

MORALITY AND MORTALITY: THE ROLE OF VALUES IN THE ADOPTION OF  
LAWS GOVERNING THE INVOLUNTARY REMOVAL OF LIFE  
SUSTAINING MEDICAL TREATMENT IN U.S. STATES

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Disputes between patients and providers regarding life-sustaining medical treatment (LSMT) are universal across all U.S. states, yet policies regarding these disputes differ significantly. This dissertation determines that all 50 states have advance directive laws that protect a patient's right to refuse LSMT even when a healthcare provider objects, yet only some states have policies that protect the patient's right to choose to continue LSMT when a healthcare provider objects (a dispute known as medical futility). Some states have pro-patient laws that protect the patient's right to make the final decision, while other states have enacted pro-provider medical futility policies that explicitly grant the provider authority to remove LSMT against the patient's wishes. Finally, in one state, the law delegates the final decision to a third-party: institutional healthcare ethics committees. This dissertation studies the innovation and adoption of these 17 state medical futility policies, examining the theory that values determine both whether the state adopts a medical futility policy as well as what type of medical futility policy a state will adopt- as the policy actors that represent these values: policy entrepreneurs and interest groups. A comparative case study of successful third-party policy adoption in Texas contrasted against a failed effort in Idaho could not affirm the necessity of policy entrepreneurs for policy adoption but did affirm the necessity of interest group consensus and the role of values. Furthermore, quantitative analysis failed to offer statistically-significant evidence of value indicators, but did suggest that government ideology and political party affiliation may potentially become indicators of the type of medical futility policy that states choose to adopt.

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# TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS .....	iii
LIST OF TABLES .....	vii
LIST OF FIGURES .....	viii
CHAPTER 1 MEDICAL DISPUTE POLICY .....	1
Introduction.....	1
The Genesis of Medical Disputes and Early Attempts to Mediate These Conflicts.....	2
Landmark Court Cases and the Adoption of State Advance Directive Policy .....	6
The Policy Gap: Medical Futility Disputes .....	11
Conclusion .....	18
CHAPTER 2 MEDICAL FUTILITY POLICY .....	20
Introduction.....	20
Grounds for Medical Futility Determinations.....	21
Competing Concerns of Patients and Providers in Medical Futility Policy .....	26
Medical Futility Disputes and State Law: Who Decides? .....	31
Factors that Indicate a Medical Futility Policy .....	37
Understanding Medical Dispute Policy by Designated Decision-Maker .....	41
Further Understanding State Medical Futility Policy .....	45
Conclusion .....	48
CHAPTER 3 VARIABLES AFFECTING MEDICAL DISPUTE POLICY .....	51
Introduction.....	51
Moral Aspects of Advance Directive Law and Medical Futility Policy.....	54
Factors Affecting the Innovation of Advance Directive Law.....	62
Factors Affecting the Diffusion and Reinvention of Medical Futility Policy .....	67
Theory And Hypotheses .....	73
Actors Required for Innovation: The Roles of Policy Entrepreneurs and Interest Groups .....	79
Indicators of State Values and Expected Effects on MFP Adoption .....	84
Sampling and Methods .....	88

Conclusion .....	90
CHAPTER 4 THE MEDICAL FUTILITY POLICY PROCESS: THE CASES OF TEXAS AND IDAHO.....	92
Introduction.....	92
Instrumentation and Methods .....	94
The Formulation of the Texas Advanced Directives Act of 1999: A Case for Consensus .....	101
Policy Entrepreneurship and MFP in Texas .....	107
Interest Groups and MFP in Texas .....	111
A Symbiotic Relationship.....	113
An Impossible Impasse: The Case of Idaho .....	116
Policy Entrepreneurship and MFP in Idaho.....	122
Interest Group Activities and MFP in Idaho.....	126
An Adversarial Relationship.....	127
The Role of Policy Entrepreneurs Across States .....	129
The Functions of Interest Groups Across States.....	131
Conclusion .....	134
CHAPTER 5 THE ROLE OF VALUES ON MEDICAL FUTILITY POLICY TYPE.....	136
Introduction.....	136
Previous Efforts to Examine the Role of Values in Policy Adoption.....	137
Indicators of State Values and Policy Type.....	140
Control Variables: Characteristics of the State Apart from Values .....	143
Research Methods.....	148
Limitations and Challenges with Methods and Instrumentation .....	149
Factors Affecting the Likelihood of Medical Futility Policy Adoption .....	153
Factors Indicating Values and MFP Policy Type .....	157
Conclusion .....	161
CHAPTER 6 CONCLUSION.....	166
Introduction.....	166
Values and the MFP Process: A Theoretical Framework Revisited.....	168
The Theoretical Implications of Empirical Results .....	170
Beyond Policy Adoption to Policy Implementation, and Implications for ADL States. ....	175

Assessment of Research Methods and Suggestions for Future Research.....	178
Conclusion .....	182
APPENDIX A INFORMED CONSENT FORM .....	184
APPENDIX B INTERVIEW SCRIPT .....	188
REFERENCES .....	194

## LIST OF TABLES

	Page
Table 1 <i>Dispute Matrix</i> .....	13
Table 2 <i>Grounds for Medical Futility Disputes</i> .....	21
Table 3 <i>Medical Dispute Policies by Type</i> .....	40
Table 4 <i>MFP by Decision-Maker</i> .....	42
Table 5 <i>Comparison of Idaho and Texas by Control Variables</i> .....	95
Table 6 <i>Interview Questions that Key Indicate Policy Actor Functions</i> .....	98
Table 7 <i>Policy Entrepreneurship in Texas</i> .....	108
Table 8 <i>Texas Interest Group Functions in 1999</i> .....	112
Table 9 <i>Policy Entrepreneurship in Idaho</i> .....	123
Table 10 <i>Idaho Interest Group Functions in 2009</i> .....	126
Table 11 <i>Functions of Policy Entrepreneurs in Both Texas and Idaho</i> .....	130
Table 12 <i>Interest Group Functions Across States</i> .....	131
Table 13 <i>MFP Adoption by Urbanization, Legislative Professionalism &amp; Political Competition</i> .....	154
Table 14 <i>Partisanship and MFP Adoption</i> .....	155
Table 15 <i>MFP Adoption by Pro-Patient Value Indicators</i> .....	156
Table 16 <i>MFP Adoption by Pro-Provider Value Indicators</i> .....	157
Table 17 <i>MFP Type by Government Ideological Liberalism</i> .....	158
Table 18 <i>MFP Type by Hospitable Right-to-Life Political Environment</i> .....	159
Table 19 <i>MFP Type by Pro-Provider Value Indicators</i> .....	160
Table 20 <i>MFP Type by Urbanization, Legislative Professionalism &amp; Political Competition ...</i>	160
Table 21 <i>MFP Type and Partisanship</i> .....	161



## LIST OF FIGURES

	Page
Figure 1 <i>Medical dispute policy by state and decision-maker</i> .....	45
Figure 2 <i>Medical futility policy process</i> .....	77

# CHAPTER 1

## MEDICAL DISPUTE POLICY

### Introduction

Disputes between patients and healthcare providers regarding medical treatment are complex and multidimensional, presenting a wicked problem for governance via public policy. Each dispute has moral, philosophical, pragmatic, ethical and economic aspects; all suspended in various combinations exclusive to each particular case. Disputes involving life-sustaining medical treatment (or care that, if removed, will likely result in a patient's imminent death) further complicate policy choices. These scenarios are literally vital: life or death, imbuing substantial pressure on policymakers to enact laws that not only respect each citizen's right to autonomy in making their own end-of-life decisions, but safeguards the rights of other citizens (particularly healthcare providers) that deliver such treatment and may have ethical, moral or conscientious objections that also need respected.

Prior to this dissertation, literature failed to address the adoption of policies that resolve medical disputes, particularly disputes where patients desire life-sustaining medical treatment (LSMT) and the healthcare provider objects. Since these disputes present a contentious policy problem with high stakes and potential vehement objections from both patients and healthcare providers, how have states innovated and adopted policies to resolve these disputes? In spite of the controversy, 17 U.S. states have passed laws to address this issue, finding compromises to gain the support of both parties (patients and healthcare providers) in order to adopt the law, yet most often crafting a policy that favors one party over another yet still had enough support to be enacted. By analyzing the policies that have been successfully adopted in spite of the contentious nature of this problem, this dissertation details all of the policy solutions states have enacted- and

also examines what factors promote the adoption of these policies, both the innovations as well as the diffusion, providing the first academic study on these vital state laws.

In order to understand policy solutions that states create to address medical disputes, it is critical first to understand the nature of these disputes and the challenges these disputes present. This chapter explains the two types of medical disputes: right-to-die disputes, wherein a patient wants LSMT removed, and the healthcare provider refuses to remove LSMT- and medical futility disputes, where a patient desires LSMT and the healthcare provider refuses to provide care or petitions to remove LSMT against the patient's wishes (Pope, 2007; Robert Powell Center for Medical Ethics, 2011). While the purpose of this dissertation is discovering how states adopt medical futility policy (MFP) to resolve medical futility disputes, right-to-die disputes and policies enacted to address these disputes were the precursor to all MFP and some of these laws govern medical futility disputes in states that have not yet adopted MFP. Understanding right-to-die disputes and policies are also necessary in order to understand medical futility disputes and policies, the focus of this research.

I begin by explaining right-to-die disputes, the nature and causes of these conflicts and a chronological history of these cases and their impact on state and federal policy. I then examine the converse scenario, medical futility disputes, and explain how law designed to address right-to-die disputes contain a significant policy gap that fails to acknowledge or sufficiently address these conflicts. Finally, I detail what constitutes a medical futility dispute and the grounds for these disputes, in order to provide the proper foundation for this study, in which I analyze state policy innovations created to govern medical futility disputes and the adoption of these laws.

### The Genesis of Medical Disputes and Early Attempts to Mediate These Conflicts

Bioethics regarding end-of-life decisions can be complex with multiple dimensions. But

while there may be multiple dimensions, there are only two sides in a patient/provider dispute: the patient and the healthcare provider. Although these two sides can involve many parties in each, this must be reduced to one entity that makes the determination, especially in cases of patient incapacitation where that the patient may have family members fighting amongst themselves on whether mom or dad, sister or brother continues to receive LSMT.

Specifically on the patient side of the conflict, the issue exists with determining next-of-kin and decision-makers (a designated person chosen to render a medical decision for someone else, known as a healthcare proxy). This is a problem that necessitates public policy, since a widow can have multiple children, all with equal stake, in disagreement about their mother's care and not be able to give any consensus to guide a provider on how to treat her (Breen, Abernathy, Abbott, & Tulskey, 2001, p. 285; Parks et al., 2011, p. 179). Even laws that recognize one party as the healthcare proxy, such as a spouse or other family members may still make a court case attempt to gain that authority themselves, leaving the patient essentially caught in the middle while an objective third-party, typically a judge, decides whether that patient lives or dies (Pope, 2007).

This first attempt to prevent these disputes within families was to compel the patient to declare their wishes in advance and in writing. This gave rise to the living will, a document that allowed the patient to declare for themselves the desire to refuse treatment even if a medical condition, like coma, stroke or brain death rendered them unable to communicate. This is especially relevant in disputes regarding life-sustaining medical treatment (LSMT), since most cases that necessitate LSMT incapacitate the patient and the patient would not have the physical or intellectual ability to make their wishes known (Emanuel & Emanuel, 1990).

The living will was created in 1967 in order to address the widespread fears that accompanied newly-developed life-prolonging technology that began to emerge 20 years prior in the 1940s (Glick, 1992, p. 13; Kutner, 1969). Many patients were anxious about the idea of being kept alive artificially, the associated monetary costs of this unwanted treatment, and also, emotional toll that prolonging death might have on their families. Others saw being hooked up to machines as a threat to their dignity, or feared that they may be suffering unnecessarily by prolonging their inevitable demise (Sabatino, 2010). Still another common fear is the aforementioned squabbling between the family members, even good faith disagreements on what is best for the patient (Breen et al., 2001).

Perhaps most overriding concern addressed by living will was simply ensuring that the provider honored the patient's wishes and not someone's mistaken guess of the patient's wishes. Patient autonomy is the most often-listed reason in literature for the completion of an advance directive (McCormick, 2011). The living will was the innovation intended to address all of these issues of concern to patients, taking the decision out of the hands of family members as well as questions about what decision should be made (Emanuel & Emanuel, 1990).

Living wills were created to direct one course of action: the refusal of LSMT (Kutner, 1969). The document explained explicitly what types of LSMT the patient did not want and in what circumstances the patient would insist that the care be discontinued. The living will exists on the premise was that care is provided by default, and therefore the patient must "opt out" if they do *not* desire such care. The documents were created for termination of specific forms of LSMT, and when patients desired to communicate other medical directives, like establishing a proxy to make their healthcare decisions in situations that the living will did not address, living wills were amended to what are known today the advance directive.

Advance directives, while more complex than the living will, still worked on the assumption that LSMT would be provided unless the patient declared that they did not want treatment- in fact, this was standard procedure among healthcare providers (Fowler, 2008). However, wishes to refuse treatment declared in a patient's living will or advance directive were not always honored, even when these wishes were made in writing, notarized and presented no ambiguity- in part because physicians disagreed with the patient or were afraid of legal or ethical consequences (Glick, 1992a).

A provider's refusal to remove LSMT from a patient upon their request is known as a right-to die dispute. A right-to-die dispute involves the patient deciding they want to discontinue LSMT and the physician refusing to comply with that request (Pope, 2007). The reasons providers gave for refusing to remove care were as diverse as the reasons why a patient would want it removed. Common reasons include a simple desire not to participate, even passively, in a patient's death (Christakis & Asch, 1995). Other reasons involved ethical quandaries of whether the provider was doing harm to a patient by removing LSMT and therefore in violation of the Hippocratic Oath (Christakis & Asch, 1995). Religious objections were also common, for even those providers that saw no mandate in medical ethics to artificially prolong a patient's life against their wishes still personally felt it was morally wrong to bring about the patient's death (Curlin, Nwodin, Vance, Chin, & Lantos, 2008).

These philosophical, moral and religious aspects of a provider's opposition notwithstanding, providers also had an additional, tangible fear: civil or criminal prosecution. Even providers that had no other objections to comply with patient requests were afraid of breaking the law (Glick, 1992a). Even those without fear of criminal charges were still daunted at the thought that a family member who disagreed with the living will or advance directive

would sue the provider in civil court for malpractice or wrongful death (Glick, 1992a). Regardless of how likely such an effort was to succeed, the absence of policy and precedent made it more likely that a physician would simply refuse to remove care than take any chances of the unknown with the stakes being so high. When no laws yet existed that said the provider was obligated to comply with a living will or advance directive, the safest most conservative form of action was to simply refuse any and all requests to remove LSMT, even if that action resulted in court intervention (Hoeftler & Kamoie, 1994). This issue was complicated in the absence of a written directive, and especially in the absence of policy that declared a decision-maker on behalf of the patient. Yet, even with an advance directive and complete unified support healthcare proxy (typically, the family), providers still routinely denied requests to remove LSMT leading to several high-profile court battles and eventually, state law.

### Landmark Court Cases and the Adoption of State Advance Directive Policy

The first landmark case to address disputes over the removal of LSMT was that of Karen Ann Quinlan in 1976. Quinlan, a 21-year-old college student in New Jersey who had taken a dangerous combination of drugs and alcohol at a party, stopped breathing (Cantor, 2001). She was resuscitated via mouth-to-mouth, yet suffered irreversible damage to her brain and was placed on a ventilator as well as fed via a nasogastric tube. Her physical condition deteriorated over several months, steadily losing weight until one point where she weighed only 80 pounds (Quinlan & Rodimer, 2005). Medical tests indicated only abnormal, slow-wave brain activity, with no reasonable hope for recovery (Quinlan & Rodimer, 2005). Devout Roman Catholics, Quinlan's parents opposed euthanasia, but Catholic moral teaching on cases such as this suggest that the removal of "extraordinary means" does not equate to euthanasia, as it is not intended to

kill nor deny a patient their due dignity: food, water, comfort, and hygiene, but merely allow nature to take its course (Henke, 2005; Quinlan & Rodimer, 2005).

The Quinlans believed that their daughter was being kept alive by extraordinary means against all hope of recovery and continuing to deteriorate by being kept alive artificially was a threat to her human dignity (Quinlan & Rodimer, 2005). They expressed their wishes to remove the mechanical ventilator with hospital administrators. The administrators agreed with the Quinlan family, yet were faced with threats of homicide charges by the county prosecutor, citing New Jersey state law (Cantor, 2001). The hospital joined forces with the Quinlan's to challenge this in courts and the case ultimately made its way to the Supreme Court of New Jersey, which sided in favor of the Quinlan family (Cantor, 2001). Shortly thereafter, Quinlan's mechanical ventilator was removed, yet she continued to breathe unaided and lived another nine years in a persistent vegetative state (PVS), not comatose, but unable to interact with her environment. She was fed via nasogastric tube, finally succumbing to pneumonia and passing away in 1985 at 31 years old (Quinlan & Rodimer, 2005).

The Quinlan case spurred the discussion on LSMT and advance directives. States, recognizing the need for policy and the burden on the court system of addressing such a common occurrence, began looking at options that would resolve these disputes and protect patients and providers equally (Glick, 1992a). The Quinlan case also highlighted that even when patients and providers agree, laws existed that did not honor either party (Cantor, 2001).

Policymakers began to draft laws that would respect the patient's wishes while addressing provider concerns. Florida had made several attempts to create a law to resolve this problem but had failed since all policy innovations were met with opposition for not equally addressing the concerns of both patients and providers (Glick, 1992b). In 1976, the year the



Quinlan case made national headlines, the state of California created a policy innovation that struck a compromise to respect both patient and provider concerns (Glick, 1992a). This law would ensure the patient's living will was honored but likewise honored a provider's conscientious objections. It would do so by mandating that the provider transfer care of the patient to another provider who had no conscientious objections and would therefore comply with the patient's request to remove LSMT. The legal concern was addressed as well, since physicians who comply with patient requests would be guaranteed full legal immunity (Hoeftler & Kamoie, 1994). This was a mutually-agreed upon solution between stakeholders that represented both patient rights and those that represented the rights of providers- and this innovation was quickly noted by the Uniform Law Commission, who, with the aid of other organizations, lobbied ferociously to pass this legislation across all fifty U.S. states (Sabatino, 2010).

The federal government also took note of advance directives during this tumultuous time. While court battles continued to rage and living will laws diffused from state to state, economists started to note, albeit not publically, the economic benefits of advance directive policy (Derzon, 1977). Federally-funded programs like Medicare and Medicaid often bore the cost of prolonging patient death simply because a patient had not expressed their desire to not receive LSMT before they became incapacitated, and therefore unwanted care was provided. Policy analysts considered promoting living wills as a symbiotic benefit: first, assuring that patients do not receive care against their will and second, decreasing wasteful spending that could be spent on wanted medical care that would provide more tangible benefits (Derzon, 1977).

One of these analysts was Robert Derzon, the first director of the Health Care Financing Administration (HCFA), the agency charged with financing Medicare and Medicaid. In 1976,

Derzon prepared an internal memorandum for President Carter, detailing ways to more cost-efficiently manage these programs (Derzon, 1977). Noting the Quinlan case, his memo stated that one-fifth of Medicaid expenditures were incurred in the last year of life and estimated that in fiscal year 1978, these costs would exceed \$4.9 billion (Derzon, 1977). He estimated that if only a quarter of Medicaid patients adopted an advance directive refusing unwanted care, the program could save \$1.2 billion. He stated that withholding funding to states that did not have an advance directive law would encourage states to enact these policies and promote the adoption of living wills among citizens (Derzon, 1977).

This suggestion for states to implement living will laws was one of many advisory remarks made in the lengthy memo. Some of these suggestions were as benign as promoting greater education of healthy lifestyle changes like smoking cessation and weight control (Derzon, 1977). However, between the suggestion on advance directive policy promotion and public health education, Derzon also advocated for federal funding of abortion on the grounds that every \$100 spent on abortions for poor women would net a \$1000 savings in welfare payments (Derzon, 1977). When news of Derzon's suggestion leaked to the media, it incurred significant scorn from right-to-life organizations for both promoting abortion and advance directives, which critics claimed was a way to simply kill costly patients (Weaver, 2009). Derzon was fired shortly thereafter and while the official record is that he was terminated from failure to restructure Medicaid and Medicare as quickly as he was instructed, the controversy from what is still known infamously as the "Derzon Memo" could have played a role in his short tenure at HCFA (Cohn, 1978).

In spite of this gaff at the federal level, at the state level, the California approach to advance directive policy diffused quickly, moving geographically from the West Coast to finally

the East Coast (Hays & Glick, 1997). The National Conference of Commissioners on Uniform State Laws drafted this solution as a model, drafting the Model Health Care Consent Act in 1982 which they promoted to state legislatures (The National Conference of Commissioners on Uniform State Laws, 2010). While states were enacting policies, certain battles in other states where the law had not yet diffused had exhausted state courts and made their way to the U.S. Supreme Court. In a 1983 Missouri case, Nancy Beth Cruzan lost control of her car that had no seat belts and was thrown from the vehicle, face-down, into a ditch filled with water (Leschensky, 1991). Like Quinlan, she was resuscitated yet suffered brain damage and fed via a gastric tube (Glick, 1992a; Quinlan & Rodimer, 2005).

After four years, Cruzan's family petitioned to have her feeding tube removed, stating that it would have been her wish to do so even though she had no written advance directive (Leschensky, 1991). Courts disagreed, citing a lack of evidence. The case eventually made it to the Supreme Court of the United States in 1990, who sided with Missouri, setting a precedent that the states have the right to demand "clear and convincing evidence" of a patient's wishes in order to deny medical treatment like LSMT (Leschensky, 1991). However, it also set two other critical precedents: first, that American citizens have the Constitutional right under the due-process clause of the 14th amendment to refuse medical care, even life-sustaining medical care and second, it specifically established artificial nutrition and hydration (ANH), or food and water provided through a tube, to qualify a medical treatment that could be legally denied to a patient (Leschensky, 1991). Cruzan's family returned to the Missouri court with additional evidence and won. They removed Cruzan's feeding tube in 1990 and she died of starvation and dehydration 12 days later (Leschensky, 1991).

This national case affirmed state policy-makers. With the newfound assurance that advance directive laws, like that in California would withstand judicial review, the few laggard states who had not yet adopted continued to enact advance directive law (Glick, 1992b; Hoefler, 1994). That same year, emboldened by the Cruzan decision, the U.S. legislature re-examined federal advance directive policy and passed the Patient Self-Determination Act as an amendment to the Omnibus Budget Reconciliation Act of 1990, a law which mandated advance directives be offered to patients at all institutions that employ Medicaid/Medicare (Hays & Glick, 1997). By 1991, all but six states had advance directive laws, four enacting laws immediately following the Cruzan case, implying that if federal law had any influence, it was simply a catalyst to those states who had not yet adopted the advance directive legislation trend (Hoefler, 1994, p. 165).

In the United States by 1992, there was a widespread consensus on how right-to-die disputes were handled. All U.S. states had advance directive laws (ADL) that guaranteed the now constitutionally-protected right to refuse unwanted medical care, including care required to live (Hecht & Shiel, Jr., 2012). Providers were free to comply with patient requests without fear of legal consequence and were likewise free to conscientiously object, all while patients retained the right to self-determination to refuse LSMT. By all accounts, the right-to-die, at least in regards to refusing LSMT, was settled law that equally respected both patient and provider autonomy.

### The Policy Gap: Medical Futility Disputes

The nationwide passage of ADL represents a long road between the advent of life-prolonging technologies in the 1940s to the ability to refuse them achieved in the precedent of

the Cruzan case and reinforced through federal law (Glick, 1992a; Leschensky, 1991). LSMT was the default, assumed, an understood right if not explicitly-mentioned right of the patient until the patient declared they wanted it discontinued (Fowler, 2008). For half of a century, the battle was refusing unwanted care, and all laws were created to grant patients this right to refuse LSMT.

When these laws were enacted, the converse scenario—a physician choosing to discontinue LSMT against the patient’s wishes—was virtually unheard of and therefore, not addressed in state law. After fifty years of fighting to have LSMT removed, the possibility of having LSMT refused was not on the radar of policymakers. The laws they enacted gave full immunity to providers who conscientiously object to a medical decision, knowing that the patient’s wishes would ultimately prevail at the hands of another physician (Hoefler & Kamoie, 1994). No one considered that a provider could conscientiously object to a decision to provide care that would save a patient’s life, especially given the half-century battle to get providers to remove care that ends patient’s lives. The very laws designed to prevent physicians from being forced to end a patient’s life at the patient’s behest were now being utilized in order to end a patient’s life against their will (Robert Powell Center for Medical Ethics, 2011). This was a rapid departure from the scenarios and ethics that modeled ADL and spurred widespread policy reforms in a majority of U.S. states.

Sometimes referred to as “reverse right-to-die,” (as it is in direct contrast with right-to-die disputes upon which ADL was based), these scenarios propose a problematic issue when governed by laws designed for a converse purpose (Pope, 2007, p. 8). ADL mandates that providers procure a transfer for patients when they do not wish to comply with the patient’s wishes to have care *removed*--- therefore the patient is stable until a transfer may be made. In a

situation where the provider is opposed to providing LSMT, care without which, the patient will die, the provider literally makes a life or death decision on behalf of the patient, simply by refusing to provide care the patient requires in order to live. A dispute in these cases it means the provider is saying “no” to LSMT and the patient is saying “yes” to LSMT, and if the provider prevails, the patient is likely to die. Table 1 demonstrates the scenarios that constitute medical futility disputes vs. a traditional right-to-die dispute.

Table 1

*Dispute Matrix*

	Provider: LSMT “Yes”	Provider: LSMT “No”
Patient: LSMT “Yes”	Consensus- No Dispute	Medical Futility Dispute
Patient: LSMT “No”	Right-to-Die Dispute	Consensus- No Dispute

*Source.* Pope, 2007, p. 9

According to bioethicists, the problem of medical futility disputes emerged in the last fifteen years. The Robert Powell Center for Medical Ethics (2011) quotes Dr. Lachlan Forrow, director of ethics programs at Boston’s Beth Israel Deaconess Medical Center:

About 15 years ago, at least 80 percent of the cases were right-to-die kinds of cases. Today, it’s more like at least 80 percent of the cases are the other direction: family members who are pushing for continued or more aggressive life support and doctors and nurses who think that’s wrong. (p. 3)

Much like right-to-die disputes, the grounds upon which medical futility disputes are based are also philosophically, morally and otherwise diverse. While it is clear that the dispute involves a provider wanting to deny LSMT that a patient wants continued, the provider’s reasons for doing so may vary. These reasons are all dubbed “medical futility” because the underlying basis for denial of treatment is that it is futile, or provides no substantive benefit. Schneiderman, Jecker and Jonsen define medical futility as “an action, intervention or procedure that might be

physiologically effective in a given case but cannot benefit the patient, no matter how often it is repeated. A futile treatment is not necessarily ineffective, but it is worthless either because the medical action itself is futile, (no matter what the patient's condition) or the condition of the patient makes it futile" (P. Clark, 2002, p. 69).

Like notable court cases mobilized awareness in policymakers of the need for laws to address right-to-die disputes, notable cases of provider refusal to provide LSMT or unilateral removal of LSMT in spite of advance directive decree or proxy instructions started to catch the attention of bioethicists and physicians within the medical field (Cranford, 1991; N. S. Jecker & Pearlman, 1992). These cases did not make national news as right-to-die cases had, but were noted in professional circles and became evident in literature in the mid-1990s (Annas, 1994; Associated Press, 1995; Brody & Halevy, 1995; F. I. Clark, 1993; Cranford, 1991; Grant, 1992; HarveyParedes, 1992; N. Jecker, 1991; N. S. Jecker & Pearlman, 1992; Truog, Brett, & Frader, 1992).

The first notable case caught bioethicist attention in 1990. Helga Wanglie was an 86-year-old woman from Minnesota with severe brain injuries whose family wanted to continue to receive a respirator, although the providers opposed the care as futile since Wanglie had no hope for recovery. They also considered the treatment wasteful, noting the medical bills for her care had exceeded \$80,000 (Cranford, 1991). Her family won, and Wanglie died still attached to her respirator just days after the ruling, yet this is one of the two most-referenced medical futility disputes in literature (Callahan, 1991; Capron, 1991; Cranford, 1991; Fine, 2001; N. S. Jecker & Pearlman, 1992; N. S. Jecker & Schneiderman, 1993; Schneiderman & Jecker, 1995; Truog et al., 1992).

The other case was Stephanie Keene, known in bioethics as Baby K. -an infant with anencephaly born in Fairfax, Virginia in late 1992 (Tousignant & Miller, 1995). Anencephaly is a birth defect that results in the absence of a large part of the brain and skull, causing children to often die in childbirth or within hours or days (Annas, 1994). Keene's mother insisted on preserving her daughter's life, opting for resuscitation following frequent respiratory arrests which providers considered both futile and harmful to Keene due to her terminal condition (Tousignant & Miller, 1995). The mother ultimately won because the judge ruled that Keene was legally entitled to life-saving treatment under the Emergency Medical Treatment and Active Labor Act (EMTALA), a federal law which mandates that hospitals who receive government funding provide life-saving treatment in emergency rooms (Annas, 1994). Keene lived 2 years and 174 days, perhaps the longest surviving child with anencephaly (Associated Press, 1995). This case is cited as an example of the law demanding providers perform contrary to medical standards and is another illustration of a medical futility dispute (Fine, 2001; Schneiderman & Jecker, 1995).

While the term "medical futility" had not yet been widely accepted, this "problem without a name" as it was known was oft addressed by medical ethicists in literature as healthcare providers sought some process to resolve these disputes in the absence of any state policies to guide their actions (Callahan, 1991, p. 21). Their actions were under the governance of ADL, policies written for another purpose- so ambiguity existed on whether providers could refuse to provide LSMT that they deemed inappropriate, wasteful or immoral. ADL granted providers the right to refuse to provide care they opposed as long as they transferred to the patient to another provider. This is a win-win situation for right-to-die disputes yet with medical futility disputes, this process fails.



Under ADL, providers who do not wish to comply with a patient's directive to continue LSMT are still advised to seek a transfer, although the law as written protects the provider's right to not participate in an act with which they disagree. This is an inherent contradiction: providers are not required to act contrary to their consciences; however they *must* act contrary to their consciences to provide treatment while seeking a transfer. If the provider invoked their right not to participate and refused LSMT, the patient would die, leaving the provider could unable to fulfill their legal obligation to procure a transfer. If the provider fulfills the obligation to transfer, in order to do so, they must provide the very care they oppose. Therefore the law both gives providers the right to refuse LSMT but makes providers waive that right in order to fulfill the mandate to transfer the patient. While in practice, the removal of care is rare, the law does not expressly forbid it and providers have been forced to do so when they could not obtain a transfer and not always without legal consequence (Pope, 2007). This ambiguity extends to patients as well, who are unsure of what their rights are when a provider opposes their directive.

In lieu of public policy, and in many cases *in spite* of public policy, hospitals attempted to create institutional policies that would govern medical futility disputes and allow the unilateral removal of care in spite of legal uncertainty. There was a heavy emphasis on communication and mediation between patients and providers, with consultants called to negotiate an agreement between the provider and the proxy (Fine & Mayo, 2003; Pope, 2007; Pope & Waldman, 2008). Since disputes were not always resolved in mediation, there was also the use of healthcare ethics committees (HECs) to review the dispute and issue an opinion on whether treatment is beneficial (and should continue) or futile (and should be denied) (Halevy & Brody, 1996; Heitman & Gremillion, 2001; Pope & Waldman, 2008). Some hospitals have attempted to change the healthcare proxy to someone who would agree to remove care, and in some cases, seek

guardianship of the patient themselves if they have a compelling case that the proxy is not making good-faith decisions to benefit the patient (Pope, 2007). There were also attempts to transfer the patient, with unilateral removal being the last resort after the previous mechanisms failed (Pope, 2007). Hospital protocols would include some combination of these steps, some ending in the unilateral removal of care (Halevy & Brody, 1996).

Hospital policies did not supersede state policies which made providers reluctant remove care (Halevy & Brody, 1996; Heitman & Gremillion, 2001; Pope, 2007). Civil sanctions, malpractice, wrongful death and even homicide charges have been brought against providers that unilaterally removed care (Pope, 2007). While some judges would approve the protocol as fulfilling the “reasonable efforts” to transfer that mandated in some state ADL or recognize the right to refuse to comply within state ADL, other judges did not, and the entire process remained fraught with uncertainty and significant legal risk for providers (Halevy & Brody, 1996; Heitman & Gremillion, 2001; Pope, 2007).

Patient advocacy groups were also concerned about hospital policies that allowed unilateral removal (Graham, 2005; Heitman & Gremillion, 2001). Even policies that did not mention unilateral removal were opposed by patient advocacy groups because they forbid treatment like CPR for patients in certain conditions and therefore, unilateral removal was implied (Bay Area Network of Ethics Committees Non-Beneficial Treatment Working Group, 1999, Smith, 2002). ADL did not impart explicit protection for patients in medical futility disputes, and this gap was used to remove care, much as it would also inhibit the removal of care. To explain, providers were not explicitly allowed under law to unilaterally remove care, which made them reluctant to do so (Halevy & Brody, 1996; Pope, 2007). Yet they were not explicitly forbidden to do so, which means that sometimes they did remove care (Halevy &

Brody, 1996; Pope, 2007). Providers wanted explicit permission to unilaterally remove care, and patients wanted explicit prohibition to cease the removals of care that, although rare, were already happening (Graham, 2005; Heitman & Gremillion, 2001).

The ambiguity in ADL affronted the concerns of both patients and providers and both sought to close the policy gap by amending their state ADL into medical futility policy (MFP), beginning in 1993 (Robert Powell Center for Medical Ethics, 2011). As of 2010, 17 states have enacted MFP, some granting protection to patients against unilateral removal of care and some granting protection to providers in the form of legal immunity when unilaterally removing care. Chapter 2 explains these laws, as well as provides greater detail on grounds for medical futility disputes and the competing interests of patients and providers.

## Conclusion

The advent of medical technologies that sustain life brought with it medical disputes between patients and providers, and thus the need to resolve these conflicts in public policy. The right-to-die dispute was the first issue that public policy was compelled to address, and policy-makers crafted ADL, a mutually-beneficial solution to honor the concerns of both patients and providers (Glick, 1992a). Bolstered by Supreme Court cases that garnered national attention and established the right to refuse medical treatment, state policy-makers implemented this single solution nationwide (Hays & Glick, 1997). Although it took nearly 50 years for all U.S. states to adopt ADL, by 1992 the resolution of right-to-die disputes was settled law (Hecht & Shiel, Jr., 2012).

Medical futility disputes appeared on the radar of the medical community around 1990, highlighting the insufficiency of ADL in addressing this issue (Annas, 1994; Cranford, 1991).

ADL gives conflicting mandates when applied to medical futility disputes, allowing the provider the right to refuse care, but specifying that the provider transfer the patient, an action that cannot be achieved if the provider does refuse care. Likewise, providers found that transfers were not always available, with other providers also unwilling to provide treatment (Pope, 2007).

Institutional-level policies that included the unilateral removal of care too proved insufficient to alleviate provider concerns with removing LSMT, and also raised the ire of pro-patient groups opposing the protocol (Graham, 2005; Heitman & Gremillion, 2001).

In 1993, states began amending ADL to either accommodate patient concerns to continue care or accommodate provider concerns to remove care. In Chapter 2, I explain medical futility disputes in greater detail, the grounds for these disputes as well as the competing concerns of patients and providers in these scenarios. Most importantly, I offer an analysis of all the policy solutions that states have adopted to resolve this issue, a critical first step in determining why states adopt MFP and furthermore, why states choose one policy solution over another.

## CHAPTER 2

### MEDICAL FUTILITY POLICY

#### Introduction

Chapter 1 offers a history of medical disputes and medical dispute policy, as well as the two types of medical disputes: right-to-die and medical futility. Medical futility disputes are more complicated than right-to-die disputes in that there are often technical grounds under which providers seek to remove care. Moreover, there are value judgments that often come into play in these scenarios, values that may differ between patients and providers and create a dispute. Medical futility disputes regarding life-sustaining medical treatment (LSMT) are rarely about whether or not LSMT will work as expected, but judgment calls on whether or not LSMT is worthwhile considering the whole of the patient's circumstances. These values are also evident in the policy solutions that may be chosen; therefore it is critical to understand both the technical disagreements about what qualifies care as futile, as well as the value conflicts between parties that are presented in these disputes.

In this chapter, I offer greater detail about the grounds for medical futility determinations, reasons why care may be deemed futile, and how those grounds contribute to disputes and ultimately affect the states choice of medical futility policy (MFP), explaining the concerns of patients and providers in each scenario and why either party supports or opposes different policy solutions that allow or prohibit the unilateral removal of care. Finally, I analyze U.S. state law to determine all the policy solutions that states have enacted, determine which states have MFP, and the mechanisms within each state to resolve medical futility disputes, concluding with a typology that serves as the groundwork for further study.

## Grounds for Medical Futility Determinations

A medical futility dispute was clearly defined in Chapter 1 as the scenario where a patient wants LSMT continued and the provider wants LSMT removed. It is crucial to understand the reasons why a provider would want LSMT removed and what qualifies LSMT as futile. Scholars have been able to provide some parameters that help explain the common reasons why treatment is deemed futile by providers, and these categories that define futility provide an essential outline for the four most-often cited rationale for the provider's unwillingness to provide LSMT (Brody & Halevy, 1995; F. I. Clark, 1993; Schneiderman & Jecker, 1995). Table 2 lists these four criteria.

Table 2

### *Grounds for Medical Futility Disputes*

Quantitative Treatments which fail to achieve their intended physiological effect no matter how often they are given	Imminent Demise Patient will die in the near future (typically hours or days) regardless of treatments
Lethal Condition Patient has some underlying condition which will cause premature death even treatments are provided	Qualitative Even if the treatment is successful, it fails to achieve an acceptable quality-of-life for the patient.

*Source.* Brody & Halevy, 1995

The first and least contested grounds for a provider seeking to deny medical care is called *quantitative futility*. Quantitative futility means that the care is ineffectual, meaning the treatment simply will not achieve its intended purpose no matter how often it is repeated (Brody & Halevy, 1995). This is also known as physiological futility, because it is physiologically inappropriate (Brody & Halevy, 1995). A good example would be someone demanding kidney dialysis to treat cirrhosis of the liver. No matter how often kidney dialysis is performed, that person's liver function is not expected to change. Quantitative futility represents these scenarios where care is

outside of “generally-accepted medical standards” and providers are under an ethical obligation not to provide such treatments (Brody & Halevy, 1995). Quantitative futility is the least-contested type of medical futility determination because typically, an explanation of why the care would not work will satisfy the patient and end the dispute. In the case of LSMT, it is not quantitatively/physiologically futile: it is designed to sustain life. If it fails in ineffective and fails to achieve this purpose, the patient will die, just as they would if the care were effective, but denied. Therefore in cases of disputes over LSMT, the dispute is not over whether or not life-sustaining treatment would achieve its intended effect to sustain life, but that providers believe sustaining life is not beneficial to the patient due to other conditions or circumstances (Pope, 2007).

One such condition or circumstance is when a patient is expected to die soon, in spite of LSMT. This comprises the second category of futile care known as *imminent-demise futility*. This is the scenario where care may be physiologically effective, but the patient is still expected to die shortly, typically within a few days, so the outcome (benefit) does not justify the effort (cost) (Brody & Halevy, 1995). These cases are prominent in emergency rooms with trauma patients, where for example, surgery to treat stab wounds in the patient’s abdomen is deemed futile because the patient was also stabbed in elsewhere and is not expected to survive those wounds. Physicians ethically oppose this care not because it is ineffectual, but because they do not wish to inflict additional pain on a patient by providing a treatment that offers that patient no benefit (Clark, 2002). Such care is also considered a wasteful misuse of healthcare resources (Pope, 2007). In such cases, LSMT’s function to sustain life would be physiologically ineffective since life will inevitably end, meaning that it would be quantitatively futile as well.

Like imminent demise futility, there is *lethal-condition futility*, where the patient is expected to die regardless of treatment but it differs in that the patient suffers from an underlying condition that will not take their life immediately (within a few days), but is still expected to cause the patient's death (typically within six months) (Brody & Halevy, 1995; Clark, 2002). In these cases, providers argue that providing additional care would only serve to burden the patient and will not improve their outcome or provide relief or comfort, violating their ethical obligation to first "do no harm" (Schneiderman & Jecker, 1995). An example of lethal-condition futility would be cardio-pulmonary resuscitation of a hospice patient, breaking their ribs and causing gratuitous, undue pain at the end of their lives (Iserson, 1991). Some providers see the use of LSMT for the terminally ill as "prolonging the agony of death" since such treatment will not change the outcome and can only serve to harm the patient with pain or discomfort (Iserson, 1991, p. 24). Providers maintain that they have a duty not to treat the patient in these cases, citing not just the patient's well-being, but also the monetary costs associated with doing so (Schneiderman & Jecker, 1995). With regard to LSMT specifically, providers argue that the LSMT will not sustain the life of a patient who is succumbing to another condition and therefore, is both wasteful and harmful to the patient and should therefore be withheld (Schneiderman & Jecker, 1995).

The fourth and final category of medical futility is *qualitative futility* (Brody & Halevy, 1995). Qualitative futility is when a provider deems a medical treatment to be futile and not worth providing, not because it is ineffective or patient has a complicating condition that will bring about their death. Instead, the provider claims the treatment is worthless because they do not think it will provide an acceptable "quality of life" for the patient (Clark, 2002). A common example is a hospital denying emergency treatment to a pre-mature neonate with a good



likelihood of survival (80 to 90% survival rate at 26 weeks), because there exists a significant chance that the child will face disabilities like cerebral palsy, low IQ or deafness/blindness. Some physicians maintain that there is a “duty not to treat” when treatment will be successful (i.e. address the health problem and resolve said problem, saving the patient’s life) but when that life saved is not of good quality, according to the provider (N. S. Jecker & Schneiderman, 1993, p. 151). Of course, for there to be a dispute the patient or proxy obviously disagrees about the quality of the patient’s life. Because of the subjectivity and value differences in making these determinations, qualitative futility is the most hotly-contested dimension in these disputes (Pope, 2003).

In the case of LSMT, medical futility disputes involve the provider claiming that the life is not worth sustaining because LSMT would not increase the patient’s quality of life- while the patient disagrees (Pope, 2007). The overt implication is that life with a disability or chronic illness is not worth living, a charge that has elicited serious concern and outrage from disability-rights organizations and those that fear that care will be denied to them because of their pre-existing disability (Batavia, 2002; Stith, 2006; Werth, 2005). Other concerns are the power imbued to a physician to decide who lives and who dies based on their own values and assessments of quality of life (Truog et al., 1992). From a provider’s perspective, they could deem sustaining the life of a person when they anticipate nothing but suffering for a patient as contrary to their convictions, demonstrating the other concerns at play in medical futility disputes, namely, the right of the provider to exercise their right to conscientious objection (Schneiderman & Jecker, 1995).

These grounds upon which care may be deemed futile are not mutually-exclusive, and determinations can sometimes be an amalgamation of these reasons. For example, providers may

recommend the cessation of kidney dialysis for a patient in later stages of Alzheimer's disease who is confused and combative, and she must be restrained to prevent her from pulling the tubing from her arm. Providers may argue both lethal condition and qualitative futility, stating that premature death is already anticipated and that the patient does not benefit from the treatment, but rather the process is burdensome and does not increase the quality of the patient's life. Rather, they feel like the patient is subjected to unnecessary torment during treatments that do not make her life better between treatments.

Again, though, enters a value judgment that can spur a medical futility dispute: The patient's proxy, her adult daughter, may disagree with this assessment that treatments are overly burdensome, noting that are needed only three times per week and the patient enjoys the rest of her time in more familiar surroundings and would want to live. The proxy could argue that simply living is the benefit of the treatment, and treatment allows the patient to live longer and is worth the temporary discomfort for a few hours every other day, especially since the patient is not in pain and immensely enjoys spending time with her grandchildren. Since time is already limited, the proxy does not want to hasten death even by a single day, and feels it would be morally wrong to rob the patient (her mother) of what little time she has. The providers could counter that the renal failure is progressing faster than the Alzheimer's, and treatments would eventually increase in frequency to every day or several times per day- meaning that continuing to burden the patient with dialysis now would only lead to burdening her even more so later. They could also simply disagree that merely living longer is a benefit that justifies frightening and restraining the patient on a regular basis, and that the proxy's position may be an inability to face her mother's mortality- trying to delay death not because of the best interest of the patient, but because of the proxy's fear of grief and loss. The patient's proxy also senses that the

providers may simply want to dispose of a difficult patient- since it is easier to deny care than to provide it to a hostile, combative patient. Providers can additionally object terrifying and overpowering a sobbing patient to provide treatment, feeling it would be abusive and immoral to do so and thus a violation of their right to conscience. The patient (as represented by their proxy) would think it immoral not to provide treatment and denying them precious time to enjoy what is left of their life. The disagreements can volley back and forth on what is right or wrong for the patient without resolution, yet what breaks the deadlock? Who, ultimately, should have the final decision on whether LSMT continues? In order for there to be public policy, there must be some arbiter: patient, provider or other.

### Competing Concerns of Patients and Providers in Medical Futility Policy

Patients and providers bring competing concerns and differing values to medical futility disputes. Patients want to retain the ultimate decision to live while providers want the freedom to practice medicine in accordance with their expertise and ethics. Therein lays a trade-off inherent in these disputes: patient autonomy vs. provider autonomy. In the case of a medical futility dispute, protecting one violates the other: infringing upon the provider's right to conscience or the patient's right to self-determination. Policy can vainly attempt to validate each value-set (patient values and provider values) in an unending myriad of medical futility scenarios, uniformly siding with the patient and declaring the patient's interest greater than the provider, since the patient stands to lose his/her life. Policy can also uniformly side with the provider, erring on the side of medical expertise and ethics in determining what LSMT is or is not futile and not forcing providers to act in direct opposition to their consciences.

People and organizations who oppose policies that grant the provider the right to remove care list several reasons for their opposition. The first is ideology-based and suggests that patients and their proxies have the absolute right to make decisions regarding their own medical treatment, whether others agree with their decisions or not (Robert Powell Center for Medical Ethics, 2011). They see policies that grant this decision to providers as a threat to personal freedom by affording providers the power to usurp decisions that they believe belong solely to the patient, something opponents have referred to as “medical fascism” (Smith, 2002, para. 38). Wesley J. Smith, lawyer for the Patients’ Rights Council opposes what he views as paternalistic “doctor knows best” determinations that supersede patient autonomy (2002, para. 37). Smith notes that patient autonomy was established in right-to-die disputes, and argues that this autonomy is sacrosanct in medical futility disputes as well saying, “If people can say no to life-saving medical treatment in the name of autonomy, consistency requires that they also be allowed to say yes” (2002, para. 8).

Additionally, some are morally-opposed to the definition of LSMT including treatments that they do not consider extraordinary measures, like artificial nutrition and hydration (ANH), supplemental oxygen and kidney dialysis (Zientek, 2006). Some value-sets make a moral distinction between removing a ventilator from a brain-dead patient and denying kidney dialysis to a conscious patient, equating the former to heroic means to prolong a life that would have otherwise died and the latter to preventing the death of a person (Coleman & Drake, 2006). Others staunchly oppose the cessation of feeding as a medical treatment and regard food and water as a basic human right and comfort care (Craig, 1994). The Catholic Church declares that ANH is not extraordinary care in most cases and should not be denied to the comatose or permanently unconscious (Zientek, 2006). Since some futility policies allow providers to

remove ANH and other medical treatments not considered to be “extraordinary,” this alone is an oft-cited reason for opposing such policies (Robert Powell Center for Medical Ethics, 2011).

Beyond the prevailing ideological concerns, there are implementation concerns as well. Some believe that patients and their proxies have a stronger interest in the patient’s well-being than a provider does and also have a better understanding of what the patient wants or needs (Burns & Truog, 2007). Others fear these laws will allow providers to dispose of difficult or poor patients because it is expedient or cost-effective, arguing that it is easier and cheaper to declare treatment futile than to provide it (Tomlinson & Czlonka, 1995). There are accusations of utilitarianism: providers choose to deny treatment to a particular patient because they believe those resources would be better served treating others (Smith, 2002). This imposes an additional fear of discrimination for patients that they, in particular might be denied care for the sake of other patients because their lives are considered less important than the lives of others or that they consume more healthcare resources than they should (Smith, 2002). Many fear that patients with disabilities, chronic illnesses or the aged will be denied care as a form of healthcare rationing (Smith, 2002). This is compounded with the fear of bigotry, that a provider would deem treatment to be futile because a disability or illness does not offer the “quality of life” a provider finds acceptable (Batavia, 2002; Stith, 2006; Werth, 2005).

Conversely, those in favor of policies that allow providers to remove care list the best interest of their patient as their motivation. Providers insist that they oppose treatments out of concern for the well-being of their patients, not an imposition of their personal values (Fine, 2000). They cite many cases where a patient (most often, the patient’s proxy) demands care that could only cause additional pain and suffering, care the provider could not ethically or morally consent to providing without violating their oath to “do no harm” (Schneiderman & Jecker,

1995; Wreen, 2004). They note that many proxies demand care without understanding the consequences for their patient and insist “everything be done” to prolong the patient’s life and therefore, providers are ethically obligated to protect a patient from their proxy in those circumstances (Pope, 2007). Although the providers attempt to resolve the dispute, they cite the limitations of mediation and the need for policy to intervene when stalemates threaten patient well-being (Pope & Waldman, 2008; Pope & Waldman, Ellen, 2007; Schneiderman & Fein, 2001).

Scholars and bioethicists refute the concerns that medical futility is used as a smokescreen for cost-containment, asserting that decisions are made on a case-by-case basis with no regard for a patient’s finances (Schneiderman & Jecker, 1995). They argue simply that treatment is only denied when it is futile, and treatment would be futile even if patients wanted to pay for it (Schneiderman & Jecker, 1995). There is evidence that cost has played into medical futility decisions, in particular a case where the hospital ethics committee considered whether they should continue to provide treatment on a terminally-ill patient whose costs were already approaching half a million dollars, thinking that these funds would be better spent on treating patients with a hope of recovery (Pope, 2007 p. 20). However, the physician who declared the care futile did not consider the cost when making that determination, and made the decision on the merits of that individual case. Scholars also cite the Americans with Disabilities Act to quell concerns that patients with disabilities will suffer discrimination, citing that it is illegal to deny care on the basis of disability alone (Batavia, 2002).

Finally, providers have a professional and personal interest in maintaining their autonomy and assert that being forced or coerced to participate in medical treatments they deem harmful or unnecessary violates their freedom of conscience. Pope explains this opposition in the words of

the providers themselves, who state that giving a patient the legal right to demand treatment equates a physician to a “vending machine” or a grocer, and reduces medicine to a consumer commodity like breakfast cereal or toothpaste (2007, p. 14). Pope also notes that medicine is self-governing with a distinct set of ethics, so providers see policies that refuse to honor these standards as an affronts to the integrity of the medical profession and goals that transcend merely keeping a patient alive (2007, p. 15). Physicians have concluded that valuing patient autonomy is not a mandate to do whatever the patient demands, and rather that providers need to be legally free to deny treatment inconsistent with the goals and values of the medical profession (Pope, 2007, p. 16).

Patients and provider concerns with medical futility policy are multi-dimensional, yet neither party’s concerns appear to present a disregard for the other party. It would be dishonest to suggest that providers seek policies that grant them the ultimate decision to continue care because they oppose patient autonomy, but instead believe that patient autonomy does not extend to demanding futile treatment (Pope, 2007). Nonetheless, if patient autonomy did allow for such demands, providers believe that medical ethics have preeminence over patient requests stating, “futility is a professional judgment that takes precedence over patient autonomy and permits physicians to withhold or withdraw care deemed to be inappropriate without subjecting such a decision to patient approval” (Schneiderman, Jecker, & Jonsen, 1990, p. 112). Ultimately, providers insist that they have a good-faith conviction that these policies are best for patients as well as providers, providing the best care of a patient while honoring the standards of the profession (Pope, 2007).

Likewise, those that support policies granting patients the final decision do not do so because they oppose a provider’s right to conscience, but because they also believe these policies

to be best for patients (Robert Powell Center for Medical Ethics, 2011). They believe that provider autonomy and the right to conscience can be achieved through patient transfer without violating patient autonomy. Much as providers feel that medical judgment takes precedence over patient autonomy, others feel like the stakes are higher for patients and the temporary violation of the provider's autonomy is preferable to the permanent loss of life if LSMT is denied.

The concerns of those supporting policies that favor patients are both principled and pragmatic, much like the concerns of those supporting policies that favor the provider. Both parties, patients and providers have principles that either assert bodily autonomy or professional ethics, and both parties have pragmatic concerns about the well-being of patients. Both policy choices have negative consequences for one party, either denying the patient the right to make their own decision (and continue to live) or denying the provider the right to refuse to participate in something they consider unethical or immoral. These two outcomes are not easily reconciled in law and can explain the diversity in policies created to address this issue and on-going debate regarding these policies.

### Medical Futility Disputes and State Law: Who Decides?

State policies can either govern medical futility disputes by omission, leaving the resolution to ADL designed for right-to-die disputes, or legislators can address these disputes directly by enacting a medical futility policy (MFP) that designates a final decision-maker.

Until now, policies that address medical futility disputes have not been examined holistically across U.S. states. Scholars have not yet examined the whole of MFP in the United States: determining what states have policies and what those policies entail (Robert Powell Center for Medical Ethics, 2011). There are only two publications that examine state law and



medical futility, and these publications sought to explain the outcomes of current law on either providers or patients rather than analyze the creation and adoption of these laws, which is the focus of this dissertation. These articles, from dueling perspectives, offer an excellent foundation for analyzing state statutes to determine what states have MFP and how each policy resolves medical futility disputes.

The first of the two articles is authored by attorney and professor Thaddeus M. Pope, titled "Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment" (2007). Pope's article examines state laws from a provider's perspective and what he calls "unilateral decision statutes" that allow providers the legal right to unilateral removal of futile treatment (2007). The other is a report by the Robert Powell Center for Medical Ethics, an arm of the National Right to Life Committee (NLRC) entitled, "Will Your Advance Directive be Followed?" and examines state laws from the patient's perspective, explaining what would happen in a medical futility dispute under each state's current law (2011).

While each author examines state laws that address medical futility disputes, neither offer an overview of MFP in the United States. These are legal analyses written by attorneys rather than articles about the policy process. Pope's article explains the liabilities of unilateral decision statutes in providing a haven ("safe harbor") where providers feel legally protected when denying LSMT (2007). The article offers a comprehensive examination of provider interests in developing MFP, but not the process by which policies are developed and adopted. It also notes that unilateral decision statutes can allow only unilateral decisions to provide treatment, not withhold it (Pope, 2007). Likewise, the NLRC report lists all policies by how they affect patient autonomy, yet does not address the creation and adoption of MFP. It neither mentions unilateral decision statutes that allow removal of LSMT nor statutes that forbid it (2011).

The NLRC report lists all state statutes in an appendix, categorized by the degree of protection each statute provides for patients in a medical futility dispute (2011). The NLRC report defines protection for patients as the legal requirement for providers to provide LSMT during transfer (Robert Powell Center for Medical Ethics, 2011). It lists all 50 states, those that are “unprotective” and do not specify providing LSMT during patient transfer, “protective” laws that do specify LSMT during the transfer, laws that limit the amount of time patients can receive LSMT and finally, “questionable” laws, that are either ambiguous about the provision of LSMT or give contradictory mandates (Robert Powell Center for Medical Ethics, 2011). Those contradictory mandates that lead the authors to label these laws “questionable” is the same policy gap that is mentioned in Chapter 1: mandating a transfer yet allowing the provider the right to not comply with treatment requests for LSMT.

Furthermore, other statutes in the appendix, listed as both “protective” and “unprotective” have the same wording employed in ADL and appear no different from ADL. This, too, is an example of the policy gap. To explain, the language used in ADL to resolve right-to-die disputes indicates that a provider is not forced to comply with a patient’s declaration, but to arrange a transfer (Glick, 1992a). The text of the Model Health Care Consent Act (MHCCA) upon which many states based its ADL lists in section 7, “An attending physician or other health-care provider who is unwilling to comply with this [Act] shall as promptly as practicable take all reasonable steps to transfer care of the declarant to another physician or health-care provider” (Special Committee on Aging, 1987). In right-to-die disputes, transfers are easily procured, but they are rarely procured in medical futility disputes (Pope, 2007). Apparently, more providers are willing to remove LSMT at a patients’ request than to provide ongoing care at the patient’s request that other providers have deemed futile. Additionally, another facet of ADL mentioned in

some state statutes was that the provider had to treat the patient during the transfer, so the patient would not be neglected or abandoned. This is interpreted by the NLRC report authors as providing LSMT until the transfer is found.

Some statutes require only “reasonable efforts” to find a transfer, yet others do not qualify the efforts and simply say “effect the transfer,” making the legal obligation for the provider not to simply attempt to transfer, but to achieve the transfer (Robert Powell Center for Medical Ethics, 2011). Therefore, in states that mandate that the provider treat the patient during a transfer, a provider who makes a reasonable effort to transfer the patient and does not find a transfer has met their legal obligations in a state with this “reasonable effort” standard, and is not required to continue LSMT. Yet in states that mandate that the provider treat the patient during a transfer that simply declare that a provider must effect a transfer-all efforts, even efforts that exceed those that other states would consider reasonable- these efforts do not alleviate the burden of the provider to continue LSMT. The ambiguity in ADL benefits the patient in these states, which is why it would be categorized as “protective” (Robert Powell Center for Medical Ethics, 2011). Yet states with ADL that does not mention the requirement of providers to treat patients during transfer at all are categorized as “unprotective” (Robert Powell Center for Medical Ethics, 2011).

These nuances in ADL affect patient outcomes in medical futility disputes, however this is can be a consequence of phrases within the law that were intended to address right-to-die disputes interpreted to favor patient or provider, not necessarily a consequence of reforms made to the law to address medical futility disputes- MFP. A state statute listed in the “protective” category may not be MFP designed to favor the patient. Likewise, states listed in the “unprotective” category may not be MFP designed to allow providers the right to unilaterally

remove LSMT. Some statutes are clearly MFP, amended to address the policy gap to either benefit patient or provider, but most appear to simply be unreformed ADL.

Kansas, for example, is listed in the “protective” category. Kan. Stat. Ann. § 65-28,107(a) reads:

An attending physician who refuses to comply with the declaration of a qualified patient pursuant to this act shall effect the transfer of the qualified patient to another physician. Failure of an attending physician to comply with the declaration of a qualified patient and to effect the transfer of the qualified patient shall constitute unprofessional conduct as defined in K.S.A. 65-2837, and amendments thereto.

The statute does not have the “reasonable efforts” standard (like MHCCA); it simply mandates that the provider effect a transfer, lest they be guilty of unprofessional conduct. This was written in 1979 as the “Kansas Natural Death Act,” which explicitly reference right-to-die disputes, stating: “adult persons have the fundamental right to control the decisions relating to the rendering of their own medical care, including the decision to have life-sustaining procedures withheld or withdrawn in instances of terminal condition” (Donaldson, 2006, p. 20). The legal obligation to find a transfer was to avoid patient abandonment as defined in the Kansas Healing Arts Act, not to force an opposed physician to provide LSMT in a medical futility dispute. The statute pre-dates such disputes by 20 years. Furthermore, one unilateral decision in Kansas where the mechanical ventilator of an 81-year-old stroke victim was unilaterally removed resulted in not just the revocation of the physician’s license, but an indictment for murder (Alpers, 1998). This was eventually overturned on appeal, yet the law remains unchanged (Pope, 2007). While Kansas ADL does protect patients, the policy gap fails to provide any mechanism to relieve providers from the burden of delivering on-going futile treatment.

Like the policy gap in ADL can be deemed “protective” for patients, it can also be deemed “unprotective.” North Carolina’s statute, N.C. Gen. Stat. § 90-321 reads:

(k) Notwithstanding subsection (c) of this section: (1) An attending physician may decline to honor a declaration that expresses a desire of the declarant that life-prolonging measures not be used if doing so would violate that physician's conscience or the conscience-based policy of the facility at which the declarant is being treated; provided, an attending physician who declines to honor a declaration on these grounds must not interfere, and must cooperate reasonably, with efforts to substitute an attending physician whose conscience would not be violated by honoring the declaration, or transfer the declarant to a facility that does not have policies in force that prohibit honoring the declaration.

Note that this law only mandates a reasonable cooperation in transferring the patient, and does not mention that the requirement to treat the patient during the transfer process. Also note the distinct reference to right-to-die disputes, “a desire of the [patient] declarant that life-prolonging measures *not be used*.” The emphasis is mine, drawing attention to the fact that the statute explicitly states the disputes it was designed to resolve. This statute was passed in 1977 as the “North Carolina Right to a Natural Death Act,” and resolves right-to-die disputes the same way that other ADL does: transfer the patient. But as you can see in contrast, the nuances in the law have very different outcomes with medical futility disputes, with ADL in Kansas favoring the patient and ADL in North Carolina mandating only that providers make “reasonable efforts” to comply, a policy gap that offers no tangible protection for patients in these disputes. Providers are reticent to remove care because of uncertainty regarding what efforts are “reasonable,” but are not explicitly required to provide on-going LSMT. Nonetheless, there have been publications by providers about the problems with ADL in North Carolina and the need to modify ADL into MFP to ease this uncertainty (A. E. Kopelman, Parker, Ho, Willson, & Kopelman, 2005; Kussin, 1995).

The authors of the NRLC report do not segregate MFP from ADL (2011) and Pope’s analysis lists unilateral decision statutes, but not explicitly what each statute entails and how the disputes are resolved. Therefore, the next step is to examine all 50 state laws to determine which

states have amended ADL to MFP. As of 1992, each U.S. state has an ADL that resolves right-to-die disputes and reflects the constitutional right to refuse medical care, however only some states have added provisions to address medical futility disputes (Hecht & Shiel, Jr., 2012; Hoefler & Kamoie, 1994). These laws must be analyzed to determine who would make the ultimate decision in a medical futility dispute as well as determine the approaches policy-makers take when adopting MFP. This results in a meaningful typology of MFP, and how each addresses medical futility disputes, determining the ways state lawmakers attempt to reconcile patient autonomy with provider autonomy or favor one party over another.

### Factors that Indicate a Medical Futility Policy

I examined each state law as of 2010 for any mention of medical futility disputes (not merely right-to-die scenarios). The first criteria employed to analyze these statutes is the mention of continuing LSMT. No laws prior to 1993 addressed the *continuation* of LSMT since advance directive laws were specifically adopted to address right-to-die disputes and designed to protect the patient autonomy to *remove* LSMT. The continuation of LSMT was implied, since these laws were written to address right-to-die disputes wherein the patient wanted care removed, not continued (Fowler, 2008). Any law that mentions the continuation of LMST represents a reform that acknowledges medical futility disputes- that continuation of care is threatened by the provider and must be mandated in law. Therefore any policy that addresses the continuation of LSMT is MFP, regardless of how that policy dictates the medical futility dispute is to be addressed.

For example, Maryland law has providers assist in the transfer but notes:

Pending the transfer, [the provider must] comply with an instruction of a competent individual, or of a health care agent or surrogate for an individual who is incapable of

making an informed decision, *if a failure to comply with the instruction would likely result in the death of the individual*. (Md. Code Ann., [Health-General] § 5-613 (a))

The emphasis is mine, to demonstrate how Maryland law mentions the continuation of LSMT, forbidding its removal by the provider. Delaware law also mentions the continuation of care, but allows unilateral removal by the provider:

A health-care provider or institution that declines to comply with an individual instruction or health-care decision shall: (2) *Provide continuing care, including continuing life sustaining care*, to the patient until a transfer can be effected. [But] (a) A health-care provider or institution acting in good faith and in accordance with generally accepted healthcare standards applicable to the health-care provider or institution is not subject to civil or criminal liability or to discipline for unprofessional conduct for: (5) Declining to comply with a health care decision or advance health-care directive because the instruction is contrary to the conscience or good faith medical judgment of the health care provider or the written policies of the institution. (Del. Code Ann. tit. 16 § 2508(g), Del. Code Ann. tit. 16 § 2510(a)(5))

Again, the emphasis is mine. Delaware law does mention the continuation of LSMT, yet allows the provider the legal right to refuse LSMT that conflicts with the medical standards or the provider's conscience. While this presents some ambiguity of its own, Delaware's law is clearly MFP.

Examining all 50 state laws, 17 states mention the continuation of LSMT or otherwise specifically mention what is expected in a medical futility dispute. Indiana law, for example, explicitly mentions situations where “an attending physician refuses to *use*, withhold or withdraw life pro-longing procedures.” (Ind. Code Ann. § 16-36-4-13). I emphasize the word “use” as it applies when a provider objects to providing or continuing LSMT, not merely removing it. Other state laws, California, Hawaii, New Mexico for example, specifically note how to resolve disputes over “medically ineffective healthcare,” resolving the disputes in different ways, but still clearly examples of MFP (Pope, 2003). And some states, North Dakota for example, explicitly mention the types of medical dispute:

A health care provider who administers health care necessary to keep the principal alive [LSMT], despite a health care decision of the agent to withhold or withdraw that health care, *or a health care provider who withholds health care that the provider has determined to be contrary to reasonable medical standards, despite a health care decision of the agent to provide the health care...*" (N.D. Cent. Code § 23-06.5-12).

The emphasis is once again mine, but North Dakota law is clearly MFP, designed to address medical futility disputes in addition to right-to-die disputes.

In spite of no previous analyses of all state laws to determine what does and does not qualify as MFP, this analysis, if repeated by other researchers should yield the same list of 17 states that have MFP. It is true that all state laws have a mechanism that addresses medical futility disputes, these 17 are the only states that mention medical futility disputes and direct a protocol for their resolution.

The other 33 states have laws that may have been reformed since they were first enacted, but none of those reforms explicitly address medical futility disputes, leaving these states as ADL. Although some states have amended their medical dispute policies in minor ways, due to the simplistic nature of most of these laws and the uniform language of advance directive laws, as expected, states with no MFP likely still operate on an ADL it originally adopted to address only right-to-die scenarios. All ADL was originally adopted in 1992 or earlier and all policies that do address medical futility disputes were enacted afterwards. Since the first states to enact MFP passed this law in 1993, every state verified to have a MFP passed their laws in 1993 or later (Sposato, 2010).

The final result of analyzing all 50 state statutes yields two distinctive types of medical dispute policy: advance directive law (ADL: designed to address right-to-die disputes) and medical futility policy (MFP: designed to address medical futility disputes). Table 3 lists all states by policy type.



Table 3

*Medical Dispute Policies by Type*

Advance Directive Law (ADL)		Medical Futility Policy (MFP)	
State	Statute	State	Statute
Arizona	Ariz. Rev. Stat. Ann. § 36-3205 (C)	Alabama	Ala. Code § 22-8A-8(a)
Arkansas	Ark. Code Ann. §§ 20-17-207, 20-17-210 (f)	Alaska	Alaska Stat. § 13.52.060
Colorado	Colo. Rev. Stat. § 15-14-507 (5)	California	Cal. [Probate] Code § 4734, 4736
Florida	Fla. Stat. Ann. § 765.1105 (1)	Connecticut	Conn. Gen. Stat. §§ 19a-571; 19a580a
Georgia	Ga. Code Ann. § 31-32-8(2)	Delaware	Del. Code Ann. tit. 16 § 2508(g)
Idaho	Idaho Code § 39-4513	Hawaii	Haw. Rev. Stat. § 327E-7 (e), (f), (g)
Illinois	755 Ill. Comp. Stat. Ann. 35/3	Indiana	Ind. Code Ann. § 16-36-4-13
Iowa	Iowa Code § 144A.8	Maryland	Md. Code Ann., [Health-General] § 5-613 (a)
Kansas	Kan. Stat. Ann. § 65-28,107(a)	Minnesota	Minn. Stat. § 145C.15
Kentucky	Ky. Rev. Stat. Ann. § 311.633 (2)	New Hampshire	N.H. Rev. Stat. Ann. § 137-J:7
Louisiana	La. R.S. § 40:1299.58.7	New Mexico	N.M. Stat. Ann. § 24-7A-7 (E),(F),(G)
Maine	Me. Rev. Stat. Ann. Tit. 18-A, § 5-807 (G)	North Dakota	N.D. Cent. Code § 23-06.5-12
Massachusetts	Mass. Ann. Laws ch. 201D § 14, 15	Ohio	Ohio Rev. Code Ann. § 1337.16 (B) (2)(b)
Michigan	Mich. Comp. Laws § 700.5511(3)	Oklahoma	Okla. Stat. Ann. Tit. 63 § 3101.9
Mississippi	Miss. Code Ann. § 41-41-215 (7)	Texas	Tex. Code Ann. § 166.046
Missouri	Mo. Rev. Stat. § 404.830	Virginia	Va. Code Ann. § 54.1-2987
Montana	Mo. Rev. Stat. § 404.830	Wyoming	Wyo. Stat. Ann. § 35-22-408 (g) ii
Nebraska	Neb. Rev. Stat. § 30-3428		
Nevada	Nev. Rev. Stat. § 449.628		
New Jersey	N.J. Stat. Ann § 26:2H-65.a(4)		
New York	N.Y. [Public Health] Law § 2984(3)		
North Carolina	N.C. Gen. Stat. § 90-321		
Oregon	N.D. Cent. Code § 23-06.5-12		
Pennsylvania	Pa. Stat. Ann. tit. 20 § 5424		
Rhode Island	R.I. Gen. Laws § 23-4.10-6		
South Carolina	S.C. Code Ann. § 44-77-100		
South Dakota	S.D. Codified Laws § 34-12D-12		
Tennessee	Tenn. Code Ann. § 32-11-108 (a)		
Utah	Utah Code Ann. § 75-2a-115		
Vermont	Vt. Stat. Ann. Tit. 18 § 9707		
Washington	Wash. Rev. Code Ann. § 70.122.060(2)		
West Virginia	W. Va. Code § 16-30-12		
Wisconsin	Wis Stat. Ann. § 154.07(1)(a)		

Source. Robert Powell Center for Medical Ethics, 2011

## Understanding Medical Dispute Policy by Designated Decision-Maker

After examining all 50 state policies and separating them into either ADL or MFP, the next step is examining the mechanisms within the policy that resolve the dispute. The laws were again analyzed to determine what party is granted the final decision in medical futility disputes. There is only one mechanism to resolve right-to-die disputes in ADL: grant the patient the final decision through obtaining a transfer. However, the 17 states with MFP established different decision-makers from state to state, with the patient granted the ultimate decision in some state policies and the provider granted the decision in other state MFPs.

This diversity in MFP that does not exist in ADL is merely a consequence of medical futility disputes presenting a more complex problem than right-to-die disputes. For example, in those 33 states with ADL but no MFP, provisions designed to address right-to-die scenarios are applied: the legal right for the provider not to comply with the patient's directive, provided that they seek a transfer. For the right-to-die disputes that this process was designed to address, this is a win-win, protecting both patient autonomy and provider autonomy. However, with medical futility disputes, this process fails. The NLRC analyzed all state laws to determine the likelihood that a patient's advance directive to receive LSMT would be followed and put ADL into polar opposite categories: indicating ADL can either favor the patient (for fear of legal reprisal by the provider) or favor the provider (by allowing sufficient latitude to remove care from patients when a transfer is not found). There is no designated decision-maker for medical futility disputes in ADL, as it was designed to accommodate both patients and providers in right-to-die disputes, something not as easily accomplished in medical futility disputes.

This means that 17 states that have adopted MFP have addressed the unique nature of these disputes and the inherent trade-off between patient and provider autonomy in several ways.

Some states grant the ultimate decision to the patient by default. Other states defer to medical judgment and grant the decision to the provider, while a third, final approach is to remove the decision from both the patient and provider and designate a third-party to examine each case and render a verdict. Table 4 shows the three types of MFP and their respective states.

Table 4

*MFP by Decision-Maker*

<b>Medical Futility Policy (MFP) by Decision-Maker</b>					
<b>Patient</b>		<b>Provider</b>		<b>Third-Party</b>	
State	Statute	State	Statute	State	Statute
Alabama	Ala. Code § 22-8A-8(a)	California	Cal. [Probate] Code § 4734, 4736	Texas	Tex. Code Ann. § 166.046
Alaska	Alaska Stat. § 13.52.060	Connecticut	Conn. Gen. Stat. §§ 19a-571; 19a580a		
Hawaii	Haw. Rev. Stat. § 327E-7 (e), (f), (g)	Delaware	Del. Code Ann. tit. 16 § 2508(g)		
Maryland	Md. Code Ann., [Health-General] § 5-613 (a)	Indiana	Ind. Code Ann. § 16-36-4-13		
Minnesota	Minn. Stat. § 145C.15	New Mexico	N.M. Stat. Ann. § 24-7A-7 (E),(F),(G)		
New Hampshire	N.H. Rev. Stat. Ann. § 137-J:7	North Dakota	N.D. Cent. Code § 23-06.5-12		
Ohio	Ohio Rev. Code Ann. § 1337.16 (B) (2)(b)	Virginia	Va. Code Ann. § 54.1-2987		
Oklahoma	Okla. Stat. Ann. Tit. 63 § 3101.9				
Wyoming	Wyo. Stat. Ann. § 35-22-408 (g) ii				
Total State(s): 9		Total State(s): 7		Total State(s): 1	

States with statutes that primarily grant decision-making power to the patient are called “pro-patient” states. I categorize a state as pro-patient when the state mandates that LSMT continue until a transfer is found, and make provision to the removal of LSMT even if a transfer cannot be found. The ultimate decision belongs to the patient, in spite of the imposition upon providers. The analysis yielded nine states with such laws. New Hampshire law specifically

states, “[a healthcare provider] shall not deny health care treatment, nutrition, or hydration which denial would, within a reasonable degree of medical certainty, result in or hasten the qualified patient’s death against the express will of the qualified patient, the advance directive, or the agent” (N.H. Rev. Stat. Ann. §137-J:7). Ohio law, Ohio Rev. Code Ann. § 1337.16 (B) (2)(b) likewise states, “[a healthcare provider] shall use or continue the life-sustaining treatment or cause it to be used or continued until a transfer as described in division (B)(2)(a) of this section is made.” Additionally, Wyoming law states, “[a healthcare provider must] provide continuing care, including continuing life sustaining care, to the patient until a transfer can be effected” (Wyo. Stat. Ann. §35-22-408 (g) ii). All pro-patient MFP forbids the removal of LSMT by the provider, mandating its continuation until a transfer is found with the care will also continue. These laws attempt to accommodate provider autonomy through patient transfer, but ultimately favor the patient by granting the patient the ultimate decision even at the provider’s expense.

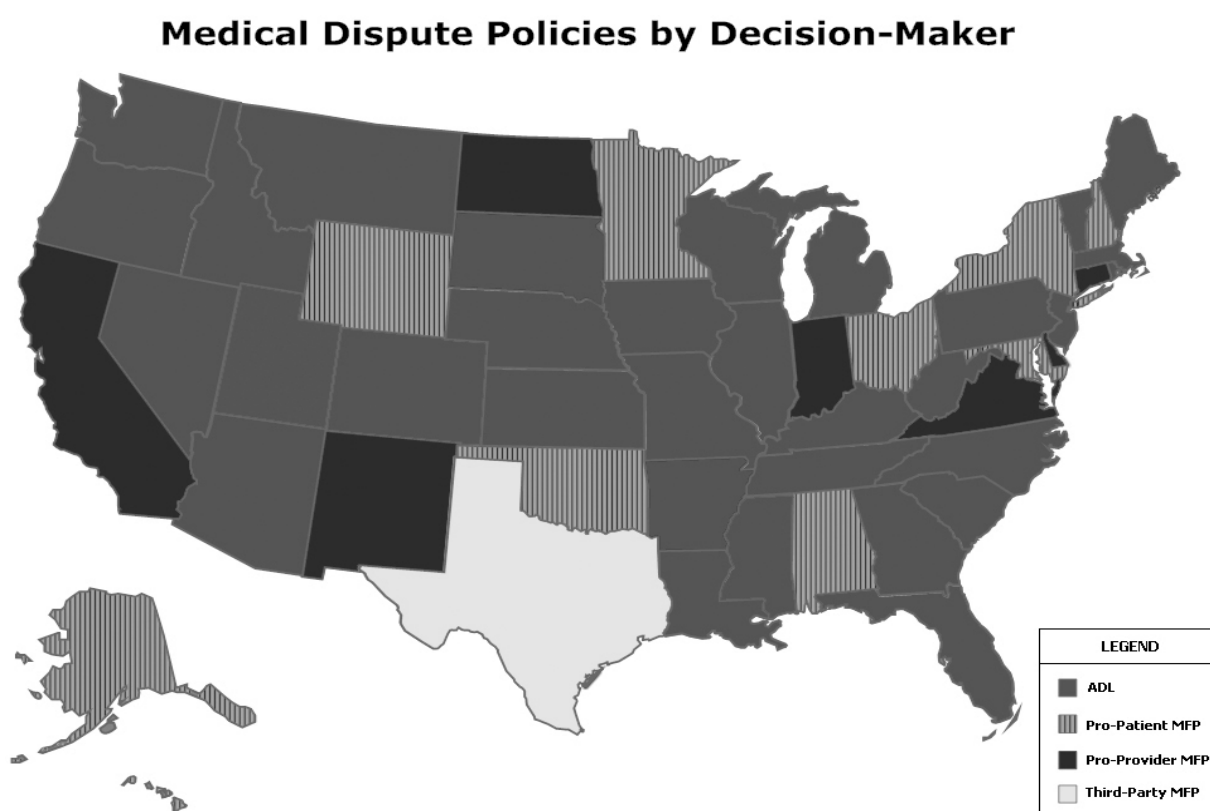
Other states leave the ultimate determination to remove LSMT solely with the provider, yet like Delaware’s statute, these laws are less straightforward than pro-patient MFP and tend to employ a protocol before providers can remove LSMT. There are seven pro-patient states, all of which acknowledge patient autonomy by dictating steps a provider must take before removing care, like consulting with the patient, seeking a transfer for the patient or offering the patient a certain amount of time wherein they may seek a transfer (The National Conference of Commissioners on Uniform State Laws, 2010). California allows providers the ability to remove LSMT against the patient’s wishes only after a transfer cannot be found (Cal. [Probate] Code § 4734, 4736). Virginia mandates that providers continue LSMT for 14 days, offering the patient two weeks to find an alternative provider (Va. Code Ann. § 54.1-2987). Some states have contradictory laws that state treatment should continue during a transfer but declare the provider

immune from civil or criminal liability if they deny care outside of generally-accepted medical standards, like in the Delaware statute ( Del. Code Ann. tit. 16 § 2508(g), Del. Code Ann. tit. 16 § 2510(a)(5). Policies in these states leave the final determination to the provider and not the patient when granting that authority, even if the law also prescribes attempts at transfer. Therefore, these states will be known as “pro-provider.”

There is one final type of MFP that does not grant the patient or the provider the ultimate determination on continuing LSMT. Instead, this type of law attempts to strike a balance by delegating a healthcare ethics committee (HEC) to make the final decision regarding treatment. When a dispute arises between the patient and attending physician, the physician refers the case to the HEC within the institution- and both sides are offered the chance to present their case for why care should be removed or continue. LSMT is continued during this process, and if the HEC agrees with the physician that care should be removed, the patient is still allowed a window of ten days to transfer to another provider (O’Callaghan, 2008). This type of policy will be known as a “third-party” policy.

There are differing requirements imposed by law before the decision may be carried out, nonetheless all states with MFP address medical futility disputes by delegating a decision-maker. MFP can therefore be qualified by who the law designates as the final decision-maker: the patient, the provider or a third-party. These 17 policies subdivide into three categories nine pro-patient states, seven pro-provider states and one third-party states. States of each category are diversely distributed across the United States, with no discernable geographic trends indicating that certain regions adopt one MFP type over another. Rather, neighboring states with MFP always have a different type of MFP. No two MFP states that share a border share the same type of MFP- rather, pro-patient states border pro-provider states and vice versa. Texas, the lone

third-party state is bordered by all medical dispute policy types on every side, with pro-provider state New Mexico to the west, pro-patient state Oklahoma to the north, and Louisiana and Arkansas with ADL to the east. Figure 1 demonstrates all state medical dispute laws by decision-maker: patient, provider, third-party for MFP and unknown in states with ADL.



*Figure 1.* Medical dispute policy by state and decision-maker.

### Further Understanding State Medical Futility Policy

While MFP is best understood by decision-maker and collapsed into those categories as a starting point for policy research, these categories do not imply that policies within each category are identical. MFP may differ in content even if they share the same category of decision-maker.

States that adopt pro-patient policies all designate the patient as the final decision-maker, are all alike in that they all involve “treatment pending transfer” or “treat till transfer” (TTT)

(Robert Powell Center for Medical Ethics, 2011). Pro-provider laws, however, differ significantly in the demands they make on providers. Some states have TTT, but with limits that still allow the provider the ability to remove care after the TTT obligations are fulfilled. Connecticut is the only state with a law that merely mandates the provider to consider the patient's wishes before removing care without making any attempts to transfer or offering the patient time to find a transfer themselves (Conn. Gen. Stat. §§ 19a-571; 19a-580a). The prevailing trend is more like California and makes much more stringent demands of providers for the purpose of benefitting patients (Cal. [Probate] Code § 4734, 4736). Many pro-provider laws like California are based upon the tenets of the Uniform Health Care Decisions Act (UHCDA) written by the Uniform Law Commission (The National Conference of Commissioners on Uniform State Laws, 2010). The commission started to take an interest in medical futility disputes in 1993 as an amendment to MHCCA (The National Conference of Commissioners on Uniform State Laws, 2010). UHCDA amended the MHCCA to address medical futility disputes, and clearly stipulates that it is the physician's duty to treat the patient pending transfer to another provider if the provider seeks to deny care for reasons of conscience (The National Conference of Commissioners on Uniform State Laws, 2010). UHCDA only sanctions the removal of care by the provider when no alternative medical care facility may be found, acting on the assumption that this failure to find a provider willing to take the patient as a transfer validates the initial provider's opinion that the care was medically inappropriate (Pope 2007, 67).

Another pro-provider policy involves setting a time-limit for TTT. Unlike some pro-provider laws where the provider seeks a transfer in all cases, these laws offer a time period during which the patient is expected to find another provider. The only law of this type was enacted in Virginia in 2000 and while there have been several reforms to the law; the 14-day

period has remained without additional qualifications for over ten years. The law specifies a 14-day period for LSMT to continue, yet offers no direction for action at the end of that 14-day period (Robert Powell Center for Medical Ethics, 2011).

In North Dakota, Indiana and New Mexico, there is no time limit associated with transfer, only the mandate that these efforts be reasonable (Robert Powell Center for Medical Ethics, 2011). In Delaware, the provider is supposed to continue LSMT until a transfer is affected but yet, is not required to provide LSMT at all if it is outside of medical standards or in opposition to the provider's conscience (Robert Powell Center for Medical Ethics, 2011). While all pro-provider states are similar in that the provider makes the final decision these requirements indicate how different these policies can be.

Unlike pro-provider states with substantive differences, a policy that designates a third party as the final decision-maker is limited to one policy in one state. The Texas Advance Directives Act of 1999 is modeled after the medical futility dispute resolution protocol advocated by the American Medical Association (Fine & Mayo, 2003). This approach, known as the due-process approach, calls for an ethics committee review of each situation on a case-by-case basis rather than a policy that is designed to favor either the patient or the provider. It was created by bio-ethicists, physicians and healthcare administrators for institutional use specifically to resolve medical futility disputes (Halevy & Brody, 1999; Tomlinson & Czlonka, 1995). This approach was heralded in academic literature as a neutral way to resolve medical futility cases in a manner that put the patient's best interests first rather than the interest of the attending physician or patient's proxy (Tomlinson & Czlonka, 1995). While states have tried to emulate a third-party policy like TADA, but re-invented with minor differences, this policy remains the only law of its kind (Pope, 2009).



Understanding pro-patient, pro-provider and third-party MFP and what each entail is crucial when addressing larger questions of why there is such a variation in policies intended to address the same problem. Pro-provider laws that grant all the power to the provider often have processes intended to promote patient autonomy, like options for transfer. Likewise, pro-patient laws that grant all the power to the patient also seeks to relieve the provider through patient transfer. Finally, third-party policies involve both providers and patients surrendering their power in an attempt to strike a balance rather than concentrating decisions in the hands of either party. Although critics on both sides complain that this good faith attempt fails in this effort to be neutral since both patient and provider autonomy are surrendered to a committee, the due process approach is the only policy attempt to reconcile both patient and provider interests (Graham, 2005; O'Callaghan, 2008; Pope, 2007; Truog, 2007). Furthermore, in spite of concerns from both providers and patients, these laws represent an inherent compromise, with neither party insisting on absolute decision-making authority. While states that enact decidedly pro-patient or pro-provider laws suggest the triumph of one interest over the other, the due-process approach policy is academically fascinating as it likely presents a compelling case of compromise. The manner in which a state succeeds in passing such a law that requires the cooperation of parties who both surrender their autonomy is an important question to address in policy, not simply in understanding medical futility reform but the role of certain political influences themselves. Therefore while third-policy MFP is an anomaly, it must also be studied to understand all facets of MFP adoption.

## Conclusion

The grounds upon which providers can declare LSMT futile are wrought with

controversy. While few people oppose a provider's right to oppose medical care that would be physiologically ineffective (or quantitative futility), LSMT by its nature does not present this issue. In simplest terms: if LSMT is provided but is ineffective, the patient dies- just like if LSMT is denied, the patient dies. Since the outcome is the same if ineffective LSMT is provided or denied, the patient dies, the outcome that the providers fear is that LSMT is not ineffective: the patient lives. This is a value judgment that death is preferable to life for the patient, or the patient's life is not worth saving. This value judgment may also be made on technical grounds (like a patient's impending death from other causes), yet there is still a value judgment, and value conflicts between patients and providers lead to medical futility disputes and the need for public policy to resolve these disputes.

Public policy designed to address right-to-die disputes do not sufficiently address medical futility disputes. ADL gives conflicting mandates when applied to medical futility disputes- making it unknown whether the patient or the provider has the decision-making power. While the ambiguity in ADL can favor one party over another due to nuances in the language, but it is insufficient as a policy solution to resolve medical futility disputes, leading to the creation of MFP.

States began enacting MFP in 1993, and an analysis of these laws determined all types of MFP designate a decision-maker to resolve disputes. These laws either grant the power to the provider to remove care, grant power to the patient to maintain care, or place the decision in the hands of a third-party. In every case, the dispute is resolved by mandating a course of action. While pro-patient MFP alleviates the concerns of patients and pro-provider MFP addresses the concerns of providers, providers are required to provide LSMT against their will in pro-patient states, and patients are denied care they need to live in pro-provider states. The dispute is

resolved, but the resolution is not likely to be acceptable to both parties. Third-party MFP does not defer to one party over the other, but in 16 of 17 states, the MFP chosen is likely supported by one party and opposed by the other.

Due to the competing concerns from both patients and providers with each type of policy, the question remains on how states adopt MFP. As of 2010, 33 states have not addressed the policy gap in ADL by adopting MFP of any type, in spite of medical futility disputes being a universal problem- so what aspects within these 17 states have led to lawmakers adopting MFP? Since MFP types are radically different, there is also the question of what contributes to the choice to adopt one type of MFP over another. In Chapter 2, I take a closer look at the adoption of similar laws with distinct value conflicts, as well an empirical and historical look at ADL to uncover variables likely to affect a state's choice to adopt a MFP of any type, including how the policy type itself may affect policy adoption.

## CHAPTER 3

### VARIABLES AFFECTING MEDICAL DISPUTE POLICY

#### Introduction

While advance directive law (ADL) enacted to address right-to-die disputes are homogenous, reforms that address medical futility disputes are diverse. Classifying the policies by decision-maker alone yields three categories which could easily be further delineated into several subcategories. Apparently there is not a mutually-agreed upon policy solution for medical futility disputes like there was for right-to-die disputes. ADL found a solution to respect both parties in right-to-die disputes, one mechanism which all 50 states codified into law (Sabatino, 2010). Medical futility disputes are also a universal problem, yet only 17 states have adopted MFP and those policies differ significantly- not merely differing versions of the same protocol, but polar opposite outcomes, allowing providers to remove LSMT or expressly forbidding it. In total, there are three mechanisms that states employ in medical futility policy (MFP) to resolve medical futility disputes, grant the final decision to the patient, grant the final decision to the provider, or grant the final decision to a third-party.

How then is MFP adopted? Unlike ADL, where legislators crafted a compromise that was likely adopted because it that could garner support from both parties- all but one MFP (third-party) involves one interest, patient or provider violating the autonomy of the other. This is likely to draw the ire of the losing side, yet these policies are still adopted in spite of potential opposition. Since these 17 states only represent success in policy adoption, it is unclear how many states have attempted to adopt MFP but failed. What factors then contribute to the successful adoption of MFP, as well as the diversity of policies?

Literature does not address these questions because MFP has yet to be examined by policy scholars. There is a wealth of literature about medical futility disputes themselves, particularly clinical practices and ethics, but there is no literature regarding the innovation and adoption of MFP. Literature offers virtually no information beyond that these policies exist and expert commentary about the merits and problems with each policy (Fine, 2000, 2001; Fine & Mayo, 2003; Graham, 2005; O'Callaghan, 2008; Pope, 2007; R. D. Truog, 2007; Robert D. Truog, 2009). Therefore, a thorough examination of all literature about MFP yielded no information to address our research question, compelling a broader search into related areas of policy and established theories of the policy process in general.

In the absence of information on MFP adoption, the greater canon of public policy literature will be used to determine what factors affect adoption and policy choice. While no studies exist on MFP, a wealth of literature exists on its predecessor: ADL, with which MFP shares several key characteristics. Current battles over particular policies find that the stakeholders represent the same interests that proposed and opposed ADL, and for typically for the same reasons (Fine, 2000; Graham, 2005).

MFP also involves many of the same interests and values that guided the creation of ADL. The interest of patients that led to the creation of ADL was to protect patient autonomy and give patients' assurance that their directives will be honored (McCormick, 2011). Provider autonomy was addressed as well, to ensure that medical professionals were not forced to fulfill the patients' directives when doing so violated their consciences. Additionally, providers wanted the assurance that complying with a patients' wishes to remove the care that was keeping them alive would not result in legal problems (Glick, 1992a).

Patients and providers have the same interests with regard to MFP. Patients want the autonomy to continue care and assurance that this determination is honored (Robert Powell Center for Medical Ethics, 2011). Providers want autonomy to refuse to provide care with which they disagree and assurance that they will not be forced to comply (Pope, 2003). Since the interests of the parties remain the same, the parties themselves are likely the same as well (and what little literature offers suggests this is so) (Fine, 2000; Graham, 2005). Hospitals and medical associations that supported ADL to protect providers likely would support pro-provider MFP reforms to protect the enduring value of provider autonomy (Glick, 1992a). Right-to-life groups would likely support pro-patient MFP reform. The desires of patients have transposed from wanting to die to wanting to live, but the undergirding premise is the desire of patients to have the ultimate determination regarding their medical care. While the medical dispute type differs between ADL and MFP, the values that promote or inhibit adoption have endured, and also appear to be promoted by the same interest groups.

Clearly medical futility disputes and right-to-die disputes are not identical, or ADL would be sufficient and there would be no need to reform to MFP, especially the majority of reforms that are likely to displease either patients or providers. MFP is indeed different, but similar enough that studies about ADL can inform theory about MFP adoption as long as the differences between the two types of medical dispute policy are acknowledged. Therefore, a review ADL literature to determine how these laws were adopted and how differences in the law affected adoption is information that can be used to form a theory about MFP. If values are the guiding force and morality policy applies, drawing from studies of ADL adoption should be very helpful in forming a theory about MFP adoption.

Thoroughly examining ADL policy studies as well as broader studies on similar, controversial laws will allow for both an up-close and holistic approach for forming a theory, as well as uncovering variables useful for addressing the research question. I will begin with this comprehensive overview and conclude with a closer look at ADL and what these laws can potentially tell us about MFP and how MFP may be adopted.

### Moral Aspects of Advance Directive Law and Medical Futility Policy

To gain an overview on adoption and innovation theories in the absence of MFP literature, it is critical to determine where MFP “fits” in the universe of policy types. The closest relative of MFP is ADL. ADL is the predecessor for all medical futility policies and both address LSMT, life-or-death decisions, and patient/provider autonomy. ADL and MFP are clearly similar in key aspects and the adoption of these laws could be inhibited or assisted by these shared characteristics.

Theorists note that policies like ADL have consistently examined the issues from the perspective of morality, noting that these issues inspire deeply-held notions of right and wrong (Mooney, 2000; Mooney & Lee, 1995, 2000). Policies that impose such judgments are studied in literature as “morality policy” proposing that their value-laden nature places these policies in a larger, unique category when contrasted against other types of law (Mooney, 2000).

Christopher Mooney, the scholar who coined and defined the concept of morality policy, first defines morality policy as policies based foremost on values rather than instrumentality, meaning that these laws are not focused with finding a solution for a problem but rather, asserting a moral value (2000). A primary argument by an interest group for or against a morality policy is that an action is absolutely right or absolutely wrong (2000, p. 173). Morality policies

generate conflict over fundamental moral values and are neither tactical nor strategic, intended to bring out a certain outcome (Mooney, 2000). Instead, these policies make authoritative statements about the prevailing values of the citizenry and leave little room for compromise (2000, p. 173). Morality policy involves morally-charged issues like abortion, physician-assisted suicide, gambling, prostitution and capital punishment, issues on which there are no complete consensus but rather, two distinct opposing factions. Most theories of policy-making are derived from studying policies about regulatory or distributive policies, not policies that validate or condemn contentious issues. For this reason, studies of morality policies are not well-served by these theoretical models that examine factors like demographics as variables in policy adoption. Mooney suggests that morality policies are affected by *values* and have unique attributes that affect policy adoption (Mooney & Lee, 1995)

Both ADL and MFP govern life and death as well as people's values regarding the rightness or wrongness these medical treatments and who should or should not have the power deny care. The values in contrast are patient autonomy vs. provider autonomy, freedom for patients and freedom for providers. Policies to address these disputes are forced to acknowledge these two, seemingly incompatible positions. These policies are also vital, governing life and death and these stakes may very well illicit stronger moral reactions that affect policy-making. If MFP qualifies as morality policy, studies on morality policy theory could potentially offer insight into what factors affect the adoption of MFP.

The first characteristic is technical simplicity that the policy focuses not on the outcomes of a policy if implemented, but the rightness and wrongness of the value it espouses. Secondly, morality policies are highly salient, meaning people appear to care more deeply about morality policies compared to policies addressing other issues and view these policies as having greater



importance (2000). The third and final criterion is higher than normal levels of citizen participation. Mooney argues that the incitement of values and technical simplicity of morality policy (the relative ease of understanding such policies and refusal to look at the more complex implementation concerns), as well as its perceived high level of importance yields a higher degree of citizen involvement when compared to other policy types (2000). People tend to campaign more, vote more, have greater contact with legislators and actively participate in policies dealing with moral issues (Mooney, 2000). A cursory look would suggest that MFP can likely be qualified as morality policy. However, I will have to examine MFP by Mooney's three tenets to determine if like ADL, MFP does qualify as morality policy- meaning the empirical studies on related policy could then be used to inform my theory in the absence of other literature.

In terms of Mooney's first tenet, technical simplicity and the issue of "rightness" or "wrongness" of a potential policy, in the case of medical dispute policy, this is reduced to an individual's values: either opposing the removal of LSMT by any party, a value that arose during the debate about ADL, or vehemently believing that one party over another should have the final decision in a medical futility dispute. There are advocacy coalitions that assert it is absolutely wrong for a provider to remove LSMT against a patient's wishes in principle, or that it is wrong to deny care based on bigotry or discrimination against certain populations (Batavia, 2002; HarveyParedes, 1992; Robert Powell Center for Medical Ethics, 2011). The Catholic Church asserts that it is absolutely wrong to deny artificial nutrition and hydration (ANH) except in very rare instances (Zientek, 2006).

There are implications of right and wrong, even when not as explicitly-stated. It is not so much a diametric opposition that suggests patient autonomy is right while provider autonomy is

wrong or vice-versa. Rather, providers that write about MFP assert that they are not opposed to patient autonomy, but argue that patient autonomy does not extend to futile treatment (N. S. Jecker & Pearlman, 1992; Pope, 2003; Schneiderman et al., 1990). In this case, a policy would not be about decrying patient autonomy as “wrong,” but that the breadth of it is limited and therefore, not being compromised when a provider denies inappropriate care. They are implicitly suggesting that it is wrong to provide futile care and it is right to deny it, and some state this explicitly, declaring that there is an ethical “duty” not to treat (Jecker & Schneiderman, 1993). Likewise, those that assert that patient autonomy does extend to making the decision to continue futile care would not say that provider autonomy is “wrong” - but that also, it does not extend to making life and death decisions for a patient.

These ideas of technical simplicity that spur morality policy translates into a lack of concern about outcomes and implementation. Mooney states that morality policies are driven by values rather than results (2000). For example, a group may support a pro-patient law that results in patients harming themselves with inappropriate treatments because that group’s prevailing value is that the patient should have the right to decide (Mooney, 2000). The result is bad for the patient, but the principle is the key concern. Likewise, a pro-provider group could propose a policy that allows generally-accepted medical standards to determine if care is removed, but forces the provider to provide futile care against their will while seeking a transfer. The outcome forces the provider to violate their autonomy for a certain length of time, but the principle of respecting medical standards is preserved. Both positions, to some degree, are willing to accept unfavorable outcomes to preserve their primary value. While implementation is not completely ignored by policy-makers, as evidenced by the many provisions in some MFP, the value of one party deciding over another prevails in 16 of 17 laws. Only one type of MFP, the third-party

policy affronts the issue of technical simplicity, since it does not favor one value over another, meaning that some may not profess an absolute “right” or “wrong” on the issue of who gets to decide and be willing to compromise values for better outcomes.

Mooney also states that morality policies are highly salient (Mooney, 2000). Indeed, the literal life-and-death nature of medical dispute policy would imply such saliency. Saliency also extends into enduring debates in medical and ethics journals, which parallels Mooney’s third tenet- increased citizen participation (Mooney, 2000). Dueling articles critiquing MFP are rife, with points and counterpoints, articles and responses. Most are in support of or strongly opposing one type of MFP: third-party policy, the Texas Advance Directives Act of 1999 (TADA) and its tenets (Fine, 2000, 2001; Fine & Mayo, 2003; Graham, 2005; O’Callaghan, 2008; Pope, 2003; Robert Powell Center for Medical Ethics, 2011; Truog, 2007, 2009). On this one third-party policy alone, there are hundreds of articles that reference TADA, many of which analyzing the outcomes of the law but most supporting or criticizing the law itself (Fine, 2000, 2001; Fine & Mayo, 2003; Graham, 2005; O’Callaghan, 2008; Pope, 2003; Truog, 2007, 2009; Warneke, 2007, 2007). For example, Dr. Robert Fine, the head of Clinical Ethics for the Baylor Healthcare system that runs an extensive set of hospitals in the North Texas region, writes passionately in defense of the law, citing cases that he personally oversaw in his role and how the law helped resolve those cases in the patient’s best interest (Fine, 2000, 2007, 2009). Another physician, Dr. Robert Truog, writes strongly opposing TADA as “ethically-flawed,” (2006, 2007, 2009) and continually comments of landmark patient cases to make his broader point that the law is fundamentally problematic (2007).

This saliency also indicates interest group participation in the limited literature of MFP and also ADL (Coleman & Drake, 2006; Graham, 2005; Robert Powell Center for Medical

Ethics, 2011). Many of the authors participating in MFP debates are representatives of larger groups who are also on record as supporting or sharply opposing medical futility legislation (Coleman & Drake, 2006; Graham, 2005; Robert Powell Center for Medical Ethics, 2011). Additionally, the Commission for Uniform State Laws created and promoted Uniform Health Care Decisions Act to address medical futility disputes and also designed and promoted its predecessor- the Model Health Care Consent Act, a form of ADL (The National Conference of Commissioners on Uniform State Laws, 2010). Therefore the presence of interest group participation is known in both ADL and MFP. There is not enough literature to know about the role of citizens in MFP or ADL adoption, interest group participation is almost assuredly present in many MFP reform efforts, as Mooney's theory would suggest (2000).

Literature on MFP affirms morality policy theory in many aspects. Literature demonstrates MFP as highly salient, regarded by many with differing values to be of critical importance. Direct citizen participation is not evident, but there is a significant showing of interest groups advocating their pro-patient or pro-provider positions (The National Conference of Commissioner on Uniform State Laws, 2012; Robert Powell Center for Medical Ethics, 2011). The third tenet, technical simplicity applies in the vast majority of cases. If MFP was split only two ways: pro-patient or pro-provider, the theory would more solidly apply in spite of minor compromises. The fact that seemingly mutually-exclusive interests have enacted policies that completely negate all autonomy and abdicates power to a third-party suggests that in one case, implementation concerns prevailed over values. Even though this one policy type counters the tenet of technical simplicity, it abundantly demonstrates the tenets of saliency and increased citizen participation associated with morality policies as evidenced by the attention this one law gets in literature (Carla L. Smith, Martin L. Gremillion, Ginny, Slomka, Jacquelyn, Warneke,

2007, 2007; Fine, 2000, 2001; Fine & Mayo, 2003). Morality policy theory therefore still applies to third-party policies, just not as aptly as it applies to the majority of MFP which exemplify both the premise and tenets of morality policy.

If I dismiss the single third-party policy as an outlier to focus on the bulk of MFP, the premise of morality policy is clearly at play. This premise, that policies are mostly driven by values could explain how one value (and one party) trods over another value (and the other party) in 16 of 17 policies. These policies are technically simple, granting authority to decide to one party or the other in spite of the implementation affects and outcomes this may present. Perhaps states adopt an MFP because the type of MFP proposed is in tune with the values of the state, which can explain why some states pass laws that assert pro-patient values while other pass laws that value the provider. These legislators could be affixed on the rightness or wrongness of a policy, not striking a balance to honor the rights of each party. Since morality policies are highly salient and garner greater citizen participation, perhaps the values of the citizens and interest groups a.) sabotaged MFP proposals that countered their values or b.) bolstered those proposals that reinforced their values. Examining the political environments of the states themselves against the policies they choose could uncover that certain characteristics within a state promote either adopting MFP or adopting a specific type of MFP that conforms to that state's pervasive value-set.

Policy scholars have several key factors or “usual suspects” they employ when looking at reforms, some of which are employed by to see if morality policy is affected by these factors as other reforms are (Mooney & Lee, 1995). A, estimation of how innovative each state is examined as some states more likely to lead others in making policy changes than other states in general, characteristics of morality polity aside (Mooney & Lee, 1995). Beyond that is a test of

state ideology across the liberal-conservative continuum, to see if these values affect morality policy adoption- with the expectation that more liberal states would enact more liberal policies and vice-versa. Since citizen participation is an integral aspect of morality policy theory, many scholars examine the role of public opinion on the policy topic (Cocca, 2002; Mooney, 2000; Mooney & Lee, 1995, 1999, 2000).

The “usual suspects” were mostly insignificant just as scholars suspected when studying morality policy, yet some are worth examining in regards to studying MFP (Mooney & Lee, 1995). Does the ideology of the state affect the adoption and type of MFP policy? While the morality policies studied, abortion and the death penalty clearly split down conservative-liberal lines, MFP does not. It would therefore be interesting to learn if political ideology plays a role in spurring MFP adoption, and what ideology favors what type of MFP.

Morality policy theory is fruitful in offering several variables that could affect MFP adoption, as well as the types of MFP that states adopt. It was useful in spite of the fact that no studies existed on MFP itself. Fortunately, there are a wealth of studies on ADL that should also assist in uncovering variables that address this question and also finding those additional variables that could supplement the “usual suspects” in studying MFP policy adoption. Morality policy studies typically use these suggested factors as control variables and examine variables related to the policy issue, like the number of women in the workforce likely to be in favor of legal abortion was used to examined abortion reform laws (Mooney & Lee, 1995). Reviewing ADL literature should also provide variables that can be tested to address my question of MFP adoption.

## Factors Affecting the Innovation of Advance Directive Law

Unlike MFP, there is a wealth of research about ADL from many perspectives and with many methods. Scholars have not only studied the innovation of ADL in-depth through case studies, they have studied the diffusion of ADL across all 50 states. Researchers have thoroughly examined the impetus for ADL, questioning the role that federal law and landmark court cases at the state and federal level (like *Quinlan* and *Cruzan*) may have played in promoting state law adoption (Glick, 1992b; Glick & Hays, 1991; Hoefler, 1994). In addition to detailed case studies about the adoption process in sampled states, there is an event-history analysis and other quantitative methods employed about what aspects of the state itself might affect adoption (Glick, 1992a; Glick & Hays, 1991). And although there is one prevailing type of ADL, scholars have also examined policy reinvention, the minor amendments at each state level that allowed for the rapid diffusion of ADL across the United States (Glick & Hays, 1991; Hays, 1996).

In the study of not just ADL, but public policy in general, theories note that policies do not spontaneously manifest without some sort of stimulus (Sabatier, 2007). Typically, the proverb is “necessity is the mother of invention” and states become alerted to problems and adopt policies to address those problems (Hays, 1996). The need for ADL is clearly documented, and also highlighted by contentious landmark court cases. While events like court battles often alert states to the need for policy, it takes individuals to initiate these changes—individuals who identify the problem, craft policy solutions and build coalitions. These individuals are known as policy entrepreneurs, and case studies on the innovation of ADL assert that these actors played a critical role in the innovation of the first laws regarding medical disputes (Glick, 1992a).

In 1976, the first state advance directive law was passed in California just months after the Quinlan decision (Glick, 1992a). However, this law was first proposed and defeated in 1974, and this proposal in California was not the first proposal of ADL legislation. The first advance directive law proposal was made in 1967 in Florida and was not passed until 1984 (Glick, 1992a). Case studies on both California and Florida suggest why it took one state 17 years to adopt a law that only took two years in another. In California, a skilled policy entrepreneur was able to create a consensus which garnered the political support needed for adoption, but in Florida a lesser-skilled policy entrepreneur could not foster a consensus and lacked the support for adoption (Glick, 1992a).

According to Glick (1994) and Hoefler and Kamoie (1994)—both highly acclaimed authors in the topic of state advance directive law—the utilization of policy entrepreneurs is a powerful way of implementing groundbreaking policy in spite of highly vocal and powerful opposition. In both California and Florida, interest groups raged against the proposed ADL (Glick, 1992a) and were successful in inhibiting policy efforts. The legislators that crafted ADL proposals in California and Florida took contrary strategies to address interest group opposition, one strategy successful while the other was not (Glick, 1992a).

In California, Barry Keene was elected as a freshman Democrat in the 1972 state Senate, and his background as an attorney prepared him to aggressively defend his proposal (Glick, 1992a). Keene pursued a favor from the Speaker to appoint him and four like-minded senators to the Committee on Health, where his advance directive bill would land (Glick, 1992a). The bill failed due to opposition from the California Pro-Life Council and California Catholic Conference but Keene spent the next two years winning opponents to his side, although these groups remained opposed (Glick, 1992a). The more vocal CPLC called the bill “the first step on the



slippery slope to active euthanasia” and opponents demonstrated loudly outside of his office and distributed flyers comparing him to Adolf Hitler (Glick, 1992a).

Keene’s strategy became consensus-building while seeking and winning the support of those with influence most likely to be sympathetic to his cause- like the California Medical Association (Glick, 1992a). He continued to court his opponents and recruited a Catholic priest to approach the bishop, and they ultimately won the bishop’s agreement although he would not publicly endorse the proposal for fear of a backlash. Keene sought to mobilize public opinion through the mass media and took full advantage of the Quinlan decision to publicize his bill and cultivate support (Glick, 1992a).

When California Catholic Conference suspected that the bill would pass, the group became willing to drop their opposition and become neutral in exchange for amendments they believed would protect patients who would not have otherwise been protected if the bill passed as written (Glick, 1992a). They also believed that working with Keene would grant them future access to a Senator who was proving to be a powerful player in the legislature (Glick, 1992a). Keene brokered this compromise, which included many new amendments like a declaration against active euthanasia, extensive witnessing provisions, giving living wills an expiration date of five years, making the law inapplicable to pregnant women, insisting upon two physicians to validate a terminal diagnosis, plus a 14-day waiting period after diagnosis before a patient can execute their living will. The bill passed easily (Glick, 1992a).

In contrast, Walter Sackett introduced his proposal to the Florida Senate in 1967 (Glick, 1992a). Sackett was a new legislator like Keene, but had lacked Keene’s savvy for creating a hospitable legislative environment as well as winning over outside opponents (Glick, 1992a). Glick explains Sackett’s strategy for passing bills as nothing more than “filing them and hoping

for the best” (Glick, 1992a). His bill also included many controversial proposals, such as denying medical care to wards of the state with significant mental retardation. This incited disability rights advocates as well as the Florida Catholic Conference and other right-to-life organizations (Glick, 1992a). With such staunch opposition, all of Sackett’s proposals failed, even when he amended the bills to only address competent adults (Glick, 1992a). Not only could Sackett not win over the opposition, he was only able to gain the support of one organization: the Florida Department of Health (Glick, 1992a). Although most state legislators in Florida ran unopposed and very few were ever unseated, Sackett was defeated for re-election in 1976 when his opponent distributed pictures of the Senator sleeping during legislative sessions (Glick, 1992a).

In 1984, the Florida Hospital Association sought legislators to draft an advance directive law, and under pressure from state court cases that the Florida Catholic Conference feared would be more problematic for patients than legislation, the FCC declared itself neutral on a law in exchange for several provisions to mitigate their concerns, similar to the provisions demanded by the California Catholic Conference eight years prior (Glick, 1992a). Consensus was finally achieved, and the Florida law passed (Glick, 1992a).

The case studies of California and Florida suggest the power of consensus but moreover, the necessity of a skilled policy entrepreneur to facilitate consensus (Glick, 1992a). These studies suggest that skill is needed to both craft an innovative policy and broker compromises in order to win the support of groups necessary for the policy to be successfully adopted. The skill of mediating the values and interests of opposing groups proved critical, since the enduring opposition of interest groups to Florida proposals is credited for delaying policy adoption while the withdrawal of opposition in California is credited for passing the first advance directive law

in the United States (Glick, 1992a). It is impossible to know if California would have passed the law in 1976 without California Catholic Conference's concession, but it is apparent that the group's former opposition played a role in the bill's defeat two years earlier and Keene's ability to placate the group assisted in policy adoption (Glick, 1992a). It also appears that Keene believed that California Catholic Conference's opposition was a legitimate threat to his bill, which is why he was willing to amend the bill to neutralize this opposition. This is supported by the case of Florida, where every advance directive bill was met with opposition until the bill that finally passed (Glick, 1992a). In both cases, consensus preceded successful policy adoption and the lack of it resulted in failure to adopt.

While the case studies credit consensus for the adoption of ADL, the studies further suggest that consensus is not happenstance, but the deliberate effort of an individual, a policy entrepreneur, with political savvy who endeavors to build it. Keene made calculated efforts to try to win the support of his opponents and perhaps even won California Catholic Conference by first winning the support of California Medical Association. Sackett might not have attempted to build consensus or he was merely inept at it (Glick, 1992a). Anecdotes declare that Sackett continued to defend the controversial measures of his proposals, like denying care to the disabled, even after these measures had been amended out of the bill (Glick, 1992a). This suggests more ineptitude, since he was willing to amend the bills to address the concerns of his opponents yet made it clear the amendments were "a first step" towards his other goals that these groups opposed, which made the groups apprehensive to accept any legislation at all that Sackett endorsed (Glick, 1992a p. 108). Whether Sackett either did not seek consensus or failed to build it, Keene's efforts to build consensus were successful and he is credited for the passage of the California bill while Sackett is faulted for nine years of failed attempts (Glick, 1992a).

While Glick's case study of ADL testifies to the power of a skilled policy entrepreneur, many empirical studies reinforce the theory that policy entrepreneur plays a pivotal role in policy adoption. A review of studies by Mintrom on 23 policy innovations found that the policy entrepreneur was deemed "important or very important" in 15 cases and only "unimportant" in three cases (1997). While the studies that Mintrom cites that affirm the effectiveness of policy entrepreneur involvement tend to focus on policies which are less value-laden and volatile than medical futility, like school vouchers, Mooney himself notes that a policy entrepreneur has a critical role in morality policy, often harnessing the saliency in morality policy to win public support (Mintrom & Norman, 2009; Mooney & Lee, 2000). Even if support is so substantial that no compromises are needed, the policy entrepreneur would be required to both craft and propose the law.

Furthermore, since interest groups played a significant role in both promoting and inhibiting the adoption of ADL, it is likely that they play a similar role in MFP. Interest groups were involved with the drafting and passage of TADA, a third-party law where compromise clearly was needed. An article from the president of one particular right-to-life group states that the group's opposition convinced the governor to veto the bill and send the parties back to the table for negotiations (Graham, 2005). The role of interest groups in policy innovation and adoption cannot be dismissed.

### Factors Affecting the Diffusion and Reinvention of Medical Futility Policy

Every ADL in each state, despite minor differences, all share the same mechanism for resolving disputes: patient transfer. This mechanism was innovated in California prior to the wide-spread attention from landmark U.S. Supreme court cases. However, the California Natural

Death Act of 1976 was passed within months of the Quinlan decision, both alerted law-makers to a problem and providing a policy solution at the same time. These landmark cases are credited by scholars as the stimulus that fueled mass media and public opinion on the need for ADL contributed to the diffusion of these laws (Hays & Glick, 1997). Scholars also examined the influence of state supreme courts, saying that these courts served to either create de facto laws that legislators wanted to supplant with their own laws, or at the very least, these courts alerted policy-makers to the need for ADL (Glick, 1992b; Hoefler, 1994). They also note that 80% of state courts cited the Quinlan decision in their rulings, meaning that even if state courts influence the adoption of ADL, the influence of federal cases may have indirectly affected the states in this way (Glick, 1992b).

Literature does not offer any evidence that court cases affect the adoption of MFP, neither by being the impetus that draws attention to the need for policy- nor commanding legislator attention. There are a few high-profile cases that permeate literature on medical futility disputes and are known by bioethicists and scholars, but are these hardly household names (Annas, 1994; Cranford, 1991). The first is the 1990 case of Helga Wanglie, which is mentioned in Chapter 2. The Wanglie case took place in Minnesota, and while there are widespread studies on the impact of particular cases on state ADL, the consequences of this case on Minnesota state law is not addressed in literature. However, Minnesota is a pro-patient state since 1993, only a few years after the Wanglie case. Perhaps this case did alert lawmakers to medical futility disputes, and lawmakers chose to pass a law that favors the patient. In the absence of evidence, any assumption that this case had implications for MFP akin to cases like Quinlan and Cruzan and their effects on ADL, would be speculative. The second case mentioned in Chapter 2 as well is the Baby K case of Virginia from 1992 (Tousignant & Miller, 1995). Like

the Wanglie case in Minnesota, it is not evident in literature if this case affected Virginia law. The current statute that favors physicians and limits LMST to 14 days was not passed until 2000 and also, would not address an acute scenario like Baby K, where the mother kept returning to the ER to life-saving care rather than on-going LSMT. While the Baby K case clarified the limits of provider discretion in emergency rooms, there is no evidence that this case affected the adoption of MFP (Annas, 1994). Across the board, there is simply not enough compelling evidence to consider court cases as either promoting innovation or diffusion of MFP, pointing again to the role of policy entrepreneurs and interest groups.

Policy entrepreneurs and interest groups as the stimulus for MFP also explain why the necessity that prompts the advent of MFP in 17 states has not caused enough turmoil to compel the remaining states to adopt MFP. Both patients and providers have an interest in changing ADL to an MFP, and these actors could engage sympathetic law-makers to propose laws that favor their concerns- therefore the presence of policy entrepreneurs and interests groups can explain why only 17 states have adopted reforms: perhaps only these 17 states have policy entrepreneurs and interest groups to undertake policy reform efforts. Regardless of the impetus for MFP, there need also be a hospitable political environment that favors these positions for the proposals to pass into law.

Scholars of ADL have also looked at variables of the political environment that would affect agenda-setting and policy adoption. Additionally they examined “state context” variables that affect the adoption of policies relevant to the state itself beyond just its legislature (Hays & Glick, 1997). For the model on agenda-setting, the scholars employed many of the “usual suspects,” which, like Mooney, proved to be insignificant (Hays & Glick, 1997; Mooney & Lee, 1995). As expected, demographics like income and education were insignificant. However, the

variable of innovativeness was significant, but not in the expected direction, signifying that more innovative states were less likely to adopt ADL (Hays & Glick, 1997).

Scholars added other variables that they felt would affect ADL adoption by spurring agenda-setting, like the prevalence of court cases, the attention of mass media, public opinion, the percentage of Catholics in the state, and number of neighbors adopting ADL (Hays & Glick, 1997). They found, contrary to their hypothesis and earlier studies that court cases were not significant, but mass media and public opinion certainly were suggesting that perhaps these cases influenced mass media and public opinion, assisting the adopt of ADL indirectly (Glick, 1992b; Glick & Hays, 1991).

Scholars also found that states are more likely to adopt ADL if states around them are not adopting, the converse of their hypothesis and other studies that assert regional diffusion as the method by which ADL spread nationwide (Glick & Hays, 1991; Hoefler & Kamoie, 1994). Whether regional diffusion is or is not an explaining for ADL diffusion, a cursory glance at the map of medical dispute policies instantly discredits regional diffusion. Figure 1 demonstrates that no like MFP type shares a border. While the map is mostly ADL, when two MFP states share a border, those states always have different types of MFP. New Mexico, Oklahoma and Texas all have MFP, yet all have different types of MFP. If the differences in MFP types were minor, regional diffusion could be considered. However these states represent policies of substantive and fundamental differences, likely indicative of different value-sets in each state.

Values examined in ADL research reinforce morality policy theory. Variables related to state value-sets were significant across the board with the adoption of ADL. Ideological liberalism and Democratic control of the legislature were significant, since ADL was hypothesized to more likely gain the support of liberals. Likewise, since the Catholic Church was

a main opponent of ADL, they expected states the higher percentages of Catholics in a state to inhibit policy adoption, which was confirmed (Hays & Glick, 1997).

These value-based variables found significant in ADL are also most likely to be significant in MFP adoption when modified to accommodate key differences between the two policies. Ideological liberalism is gauge of values more applicable to MFP than Democratic control or party-based measures, since there is no clear connection between a type of MFP and political party affiliation. While right-to-life arguments employed to oppose pro-provider MFP suggest conservative support, bodily autonomy arguments that are also used to oppose pro-provider policies suggest liberal support. In addition to conservatives touting her right-to-life, outrage on internet message boards and blogs about Texas immigrant Tirhas Habtegeris predominately blamed conservatives for allowing providers to kill the conscious cancer patient for being unable to pay her medical bills (Hollinger, 2006; Landsburg, 2006). A blogger that calls herself Progo35 at RH Reality Check, an online community that advocates access to abortion notes the Texas Chapter of the American Civil Liberties Union (ACLU) efforts to oppose the unilateral removal of LSMT by providers, saying “This is a threat to both the sanctity of life and the sanctity of personal choice, thus, both pro-life and pro-choice people have a stake in this matter” (RH RealityCheck.org, 2010). While right-to-life organizations take the lead in opposing pro-provider MFP and are associated with conservatism, there is no party platform on medical futility disputes, so I cannot attribute one type of policy to Republicans and another to Democrats. This needs to be examined to determine if certain biases do exist, yet focus on values should be focus more on ideology than party affiliation.

Likewise, while many Catholics may oppose MFP from a right-to-life perspective, there is no official platform on medical futility issues, either. The percentage of Catholics was



significant in the study of abortion legalization, but the Catholic Church has clear, unchanging teachings condemning abortion (Catechism of the Catholic Church, 2000). While many Catholics' values on human life may lead them to condemn pro-provider MFP, attempts in 2007 to re-affirm but slightly modify the third-party law in Texas was supported by the Texas Catholic Council, representing the views of all 24 bishops in the state (Aymond, 2007). And on the contrary, Dr. Ronald Hamel, senior director of ethics for the Catholic Health Association questions the efficacy of having futility policies at even an institutional level, stating that medical futility disputes can be best resolved by prevention, through enhancing patient-provider communication rather than by heavy-handed authority (Hamel & Panicola, 2003). While religious values may play a role in MFP adoption, particularly in garnering support for sympathetic proposals, there is not an apparent distinction to form a hypothesis on what this relationship may be.

Finally, ADL scholars examine policy reinvention as a catalyst for diffusion. These studies are not efficacious toward forming theory about MFP since all ADL that was reinvented through minor amendments still did not change the decision-maker in right-to-die disputes. No state reinvented ADL to deny patients the decision to remove LSMT, nor force a provider to remove LSMT against their values. MFP, on the other hand, is not adopted across states because the states tweak the same policy with minor amendments. Rather states adopt completely different types of MFP that espouse completely different values. Furthermore, any reinventions of MFP still assign a final decision-maker, with amendments for pro-patient laws allowing judicial relief if a transfer cannot be found, and amendments for pro-provider laws mandating that providers consider patient wishes or make attempts at transfer before executing their decision. Since literature suggests values as the driving force behind MFP adoption, the values

inherent in allowing patients to decide or deferring the decision to medical professionals appear to play a larger role than amendments that modify the implementation, but still assert one value over another. Since ADL reinvention involves minor amendments to ADL which do not markedly change the values or the decision-maker, these studies only serve to suggest that reinvention within the context of pro-provider or pro-patient values likely spurs adoption, but does not directly affect the type of policy adopted.

### Theory And Hypotheses

This study approaches the question, “How do states adopt MFP?” This question is significant not because of the saliency of this vital issue, but because there is no clear policy solution to address the problem of medical futility disputes. There are no “best practices” in MFP, only policy options which are assured to be vehemently opposed by one party or the other. An analysis of these laws found this to be true, that 16 of 17 states have enacted policies that assert one party (and one set of values) over another, likely drawing the ire of the losing side. And yet, somehow, these policies were adopted, most likely in spite of opposition. Fortunately, literature on morality policy and ADL points to a potential explanation for how these policies were likely passed in spite of their value-laden, contentious nature.

Unlike ADL, this study does not examine the adoption of one type of policy across states, but three different types of policies. When looking at only the decision-maker and the prevailing value that suggests, these policies address futility disputes in polar opposite ways. Typically, differences in policies such as these are attributed to differences in the states themselves (Sabatier, 2007). While this is typically explained as states adopting different policies because they have different problems or needs, the problem and need with MFP is the same across states

(Sabatier, 2007). Therefore, the difference across states seems to be a difference in *values*, with states adopting MFP that is congruent with their values and rejecting MFP policies that are incongruent.

The state itself does not espouse values that are either pro-patient or pro-provider. The more likely explanation is that states favor interest groups that hold either of these values, imbuing more influence to pro-provider interest groups like medical associations than pro-patient interest groups, like right-to-life organizations. Conversely, legislatures who sympathize with right-to-life groups or simply need the group's support for re-election are more likely to favor these groups. State ideology may come into play, with more ideologically conservative states more likely to elect conservative state legislators, who are in turn more likely to sympathize with right-to-life groups supporting pro-patient policies. A state that favors one interest group (and the values they represent) will likely not support a policy which that group deems unacceptable to their values. Therefore if an opposing group (with opposing values) wishes for a policy to pass, they must find compromises acceptable to the interest group that is favored in the current political environment. The role of values is central, but the influence can be direct or indirect: direct, by guiding the actions of interest groups, or indirect, creating a political environment that favors one group over the other.

Variables at play in other value-laden and contentious policies appear to also affect the adoption of MFP- particularly, the role policy entrepreneurs and interest group involvement. Since there were no high-profile events to spur the development of MFP, literature suggests the presence of a policy entrepreneur to note the problem, craft and propose a solution, and most importantly, obtain support to pass these laws. While ADL had landmark cases that alerted legislators to the need for policy, it was still a policy entrepreneur that first crafted ADL and

performed several other critical functions that led to successful adoption (Glick, 1992a). These functions are likely more necessary in morality policy like MFP, as someone is required to appease the opposition through amendments or gain enough support through coalition-building to overpower opponents. In the case of ADL, a policy entrepreneur was necessary to seek interest group support and neutralize interest group opposition, meaning that interests groups also play a role in MFP adoption (Glick, 1992a).

Interest groups, too, can serve as the stimulus for MFP, with an interest group creating a values-based proposal and recruiting an advocate in the legislature, often a policy entrepreneur to take up the cause. Interest groups promote values, represent large groups of citizens and mobilize their supporters to either promote or protest a proposal (Jenkins-Smith & Sabatier, 1994). They are both the indicator and representative of values, endorsing a proposal as in-line with their ideology or condemning it as contrary to it (Jenkins-Smith & Sabatier, 1994). ADL literature shows that the influence that interest groups have in sabotaging proposals that affront the group's values, simply by opposing the legislation (Glick, 1992a). Interest groups needed to withdraw their opposition for the measures to gain the votes to pass, indicating the influence that these groups had in the legislature. It was a policy entrepreneur in California that achieved this consensus that finally passed the bill, something he had failed to do without this consensus (Glick, 1992a).

Since opposition and interest group involvement is evident in MFP, there are a few broad explanations from how these policies are adopted. The first is that, like in the case of ADL, the policy entrepreneur achieves interest group consensus, either by crafting a proposal intending to gain the support of both parties (like a third-party MFP) or passing amendments to pro-patient or pro-provider policies that cause opposing groups to either support the policy or withdraw their

opposition. The likelihood that the opposing groups would ever support a pro-patient or pro-provider policy is rare, but there is evidence within some of these policies to suggest amendments to appease these groups, amendments that would have only been made in exchange for the groups support or neutrality.

The second explanation is that the values of the state (i.e. sympathetic to right-to-life vs. favoring medical judgment) creates a political environment that negates the need for consensus. A policy is congruent with the values of the state when it has sufficient support to pass in spite of any opposition- because legislators favor the interest groups that express these values, an influence that the opposition does not have. Likewise, a policy is incongruent if proponents fear it cannot pass without accommodating the values of the opposition, and the policy needs to be modified to come into alignment with these values in order to be adopted.

If a policy entrepreneur introduces a policy that is incongruent with the values of the state, an interest group representing the values required to bring the policy into congruence could refuse to withdraw their opposition, knowing the proposal could not pass without their approval. If a policy entrepreneur introduces a policy that is congruent with the values of the state, this proposal could pass in spite of minority opposition, providing no need to amend these laws and achieve consensus, explaining why some policies clearly favor one value over another.

This process applies to any type of MFP proposed. First, a policy is proposed, and this policy can either be congruent or incongruent with the state's values. By congruent, this means that the policy represents the values of the state, values espoused by an interest group with greater legislative support than opposition. If it is congruent and manages to remain so after any amendments that are made, it will pass. If a proposed policy is incongruent, then a policy entrepreneur must find a way to make it congruent, either winning consensus through persuasion

or more likely, through amendments. If consensus is achieved, the final policy becomes congruent with state values and it will be adopted. If not, the policy will fail.

Since this study proposes the examination of a multi-faceted and complex topic, one that likewise does not have the benefit of previous empirical research, this broad and exploratory approach will serve as a theoretical framework to guide my efforts. It proposes that values drive MFP adoption, creating a political environment hospitable to either pro-patient or pro-provider values promoted by interest groups. A policy entrepreneur crafts legislation that reflects (is congruent) with the prevailing values or must skillfully work within the political environment to bring the legislation into congruence, by either changing the legislation or changing the political environment. Figure 2 is an overview of the policy process that indicates how a state's affects the adoption of MFP.

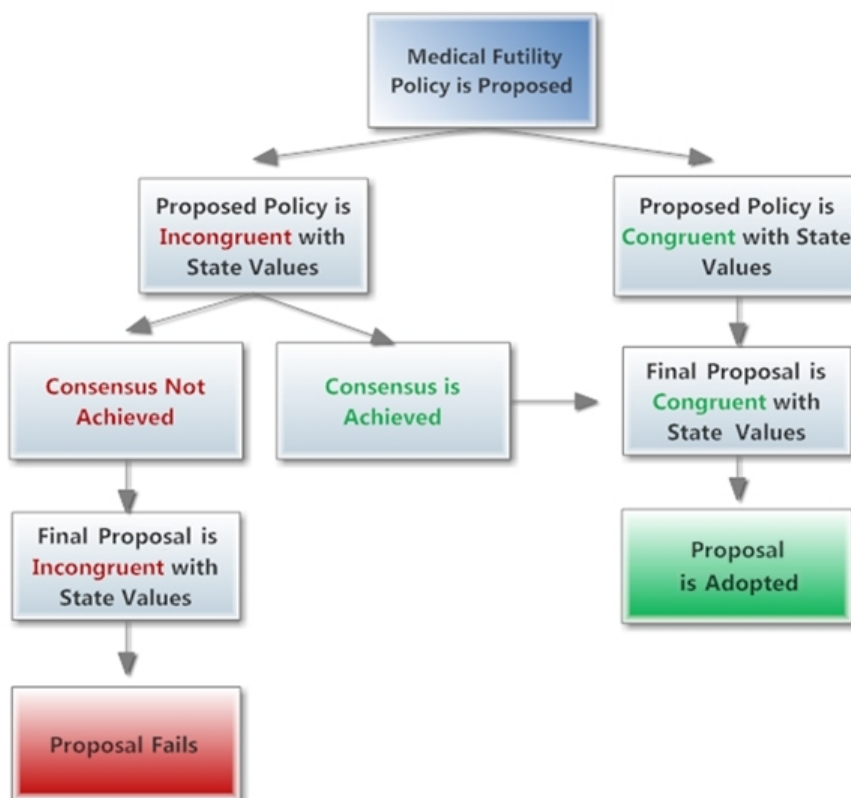


Figure 2. Medical futility policy process.

Figure 2 might to be misread to imply that consensus already exists if a proposed policy is congruent. This is not true. The theory is that if a policy is congruent, there is no need to achieve consensus, since the political environment is already hospitable to the policy, leaving no reason to concede amendments in order to gain additional support. Therefore groups in opposition will likely remain in opposition, and the policy will pass in spite of these objections. Consensus is only needed when proposed policies are incongruent and thus unacceptable to opposing interest group that opponents fear hold enough influence to potentially subvert the policy. In that case, proponents will concede lesser aspects of the policy in order to placate the opposition. If these amendments acceptable to one party are not acceptable to the other, consensus is not achieved and the policy fails. Since a proposed policy that is congruent with values would already be the acceptable to the interest group with this degree of influence, there would be no need to neutralize the opposition, as the opposition as not viewed as influential enough to kill the proposal.

Regardless of policy type, a policy entrepreneur is needed to propose and escort MFP through the policy process, building consensus if needed by brokering compromises or mobilizing the support of interest groups in order to pass the policy. Likewise, interest groups are required to advocate for policies that align with their values or withdraw opposition in order to gain amendments that support their cause. The particular functions each actor will perform will differ according to the situation, but both a policy entrepreneur and interest group involvement are required to pass MFP.

While I propose that the policy entrepreneur and interest groups are the primary actors in MFP adoption, the driver that determines MFP adoption is state values: since I expect that the state will reject policy types that assault their values and adopt policy types aligned with their

values. In order to determine state values on MFP, there are several variables that will be used as indicators of what interest groups a state is more likely to support. Since conservative legislators are more likely to be influenced by right-to-life groups (representing pro-patient values) than liberals would be, granting that interest group more influence, ideology across the liberal-conservative continuum will be examined for both citizens and the state legislature. Right-to-life-ideology will be examined as well, rating the state's passage of controversial abortion prohibitions, with the assumption that states which pass more laws sympathetic to the right-to-life position are therefore more likely to pass pro-patient MFP. Likewise, as a surrogate measure of pro-provider values, the American Medical Association's report regarding the number of active physicians in each state will be examined- as well as prevalence of hospitals in a state, since both state medical associations and hospital associations lobby for pro-provider policies. Additional control variables found in literature that could potentially affect the political environment will also be employed to see if they play any role in MFP adoption.

The following section will further explain the roles each of these variables are expected to play in each different scenario of MFP adoption. Detailed research methods, including the choice and operationalization of these variables that will be used to test these hypotheses will be related in later chapters.

#### Actors Required for Innovation: The Roles of Policy Entrepreneurs and Interest Groups

The actions of policy entrepreneurs were found to be critical in the adoption of ADL, a policy process that involves many of the same value concerns and stakeholders involved with MFP (Glick, 1992a). Likewise, literature has demonstrated that interest groups were already



involved in the drafting of one MFP: The Texas Advance Directives Act- and are a likely explanation for the adoption of MFP in other states (Fine, 2001; Graham, 2005).

A policy entrepreneur is necessary to create a policy solution and get their proposal on the agenda, which interest groups can then either support, oppose or declare neutrality. A key function of a policy entrepreneur is coalition-building and the brokerage of ideas, both developing a group of allies to support the proposal while also attempting to win the support of those opposed (Mintrom & Norman, 2009). In the case of pro-patient and pro-provider policies, the odds of a policy entrepreneur winning the support of an opposing group is slim, making the role of coalition-building that much more important to overpower the opposition. In the case of third-party policies, this role is even more critical, as a skilled facilitator is needed to moderate the two extreme interests to draft a compromise that can gain consent, especially one where both patients and providers abdicate their autonomy to a third-party. The policy entrepreneur represents the mediator between two sides, willing to work with all stakeholders involved to get the bill passed.

Interest groups may share similar characteristics with a policy entrepreneur as both parties strive towards the same goal of enacting a policy (Gerston, 2007; Mintrom & Norman, 2009). What can also be confusing is that a policy entrepreneur will often convene coalitions around their policy for support and negotiations, coalitions that often include interest group representatives. It is, therefore, essential to clearly define how a policy entrepreneur and interest groups differ since the theory suggests that these variables play distinct roles in the adoption of MFP.

The foremost, easiest and most meaningful way to differentiate a policy entrepreneur from an interest group is that a policy entrepreneur is defined as an individual, whereas an

interest group is indeed a group, established to rally around a common value (Roberts & King, 1991). Therefore, any interest group activities committed under a group name, even if those activities are similar to the functions of a policy entrepreneur, represent an interest group. Secondly, some key legislative functions are unique only to a policy entrepreneur, whilst others may be shared. The innovation and proposal of the policy into the political system is a key characteristic of a policy entrepreneur (Roberts & King, 1991). This is one of the necessary functions that must be performed by an individual in order for him/her to qualify as a policy entrepreneur in this study. Interest groups may “shop” for an individual to the legislation, but they (being a group) are not capable of making a formal bill and are likewise not readily capable of agenda-setting. Finally, a policy entrepreneur is policy-driven, whereas an interest group is cause-driven and simply supports a policy that is profitable to their cause (Mintrom, 1997; Roberts & King, 1991). A policy entrepreneur seeks to pass a bill and any coalitions they create are for that sole purpose rather than advancing a larger value-set (Mintrom, 1997; Mintrom & Norman, 2009). Conversely, interest groups typically represent their cause, in contrast to policy entrepreneurs, who represent the policy (Mintrom, 1997; Roberts & King, 1991). It is the policy entrepreneur who will mediate these changes to appease the agendas of the other political actors. This must be clearly noted, as interest groups could claim to broker policy by simply being present at the table during key negotiations.

Akin to a policy entrepreneur, interest groups do mobilize public opinion. In fact, the influence on public opinion that interest groups have can potentially exceed that of a policy entrepreneur, as the former have influence over their membership and sufficient financial backing with which to inform their members and address the public through advertising and grass-roots activities (Gerston, 2007). Given that issues of saliency and public opinion are key

factors in morality policy adoption, as well as the historical narratives of grassroots opposition to ADL, this role can be critical (Mooney, 2000).

Interest groups also have influence with candidates who are sympathetic to their cause may have influence over other legislators who support the cause the interest group represents (Burstein, 2003). While legislators are labeled by their party affiliation, interest groups are non-partisan and are better-equipped to gain the support of legislators across party lines- a feat that might prove more difficult for an individual policy entrepreneur, especially if that policy entrepreneur is a legislator themselves (Gerston, 2007).

Literature does not suggest a positive relationship between interest groups and policy adoption, meaning that interest groups support does not equal adoption. Case studies suggest instead that interest group opposition is an inhibitor to policy adoption. Laws were not passed because opposing interest groups decided to support the legislation. Rather, laws were passed simply when these groups dropped their opposition to assume a “neutral” stance (Glick, 1992a). This suggests the power of consensus in the policy-making process.

Consensus does not imply solidarity or even agreement. Instead, consensus requires consent, a stakeholder consenting to a policy option that it not ideal but acceptable (Heitzig & Simmons, 2010). This was the case in both California and Florida (Glick, 1992a). Neither right-to-life interest group in either state supported advance directive legislation nor agreed with its proponents, but consented to the policy in exchange for concessions the group deemed preferable to the alternative (Glick, 1992a). These moves were damage-control efforts, made to limit the problems the interest groups expected the bills to cause when they anticipated that the contrary value was supported enough to pass. This could be the case in many MFP that are pro-patient or pro-provider, yet include some provisions to promote the autonomy of the other party.

Amendments to pro-patient MPF that allow for “judicial relief” if a transfer cannot be found is one example, while amendments to pro-provider laws that mandate a 14-day treatment period for patients to find a transfer is another example. These provisions could have been bargaining chips to achieve consensus.

Both interest groups and a policy entrepreneur are necessary conditions for policy adoption, but neither can function independently and still pass an MFP. A policy entrepreneur serves as the explanation for the agenda-setting as well as any negotiations and coalition-building that a particular MFP would require. Interest groups are also necessary as an equally plausible explanation for innovating an MFP and providing the support it requires for adoption. A policy entrepreneur requires interest groups to take a position on a proposal, gaining the support of legislators, while interest groups require policy entrepreneur is necessary to guide the MFP through the process detailed in Figure 2, whether a policy proposal is congruent or incongruent. While the functions differ depending upon whether the proposed policy is congruent or incongruent, a policy entrepreneur must perform all necessary functions of a policy entrepreneur in order for a policy to pass. If a policy entrepreneur fails in a necessary function, particularly consensus-building with an incongruent policy, then the policy will not pass. Therefore, the following relationship between a policy entrepreneur and MFP adoption is expected:

H<sub>1</sub>: A state that has a policy entrepreneur who performs all necessary functions as a policy entrepreneur will adopt any type of MFP, while states that have no policy entrepreneur, or a policy entrepreneur who fails at necessary policy entrepreneur functions will not succeed in adopting any type of MFP.

Additionally, while a policy entrepreneur is needed by an interest group to propose a law and navigate the proposal through the policy process, interest groups are needed to perform functions unique to interest groups. The main function is that they have influence with powerful

players in the policy process, key legislators that can pass or fail a bill- therefore their formal endorsement garners support and their formal opposition inhibits support. In order for an MFP of any type to pass, at least one interest group must exert this influence, either by endorsing a bill or dropping formal opposition so that allies may vote in favor of the bill. While interests can perform other functions (like those mentioned earlier), they need not perform all functions for a bill to pass. It is possible that merely endorsing a bill without additional effort can win the support needed for a bill to pass, and that a bill as salient and contentious as MFP, regardless of type, could not pass without the formal endorsement of an interest group. Likewise, literature and my framework suggests that any group willing to concede to another group will be unable to pass the bill without the cooperation of the threatening group. Therefore, the following relationship is expected:

H<sub>2</sub>: A state that has interest groups that propose a policy *who are willing to concede aspects of the proposal to gain the support of an opposing interest group* will be unable to adopt any type of MFP without the opposing group's support.

In order to properly test H<sub>1</sub> and H<sub>2</sub>, a detailed look of the policy process is necessary to determine what functions each variable actually performed as well as a control scenario for contrast, to determine what functions can explain MFP adoption. A comparative case study of two states, one that passed MFP, and one that proposed MFP that ultimately failed will be undertaken to assess the aforementioned theory of the policy process as well as the roles of these two variables.

#### Indicators of State Values and Expected Effects on MFP Adoption

State values are operationally-defined as a prevalent ideology (either pro-patient or pro-provider) with sufficient support to pass MFP in spite of opposition. As explained earlier, states

themselves do not espouse values that are either pro-patient or pro-provider, however interest groups assuredly do. The influence afforded to each respective interest group (and the values they present) is likely an indication of greater ideology. Measures employed are chosen to reflect the presence of certain interest groups who propose policies that represent their ideology, as well as a political environment that would favor a pro-patient or pro-provider MFP.

The first measure of state values is one of the “usual suspects” in policy adoption studies: a measure of ideological liberalism (Berry, Fording, Ringquist, Hanson, & Klarner, 2010). This measure will focus on the ideology of the government, based on roll call votes of legislators compiled by interest groups. This is an indicator of how hospitable a legislature is to conservative interest groups vs. liberal interest groups. Dominantly conservative states are more likely to support right-to-life interest groups who espouse a conservative ideal. Likewise, states with more citizens that hold a more liberal ideology could potentially overcome the influence of pro-patient forces. However, associating pro-patient interest group with conservatism does not conversely suggest that pro-provider lobby groups would be liberal, the only expected affect would be between stronger conservative ideology and adoption pro-patient MFP more frequently than states with a less strong conservative ideology. Even though the sample size is small, states can be characterized as dominantly conservative or dominantly liberal, and contrasted by the type of MFP adopted. Therefore, the following relationship is expected:

H<sub>3</sub>: States with government officials that espouse a dominantly conservative ideology will adopt pro-patient MFP more often than pro-provider MFP.

Since my theory is based on the influence of values, literature suggest right-to-life groups as the primary lobby force for pro-patient MFP (Graham, 2005; Heitman & Gremillion, 2001; Robert Powell Center for Medical Ethics, 2011). I theorize that the influence of these interest groups in each state could affect the adoption of pro-patient MFP. In lieu of other measures to

gauge right-to-life interest group influence, success in passing other morality policy is employed. Notably, two controversial abortion restrictions, passed in the same time frame as MFP adoption indicates a hospitable environment for right-to-life interest groups to enact pro-patient policies. States that have more controversial abortion restrictions are expected to have a more powerful right-to-life lobby who would favor pro-patient MFP. Therefore, the following relationship is expected:

H<sub>4</sub>: MFP States with a more hospitable right-to-life political environment will enact pro-patient MFP more often than they adopt pro-provider MFP.

Finally, measures clearly intended to estimate the likelihood of pro-provider lobbying efforts and pro-provider MFP support include two ratios: first, the ratio of physicians to citizens in each state, as well as a ratio of hospital beds to the total population. The first measure takes into account only active members of the American Medical Association, those likely to join in supporting state medical associations in promoting a pro-provider policy (American Medical Association, 2010). The second, is also intended to indicate the prevalence of hospitals, as hospital associations also lobby in favor of pro-provider policies (American Hospital Association, 2009). Both ratios are intended to be correlated with pro-provider MFP:

H<sub>5</sub>: MFP States that have above average ratios physicians to the general public will adopt pro-provider MFP more often pro-patient MFP.

H<sub>6</sub>: MFP States that have above average ratios physicians to the general public will adopt pro-provider MFP more often pro-patient MFP.

Two sets of indicators for each value-set, pro-patient and pro-provider, will be employed to test the theory that values drive MFP adoption. Additionally, there are aspects of the political environment irrespective of values that may also affect MFP adoption. These will be examined as control measures.

The first control variable is urbanization, one of policy studies “usual suspects” tested as a control in morality policy studies, only statistically significant in the case of capital punishment reform (Mintrom, 1997; Mooney & Lee, 1995, 2000). There is no expected relationship between MFP adoption and population density, but since it was unexpectedly significant in one study and is part of the canon of variables previous authors have employed, it will be used to compare states that have adopted MFP to those which have not, as well as policy type. The potential exists for significance, that more urbanized states have a greater need for eliminating strains on healthcare resources by determining some method of resolving medical futility disputes and keeping these cases out of the court system. Or perhaps rural states have fewer providers and can therefore overpower pro-provider interest groups to enact pro-patient policies. Significance is not expected, and any relationship would require greater inquiry before it could be defensible explained.

The second control variable is legislative professionalism, or the resources a state affords its legislators that promote innovation, like higher salary and better benefits, greater demands on legislator time, staff and resources (Squire, 2007). Legislature professionalism has been a significant variable in other policy studies and associated with increased innovativeness, meaning that some states may be more apt to adopt MFP of any type because they have these advantages. Since legislative professionalism is a confounding aspect of the political environment, it will be examined although no relationship is expected.

The third control variable looks at partisanship, or the control of the state legislature by one party or the other. No relationship is expected, but this variable will explore if political affiliation might play a role in MFP adoption. Democrat-controlled legislatures may be more apt to adopt any type of MFP as progressives rather than conservatives, who may be more change



averse. Likewise right-to-life groups are most likely to be favored by Republican legislators and therefore, more able to adopt pro-patient MFP. While there is no relationship expected between MFP adoption or policy type, there is potential for a correlation that needs to be explored.

The fourth control and final control variable examines political competition, which can inspire legislators to vote in favor or opposed to policies in order to secure re-election when they feel their seat is at risk. This measure looks at district-level state election results, to see the margin between the winning party and the losing party to aggregate a score for the each state over how secure, on average, legislators are about keeping their office (Holbrook & Van Dunk, 1993). Since MFP does not divide down party lines, legislators looking to please constituents and win re-election may tend to vote against MFP adoption or in favor. They might also lean toward supporting an MFP type that they feel will gain them votes. There is likely no relationship, but since competition affect the political environment apart from values, it is an appropriate control variable to employ.

### Sampling and Methods

In order to examine the role of policy entrepreneurs and interest groups by the functions each perform (and test  $H_1$  and  $H_2$ ), a comparative case study employed semi-structured interviews of policy actors in two sampled states: Texas, the lone third-party MFP state and Idaho, an ADL state that attempted to adopt a third-party MFP and failed. These states were chosen for several reasons. First, these states were chosen because of the necessity to study third-party MFP separately in order to make any valid conclusions about this unique form of MFP and second, they were chosen because of the inherent compromise that a third-party policy would suggest, which made it fertile ground for detailed data on the roles policy actors play and their

values as well. Texas was chosen as an example of successful MFP adoption and Idaho an example of failure to adopt, and since Idaho proposed a policy similar to Texas, which controlled for any role the policy type itself might play in promoting or inhibiting MFP adoption. Idaho was the most similar state to Texas that could offer a meaningful comparison of the policy process and the roles policy entrepreneurs and interest groups play to test  $H_1$  and  $H_2$  as well as provide a comprehensive examination of the MFP policy process. Additional details on methodology as well as the operationalization and coding of interest group and policy entrepreneur functions are offered in Chapter 4.

As for the remaining hypotheses, all measures listed to test these hypotheses as well as the control variables will compare MFP states (17) to non-MFP states (33) to determine if any of these factors affect a state's decision to adopt MFP. Contrasting variables intended to indicate values and propensity toward one type of MFP need to be ruled-out as affecting the adoption of any type of MFP. Likewise, variables simply intended to control for non-value-based aspects of the political environment must be tested to ensure that they do not affect MFP adoption or the type of MFP that a state chooses. The sample size is adequate for Pearson's Chi-square (frequency per category exceeds 5) and subsequent Cramer's V as appropriate.

Secondly, all variables will be examined by policy type: pro-patient (9), pro-provider (7). Third-party policy is examined only in the larger sample of 17 and via comparative case study, and omitted within this smaller sample as not to interfere with the analysis of variables intended to indicate pro-patient or pro-provider values. The small sample size is problematic, but the policies are plotted by variable in contingency tables and tested for independence with Fisher's exact and Cramer's V, when appropriate. Additional details on research design as well as the operationalization of coding of all eight variables are offered in Chapter 5.

## Conclusion

Borrowing from morality policy theory and studies on ADL specifically creates a theoretical framework for explaining both the process for MFP adoption as well as the factors intended to affect the type of MFP that is adopted. It essentially becomes a question of values, with states adopting the type of MFP that best reflect their value-set.

A comprehensive examination of ADL research yielded two variables: policy entrepreneurs and interest groups, both necessary conditions for policy adoption. These variables were critical in the adoption of ADL and are also noted to play a significant role in the adoption of morality policy (Glick, 1992a; Mooney & Lee, 1995). In the absence of court cases to credit for stimulating 17 states to adopt MFP, policy entrepreneurs and interest groups explain the genesis of MFP, while values are expected to guide the policy process. Interest groups are arbiters of values, indicating what policy types are acceptable to their ideology and policy entrepreneurs skillfully manipulate the political process: innovating a proposal, agenda setting, amending as proposal, building coalitions, neutralizing opposition- all functions that bring the policy congruent with state values. Both parties work in different ways, and a comparative case study is intended to follow two attempts at MFP adoption, one success and one unsuccessful to determine if these parties behave as hypothesized and the consequences of that behavior. Chapter 4 offers a history of medical dispute policies in each state, the circumstances and actors that led to the creation of an MFP proposal and the process each proposal followed, tying the actions of policy entrepreneurs and interest groups to the outcome of the proposals in each state and contrasting this data to address both hypotheses and theory.

Chapter 5 studies the bulk of MFP by variables indicating which value-set (and interest group) has more influence in each state. These variables include political ideology and political

environment intended to favor right-to-life groups that support pro-patient policies and the prevalence of physicians and hospital beds, intended to indicate interest groups who lobby for pro-provider MFP. This comprehensively examines whether these values, pro-provider of pro-patient affect the type of MFP that a state adopts. Additionally, several variables that may also affect MFP adoption, variables like characteristics of legislatures are tested to see what role these may play as well.

## CHAPTER 4

### THE MEDICAL FUTILITY POLICY PROCESS: THE CASES OF TEXAS AND IDAHO

#### Introduction

Interest groups are widely regarded in literature as instrumental players in policy adoption. In fact, the role these groups play is deemed so significant that an entire theoretical framework has been dedicated to explaining how interest groups affect policy change (Jenkins-Smith & Sabatier, 1994). With the exception of the critical role of policy entrepreneurs in my proposed framework, the Advocacy Coalition Framework (ACF) suggests that groups will sacrifice their secondary values to profit their primary (core) values- which is more defined way of saying that groups will concede, a key aspect of my framework as well (Sabatier & Weible, Christopher, 2007). Since both frameworks suggest that 100% pro-patient or 100% pro-provider MFP proposals would not be acceptable to powerful opponents, this reinforces conceptions about how pro-patient and pro-provider groups can reach an impasse, where core beliefs are incompatible, meaning that for legislation to pass, one interest group must triumph over the other. The very fact that 100% pro-patient and 100% pro-provider policies exist are a testament to stalemates between groups that still resulted in adoption.

There is one notable exception with regards to MFP: third-party policy. In fact, the Texas Advance Directives Act of 1999 (TADA) it is the most-noted exemption, the subject of dozens of articles in commentary either heralding it as an innovative, model policy solution or condemning it as unjust, flawed and perhaps even unconstitutional (Burns & Truog, 2007; Fine, 2000, 2001; Fine & Mayo, 2003; Graham, 2005; Hill, 1981; Marietta, n.d.; O'Callaghan, 2008; Smith, 2007; Truog, 2007; Zientek, 2006). While those arguing in favor of the policy readily admit that the law is not without fault, those arguing against it condemn the law entirely, even

those present for negotiations when this law was passed over a decade ago (Fine, 2001; Graham, 2005).

Although the anomaly, third-party policies present a perfect landscape to address the theory of values and interest group involvement in MFP, as well as determine how these laws are innovated and any role that a policy entrepreneur may play. TADA clearly indicates compromise on the part of both patients and providers, as both abdicate their autonomy to a third-party. It is also the most unique solution for medical futility disputes, as it tries to define a statutory process to obtain a middle ground between the interests of patients and providers. It serves not only to test my theoretical framework and hypotheses, but to also give this most intriguing case the attention it deserves that it simply could not get with the quantitative methods alone.

Furthermore, Texas in 1999 provides an excellent case of MFP adoption in comparison to another case of policy failure in 2009. Idaho attempted to pass revise their ADL with a modified version of TADA, which sailed through the Senate unanimously only to die in the House (Pope, 2009). If my theoretical framework and related hypotheses are correct, the bill was deemed unacceptable by an interest group (and value-set) that had enough influence to stop the proposal when they were not pleased with the policy alternatives that may have been offered. Theory and hypotheses suggest that either a policy entrepreneur was not present or did not perform the functions necessary to build a consensus in Idaho, or that no interest group formally endorsed the policy. If these variables prove present in the case of Texas, their absence in the case of Idaho would likely support the hypotheses. Even if the evidence fails to support the hypotheses or contradicts my framework, this information will be integral to forming better theory and examining alternative explanations for the adoption of a type of policy that has yet to be

addressed at all. All efforts stand to be efficacious, yet all efforts will be guided by MFP theory and examined through that lens.

### Instrumentation and Methods

This chapter employs a comparative case study of policy processes in Texas from 1995-1999 and Idaho from 2005-2009, examining each policy from its conception to its ultimate fate. Texas and Idaho were chosen for several reasons, not simply because of the necessity to examine third-party MFP individually, but also because one state is an example of successful MFP adoption while the other is an example of failure, granting a clear contrast on the dependent variable. While selecting cases on the dependent variable is greatly problematic in statistical research, this is a common approach in comparative case studies, allowing the research to highlight which variables are not necessary or sufficient conditions for the selected outcome (George & Bennett, 2005). Since my theory suggests both policy entrepreneurs and interest groups are necessary but not sufficient conditions for MFP adoption, selecting comparable cases by dependent variable was the best approach.

Since only one state has successfully adopted third-party MFP, Texas essentially selected itself. The task became finding states that proposed third-party MFP, so that the policy type would interfere with the results. Unfortunately, this did not yield a selection of states from which to choose, since only Idaho had proposed a third-party policy that survived long enough for a valid comparison. Fortunately, though, Idaho was similar to Texas on several additional variables that could interfere with the results, variables found (in Chapter 5) to be statistically significant or with the potential to become so in the future, and the variables where the two states differ were found to be completely inconsequential. Table 5 compares the states by these

variables. In sum, the states were expected to only vary on the independent variables of interest: policy entrepreneurs and interest group consensus, in accordance with “most similar” case study design (Yin, 2008).

Table 5

*Comparison of Idaho and Texas by Control Variables*

<b>Control Variables</b>	<b>Texas (1999)</b>	<b>Idaho (2009)</b>
Partisanship	Republican Majority	Republican Majority
Political Competition	54.25 (Highest Quintile)	41.61 (Second Highest Quintile)
Legislative Professionalism	.22 (Second Highest Quintile)	.14 (Second Lowest Quintile)
Urbanization	81.2 (Second Highest Quintile)	53.82 (Second Lowest Quintile)

H<sub>1</sub> states that a policy entrepreneur must be present and must perform all the necessary functions of a policy entrepreneur in order for MFP to pass. There are many definitions from literature on what constitutes a policy entrepreneur and what their functions are. These have been listed by Roberts and King, who define a policy entrepreneur as an individual who performs any, not necessarily all, of the following functions: advocating new ideas and developing proposals; brokering the ideas among the many policy actors; helping set the decision-making agenda; defining and reframing problems; specifying policy alternatives; and mobilizing public opinion. Some of these functions can also apply to interest groups and other policy actors, but the first three are unique to the policy entrepreneur (1991). In order to be coded as 1 (present), the policy entrepreneur must perform all three of these necessary functions in the list that are unique to a policy entrepreneur, as determined by a general agreement across respondents that these



functions were performed by an individual, not an interest group.

The individuals most likely to either be a policy entrepreneur or be able to identify the policy entrepreneur were the bill authors of the proposed policies. This was intended to increase the likelihood that any policy entrepreneur that exists would be found. Moreover, the bill authors were not just asked “if” they performed any of the five functions, but “how.” This was accomplished through semi-structured phone interviews. Phone interviews were chosen over surveys to allow for probing and the ability to get more detailed, thorough responses as well as additional information on functions that they might perform that the researcher might not know of and therefore could not list on a survey. Respondents were asked the same questions that indicate those five functions and the open-ended nature of the questions allow them to supply additional functions as well. The interview script is available in Appendix A.

Furthermore, the bill authors were asked to identify participating interest groups and other parties (if any) that they believe to have played a significant role in the policy process. In other words, if the respondent did not qualify as a policy entrepreneur, the strategy was that he or she would potentially identify others who may qualify. Interviews of key personnel ceased once saturation is accomplished, meaning once respondents list the same players, and all those players have been sought for an interview. Likewise, the answers of respondents corresponded to each other and there was a reasonable expectation that additional interviews with non-essential players would reiterate the same information. In contrast, a failure to receive homogeneity (similar responses) on the same scenario across different groups would signify the need for additional interviews, key personnel or otherwise, until all potential respondents were exhausted.

Once saturation was reached and all potential respondents had been interviewed, the interviews were transcribed and coded to identify the absence or presence of a policy

entrepreneur (coded as 0 if not present or 1, respectively). This was done in concordance with the questions on the script that indicate or fail to indicate the presence of a policy entrepreneur. Such an approach allowed for the answers that address the necessary functions to be linked with verbatim quotes that indicate that the respondent, indeed, performed that function and, therefore, qualified to be coded as a policy entrepreneur. Indicating that multiple respondents agreed that each function was performed increases the validity of this measure and the confidence that a policy entrepreneur was, indeed, present.

The functions were coded using numerical values—so that each function performed by the policy entrepreneur was recorded in a dataset. I then used classical content analysis to determine the number of respondents who agreed that a particular function was performed by a policy entrepreneur. During the coding process, the narratives were examined for additional themes and other functions beyond those that literature has offered that may have also played a role in policy adoption to report by prevalence and percentage. Coding these functions will allowed for inference of what functions, across cases, may contributed to policy adoption in each state. Moreover, this approach did not just test  $H_1$  regarding whether or not a policy entrepreneur is a necessary condition for MFP reform; it addressed the theory that undergirds this hypothesis—that a policy entrepreneur performs some function or combination of functions that contribute to policy adoption.

To address  $H_2$  and the second key variable, the endorsement and activity of interest groups, the same script as the one used in interviewing policy entrepreneurs was employed for interviews of interest group representatives. Interest groups are established, named groups that endorse a policy effort (Sabatier & Weible, Christopher, 2007). The conditions that an interest group must meet to qualify as such were both to meet this simple definition as well as perform a

function unique to interest groups, namely, the formal endorsement of MFP. This was determined through the first question on the interview script, where the respondent was asked to list their organizational affiliations and question six in the interview script, where the respondent lists the supporters of the bill. The presence of an interest group is a nominal variable; hence, it was coded as 0 if not present, and 1 if present. Additionally, universal endorsement of the policy by all respondents indicates consensus, a critical aspect of my theoretical framework.

With respect to determining their functions, Table 6 lists the functions interest groups play and the interview questions aimed to determine if they, indeed, performed those functions. The open-ended nature of the questions was also intended to reveal potential additional functions that interest groups perform. Table 6 also indicates the questions that indicate the presence of a policy entrepreneur.

Table 6

*Interview Questions that Key Indicate Policy Actor Functions*

Interest Group & Policy Entrepreneur Functions	Scripted Interview Question
Official Endorsement of Policy**	1. Please tell me about the role you played with regards to this particular policy. (i.e. bill author, committee member, member of advocacy coalition, etc.) 6. Please tell me who the key players that supported the bill as it was proposed were. 16. Please tell me who the key players were that ultimately supported the bill after any amendments and negotiations.
Advocating new ideas and developing proposals*	3. Are you aware of who had the original idea for the bill? 4. Who proposed the bill?
Defining and reframing problems	2. How would you define the problem that this bill was designed to address?
Specifying policy alternatives	12. Were alternative policy options or compromises offered to encourage opposing parties to reconcile and join forces in supporting the bill?
Brokering the ideas among the many policy actors*	8. Was there any major opposition to the proposed bill?
Mobilizing public opinion	7. How did you seek to mobilize public opinion in favor of the bill?
Helping set the decision-making agenda*	5. Please tell me about your role (if any) in the introduction of the successful bill and how you worked to get it on the agenda (if applicable) 8. Was there any major opposition to the proposed bill?
Influencing Legislators	11. How was their opposition overcome? (If this opposition included bill amendments, how the amended bill compared with the proposed bill.)
Advertising in Favor of Policy to Group Membership**	7. How did you seek to mobilize public opinion in favor of the bill?

\*Function Unique to Policy Entrepreneurs; \*\*Function Unique to Interest Groups

In the absence of a referral from the bill author, certain interest groups were contacted directly for an interview. These interest groups included those groups that previous studies identified as responsible for the passage of original advance directive law and would thus have a potential stake in medical futility reform. Such groups include state councils of Catholic bishops, physician's guilds, state medical associations, state right-to-life organizations, and hospital associations.

In line with the procedure followed when interviewing the bill authors, each respondent was asked to provide referrals to other participating parties representing interest groups that they credit for the bill passage or defeat in previous sessions. Thus, by following this approach, the responses naming of multiple, related parties on the same questions addressing the same policy provides triangulation, to validate and illuminate the answers given by other respondents. These interviews serve not only to determine interest groups involvement to test hypotheses, but to validate the presence of policy entrepreneur as well. All interviews were transcribed and analyzed in the same manner as described earlier. Thus, the presence of the key variables and functions were coded as well as any additional themes..

While legislators, interest groups and associated personnel have their positions on these bills listed as a matter of public record, confidentiality was assured to respondents. The informed consent document is available in Appendix B and details the respondents' rights to have their identities withheld. This was foremost to protect respondents from potential conflicts resulting from their responses but also to get the most candid responses possible. For the sake of confidentiality for respondents, the case study does not identify individuals other than legislators. Interest groups and their respective positions (pro-patient or pro-provider) are critical to this analysis but unfortunately, identifying responses by organizational affiliation violates

confidentiality. In order to protect respondent privacy as much as possible, all efforts are made to not make reference to interest groups nor individuals by name, and also avoid job titles and positions. The theoretically-relevant information is about values advocated and functions performed, therefore this case study reports the whole of the story as a conglomeration of opinions, noting disagreements and discrepancies by the values-set each interest group represents. No reference is made to any specific respondents and the information they disclosed beyond validating the key functions of policy entrepreneurs and interest groups.

Beginning with Texas, the whole of the policy process is presented first, followed by the analysis of policy entrepreneur functions. Interest group functions are analyzed and the sum of these actions for the entire state are subsequently addressed. Idaho follows the same pattern: first an overview of the policy process and the role of both policy entrepreneur and interest groups, concluded by an analysis of how these actors worked together for the ultimate outcome. Finally, Texas and Idaho are contrasted by both policy entrepreneur and interest group functions and analyzed for how these states compare and differ, in order to address  $H_1$  and  $H_2$ .

My theoretical framework suggests that values drive MFP adoption, and neither policy entrepreneur nor interest group endorsements are sufficient conditions for MFP adoption. However, these actors are necessary conditions that work together to conform a bill to state values in order for it to be adopted. A policy entrepreneur performs functions that build consensus among interest groups when policies are incongruent with state values, and it is that consensus which spurs MFP adoption. Policy entrepreneur and interest groups also mobilize public opinion and influence legislators in order to overcome weaker interest groups when policies are congruent and can be passed in spite of minority opposition. These interviews determined what functions were actually performed by policy entrepreneur and interest groups,

that consensus was needed, in what ways it was achieved, and what functions can be credited for these outcomes. Therefore, this analysis did not just provide evidence to support or fail to support  $H_1$  and  $H_2$ , but spoke to the validity of my theory as well.

### The Formulation of the Texas Advanced Directives Act of 1999: A Case for Consensus

Texas was an early adopter of advance directive law (ADL), passing the Texas Natural Death Act of 1977 only a year following the creation of ADL in California (Farabee, 1977). This law took effect on August 29, 1977, and only slightly amended in 1979, by withdrawing the requirement that the advance directive be notarized (Delisi & McCarty, 2006). The law was further amended in 1985 and 1989, each time clarifying issues regarding who could witness health declarations, specifically excluding people who stood to benefit financially from the patient's death (Premack, 1990). For over 20 years, any changes to Texas law regarding advance directives were minor housekeeping and clarification amendments. The manner in which right-to-die disputes were resolved remained the same: providers that did not wish to comply with a patient's directive must make a "reasonable effort" to transfer the patient to another provider willing to comply with the patient's wishes (Greenfield, 1986; Premack, 1990).

Although traditional right-to-die disputes were addressed in Texas law, patients were dealing with a different kind of right-to-die dispute. Terminally-ill patients who were choosing to live out their final months at home were being subjected to unwanted cardio-pulmonary resuscitation (CPR) extending their life against their wishes (Iserson, 1991). Hospice workers and care-givers would call 911 when a patient passed away, not knowing that the law in Texas at the time mandated that emergency medical personnel perform CPR on any coding patient, even when the patient had a documented do-not-resuscitate order and CPR would likely break the

patient's ribs and cause other injuries. This caught the attention of Texas hospice associations as well as their lead counsel, who drafted the “Out-of-Hospitable Do Not Resuscitate (DNR) Act of 1995” (Cherry & Engelhardt, 2010). This law created a process for issuing a DNR order that would be legally enforceable outside of the hospital, honoring a patient’s right to refuse unwanted medical treatment established in the Cruzan decision (Cherry & Engelhardt, 2010; Leschensky, 1991). This law was based upon and reinforced the premise and value of patient autonomy inherent in the Texas Natural Death Act of 1976: the right to a natural death.

On the heels of this victory, the advocacy coalition that was convened to pass the Out-of-Hospital DNR Act repurposed itself to address other policy gaps. One such gap was conflicting definitions across various health policies enacted throughout the years. Another gap was the ambiguity in the Texas Natural Death Act- which gave conflicting mandates to providers, ordering them to make reasonable efforts to transfer the patient in a medical futility dispute, but still allowing them to refuse to participate. Providers were unsure what constituted a “reasonable effort,” essentially forcing them to continue to provide treatment rather than risk legal troubles by removing care. They wanted a clear process that mandated precisely what they should do in a medical futility dispute.

A collaboration of providers in Houston had formed a taskforce to address this issue, culminating in the “Houston Citywide Policy on Medical Futility” (Halevy & Brody, 1996). This was later known as the “Houston protocol”, a policy which offered a nine-step dispute resolution process via an institutional review body (or health care ethics committee), which states, “If a finding of medical inappropriateness is affirmed by the institutional review body, medically inappropriate intervention may be terminated and a plan of care established that addresses comfort care and the preservation of patient dignity” (Halevy & Brody, 1996;

O’Callaghan, 2008). Alternative language suggested was “must be terminated” rather than “may be terminated,” and transfers to other physicians within the institution was forbidden after the health care ethics committee (HEC) ruled the care to be inappropriate (Halevy & Brody, 1996). This protocol would allow for due-process for the patient, but also offer a solution for cases that had previously had no solution (Tomlinson & Czlonka, 1995).

While regaled in the *Journal of the American Medical Association (JAMA)*, the policy was also opposed by state right-to-life organizations. Opponents of Houston protocol insist that while the policies forbid intra-institutional transfers following a HEC decision to remove treatment, there was also an understanding that hospitals who also employed the nine-step process would not accept a transfer either. This left patients with no opportunities but to transfer outside of the Houston metro area for treatment. If neighboring cities also adopted the policy, soon patients would have become unable to transfer to those cities as well. While opponents of the Houston protocol decried the principal behind it, they also foresaw implications for patients everywhere, not just in Houston, if indeed the Houston protocol expanded to other locales as the authors of the article suggested (Halevy & Brody, 1996).

The policy did not spread. The uncertainty regarding the legality of these policies made hospitals reticent to employ them, even with the institution’s support (Heitman & Gremillion, 2001). The authors of the *JAMA* article expressed similar concerns:

There is still residual uncertainty about the legal standing of such a policy in light of the Baby K decision, which mandated life support for an anencephalic infant at parental request despite physician and institution insistence that such interventions were futile. Moreover, several of the participating institutions desire an amendment to the Texas Natural Death Act codifying such a futility mechanism while others would like to see similar process-based policies developed in other cities and states. So there is more work to be done. (Halevy & Brody, 1996 p.574)

The coalition responsible for the Out-of-Hospital DNR Act (hereafter known as “the



coalition”) began working on a legal remedy, and coalition leadership (and legal counsel for pro-provider organizations) crafted Senate Bill (SB) 414 to address futility disputes and standardize the language across different statutes related to medical decisions (Fine, 2001; Graham, 2005; Heitman & Gremillion, 2001). SB414 did not directly address medical futility disputes, except to remove legal consequences for providers who withhold care contrary to the patient’s directive. This solution was agreeable to the coalition which was compromised of representatives from healthcare provider interest groups and their legal counsel.

The bill was crafted with the consent of all members, explained by the chairperson as, “Not what each group wanted, but, “Is this something you can live with?” The coalition worked by consensus, with any member having the ability to veto a suggestion. The coalition was also open to anyone with a stake in advance directive law, meaning that any group could have potentially de-railed this effort and yet, no one did. Since all coalition members had consented to the proposal, SB414 was routed to the Local and Consent Committee in the Texas House of Representatives, a committee for noncontroversial bills with no official opposition.

There was opposition, a state right to life organization, but this interest group was not a member of the coalition. The group was already aware of medical futility disputes through the JAMA article, and SB414 would grant immunity to providers implementing the Houston protocol which they condemned (Halevy & Brody, 1996). This interest group believed SB414 would legalize involuntary euthanasia, allowing providers to deny life-saving treatment to patients with no opportunity for the patient to find another provider. Unlike the Houston protocol, SB414 had no provisions for a HEC and but granted full civil and criminal immunity to providers who remove LSMT against patient directives, including (and specifically listing) life-sustaining measures. The state right-to-life organization (hereafter known as “state pro-patient

group”) succeeded in passing amendments that would provide time for a transfer, but these amendments were ultimately stripped in the Senate just before the final vote, which passed SB414.

At this point, the state pro-patient group petitioned the governor, George W. Bush, their ally in other right-to-life legislation. They persuaded the governor to veto the bill on the basis of their objections. The governor did veto the bill and echoed the state pro-patient group’s concerns as the basis of his objection, saying, “Senate Bill No. 414 contains several provisions that would permit a physician to deny life-sustaining procedures to a patient who desires them” (Bush, 1997). The governor then convened a taskforce and implored the state pro-patient group to work with the coalition and create a compromise that would be acceptable to everyone, and return the following legislative session when a bill was crafted that all parties could support.

The coalition, comprised almost exclusively of healthcare providers, had proposed a 100% pro-provider policy. Amendments the state pro-patient group had offered, which did not prevail, would have turned SB 414 into a 100% pro-patient policy. Now both pro-provider and pro-patient interests were charged with reconciling these positions into a policy that both sides could support. What ensued was two years of negotiations prior to the next legislative session. The state pro-patient group became an official member of the coalition, and called in a nationwide right-to-life organization (hereafter known as “national pro-patient group”) to aid them in negotiating a compromise that was aligned with right-to-life values.

The state and national pro-patient groups were trying to craft legislation as close to 100% pro-patient as possible, essentially seeking a treatment til transfer (TTT) law. The first wave of negotiations involved both state and national pro-patient groups seeking six months of time for treatment before it be discontinued. The veracity of the negotiations took this time period from

six months to only two weeks, and at the additional insistence of hospital interest groups, this number was finally whittled down to ten days (Fine, 2001; Graham, 2005; Heitman & Gremillion, 2001; O’Callaghan, 2008). This compromise was coerced by a limited amount of time before Governor George W. Bush was expecting a newly-proposed bill.

While there were many other values-based conflicts, like the definition of terminal illness, the TTT provision that allowed patients the ability to transfer and continue treatment is cited by state and national pro-patient groups as the primary provision to make a law acceptable to them. Pro-provider forces saw the potential to pass a law in the next legislative session that they did not want to miss while pro-patient forces did not want to overstep the favor they had received from the governor by placing him in the middle of another politically-charged dilemma.

Regardless of the political environment, it is evident from interviews that neither side, pro-patient nor pro-provider, felt an impasse was acceptable. Both national and state pro-patient groups were concerned about what was already taking place in Houston hospitals, and pro-provider groups were uncomfortable with the ambiguity under the current law, not telling them what they legally could or could not do. Both sides mentioned that their concern for patients, pro-provider representatives not wanting to prolong patient suffering due to fears of legal reprisal, and pro-patient groups fearing that patients would be killed because providers did not see inherent value in their lives. Pro-provider representatives present the competing concerns as “groups that actually care for patients” vs. ideologues with overarching moral concerns, while pro-patient representatives claim it was a battle to protect the vulnerable against those “who did not see the value or quality of life in dying and disabled and ailing patients” vs. the only organization on the side of patients rather than providers.

Ultimately, pro-providers groups would still get legal civil and criminal immunity if they

employed the process of notifying the patient, convening a committee and honoring the ten day treatment period. Pro-patient groups were given the assurance that patients had proper notice and an opportunity for transfer. There was also a provision that would allow for a court order to extend the time period in cases where it was reasonable to believe that a transfer could be found if treatment continued. While this compromise was not what either position was seeking, it was acceptable to both positions, and preferable to the status quo. In what is noted as an “unexpected and unusual consensus,” all groups signed on in support of Senate Bill 1260, with no opposing testimony (Heitman & Gremillion, 2001). The law passed, and was signed by Governor George W. Bush on June 18, 1999 (Moncrief, 1999).

### Policy Entrepreneurship and MFP in Texas

Testimony on SB1260 uncovered several key respondents for interviews. The bill author, Michael Moncrief left the legislature in 2003 to assume the role of mayor in a large Texas city. He retired the summer of 2011 after nearly forty years in public service, and was unavailable for interview. Likewise, bill sponsors and co-sponsors, many of whom are still active legislators, were also unresponsive to numerous interview requests. However, later interviews determined that these actors were not involved in negotiations whatsoever, deferring almost entirely to the coalition to bring them a proposal that had universal support.

Testimony pointed to the coalition and several member interest groups, which were contacted for interviews. Members of the coalition, and the key players at the final negotiation table were available for interview. Five key players involved in TADA negotiations- and interviews were secured from four of them, two representing pro-patient values and two representing pro-provider values. Aside from the final fifth member of negotiations, all

respondents candidly referred to the same five people as integral to the creation and passage of TADA. None of the respondents were legislators, and therefore their responses must be kept anonymous, and they will be listed as TX Pro-Patient 1, TX Pro-Patient 2, TX Pro-Provider 1, and TX Pro-Provider 2 only in tables that will connect responses to interest group and policy entrepreneur functions but not in direct quotes about the policy process that could threaten their confidentiality. If the respondent indicates a function was performed, this is coded in the table as a 1, and if the respondent lists that a function was not performed, it is coded as a 0. The final column indicates the percentage in agreement over whether a function was or was not performed. The first table looks at policy entrepreneurs and the functions performed.

Table 7

*Policy Entrepreneurship in Texas*

	TX Pro-Patient 1	TX Pro-Patient 2	TX Pro-Provider 1	TX Pro-Provider 2	Agreement
Advocating new ideas and developing proposals*	1	1	1	1	100%
Defining and reframing problems	0	0	1	1	50%
Specifying policy alternatives	0	1	1	1	75%
Brokering the ideas among the many policy actors*	1	1	1	1	100%
Mobilizing public opinion	0	0	0	0	100%
Helping set the decision-making agenda*	1	1	1	1	100%
Influencing Legislators	0	0	1	1	50%

\*Key Function

My conceptual framework posits that the policy entrepreneur innovates a solution and performs several functions to bring that solution into congruency with state values. The first key function, advocating new ideas and developing proposals has universal agreement across all respondents. The creation of the proposal is credited to an attorney, legal counsel for healthcare associations with extensive experience representing the interests of clients before the Texas

legislature. The idea for reforming the law was proposed by a client, emboldened by the recent victory with the Out of Hospital DNR Act. This attorney took the lead in creating a bill to address the issue, leading the coalition and incorporating the concerns that members would voice. According to respondents, the new ideas presented in the proposal and the development of the proposal itself was attributed solely to the leader of the coalition.

The second key function involves brokering the ideas among several policy actors. This also has universal agreement, and respondents list that the policy entrepreneur performed this function primarily within the coalition, but that the policy entrepreneur was responsible for finding bill authors and sponsors in both the House and Senate, as well as testifying at hearings. The policy entrepreneur also invited and welcomed all stakeholders into the coalition, citing an “open door policy.” One respondent noted an exception, when a pro-euthanasia group became involved in the policy process during the 1999 hearings and was asked to “please stay out of it.” Otherwise, the policy entrepreneur interfaced with healthcare providers, right-to-life organizations and legislators, brokering ideas among all of these actors until all the actors were in agreement.

The third key function of a policy entrepreneur is “helping set the decision-making agenda.” The policy entrepreneur took the lead on agenda-setting, finding legislators to sponsor the bill and organization testimonies for committee hearings. The policy entrepreneur also facilitated coalition meetings and was responsible for addressing orders of business. However, not all decisions were made exclusively in the meeting room. Some business took place outside of coalition meetings, including the invitation of a pro-patient respondent to spend a day touring a pro-provider’s health care institutions and witnessing HECs in action. The pro-provider respondent credits the visit as a turning point in negotiations. All official business took place

under the auspices of the coalition and the facilitation of the policy entrepreneur, yet there were additional activities that affected the decision-making agenda.

The policy entrepreneur also notes that while the meetings had an agenda, the decisions that were made manifested from the membership. While all facilitation was done with the goal of making decisions on key aspects of legislation, all member of the groups were granted equal standing, with every group having the ability to strike down a suggestion. While the policy entrepreneur help set the decision-making agenda, the decisions that were made had to be unanimous. Authority to determine what decisions were made was external to the PE, The PE's role in setting the decision-making agenda, beyond facilitating the meetings, was finding a legislative vehicle for proposals that everyone in the coalition supported.

All three key functions were performed, meaning that a policy entrepreneur was present and active during the MFP process. The policy entrepreneur performed other functions as well, with 50% noting that the policy entrepreneur helped define and reframe problems. While the fact that the policy entrepreneur created a policy to address a problem, the problem the policy entrepreneur defined was not the problem defined by pro-patient groups. The disagreement across respondents was ideological, noting a difference between what pro-patient and pro-providers define as a "problem." Pro-patient advocates note that the other side over-simplified and failed to understand their concerns. They suggest that they were accused of standing on principal without yielding to offers that opponents made, when the offers that were made were unacceptable not on principal, but in practice. One respondent notes, "One of the biggest debates in the pro-life movement is always this issue of are you analyzing too much, are you being sufficiently sensible. The fact is whatever you start out to say, when it's got to be all or nothing, you generally end up with nothing." Ending with nothing was not an option, so pro-patient

groups insisted that they were not being inflexible, but just that offers made would not alleviate their concerns.

The next function, “specifying policy alternatives” had only 75% of respondents attributing this to the policy entrepreneur, while the final respondent mentioned only policy alternatives that their organization suggested to address their concerns. This was similar to the 50% agreement on “influencing legislators”- the pro-patients respondents mentioned only the work they had done in that regard with trying to get amendments to kill the unacceptable bill as well as final testimony in 1999. There was no mention of the policy entrepreneur performing this function by pro-patient respondents, beyond finding a bill sponsor with leadership in the most advantageous committee. However the policy entrepreneur and other pro-provider respondent spoke intimately of conversations with legislators.

The final function did have 100% agreement, in that all respondents agreed that it was not performed. All respondents mentioned that they made no efforts in 1999 to mobilize public opinion. While they all mentioned that they could not speak for everyone involved, no one (including the policy entrepreneur themselves) made efforts to influence public opinion. They note that this was not necessary with total coalition agreement and an uncontested bill.

### Interest Groups and MFP in Texas

Interest groups perform many of the secondary functions attributed to a policy entrepreneur, as well as functions unique only to interest groups. These functions are listed in the following table, with 1’s indicating what functions were performed and 0’s indicative that the function was not performed.



Table 8

*Texas Interest Group Functions in 1999*

	TX Pro-Patient 1	TX Pro-Patient 2	TX Pro-Provider 1	TX Pro-Provider 2	Agreement
Officially Endorsing the Policy*	1	1	1	1	100%
Defining and reframing problems	1	1	1	1	100%
Specifying policy alternatives	1	1	1	1	100%
Mobilizing public opinion	0	0	0	0	100%
Influencing Legislators	1	1	1	1	100%
Advertising in Favor of Policy to Group Membership	0	0	0	0	100%

As the table indicates, interest group functions are more straightforward than with the policy entrepreneur. Everyone agreed that organizations represented formally endorsed the policy (each checkmark representing a separate interest group). All respondents also agreed that state and national pro-patient interest groups redefined policy problems and offered policy alternatives. Additionally, the universal agreement on policy endorsements indicates that in Texas, consensus was achieved.

Likewise, all respondents note that interest groups gave testimony in support of the final bill, but little else. The state pro-patient group explained how they recruited allies in the legislature to present amendments in the 1997 session, yet they had no such interactions in the 1999 session after an agreement was reached. Moreover, while the governor was not exactly a legislator, the influence that the state pro-patient group with this individual resulted in legislation being through in the trash in 1997 and replaced with a more palatable alternative. While this does not correspond with questions about opposition and bill amendments, it was mentioned in other answers and certainly applies.

Finally, while not all respondents spoke authoritatively on the actions of other interest groups, representatives of the interest groups themselves say that they did nothing to mobilize public opinion in the 1999 session. They also did not contact their membership, as additional support was not needed. This means that the only function that interest groups in Texas performed in the adoption of MFP was formally endorsing the final bill. While these groups also spent two years in negotiations to make this endorsement, the most integral function they offered was their approval. Their disapproval ended in a veto in 1997, yet TADA could likely not have passed in 1999 without their consent according to all respondents, both pro-patient and pro-provider. The main, vital function of an interest group in bill adoption: formal endorsement, was present in Texas.

#### A Symbiotic Relationship

I have established that both policy entrepreneurs and interest groups were intimately involved in the passage of the third-party law in Texas- what functions were performed and which functions were universally ignored. Texas was able to pass MFP without mobilizing public opinion. The influence imbued upon pro-patient (right-to-life) organizations by the governor made these interest groups the arbiter of what policies would become law, as the coalition consisting of over 30 interest groups in agreement could not overcome the opposition of one set of values. Although the legislature passed the bill in 1997, the veto based solely upon right-to-life values espoused by one state level interest group demonstrated the power of pro-patient values in Texas.

Although the policy entrepreneur performed all three critical functions unique to a policy entrepreneur and a consensus was ultimately achieved which led to MFP adoption- the consensus

and success cannot be solely attributed to the policy entrepreneur. Case studies on ADL credited the policy entrepreneur for building the consensus necessary for policy adoption, yet there were complicating factors in Texas that coerced consensus (Glick, 1992a). These factors that forced compromises had nothing to do with policy entrepreneur activities. The policy entrepreneur may have been needed to take advantage of these factors, yet the policy entrepreneur could not create the factors.

The first complicating factor was that the status quo was unacceptable to both pro-patient and pro-provider interests. Neither party would “win” if no law was passed. Pro-patient groups would continue to fear the use of institutional policies like the Houston Protocol that denied care, and pro-provider groups would continue to fear legal prosecution from employing these policies or be forced to provide care they deemed unethical. An outright refusal to compromise would not have benefitted either party. This was a non-zero-sum game, and the gains for each party would exceed each party’s losses if a compromise was achieved, whereas with no compromise, both parties would gain nothing.

The second complicating factor, and arguably the most influential was the edict from the governor to create a policy that all interests could support. The Texas Legislature meets bi-annually, and two years of negotiations only came to an end because the next legislative session was commencing. Without this deadline, negotiations could have endured without any resolution. However, since the Governor George W. Bush had tasked pro-patient and pro-provider groups to return with a reconciled bill, interest groups representatives stated that they believed that they could not defy this order. Pro-patient groups recognized the substantial risk that the governor had taken in affronting powerful pro-provider lobbyists, and would make compromises they otherwise might not have simply to shield their ally from further controversy.

For pro-provider groups, Bush's instruction to create a compromise meant that he had intentions to support and sign whatever they mutually-agreed upon and put before him, an opportunity they did not want to miss.

Both of these external factors were critical in the adoption of TADA, as even the most skilled policy entrepreneur would have likely failed to achieve consensus without the exertion of these external circumstances. The policy entrepreneur in Texas was highly-skilled, experienced and successful as a policy advocate- responsible for the Out of Hospital DNR Act among other victories. In 1997, the policy entrepreneur managed to create a policy solution, build a coalition of very powerful interest groups, find common ground among dozens of organizations, and obtain legislator support, and ultimately passed the bill. Yet, if not for complicating environmental factors, even this legislative professional might not have been able to neutralize pro-patient opposition and obtain the governor's signature.

While the functions the policy entrepreneur performed cannot, in themselves be attributed to achieving consensus apart from the external environment, these functions likely played a necessary role in policy adoption. Simply put: the respondents states that without the policy entrepreneur, there would be no policy. First, the policy entrepreneur innovated the proposal, got it on the agenda- and after it failed, the policy entrepreneur continued for two years to facilitate regular, sometimes monthly meetings to create the final compromises that resulted in an acceptable bill. The policy entrepreneur still played a critical role according to respondents, but this case reinforces the policy entrepreneur as a necessary condition for MFP adoption, but not a sufficient condition that can affect change by itself. However, the comparative case study is needed to verify the absence of a policy entrepreneur in Idaho before  $H_1$  can be supported.

This case also reinforces that interest groups are a necessary condition, but not sufficiently capable of passing MFP alone. Interest groups did not perform the critical functions that policy entrepreneur performed, functions that respondents credit for passing the bill. Interest group interaction and influence with legislators was limited, while the policy entrepreneur was intimately involved with senators and representatives that authored and sponsored the legislation. Interest groups did not even need to solicit support from their membership. The theory that interest groups and a policy entrepreneur are co-dependent is reinforced by this Texas case, even if the theory that a policy entrepreneur can easily achieve consensus by performing certain functions appears inadequate in light of complicating circumstances. Again, the comparative case study is needed to verify the role of interest groups in Idaho before H<sub>2</sub> can be affirmed or rejected.

While the MFP process in Texas conforms to the tenets of my theoretical framework, this case is not examined in isolation, but in contrast to another case. By employing the same research design in Idaho where third-party MFP failed, I can determine what functions in both cases contributed to their respective outcomes.

### An Impossible Impasse: The Case of Idaho

Like Texas, Idaho was also among the first wave of adopters of ADL, enacting the Idaho Natural Death Act on March 1, 1977 (Jacobs & Martyn, 1984). This law has gone through numerous revisions since its early adoption, including a revision in 1986 that mobilized both pro-provider and pro-patient advocates to attempt to emulate third-party MFP. Like the policy gap in Texas that did not afford patients the right-to-die outside of hospitals, disability rights advocates

were inhibited by Idaho laws that limited the rights of parents to refuse treatment for their disabled children.

The change in Idaho law in 1986 was a consequence of federal action to protect children with disabilities, passed in 1984. Akin to the Cruzan and Quinlan cases, cases where infants with disabilities were denied life-saving treatment caught the attention of the nation, the President, the U.S. Surgeon General and finally, Congress. On April 9, 1982, “Baby Doe” was born in Bloomington, Indiana with trisomy 21 (otherwise known as Down syndrome) and a tracheoesophageal fistula and esophageal atresia, a common congenital abnormality where the esophagus does not connect to the stomach and allow the infant to eat normally (L. M. Kopelman, 2005). While this would have been easily correctable with surgery, the child’s parents refused treatment, including intravenous feeding, on the grounds that their son would still have Down syndrome, making him developmentally disabled (Lang, 1985). The doctor who advised the parents put it this way: “I believe there are things that are worse than having [such] a child die. And one of them is that it might live,” reinforcing that the decision was more of an assault of persons with disabilities and less of a medical judgment (Lyon, 1985). The case raced through the county and state supreme courts, both of which sided with the parents. It was appealed to the U.S. Supreme Court, but the infant died six days after birth on April 15, 1982 (Lang, 1985).

A year later on October 11, 1983, Baby Jane Doe was born in Stony Brook, New York with several congenital defects including spina bifida, for which her parents decided to forego surgery to close the opening at the base of her spine (L. M. Kopelman, 2005). They were advised that Jane (now known as Keri-Lynn) had a malformed brain and would never interact with her environment or form interpersonal relationships, and even with surgery, would likely never live

past 20 years old (Talan, 2003). The Reagan Administration's Department of Justice (DOJ) and Surgeon General C. Everett Koop intervened on the grounds that Keri-Lynn's civil rights as a disabled person (under section 504 of the Rehabilitation Act of 1973) were being violated (L. M. Kopelman, 2005). While a lengthy battle ensues, Keri-Lynn's parents consented to some surgeries as comfort care and the opening at the base of her spine healed on its own. Keri-Lynn defied prognoses (at last update in 2003, Keri-Lynn was a happy, talkative 20-year-old, although developmentally-delayed and in need of a wheelchair) (Talan, 2003).

The Baby Jane Doe case thrust the Reagan Administration's DOJ and Surgeon General C. Everett Koop into a nationwide battle on behalf of children with disabilities, continuing attempts to apply the Rehabilitation Act to Keri-Lynn's case and cases nationwide (L. M. Kopelman, 2005). The Reagan Administration ultimately opted to lobby Congress to amend the Child Abuse Prevention and Treatment Act (CAPTA), an amendment that defined the refusal of life-saving medical treatment, food and fluids as child abuse. It would deny federal funding for child abuse programs if states did not enforce these laws (L. M. Kopelman, 2005).

Idaho, like many states, amended their statutes to satisfy this requirement and maintain eligibility for federal funding (Stanger, Gustavson, & Hamilton, 2008). The protections afforded to children with disabilities were supported by disability-rights advocates and right-to-life groups alike, yet there were wide-reaching, unintended consequences that extended to adults with developmental disabilities who were not legally allowed to effectuate their own advance directives. The disability rights community was fearful of discrimination (medical care being denied on the basis of disability) yet they also felt discriminated against in being denied the autonomy to make their own medical decisions. The law inhibited them, and was designed to inhibit their guardians.

Likewise, Idaho law demanded a diagnosis of “imminent” death before care could be removed. Since there was no assurance of what was imminent, the disability rights community believed that people with developmental disabilities were languishing unnecessarily by being forced to submit to LSMT. Both pro-patient and pro-provider representatives state that these standards for removing care from an individual with a developmental disability were prolonging the suffering of the very people the law was created to protect, saying, “These people were being forced to essentially undergo torture.”

In 2005, pro-provider groups approached disability rights organizations to draft new legislation to address this problem. Disability rights organizations joined an existing coalition of providers that researched and advocated for better end-of-life care. A coalition, a kin to the one in Texas, formed with provider representatives as well as disability-rights and other patient advocacy groups, all of whom convened to seek a solution. Literature suggested HEC involvement as a way to assure that parent objections were legitimate, and not merely attempts to terminate their child due to a disability (Carter, 1993; Shapiro & Barthel, 1986). This solution appealed to disability rights organizations and legal counsel for healthcare providers alike. Pro-provider groups believed the use of a HEC not only addressed needs of patients with disabilities, but would also serve to litigate other issues of medical futility and offer legal immunity to providers. The bill also allowed a 14-day treatment ‘til transfer period (TTT) to give patients an additional opportunity to have their wishes honored.

Four years of discussion led to Senate Bill (S)1114, proposed on February 16, 2009 (Lodge, 2009). S1114 was drafted by a leader in the coalition, an attorney for pro-provider interest groups with the full support of coalition members. While disability rights organizations wanted HEC reviews to be mandatory, the bill listed the HEC as a voluntary option. It did



specify equal treatment for patients with developmental disabilities, but without the assured, added HEC committee protection that disability rights groups were seeking. Still, these groups found the new bill to still be preferable to the status quo. The proposal had no opposition and was treated as an uncontested bill. It passed the Senate unanimously, 34-0, with one member absent (Lodge, 2009).

Immediately following the vote, right-to-life bioethicists became aware of the S1114 (Smith, 2009). Coalition members hypothesize that the word “futile” triggered internet news alerts. One anti-euthanasia leader alerted a blogger with significant readership, who publicized criticisms of S1114 on his blog, after having contacted state and national right-to-life organizations (Smith, 2009). These groups immediately launched a grassroots campaign which, according to some respondents, got downright hostile. Right-to-life advocates sent scathing emails to the Senate sponsor, Sharon Block for allowing a bill to pass that would “promote killing patients and euthanasia,” some of which condemned her to hell for her participating in S1114.

There was such discord, Patti Anne Lodge, chairperson of the House committee refused to allow a hearing until the dissenting voices came to an amicable solution. While Lodge was on record as a right-to-life advocate, her reasons for refusing to continue were less ideological and more pragmatic: to avoid an ugly and contentious battle. Perhaps for different reasons than those which compelled the governor of Texas, Lodge directed the two parties to reconcile their concerns and return with an agreement.

Like Texas, Idaho state right-to-life organizations also invited national representatives to help negotiate a compromise. The groups agreed that amendments were needed regarding the rights of patients with developmental disabilities, but would not agree to support any bill

allowing the removal of care without patient consent. Right-to-life organizations were willing to make those changes, but still could not support anything less than unlimited TTT, or a 100% pro-patient bill. These organizations had learned from Texas that HECs and time-limited TTT that a third-party policy did not provide the outcomes they wanted for patients. The “rare and difficult circumstances” TADA was designed to address were hardly rare, or unusual. Rather, patients were being denied on-going treatments like kidney dialysis. Providers were invoking the ten-day period on a Friday and not providing medical records until the following week, leaving only a few days to find a transfer. Pro-patient negotiators also admitted that in 1999, they were not yet aware of how challenging it was to find a transfer for patients that other facilities had “written off.” While TADA was the best efforts of right-to-life negotiators in the early days of medical futility legislation, hindsight indicated that the TADA did not function as expected, and all the unintended consequences also had a public relations backlash against those that represented right-to-life values, especially George W. Bush (Graham, 2005; Hollinger, 2006; Landsburg, 2006). Right-to-life groups were not eager to indulge any experiments that could potentially backfire, and took the hardline 100% pro-patient approach (which they call “solid, black-letter law”) as the only acceptable alternative to ambiguous ADL. Furthermore, experiences in 100% pro-patient states found that direct prohibition of a provider withholding wanted LSMT compelled providers to find transfers, rather than simply wait out the clock. Right-to-life organizations desired 100% pro-patient LSMT not because of ideals, but because they deemed this approach to be the only one to help patients- and therefore, the only approach aligned with their values.

Disability rights organizations at the negotiation table were also contacted by other disability rights organizations in Texas, all of which discouraged the use of HECs in state law.

These organizations shared their experiences with TADA, and recounted cases where HECs denied LSMT on the basis of a disability, something the Idaho group was trying to assure would not happen. Therefore, not only was S1114 not successful in forwarding the disability rights' cause, there was new reason to believe that it could be harmful.

Disability rights organizations negotiated several aspects of the HEC to serve as a safeguard, but since the HEC was amended to be optional, those safeguards would not always apply. While the group remained optimistic about the bill in spite of new concerns, they felt ultimately defeated, saying, "We really only succeeded in getting them [the coalition] not to do some things that we really hated." The groups concluded that there was nothing to support, but after four years of negotiation, they had no intention to oppose the bill either and become adversarial with pro-provider interest groups. The organization chose instead to withdraw their support and assume a neutral stance.

Coalition representatives were willing to make several changes to neutralize right-to-life opposition, but there was no amending S1114 to appease these organizations that would not result in negating the bill completely for pro-provider groups. Everyone present at the negotiation table agreed that no bill would be able to pass without right-to-life group consent, but there was no common ground. Right-to-life organizations held firm to their demand of unlimited TTT and the coalition continued to refuse this proposal, therefore right-to-life groups remained officially opposed. Since no changes were acceptable to either party, the bill was hopelessly deadlocked, and died in the House without a vote.

### Policy Entrepreneurship and MFP in Idaho

The statement of purpose for S1114 offered an initial contact for interviews, through

which other respondents were found. The Idaho Legislature was in recess during data collection, however, like Texas, later interviews determined that these actors were not involved in negotiations. A majority of those present at the negotiation table were able to be interviewed, with the exception of one, who had left Idaho for a national advocacy position and, in spite of phone calls and emails to Washington D.C., was unable to be reached for an interview. There were a total of four interviews, with two representing pro-provider interests, and two representing pro-patient interests. The four respondents are = listed a ID Pro-Patient 1, ID Pro-Patient 2, ID Pro-Provider 1, and ID Pro-Provider 2 in tables that will connect responses to interest group and policy entrepreneur functions.

Table 9

*Policy Entrepreneurship in Idaho*

	ID Pro-Patient 1	ID Pro-Patient 2	ID Pro-Provider 1	ID Pro-Provider 2	Agreement
Advocating new ideas and developing proposals*	1	0	1	1	75%
Defining and reframing problems	0	1	1	1	75%
Specifying policy alternatives	1	1	1	1	100%
Brokering the ideas among the many policy actors*	1	1	1	1	100%
Mobilizing public opinion	0	0	0	0	100%
Helping set the decision-making agenda*	1	1	1	1	100%
Influencing Legislators	0	0	1	1	50%

\*Key Function

Unlike the analysis of the Texas case, the two pro-patient organizations do not represent the same values. Rather, their values reflect the organization they represent. One organization, ID Pro-Patient 1 is a state right-to-life interest group while ID Pro-Patient 2 represents a disability rights organization. The interests and values of these two groups, while pro-patient, are still very different. In contrast, the two respondents that represented pro-provider values had

unified, similar interests in spite of different organizational affiliations. This, in part, explains why pro-provider responses were identical and pro-patient responses vary.

Across four organizations and four respondents, there was 75% agreement on the first key function for a policy entrepreneur: advocating new ideas and developing proposals. These three respondents were involved in the development of S1114 over four years, the other part of the explanation on why answers on these items differ. The three coalition members verified that the policy entrepreneur was responsible for both advocating the idea of a bill to address disability right issues and medical futility disputes as well as developing the proposal. Again, the final respondent was not a member of the coalition, instead becoming involved after S1114 had already been set on the legislative agenda and therefore could not speak to the genesis of the proposal.

Like in Texas, the policy entrepreneur that convened a coalition and drafted S1114 was an attorney for pro-provider organizations and also had years of experience in advocating for pro-provider interest groups to the state legislature. The policy entrepreneur drafted the bill not just at the direction of the pro-provider clients, but had a personal interest in policy change. Having served on HECs in Idaho, the policy entrepreneur believed the standards imposed open patients with developmental disabilities were mandating care that the policy entrepreneur deemed “unethical, if not inhumane.”

The policy entrepreneur tried to identify stakeholders and built a coalition to support efforts for reform, brokering the ideas among policy actors. All four respondents verified the role the policy entrepreneur had in communicating the goals of a policy change to stakeholders as well as legislators. The policy entrepreneur also had to find sympathetic legislators and otherwise

convince policy actors of the need and merit of changing Idaho law and had to also reconcile the concerns of coalition members over the four-year preparation period.

The third key function, helping set the decision-making agenda had 100% agreement. All respondents credit the policy entrepreneur for getting the bill on the agenda and facilitating coalition meetings as well as negotiations with state and nationwide right-to-life organizations. The policy entrepreneur in Idaho performed all three key functions of a policy entrepreneur and like in Texas, was beset with value-differences that manifested in the responses.

For example, there was only 75% agreement regarding whether or not the policy entrepreneur participated in defining and reframing problems. While both pro-provider respondents counted medical futility disputes as a problem S1114 would address, they also equally acknowledged the disability rights component. Pro-provider respondents and ID Pro-Patient 1 report that the policy entrepreneur sought common ground by pointing out the mutual concern all parties had for people with developmental disabilities. While state and nationwide right-to-life organizations agreed, this problem was not the problem they wanted address. These groups were more than willing to address this problem, but not at the expense of patient autonomy and human life. Attempts to define the problem solely as a disability rights issue rather than a medical futility issue did not sway right-to-life organizations who defined the problem much differently.

The 50% agreement on influencing legislators was between pro-provider respondents only. Pro-patient respondents did not refute that the policy entrepreneur, but since the question was not asked directly, the measure relies on what the respondents freely mention in response to the same set of scripted questions, and pro-patient groups did not indicate the actions of the policy entrepreneur on these items. This does not mean that the policy entrepreneur did not

influence legislators as the other two respondents stated, only that there is not enough evidence to empirically verify this action. There was, however, 100% agreement across all respondents that the policy entrepreneur made no efforts to mobilize public opinion, just like in the case of Texas.

### Interest Group Activities and MFP in Idaho

Like Texas, many interest groups were represented in the Idaho policy process, Table 10 indicates the activities performed by these groups.

Table 10

#### *Idaho Interest Group Functions in 2009*

	ID Pro-Patient 1	ID Pro-Patient 2	ID Pro-Provider 1	ID Pro-Provider 2	Agreement
Officially Endorsing the Policy*	0	0	1	1	50%
Defining and reframing problems	0	1	1	1	75%
Specifying policy alternatives	1	0	1	1	75%
Mobilizing public opinion	1	0	0	0	25%
Influencing Legislators	1	0	1	1	75%
Advertising in Favor of Policy to Group Membership	0	0	0	0	100%

\*Key Functions

Idaho was unlike Texas, which had homogeneity across responses regarding interest group functions. The first clear disparity is the primary key function of an interest group: the official endorsement of the policy. The state right-to-life group (and their national counterpart that the respondent represented) remained official opposed to S1114. Likewise, the other pro-patient interest group, a disability rights organization withdrew their official support after amendments to the bill rendered it of limited use to their cause. While both pro-provider groups including the coalition continued to officially endorse the bill, it lacked the political capital to

continue through the legislative process. While not an official question on the interview script, all four respondents attribute the failure of the policy to the sole opposition of right-to-life organizations, including the right-to-life organizations themselves.

Just as the policy entrepreneur tried to define and reframe problems, right-to-life organizations were still displeased with the compromises pro-provider groups offered to address their concerns. Both pro-provider groups and the right-to-life organizations offered policy alternatives, but none were acceptable to the opposing party. Unlike Texas, one interest group, the state right-to-life organizations did attempt to mobilize public opinion, but in *opposition* to the policy. Additionally, all respondents except the disability rights organization attempted to influence legislators, with the final organization forbidden from direct advocacy due to the receipt of government funds. Finally, no organizations alerted their membership to lobby on behalf of bill, although right-to-life organizations did alert their membership to contact legislators and declare their opposition to S1114.

### An Adversarial Relationship

While the policy entrepreneur and interest groups in Texas had a symbiotic relationship, the relationship between the policy entrepreneur and interest groups in Idaho was adversarial. While the policy entrepreneur was attempting to pass a law, the status quo for both sets of values was preferable to the implications of a pro-patient or pro-provider victory. If pro-provider forces acquiesced to pro-patient values and enacted an unlimited TTT policy, not only would this have not solved the concern for the developmentally disabled, but it would have exacerbated it. Pro-patient groups were willing to address this problem in pro-provider groups would agree to unlimited TTT, yet a 100% pro-provider policy would have still caused additional problems for



providers seeking freedom from providing care they deemed to be unethical or immoral. Neither position had the support necessary to pass a proposal of their own, which was why the groups had to negotiate. Yet, the scenario was Pareto optimal- if pro-provider interest won, pro-patient interests suffered and vice-versa. Each interest stood to lose more than they could gain by compromising which why negotiations ceased and the bill failed.

This again points to the influence of complicating factors in MFP adoption. Texas had external circumstances that pressured both sides to compromise. Idaho had no such pressures. While the plight of the developmentally disabled likely cajoled both parties to try and find common ground, this circumstance was not deemed dire enough by either right-to-life or pro-provider groups to merit a compromise that assaulted either group's core values.

This case also highlighted the role of policy-oriented learning, a major facet of the Advocacy Coalition Framework (Sabatier & Weible, Christopher, 2007) which examines the role of interest groups in affecting policy change over a period of ten years or more. Policy-oriented learning suggests that policy changes come as a consequence of more, or better information regarding the policy revealed over time. The nationwide right-to-life representative that negotiated for third-party policy in Texas, 1999 firmly rejected Idaho's attempt to replicate this law ten years later because a decade of experience provided more and better information about how third-party policies affect patients. Experience indicated that HEC involvement did not offer patients the protections the right-to-life group had hoped. The organization also did not realize the difficulty in procuring a transfer for a patient following a HEC decision, and the hostility and lack of cooperation from hospital personnel in transferring a patient after the HEC has declared that care be withdrawn. Ten days had never proven to be long enough in Texas, and the 14-day period in Idaho was also expected to be insufficient. Furthermore, the process was

applied in cases that the right-to-life, pro-patient negotiators in Texas were assured that it would never be used, and was invoked far more often than what pro-provider groups predicted.

Policy-oriented learning regarding TADA, but also the success of pro-patient laws in other states had indicated to pro-patient groups what MFP option corresponded to their values, and third-party policies were no longer viewed as congruent with their values. Had this information been available in Texas a decade earlier, right-to-life organizations may very well have defied external pressures and refused any bill, monitoring the Houston protocol situation and hoping for a window of opportunity to enact a 100% pro-patient policy. If right-to-life groups did not have any information, they might have conceded to pro-provider groups, believing as they had in Texas, that MFP with a time-period to find a transfer was preferable to ADL.

### The Role of Policy Entrepreneurs Across States

Texas and Idaho proposed similar policies and involved similar policy actors. Both states had a policy entrepreneur as well as interest group involvement. The next step compared functions of these actors across both states to see what varied, leading to an explanation of each state's respective outcome. This analysis tests  $H_1$ :

$H_1$ : A state that has a policy entrepreneur who performs all necessary functions as a policy entrepreneur will adopt any type of MFP, while states that have no policy entrepreneur, or a policy entrepreneur who fails at necessary policy entrepreneur functions will not succeed in adopting any type of MFP.

Texas and Idaho both had universal agreement of two of the three key functions of a policy entrepreneur: brokering ideas among many policy actors and helping set the decision-making agenda. The mild disparity on the third function, advocating new ideas and developing proposals was not disputed by a respondent in Idaho, the respondent was just introduced to the

policy process substantially later than the other three and did not speak to the development of the policy. Table 11 examines the role of the policy entrepreneur in both states.

Table 11

*Functions of Policy Entrepreneurs in Both Texas and Idaho*

	Agreement in Texas	Agreement in Idaho	Difference
Advocating new ideas and developing proposals*	100%	75%	25%
Defining and reframing problems	50%	75%	25%
Specifying policy alternatives	75%	100%	25%
Brokering the ideas among the many policy actors*	100%	100%	0%
Mobilizing public opinion	100%	100%	0%
Helping set the decision-making agenda*	100%	100%	0%
Influencing Legislators	50%	50%	0%

As for secondary functions, Texas and Idaho most differed regarding how the policy entrepreneur in each state defined or reframed problems. In Idaho, while two respondents represented pro-patient values, one of the pro-patient respondents was in agreement with pro-provider groups regarding the problem the policy was designed to address. Attempts by the policy entrepreneur to re-define and reframe the problem in order to concoct a solution acceptable to right-to-life organizations was not perceived as such by right-to-life groups. These groups represented two respondents in Texas, yet only one in Idaho, which accounts for the slight difference (25%). Since the policy entrepreneur in Texas fared worse on this function in Texas and yet the Texas law passed, that indicated this to be a less critical function for the policy entrepreneur. This also appeared to be so with specifying policy alternatives. One respondent in Texas did not state policy alternatives offered by the policy entrepreneur, yet the proposal passed in Texas and not Idaho, also casting doubt on the importance of this function.

*Overall, a comparison of policy entrepreneur functions across states demonstrates*

*similar activities by each policy entrepreneur, yet one state achieved consensus and MFP adoption and the other did not, therefore the evidence fails to support H<sub>1</sub>.* The expectation that the performance of key functions would lead to consensus failed to take into account the exogenous variables that exert tremendous pressure on policy actors. The policy entrepreneur in Idaho performed the same functions and has a similar degree of skill and experience, but could not win right-to-life group support because right-to-life groups had nothing to lose- no circumstances pressuring them into a compromise. Likewise, right-to-life groups were armed in Idaho with ten years of information they had not known a decade earlier. The lack of consensus did not appear to be a failure on the part of the policy entrepreneur in Idaho, but rather a consequence of more dimensions than my theoretical framework addressed.

### The Functions of Interest Groups Across States

There are far more differences in the functions performed by interest groups in Texas vs. Idaho. This analysis will test H<sub>2</sub>:

H<sub>2</sub>: A state that has an interest group formally endorsing a policy will adopt a policy, while states that do not have a formal endorsement of an interest group will not adopt MFP.

Table 12

#### *Interest Group Functions Across States*

	Agreement in Texas	Agreement in Idaho	Difference
Officially Endorsing the Policy*	100%	50%	50%
Defining and reframing problems	100%	75%	25%
Specifying policy alternatives	100%	75%	25%
Mobilizing public opinion	100%	25%	75%
Influencing Legislators	100%	75%	25%
Advertising in Favor of Policy to Group Membership*	100%	100%	0%

\*Key Functions

The disparities in interest group functions across states are substantial. The primary function theorized to affect policy adoption, official endorsement of the policy, shows a clear consensus in Texas and contested in Idaho. Respondents in Texas credit consensus for policy adoption while respondents in Idaho blame the bill failure on the lack of consensus. While my theory that the performance of critical policy entrepreneurs functions would result in consensus (and therefore MFP adoption) was incorrect, *the theory regarding the necessity for consensus in policies incongruent with state values is supported as well as the H<sub>2</sub> that says “a state that has interest groups that proposes a policy willing to concede aspects of the proposal to gain the support of an opposing interest group will be unable to adopt any type of MFP without the opposing group’s support.”* Texas pro-provider forces won the endorsement of both state and nationwide pro-patient groups and passed the legislature. These same groups remained opposed in Idaho and the legislation failed, as H<sub>2</sub> predicted.

The difference in interest group functions between a state that adopted MFP and a state that did not points to the significance of interest group involvement. While our theoretical framework attributes ultimate bill success and failure to consensus and interest group endorsement, other factors may also affect MFP adoption. For example, interest groups in Idaho found it more difficult to define and reframe problems in order to unify in a search for a mutually-agreeable solution, since the interest groups represented more than right-to-life concerns and provider concerns, having the third dimension of disability rights. One pro-patient interest group representing disability rights in Idaho also failed to provide alternative policy solutions, unlike interest groups in Texas. Furthermore, while no interests groups attempted to mobilize public opinion in favor of the Texas bill, the bill passed, while in Idaho, the right-to-life group’s decision to compel the public to voice their opposition to S1114 may have solidified pro-

provider group's opinion that right-to-life organizations had sufficient political clout to kill all hopes of MFP. And finally, the minor difference between Idaho and Texas with influencing legislators is that Idaho right-to-life groups influencing legislators to reject rather than adopt MFP, while Texas right-to-life groups testified in favor of MFP after it was successfully amended.

Interest group functions are what vary most across the two states and the most likely explanation for MFP adoption. This is not surprising, given that the Advocacy Coalition Framework (ACF) has been employed over 100 times worldwide since its inception to specifically examine the role of interest groups in creating policy change (University of Colorado-Denver, 2010). It aptly applies to this analysis, but was rejected as a framework for this study because it fails to address the role of policy entrepreneurs, a significant variable in other policy adoption research and an intimately involved actor in MFP innovation in Texas and the 2009 attempt in Idaho (Glick, 1992a; Mintrom, 1997; Mintrom & Norman, 2009).

The analysis did not suggest that policy entrepreneurs were not significant variables in MFP adoption, only that exogenous variables can exude influence of the political environment that can be beyond the policy entrepreneur's control. Likewise, these exogenous variables can be beneficial for policy entrepreneurs as they were in Texas, coercing the powerful right-to-life group into negotiations which culminated in policy adoption. ACF accounts for these variables where my framework did not (Jenkins-Smith & Sabatier, 1994). The hypothesis about the necessary function of policy entrepreneurs was rejected, yet the greater narrative suggests that these players still may serve many critical functions. Therefore it is possible to expand the framework to include the greater political environment, while still asserting the role of the policy

entrepreneurs and the causal driver of values as critical to interest group actions and thus, policy adoption.

## Conclusion

The comparative case study of Texas and Idaho revealed the functions that both policy entrepreneurs and interest groups perform that may have led to MFP adoption, determining that a lack of consensus in Idaho is blamed for policy failure while consensus in Texas is heralded as the reason for success. This is aligned with my theoretical framework which suggests that policies incongruent with state values will fail, and the proposals must come into congruence in order to pass. The 1997 attempt at reform in Texas was incongruent with state values, therefore it was rejected and a policy was only passed that reflected the pro-patient values of the state's executive.

Likewise, pro-patient (exclusively right-to-life) organizations launched a grassroots campaign in Idaho that effectively killed four years of concerted efforts by many other interest groups. The policy that was proposed did not align with state values, as evidenced by the ability of right-to-life organizations to sabotage any bill that did not completely protect patient autonomy.

While the analysis corresponds with my theoretical framework, only one of two related hypotheses was supported.  $H_2$  that posits the role of interest groups and the necessity of consensus was supported. However-  $H_1$  was patently rejected, pointing out glaring oversimplifications and gaps in my already broad approach to examining MFP. The theory that a policy entrepreneur performing key functions of a policy entrepreneur would result in consensus between opposed interest groups failed to account for other confounding variables. An

examination of the functions of policy entrepreneurs revealed that not only is my assumption false, but an examination of the greater policy environment uncovered complicating factors that could either promote or inhibit chances of obtaining a consensus. Other frameworks (the Advocacy Coalition Framework, for example) factor in the exogenous variables, but ACF was not employed for this analysis because it does not properly account for the significance of a policy entrepreneur. Since policy entrepreneurs could be an integral aspect of MFP adoption, my theoretical framework that incorporates this variable simply needs to be modified to address the gaps the case studies revealed.



## CHAPTER 5

### THE ROLE OF VALUES ON MEDICAL FUTILITY POLICY TYPE

#### Introduction

Cases studies on MFP reinforce the role of values on policy adoption. Interest groups espousing one set of values were not capable of passing a policy without the approval of interest groups representing a contrary set of values. Right-to-life forces in Texas were able to wield enough influence to get the amendments needed for the law to be acceptable, and right-to-life forces in Idaho, who found no amendments acceptable and demanded a 100% pro-patient policy, also had enough influence to ensure that nothing less would become Idaho law. It can be assumed that if either right-to-life group did not have influence with elected officials who favored their values, that both states would have very different policies.

Many factors converge to create a political environment, and that political environment can either be hospitable to an ideology or hostile to it. In Texas, that environment was hospitable enough toward right-to-life values for an interest group to at least achieve certain amendments that made the policy acceptable to them. In Idaho, the environment was hospitable enough that right-to-life groups could demand a policy even more in line with their values, knowing that without their support, the unacceptable policy would never pass.

Case studies provide a detailed look on these values in those two states, but there is still the need to assess the values in the other 16 states who have adopted radically different types of MFP. My theoretical framework suggests that the values of the state dictate the type of law that can pass, and the different types of laws reassert different values. Therefore there is a need to examine indicators that would compel a state to adopt both pro-patient and pro-provider MFP. Unlike morality policy diffusion studies that examine values against the adoption of one policy

type, this study examines factors unrelated to values as control variables which may make the state more apt for the adoption of any type of MFP, as well as address the theory that values dictate what MFP is successfully adopted.

In order to set up a proper research design, I will explain how policy scholars typically examine the roles of values in policy adoption, both in morality policy and state diffusion research in general. Then, considering the differences in methodology that MFP theory presents, I will craft variables and research methods to best address my hypotheses while also addressing confounding explanations for why states adopt the MFP at all.

### Previous Efforts to Examine the Role of Values in Policy Adoption

Chapter 3 details studies on policy diffusion, particularly morality policy studies that attempted to determine the role of values on policy adoption. Scholars typically use public opinion as a measure for state values on a given topic, employing surrogate measures if this data is not available (Mintrom, 1997; Mooney & Lee, 1995, 2000; Norrander & Wilcox, 1999). In fact, this data is typically not available, because national polls lack the sample size for generalization to states, leading some scholars to pool and disaggregate national polls in an attempt to gain data and other scholars to employ surrogates measures for public opinion (Erikson, Wright, & McIver, 1994; Mooney & Lee, 1995, 1999). Mooney explained the absence of public opinion data on abortion during the time frame for his study, and used the number of women in the workforce as a surrogate measure of public opinion on abortion, as well as religious demographics (2000).

Since public opinion at a state level is very hard to estimate, election results are also used to indicate a majority of the public's ideology (Berry et al., 2010). Measures of partisanship and

party control are often employed to indicate how the citizens “feel” on a given morality policy topic, like citizens who elect a Democratic majority as a sign that they either support the adoption of legal abortion or policy opposing capital punishment (Mooney & Lee, 1995, 2000).

Measures of partisanship, or scores gauging the control that each party has in the legislature are good indicators of how a state may vote on issues that clearly have party-lines, like abortion and capital punishment (Klarner, 2003; Mooney & Lee, 1995, 2000). For other policies, like MFP, scholars have created measures of ideology that are either not based upon election results or regard partisanship as only one factor among others when creating an index to qualify a state’s ideology (Berry et al., 2010). One technique of gauging ideological liberalism is not to assume ideological liberalism based upon a calculation of party strength (and likewise assume that all legislators vote down party lines), but to instead look at how the legislators voted on specific topics. This approach of using “roll call votes” of legislators compiled by self-proclaimed conservative and liberal interest groups is a commonly used assessment of government ideological liberalism (Berry et al., 2010). This was created as a compliment to election-based assessments of citizen liberalism by the same scholars, and not surprisingly, these measures are highly correlated and have survived vetting by policy researchers for over a decade (Berry et al., 2010).

After morality policy scholars determine what indicators they will use to operationalize values, (values that would support or oppose a particular policy), the next step is often to employ indicators rife in innovation and diffusion research as control variables (Glick & Hays, 1991; Hays, 1996; Hays & Glick, 1997; Mooney & Lee, 1995, 2000). These include demographic measures like urbanization and wealth can indicate the demand for a policy, either more people in densely populated areas that require regulatory policies, and wealth as an

indicator of need for distributive policies (Hays, 1996; Mooney & Lee, 1999). In morality policy study, these are often insignificant (as expected), since demand for policies is attributed to values (Glick & Hays, 1991; Mooney & Lee, 1995, 1999).

Other typical measures include scores of general innovativeness, to determine if states are simply more apt to adopt a policy apart from the role of values (Hays, 1996). By looking at how often states have adopted other policies, scholars claim they can predict the likelihood of a state to adopt the policy in question (Glick & Hays, 1991; Mooney & Lee, 1995, 1999). Scholars also look at legislative professionalism- the resources afforded to legislators in each state like staff, salary and time, which grant states with more professional legislatures an advantage in policy innovation (Hays, 1996; Squire, 2007). Another potential advantage is political competition, a measure of power between political parties, which scholars suggest that legislatures with a clear majority are more likely to innovate than legislatures that are divided (Karch, 2007; Meier, 1994). Still others look at the competition not between parties in the legislature, but between candidates, suggesting that legislators who are secure in their offices and do not fear being unseated are not as likely to innovate laws as legislators who are campaigning for reelection (Holbrook & Van Dunk, 1993).

These traditional measures for studying policy innovation provide solid footing for this analysis on MFP adoption. In the absence of previous research on MFP on which to base this study, it is critical to employ the tried and tested measures and methods of policy scholars wherever possible. While this study lacks the benefits of public opinion data or previous research demonstrating an effective indicator of values on end-of-life issues, the progress on gauging ideology provides an excellent, normed measure to assess the theory that pro-patient policies are favored by conservatives (Berry et al., 2010). Likewise, the “usual suspects” in policy studies

should also be tested, not because of any expected relationship, but merely as control variables and additional information on a topic that has had no previous empirical inquiry. I will add new measures specifically crafted to address the values in MFP adoption, the crux of my theory.

### Indicators of State Values and Policy Type

Specifically questioning the role of values and MFP policy type involves revisiting my four hypotheses and explaining the indicators chosen to test each hypothesis. The first hypothesis relates to ideological liberalism:

H<sub>3</sub>: States with citizens that espouse a dominantly conservative ideology will most often adopt pro-patient MFP over pro-provider MFP

This contrasts the type of MFP of each state against a score of government ideology, a measure constructed not by mere political affiliation, but actual votes on legislation as graded by state interest groups. Interest groups indicate whether or not a legislator is aligned with conservative or liberal values, and this index assigns higher values with higher degrees of ideological liberalism on a scale of 0-100 (Berry et al., 2010). These scores have a normal distribution (skewness = .006) and a range from 5.67 to 94.50. Like other interval level measures, these scores were averaged ( $\bar{X} = 46.74$ ) entered according to the year of MFP adoption, and then coded as 0 = Conservative ( $\leq \bar{X} = 46.74$ ) and 1 = Liberal ( $\geq \bar{X} = 46.74$ ). Unfortunately, the latest year for this measure is 2004, and two states adopted MFP in 2005 (North Dakota) and 2006 (New Hampshire). While the absence of data across all years of MFP adoption was grounds for dismissing other measures, the tested validity and reliability of this measure still compelled its use. Moreover, the fact that it examines ideology apart from party affiliation eliminates the additional uncertainty with linking values in MFP to party affiliation, since there is no definitive

link between political party and pro-patient or pro-provider values. Rather it looks at ideology directly and grants insight into how ideological liberalism translates into MFP adoption (Berry et al., 2010). Therefore, for 2005 and 2006, the latest (2004) score is substituted, and all non-MFP states will be coded by the 2004 score as well. The breakdown is 28 states coded as Liberal and 22 states coded as Conservative.

The next hypothesis states:

H<sub>4</sub>: States with more laws reflecting the influence of right-to-life interest groups will adopt pro-patient MFP more often than they adopt pro-provider MFP.

In the absence of interest group reports that gauge the effectiveness of lobby efforts in each state, I assess the effectiveness/influence of right-to-life interest groups by controversial abortion restrictions, passed in the same time frame as MFP adoption (New, 2011). These laws, that mandate parental involvement, parental notification, informed consent, or waiting periods before having an abortion emerged in the exact same time frame as MFP, with virtually no states having informed consent statutes in 1992, but 33 states adopting by 2005 (New, 2011). Likewise, no states had waiting periods in 1992, but by 2005, 22 states had these laws (New, 2011). This corresponds with the first MFP being adopted in 1993, with 17 laws by 2006, and pro-patient MFP is likely supported by the same interest groups that lobbied for these abortion restrictions. Regardless, states that passed these laws in spite of heavy opposition are likely to have a stronger right-to-life lobby than state with no laws. This variable is coded as 0 = Inhospitable Right-to-Life Political Environment (states with  $\leq 1$  law) and 1 = Hospitable Right-to-Life Political Environment (states with  $\geq 2$  laws).

The next hypothesis examines values expected to promote pro-provider MFP:

H<sub>5</sub>: States that have above average ratios physicians to the general public (1:10000) will adopt pro-provider MFP more often than they adopt pro-patient MFP.

This variable is intended to estimate the influence of pro-provider lobbying efforts. The American Medical Association reports a ratio of physicians to 10,000 citizens in each state every year (American Medical Association, 2010). This takes into account only active members of the American Medical Association, those likely to join in supporting state medical associations in promoting a pro-provider policy (American Medical Association, 2010). These numbers are reported to the National Center for Health Statistics at the Centers for Disease Control (CDC), and are available in the CDC report “Health, United States” for each year (National Center for Health Statistics, 1995, 1996, 1997, 1998, 1999, 2000, 2001, 2002, 2003, 2004, 2005, 2006, 2007, 2008). This data are not a normal distribution (skewness = .924), so the median was calculated (median = 23.85) and coded into two equal groups, 0 = Fewer Physicians (< 23.85) and 1 = More Physicians (> 23.85)

The final variable is also intended to assess the influence of pro-provider interest groups:

H<sub>6</sub>: States that have above average ratios of hospital beds to the general public (1:1000) will adopt pro-provider MFP more often than pro-patient MFP.

This is intended to indicate the prevalence and size of hospitals, as hospital associations also lobby in favor of pro-provider policies (American Hospital Association, 2009). Rather than a number of hospitals by state, hospital beds take into account the size of the hospitals, as small community hospitals likely do not have the networking connections or funding of larger hospitals and health systems. This ratio of beds to every 1,000 citizens per state is reported yearly by the American Hospital Association to the Centers for Disease Control ((American Hospital Association, 2009). Like the ratio of physicians, this data is not normally distributed, (skewness = .924), and many states share the same value so the median (2.7) will be used instead of the mean (2.98). This is coded similarly to other variables to other variables: 0 = Fewer Hospital Beds ( $\leq 2.7$ ), 1 = More Hospital Beds ( $\geq 2.7$ ). The total is 24 states with Fewer

Hospital Beds and 26 states with More Hospital Beds. It is expected that states with more hospital beds have more lobby power or funding and that this result in these states adopting more pro-provider policies than pro-patient policies.

#### Control Variables: Characteristics of the State Apart from Values

My theoretical framework is based upon morality policy theory, stating that values are the driver of policy adoption, indicating not just whether or not a state adopts and MFP but the type of MFP a state adopts. The variables previously listed reflect those values but nonetheless there are other factors that may explain policy adoption and policy type apart from values, like characteristics of the state that might lend itself to innovation. For example, states that afford legislators more resources like staff, pay and session length have been found to innovate more policies than states without these resources (Squire, 2007). This is one factor that would be an alternative explanation for MFP adoption and must therefore, be controlled for in this study.

Morality policy scholars test these and other variables often used in non-morality policy research to enhance their research and further validate their theory (Hays, 1996; Mooney & Lee, 1995, 1999). Morality policy theory suggests that models of research and variables that are based upon regulatory and distributive policies are inapplicable to morality policy studies, since values drive policy change (Mooney, 1999). Using variables that predict the adoption of non-morality policies alongside of variables that indicate values increases the internal validity of morality policy studies, controlling for these other factors so that values can be isolated as the cause for policy adoption. Testing these variables that may affect policy adoption (but are not expected to) also enhances the external validity of morality policy theory: that values not typically accounted



for in other models are explained by morality policy theory, making the theory a good model for widespread use for morality policy studies.

Employing control variables is equally is not exceedingly important in this study, to isolate the role of values but lend credence to the differences between my theoretical framework and morality policy. The premise is the same, but morality policy studies look at how values affect whether or not a single morality policy type is adopted (Glick, 1992b; Glick & Hays, 1991; Hoefler, 1994; Mooney & Lee, 1995, 1999). The study of MFP is not as straight-forward as the values that would affect MFP adoption differ across MFP type: pro-patient or pro-provider. The theoretical framework I suggest accounts for this difference, but has not been vetted like morality policy theory, determining its merits and liabilities. Case studies offered in Chapter 4 suggests that the framework aptly applied as expected, but was too narrow in one aspect and needs modification to account for the greater political environment. Control variables used here account for some of these exogenous variables and alert to other aspects of the framework that could be modified before future research is conducted. At the very least, these control variables increase the interval validity of the study, allowing for greater confidence when interpreting the results of value-based indicators that the values indicated are indeed responsible for the variation in MFP type.

The first control variable is urbanization, one of policy studies “usual suspects” tested as a control in morality policy studies, only statistically significant in the case of capital punishment reform (Mintrom, 1997; Mooney & Lee, 1995, 2000). Since it was unexpectedly significant in one study, the potential exists that more or less urbanized states could be more apt to adopt any type of MFP. Perhaps the disparity of providers in more rural states means that those states have an interest in determining some resolution of any kind for medical futility disputes. Likewise,

maybe states with higher population density may have larger hospitals with more money and lobbying power, apt to adopt pro-provider MFP. While no relationship is expected, this variable merits testing to determine if it has any role in MFP adoption, as it has been correlated one other type of morality policy (Mooney & Lee, 1999). The measure of urbanization is the percentage of the population of each state living in a Standard Metropolitan Statistical Area (SMSA), reported by the U.S. Census Bureau and compiled by State Politics and Policy Quarterly for researcher use (Lindquist, 2007). The values were entered by state, according to the year each MFP was adopted (and 2004 for states with no MFP). The mean score was 70.29, with a range of 56.2 (94.4 to 38.2). All scores falling below the mean ( $n = 25$ ) are coded of 0 = less urban and all scores exceeding the mean ( $n = 25$ ) are coded as 1 = more urban.

The second control variable is legislative professionalism, or the resources a state affords its legislators that promote innovation, like higher salary and better benefits, greater demands on legislator time, staff and resources (Squire, 2007). Legislature professionalism has been a significant variable in other policy studies and associated with increased innovativeness, with scholars noting a bivariate correlation of .673 ( $p = .000$ ) between Walker's measure of innovativeness and Grumm's measure of legislative professionalism (Hays, 1996). In the absence of an innovativeness measure for my time period, this variable not only controls for the affect legislative professionalism may have on MFP adoption, but could potentially serve as an explanation for why some states are more likely to adopt any type of MFP than other states. States with higher scores have greater resources to devote to a contention policy battle, so it is possible that this variable could promote the adoption of MFP.

The Squire Index provides an updated version of Grumm's measure that fit the necessary timeframe (Squire, 2007). Since the scores are not evenly distributed (skewness = 1.446) and

many states have identical scores, the median was determined (median = .15) and the data coded as 0 = Less Professional ( $\leq .15$ ) and 1 = More Professional ( $\geq .15$ ) (Squire, 2007).

The third control variable looks at partisanship, or the control of the state legislature by one party or the other. This also controls for state innovativeness (the predisposition to adopt policies), since divided legislatures are less likely to innovate any type of policy (Klarner, 2003). Additionally, this measure allows for a look at what kind of legislators favor MFP adoption, as well as the type of MFP adopted. While medical futility dispute policy is not associated with a political platform, right-to-life groups are most likely to be favored by Republican legislators. Considering that states with pro-patient MFP slightly outnumber pro-provider policies, this could be a consequence of a Republican political environment. Since states who adopt MFP are more likely to adopt pro-patient MFP, the partisanship in legislatures could potentially relate to a greater likelihood of adoption across the board although this is unlikely due to the fact pro-patient MFP only outnumbers pro-provider MFP by two states. The chance also exists that majority Democratic legislatures are more apt to adopt MFP in spite of the fact that most MFP is pro-patient, and this would be further examined as a consequence of values. Since both pro-patient and pro-provider policies are relatively equal (7:9), any political affiliation is not expected to affect the adoption of MFP but only, perhaps the type of MFP lawmakers adopt.

Partisanship data was provided and coded by Klarner as 0 for Republican control, .5 for division and 1 for Democratic control (2003, 2012). This data was entered by the year of MFP adoption, or 2004 for states without MFP, totaling 33 Republican states and 16 Democratic states, with no measure for Nebraska and its non-partisan legislature. Again, this measure was not intended to reflect values, but only the how divided or united legislatures may affect MFP adoption. The could have been coded merely “divided legislature” or “united legislature” but this

would be missing an additional opportunity to see if there is any relationship at all between political parties and MFP type. If one political party is statistically more likely to adopt MFP that could affront my theory of the critical role of values and merit greater inquiry in the second part of this analysis where policies will be examined by MFP type.

The fourth control and final control variable examines political competition, which can inspire legislators to innovate policies to secure re-election when they feel their seat is at risk (Holbrook & Van Dunk, 1993). This variable also controls for aspects of the legislature apart from values that could affect MFP adoption. The measure looks at district-level state election results, to see the margin between the winning party and the losing party to aggregate a score for the each state over how secure, on average, legislators are about keeping their office (Holbrook & Van Dunk, 1993). This is not anticipated to affect the adoption of MFP, but could inspire states with legislators eager to earn votes to innovate a policy, although the policy type they innovate would be a consequence of values. This variable attempts control to aspects of the political environment independent of values but will also be examined by policy type, simply to see if there is a correlation. The scores are negatively skewed (skewness = -.407) so the median was calculated (median = 39.55) and scores below the median were coded as 0 = Less Competitive and scores above the median were coded as 1 = More Competitive. Data was not available for Louisiana due to reporting issues, but fortunately, Louisiana is not an MFP state. The total  $n = 49$ , with 24 states coded as Less Competitive and 25 states coded as more competitive.

Across all of the variables, both control and predictive, these measures were tested to determine if they had any relationship to each other. Since some variables are similar, like partisanship and government ideological liberalism, an initial test was conducted to ensure that

these variables measure different constructs. As expected, partisanship and government ideological liberalism had a very strong, positive statistically-significant relationship ( $p = .026^*$ , Cramer's  $V = .318$ ), in part because the government ideological liberalism measure takes party affiliation into account when creating the composite score. However, while these items are highly correlated, they still indicate different constructs. All the other variables, like hospitable right-to-life political environment (which could be related to ideology or political party) were tested against each other as well, and no other set of variables is correlated.

### Research Methods

For the first part of this analysis, examining MFP states ( $n = 17$ ) with non-MFP states ( $n = 33$ ), contingency tables were created for each variable. If a frequency of five is available in each column, a Pearson's chi-square was conducted, and Fisher's exact for smaller values. The strength of any statistically significant relationships was further examined by Cramer's  $V$ , and all values were reported by table.

The second part of the analysis continued similarly, only examining all variables across MFP policy type. Contingency tables were created to demonstrate how many states, by category, fall into the additional categories provided by each independent variable. Since one column, third-party policy, involves only one case, this case was dismissed as an outlier with the focus remaining on pro-patient and pro-provider states. All hypothesis related to third-party policy were examined (as well as MFP theory as a whole) through detailed case study, and all remaining hypotheses focus on pro-patient and pro-provider MFP outcomes. This leaves the potential for values in each column to exceed five, allowing for Pearson's chi-square and a subsequent Cramer's  $V$  on any statistically-significant variables. If values were still too small to

confidently apply chi-square, Fisher's values were reported. All values are reported by table as well.

### Limitations and Challenges with Methods and Instrumentation

Although all efforts were made to utilize the methods and measures vetted by scholars over the years, many aspects of this topic created challenges that limit the methods and measures that could be employed. Most scholars who study innovation and diffusion have the benefit of looking at the diffusion of one type of policy across time, comparing notable public events like court cases and the adoption of federal laws to the incidence of states adopting (Glick, 1992b; Glick & Hays, 1991, 1991; Hoefler, 1994). This analysis differs from all previous work not just because it addresses an entirely new topic to policy studies, but because it examines the adoption of a policy that can take three distinctive types, each expected to be affected by different values. The benefit of looking at one policy across time and space is replaced with looking at three different types of policies, adopted at different times and in different places.

For example, the state policy studies mentioned all have a nominal, dichotomous dependent variable (adopt or not adopt). However, my theory is that values (y) affect the type of MFP that a state adopts (x). While policy scholars could see if values (like religion) affected the diffusion of a single policy across states as dichotomous (adopt or not adopt), this study cannot. Rather, I have the question of "adopt or not adopt" split in three directions: pro-patient, pro-provider or third-party. While there are methods that address nominal dependent variable with three categories (multi-nominal logistic regression), one of the categories, third-party policies, has a sample size of 1. When dismissing that one state to focus on the bulk of MFP, it yields  $N = 9$  (pro-patient) and  $N = 7$  (pro-provider). Control variables examine all 50 states, where

additional analysis might be possible, but my primary theory and hypotheses address only subsets of 17 total states. While this is the whole of MFP policies and not a representative sample, it is still a small value not advisable for many kinds of statistical tests.

The most appropriate choices of methods with the dependent variable and sample size are independence tests via contingency table. Tables allow for the grouping of states by policy type and characteristics granting the opportunity to explore characteristics more closely, beyond just tests for statistical significance. Since contingency tables and independence tests require categorical data, variables were sought that best reflect the construct which were already nominal, meaning that a nominal measure was chosen if equally valid to interval-level measures. For example, one of the control variables is partisanship, or the political party controlling the state legislature the year MFP was passed. Klarner's index of partisanship was an aggregation of party control in both the state house and senate, and provides a scale of 0 to 1, with scores closer to 0 representing Democratic control and scores closer to 1 representing a higher degree of Republican control (2003). This index also offered an alternative measure that reduced partisanship to either a 0, .5, 1, for Democratic control, divided legislature or Republican control which Klarner has updated through 2011 and offered for academic use via website through the Indiana State University Political Science Department (2012). While this nominal measure is not as precise as its interval counterpart, it is still valid and able to be analyzed with the methods the dependent variable and sample size allow.

Some variables did not have a nominal counterpart, so this required changing interval-level data into nominal data. While a more precise measure would be finding the mean or median and dividing the data into quartiles- highest, high, neither high nor low, low, lowest- this again would segregate an already small sample into categories with so few states that no potential

relationship could be discerned (and also, further limit my already limited choices of statistical tests). Therefore, interval values were plotted by year of MFP adoption, tested for normal distribution, and scores that exceed the mean (or median in cases with significant outliers) were coded as 1, while scores falling below the mean coded as 0, as either demonstrating more or less of the construct it indicates. Again, while not as precise, it offered at least some starting point for further inquiry.

After issues with variable type and sample size, the third challenge was the unit of analysis and time frame. Finding data for all 17 MFP states across 13 years (1993-2006) eliminated several options. While some variables are relatively static, others are not, so it was critical to find data across all years of MFP adoption, especially since I am examining an already small sample. Some indicators had to be dismissed because critical years were missing, specifically several measures of innovativeness which were sought as a control variable. With only 17 states, there was not much latitude to accept missing values for certain states. Fortunately, there was latitude with critical control variables and non-MFP states, since the year is not relevant for states without MFP and the values from the most recent year could apply when held constant across all ADL states. Unfortunately, the indicators I sought that would best reflect some values were simply non-existent, forcing me to use other indicators that I would not have chosen if there were better options.

For example, when seeking measures that would reflect pro-patient values, public opinion polls for my time-frame and available at the state level were non-existent. Not only did none of the major polling firms like Harris and Gallup have data about patient rights, even surveys about abortion that may indicate sympathy toward right-to-life values were not large enough to disaggregate to states. There was one poll that questioned medical futility specifically,



but it had fewer than 1,000 respondents and could not be used at the state level (Robert Powell Center for Medical Ethics, 2011). Also, these polls would only indicate attitudes at one point in time, not specific to the dates that MFP was passed.

Without public opinion data, a variable heavily utilized in morality policy research, the next step was to gauge the likelihood of sympathy towards right-to-life interest groups and their pro-patient policy priorities by examining how successful right-to-life interest groups rate states with promoting right-to-life values. The measure first sought was a ranking by Americans United for Life (AUL), a national right-to-life organization, grading the states on their adoption of laws that favor right-to-life convictions, like regulations limiting abortion, bans on embryonic stem-cell research and statutes related to physician-assisted suicide (Americans United for Life, 2009). This could not be used, as data was only available from 2003 to present. Likewise, state rankings from NARAL Pro-Choice America that also gauged abortion-related legislation were not available for my timeframe.

Another measure intended to indicate issues more closely related to the MFP construct without the influence of other issues isolated just a state's laws regarding end-of-life issues: the presence of laws regarding physician-assisted suicide and the state's promotion of palliative care at the end-of-life (Americans United for Life, 2009). Americans United for Life began this ranking in 2003 as well, so earlier rankings were sought from other organizations. Robert Wood Johnson Foundation produced a report called "Means to a Better End: A Report on Dying in America Today" that also ranked states by laws on end-of-life issues, but this too lacked the proper timeframe (2002). Eventually, I scoured the literature for measures that would indicate interest group influence in general and still failed, ultimately requested a dataset from a colleague who studied the effects of controversial abortion statutes on state abortion rates (New,

2011). While he shared my concerns with turning this data into a measure that represented right-to-life interest group success, he conceded that this would likely be the best measure that existed given my constraints. Since Mooney himself has been known to use mere gender as a surrogate for public opinion, hypothesizing that greater numbers of women in the workforce would equate to greater support for legal abortion, the problem of precise measures does not seem to plague only my efforts (1995). Mooney's approach was methodologically accepted and the variable was statistically significant, therefore I had hope that my last resort for certain measures may in fact, still be good measures (Mooney & Lee, 1995).

In spite of challenges that affected data collection and statistical methods, this analysis examined my theoretical framework and four related hypotheses with eight variables: four that indicate state values in order to test my theory and specific hypothesis, and an additional four control variables that assess other aspects of the state that could affect MFP adoption. All eight variables were tested to see if they were related to either a state's choice to adopt MFP and the type of MFP that states choose.

#### Factors Affecting the Likelihood of Medical Futility Policy Adoption

My theoretical framework suggests that values guide the adoption of MFP, and since each MFP type requires different values, I cannot attribute one set of values to why some states adopt MFP and others do not. However, there could be aspects related to the legislatures themselves, apart from values, which could compel a state to adopt MFP. Perhaps states with professional legislatures simply have more resources to promote the adoption of any type of policy. Perhaps the number of physicians or hospitals increases the likelihood that states will adopt any type of MFP, simply to resolve these disputes and keep the cases out of the court

system. Therefore both control variables and values-based variables will be tested to see if they have any relationship to MFP adoption.

The first test involved only three out of four control variables related to state demographic and legislature characteristics: urbanization, legislature professionalism and political competition. Each of these variables was categorized are higher values vs. lower values.

Table 13 demonstrates how MFP and Non-MFP states fall into these four categories:

Table 13

*MFP Adoption by Urbanization, Legislative Professionalism & Political Competition*

		State Has MFP	State Does Not Have MFP	Total States by Ranking:	Pearson $X^2$	
Urbanization	Lower	8 (47%)	17 (52%)	25 (50%)	$X^2 = .089$ ,	$p = .765$
	Higher	9 (53%)	16 (48%)	25 (50%)		
Political Competition	Lower	5 (29%)	20 (61%)	25 (50%)	$X^2 = 4.367$ ,	$p = .037^*$
	Higher	12 (71%)	13 (39%)	25 (50%)		
Legislative Professionalism	Lower	10 (59%)	16 (48%)	26 (52%)	$X^2 = .480$ ,	$p = .488$
	Higher	7 (41%)	17 (52%)	24 (48%)		

As expected, chi-square analysis indicates that urbanization plays no role on a state's choice to adopt MFP. In fact, a cursory glance indicates states with MFP have equally high and low scores of urbanization. Contrary to expectations, political competition was statistically significant and has a low to moderate relationship with MFP adoption (Cramer's  $V = .296$ ). Of the 17 states that have MFP, 12 (71%) have higher scores of political competition, meaning that MFP adoption could be attempts by legislators to innovate a policy that will win support for their re-election campaign. This could be an example of position-taking, a tactic used by legislators where legislators take a stand on an issue simply to win the votes of constituents that share that position (Mayhew, 2004).

Also, while not statistically significant, 17 states that have adopted MFP, 10 of these states less professional legislatures. While no relationship was expected, literature suggests that any relationship that would exist between legislative professionalism and policy innovation typically demonstrates more a greater likelihood of policy adoption from states with higher scores on Squire's Index (Squire, 2007).

The fourth control measure examines partisanship; the control of each state's legislature the year MFP was adopted. Table 14 offers the frequencies of MFP adoption vs. non-adopting by political party.

Table 14

*Partisanship and MFP Adoption*

		State Has MFP	State Does Not Have MFP	Total States	Pearson $X^2$
Legislative Control	Republican	10 (59%)	21 (67%)	31 (63%)	$X^2 = .221$ , $p = .638$
	Democrat	7 (41%)	11 (36%)	18 (37%)	

As expected, there was no statistically significant relationship between partisanship and MFP adoption. However, it is interesting to note how the partisanship scores could potentially correspond with MFP type. This brings us back to my original theory of values, since nine states have pro-patient policies (more likely to be passed by Republican more conducive to right-to-life interest group) and seven have pro-provider policies. The final third-party policy was passed in a Republican-controlled legislature. It would be interesting if this breakdown did correlate to policy type and values. While there are no indications that types of MFP require party-affiliated support, contrasting this measure against the types of MFP adopted the may demonstrate partisan bias from either party.

As for value-based indicators, before examining types of MFP policy by the measures

designed to indicate a propensity toward pro-patient or pro-provider MFP, the next step was to evaluate these measures across all 50 states to see if they somehow affect a state's choice to adopt. No relationship was expected, but any relationship discovered requires further investigation before conclusions can be drawn regarding hypotheses.

Two values-based measures are intended to reflect pro-patient values: government ideological liberalism and hospitable right-to-life political environment. Table 15 demonstrates how MFP and non-MFP states compare based on these measures.

Table 15

*MFP Adoption by Pro-Patient Value Indicators*

		State Has MFP	State Does Not Have MFP	Total States by Ranking	Pearson $X^2$
Government Ideological Liberalism	Liberal	8 (47%)	20 (61%)	28 (56%)	$X^2 = .836$ $p = .361$
	Conservative	9 (53%)	13 (39%)	22 (44%)	
Hospitable Right-to-Life Political Environment	Inhospitable	10 (59%)	18 (55%)	28 (56%)	$X^2 = .083$ , $p = .773$
	Hospitable	7 (41%)	15 (45%)	22 (44%)	

As expected, the neither government ideological liberalism nor the presence of hospitable right-to-life environment appeared to affect the adoption of MFP. However, a majority of MFP (10 states) passed in an inhospitable right-to-life environment, even though nine policies are pro-patient. This is further examined by looking at MFP policy type, to see if ideology also affects the type of policy adopted, as MFP theory suggests.

The final two values-based measures are intended to reflect pro-provider values: the ratio of physicians to state population, and the ratio of hospital beds to state population.

Table 16

*MFP Adoption by Pro-Provider Value Indicators*

		State Has MFP	State Does Not Have MFP	Total States	Pearson $X^2$
Ratio of Physicians to State Population	Lower	10 (59%)	17 (52%)	27 (54%)	$X^2 = .109, \quad p = .741$
	Higher	7 (41%)	16 (48%)	23 (46%)	
Ratio of Hospital Beds to State Population	Lower	8 (47%)	16 (48%)	24 (48%)	$X^2 = .009 \quad p = .924$
	Higher	9 (53%)	17 (52%)	26 (52%)	

As expected, states are no more likely to adopt MFP with greater numbers of neither physicians nor hospital beds. In fact, MFP states with fewer physicians outnumber states with more physicians (10:7). These numbers are statistically equal, but like the legislative professionalism present equal numbers still contrary to any expectations, this is noteworthy. Again, additional analysis of MFP by type will determine how the choice of pro-patient or pro-provider policies may be affected by these variables.

## Factors Indicating Values and MFP Policy Type

The affect that values play on MFP adoption is theorized across all types of MFP, yet the two competing values: patient autonomy vs. provider autonomy, are more clearly demonstrated in 16 of the 17 MFP states. Since a category of only one state would threaten quantitative analysis, third-party policy was examined qualitatively in Chapter 3 and Texas is excluded from the following analyses on MFP type. The analysis looks exclusively at the other 16 states and how the chosen variables correlate to pro-patient or pro-provider MFP.

The first variable, government ideological liberalism was designed to indicate the adoption of pro-patient policies and test  $H_3$ :

H<sub>3</sub>: States with government officials that espouse a dominantly conservative ideology will most often adopt pro-patient MFP over pro-provider MFP.

Table 17 examines the distribution of states by MFP type and government ideological liberalism.

Table 17

*MFP Type by Government Ideological Liberalism*

		Pro-Patient	Pro-Provider	Total States:	Fisher's exact
Government Ideological Liberalism	Liberal	3 (33%)	5 (71%)	8 (50%)	$p = .315$
	Conservative	6 (67%)	2 (29%)	8 (50%)	

While not statistically significant, this could be a consequence of a small sample size, as the columns show a large spread within the policy type. While Texas (a conservative state) was excluded from analysis in order not to inhibit statistical tests, conservative states choose pro-patient MFP three times as often than they choose pro-provider MFP (6:2), and pro-patient policies were enacted twice as often in conservative states vs. liberal states (6:3). Pro-provider policies are chosen 5:3 over pro-patient policies in liberal states, and pro-provider policies are 2.5 times more likely to pass in a liberal state. Even though this did not achieve statistical significance, when conservative states adopt MFP, they adopt pro-patient MFP more often than pro-provider. Likewise, there may also be reason to believe that liberal states favor pro-provider policies, yet there is not enough evidence yet to conclusively say.

In addition to government ideological liberalism, it was expected that previous success passing controversial abortion restrictions would result in a political environment hospitable to right-to-life groups promoting pro-patient policies as explained in H<sub>4</sub>:

H<sub>4</sub>: States with more laws reflecting the influence of right-to-life interest groups will adopt pro-patient MFP over pro-provider MFP.

Table 18 demonstrates MFP policy type by hospitable or inhospitable right-to-life political environments.

Table 18

*MFP Type by Hospitable Right-to-Life Political Environment*

	Pro-Patient	Pro-Provider	Total States	Fisher's exact
Inhospitable	6 (67%)	3 (57%)	9 (56%)	$p = .615$
Hospitable	3 (33%)	4 (43%)	7 (44%)	

Analysis suggests no statistically-significant relationship between a hospitable right-to-life political environment and pro-patient MFP. Examining these small numbers indicate that pro-patient MFP passes twice as often in an inhospitable right-to-life political environment (6:3). This is in diametric opposition to expectations. States with an inhospitable right-to-life political environment also pass more MFP than states with a hospitable environment (9:7). Statistically there is no relationship either in the neither expected nor unexpected direction, but the frequencies were contrary to expectations. Overall, the analysis fails to support H<sub>4</sub>: states with a hospitable right-to-life political environment do not adopt pro-patient MFP more often than pro-provider MFP.

Variables which indicate the influence of pro-provider lobby groups, the ratio of physicians and hospitals beds to the state population are expected in H<sub>5</sub> and H<sub>6</sub> to correlate to the choice to adopt pro-provider more often than pro-patient MFP:

H<sub>5</sub>: States that have above average ratios physicians to the general public will adopt pro-provider MFP more often pro-patient MFP.



H<sub>6</sub>: States that have above average ratios physicians to the general public will adopt pro-provider MFP more often pro-patient MFP.

Table 19 demonstrates how these variables affect policy choices.

Table 19

*MFP Type by Pro-Provider Value Indicators*

		Pro-Patient	Pro-Provider	Total States	Fisher's exact
Ratio of Physicians to State Population	Lower	5 (56%)	4 (57%)	9 (56%)	$p = 1.000$
	Higher	4 (44%)	3 (43%)	7 (44%)	
Ratio of Hospital Beds to State Population	Lower	4 (44%)	4 (57%)	8 (50%)	$p = 1.000$
	Higher	5 (56%)	3 (43%)	8 (50%)	

Analysis fails to support either H<sub>5</sub> or H<sub>6</sub>, as there is both no statistical significance for either variable and pro-provider policies pass equally in states with both high and low ratios of physicians to the population. Furthermore, pro-provider policies passed in two states with lower than average ratios of hospital beds, contrary to expectations.

Reexamining control variables, particularly urbanization, legislative professionalism and political competition, Table 20 shows these variables contrasted by policy type.

Table 20

*MFP Type by Urbanization, Legislative Professionalism & Political Competition*

		Pro-Patient	Pro-Provider	Total States	Fisher's exact
Urbanization	Lower	6 (67%)	2 (29%)	8 (50%)	$p = .315$
	Higher	3 (33%)	5 (71%)	8 (50%)	
Political Competition	Lower	4 (56%)	1 (86%)	5 (31%)	$p = .308$
	Higher	5 (44%)	6 (14%)	11 (69%)	
Legislative Professionalism	Lower	5 (56%)	5 (71%)	10 (63%)	$p = .633$
	Higher	4 (44%)	2 (29%)	6 (38%)	

There is no statistically-significant relationship between any of these control variables and MFP type, confirmed by high p-values across all three constructs. Political competition has no correlation to MFP type, just to the adoption of MFP in general. The frequencies on

urbanization are interesting, with more rural states enact pro-patient policies three times as often as pro-provider policies (6:2), and states with higher population density enact pro-provider policies more often than pro-patient (5:3), Pro-provider policies are enacted 2.5 times as often in urbanized states (2:5), while pro-patient policies outnumber pro-provider policies two to one (6:3) in rural areas. Perhaps there would be a relationship with a larger sample, if the sample continued with these trends.

Finally, I reexamine the partisanship variable by MFP type:

Table 21

*MFP Type and Partisanship*

	Pro-Patient	Pro-Provider	Total States	Fisher's exact
Republican	6 (67%)	3 (43%)	9 (56%)	$p = .615$
Democrat	3 (33%)	4 (57%)	7 (44%)	

Again, statistically the two constructs are equal and party affiliation has no relationship to MFP type. Yet, this again could be a consequence of the small sample size, because by frequency only, Republican-controlled legislatures passed pro-patient policies two to one over pro-provider (6:3), and pro-patient policies pass twice as often in Republican-controlled legislatures than in Democrat-controlled states. If these trends continue, a larger sample might yield a statistically significant relationship in the future.

### Conclusion

Several aspects of MFP do not lend themselves well to quantitative study. The most challenging aspect is dealing with an N of 17, categorized into groups of nine, seven, and one. Even when looking at the two larger groups, splitting these small numbers again by variables does not favor a generalizable outcome. Therefore caution must be taken when using these

results to support any theory, but rather utilized as cursory information to compel research in more probable directions, with some variables showing promise with greater inquiry and others making a case for different measures.

The only statistically-significant variable was a control variable: political competition, and there is only a relationship between the degree of competition and MFP adoption, not policy type. States with higher degrees of political competition enact over twice as many MFP as states with less competition (12:5), although they enact pro-patient and pro-provider policies equally. While value-based variables did not support my theory that values determine policy type, it appears that political competition spurs innovation, yet there are no data on why states choose to innovate one type of MFP over another as variables correlated to values all failed to explain MFP policy type.

While I expected difficulties achieving statistical significance with an N of 17, I expected the frequencies within the cells to match expectations, even if there were not a large enough disparity between the categories to be statistically significant. Some tables showed results contrary to that expectation. The measure of Hospitable Right-to-life Political Environment reported the opposite of expectations, as well as measures on pro-provider values as indicated by the prevalence of physician and hospital beds within the state. The fact that there was no relationship- combined with frequencies that defy theory and logic- this affirmed that these variables were simply not related to MFP type. The variables could be theoretically correct (the influence of right-to-life lobby groups, the prevalence of medical providers in each state), but the operationalization of these variables was problematic. The time frame and unit of analysis limited what data was available, and that data was further limited by its conversion to a dichotomous variable, due to sample size. The theory may have been incorrect, but it could have

also been a combination of data limitations and sample size. If the frequencies were as expected, but just not statistically-significant, sample size alone could have been more easily isolated, but the fact that the frequencies showed no promise of forming a trend with more data points affirms that there is no relationship between MFP and these measures.

However, some variables did fail to achieve statistical significance, yet the frequencies were as expected. The measure of government ideological liberalism as well as the control measure of partisanship by party affiliation indicated a potential relationship is possible with more data points. Statistically, Democrat and Republican-controlled legislatures adopt both types of MFP equally. However, looking at pro-patient states alone, a Republican-controlled legislature adopted pro-patient MFP two to one (67% of the time), and twice as often as Democrat-controlled legislatures (33%). Democrat-controlled legislatures have no disparity between policy type they choose, with three pro-patient policies and four pro-provider policies, but the gap is larger with Republican controlled states. I reiterate that statistically there is no relationship, but this could be a consequence both the small sample size and Democrat-controlled legislatures having no preference on MFP type, and unlike the other measures, is not a consequence of operationalization. More data could show a trend of Republican-controlled legislatures adopting pro-patient policies more often than pro-provider, even if Democrat-controlled legislatures continue to show no preference between MFP types. Roll-call votes on MFP, both pro-patient and pro-provider could examine this further, to see if there may be penchant for Republicans to vote in favor pro-patient policies, even if Democrats are not opposed.

Voting data from legislators would also remedy the sample size problem inherent at looking only at 16 states. Examining two states, one pro-patient and one pro-provider could

uncover a wealth of information about how legislators vote and if policy entrepreneurs and interest groups play a similar role in these states as they did in Texas and Idaho.

Overall, these results do not yet offer enough evidence to support my theoretical framework, but evidence that would refute it is also weak. Although the indicators, combined with the small sample size did not yield statistically significant outcomes, the conclusions of the comparative case study in Chapter 4 still suggest the role of values in MFP adoption. This analysis could be replicated with new indicators, yet all the indicators that could be obtained to test pro-patient and pro-provider values were tested, seriously limited by the unit of analysis and time frame.

A detailed exploratory case study of other pro-patient states would grant a wealth of information that could also translate into better measures for quantitative analysis. Surveying legislators by political party and the rationale they give to justify pro-patient or pro-provider votes could expand this discussion beyond interest groups and policy entrepreneurs to the roles of legislators, individually and collectively in the adoption of MFP. Whether further research is attempted via qualitative or quantitative methods, more information is needed to create more precise measures that validly indicate pro-provider values. Likewise, since right-to-life groups may not work alone in other states, there is an additional case for better measures of pro-patient values.

Overall, MFP adoption in 2012 is not well-served by quantitative study. Even if new indicators are obtained, the sample size problem remains while MFP is still limited to 17 states splits into three subcategories. Qualitative research could yield better measures for statistical study as well as offer a detailed look at MFP types while the pool of states is still shallow. As the number of states adopting MFP grows, the challenges with conducting externally-valid case

studies grow as well. This would further necessitate the need for data, and case studies could potentially provide direction for new sources of data.

While the numbers for this quantitative analysis may be too negligible to make a strong case in favor of my values-based framework, these results assuredly make a case in favor of additional research. Likewise, the comparative case studies yielded interesting results that merit further inquiry. Chapter 6 offers a comprehensive overview of both the qualitative and quantitative approaches I've undertaken to study MFP and what conclusions may be inferred from these analyses. I reexamine the theoretical framework and the framework's underpinnings like morality policy theory, to see how these perspectives fare against the results of all analyses. Finally, I offer future directions for the study of MFP adoption.

## CHAPTER 6

### CONCLUSION

#### Introduction

This dissertation is the first scholastic undertaking to examine the adoption of state policies designed to resolve medical futility disputes. Apart from Pope's article that addresses the need and limitations of policies that allow for unilateral removal of LSMT in these scenarios, the only articles about medical futility disputes that even mention policy simply cite the need to adopt policies, critique an adopted policy, praise an adopted policy, or examine the implementation or consequence of an adopted policy (Fine, 2000; Fine & Mayo, 2003; A. E. Kopelman et al., 2005; O'Callaghan, 2008; R. D. Truog, 2007; R. D. Truog, 2009). Furthermore these articles almost exclusively address the Texas Advance Directives Act of 1999, the lone third-party policy, a law which my analysis of all 50 state laws determined to be an anomaly among MFP.

Beyond articles on TADA, most of which are commentary from medical, legal and moral perspectives that reflect the position of their respective authors- there was no indication of how states adopt an MFP and moreover, what mechanisms these policies employ to resolve medical futility disputes. The Robert Powell Center for Medical Ethics' report categorized states by a patient's likelihood to have their wishes honored in a medical futility dispute, but this article did not segregate existing advance directive law (ADL) from MFP (2011). Likewise, Pope's article provides the difficulties from a provider's perspective (2007). Neither publication nor the sum of both publications provide an objective, holistic look at state laws that address medical futility disputes. Therefore all state laws needed to be analyzed and examined historically to see what states had indeed adopted MFP and how the policies resolve medical futility disputes. This

typology offers the first list of state medical futility policies and then a meaningful categorization of how these policies work.

Initial attempts to categorize MFP yielded far more categories than just three, segregating pro-provider states by the level of difficulty each imposed on providers before they were allowed to unilaterally remove LSMT. While all laws designed to address medical futility disputes are within the same policy “kingdom” (MFP), these laws are not all in the same phylum, class, order, family, genus or species. All MFP address the same thing but in different ways and with polar outcomes, so comparing all MFP collectively as if they were all the same would be fruitless. Not to sound trite, but comparing all types of MFP as if they were identical would be akin to comparing apples and oranges because they are both members of the plant kingdom. There are differences between MFP policy types, yet not all differences are critical. MFP cannot be treating as identical, but it furthermore cannot be segregated to a degree where the differences lose all meaning.

To better explain, classification of MFP can detail differences too much and miss the distinctions that truly matter. What all MFP types share is that they all represent successful efforts by the state to address the problem of medical futility disputes and where they substantively differ is the main way they resolve this problem. Most resolve the problem by uniformly siding with one party over the other, while one designates a third-party. Segregating policies by decision-maker, although not accounting for differences within the laws is still the most meaningful and solid distinction that can be made among MFP types. The decision-maker is the primary distinction, in spite of differences in protocol.

While the original analysis was more precise and noted the differences within MFP types, this question of detail pitted against simplicity presented trade-off between precision and a



firm foundation. Detailed distinctions within MFP types provided too complex and too convoluted of a dependent variable for the first empirical study of MFP adoption. The Law of Parsimony suggests that the simplest explanation is typically the right one and scientific inquiry dictates a simplistic approach (Meier, 2009).

This chapter reexamines my theoretical framework against the results of hypothesis tests to see where approaches may have been too simple and where they may still need to be simplified. It explains the factors that affected the construction of the framework and whether these factors are still relevant in light of my findings. It offers alternative explanations for the policy process that should be examined as well and predictions on the future of MFP, both the 17 MFP states and the 33 states that have yet to adopt MFP. Finally, it concludes with suggestions to guide subsequent research on MFP adoption and a discussion of the contributions this research offers that are expected to enhance the body of knowledge on this subject.

#### Values and the MFP Process: A Theoretical Framework Revisited

The theoretical framework I constructed to explain the MFP adoption process is an example of the simplest explanation for a complicated problem. I needed a theory that would be broad enough to explain the adoption of MFP in general while still recognizing the fundamental differences within MFP, a theory that would birth testable hypothesis to explain how MFP is adopted and the diversity across policy types.

Policy scholars suggest that policy differs across states due to internal determinants: differences within each state which are typically differences in the needs and problems state have to regulate with policy (Sabatier, 2007). Literature suggests that with medical futility disputes, the problem is universal across all states (Pope, 2003; Robert Powell Center for Medical Ethics,

2011). The only impetus that literature suggested to explain why 17 states had enacted policy while a majority of states have not is a vested policy actor: a policy entrepreneur, a variable that was critical in the adoption of ADL (Glick, 1992a). What little literature exists on MFP also points to the role of interest groups, a variable that was also noted as the additional support required to pass ADL (Coleman & Drake, 2006; Glick, 1992a; Graham, 2005). Literature additionally pointed to morality policy theory, how values affect the policy process of proposals with moral significance (Mooney, 1999).

For the sake of parsimony, I sought established theoretical frameworks to guide my study. Since the study of MFP is new, I thought it best to adhere to tried and true approaches in order to limit any uncertainty from the results that could be a consequence of not having any previous policy studies on this topic. The Advocacy Coalition Framework (ACF) is certainly established and would address the role of values and interest groups, yet ACF does not take policy entrepreneurs into consideration (Mintrom, 1997; Mintrom & Norman, 2009; Sabatier, 2007). It would have been problematic to ignore policy entrepreneurs as a variable, and likewise expedient and disingenuous to employ ACF in spite of this liability.

Likewise ACF and morality policy theory were slightly at odds, since morality policy theory sometimes downplays the influence of interest groups (Mooney, 1999). Morality policy theorists suggest that the technical simplicity in morality policy negates much of the need for interest groups to provide expertise required to make policy decisions (Mooney, 1999). Theorists note that there is a high correlation between interest group influence and public opinion, but suggest that public opinion can have more influence in morality policies than interest groups do (Mooney, 1999). This was not the case with the innovation of ADL, and additional literature shows that interest groups are often considered the equivalent of public opinion by legislators

(Herbst, 1998). The two theories that literature suggested for explaining MFP either emphasized the importance of interest groups (ACF) or denigrated their role (morality policy theory). Furthermore, morality policy theory notes the role of policy entrepreneurs while ACF does not (Mintrom & Norman, 2009; Mooney & Lee, 2000).

In light of a failure of existing theoretical models to completely encompass the facets of MFP, I created a framework of my own that would recognize all critical variables. Relying on literature that historically and empirically suggests the importance of values in medical dispute policies, I established an explanation would include all actors and acknowledge values as a causal driver, explaining the adoption of MFP while accounting for the diversity across MFP types. It simply suggests that values explain the difference across MFP types and policy actors like interest groups and policy entrepreneurs mold policy according to these values, only successfully adopting MFP that adheres with the prevalent values in the state.

Hypotheses related to these variables were tested by both comparative case study and quantitative methods. While the results were analyzed to determine if the individual hypothesis were supported, the aggregate of these results must be used to scrutinize theory, especially since this theoretical framework is original and previously untested work.

### The Theoretical Implications of Empirical Results

The theoretical framework yielded six hypotheses. H<sub>1</sub> suggested the necessity of policy entrepreneurs for MFP adoption and H<sub>2</sub> suggested the necessity of interest groups consensus, while H<sub>3</sub> and H<sub>4</sub> indicate pro-patient values and H<sub>5</sub> and H<sub>6</sub> reflect pro-provider values. The results of both qualitative and quantitative analyses failed to support all but one hypothesis: H<sub>2</sub>, the necessity of interest group consensus.

First, the case study that documented the functions of policy entrepreneurs in Texas (with successful adoption of MFP) and Idaho (where adoption of MFP failed) determined that policy entrepreneurs were present in both states and performed nearly identical functions. According to case studies on the creation of ADL, a policy entrepreneur was able to build consensus in one state that led to policy adoption, and the lack of consensus in another state was blamed for a failure to adopt ADL (Glick, 1992a). Scholars credit consensus for policy adoption and policy entrepreneurs for performing functions that create this consensus (Glick, 1992a).

This was my expectation as well, that consensus would exist in Texas and be attributable to a policy entrepreneur's actions, and likewise that consensus was not achieved in Idaho, which would be attributable to the absence of a policy entrepreneur or the failure of the policy entrepreneur to perform a critical function. Since policy entrepreneurs performed identical functions and yet this did not result in MFP adoption in Idaho, my hypothesis that policy entrepreneurs and the functions they perform are a necessary condition build consensus was incorrect. However,  $H_z$ , my hypothesis regarding the necessity of interest group consensus was validated.

Speaking to respondents from both pro-patient and pro-provider orientations provided the whole story of what happened in both Texas and Idaho. Indeed, interest group consensus, as suggested in both  $H_2$  was credited by all respondents for the passage of MFP in Texas and the failure of the MFP proposal in Idaho. However, the assumption that policy entrepreneurs wield the power to create consensus exclusive of other environmental factors was found to be short-sighted. While policy entrepreneurs may be able to build consensus exclusively of environmental factors, this was not the case in Texas and Idaho. Rather, in these states it is clear that environmental factors can nurture and even mandate consensus- and factors can inhibit

consensus as well. In Texas, the status quo where patients were dying, coupled with the edict from the governor to create an acceptable MFP proposal made pro-patient groups willing to make concessions that say they would not have made otherwise. Likewise, the ambiguity under Texas ADL made pro-provider groups willing to make concessions that would ease uncertainty in unilateral removal of LSMT. Idaho has none of these exogenous variables spurring consensus. Rather, the status quo was preferable to both parties than anything they would gain by conceding in order to pass an MFP proposal. While the policy entrepreneur in Texas certainly harnessed these exogenous variables to build consensus, no efforts made by the policy entrepreneur in Idaho would convince two parties to concede to a policy where both sides stood to lose more than they would gain.

Just because the cases of Idaho and Texas demonstrated that policy entrepreneurs could not build consensus in all policy circumstances, that does not invalidate their role. The respondents all mentioned that there would have been no policy proposal or negotiations whatsoever if it was not for the actions of the policy entrepreneur. Furthermore, respondents in Texas credit successful negotiations and the ultimate passage of MFP to the policy entrepreneur. The results suggest that policy entrepreneurs can play a role and that role does involve consensus building- but that the broader political environment can limit what a policy entrepreneur can achieve.

The case study also reinforced the premise that values arbitrate the MFP process, but did not otherwise conform to tenets of morality policy theory. Yes, the negotiations were value-driven but not at the expense of implementation. Mooney states that morality policies are more concerned with making authoritative statements than outcomes for citizens (Mooney, 1999; Mooney & Lee, 2000). While values dominated the decision-making process in both Texas and

Idaho, the negotiations were lengthy and lasted several years specifically *because* of outcome concerns. Pro-patient and pro-provider respondents negotiated the technical definition of terminal illness in Texas and pro-patient groups in Idaho fought to control the composition of HECs, in order to ensure that disability rights advocates would have a say in futility determinations. These are strategic moves, not ideological statements about right and wrong. Likewise, even when pro-patient forces took a hardline position to accept nothing but 100% pro-patient MFP, this was not unyielding due to morality, but because policy-oriented learning had revealed implementation problems with third-party policies, so anything less than 100% pro-patient MFP would not result in the outcomes that pro-patient groups deemed acceptable to their values. While policies are pro-patient or pro-provider the vast majority of the time, this might not be because these policies were intended to validate patient or provider values. It could simply be that lobbyists on either side believe these laws to have the best outcome, and they pursue that outcome. This would not be value-free, of course, but Mooney's suggestion that these policies are exclusively value-driven apart from implementation concerns is not supported by this comparative case study (Mooney, 1999; Mooney & Lee, 2000). Rather the comparative case study suggests that values do lead negotiation, but implementation and outcomes play a role as well.

Quantitative analyses of value-based indicators were intended to support my theory on the critical role of values, yet all hypotheses were unsupported. I maintain that this was not because values are not a critical in the policy process- the case study clearly suggests that they are, but this is likely a consequence of small sample size and a limited choice of indicators. In spite of a failure to achieve statistical significance, as examination of the frequencies within the contingency table shows promise that addition MFP adoption in time may reveal some variables

to be related to MFP adoption. For example, government ideological liberalism and partisanship had no relationship to MFP adoption or MFP type, yet examining the columns individually, just looking at the MFP type alone showed a bias of conservative and Republican-controlled legislatures to adopt pro-patient MFP. Six of the nine pro-patient MFPs were adopted by a Republican legislature, and Republican legislatures adopted six pro-patient MFPs to only three pro-provider MFPs. Democrat-controlled legislatures showed no bias, adopting three pro-patient MFPs and 4 pro-provider MFPs, but conservative and Republican affiliation may prove to affect MFP adoption in the future. Again, this was not statistically significant, but could be the start of a trend that correlates Republicans and conservatives to pro-patient MFP.

In spite of the potential for conservatives to favor pro-patient policies, the case studies also noted the ideological divide. State chapters of the American Civil Liberties Union (ACLU), a staunch opponent of anti-abortion lobby efforts have joined forces with state anti-abortion organizations, and Conferences of Catholic Bishops who typically lobby alongside anti-abortion groups have testified against pro-patient MFP proposed by these right-to-life groups, arguing that for provider's right-to-conscience over patient's needs for LSMT (Aymond, 2007; Smith, 2007). Self-proclaimed liberal bloggers condemned medical futility policies that allow the removal of care as a conservative war against the poor who cannot pay their medical bills (Hollinger, 2006; Landsburg, 2006). Finally, disability rights advocates opposed MFP that allows the unilateral removal of care against patient wishes as sanctioning bigotry and discrimination against persons with disabilities (Coleman & Drake, 2006). The way groups have sorted themselves in either the pro-patient or pro-provider camps would defy the way most would sort them, assuming that Catholic organizations that typically support right-to-life groups would align with these groups rather than the ACLU which often oppose right-to-life legislation. Mooney's attempt to correlate

the percentage of Catholics in a state to the likelihood of abortion restrictions works, but attempts to correlate groups of people to values would not work with MFP studies (Mooney & Lee, 1995). MFP is value-laden, but those values are not as clearly delineated in MFP as they are in other morality policies.

While empirically the quantitative data fails to support the role of values, the case study affirms the role of values. Aside from the need for consensus, none of the observations from data support an idea that value-laden policy process for MFP is free from implementation concerns like Mooney suggests (Mooney, 2000). Likewise, while there is a clear line between pro-patient and pro-provider values, the way that citizens assemble themselves around these issues is anything but clear. Attempts to develop a simple theory to explain MFP adoption and type could very well be too simple- not so simple as to be invalid, but certainly in need of expansion to include exogenous variables and greater qualitative analysis to find indicators of values that reflect the diversity of pro-patient and pro-provider advocates.

#### Beyond Policy Adoption to Policy Implementation, and Implications for ADL States

Understanding that the policy process for MFP is not free from implementation concerns begs the question of how implementation issues affect the choice of a state to adopt MFP. No states have successfully adopted MFP since 2006, which does not indicate a lull in MFP adoption but an abrupt cessation.

I reject the suggestion that the remaining 33 states would fail to adopt MFP because they do not need MFP, maintaining that medical futility disputes are a universal problem across all states. Literature reinforces that either one or both parties (pro-patient or pro-provider) are dissatisfied with the way ADL is applied to medical futility disputes, meaning that in the



remaining 33 states, one interest or the other (if not both) would appreciate a policy change, given that the policy change reflects their respective values (Pope, 2007; Robert Powell Center for Medical Ethics, 2011).

The status quo can favor one party, greatly inhibiting any incentive for compromise, but certainly providing an incentive for the disadvantaged party to enact policy change. Kansas is a prime example. The Robert Powell Center for Medical Ethics approves of Kansas law, even though it is simply ADL and was passed in 1979, twenty-three years prior to the first MFP. The wording added to Kansas law was intended to prevent patient abandonment in the cases where a provider wished not to comply with a patient's directive, mandating that the provider continue to care for the patient until care was successfully transferred to another provider. This was not written to force a provider to provide LSMT against their wishes but rather, the statute explicitly mentions right-to-die disputes only (Donaldson, 2006, p. 20). And yet, the courts have interpreted the law to force providers to continue LSMT until a transfer is found, making this law functionally the same as pro-patient MFP. Therefore, there are some ADL states where, if the dominant interest is already favored by ADL, there is little incentive to modify the law.

Since there are two parties and one is decidedly disadvantaged, there is always an incentive for some interest to adopt MFP over ADL. According to my framework, the dominant interest may be able to defeat contrary reform efforts and remain ADL, or the dominant interest could achieve their choice of MFP type. However, there is another explanation that inhibits reform: the possibility that the incentives of adopting MFP for either party (or perhaps even both), simply do not merit the costs, leading the parties to prefer a flawed ADL to potentially worse problems with compromises required to pass MFP, stymieing negotiations.

The failure of Idaho in 2009 illustrates this point. Neither party was satisfied with the state's ADL, yet both parties were willing to endure the existing problems from the ADL rather than invite additional problems by enacting an MFP. Pope's extensive research into the implementation concerns with unilateral decision statutes notes that providers are still fearful of the constitutionality of these laws and fearful that federal law like EMTALA may pre-empt state laws (2007). EMTALA, successful in preventing the withholding of care from Baby K in Virginia was indeed used on behalf of a disabled toddler to challenge the constitutionality of TADA in 2007, along with additional claims that TADA was also in conflict with the Americans with Disabilities Act and the Rehabilitation Act of 1973, the predecessor of Baby Doe laws (Annas, 1994; Fine, 2009; L. M. Kopelman, 2005; O'Callaghan, 2008). Even though the case was made that TADA violated both the state and federal constitutions, the law was upheld (Fine, 2009). Likewise, legal challenges to other types of MFP have similarly resulted in the law prevailing, and even when proponents of the law admit to procedural and ethical flaws, these laws are not revoked nor reformed (Mayo, 2009; Pope, 2007). With the longevity of these reforms and the difficulty to even make modifications, states could be risk-averse, reticent to tackle the issue at all especially with the degree of scrutiny and controversy some laws create. Additionally, states could simply look at the criticisms of existing MFP and determine that the problems with ADL are preferable to the problems of MFP.

This highlights the role of policy-oriented learning. States have the benefit of seeing the outcomes of other states, and advocacy coalitions also alter their approach to an issue when they receive new or better information. No MFP has reporting requirements, making valid policy analysis difficult and often times limited to hard cases that compel pro-patient interest group attention. In Idaho, pro-patient lobbyists explained that they had learned by studying the

implementation of MFP that certain compromises they previously made were counter-productive to their goal making them unwilling to negotiate a passable bill. Since the same national pro-patient lobbyists advocate nationwide, what these groups have learned about aspects of MFP could make them unyielding, preventing a bill from passing even when law-makers are willing to entertain adopting an MFP. There are many factors among the many policy actors that inhibit MFP adoption, with seemingly few incentives for reform. Even if a scenario where one party stands to make tremendous gains, the contentiousness itself could damage reform efforts. This could explain the failure of MFP proposals for over five years, and does not suggest a renaissance of MFP adoptions nationwide. The more likely prediction would be fewer states even entertaining MFP proposals, fewer attempts to pass modified versions of MFP types and ultimately, fewer states adopting new MFP. Federal healthcare policies could potentially produce the exogenous factors to encourage MFP adoption, perhaps even a mandate for states that receive federal funds to enact MFP, but as of 2012, the political environment appears stagnant for MFP reform.

Additional research on MFP implementation and the policy process could yield innovations which might break this stalemate. The next step then is to critique the whole of the methods employed in this dissertation to determine ways research may be improved, as well as offer suggestions for future research efforts.

#### Assessment of Research Methods and Suggestions for Future Research

Qualitative methods were far more efficacious than quantitative methods, mostly because of the shallow pool of states only 17 states and the fact that they are further segregated into three even smaller categories. This simply does not lend itself to statistical analysis, especially when

compounded by the fact that variables had to fit a narrow set of criteria in order to work. Indicators had to include all MFP states and most if not all ADL states, and indicators had to be entered for each MFP state by the year each MFP was adopted, also limiting indicator choices to data available from 1993-2006. Interval-level data was also reduced to nominal-level data, and because quartiles would further segregate data into categories much too small to be analyzed, these had to be coded in only two categories of “higher” or “lower,” robbing the data of precision. Quantitative analysis was indeed a worthwhile effort, but simply not as fruitful as the comparative case studies.

Being the first policy study on MFP, this research was in many ways exploratory, even though it was conducted as conclusive research. I sought to test and confirm hypotheses based on a theoretical framework, and two of these hypotheses were best served by a comparative case study. The comparative case study offered sufficient latitude to learn about external factors that affected the policy process in Texas and Idaho, latitude that quantitative analysis did not offer. For example, variables selected to indicate values lacked statistical significance in the quantitative study, which could be a consequence of the challenges that I listed, but lacks a definitive answer for my these hypotheses were rejected. Yet, when the functions of policy entrepreneurs could not be correlated to MFP adoption, the data provided an answer as to why: exogenous variables in the political environment. I would not have become aware of these variables without conducting a comparative case study. Additional variables that in-depth qualitative research could discover may serve quantitative methods as well, but it would require additional case studies to get this information.

Case studies are best conducted now while quantitative methods are still limited and the pool of states is still limited as well. This study relied on statistical analysis for the majority of

MFP (16 out of 17 states) and employed the case study to examine the one anomalous state against a state that had not adopted any MFP, in order to determine how MFP is crafted apart from policy type. It served that function well, but since Texas has the only MFP of its kind, it is impossible to generalize what happened in Texas and suggest that the process for adopting MFP in Texas is the process which other states follow.

Therefore the next step would be conducting case studies on pro-patient and pro-provider MFP. While case studies are inherently problematic to generalize, at least sample pro-patient states are expected to have similarities to other pro-patient states- as opposed to Texas, which is not expected to reflect any other state. Simply knowing the process for all types of MFP, whether done in isolation or comparison, these studies would assuredly be beneficial in adding to the body of knowledge on this subject. Aside from the findings in this dissertation, there are no other policy studies that examine the adoption of MFP, so even if these case studies reaffirm the findings of this dissertation and do not add any unique findings, this would still be beneficial in suggesting that the MFP process transcends MFP type. With the differences between MFP types and the diversity among MFP states, it is doubtful that case studies would not yield new findings. However no matter what the outcome, these studies would certainly be worthwhile in these early stages of MFP research where all information is new information.

There are also certain variables from Chapter 5 that need further explanation. Political competition was the lone measure that was statistically significant when looking at MFP adoption. Additional inquiry is needed to determine why this is. The explanation that literature offers is that legislators who are fearful of losing their seat are more likely to champion policy innovations in order to gain votes (Holbrook & Van Dunk, 1993). An additional explanation could be that legislators support MFP as a form of position-taking, a strategy used by legislators

to gain votes (Mayhew, 2004). Position-taking is simply declaring a stance on an issue or bill and gaining support from constituents who share that stance (Mayhew, 2004). Indeed, legislators could just be taking a pro-patient or pro-provider position to gain political clout, something they might not otherwise do if they felt secure in getting reelected. MFP could transcend party lines, so perhaps threatened legislators would work together to pass a law for which they can take credit or advertise their success. Credit-claiming and advertising are also techniques legislators use to get re-elected and may be at play here (Mayhew, 2004). Because political competition was statistically significant, it deserves attention in future statistical analyses and during interviews for case studies.

Finally, the examination of political affiliation with regard to MFP type would be an excellent progression in MFP research. It would both enhance case studies and provide data on how party affiliation affects votes for particular types of MFP. In Texas, MFP passed on the “Local and Consent” calendar for uncontested bills, so there were no roll-call votes {Citation}. In Idaho, the proposal was passed unanimously in the Senate before controversy erupted that led to the proposal’s failure in the House (Lodge, 2009). Certainly roll call votes exist in at least some of the remaining 15 MFP states, and this information could be obtained with relative ease. Furthermore by changing the unit of analysis from states to legislators, this would eliminate sample size limitations and the uncertainty this causes, leading potentially to statistical results that either support or fail to support a correlation between party affiliation and MFP type. Even if an analysis of roll call votes fails to suggest any relationship between the two variables, simply ruling out party affiliation as a factor in MFP adoption would be solid progress in developing the body of knowledge on this subject.

## Conclusion

The work I present in this dissertation provides several significant contributions to the body of knowledge regarding policy studies. First, it offers an explanation of all policies designed to address medical futility disputes and provides a replicable typology of MFP. This is a significant contribution not only in that it is the first typology to explain the state of medical dispute policy in the U.S., but it also provides the necessary groundwork for further study. Furthermore, if other scholars employ my typology, there would be standardization across studies that would enable researchers to continue to build upon the progress of their colleagues.

Secondly, the empirical findings from both qualitative and statistical analysis offer a primed starting point for additional research. I tested the typology that I created, contributing the first set of variable shown to affect both MFP adoption and type. The findings from the comparative case study suggest the critical role of interest groups and the power of consensus. The findings of statistical analyses also suggest variables that while not statistically significant, show promise that they might potentially affect MFP adoption and policy type in the future.

Third, I provide the beginnings of a theoretical framework to explain the adoption and diversity of MFP which has the potential to be used to guide further scientific inquiry. While the empirical results do not conclusively validate this approach, and I am reticent to endorse the framework prematurely without this and other support, there is evidence that this way to conceptualize the MFP process is the start of a good guide for research efforts. The key facet of consensus was indeed the critical factor for MFP adoption in Texas, affirmed by the lack of consensus and failure to adopt MFP in Idaho. Even though statistical tests of value-based indicators were insignificant, the case studies affirm the role of values. The framework has only

been employed once, and shows promise to merit additional uses to determine its merits and remedy its liabilities.

Overall, the work provided in this dissertation is both conclusive, providing knowledge that was not known before as well as a springboard for the acquisition of new knowledge and this previously unaddressed by timely policy topic. Variables that were statistically significant can be examined more closely, and with different methods. The typology offered can be examined with similar methods, but different variables- and additional states can be sampled and the case studies replicated to determine differences within the MFP types that were not qualitatively studied in this dissertation. There is now research on medical futility policy adoption where there previously was none, providing resources for additional research on this vital issue.



APPENDIX A  
INFORMED CONSENT FORM

## INFORMED CONSENT FORM For Medical Futility Policy Study

**STUDY TITLE:** Advanced Directives and Medical Futility: The Effects of Political Culture, Policy Entrepreneurs and Advocacy Coalitions on the Degree of Patient Self-Determination in U.S. State Law

**PRINCIPAL INVESTIGATOR:** Jacqueline Harvey, MSSW  
**ADVISOR:** Dr. Brian K. Collins

### INTRODUCTION

You are invited to consider participating in this research study. Please take as much time as you need to make your decision. Feel free to discuss your decision with whomever you want, but remember that the decision to participate, or not to participate, is yours. If you decide that you want to participate, please sign and date where indicated at the end of this form. If you have any questions, you should ask the researcher who explains this study to you.

### BACKGROUND AND PURPOSE

This study is being conducted as part of a doctoral dissertation to determine the role of certain individuals and groups in the adoption of policies that govern the discontinuation of life-sustaining medical treatment against the wishes of the patient (medical futility policy). This study is being done in order to determine the role that key personnel (legislators, citizens and members of advocacy groups) may have in the adoption of different types of laws that address this issue in varying ways.

**You are being asked to take part in this study because you have been identified as a key individual that has affected such policies in your state.**

If you decide to participate in this study, you will be asked to participate in a phone interview. This interview will be scheduled at your convenience and should last approximately one-hour. During this time you will be asked to speak about your role in supporting or opposing the a specific bill that addressed medical futility in your state. These interviews will be recorded and transcribed for research purposes.

### RISKS

There are minimal risks associated with participating in this study. These risks include potential psychological discomfort in revealing political affiliations and activities and the potential for others to criticize the affiliations and activities that you reveal. If you do not wave to right to be quoted by name but rather job title/ type of organization, it is still possible for others to identify your input within the final report due to the close nature of people working together in the political area and the need to identify the nature of the group you may be representing. The researcher will attempt to mitigate these risks by avoiding any unnecessary details about group affiliations whenever possible for those that decline to be quoted by name.

## BENEFITS

If you agree to take part in this study, there will be no direct benefit to you. However, information gathered in this study may contribute to a greater understanding of what types of individuals and groups succeed in passing different kinds of medical futility policy.

## CONFIDENTIALITY

Every effort will be made to keep any information collected about you confidential. However, for the aforementioned reasons, it is impossible to guarantee absolute confidentiality. We would like to include your organizational affiliation and title for attribution and explanatory purposes. However, you have the option to not have your name used when data from this study are published; if this is the case, please indicate so on the last page of this form, etc.). Please note that, even if your name is not used in publication, the researcher will still be able to connect you to the information gathered about you in this study.

In order to keep information about you safe, audio recordings and transcripts will be identified only by number and encrypted with password protection. This informed consent document that identifies you by name will be kept behind two locked doors in the Public Administration Department at the University of North Texas. Only the principal investigator and the advisor will have access to this file.

## YOUR RIGHTS AS A RESEARCH PARTICIPANT

Participation in this study is entirely voluntary at all times. You can choose not to participate at all or to leave the study at any point. If you decide not to participate or to leave the study, there will be no effect on your relationship with the researcher(s) or any other negative consequences. Any information you have already provided will not be used and promptly destroyed. If you decide that you no longer want to take part in the study, you are encouraged to inform the researcher of your decision.

## QUESTIONS OR CONCERNS?

If you have questions about the study, you may contact Jacqueline Harvey, MSSW. You may also contact the researcher's faculty advisor, Dr. Brian Collins at (940) 565-4466

## CONSENT OF PARTICIPANT

I understand all of the information in this Informed Consent Form.

I have gotten complete answers for all of my questions.

I freely and voluntarily agree to participate in this study.

I understand that I will be (audio recorded) as a part of this study.

Participant Signature

Date

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Printed Name of Participant

Once you sign this form, you will receive a copy of it to keep, and the researcher will keep another copy in your research record.

If participants have the option to choose whether or not their names are used when data from this study are published, include (revising as necessary):

Please indicate whether you agree to have your full name used alongside your comments in the final (publication/presentation/essay/etc.) that results from this research.

- ☐ YES (If you change your mind about this at any point, please let the researcher know)
- ☐ NO

APPENDIX B  
INTERVIEW SCRIPT

**End-of-Life Policy Personnel  
Semi-Structured Interview Script**

Interview Number: \_\_\_\_\_

Interview Date: \_\_\_\_\_

**Pre-interview Checklist:**

- ☐ Respondent has signed informed consent form
- ☐ Respondent has been read the informed consent document and reaffirmed his or her consent to be interviewed

1. Please tell me the role you played with regards to this particular policy. (i.e. Bill Author, Committee Member, Member of Advocacy Coalition, Etc.)

2. How would you define the problem that this bill was designed to address?

3. Are you aware of who had the original idea for the bill? (i.e. Who approached you with the idea to propose the bill? If respondent answers that he/she is the innovator of the policy, ask him/her how they reframed the problem to create the proposed solution)

4. Who proposed the bill? (If the respondent is the bill author, this skip to item 5.)

5. Please tell me your role (if any) in the introduction of the successful bill and how you worked to get it on the agenda (if applicable). (i.e. Respondent is the bill author, co-author, or the respondent sought an author).

6. Please tell me the key players that supported the bill as it was proposed.

7. How did you seek to mobilize public opinion in favor of the bill?

8. Was there any major opposition to the proposed bill? (If no, skip to item 13)

9. Who was opposed to the bill?

10. Why were these parties opposed to the bill as proposed?

11. How was their opposition overcome? (If this opposition included bill amendments, ask how the amended bill compared with the proposed bill.)

12. Were alternative policy options or compromises offered to get opposing parties to reconcile and join forces in supporting the bill? (If no, skip to item 16)

13. What alternative policy options were offered?



14. Who offered these alternative policy options?

15. Who brokered the compromise that allowed the opposing groups and proposing groups to both ultimately support the final version of the bill?

16. Please tell me the key players that ultimately supported the bill after any amendments and negotiations.

17. What do you think the greatest contribution is from each party you mentioned (name parties) that led to ultimate success? (i.e. What did each contributor bring to the table that led to the policy being adopted?)

18. Overall, who/what do you credit for ultimately passing the bill?

19. Is there any information you think I need to have an accurate understanding of how the final policy was enacted?

20. Will you provide me with the names of the key individuals in the aforementioned groups that were present during the legislative session so I may contact them for an interview to hear their insights?

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