

THE LEGAL AND ETHICAL IMPLICATIONS OF THE INDIANA
SURROGATE DECISION MAKING ACT ON PHYSICIANS AND
PATIENT CARE IN INDIANA HOSPITALS

Amber R. Comer

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Ross D. Silverman, JD, MPH, Chair

Alexia M. Torke, MD, MS

Doctoral Committee

Jason T. Eberl, PhD

April 7, 2015

Margaret G. Gaffney, MD

Cynthia L. Stone, DrPH, RN

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DEDICATION

“Either write something worth reading or do something worth writing”

-Benjamin Franklin

To my patient, loving, and supportive husband, Dr. Adam D. Comer, who has enabled me to succeed in both writing something worth reading and doing something worth writing

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Nullius in verba

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Ad patrem meum . . . mentoris mea et familiaris meus . Omnia enim propter vos ego.

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Background: When a patient is incapacitated and unable to make health care decisions, a surrogate decision maker must be designated to make decisions about the patient's care in his or her place. Studies show that fewer than 20% of patients in hospitals present with a designated health care representative form. Therefore, the overwhelming majority of surrogates in hospitals are identified via default state statutes. Little is known about the implications of state default surrogate decision making statutes on physicians and patient care in clinical practice.

Methods: An evaluation of state surrogate decision making statutes was conducted in order to determine variability among state laws. Additionally, a statewide, quantitative, descriptive, cross-sectional survey of a random sample of 405 physicians working in Indiana hospitals was conducted to determine: 1) physicians' knowledge of Indiana's surrogate decision making law; 2) physicians' approaches to hypothetical cases they might encounter in hospital practice; and 3) any delay in patient care physicians experience as a result of state surrogate decision making laws.

Results: There is very little consistency among states regarding who may serve as a surrogate decision maker. In Indiana, less than half of the surveyed physicians (47.90%) were able to correctly identify legally allowable surrogates. When presented with clinical vignettes, nearly all physicians (84.90%) report that they would allow a grandchild to act as a surrogate decision maker, even though grandchildren are not legal surrogates under

the law. Additionally, more than half of physicians (53.8%) experienced a delay in patient care due to the inability to identify a legal surrogate.

Conclusions: The narrow construction of state laws can leave patients in situations where they either have no qualified surrogate under the law or where they have multiple surrogates. If there are multiple surrogates with competing interests a consensus may not be reached on the patient's medical care. These situations result in a delay of patient care. The results of this study show that the Indiana Surrogate Decision Making law is flawed as it does not reflect the composition of Indiana families and leads to delays in patient care.

Ross D. Silverman, JD, MPH

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Chapter 1

Introduction

Since the dawn of mankind, there has always been sickness, suffering, and death. Given that no one has ever made it out of life alive, it can be argued that humans are, on some level, innately aware of their mortality. Although humans have an awareness of death, we still struggle to come to terms with the fact that we will one day, as did our ancestors before us, die. In an effort to preserve life, medical treatments have been developed and refined over centuries to relieve suffering, treat sickness, and ultimately, delay death. A testament to the success of medical interventions can be seen in the exponential increase of life expectancy throughout the world which more than doubled from approximately 40 years in 1800, to approximately 83 years in 2012 (1). Although life expectancy has increased due to medical advancements, humans have yet to discover the key to immortality.

In the past, the medical management of illness and death were less complicated due to limited health care options. If a person became ill and there was no treatment, he would be offered comfort care until he eventually succumbed to the disease. Today, treatments and cures are available for diseases that once threatened to exterminate entire populations. For example, smallpox was once known to be the most devastating disease on the planet. For over 3,000 years smallpox plagued communities around the world killing every fourth person it infected (2). However, due to the discovery of a vaccination, smallpox has officially been eradicated from the planet.

In many cases, the medical community's quest to preserve life through medical advancements has blurred the line between what is treatment and what is a prolongation of the dying process. In an effort to help treat disease and save patients' lives, medical technologies such as mechanical ventilation are now used on a routine basis in hospitals. Mechanical ventilation preserves lives that would otherwise be lost. In some cases, mechanical ventilation allows patients to live for decades, but often at great cost to the patient, as well as the patient's family. Too often, mechanical ventilation keeps the patient alive, but the patient is incapacitated and unable to interact with the outside world.

Hippocrates wrote, "as to diseases, make a habit of two things – to help, or at least to do no harm"(3). As medical technologies progress, the line between treatments that are a benefit and treatments that in effect cause harm to the patient has become blurred. Historically, if multiple medical options were available to the patient, the physician would act as his surrogate and make medical decisions for him, a concept known as paternalism. However, a move toward patient autonomous health care decision making in the 1970s shifted the care decisions of incapacitated patients away from physicians and to the patient, and in effect to the incapacitated patient's surrogate (4-6).

When a patient is medically incapacitated and unable to make his or her own medical decisions, a health care proxy, known as a surrogate decision maker, must step in and make decisions on behalf of the patient. The surrogate decision maker is responsible for making the patient's medical decisions in one of two ways: 1) through substituted judgment – in which the surrogate tries to make the decision that the patient would make; or 2) based on what is in the patient's "best interests"(7). Whether a surrogate should

make medical decisions based on substituted judgment or on what is in the patient's best interests is determined on a state-by-state basis (8).

Life prolonging medical technologies, such as mechanical ventilation, have facilitated a growing reliance on surrogate decision makers to render life and death decisions about patient care. A recent study found that more than 90% of deaths in Intensive Care Units result from a surrogate's decision to withdraw life support (which includes ceasing mechanical ventilation) (7, 9-12). Facing the arduous task of making end-of-life medical decisions, surrogates sometimes have difficulty deciding what is in the patient's best interest.

In order to assist patients and physicians with such difficult and arduous decisions, including when it is appropriate to withdraw life support, hospital systems formed ethics committees. Ethics committees that provide ethics consultation services within hospitals are now common, with 95% of general hospitals offering some form of ethics consultation services (13). In 2013, I was selected to serve as an Indiana University Health Medical Ethics Fellow. As part of my ethics training, I attended ethics committee meetings and served as an ethics consultant in the hospital system.

It was during my time as a medical ethics fellow that I first came to understand the problems that surrogates face when making medical decisions for incapacitated patients. One of my first ethics consults required my mentor, Dr. Alexia Torke, and me to address a situation involving the withdrawal of life support from a patient whose friend was acting as a surrogate decision maker. The patient was an elderly widow with no children or known family who was incapacitated, in great pain, and close to death. Mechanical ventilation was prolonging her suffering and the dying process.

The patient presented with a medical advance directive form which named a lifelong friend as her surrogate medical decision maker. When contacted, the friend informed us that she herself was elderly, in poor health, and would not be able to come to the hospital to make decisions for the patient. The surrogate further informed us that she would defer her decision making to us, as the ethics consultants. We informed the surrogate that we thought the ethical decision would be to withdraw life support and allow the patient to die a natural death. The surrogate agreed, and the patient subsequently passed away peacefully within hours of removing life support.

Although this situation had an arguably good outcome because the patient did not suffer needlessly and was able to die a peaceful death, it is easy to imagine a situation in which this patient would not have had a surrogate available to make her medical decisions. If not for the patient's advance directive, the potential surrogate would have been required to pursue a guardianship through the court system in order to make the decision to withdraw this patient from life support. The ethics consultation on this patient occurred on a Friday afternoon, a difficult time to arrange a guardianship.

Had this patient's friend needed to pursue a guardianship to make the decision to withdraw life support, this patient's care would have been delayed because she would have been left on life support over the weekend until the courts could be reached on Monday. Although it is hard to imagine needing to delay the withdrawal of life support on such a sick patient for days simply because court intervention is necessary, the law in the state of Indiana requires a guardianship be pursued when a patient has not appointed a health care surrogate decision maker and no immediate family member is present to make health care decisions.

I will never forget this patient's case because it is when I first realized the challenges surrounding surrogate decision making laws in Indiana. After this patient, I began to pay close attention to all of the cases in which the ethical dilemma was rooted in a surrogate decision making issue. During my time as an ethics fellow, I experienced firsthand the frustration of a long term partner who was told he could not make medical decisions for his loved one without pursuing a guardianship through the court because he and the patient were not legally married. I also experienced cases in which patient care was delayed because there were too many surrogates and a consensus on patient care could not be reached.

After experiencing these issues in the hospital, I turned to the literature for an explanation of what was being done to correct these problems that health care professionals experience each day in Indiana hospitals. Much to my surprise, these issues were not being adequately addressed in the literature. An essential part of the ethics fellowship is to complete a project. Due to my personal experience with surrogate decision making issues in Indiana hospitals, I decided that I would focus my ethics fellowship project on examining the legal and ethical issues surrounding the Indiana Surrogate Decision Making law. As I began working on my ethics project, I expanded the project into a research study that I could utilize for my PhD Dissertation.

The following chapters offer a review of surrogate decision making laws throughout the United States, as well as an analysis of the specific issues with Indiana's Surrogate Decision Making Act. Chapter 2 conducts a 50 state review of state legislative codes to determine: 1) whether the state has a default surrogate statute; 2) what persons

are included as acceptable legal surrogates under the statute; and 3) whether there is a hierarchy to determine a final decision maker.

In order to determine whether physicians in Indiana hospitals understand and follow the law in practice and whether physicians experience a delay in appropriate patient care due to the surrogate decision making law, Chapters 3 and 4 report the results of a survey of physicians who work in Indiana hospitals. In Chapter 3, the survey addresses: 1) whether physicians practicing in Indiana hospitals can identify appropriate surrogate decision makers under Indiana law; and 2) whether these physicians follow the law in practice when family members who are not named in the Indiana statute as authorized surrogates are available for decision making at a patient's bedside.

In Chapter 4, the survey addresses: 1) the number of times physicians experience a delay in appropriate patient care due to no legal surrogate being available; 2) the number of days that the absence of a legal surrogate delays a decision about the plan of care; 3) the number of times physicians experience a delay in appropriate patient care due to the presence of too many legal surrogates who cannot agree on the patient's plan of care; and 4) the number of days that appropriate patient care is delayed due to the inability of surrogates to reconcile a plan of care.

Lastly, Chapter 5 outlines a plan for how I will utilize the research findings from this dissertation in an effort to address the challenges with the current Indiana Surrogate Decision Making Act. Additionally, Chapter 5 addresses future research endeavors in the area of surrogate decision making.

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Chapter 2

“What do you mean I cannot consent for my grandmother’s medical procedure?”

Key issues with state default surrogate decision making laws

2.1 Abstract

Background

When a patient is unable to make medical decisions, a health care surrogate must be designated to make decisions on the patient’s behalf. Studies show that fewer than 20% of patients have completed a health care representative form to legally designate a surrogate. Without a prior designation, surrogates are determined via state statute. Currently, there is no up-to-date comprehensive evaluation of state surrogate legislation.

Methods

A review of state legislative codes was conducted to determine: 1) whether the state has a default surrogate statute; 2) the persons included as acceptable legal surrogates; and 3) whether there is a hierarchy to determine a final decision maker.

Results

Currently, 36 states have enacted some form of surrogate statute. There is little consistency between states regarding who may serve as a surrogate decision maker. The key challenges with state laws include: 1) a narrow list of persons who qualify as allowable legal surrogates; and 2) a lack of a hierarchy to determine a final decision maker.

Conclusions

The results of this review show that state surrogate decision making laws have many flaws which could affect patient care. The narrow construction of state laws can leave patients in situations where they either have no qualified surrogate under the law, or where they have multiple surrogates with competing interests who may be unable to reach consensus on the patient's medical care. State laws need to be expanded to allow a broader spectrum of potential surrogates in order to accurately reflect the realities of clinical practice.

2.2 Introduction

An elderly widow with dementia, whose only child is deceased, has been cared for by her adult granddaughter for the past three years. After being admitted to the hospital for complications from aspiration pneumonia, the elderly woman is stable, but her treating physician has determined that she needs a bronchoscopy of her left lower lobe, a procedure that requires informed consent. It is clear that the granddaughter has provided excellent care for her grandmother and wants nothing more than to see her grandmother get better and come home. Would it be appropriate for the granddaughter to consent for her grandmother?

Although the answer to this question seems simple when basic concepts of medical ethics are applied, the legality of allowing the granddaughter to consent for her grandmother varies from state to state. While it would be ethically defensible to allow the granddaughter to consent for her grandmother, in many states it would be illegal to simply defer to the granddaughter's judgment under state law.

When a patient is incapacitated and unable to make decisions for him or herself, a surrogate decision maker (also referred to as a proxy decision maker), must be designated to make decisions about the patient's care in his or her place (1). Surrogates are needed in order to protect the patient's autonomy and ensure that health care providers act in the patient's best interests (1-4). Barring any conflicts of interest, the person who knows the patient the best and is in the best position to understand the patient's desires, needs, and goals is an ethically appropriate surrogate (1, 3-5). Failing to allow an ethically appropriate surrogate decision maker to act adversely affects the scope, quality, and timing of care. It also creates significant and avoidable adverse outcomes and moral

distress for patients, their families and loved ones, as well as for the physicians providing patient care (6-8).

Traditionally, immediate family members have filled the role of the surrogate decision maker because family members are assumed to hold the strongest concern for protecting their loved one's interests (1, 3, 4, 9-11). Additionally, family members are thought to be in the best position to determine patient preferences based on substituted judgment (9). Although family members are traditionally thought to be in the best position to serve as a surrogate decision maker, the concept of a family has changed over the past several decades necessitating a reevaluation of who should serve as a surrogate decision maker (12, 13).

The laws governing health care surrogate decision making vary from state to state. Under state laws, surrogate decision makers can generally be identified in three ways: 1) a court order, usually in the form of a guardianship; 2) a health care power of attorney document or health care representative form where the patient appoints his or her representative prior to incapacitation; and 3) a default state surrogate decision maker statute (14, 15). The documented presence of a legal health care representative upon patient admission to the hospital is less than 20% nationally (16-19). This means that in the hospital, at least 80% of patient surrogate decision makers will be appointed via default state surrogate decision making statutes.

In an effort to encourage patients to engage in advance care planning, the Patient Self Determination Act (PSDA) was passed at a federal level in 1990. The PSDA requires that all hospitals and health care providers ask each patient upon admission whether he or she would like to complete a health care representative form which usually includes naming a surrogate decision maker (20). In addition to simply asking whether a patient would like to appoint a surrogate decision maker, hospitals are charged with providing the resources to patients to complete these forms. Despite this national effort, the fact still remains that less than 20% of patients have a health care representative form available to the hospital (21-23).

Default state surrogate decision making laws are inconsistent and pose many challenges for untraditional families. Many states' default statutes do not permit persons such as grandchildren, unmarried partners, and close friends to make decisions for the patient, regardless of what the patient would have wanted. In these states, potential surrogates must procure a guardianship through the court system in order to make medical decisions for their loved one.

These pitfalls of state surrogate decision making laws have largely been ignored by researchers and policy makers. Although default state laws determine how the majority of surrogate decision makers are appointed, the overwhelming majority of literature focuses on surrogate decision making via advance directives and guardianships. This paper discusses the legal and ethical history of surrogate decision making, conducts a 50 state survey of surrogate decision making laws, and discusses the key challenges with these laws affecting patient care including: 1) inconsistency of state laws; 2) the narrow inclusion of persons able to serve as legal surrogates; and 3) lack of a hierarchy

among surrogates with no clear final decision maker. Additionally, this paper recommends that a federal Surrogate Decision Making Act be passed in order to provide standardization among states and provide both a legal and ethical solution to the issues presented.

2.3 Legal and Ethical History of Surrogate Decision Making

For hundreds of years, medical decisions were largely made by the patient's physician, a concept known as paternalism (24-26). The practice of paternalism remained the norm until the mid -1960s when Americans began to place an emphasis on autonomy – the right of patients to make their own medical decisions (24, 26, 27). In 1967, the concept of autonomy was extended to patients who were medically incapacitated when Luis Kutner, a human-rights lawyer, published a paper that described the concept of an advance directive (28, 29).

After the introduction of the advance directive, the concept of medically incapacitated patients retaining autonomous decision making evolved piecemeal from both a legal and ethical standpoint. In 1976, the first case to grant patients the legal right to autonomous decision making while medically incapacitated was decided by the New Jersey Supreme Court. In this case, *In re Quinlan*, the court allowed the parents of a young woman in a persistent vegetative state to act on her behalf and remove her from life support (30). The parents were the presumed decision makers because in the early days of autonomy, it was assumed that the immediate family member at the incapacitated patient's bedside was the ethically appropriate person to make medical decisions for the patient (1, 3, 4). Additionally, *In re Quinlan*, the New Jersey Supreme Court determined that the right of the next of kin to assume guardianship of an incompetent person “has

roots deep in common law” (30). The court further held that the rights of guardians to make decisions for incapacitated patients fell under the constitutional right of privacy (26). In summation, the court found that Quinlan’s parents were the appropriate guardian for Quinlan and their medical decisions were private and should be honored (26).

The Quinlan case led to change surrounding surrogate decision making laws in the United States. Later that year, California adopted the first living will statute that legalized the use of living wills by physicians when making patients medical decisions (29). Over the next decade, the use of living wills became extremely popular and by the end of 1986, forty-one states had adopted living will statutes similar to California (28, 29).

The idea of using a durable power of attorney as a tool for appointing a health care decision maker was first introduced by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in 1983 (29, 31). From this idea, Idaho passed the first state statute determining who would be able to act on behalf of incapacitated patients, as a sort of power of attorney over medical decisions in 1985 (6, 32). By 1989, fifteen states and Washington D.C. had passed surrogate decision making statutes (6).

In *Cruzan vs. Director, Missouri Department of Health* in 1990, the United States Supreme Court upheld the legal standard that incapacitated persons retain autonomous decision making through a surrogate (16). The court set the standard that a patient’s surrogate was able to refuse life-prolonging medical treatment for the patient if “clear and convincing evidence” exists that the surrogate was conforming to the patient’s wishes (33). The *Cruzan* case was the first case heard by the United States Supreme Court to

address the concept of patients retaining autonomy even after medical incapacitation. This case led to the adoption of the Patient Self Determination Act (PSDA) in 1990, which requires hospitals to ask patients upon admission if they have a health care representative, and if not, whether they would like help naming one (20).

As a result of the Cruzan case and the PSDA, the Uniform Law Commission published the Uniform Health Care Decisions Act (UHCDA) in 1993 (34). The UHCDA outlines a list of appropriate surrogates in the event that a patient becomes incapacitated without an advance directive (34). Contrary to the first surrogate decision making customs, the UHCDA expanded qualified decision makers to persons beyond just the patient's family by including a hierarchy of potential alternative surrogates. The concept of appointing a legal surrogate decision maker for incapacitated patients who do not have an advance directive became mainstream, and by 2002, thirty-five states and Washington D.C. had adopted a surrogate decision making law either through legislation or case law (7).

Surrogate decision statutes are a relatively recent concept that has been developed piecemeal throughout the country. Although the laws are not consistent, statutes are credited as one solution for resolving ethical problems with surrogate medical decision making (35). A person qualifies as an ethically appropriate surrogate when they have knowledge of the patient's preferences and values, including how the patient viewed life and how life should be lived, and the patient's attitude toward illness, pain, suffering, and medical procedures (1, 3-5). Currently, there is no up-to-date comprehensive evaluation of state surrogate decision making legislation. In order to determine the current

challenges with these laws that affect patient care, a 50 state review of surrogate decision making statutes was conducted.

2.4 Methodology

An evaluation state surrogate decision making statutes was conducted in 2014 in order to determine variability among state laws. Each state's legislative code was reviewed for the following information as it pertains to adult patients: 1) whether the state has a default surrogate law; 2) the code section in which the default state surrogate decision making statute is located; 3) the most current year in which that statute was either passed or amended; and 4) who is included as an acceptable legal surrogate under the statute. The full details of this review are located in Appendix 1.

2.5 Results

Currently, 36 states have enacted some form of surrogate decision making statute that includes a scheme for appointing a decision maker for incapacitated adult patients without a court appointed guardian, designated health care representative, or health care power of attorney (Table 1). Of the 36 states that have enacted these default surrogate statutes, there are only two consistent allowable surrogates under all state laws: spouses and adult children of the patient. In 35 states, parents are specifically named as an allowable surrogate, and in 32 states, adult siblings of the patient are specifically named as allowable surrogates.

Table 2.1. *Allowable Surrogate Decision Makers Under State Laws*

Potential Surrogate	Number of States Which Allow this Surrogate
Spouse	36
Adult Child	36
Parent	35
Adult Sibling	34
Close Friend	23
Other Adult Relative	17
Grandchild	14
Grandparent	8
Unmarried Partner	5
Aunt or Uncle	3
Physician/ Facility Representative	3
Cousin	1
Domestic Partner	2

It is important to note that under the majority of these surrogate decision making laws, same-sex partners, domestic partners, and unmarried common-law partners do not qualify as spouses. As of December 2014, only seven states have directly addressed this issue in their statutes: the states of Washington and New York, which specifically allow domestic partners to serve as surrogates, and Alaska, Arizona, Maine, New Mexico, and Oregon, which specifically allow unmarried partners to serve as surrogates.

Only one state, North Dakota, has codified the right of a step-parent to make decisions on behalf of a step-child. Additionally, only eight states, Georgia, Louisiana, New Mexico, North Dakota, South Carolina, South Dakota, Utah, and Wyoming allow grandparents to consent for grandchildren (Table 2.1). Furthermore, only 14 state statutes explicitly permit grandchildren to consent to care on behalf of their grandparents. Three states allow aunts and uncles, and only one state, South Dakota, allows cousins (see Appendix 1 for a complete list of included states).

When no family member is available, 23 states allow close friends to make surrogate decisions; two states, Indiana and Texas, allow religious superiors of patients in avowed religious orders to make decisions; and three states Arkansas, Idaho, and Pennsylvania, allow a physician with the help of an ethics committee to make decisions for incapacitated patients. This review of state surrogate decision making laws reveals that there is very little consistency among states regarding who may serve as a surrogate decision maker.

2.6 Discussion

Spouse/ Partner

This review shows that the most common surrogate decision makers in state statutes are spouses and adult children. In all 36 states with surrogate decision making laws, the spouse is listed as an appropriate surrogate decision maker. Although the practice of utilizing the spouse as the surrogate decision maker is ethically appropriate barring any evident reason that the spouse is not acting in the best interest of the patient or violating the patient's expressed autonomous wishes without due care, the data shows that the modern cultural norm has dramatically shifted and many persons are no longer legally marrying the person that they choose as their long term partner or "spouse". For example, only 156,000 persons in the 1980 U.S. Census indicated that they lived unmarried with their partner; however, by 2008, that number had increased to 6.2 million persons (36-38).

The drastic shift in unmarried partners who choose to live together poses an issue when a surrogate decision maker is needed. Only five state laws directly allow partners in this situation to make decisions for one another. In 23 states, persons living in this situation would qualify as a decision maker under the "close friend" provision; however, other people who may not be as close to the patient, such as distant relatives, would rank higher on the priority list of decision makers.

In Idaho for instance, a state that does not recognize common law marriage, an adult relative not within the patient's immediate family, such as an uncle, would qualify to serve as a surrogate before a long-term unmarried partner of 20 years (39) . In the 31 states with surrogate statutes that do not expressly permit unmarried, long-term partners to serve as decision makers, a long-term partner would not be able to serve as the patient's surrogate without first pursuing and obtaining legal guardianship through the court system.

Grandparents/ Grandchildren

Only 14 states explicitly authorize adult grandchildren to consent for a grandparent, and only eight states allow grandparents to consent for their grandchildren without a court established guardianship. Since surrogate decision maker laws were first adopted, the number of grandparents who report being the primary caregiver of their grandchild's basic needs has increased from only 3% of grandparents in 1970 to 7% (2.5 million) in 2010 (40-42). Additionally, in 2009, 5.3 million grandchildren were the primary caregiver for their grandparent (43, 44).

Although very few states directly address the issue of grandparents and grandchildren consenting for one another, 17 states allow an adult relative outside of the immediate family to serve as the surrogate decision maker, and 23 states allow close friends. Even though grandparents and grandchildren qualify under "adult relative" or "close friend" provisions in some states, the majority of states still have no way of addressing this relationship under the law. Additionally, both grandparents and grandchildren face the same hurdles as unmarried spouses under hierarchy rules when there is more than one decision maker available.

Same-Sex Partners

One of the most dynamic and rapidly evolving groups of potential surrogate decision makers is that of same-sex partners. In 1980, only 9,980 persons reported living unmarried with a same sex partner; however, by 2010 that number had increased to over half a million persons (565,000) (12, 36, 37). Recently, the Supreme Court of the United States of America declined to hear cases on Certiorari regarding state constitutional bans on same-sex marriage (45). As a result, all State Supreme Court and Federal Court decisions currently stand in regards to the constitutionality of same-sex marriage in each state – meaning, same-sex marriage is now legal in 32 states (46).

Under all state surrogate decision making laws, spouses are an allowable surrogate. Under the current law, this means that in all states where same-sex marriage is now legal, married same-sex partners qualify as spouses under surrogate decision making statutes. Although the recent Supreme Court decision not to hear cases regarding same-sex marriage has had the effect of rendering same-sex partners as spouses under surrogate statutes, this decision is not final as the Supreme Court could choose to hear a case at any time and rule that it is allowable for states to ban same-sex marriage.

If this happens, then same-sex partners will only be prioritized as surrogate decision makers in the five states that allow unmarried partners to serve as surrogates or face falling to the bottom of the hierarchy in the 23 states that allow “close friends”. Additionally, same-sex partners are only considered spouses in the 32 states where cases have been heard and thus, in 18 states, they still do not qualify as spouses under state laws. In essence, the issue of same-sex partners serving as surrogate decision makers

absent a health care representative form, health care power of attorney, or court appointed guardianship is an unsettled and evolving area.

Adult Relative/ Close Friend

Another instance of the shortcomings of state surrogate decision making laws is evidenced by the failure to account for patients who do not have immediate biological family members. Only 23 states have laws which allow for an unrelated person to be a designated decision maker in the context of a health care delivery setting, rather than to be appointed through the courts to serve as a surrogate in the event that the patient does not have a family member who is able to serve. This category of persons is important for two reasons: 1) it allows a person to serve as a surrogate who is not directly related to the patient; and 2) it allows a person to serve as a surrogate who would otherwise be disqualified due to nuances in the law such as a failure to recognize common law, same-sex marriage, or adult relative outside of the immediate family.

It is both important and ethically appropriate to include close friends on the list of potential surrogate decision makers. In states which allow close friends to serve as surrogates, close friends are only able to serve in instances where patients do not have family members who are willing and able to fill the role of health care proxy. Allowing close friends is important because it alleviates the need to pursue a guardianship through the court in instances where there is an ethically qualified individual willing to serve as the surrogate.

The Unbefriended

There is a significant population of patients that has neither an identifiable family member nor friend to serve as a surrogate. It is estimated that as many as 16% of patients who die in intensive care units fall into this category of the “unbefriended” (21). In many states, the inclusion of a broad array of available surrogates has prevented many patients from becoming “unbefriended”; however, a large number of states, including Indiana, Alabama, Arkansas, and Kentucky, have health care surrogacy laws which do not authorize close friends or persons outside of the patient’s family to serve as surrogates unless formally appointed by a health care representative form. The effect of these narrowly construed laws is that patients essentially become “unbefriended” due to the law and not due to the inability to identify a reasonable decision maker. State laws need to include ethically appropriate surrogates outside of the patient’s family in order to avoid the patient becoming “unbefriended” and requiring a guardianship.

Although allowing a broad scope of legal decision makers will alleviate many situations where patients are deemed “unbefriended”, there will still be times when a patient does not have anyone who is able or willing to act as the patient’s surrogate. In situations where there is no ethically or legally appropriate surrogate, three states, Arkansas, Idaho, and Pennsylvania have added provisions in their surrogate decision making laws which alleviate the need for a court appointed guardian. These states avoid the need for a court appointed guardianship by allowing physicians to work with hospital ethics committees to make medical decisions for patients. The remaining states require a court appointed guardian to make medical decisions.

Hierarchy

Thirty of the thirty-six states with surrogate decision making laws have included a hierarchy of decision makers. A hierarchy of decisions makers is necessary when families cannot come to a consensus on the patient's care. In states without a hierarchy, families who cannot reach a consensus about the patient's care are left without a legally recognized mechanism for resolving disagreements. In states with a hierarchy, decision makers are ranked so that one person may make a final decision about the patient's care without the necessity of court intervention in the event that the family cannot reach a consensus (47).

It is important to note that most states with hierarchies have written their laws so that the hierarchy only takes effect when two or more surrogates on the same hierarchy tier cannot reach a consensus on the patient's care. A hierarchy does not mean that families should not or cannot collaborate to make decisions on behalf of the patient. Nor does the presence of a hierarchy mean that someone higher on the surrogate list cannot step aside and allow someone of lower rank to guide decision making.

The hierarchy allows a mechanism for resolving conflicts when patient's families cannot reach a consensus. If this occurs, there is a process to efficiently identify a default decision maker who can act in the patient's best interests without involving the court system in an already delicate and difficult situation. In addition to offering clarity, the establishment of a surrogate decision making hierarchy also confers legal protection for health care providers. Health care providers reasonably relying upon decisions made on behalf of an incapacitated patient by a surrogate decision maker identified under the state

law are protected against certain types of civil lawsuits and complaints filed with licensing boards (48, 49).

Although a hierarchy offers protection from judicial proceedings in the event that surrogates disagree, a hierarchy can have the negative effect of placing an ethically appropriate surrogate decision maker in a position where he or she can be overruled legally by someone who is not as close to the patient. Several examples of this issue can be found in states that do not specifically allow long-term unmarried partners, same-sex partners, and grandparents/ grandchildren and others who would commonly be available, to serve as surrogates. This potential issue can be eliminated by adopting a comprehensive statute which specifically names persons who can serve as surrogates; however, only five states have specifically named unmarried partners, same-sex partners, and grandparents/grandchildren as decision makers, and appropriately ranked them in the hierarchy.

2.7 Recommendations

It often is assumed that people will take the initiative to adequately prepare for health care incapacitation by executing an advance directive, health care representative form, or taking advantage of the offer extended under the PSDA offered to all patients admitted into hospitals to complete advance directives during their hospital stays (20, 23). In reality, these conversations are difficult, and people do not have them, leaving the health care team no choice but to defer to default surrogate statutes when the patient becomes medically incapacitated (50). When they exist, state laws direct who the default surrogate will be in nearly all cases. In order to ensure that the incapacitated patient's autonomy is protected and that his or her interests are preserved, it is imperative the state

statutes specify who may serve as an allowable surrogate decision maker and in what order of priority each surrogate holds final decision making capacity.

Traditionally, family members have been assumed to be in the best position to know either the patient's wishes or keep the patient's best interests in mind (1-4, 51). Following this ethical justification, patients expect that their family members will act as default surrogates in the event that they are medically incapacitated (52). The majority of the issues regarding who should serve as a surrogate decision maker arise from conceptual differences on what constitutes a family or from disagreements within a family. Most state laws are premised on a "traditional" family, which is constituted of a married mother, father, and their children. However, the concept of a family member has evolved dramatically over the past several decades. In today's dynamic society, families are no longer "traditional" and the failure of state laws to recognize this change creates numerous issues when a patient requires a surrogate decision maker.

As shown in the section above, many state laws do not allow unmarried partners, same-sex partners, grandparents, grandchildren, extended family members to make decisions for patients when they are incapacitated. Thus, many situations exist in which patients do not have an available family member as defined under the state law to make medical decisions. The narrow construction of what constitutes a family member under these state laws has the potential to legally disqualify ethically appropriate surrogates, creating unnecessary stress and tension during times that are already daunting and difficult for both the patient and his or her family (6).

Another challenging issue which results when a legal surrogate is not available or a final decision maker is not appointed, is the requirement of court intervention to establish guardianship. When an available patient surrogate decision maker is not included in the state statutory list, the potential surrogate must pursue a guardianship through the court system in order to make medical decisions for the patient. Pursuing a guardianship can be expensive and time consuming, and may lead to a delay in patient care as decisions are delayed until the surrogate is officially appointed by the court (4, 7, 15, 53, 54).

It has been proposed that more education is necessary so that people will appoint their desired surrogate decision maker in advance; however, educational incentives have already been attempted and have failed to yield a drastic change (22, 23). Although there are educational incentives and national policies (such as those offered through the PSDA) presenting patients with the resources and opportunity to complete a health care power of attorney, nearly all incapacitated patients will derive their surrogate decision maker from state laws (16). In many states, the surrogate decision making statute is premised on outdated presumptions regarding who qualifies as a family member creating an ethical quandary for physicians - should physicians allow the *ethically* appropriate or the *legally* appropriate surrogate to make decisions for the incapacitated patient. Given the importance of these statutes, they should be amended to best represent the modern American family in order to protect patient autonomy and serve the best interests of the patient.

In order to achieve standardization of surrogates throughout states, the Patient Self-Determination Act should be amended to include a federal surrogate decision law. A federal law would allow consistency for patients and physicians throughout the United States and help alleviate the numerous pitfalls of surrogate decision making that many state laws currently create. The proposed federal law should be broad enough that it protects patient's autonomy and does what is in the best interest of the patient. This can be accomplished by allowing ethically appropriate surrogates who may not be related to the patient to serve as the surrogate in the event that a legally appropriate family member is not present. Additionally, the federal law should specify one final decision maker in the event that there are multiple surrogates who cannot come to a consensus.

The New Mexico Healthcare Decision Act (NMHCDA) accomplishes the aforementioned tasks. The NMHCDA provides a list of ethically appropriate surrogates in the presumed order of their closeness to the patient. The Act reads as follows:

24-7A-5. Decisions by surrogate. A. A surrogate may make a health-care decision for a patient who is an adult or emancipated minor if the patient has been determined according to the provisions of Section 24-7A-11 NMSA 1978 to lack capacity and no agent or guardian has been appointed or the agent or guardian is not reasonably available. B. An adult or emancipated minor, while having capacity, may designate any individual to act as surrogate by personally informing the supervising health-care provider. In the absence of a designation or if the designee is not reasonably available, any member of the following classes of the patient's family who is reasonably available, in descending order of priority, may act as surrogate: (1) the spouse, unless legally separated or unless there is a pending petition for annulment, divorce, dissolution of marriage or legal separation; (2) an individual in a long-term relationship of indefinite duration with the patient in which the individual has demonstrated an actual commitment to the patient similar to the commitment of a spouse and in which the individual and the patient consider themselves to be responsible for each other's well-being; (3) an adult child; (4) a parent; (5) an adult brother or sister; or (6) a grandparent. C. If none of the individuals eligible to act as surrogate under Subsection B of this section is reasonably available, an adult who has exhibited special care and concern for the patient, who is familiar with the patient's personal values and who is reasonably available may act as surrogate. D. A surrogate shall communicate his assumption of authority as promptly as practicable to the patient, to members of the patient's family specified in Subsection B of this section who can be readily contacted and to the supervising health-care provider. E. If more than one member of a class assumes authority to act as surrogate and they do not agree on a health-care decision and the supervising health-care provider is so informed, the supervising health-care provider shall comply with the decision of a majority of the members of that class who have communicated their views to the provider. If the class is evenly divided concerning the health-care decision and the supervising health-care provider is so informed, that class and all individuals having lower priority are disqualified from making the decision (25).

While the NMSDMA cannot anticipate all potential problems with surrogates, such as instances where a patient may be estranged from their family and would rather have a friend make their decisions, it is a comprehensive act that would alleviate the

majority of current pitfalls. The only way to ensure that surrogates are exactly who the patient prefers is for every patient to complete a health care representative document which they keep up-to-date. Historically, even with national efforts, patients have not been proactive in advance care planning. Given the inconstancy and pitfalls of state laws, a federal law which mirrors the New Mexico Health Care Decisions Act would be the best solution to the current Surrogate Decision Making issues the United States faces.

2.8 Conclusion

Due to the variability of surrogate decision making laws among states, it is easy to imagine a situation where a patient would not have an ethically appropriate surrogate who is recognized under current state laws. At a minimum, it is imperative that state laws be amended so that they are applicable to clinical practice. In order to best address the current pitfalls of surrogate decision making laws, a federal law should be passed which mirrors the New Mexico Healthcare Decisions Act in order to protect the patient's best interests and autonomy.

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Chapter 3

Physician Understanding and Implementation of Indiana's Surrogate Decision Making Law in Clinical Practice

3.1 Abstract

Background

In Indiana, physicians are responsible for identifying the legally appropriate surrogate decision maker for patients. Under Indiana law, a patient's spouse, adult children, adult siblings, and parents are all appropriate surrogates. In the event of a dispute between family members about an incapacitated patient's plan of care, all appropriate surrogates have equal say in the incapacitated patient's health care decisions. Although physicians are charged with identifying surrogate decision makers in inpatient hospital units, few studies have been conducted to determine whether physicians understand these laws and how these laws function in practice.

Methods

In order to determine whether physicians in Indiana hospitals understand and follow the Indiana Surrogate Decision law in practice, a survey of physicians who work in Indiana hospitals was conducted. The survey addresses: 1) whether physicians practicing in Indiana hospitals can identify appropriate surrogate decision makers under Indiana law; and 2) whether these physicians follow the law in practice when family members who are not named in the Indiana statute as authorized surrogates are available for decision making at a patient's bedside.

Results

Less than half of physicians (48.06%) were able to correctly identify all persons who qualify as legally allowable surrogate decision makers under Indiana law. When presented with clinical vignettes, nearly all physicians (84.47%) report that they would allow a grandchild to act as a surrogate decision maker, 39.32% of physicians would allow same-sex partners, 14.08% would allow close friends, and 36.17% would allow unmarried long-term partners even though these persons are not legal surrogates under the law.

Conclusions

The data show that the majority of physicians are unable to correctly identify the family members who are legally authorized to serve as surrogate decision makers under Indiana law. In other words, physicians do not understand a law that they are legally tasked with implementing. Additionally, physicians indicate that they are allowing persons to act as surrogates who are not legally appropriate under Indiana law. The results of this study show that the law in its current form is not meeting its intent. This law needs to be changed by the Indiana State Legislature so that it accurately reflects the clinical realities and ethical standards of those who are serving as patient surrogates.

3.2 Introduction

When a patient is medically incapacitated and unable to make decisions for him or herself, a surrogate decision maker, also referred to as a proxy decision maker, is required to make decisions about the patient's care in the latter's place. Surrogate decision makers can generally be identified in three ways: 1) appointment by the patient prior to their incapacitation through a health care power of attorney document or health care representative form; 2) a court order; or 3) a state surrogate decision maker law (1, 2). Studies show that fewer than 20% of patients in hospitals present with a designated health care representative (3-5). Therefore, the overwhelming majority of surrogates in hospitals are identified via default state statutes.

Each state has its own laws regarding who qualifies as a surrogate decision maker and its own approach to how these laws are implemented. As of 2014, 36 states, including Indiana, have enacted some form of law for appointing a decision maker for incapacitated patients who have not appointed a health care representative (6). In the absence of state law, physicians are left to defer to their individual hospitals for guidance (7). Although default state statutes are the most common way that surrogate decision makers are identified in inpatient hospital units, no studies have been conducted to determine how these laws function in practice (8). The purpose of this study is to fill that knowledge gap in Indiana.

Indiana law relies upon physicians to identify the legally appropriate surrogate decision maker for incapacitated patients. Under Indiana law, a patient's spouse, adult children, adult siblings, and parents are all considered appropriate surrogates (9). In the event of a dispute between family members about an incapacitated patient's plan of care,

all appropriate surrogates have equal say in the incapacitated patient's health care decisions. In the absence of an available immediate family member, such as a spouse, adult child, or parent to act as a surrogate, any other person desiring to serve as a surrogate for the incapacitated patient (including a long-term partner, grandparent, grandchild, adult relative, or close friend) is required to obtain a legal guardianship through the Indiana court system. Obtaining a legal guardianship is time consuming, costly, and emotionally taxing on the potential surrogate (10-12).

In order to determine whether physicians in Indiana hospitals understand and follow the law in practice, a survey of physicians who work in Indiana hospitals was conducted. The survey addresses: 1) whether physicians practicing in Indiana hospitals can identify appropriate surrogate decision makers under Indiana law; and 2) whether these physicians follow the law in practice when family members who are not named in the Indiana statute as authorized surrogates are available for decision making at a patient's bedside.

3.3 Methodology

A statewide, quantitative, descriptive, cross-sectional survey of physicians working in Indiana hospitals was conducted between November 2014 and January 2015 to determine physicians' knowledge of Indiana's surrogate decision making law and physicians' approaches to hypothetical cases they might encounter in hospital practice.

Survey Design

The survey was designed on the basis of information from a review of the literature. The survey was reviewed for validity by content experts in surrogate decision making research. It was pretested during three works in progress sessions sponsored by a hospital system's ethics center. Feedback regarding question clarity, choice of words, missing items, and length was obtained during the survey pretest from approximately 40 physicians. The physicians who participated in the pretest survey screening were representative of the target survey population of physicians.

In order to measure physician understanding of the law, the survey included questions which asked the physician: 1) to indicate who qualifies as an appropriate surrogate under Indiana law; 2) who is the appropriate final decision maker in the event that there are multiple legal decision makers in disagreement over patient care; and 3) to indicate the appropriate next step if no legal surrogate is available. Additionally, in order to measure whether physicians utilize the law in practice while treating patients, physicians were presented with four hypothetical vignettes. Each hypothetical vignette was designed to offer physicians the choice between allowing a seemingly ethically appropriate, but legally inappropriate surrogate under Indiana law who is present at the

patient's bedside to make the patient's medical decisions. A complete survey is available in Appendix 2.

The Indiana University Purdue University Indianapolis Office of Research Compliance, Institutional Review Board approved the survey in Protocol #1404847503.

Survey Sample

Utilizing the 2014 Physician Masterfile of the American Medical Association (AMA), all physicians who work in the inpatient clinical setting within the state of Indiana were identified. Study exclusion criteria included pediatricians and pediatric sub-specialties, as well as pathologists who work on inpatient hospital staffs. Pediatricians and pediatric sub-specialties were excluded due to their population consisting of minors who fall under a different surrogate decision making protocol than adults. Pathologists were excluded because they do not traditionally interact with patients. From the resulting 1444 physicians, the AMA randomly selected a total sample of 1200 physicians.

Survey Administration

Surveys were conducted via U.S. postal mail. Three survey distribution waves were utilized with each wave mailed approximately one month apart starting November 2014 and ending in January 2015. The first two waves included a cover letter, paper copy of the survey, and a self-addressed postage-paid envelope. The cover letter included the logos of three groups that offered their support to this study: 1) The Indiana University Richard M. Fairbanks School of Public Health; 2) Indiana University Health; and 3) Indiana State Medical Association (Appendix 3 and 4). Additionally, the first wave included a \$5 Starbucks gift card that the physician was informed they could keep regardless of whether they completed the survey.

The third wave consisted of a postcard which reminded physicians either to return the paper survey or take the survey in Redcap, an electronic survey platform accessed via an online link provided on the post card (Appendix 5). Each survey was individually labeled with a subject identification number to allow tracking of non-respondents. Upon receipt of completed surveys all data were entered and stored in Redcap.

Statistical Analysis

Power analyses were performed to determine the appropriate sample size for logistic regression models. Using an alpha level of 0.05, a sample size of 385 would provide a power level of more than 0.80 to detect an odds ratio of 2.0 or higher, using estimated proportions of physician knowledge based off expert advice from the research team, as no previous work has been done in this area. This same power holds for Chi-Square tests.

Descriptive analyses were performed in order to determine physicians' knowledge of the law and whether they follow the law in practice, shown as relative frequencies and percentages from the total sample size. Chi Square analysis was conducted in order to determine demographic predictors of physician understanding of the law. Results are presented as a percentage of the total number of study participants. All p values were two-tailed. Analytic assumptions were tested and verified. All analyses were performed using SAS version 9.4 (SAS Institute, Cary, N.C.).

3.4 Results

A total of 412 physicians completed the questionnaire, yielding an overall response rate of 34.33%. The characteristics of physicians who responded to the questionnaire are represented in Table 3.1. Gender ratio was equal to 303 males (73.54%) and 109 females (26.46%). The largest number of respondents indicated that their medical specialty was family medicine 70 (16.99%) and emergency medicine 70 (16.99%). The majority of physician respondents 229 (55.66%), indicated that they have practiced medicine for greater than 20 years.

Table 3.1. Physician Characteristics (N = 412)

Item	N (%)
Medical Specialty	
Family Medicine	70 (16.99)
Emergency Medicine	70 (16.99)
Anesthesiology	43 (10.44)
Inpatient Internal Medicine	41 (09.95)
Surgery and Surgical Subspecialties	40 (09.71)
Gynecology	13 (03.16)
Cardiology	11 (02.67)
Oncology	11 (02.67)
Intensive Care	8 (01.94)
Palliative Care	7 (01.70)
Pulmonology	5 (01.21)
Neurology	4 (00.97)
Geriatrics	3 (00.73)
Nephrology	1 (00.24)
Other	85 (20.63)
Years as a Licensed Physician	
0 – 10	47 (11.57)
11 – 20	136 (32.77)
> 20	229 (55.66)
Gender	
Male	303 (73.54)
Female	109 (26.46)
Clinical Practice Setting*	
Inpatient	217 (29.77)
Outpatient	246 (33.74)
Emergency Department	100 (13.72)
Inpatient Care Unit (ICU)	85 (11.65)
Urgent Care	23 (03.16)
Nursing Home/ Long Term Care	19 (02.61)
Other	39 (05.35)

*Physicians were able to select multiple clinical practice settings

Table 3.2 shows the frequency that physicians indicated that they believed each surrogate was legally allowable. Overall, less than half of physicians 198 (48.06%) were able to correctly answer all items regarding who qualifies as a legally allowable surrogate decision maker under Indiana law (spouse, adult child, parent, and adult sibling). Only 61 (14.81%) of physicians were able to identify that Indiana provides equal decision making authority to all appropriate surrogates under the law. More than half 237 (57.52%) of physicians were able to identify that pursuing a guardianship is the appropriate legal action in the event of an irreconcilable dispute between family members about an incapacitated patient’s plan of care.

Table 3.2.

Frequency Physician Believed Surrogate was Legal under Indiana Law (N = 412)

Item	N (%)
Spouse	409 (99.27)
Adult Child	324 (78.64)
Parent	305 (74.03)
Adult Sibling	204 (49.51)
Civil Partner	82 (19.90)
Grandchild	68 (16.50)
Close Friend	21 (05.10)
Live in Boyfriend/ Girlfriend	20 (04.85)

When presented with clinical vignettes, nearly all physicians 348 (84.47%) report that they would allow a grandchild to act as a surrogate decision maker, 149 (36.17%) of physicians would allow same-sex partners, 58 (14.08%) would allow close friends, and 162 (39.32%) would allow unmarried long-term partners, even though all such relationships are excluded as permitted guardians under state law (Table 3.3).

Table 3.3.

Frequency Physicians allow the following persons to Serve as Surrogate Decision Makers: Total Physician Population (N = 412)

Item	N (%)
Grandchildren	348 (84.47)
Unmarried/ Common Law Partner	162 (39.32)
Same-Sex Partners	149 (36.17)
Close Friend	58 (14.08)

Of those physicians who were able to correctly identify all legal decision makers ($n = 198$) (i.e. physicians who indicated that grandchildren are not legally appropriate surrogates under the law) nearly all of them 183 (92.42%) stated they would allow grandchildren to serve as surrogates in a clinical vignette. Additionally, of those same physicians, 82 (41.41%) indicated they would allow same-sex partners to serve as surrogates in practice, 39 (19.70%) would allow close friends to serve as surrogates in practice, and 80 (40.40%) would allow unmarried long-term partners to serve as surrogates in practice (Table 3.4).

Table 3.4.

Frequency Physicians who were able to accurately identify allowable surrogates under the Indiana Surrogate Decision Making law allow the following non-legally appropriate persons to serve as surrogate decision makers: (n =198)

Item	n (%)
Grandchildren	183 (92.42)
Same-Sex Partners	82 (41.41)
Unmarried/ Common Law Partner	80 (40.40)
Close Friend	39 (19.69)

Physicians' knowledge of the law varied based on demographic variables (Table 3.5). Gender was not a predictor of physician's knowledge of the law. Additionally, physician understanding of the law decreased with years in practice (Table 3.5).

Table 3.5.

Predictors for Physician Knowledge of the Law (N = 412)

Item	Correct Knowledge of Law N (%)	Incorrect Knowledge of Law N (%)
Medical Specialty		
Emergency Medicine	34 (48.57)	36 (51.43)
Family Medicine	32 (45.71)	38 (54.29)
Inpatient Internal Medicine	27 (65.85)	14 (34.15)
Anesthesiology	20 (46.51)	23 (53.49)
Surgical Subspecialties	15 (37.50)	25 (62.50)
Oncology	8 (72.73)	3 (27.27)
Palliative Care	6 (85.71)	1 (14.29)
Gynecology	4 (30.77)	9 (69.23)
Cardiology	3 (27.27)	8 (72.73)
Geriatrics	3 (100.00)	0 (00.00)
Pulmonology	3 (60.00)	2 (40.00)
Neurology	2 (50.00)	2 (50.00)
Intensive Care	2 (25.00)	6 (75.00)
Nephrology	1 (100.00)	0 (00.00)
Other	38 (44.71)	47 (55.29)
Years as a Licensed Physician		
0 – 10	27 (57.45)	20 (42.55)
11 – 20	73 (53.68)	63 (46.32)
> 20	98 (42.79)	131 (57.21)
Gender		
Male	143 (47.19)	160 (53.81)
Female	55 (50.46)	54 (49.54)

3.5 Discussion

The data show that the majority of physicians do not accurately identify the types of relationships that confer legal authority to potential surrogate health care decision makers to serve under Indiana law. In other words, physicians in this sample do not appear to understand a law that they are legally tasked with implementing. Furthermore, the data show that among those physicians who are able to correctly identify legally appropriate surrogates, almost all of them would violate the law in practice based on hypothetical cases.

For example, when confronted with a grandchild as a potential surrogate decision maker, 92.42% of physicians who correctly identified that grandchildren are not legally allowable surrogates self-identified that in practice they would confer authority for health care decision making for an incapacitated patient to a grandchild to serve as a surrogate. This pattern is similar for other non-legal surrogates; 41.41% of physicians would allow same-sex partners; 16.69% of physicians would allow close friends; and 40.40% of physicians would allow unmarried long-term (common-law) partners (Table 3.4). In each case, physicians who have knowledge of the law are more likely to allow non-legal surrogates decision making capabilities.

There are at least three possible explanations as to why physicians indicate that they would allow surrogates who are not legally appropriate to make decisions for patients. First, some physicians simply do not know the law. This is evidenced by the data demonstrating that less than half of physicians were able to correctly identify all appropriate legal surrogates. Although it is tempting to explain away the high numbers of physicians who allow grandchildren to act as surrogates in practice as naivety of the

law, only 16.50% of all physicians (whether or not they were able to correctly identify all legally appropriate surrogates) indicated that they believed grandchildren were legally appropriate surrogates (Table 3.2). The vast difference in the number of physicians who allow grandchildren to act as surrogates in practice and the number of physicians who indicated that they thought grandchildren were legally allowable surrogates cannot be explained alone by a lack of understanding the law.

Perhaps, physicians allow the ethically appropriate surrogate to make decisions, despite the law. Ethical principles informing clinical care justify allowing a person who knows the patient's preferences and values, including how the patient viewed life and how he or she wanted to live his or her life, and the patient's attitude toward illness, pain, suffering, and medical procedures to act as a surrogate decision maker (7). Whether or not this is the case is difficult to ascertain from a quantitative survey; however, the data show that this explanation is plausible. As evidenced by the data, many physicians who know the law would still allow the loving, caring person by the patient's bedside, who seems to know the patient and have the patient's best interest in mind, to act as a surrogate, regardless of his or her relationship to the patient.

Each hypothetical vignette was designed to present physicians with an ethically defensible, but legally inappropriate, surrogate (13). While this study does not reveal the number of times that physicians base their decisions on ethical principles, it can be argued that not all physicians who violate the law do so in the interest of ethical principles. It can be argued that if a physician were allowing all persons who fit the ethical definition of a surrogate to act as the surrogate, then there would not be such a discrepancy between the number of physicians who violate the law in order to allow

grandchildren to act as surrogates (92.42%) and physicians who allow close friends (19.69%) to make decisions. The numbers would be much closer if bioethical principles were strictly applied because each of the proposed surrogates could be considered appropriate under ethical standards. However, whether physicians are truly making these decisions based on ethical principles requires further study.

Physicians may simply allow the most convenient surrogate to make decisions for the patient. Regardless of physician's knowledge of the law, a large number of physicians indicated through the survey questions that they would allow the seemingly only available person at the patient's bedside to serve as the surrogate regardless of the surrogate's relationship to the patient. Admittedly, in all of these cases, it is easier to allow the surrogate at the bedside to make the decisions than to inform the surrogate that they are not legally appropriate. In each situation, disqualifying the surrogate at the bedside would delay appropriate patient care until the person who wishes to serve as the surrogate could obtain a guardianship through the courts. In reality, if only one person is available at the patient's bedside, it is unlikely that anyone will question if that person makes decisions. A physician can only be sued or held responsible if someone is around who could potentially become upset and object.

This study has several limitations. First, because the study used hypothetical vignettes, it may not accurately reflect who physicians would choose as a surrogate in practice. Second, this study does not measure factors related to why physicians allow certain legally inappropriate surrogates to serve. This limitation requires further study in order to gain a broader picture of the surrogate decision making process.

The results of this study may have some implications for the way state surrogate decision making laws are formulated. It is clear that physicians are not following the law in many instances in their effort to deliver care to patients. The reasons that physicians are ignoring surrogate decision making laws requires further study. However, regardless of the reasons, this study shows that physicians either do not understand, or do not agree with the law in practice.

3.6 Conclusion

Under Indiana's Surrogate Decision Making Act, physicians are the health care professionals legally responsible for identifying incapacitated patient's surrogate decision makers. Due to the narrow construction of the Indiana law, physicians are placed in the position where they must either: 1) choose to follow Indiana law and inform a patient's loved one (who is not a legal surrogate) that they must procure a legal guardianship through the courts; or 2) ignore the law and allow the person at the patient's bedside to act as a surrogate in order to avoid delaying appropriate care for the patient. The results of this study show that the law in its current form is not meeting its intent. This law needs to be changed by the Indiana State Legislature so that it accurately reflects the clinical realities and ethical standards of those who are serving as patient surrogates.

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Chapter 4

The Effect of Indiana's Surrogate Decision Making Law on Patient Care in Indiana Hospitals

4.1 Abstract

Background

In situations where patients have not appointed a health care surrogate, each state must determine who is able to make health care decisions for the patient when he or she is medically incapacitated. The narrow construction of state laws can leave patients in situations where they either have no qualified surrogate under the law or where they have too many surrogates with competing interests, and a consensus cannot be reached on the patient's medical care.

Methods

In order to determine how state surrogate decision making laws affect patient care in Indiana hospitals, a survey of physicians was conducted. The goal of the survey was to answer four questions: 1) the number of times physicians experience a delay in appropriate patient care due to no legal surrogate being available; 2) the number of days that the absence of a legal surrogate delays decisions about the patient plan of care; 3) the number of times physicians experience a delay in appropriate patient care due to the presence of too many legal surrogates who cannot agree on the patient's plan of care; and 4) the number of days that patient care is delayed due to the inability of surrogates to reconcile a plan of care.

Results

The data show that 53.8% of physicians have experienced a delay in patient care at least one time in the last year because they were unable to identify a legally appropriate surrogate. Almost half (46.01%) of physicians have experienced at least a partial day or more delay of patient care due to the inability to identify a final decision maker when disputes about patient care arose between two or more legal surrogates.

Conclusions

As more than half of Indiana physicians have experienced a delay in patient care due to the inability to identify a legally appropriate surrogate, state legislatures should broaden surrogate decision making statutes to include more potential surrogates. Amending state laws will minimize the delay in patient care that physicians are experiencing, reduce health care costs for patients and hospitals, and reduce costs experienced by potential surrogates while pursuing guardianships.

4.2 Introduction

A patient is deemed medically incapacitated when he or she can no longer make medical decisions for or by him or herself (1, 2). According to a recent study, 47% of geriatric patients in hospitals will require a health care surrogate to help make medical decisions on their behalf (3). While almost half of all patients will require a surrogate decision maker, less than 20% (some studies report rates as low as 5-10%) of all patients present to the hospital with an advance directive or health care representative form. This form identifies who the patient would like to act as their surrogate decision maker in the event that they become medically incapacitated (4-7).

In situations where patients have not appointed a health care surrogate, each state must determine who is able to serve as the patient's surrogate. In 36 states, laws have been passed which list who qualifies as a legally appropriate surrogate (8). Unfortunately, the narrow construction of state laws can leave patients in situations where they either have no qualified surrogate under the law or where they have too many surrogates with competing interests, and a consensus cannot be reached on the patient's medical care (7, 9, 10).

Some patients are left without a legal surrogate in many states because the state law does not allow unmarried partners, grandparents, grandchildren, or close friends to serve as surrogate decision makers (8). Conversely, disagreements between potential surrogate decision makers over life-sustaining treatment and interventions are common, with studies reporting disagreements occurring in as many as one-half of Intensive Care Unit ("ICU") cases involving more than one surrogate (1, 11).

In most states, if a surrogate not authorized under the state law wishes to assume decision making authority over the patient's medical care, the legally appropriate route is for the potential surrogate to pursue a guardianship through the court. However, some physicians may proceed with decision making in order to avoid court involvement. Additionally, in states with no hierarchy specifying a final decision maker, a potential surrogate who wishes to assume final decision making authority must also pursue a guardianship through the court (2). The pursuit of a guardianship can be expensive and time consuming (7, 12-14). Furthermore, in situations where a potential surrogate is not permitted by state law or where families cannot reach a consensus on patient care, many physicians will continue to treat the patient pursuing all possible interventions, even when these interventions are not the treatment option that the patient would have chosen for him or herself (1).

Several state laws, including Indiana, present all of the aforementioned problems. In Indiana, only immediate family members (spouses, parents, adult children, and adult siblings) are legally allowable decision makers in the absence of a designated health care representative. Any other persons wishing to serve as a surrogate decision maker, including grandchildren or non-married partners, are legally required to pursue guardianship through the courts, triggering a potentially high cost situation that may delay appropriate patient care (7, 12-14).

Additionally in Indiana, all immediate family members who qualify as an appropriate surrogate under the law are provided equal decision making authority. In situations where family members (i.e. the spouse and a parent of the patient) cannot agree on the patient's plan of care, one of the interested parties would need to pursue a legal guardianship through the court system in order to assume final decision making authority. Forcing one family member to pursue a legal guardianship over another adds to the already high stress level being experienced by the family due to the patient's illness and delays decisions about the patient's care until a legal guardianship can be obtained.

In order to determine how state surrogate decision making laws affect patient care in Indiana hospitals, a survey of physicians was conducted. The goal of the survey was to answer four questions: 1) the number of times physicians experience a delay in patient care due to the unavailability of a legal surrogate; 2) the number of days that the absence of a legal surrogate delays appropriate patient care; 3) the number of times physicians experience a delay in patient care due to the presence of too many legal surrogates who cannot agree on the patient's plan of care; and 4) the number of days that patient care is delayed due to the inability of surrogates to reconcile a plan of care.

4.3 Methodology

A statewide, quantitative, descriptive, cross-sectional survey of physicians working in Indiana hospitals was conducted between November 2014 and January 2015 to determine the delay in patient care physicians experience as a result of state surrogate decision making laws.

Survey Design

The survey was designed on the basis of information from a review of the literature. The survey was reviewed for validity by content experts in surrogate decision making research. It was pretested during three works in progress sessions sponsored by a hospital systems ethics center. Feedback regarding question clarity, choice of words, missing items, and length was obtained during the survey pretest from approximately 40 physicians. The physicians who participated in the pretest survey screening were representative of the target survey population of physicians.

The survey was designed to measure the delay in patient care physicians experience as: 1) a result of the inability to identify a legal surrogate; and 2) as a result of having too many legal surrogates who cannot agree on a patient's plan of care (a complete survey is located in Appendix 2). In order to measure the delay in care physician's experience, the survey asked physicians to recall the number of times over the past year, such concerns resulted in the delay of appropriate care of their patients. Additionally, physicians were asked to recall the number of days that patient care was delayed, meaning they could not make any further care medical care decisions for the patient. This survey section was completed as part of a larger survey which measured

physician understanding of surrogate decision making laws, and whether physicians follow these laws in practice.

The Indiana University Purdue University Indianapolis Office of Research Compliance, Institutional Review Board approved the survey in Protocol #1404847503.

Survey Sample

Utilizing the 2014 Physician Masterfile of the American Medical Association (AMA), all physicians who work on inpatient hospital staffs within the state of Indiana were identified. Study exclusion criteria included pediatricians and pediatric sub-specialties, as well as pathologists who work on inpatient hospital staffs. Pediatricians and pediatric sub-specialties were excluded due to their population consisting of minors who fall under a different surrogate decision making protocol than adults. Pathologists were excluded because they do not traditionally interact with patients. From the resulting 1444 physicians, the AMA randomly selected a total sample of 1200 physicians.

Survey Administration

Surveys were conducted via U.S. postal mail. Three survey distribution waves were utilized with each wave mailed approximately one month apart starting in November 2014 and ending in January 2015. The first two waves included a cover letter, paper copy of the survey, and a self-addressed postage-paid envelope. The cover letter included the logos of three groups that offered their support to this study: 1) The Indiana University Richard M. Fairbanks School of Public Health; 2) Indiana University Health; and 3) Indiana State Medical Association (Appendix 3 and 4). Additionally, the first wave included a \$5 Starbucks gift card that the physician was informed they could keep regardless of whether they completed the survey.

The third wave consisted of a postcard which reminded physicians either to return the paper survey or take the survey in Redcap an electronic survey platform accessed via an online link provided on the post card (Appendix 5). Each survey was individually labeled with a subject identification number to allow tracking of non-respondents. Upon receipt of completed surveys all data was entered and stored in Redcap.

Statistical Analysis

Descriptive analysis was performed in order to determine the delay in patient care physicians experience as a result of: 1) the patient having too many available surrogates and no final decision maker; and 2) the patient having no legally available surrogate. Relative frequencies of answers are provided as percentages from the total sample size. Power analyses were performed to determine the appropriate sample size for logistic regression models. Using an alpha level of 0.05, a sample size of 385 would provide a power level of more than 0.80 to detect an odds ratio of 2.0 or higher, using estimated proportions of physician knowledge based off expert advice from the research team, as no previous work has been done in this area. This same power holds for Chi-Square tests.

Results are presented as a percentage of the total number of study participants. A Pearson's Chi Square analysis was conducted in order to determine demographic predictors of physician delay in care. All P values were two-tailed. Analytic assumptions were tested and verified. All analyses were performed using SAS version 9.4 (SAS Institute, Cary, N.C.).

4.4 Results

A total of 412 physicians completed the questionnaire, yielding an overall response rate of 34.33%. The characteristics of physicians who responded to the questionnaire are represented in Table 4.1. Gender ratio was equal to 303 males (73.54%) and 109 females (26.46%). The largest number of respondents indicated that their medical specialty was family medicine 70 (16.99%) and emergency medicine 70 (16.99%). The majority of physician respondents 229 (55.66%), indicated that they have practiced medicine for greater than 20 years.

Table 4.1. Physician Characteristics (N = 412)

Item	N (%)
Medical Specialty	
Family Medicine	70 (16.99)
Emergency Medicine	70 (16.99)
Anesthesiology	43 (10.44)
Inpatient Internal Medicine	41 (09.95)
Surgery and Surgical Subspecialties	40 (09.71)
Gynecology	13 (03.16)
Cardiology	11 (02.67)
Oncology	11 (02.67)
Intensive Care	8 (01.94)
Palliative Care	7 (01.70)
Pulmonology	5 (01.21)
Neurology	4 (00.97)
Geriatrics	3 (00.73)
Nephrology	1 (00.24)
Other	85 (20.63)
Years as a Licensed Physician	
0 – 10	47 (11.57)
11 – 20	136 (32.77)
> 20	229 (55.66)
Gender	
Male	303 (73.54)
Female	109 (26.46)
Clinical Practice Setting*	
Inpatient	217 (29.77)
Outpatient	246 (33.74)
Emergency Department	100 (13.72)
Inpatient Care Unit (ICU)	85 (11.65)
Urgent Care	23 (03.16)
Nursing Home/ Long Term Care	19 (02.61)
Other	39 (05.35)

*Physicians were able to select multiple clinical practice settings

The data shows that in total 217 (52.67 %) of physicians reported experiencing a delay of patient care at least one time in the last year because they were unable to identify a legally appropriate surrogate (Table 4.2). Additionally, 151 (36.65%) of physicians reported experiencing a delay in appropriate patient care at least one time in the past year due to disputes about patient care that arose between two or more legal surrogates (Table 4.2).

Table 4.2.

Physician Reported Annual Occurrences of Delay in Patient Care (N = 412)

Number of Occurrences where Patient Care Was Delayed	1 – 3 N (%)	4 – 6 N (%)	> 7 N (%)	No Delay N (%)
Physician inability to identify a legally appropriate surrogate decision maker	163 (39.57)	31 (7.52)	23 (5.58)	195 (47.33)
Physician inability to reconcile multiple surrogate decision makers opinions	118 (28.64)	17 (4.13)	16 (3.88)	261 (63.35)

More than half of physicians, 220 (53.40%) reported experiencing at least a partial day delay of patient care due to the inability to identify a final decision maker between multiple surrogates (Table 4.3). Furthermore, in total 172 (46.01%) of physicians experienced at least a partial day delay of patient care due to the inability to reconcile multiple surrogate decision makers opinions (i.e. an issue with a lack of hierarchy among legal decision makers) (Table 4.3).

Table 4.3. *Physician Reported Length of Time Patient Care Delayed* (N = 412)

Length of Time Patient Care Was Delayed in Days	<1 N (%)	1 N (%)	2 – 3 N (%)	> 4 N (%)	No Delay N (%)
Physician inability to identify a legally appropriate surrogate decision maker	92 (22.33)	44 (10.68)	48 (11.65)	36 (8.74)	192 (46.60)
Physician inability to reconcile multiple surrogate decision makers opinions	57 (13.83)	38 (9.22)	41 (9.96)	36 (8.74)	240 (58.25)

Among physicians reporting a delay in patient care due to the inability to identify a legally appropriate surrogate, 184 (44.66%) experienced this delay while working in the inpatient setting, 99 (23.86)% experienced this delay while working in the Intensive Care Unit, and 70 (16.99%) physicians experienced this delay while working in the outpatient setting (Table 4.4).

Table 4.4

Setting where physicians' experience a delay in patient care due to the inability to locate a legal surrogate decision maker (N = 412)

Clinical Practice Location of Delay of Patient Care	Inpatient	Inpatient ICU	Outpatient	Did Not Report
N	184	99	70	59
(%)	(44.66)	(23.86)	(16.99)	(14.49)

Among physicians experiencing a delay in patient care due to the inability to reconcile multiple surrogates during times of conflict, 141 (34.23%) of physicians reported experiencing these delays while working in the inpatient setting, 92 (22.33%) reported these delays occurred while working in the Intensive Care Unit and 55 (13.35%) reported these delays occurred while working in the outpatient setting (Table 4.5).

Table 4.5

Setting where physicians' experience a delay in patient care due to the inability to reconcile too many surrogate decision makers (N = 412)

Clinical Practice Location of Delay of Patient Care	Inpatient	Inpatient ICU	Outpatient	Did Not Report
N	141	92	55	124
(%)	(34.23)	(22.33)	(13.35)	(30.09)

Physicians who identified that they practice in the Inpatient Medicine Unit and the Intensive Care Unit (ICU) reported the longest delays in patient care due to the inability to identify a legally appropriate surrogate (Table 4.6). There was a significant correlation between physicians who indicated they practiced in the hospital setting of Emergency Medicine, Inpatient Medicine, and the Intensive Care Unit (ICU) and a delay in patient care due to the inability to identify a legally appropriate surrogate decision maker (Table 4.6).

Table 4.6

P-values for association between clinical practice setting of physician and reported delay of patient care due to the inability to identify a legally appropriate decision maker

Clinical Practice Setting of Physicians	<i>p-value</i>
Emergency Department	.01
Inpatient Medicine	<.0001
ICU	<.0001
Nursing Home	.5118
Outpatient	.0004
Urgent Care	.5960
Other Setting	.0021

There was a significant correlation between physicians who indicated that their clinical area of practice was in the Inpatient Medicine Units and the Intensive Care Units and delays in patient care due to the inability to identify one final decision maker during times that multiple surrogates could not agree on a coherent plan of patient care (Table 4.7). Physicians who indicated that they worked in the Emergency Department did not show a significant correlation between delay of patient care and the inability to reconcile multiple surrogate decision makers.

Table 4.7

P-values for association between clinical practice setting of physician and reported delay of patient care due to the inability to reconcile multiple surrogates

Clinical Practice Setting of Physicians	<i>p-value</i>
Emergency Department	.2659
Inpatient Medicine	.0032
ICU	.0004
Nursing Home	.3128
Outpatient	.0011
Urgent Care	.7337
Other Setting	.0330

4.5 Discussion

Our study found that more than half of physicians report that they have experienced a delay in appropriate patient care due to the inability to identify a legally appropriate surrogate decision maker. This may occur because physicians and courts tend to err on the side of caution and prolong life until a legally appropriate surrogate decision maker can be identified (15). An unnecessary delay in appropriate patient care equates to increased care costs and may increase patient suffering and prolong the dying process as surrogates are often used for end-of-life decision making (17-20). This finding aligns with past research studies which have found that patients without an available surrogate decision maker spent twice as many days in the Intensive Care Unit as patients with available surrogates (16).

In addition to the potential of increased patient suffering and monetary costs, perspective surrogates and physicians may experience moral distress when faced with a situation where they must delay appropriate patient care due to a restrictive state surrogate decision making law. Recent studies show that deaths in ICUs are preceded by a surrogate's decision to withhold or withdraw life support in over 90% of cases (2, 17-20). It is emotionally taxing to place a perspective surrogate in the position where they must go to court to pursue a guardianship in order to make the decision to withdraw their loved one from life support (7, 13, 14).

This study has several limitations. First, this study was conducted in a single state, Indiana, which may not be representative of other states where laws may allow different family members to serve as surrogates or may have different mechanisms for resolving potential surrogate disagreement. Second, this survey asks physicians to recall the number of times patient care was delayed and the number of days that patient care was delayed in the last year. It is possible that physician recall bias may lead physicians to report different numbers than what they actually experienced during their practice (21).

Our findings align with past research and show a correlation between physicians working within the clinical setting of the ICU and delays in patient care due to the inability to identify a legally appropriate decision maker (11). The results of this study have important implications for the status of state surrogate decision making laws. As more than half of Indiana physicians in this survey identify experiencing a delay in delivering patient care due to the inability to identify a legally appropriate surrogate or a final decision maker during times of multiple surrogate disagreement, the Indiana State Legislature needs to amend the current state law.

Based on these findings, state legislatures should broaden surrogate decision making statutes to include more potential surrogates. Additionally, a mechanism, such as a hierarchy of decision makers, should be considered for reconciling the conflicting opinions of multiple surrogates. Amending state laws will minimize the delay in patient care that physicians are experiencing, reduce health care costs by reducing avoidable delays and conflicts for patients and hospitals, reduce moral distress experienced by potential surrogates while pursuing guardianships, and most importantly, more closely ensure appropriate care to reduce patient suffering.

4.6 Conclusion

Surrogate decision makers are tasked with the critical responsibility of making health care decisions on behalf of incapacitated patients. Often these decisions involve life and death consequences. In situations where a patient has not appointed a health representative in advance, state laws mandate who may serve as a surrogate. A survey of Indiana physicians shows that more than half of Indiana physicians have experienced a delay in patient care due to the inability to identify a legally appropriate surrogate decision maker. State laws, including Indiana's, should be amended to broaden the scope of available surrogate decision makers and establish a hierarchy, in order to minimize delays in patient care and alleviate the need for court intervention.

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Chapter 5

Conclusion

In this dissertation, a review of surrogate decision making laws in the United States was conducted. Additionally, a survey of Indiana physicians was completed in order to determine the following: 1) whether physicians practicing in Indiana hospitals can identify appropriate surrogate decision makers under Indiana law; 2) whether these physicians follow the law in practice when family members or others who are not named in the Indiana statute as authorized surrogates are available for decision making at a patient's bedside; 3) the number of times physicians experience a delay in patient care due to no legal surrogate being available and due to the presence of too many legal surrogates who cannot agree on the patient's plan of care; and 4) the number of days that both the absence of a legal surrogate, or the presence of too many legal surrogates who cannot reach a consensus on patient care, delay appropriate patient care.

The review of surrogate decision making laws in the United States found a variability of surrogate decision making laws among states that may create issues for ethically appropriate surrogates who are not recognized under current state laws. The survey of physicians in Indiana found that less than half of physicians (48.06%) were able to correctly identify all persons who qualify as legally allowable surrogate decision makers under Indiana law. Additionally, when presented with clinical vignettes, nearly all physicians (84.47%) report that they would allow a grandchild to act as a surrogate decision maker in practice even though grandchildren are not named surrogates under

Indiana law. These results show that the majority of physicians, as the persons tasked with correctly identifying the persons who qualify as legal surrogates under the law, do not understand the law and are allowing persons who are not legally appropriate surrogates to serve in practice.

Additionally, the survey of physicians in Indiana found that more than half of Indiana physicians (52.67%) have experienced a delay in appropriate patient care in the past year due to the inability to identify a legally appropriate surrogate. Almost half (46.01%) of physicians have experienced at least a partial day delay of patient care due to the inability to identify a final decision maker when disputes about patient care arose between two or more legal surrogates.

Due to the narrow construction of Indiana's Surrogate Decision Making Act, physicians, as the health care providers legally responsible for identifying appropriate surrogates, are placed in the position where they must either: 1) choose to follow Indiana law and inform a patient's loved one that he must procure a legal guardianship through the court; or 2) follow medical ethical principles which defend and encourage the loved one at the patient's bedside to make medical decisions on the patient's behalf, despite the law.

Most ethics literature has focused on how to make surrogate decisions, not on who is making the decisions. If the point of a surrogate is to respect the patient's prior autonomy and protect the patient's best interests, then the person best equipped to uphold these ethical premises while making medical decisions for the now incapacitated patient should be the person who knows the patient best. In the past, it was assumed that family should or would be in the best position to know either the patient's wishes or keep the

patient's best interests in mind. However, what constitutes a family has changed dramatically over the past several decades, and "non-family" may in fact be a better choice for surrogacy.

In Indiana, the current law does not allow unmarried partners, same-sex partners, grandparents, grandchildren, extended family members, or close friends to make decisions for patients who are incapacitated. The law's narrow construction and unrealistic projection of what constitutes a family causes dramatic issues during times that are already daunting and difficult. In a perfect world, people would anticipate that one day, they likely will be incapacitated, require a surrogate decision maker, and subsequently complete an advance directive appointing a surrogate. In reality, these conversations are difficult, people struggle to have them, and they often do not take these actions.

In addition to the Indiana law failing to include persons who would likely be ethically appropriate surrogate decision makers, it also fails to recognize the brevity and stress involved in making medical decisions. As Indiana's law does not have a hierarchy among legal surrogate decision makers, families who cannot come to a consensus are left in a position where they must either do everything for the patient until they can come to an agreement about care, or they are forced to hire an attorney to pursue a guardianship in the court system. In addition to providing a final decision maker, the hierarchy also protects patients so that the person closest to the patient is making their decisions, protecting the patient's autonomy and best interests.

Another instance of the Indiana law's shortcomings is evidenced by the law's failure to account for patients who do not have immediate family members, the "unbefriended." It is estimated that as many as 16% of patients do not have an appropriate surrogate under the law. Realizing that not all people have immediate family members, 23 states allow close friends to make decisions for patients when no family members are able or willing.

Due to the narrow construction of the Indiana Surrogate Decision Making Act, it is common for a situation to arise in hospitals where a patient does not have a surrogate under the current Indiana law. In order to protect patients and the physicians who care for them, it is imperative that Indiana's law be amended so that the law is applicable in clinical practice. It has long been ethically acceptable to allow the loving, caring person who knows the patient to make the patient's medical decisions when he is not able to make them for himself. Indiana's law should be amended so that it mirrors medical ethical principles and functions to protect patients and the health care providers who care for them.

The results of this dissertation show that the Indiana Surrogate Decision Making Act is not working as intended in its current form and must be amended. As presented in Chapter 2 of this dissertation, New Mexico has passed a state law which best addresses both the legal and ethical concerns involved in surrogate decision making. Now that the issues surrounding Indiana's Surrogate Decision Making Law have been identified, the next step of this project is to actively attempt to amend the Indiana law.

In an effort to amend this law, I have forged a partnership with the Indiana State Medical Association (ISMA). In 2014, the ISMA delegation adopted resolution 14-10 which resolved that ISMA will “seek state legislation and support efforts to change Indiana’s Surrogate Consent Statute §16-36-1-5-(a)(2) so that it: 1) Provides a more inclusive list of eligible individuals who can serve as surrogate decision makers; and 2) Establishes a hierarchy or dispute resolution process for cases in which more than one legal surrogate is present and cannot agree on patient care” (Appendix 6).

Drs. Margaret Gaffney and Angela Wagner presented the Resolution at the yearly ISMA convention in 2014. The Resolution adopted by ISMA was voted on by over 200 physician delegates from around the state of Indiana. In order to amend Indiana’s surrogate decision making statute, I intend to foster my existing relationship with ISMA in order to prepare a bill which can be presented to the Indiana Legislature during the 2015-2016 legislative session.

In addition to working with ISMA, I intend to foster relationships with other stakeholders in Indiana, such as Indiana University Health and the Indiana Hospital Association in an effort to gain more support for a legislative change. In order to ensure a legislative change, all efforts will be taken to engage all stakeholders and interested parties so that Indiana’s law can be amended in a way that supports ethical principles and improves the way care is provided to patients in Indiana hospitals.

In order to better understand the clinical realities of surrogate decision making in Indiana, further research studies should be conducted in the area of surrogate decision making. For instance, it would be beneficial to identify the dollar amount associated with delaying appropriate patient care due to physicians’ inability to identify a legally

appropriate surrogate or physicians' inability to reconcile multiple surrogate decision makers. Additionally, identifying the dollar amount that pursuing a guardianship through court intervention costs potential surrogates should be identified. Lastly, a study to identify who is currently serving as surrogate decision makers in Indiana hospitals would offer a more in-depth perspective on how physicians are handling the issue of surrogate decision making in clinical practice.

Although further research studies should be conducted in order to gain a more in-depth understanding of the surrogate decision making process in Indiana hospitals, this research study has identified the need for the law in Indiana to be changed immediately to more accurately reflect the realities of patient care in Indiana hospitals. Although it will be an arduous task to amend the Indiana Surrogate Decision Making Act, I am determined to utilize the findings of this dissertation to effect a positive policy change in Indiana.

Appendix 1.

A full review of state surrogate decision making statutes

STATE	CODE	YEAR	STATE HAS LAW	HIERARCHY	SPOUSE	DOMESTIC PARTNER	UNMARRIED PARTNER	ADULT CHILD	PARENT	ADULT SIBLING	CLOSE FRIEND/ UNRELATED ADULT / OTHER ADULT	COUSIN	ADULT RELATIVE	GRANDCHILD	GRANDPARENT	NIECE OR NEPHEW	AUNT OR UNCLE	STEP-PARENT	RELIGIOUS SUPERIOR	ALLOWS PHYSICIAN/ FACILITY IF NO ONE ELSE
ALABAMA	§22-8A-11	1997	X	X	X			X		X			X							
ALASKA	§47.24.016	2011	X	X	X		X	X	X	X	X		X							
ARIZONA	§36-3231	2013	X	X	X		X	X	X	X	X									
ARKANSAS	§20-6-105	2013	X	X	X			X	X	X			X							X
CALIFORNIA	§4643	1999	X								X									
COLORADO	§15-18.5-103	2010	X		X			X	X	X	X			X						
CONNECTICUT	No Statute																			
DELAWARE	16 Del. C. §2507	2014	X	X	X			X	X					X		X				
FLORIDA	§765.401	2014	X		X			X	X	X	X		X							
GEORGIA	§31-9-2	2010	X	X	X			X	X	X	X			X	X	X	X			
HAWAII	No Statute																			
IDAHO	§39-4504	2005	X	X	X			X	X		X		X							X
ILLINOIS	§755 ILCS 40/25	1998	X	X	X			X	X	X	X			X						
INDIANA	§16-36-1-5	1993	X		X			X	X	X									X	
IOWA	§144a.7	2013	X	X	X			X	X	X										
KANSAS	No Statute																			
KENTUCKY	§311.631	2004	X	X	X			X	X				X							
LOUISIANA	§1299.58.5	1991	X	X	X			X	X	X				X	X					
MAINE	§5-805	1995	X	X	X		X	X	X	X	X		X	X		X	X			
MARYLAND	6 - §5-605	2010	X	X	X			X	X	X	X		X							
MASSACHUSETTS	No Statute																			
MICHIGAN	§333.5653(1)(g)	1978	X		X			X	X	X			X							
MINNESOTA	No Statute																			
MISSISSIPPI	§41-41-211	2013	X	X	X			X	X	X	X									
MONTANA	§50-9-106	1991	X	X	X			X	X	X			X							
NEBRASKA	No Statute																			
NEVADA	No Statute																			
NEW HAMPSHIRE	No Statute																			
NEW JERSEY	No Statute																			
NEW MEXICO	§24-7A-5	2013	X	X	X		X	X	X	X	X				X					
NEW YORK	§2965	2014	X	X	X	X		X	X	X	X									
NORTH CAROLINA	§90-322	1994	X	X	X			X	X	X	X									
NORTH DAKOTA	§23-12-13	1993	X	X	X			X	X	X	X		X	X	X			X		
OHIO	§2133.08	1991	X	X	X			X	X	X			X							
OKLAHOMA	63 Okl. St. §3102A	2005	X	X	X			X	X	X			X							
OREGON	§127.635	1993	X	X	X		X	X	X	X	X		X							
PENNSYLVANIA	§6000.1013 & 6000.1014	2004	X	X	X			X	X	X	X			X						X
RHODE ISLAND	No Statute																			
SOUTH CAROLINA	§44-66-30	2013	X	X	X			X	X	X			X	X	X					
SOUTH DAKOTA	§34-12C(3)	2013	X	X	X			X	X	X	X	X		X	X	X	X			
TENNESSEE	§68-11-1806	2010	X	X	X			X	X	X	X		X							
TEXAS	§313.004	1993	X	X	X			X	X				X						X	
UTAH	§75-2a-108	2008	X	X	X			X	X	X	X			X	X					
VIRGINIA	§16-30-8	2013	X		X			X	X	X	X			X						
WASHINGTON	11.88.010(1)(c)	2010	X	X	X	X		X	X	X										
WEST VIRGINIA	§16-30-8	2013	X		X			X	X	X	X			X						
WISCONSIN	No Statute																			
WYOMING	§35-22-401	2013	X	X	X			X	X	X	X			X	X					

Appendix 2: Physician surrogate decision making survey



Indiana University Health
Charles Warren Fairbanks
Center for Medical Ethics

Physician Surrogate Decision Making Survey

Section A: For each question select all responses that apply.

1. An adult patient is incapacitated and unable to make his/her own medical decisions. The patient has not completed a health care power of attorney or health care representative form. Which of the following people are permitted to make medical decisions for the patient under Indiana law? Check all that apply.

- Spouse
- Adult children
- Civil partner
- Live-in boyfriend/girlfriend
- Parent
- Adult sibling
- Niece/ nephew
- Grandchild
- Close friend

2. In the event of a dispute between family members about an incapacitated patient's plan of care, which of the following family members has the final decision making authority under Indiana law?

- Spouse
- Adult Children
- Parent
- Adult Siblings
- Spouse and adult children share equal decision making authority
- Spouse and parents share equal decision making authority
- All of these family members share equal decision making authority

3. In the event of a dispute between legal surrogate decision makers about an incapacitated patient's plan of care, what action must the family take in order to legally specify one ultimate decision maker?

- Settle the dispute among the family
- Pursue a guardianship through the courts
- Go to mediation
- This question is not valid in Indiana because there is only one ultimate surrogate decision maker as specified by the Indiana surrogate decision making statute.

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Section B: For each question assume the following:

- Each patient has NOT executed a health care power of attorney or health care representative form;
- Each patient is located within the state of Indiana; and
- Each patient is an incapacitated adult and unable to make his or her own medical decisions.

PLEASE ANSWER THESE QUESTIONS AS YOU WOULD OR HAVE ACTED DURING PRACTICE.

1. Your patient is an elderly widow whose only child has died. Her granddaughter has been taking care of her for the past five years and is always present at the bedside. Your patient needs a procedure which requires informed consent. Would you allow the granddaughter to consent to the procedure? Yes No

2. Your patient is a gay man who is estranged from his family. His partner of twenty years and several friends are present at the bedside. Your patient's parents are aware that their son is in the hospital but have no interest in visiting. Your patient's partner would like to change the patient's code status to DNR. Would you change the code status? Yes No

3. A homeless patient is unconscious after a drug overdose. He does not have any family that can be identified. A man in the patient's room identifies himself as the patient's best friend, but says they are the only family each other has and says they call each other brothers. It is clear that the patient and his friend have a very close and caring relationship. The patient's friend claims that he and the patient have "spoken about what the patient would want done if he overdosed on drugs again." Would you allow the patient's friend to make the patient's medical decisions? Yes No

4. Your patient is a sixty year old woman who has two adult children. Since her divorce twenty years ago, she has lived with her boyfriend and has had very little contact with her children who both live out of state. The patient's long term boyfriend is present at the bedside and insists that he and the patient are married under common law because they have lived together for twenty years. The patient is in a medically induced coma and needs a simple procedure which requires informed consent. Would you allow the patient's boyfriend to give consent on behalf of the patient? Yes No

Section C: Answer each question as best as you can remember.

1. In the last year, how many times have you experienced a delay in patient care because you could not properly identify a surrogate decision maker? No delay
 1 – 3 times
 4 – 6 times
 > 7
-
2. What is the longest a patient's care was delayed? No delay
 <1 day
 1 day
 2 – 3 days
 > 4 days
-
3. Where have you experienced these delays in patient care? Check all that apply. Inpatient
 Inpatient ICU
 Outpatient
-
4. In the past year, how many times have you experienced a delay in a patient's care because the patient had more than one surrogate decision maker and the surrogate decision makers did not agree on the patient's course of treatment? No delay
 1 – 3 times
 4 – 6 times
 > 7 times
-
5. What is the longest a patient's care was delayed? No delay
 <1 day
 1 day
 2 – 3 days
 > 3 days
-
6. Where have you experienced these delays in patient care? Check all that apply. Inpatient
 Inpatient ICU
 Outpatient
-
7. Have you ever consulted with any of the following groups when faced with a surrogate decision making issue? (please check all that apply) Case Manager
 Co-Worker
 Ethics Consultant
 Legal Department
 Social Work
 Other: _____
 N/A
-

Section D: Demographic Information

1. What is your medical specialty?

- | | | |
|---|--|--|
| <input type="checkbox"/> Anesthesiology | <input type="checkbox"/> Inpatient internal medicine | <input type="checkbox"/> Pulmonology |
| <input type="checkbox"/> Cardiology | <input type="checkbox"/> Intensive care | <input type="checkbox"/> Surgery and surgical subspecialties |
| <input type="checkbox"/> Emergency medicine | <input type="checkbox"/> Nephrology | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Family Medicine | <input type="checkbox"/> Neurology | |
| <input type="checkbox"/> Geriatrics | <input type="checkbox"/> Oncology | |
| <input type="checkbox"/> Gynecology | <input type="checkbox"/> Palliative care | |

2. What is your current professional status?

- Attending
- Fellow
- Resident
- Other: _____

3. In what clinical setting do you practice? Check all that apply.

- Emergency Department
- Inpatient
- Intensive Care Unit (ICU)
- Nursing Home/ Long Term Care
- Outpatient
- Urgent Care
- Other: _____

4. How many years have you been a licensed physician?

- 0 – 10
- 10 – 20
- >20

5. What is your gender?

- Male
- Female

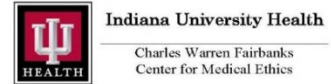
6. What is your race? Check all that apply.

- White
- Black or African American
- American Indian or Alaska Native
- Asian (Includes South Asia)
- Native Hawaiian or Other Pacific Islander
- Hispanic/ Latino
- Choose not to respond

IRB #1404847503

v.8/26/14

Appendix 3: Survey Cover Letter – First Wave



Date

Dear Dr. [Physician Name]:

I am inviting you to participate in a research study by completing the enclosed survey. The purpose of the study is to examine the relationship between the law and medical ethics in surrogate decision-making. The survey will require approximately 10 minutes of your time. A \$5 Starbucks gift card has been provided for you as compensation for participating in the survey; however, you do not have to answer the survey in order to keep the gift card. There is no known risk and participation is strictly voluntary.

In order to ensure that all information will remain confidential, please do not include your name. If you choose to participate, please answer all questions on the enclosed survey.

If you have questions, please contact me via email at Comer@indiana.edu. I truly appreciate your time and assistance.

Sincerely,

A handwritten signature in black ink that reads "Amber Comer". The signature is written in a cursive style and is enclosed in a thin black rectangular border.

Amber Comer, J.D.
Medical Ethics Fellow,
IU Health – Fairbanks Center for Medical Ethics
Ph.D. Candidate,
Indiana University – Fairbanks School of Public Health

Appendix 4: Survey Cover Letter – Second Wave



Indiana University Health
Charles Warren Fairbanks
Center for Medical Ethics

Date

Dear Dr. [Physician Name]:

Several weeks ago, you received two copies of a survey regarding surrogate decision making in Indiana. This survey is very important, and it would be greatly appreciated if you would take a few minutes to return this survey. Your time and help with this matter is greatly appreciated.

If you have questions, please contact me via email at Comer@indiana.edu. I truly appreciate your time and assistance.

Sincerely,

A handwritten signature in black ink that reads "Amber Comer". The signature is written in a cursive style and is enclosed in a thin black rectangular border.

Amber Comer, J.D.
Medical Ethics Fellow,
IU Health – Fairbanks Center for Medical Ethics
Ph.D. Candidate,
Indiana University – Fairbanks School of Public Health

Appendix 5: Survey – Third Wave



Indiana University Health

Charles Warren Fairbanks
Center for Medical Ethics

Dear Physician,

During the past month, you have received two copies of a survey regarding surrogate decision making in Indiana. This survey is very important, and we would greatly appreciate if you would take 5 minutes to either send in the paper survey you received in the mail or to take the survey online at <https://redcap.uits.iu.edu/surveys/?s=fY39ITdrXL>.

Your time and help with this matter is greatly appreciated.

Sincerely,

Amber Comer, J.D., Ph.D. Candidate

Appendix 6: Indiana State Medical Association Resolution

RESOLUTION 14-10 INDIANA SURROGATE CONSENT STATUTE

Introduced by: Margaret Gaffney, M.D., and Angela Wagner, D.O.

Referred to:

Whereas, the majority of end-of-life care decisions are made by surrogate decision makers; and

Whereas, Indiana's Surrogate Consent Statute in its current form is limited to spouse, parent, adult child or adult sibling, is not fully inclusive and does not allow other appropriate individuals, such as grandchildren, partners and close friends, to act as decision makers, leaving many patients without a legal surrogate decision maker; and

Whereas, Indiana's Surrogate Consent Statute, does not have a hierarchy or process in place to resolve disputes between legal surrogates who do not agree on patient care; and

RESOLVED, that the ISMA seek state legislation and support efforts to change Indiana's Surrogate Consent Statute §16-36-1-5-(a)(2) so that it:

- Provides a more inclusive list of eligible individuals who can serve as surrogate decision makers
- Establishes a hierarchy or dispute resolution process for cases in which more than one legal surrogate is present and cannot agree on patient care

Curriculum Vitae

Amber R. Comer

Education

- Ph.D. – Health Policy and Administration, minor in Bioethics. Indiana University Fairbanks School of Public Health, Indianapolis, Indiana (2015)
- Juris Doctor (Health Law Concentration): Indiana University School of Law - Indianapolis, Indianapolis, Indiana (2011)
- Bachelor of Arts (Dual Degree), Political Science & Religious Studies: Indiana University, Bloomington, Indiana (2006)

Fellowships

- Medical Ethics Fellowship. Indiana University Health, Indianapolis, Indiana (2013 – 2014)

Licenses

Member of the Indiana State Bar, Attorney

Research Experience

- Indiana University School of Medicine, P.I.: Amber Comer, J.D., Ph.D. Candidate. The Effects of Indiana's Surrogate Decision Making Act on Patient Care in Hospitals. Funded Quantitative Research Study (n=350) (August 2013 – May 2015)
- Indiana University School of Medicine, P.I.: Daniel Livorsi, M.D. Global Antibiotic Resistance and Physician Prescribing of Antibiotics in Hospitals. Funded Qualitative Research Study (n=30) (June 2014 – May 2015)

- Indiana University Fairbanks School of Public Health, P.I.: Cindy Stone, Dr.Ph., R.N. Health Impact Assessment Research in Indianapolis Communities. Funded Quantitative Research Studies (June 2012 – May 2015)
- Indiana University School of Medicine Center for Bioethics, P.I. Jere Odell. Contentious Objection in the Medical Profession. Funded Empirical Research (January 2013 – October 2014)

Invited Presentations

- Indiana University School of Medicine, Grand Rounds Lecture – Med-Peds – Surrogate Decision Making Laws, Ethics, and Practice (April 2015)
- Indiana University School of Medicine and Indiana University Health, Lecture for Medical Residents – Surrogate Decision Making Laws, Ethics, and Practice (September 2014)
- Indiana University School of Medicine, Lecture for Medical Students – Surrogate Decision Making Laws and Ethics (February 2014)
- Indiana University McKinney School of Law, Health Law Week Lecture Series - Advance Directives in the ICU: Ethics, Laws, and Practice (March 2013)
- Indiana University School of Medicine, Lecture for Medical Students – Advance Directives in the ICU: Ethics, Laws, and Practice (February 2013)
- Dinner and Discourse – Delta Sigma Theta, Speaker – The Affordable Care Act and College Students (November 2013)
- Indiana University School of Medicine, Lecture Medical Students – Bioethics and the Law (February 2012)

Professional Presentations

- American Medical Association, Lecture for practicing physicians, medical residents, and medical students – Legal and Ethical Pitfalls of Electronic Medical Records, developed as part of a funded American Medical Association lecture series (January 2015)
- Bioethics Association Meeting, Atlanta, GA: Poster Presentation: An Ethical Analysis of Conscientious Objection in the Healing Professions (May, 2013)
- American Public Health Association, Boston, MA: Poster Presentation, Advance Directives in the ICU: Ethics, Laws, and Practice (November 2013)
- Robert G. Bringle Civic and Community Engagement Showcase and Symposium, Indianapolis, Indiana: Improving Public Health Action in Transit Legislation (April 2014)
- IUPUI Urban Health Conference, Indianapolis, IN: Poster Presentation, A Student Collaboration to Promote Transit Legislation (April 2014)

Teaching Experience

- Indiana University Fairbanks School of Public Health, Indianapolis, Indiana University. Associate Instructor: H120 Introduction to Health Policy (August 2011 – May 2015)
- Indiana University Fairbanks School of Public Health, Indianapolis, Indiana University. Associate Instructor: H682 Global Health (January 2015 – May 2015)

Professional Experience

- Indiana Supreme Court, Disciplinary Commission, Indianapolis, Indiana. Law Clerk (May 2009 – June 2011)
- Indiana General Assembly, Indianapolis, Indiana. Senate Intern (January 2007 – June 2007)