviewed patients and the 5 interviewed surrogates expressed confidence that what was written on the POLST form accurately reflected their or their loved one's end of life wishes. The POLST was congruent with advance directives in all cases (n=12) where they existed. The chart review showed that medical care was congruent with POLST instructions in 19 (90.5%) of 21 cases. Compliance with informed consent procedures was documented in 16 (76%) of 21 cases. One chart indicated that the resident had changed her preference from DNR to resuscitate, but this was not reflected on the POLST. Several of the surrogates described the POLST as being presented in a way that made it seem mandated.

This study by Meyers et al. (2004) is the only published POLST study that attempts to measure whether what is written on the POLST form accurately reflects patient treatment preferences by asking patients or their surrogates directly. However, the tiny sample size (n=7)

does not provide much useful evidence to support the hypothesis that the POLST accurately reflects patient treatment preferences.

This study also examined medical charts to determine whether the POLST is effective. However, the presence of congruent advance directives in 12 (57%) of 21 cases is a confounding variable that makes it impossible to determine whether it was the POLST or the advance directive that animated provider behavior in these cases. The fact that the nursing homes self-selected for inclusion in the study limits the ability to generalize from the study results. The nursing facilities that agreed to participate with the study may have been committed to the POLST program. The small sample size (n=21) makes the results statistically meaningless even if sample selection issues are ignored.

The study did not seek to determine whether the POLST form was more effective than living wills or prehospital DNR forms. The study also did not examine whether the POLST was effective in hospitals or when encountered by EMS personnel.

3.2.6 Written survey of Oregon EMTs by Schmidt et al. (2004).

Schmidt et al. (2004) surveyed 1,048 randomly selected Oregon EMT providers and 572 (55%) individuals responded. In addition to collecting demographic information, the survey asked respondents about any education received about the POLST form, their experience with the form, and their opinions about the POLST program.

The study found that 74% of the surveyed EMT providers had been educated about the POLST program and 73% had treated at least one patient with a POLST form. Respondents reported that 87% of the POLST forms were filled out correctly and the POLST form changed the treatment plan for 45% of the patients. Many EMTs (25%) reported difficulty locating the

form. In 10% of cases the form was not followed because it was overridden. This included nine cases where the patient overrode the form and 17 cases where a family member, caregiver, or power of attorney countermanded it.

Most of the respondents (93%) agreed the form was useful with the patient had no pulse and was not breathing. Fewer (63%) agreed the form was useful when the patient had a pulse and was breathing. Seventy-eight EMT respondents (14%) thought the form did not reliably express patient wishes.

The study by Schmidt et al (2004) explores whether the POLST form accurately reflects patient preferences by asking EMTs, but there is no evidence that the opinions of EMTs on this issue are reliable. The study shows that many Oregon EMTs report that the POLST form influences their treatment decisions but this result may not be generalizable to other states because the Oregon regulations governing EMT scope of practice specifically require EMT providers to follow written physician or nurse practitioner orders regarding life-sustaining treatment. As with all surveys asking about past events, this survey might be subject to recall errors by participants. Given the Oregon regulations making non-compliance with a POLST a licensing violation, EMTs may have been unwilling to report non-compliance with POLST orders. The study does not provide any information as to whether the POLST form is any more effective at influencing EMS services than a living will or prehospital DNR form.

3.3 CONCLUSIONS ABOUT THE POLST RESEARCH

As noted in the beginning of this chapter, the published POLST research is often relied upon by POLST advocates and others to say that the form is effective in translating patient treatment preferences into action at the bedside. However, I contend that this conclusion is unwarranted.

All of the published POLST studies suffer from serious methodological weaknesses when measured against the standards of “good” quantitative research, where considerations of internal and external validity are highly valued. In terms of the four POLST research hypotheses I identified in section 3.1 above, there is not a single hypothesis that can be said to have good quantitative research evidentiary support.

Three studies explore whether what is written on the POLST accurately reflects patient treatment preferences. Hickman et al. (2004) and Schmidt et al. (2004) ask this question of medical providers without providing any evidence that the providers actually know. Meyers et al. (2004) asked this question of only seven patients or their surrogates. This is hardly convincing data.

Five studies measured the effectiveness of the POLST form. In three studies, the researchers examined whether medical care was consistent with what was written on the POLST form, but all of these studies are tainted by the selection of study sites that were committed to improving end of life care, and which had other interventions going on simultaneously with the study that could have caused the results. Tolle et al (1998) selected nursing homes that had high DNR rates and used family conferences. Lee et al. (2000) similarly used a study site that was committed to good end of life care and used family conferences. Meyers et al (2004) had 19 of 25 nursing homes refuse to participate in their study, and ended up reviewing only 21 medical charts. Advance directives were present in 12 of those charts. The two other studies involved

surveys. The study by Dunn et al. (1999) did not even involve a POLST form. The study by Schmidt et al. (2004) involved EMTs who are legally required by their licensing regulations to comply with the POLST. With the possible exception of the EMT survey by Schmidt et al, none of the POLST studies can be said to provide good quantitative evidence that the POLST form is effective.

No published study examines whether the POLST is more effective than living wills or prehospital DNR forms. One cannot simply rely upon existing research that shows that advance directives are ineffective, and then assume that the POLST must be necessarily better. If the effectiveness of advance directives was studied in provider settings committed to end of life care similar to those where the POLST was examined, it might very well be found that doctors would follow living wills and prehospital DNR orders with equal alacrity.

Finally, all of the POLST studies were conducted in either Oregon or Washington State, an area of the United States that has had a prolonged public debate about end of life care. No POLST studies have been conducted in hospitals. There is no evidence that the POLST “works” outside of the Pacific Northwest or in hospital settings.

4.0 CHAPTER FOUR - CONCLUSION

Like the instruction directive and prehospital DNR order before it, the POLST is another way that individuals can attempt to control the medical care they receive at the end of life after they become mentally incapacitated. Whether it is a good idea for people to try to exercise such control is debatable. One needs to be very certain about one's future medical condition, the available medical options, and one's own treatment preferences before approving any document that tries to direct medical care in the future. A surrogate who approves such a document must possess similar certainty.

As noted by Chaiten and Arnold (2001), the real problem for most patients, their families, and physicians when dealing with the dying process is knowing when a patient has "gone from critically ill to 'dying.'" Neither physicians nor families want to 'give up' too early." One reason instruction directives do not work is that the patient's instructions are usually hedged in by so many contingencies, including medical contingencies like the patient being terminally ill or permanently unconscious, that it is exceedingly hard to know when to invoke the provisions of the directive (Calahan, 2000, p. 40). The POLST "solves" this problem by eliminating the contingencies. The obvious downside risk is that the POLST will be applied to withhold or withdraw life-sustaining treatment in circumstances that were not contemplated nor intended.

The advocates of the POLST appear to assume that it is relatively easy for patients and their doctors to determine when it is appropriate to give up on life, and reject life-sustaining

technology. The assumption behind the POLST appears to be that if you are going to be dead in a year anyway, it makes no sense to fight it and risk going through what Callahan (2000) characterizes as a technologically prolonged and very unpleasant “wild death.” The POLST.ORG web site currently urges clinicians to determine whether a POLST is appropriate by asking themselves, "Would I be surprised if this person died in the next year?" If the answer is "No, I would not be surprised", then the web site suggests that a POLST form is appropriate (OHSU, 2007). However, Callahan (2000) also observes “predictions of death, unless virtually imminent become increasingly problematic. Who among us does not know of someone, stricken by a fatal cancer or heart disease, who is alive and active months or years after a predicted death?”

Additionally, the implied assumption behind use of the POLST form to reject life-sustaining treatment is that dying in a technologically driven ICU is something to be avoided. However, dying at home without the feared technology is not necessarily a better death than dying in an ICU. Teno, Clarridge et al. (2007) found that family members of individuals who died at home with nursing care services reported the patient suffered pain and breathing difficulties 42.6% and 38% of the time respectively. This is more than twice that reported for patients who died in hospitals. Moreover, families of people who died at home with nursing services reported the patient received insufficient emotional support 70% of the time. Quality end of life care means receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving the burden on loved ones, and strengthening the relationship with loved ones (Bomba & Vermilyea, 2006). If symptoms cannot be adequately managed at home, if emotional support is not available, and if family members become exhausted, then the dying process may be better in another setting where technology is available to alleviate symptoms.

Still, shouldn't we allow patients to make a choice? The answer is obviously in the affirmative. However, as is the case with instruction directives, the moral theory of precedent autonomy upon which the POLST is based is in conflict with what we know about how human beings make decisions. Any reliance upon treatment preferences expressed in advance via a POLST form assumes that the individuals signing the form can anticipate in advance their reactions to changes in their physical condition and predict their preferences for various life-sustaining treatments under those changed conditions (Ditto et al, 2006). We know from the stability of preference studies that for a substantial number of people, probably a minority to be sure, this assumption does not hold true.

Moreover, the profound lack of good quantitative research studies possessing both internal and external validity is extremely troubling. We have no idea whether the POLST accurately reflects patient treatment preferences in most cases. We do not even know if the POLST "works," in the sense of causing doctors and other medical professionals to honor its contents. The existing studies are so limited and flawed that the best that can be said about the POLST is that it might work.

I do not suggest that we should deprive individuals who have strong and stable end of life treatment preferences of the ability to use a POLST if they really want to do so. If we agree that directives are valuable to at least some segment of the population, then it is appropriate to do what we can to remove existing impediments to their use (Dresser, 1994). However, I do suggest that we need to be very careful about setting up systems and processes in our medical establishment to push the POLST on patients who may not have such strong and stable preferences. The real question about the POLST is not whether it should be made available, but what steps policymakers and health care professionals should take to try to differentiate between

these two groups of people, and to make sure that treatment preferences are authentically articulated.

The creators of the POLST have emphasized the form is supposed to be embedded into a comprehensive advance planning process but the POLST paradigm provides no details for what such a process should look like. Some of the POLST's designers have pointed to the "Five Wishes" project as an example of a new model of advance planning that preserves "the original goals of advance directives while addressing their shortcomings" (Hickman, Hammes, Moss, & Tolle, 2005). One feature of Five Wishes is a comprehensive evaluation of a patient's end of life preferences. Patients are taken through five sets of possible actions that require 47 separate decisions expressing end of life preferences. Five individual private sessions may be required to complete the Five Wishes form. The process has been described as requiring "great effort" for patients with "sustained attention to and concentration on the actions in the advance directives, along with the adaptive processes to come to terms with decisions about their own death and end of life care" (Chovan, 2007). The time and effort associated with the Five Wishes process should be contrasted with that associated with filling out the POLST, which has been described as taking "about 30 minutes to complete" ("New Physicians' Form", 2005).

Comprehensive advance care planning like that seen in Five Wishes is not something that can happen in a short interview between a social worker and a patient where the boxes on a POLST form are reviewed. Good advance care planning requires a shared understanding of the goals of care based on where a particular patient is in a disease trajectory (Beach & Morrison, 2002). Physicians, patients, and family members must all reach a shared understanding of patient treatment goals. Only with a shared understanding can we avoid the situation where doctors and family use the treatment preferences for specific interventions specified by the

patient in a form as a proxy for the patient's actual treatment goals (Beach & Morrison). "We do not advance people's autonomy by giving effect to choices that originate in insufficient or mistaken information" (Dresser, 1995). We should require people to exhibit a reasonable understanding of the choices they are making. Ibid. There is no assurance that the kind of comprehensive advance planning process that is needed for the POLST form to operate properly actually occurs when the POLST paradigm is implemented in a jurisdiction.

The POLST process combines what should be distinct steps in end of life decision making into the single step of filling out a POLST form. This is also problematic from the perspective of good advance planning. A patient or surrogate should first decide upon treatment goals with the doctor, and only then determine what specific treatments are appropriate to meet those goals. (Lynn and Goldstein, 2003). Medical orders implementing the agreed upon goals and treatments are the last step in the decisional process. Good planning seldom results when the end of life discussion is started by asking, 'Do you want everything done?' Ibid. However, this is precisely how end of life issues may be approached when a patient is asked to complete a POLST and decide whether specific medical orders should be written. It is akin to putting the cart before the horse.

The fact the POLST has limitations is rarely made clear in the many journal articles and newspaper pieces that discuss the form. The POLST form is almost invariably presented as an improvement on existing advance directives. Thus, for example, when a Pennsylvania state government task force issued a report on end of life care in 2006, it recommended adoption of the POLST without any mention of its weaknesses (Task Force for Quality at the End of Life, 2006). The President's Counsel (2005) confined its concerns about the POLST to a footnote while otherwise extolling the form as having "high rates of compliance and effectiveness." (p.

76). Published criticism of the POLST is very rare, and appears to be largely confined to right-to-life web sites.

Callahan (1989) warned of a “klutz factor,” referring to what happens to movements and practices “when they are taken out of the hands of the first pioneers, who act carefully and thoughtfully after due deliberation, and are put the hands of very large numbers of people who may not approach them with the same care” (63). The literature that exists relative to the POLST contains subtle caution flags that ought to give policymakers and POLST advocates pause. When Tolle and Tilden (2002) report that some hospitals mandate use of the POLST form at discharge, this is a caution flag suggesting that some institutions may be pushing the form on patients inappropriately. When Hickman, Tolle, et al. (2004) report POLST completion rates in Oregon nursing facilities of 92%, with 88% of these having DNR boxes checked while at the same time 40 % of Oregon nursing home patients are discharged to home, this again raises a caution flag suggesting that perhaps some patients are being steered to refuse treatment. There is a very serious caution flag in the literature suggesting that the POLST prompts providers to withhold treatment inappropriately. Dunn et al. (1996) found that 34% of surveyed providers said they would withhold treatment in circumstances that were found to be inappropriate when a predecessor to the POLST form was examined. Lee et al. (2000) similarly found that care was less invasive than requested in 33% of cases that used a POLST.

Certainly, we do not know from this literature that the POLST is being abused. However, the caution flags are there for those who look for them. We should not assume that the POLST is an unmitigated good. Use of the form may be allowing deaths to occur in circumstances that were not intended by the patient.

The POLST has potential to improve an individual's ability to control his or her end of life treatment. However, it is not clear that the form is a substantial improvement over conventional instruction directives and prehospital DNR forms. Because it is an immediately actionable medical order, the POLST has a greater potential to cause the unintended death of the patients who sign them. Policymakers need to proceed with care if they are going to allow use of the POLST.

APPENDIX

SAMPLE POLST FORM

Physician Orders for Life-Sustaining Treatment (POLST)

First follow these orders, **then** contact physician, NP, or PA. This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Last Name
First Name/ Middle Initial
Date of Birth

A	CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse <u>and</u> is not breathing.
Check One	<input type="checkbox"/> Attempt Resuscitation/CPR <input type="checkbox"/> Do Not Attempt Resuscitation/DNR (<u>Allow</u> <u>Natural</u> <u>Death</u>)
	When not in cardiopulmonary arrest, follow orders in B, C and D.

B	MEDICAL INTERVENTIONS: Person has pulse <u>and/or</u> is breathing.
Check One	<input type="checkbox"/> Comfort Measures Only Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. <i>Do not transfer to hospital for life-sustaining treatment. Transfer if comfort needs cannot be met in current location.</i>
	<input type="checkbox"/> Limited Additional Interventions Includes care described above. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. <i>Transfer to hospital if indicated. Avoid intensive care.</i>
	<input type="checkbox"/> Full Treatment Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. <i>Transfer to hospital if indicated. Includes intensive care.</i>
	Additional Orders: _____

C	ANTIBIOTICS
Check One	<input type="checkbox"/> No antibiotics. Use other measures to relieve symptoms. <input type="checkbox"/> Determine use or limitation of antibiotics when infection occurs. <input type="checkbox"/> Use antibiotics if life can be prolonged.
	Additional Orders: _____

D	ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food by mouth if feasible.
Check One	<input type="checkbox"/> No artificial nutrition by tube. <input type="checkbox"/> Defined trial period of artificial nutrition by tube. <input type="checkbox"/> Long-term artificial nutrition by tube.
	Additional Orders: _____

REASON FOR ORDERS AND SIGNATURES	
E Discussed with: <input type="checkbox"/> Patient <input type="checkbox"/> Parent of Minor <input type="checkbox"/> Health Care Representative <input type="checkbox"/> Court-Appointed Guardian <input type="checkbox"/> Other: _____	My signature below indicates these orders are consistent with the person's preferences, if known. See medical record for further documentation.

Print Physician/NP/PA Name and Phone Number ()	Office Use Only
Physician/NP /PA Signature (mandatory) _____ Date _____	

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY**Signature of Person, Parent of Minor, or Guardian/Health Care Representative**

Significant thought has been given to life-sustaining treatment. Preferences have been expressed to a physician and/or health care professional(s). This document reflects those treatment preferences.

(If signed by surrogate, preferences expressed must reflect patient's wishes as best understood by surrogate.)

Signature (optional)	Name (print)	Relationship (write "self" if patient)
----------------------	--------------	--

Contact Information

Surrogate (optional)	Relationship	Phone Number	
Health Care Professional Preparing Form (optional)	Preparer Title	Phone Number	Date Prepared
PA's Supervising Physician		Phone Number	

Directions for Health Care Professionals**Completing POLST**

Must be completed by a health care professional based on patient preferences and medical indications.

POLST must be signed by a physician/NP/PA to be valid. Verbal orders are acceptable with follow-up signature by physician/NP/PA in accordance with facility/community policy.

Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid.

Using POLST

Any incomplete section of POLST implies full treatment for that section.

No defibrillator (including AEDs) should be used on a person who has chosen "Do Not Attempt Resuscitation."

Oral fluids and nutrition must always be offered if medically feasible.

When comfort cannot be achieved in the current setting, the person, including someone with "Comfort Measures Only," should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).

IV medication to enhance comfort may be appropriate for a person who has chosen "Comfort Measures Only."

Treatment of dehydration is a measure which prolongs life. A person who desires IV fluids should indicate "Limited Interventions" or "Full Treatment."

A person with capacity, or the surrogate of a person without capacity, can request alternative treatment.

Reviewing POLST

This POLST should be reviewed periodically and if:

- (1) The person is transferred from one care setting or care level to another, or
- (2) There is a substantial change in the person's health status, or
- (3) The person's treatment preferences change.

Draw line through sections A through E and write "VOID" in large letters if POLST is replaced or becomes invalid.

The Oregon POLST Task Force

The POLST program was developed by the Oregon POLST Task Force. POLST is housed at Oregon Health & Science University's Center for Ethics in Health Care. Others seeking permission to use the copyrighted form may contact the Center for Ethics in Health Care. Research on the POLST program is available online at <www.polst.org> or by contacting the Task Force at <polst@ohsu.edu>.

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

BIBLIOGRAPHY

- Adams, J. (1993). Prehospital do-not-resuscitate orders: a survey of state policies in the United States. *Prehospital and Disaster Medicine*, 8:317-322.
- Angus, D et al. (2004). Use of intensive care at the end of life in the United States: an epidemiologic study. *Critical Care Medicine*, 32:638-643.
- American Medical Association (2005). Report of the Council on Ethical and Judicial Affairs: Universal Out-of-Hospital DNR Systems. Retrieved 10 April 2007 from: http://www.ama-assn.org/ama1/pub/upload/mm/369/ceja_6a05.pdf
- Atkins, D., Siegel, J, & Slutsky, J. (2005). Making policy when the evidence is in dispute. *Health Affairs*, 24:102-113.
- Beach, M. & Morrison, S. (2002). The effect of do-not-resuscitate orders on physician decision-making. *Journal of the American Geriatrics Society*, 50:2057-2062.
- Benjamin, M & Curtis, J. (1992). *Ethics in nursing*. New York: Oxford.
- Bomba, P & Vermilyea, D. Integrating POLST into palliative care guidelines: a paradigm shift in advance care planning in oncology. *Journal of the National Comprehensive Care Network*, 4: 819-829.
- Brock, D. (1991). Trumping advance directives. *The Hastings Center Report*. 21:S5.
- Buchanan, A. & Brock, D. (1990). *Deciding for others: The ethics of surrogate decision making*. Cambridge: Cambridge University Press.
- Burns, J., Edwards, J., Johnson, J., Cassem, N., & Truog, R. (2003). Do-not-resuscitate order after 25 years. *Critical Care Medicine*, 31:1543-1550.
- Byock, I (1989). DNR orders and living wills [Letter to the Editor]. *Annals of Emergency Medicine*, 18: 911-912.
- Callahan, D. (1989). Public policy and the cessation of nutrition. In Lynn, J. (Ed). *By No Extraordinary Means* (pp. 61-66). Bloomington, IN: Indiana University Press.
- Callahan, D. (2000). *The troubled dream of life: In search of a peaceful death*. Washington DC: Georgetown University Press.

- Casarett, D & Ross, L. (1997). Overriding a patient's refusal of treatment after an iatrogenic complication. *New England Journal of Medicine*, 336: 1908-1910.
- Casarett, D, Stocking, C., & Siegler, M. (1999). Would physicians override a do-not-resuscitate order when a cardiac arrest is iatrogenic? *Journal of General Internal Medicine*, 14:35-38.
- Chaiten, B & Arnold, R. (2001). Managing death in the ICU: the transition from cure to comfort [Book Review]. *Chest*, 120: 1428-1429.
- Chovan, W. (2007). Implementing a pilot program of advanced directives in nursing homes. *Psychological Reports*, 100:195-198.
- Clancy, C & Cronin, K. (2005). Evidence-based decision-making: global evidence, local decisions. *Health Affairs*, 24: 151-162.
- Danis, M., Garrett, J., Harris, R., & Patrick, D. (1994). Stability of choices about life-sustaining treatments. *Annals of Internal Medicine*, 120: 567-573.
- Davis, J (2002). The concept of precedent autonomy. *Bioethics*, 16: 114-133.
- Ditto, P., Danks, J., Houts, R., Coppola, K., Sucker, W., Jacobson, J., et al. (2003). Stability of older adults' preferences for life-sustaining medical treatment. *Health Psychology*, 22: 605-615.
- Ditto, P & Hawkins, N. (2005). Advance directives and cancer decision making near the end of life. *Health Psychology* 24: S63-S70.
- Ditto, P., Jacobson, J., Smucker, W., Danks, J., & Fagerlin, A. (2006). Context changes choices: a prospective study of the effects of hospitalization on life-sustaining treatment preferences. *Medical Decision Making*, 26: 313-322.
- Dresser, R. (1994). Advance directives: implications for policy. *The Hastings Center Report*, 24: S2-5.
- Dresser, R. (1995). Dworkin on dementia: elegant theory, questionable policy. *Hastings Center Reports*, 25: 32-38.
- Duke, G., Thompson, S., & Hastie, M. (2007). Factors influencing the completion of advanced directives in hospitalized patients. *International Journal of Palliative Nursing*, 13:39-43.
- Dworkin, Ronald (1993). *Life's dominion*. New York: Vintage Books.
- Emanuel, L. (1995). Advance directives: do they work? *Journal of the American College of Cardiology*, 25:35-38.

- Excellus (2007). Health care planning: Medical orders for life-sustaining treatment. Retrieved August 23, 2007 from https://www.excellusbcbs.com/guests/health_and_wellness/health_care_planning/medical_orders_for_life_sustaining_treatment.shtml#d.
- Fagerlin, A. & Schneider, C (2004). Enough. The failure of the living will. *Hastings Center Report* 34:30-42
- Farber, S, Shaw, J., Mero, J. & Maloney, W (2006). Withholding resuscitation: a new approach to prehospital end of life decisions. *Annals of Internal Medicine*, 144, 788.
- Feder, S., Matheny, R., Loveless, R. & Rea, T. (2006). Withholding resuscitation: a new approach to prehospital end of life decisions. *Annals of Internal Medicine*, 144: 634-640.
- Firlik, A (1991). *A piece of my mind. Margo's logic.* *JAMA*, 265: 191.
- Fried, T, Byers, A., Gallo, W., Van Ness, P, Towle, V., O'Leary, J & Dublin, J. (2006). Prospective study of health status preferences and changes in preferences over time in older adults. *Archives of Internal Medicine*, 166: 890-895.
- Gassiot, C., Searcy, V. & Giles, C. (2007). *The Medical staff services handbook: Fundamentals and beyond.* Sudbury, MA: Jones & Bartlett.
- Greenhalgh, T. (2001). *How to read a paper: the basics of evidence-based medicine.* London: BMJ Books.
- Hall, S. (1997). An analysis of dilemmas posed by prehospital DNR orders. *The Journal of Emergency Medicine*, 15:109-111.
- Hass, B (2005). Critical care unit organization and patient outcomes. *Critical Care Nursing Quarterly*, 4: 336-340.
- Hawkins, N., Ditto, P., Danks, J., & Smucker, W. (2005). Micromanaging death: process preferences, values, and goals in end of life medical decision making. *The Gerontologist* 45:107-117.
- Hertogh, C., deBoer, M., Droes, R., & Eefsting, J. (2007). Beyond a Dworkinian view on autonomy and advance directives in dementia. Response to open peer commentaries on "Would we rather lose our life than lose our self? Lessons from the Dutch debate on euthanasia for patients with dementia." *The American Journal of Bioethics*, 7:W4-W6.
- Heyland, D., Rocker, G., O'Callaghan, C., Dodek, P., & Cook, D. (2003). Dying in the ICU: perspectives of family members. *Chest*. 124:392-397.
- Hickman, S., Hammes, B., Moss, A., & Tolle, S. (2005). Hope for the future: achieving the original intent of advance directives. *The Hastings Center Report*. 35:S26-30.

- Hickman, S., Hammes, B., & Tolle S. (2004). A viable alternative to traditional living wills. *The Hastings Center Report* 34:4-5.
- Hickman, S., Tolle, S., Brummel-Smith, K., & Carley, M. (2004). Use of the Physician Orders for Life-Sustaining Treatment program in Oregon nursing facilities: beyond resuscitation status. *Journal of the American Geriatrics Society*. 52: 1424-1429
- Iserson, K. (1989). Prehospital DNR orders. *Hastings Center Reports*, 19:17-19.
- Iserson, K. (2002). Prehospital advance directives—a better way [Letter to the Editor]. *Journal of Emergency Medicine*, 23: 419-420.
- Kish Wallace, K., Martin, C., Shaw, A. & Price K. (2001). Influence of an advance directive on the initiation of life support technology in critically ill cancer patients. *Critical Care Medicine* 29: 2294-2298
- Kutner, J., Nowels, D., Kassner, C., Houser, J, Bryant, L, & Main, D. (2003). Confirmation of the “disability paradox” among hospice patients: preservation of quality of life despite physical ailments and psychosocial concerns. *Palliative and Support Care*, 1: 231-237.
- Lee, M.A., Brummel-Smith, K, Meyer, J., Drew, N., & London, M. (2000). Physician orders for life-sustaining treatment (POLST): outcomes in a PACE program. *Journal of the American Geriatrics Society*, 48, 1219-1225.
- Lerner, E., Billittier, A., & Hallinan, K. (2002). Out-of-hospital do-not-resuscitate orders by primary care physicians. *The Journal of Emergency Medicine*, 23: 425-428.
- Levine, Carol (2006). The President’s Council on autonomy: never mind! *Hastings Center Report*, 36:46-47.
- Lynn, J and Goldstein, N. (2003). Advance care planning for fatal chronic illness: Avoiding commonplace errors and unwarranted suffering. *Annals of Internal Medicine*, 138: 812-818.
- Martella, R., Nelson, R., and Marchand-Martella, N. (1998). *Research methods: Learning to become a critical research consumer*. Boston: Allyn and Bacon.
- Meisel, A. & Cerminara K. (2007). *The Right to die: The law of end of life decision-making* (3rd ed.). New York: Wolters Kluwer
- Meyers, J., Moore, C., McGrory, A, Sparr, J., & Ahern, M. (2004). Physician orders for life-sustaining treatment form. *Journal of Gerontological Nursing* 30: 37-46.
- Mularski, R., Heine, C., Osborne, M., Ganzini, L, & Curtis, J. (2005). Quality of dying in the ICU: ratings by family members. *Chest* 128: 280-287.

- New physicians form may help resolve some issues with care at end of life (2005, May 1). *Hospice Management Advisor*. Retrieved October 6, 2007 from LEXIS-NEXIS.
- Office of Oregon Health Policy and Research.(2003) *Oregon Nursing Homes*. Retrieved September 28, 2006 from <http://www.oregon.gov/DAS/OHPPR/RSCH/docs/2002NursingFacilityreport.pdf>
- Oregon Health and Science University (2006). *POLST.ORG*. Retrieved May 16, 2006 from www.polst.org
- Oregon Health and Science University (2007). *POLST.ORG*. Retrieved October 3, 2007 from www.polst.org.
- Oregon Health and Science University (2007a). *POLST – Guidance for Health Care Professionals*. Retrieved October 3, 2007 from www.polst.org.
- Oregon Health and Science University (2007b). *The National POLST Paradigm Initiative*. Retrieved October 3, 2007 from www.polst.org.
- Payne, D. (1999). Credentialing and privileging ensure skilled care. *Nursing Management*. 30:8.
- President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1982). *Making health care decisions*. Washington D.C: U.S. Government Printing Office.
- President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983). *Deciding to forego life-sustaining treatment*. Washington D.C: U.S. Government Printing Office.
- President’s Council on Bioethics (2005). *Taking care: ethical caregiving in our aging society*. Retrieved September 23, 2006 from <https://www.bioethics.gov/reports>.
- Rosenfeld K., Wenger, N., Phillips, R., Connors, A., Dawson, N., Layde, P., Califf, R., Roberts M. et al. (1996). Factors associated with change in resuscitation preferences of seriously ill patients. *Archives of Internal Medicine*. 156: 1558-1564.
- Rotstein, G. (2007, February 21). Forms give patients stronger say on end of life. *Pittsburgh Post Gazette*, p. C-1.
- Schmidt, T., Hickman, S., Tolle, S., & Brooks, H. (2004). The physician orders for life-sustaining treatment program: Oregon emergency medical technicians’ practical experiences and attitudes. *Journal of the American Geriatrics Society*. 52: 1430-1434.
- Shalowitz, A., Garrett-Mayer, E., & Wendler, D. (2006). The accuracy of surrogate decision makers: a systematic review. *Archives of Internal Medicine*, 166: 493-497.

- Shortell, S. & Richardson, W. (1978). *Health program evaluation*. St.Louis: Mobley.
- Silveira, M., Buell, R., & Deyo, R. (2003). Prehospital DNR orders: what do physicians in Washington know? *Journal of the American Geriatrics Society*, 51:1435-1438.
- Szalados, J. (2007). Discontinuation of mechanical ventilation at the end of life: the ethical and legal boundaries of physician conduct in termination of life support. *Critical Care Clinics*, 23:317-337.
- Task Force for Quality at the End of Life (2006). End of life care in Pennsylvania. Retrieved August 24, 2007 from: www.aging.state.pa.us/aging/lib/aging/DOA-task_force_long_report_final_2007_2.pdf.
- Teno, J. (2004). Do-not-resuscitate orders and hospitalization of nursing home residents: trumping neglect or shared decision-making at the eleventh hour. *Journal of the American Geriatrics Society*, 52:159-160.
- Teno, J, Clarridge, B. et al. (2007). Family perspectives on end of life care at the last place of care. *JAMA*, 291: 88-93.
- Teno, J., Gruneir, A., Schwartz, Z., Nanda, A., & Wetle, T., (2007). Association between advance directives and quality of end of life care: a national study. *Journal of the American Geriatrics Society*, 55:189-194.
- Teno, J., Lynn, J., Phillips, R., Murphy, D., Youngner, S, Bellamy, P., et al. (1994). Do formal advance directives affect resuscitation decisions and the use of resources for seriously ill patients? *Journal of Clinical Ethics* 5:23- 30.
- The SUPPORT Principal Investigators (1995). A controlled trial to improve care for seriously ill hospitalized patients: the study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA*, 274: 1591-1598.
- Tolle, S & Tilden, V (2002). Changing end of life planning: the Oregon experience. *Journal of Palliative Medicine*, 5:311-317
- Tolle, S., Tilden, V., Nelson, C., & Dunn, P. (1998). A prospective study of the efficacy of the physician order form for life-sustaining treatment. *Journal of the American Geriatrics Society*. 46: 1097-1102.
- Thorevska, N., Tilluckdharry, L, Tickoo, S., Havasi, A., Amoateng-Adjepong, Y., & Manthous, C. (2004). Patients' understanding of advance directives and cardiopulmonary resuscitation. *Journal of Critical Care* 20: 26-34.
- Treggiari, M., Martin, D., Yanez, D., Caldwell, E., Hudson, L., & Rubenfeld, G. (2007). Effect of intensive care unit organizational model and structure on outcomes in patients with

- acute lung injury. *American Journal of Respiratory Critical Care Medicine*, 176: 685-690.
- Truog, R., Waisel, D & Burns, J (1999). DNR in the OR: A goal directed approach. *Anesthesiology*, 90: 289-295.
- Ubel, P., Lowenstein, G., Schwartz, N., & Smith. D. (2005). Misimagining the unimaginable: the disability paradox and health care decision-making. *Health Psychology*, 24: S57-S62.
- University of Pittsburgh Institute on Aging (2007). Physician Orders for Life-sustaining Treatment: Frequently Asked Questions. Retrieved October 5, 2007 from www.aging.pitt.edu/professionals/resources-polst/POLST-FAQs.pdf
- Wicclair, M. (1993). *Ethics and the elderly*. New York: Oxford University Press.
- Wood D (2005). *A different kind of living will*. Retrieved September 26, 2006 from www.ivanhoe.com/channels/p_channelstory.cfm?storyid=11510.