

The Process Model and the Stagnation of New Public Policy:

An Analysis of the Terri Schiavo Case

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## Abstract

Though tragic, the case of Florida's Terri Schiavo offers an unprecedented case study. The instance's unique circumstances provide one with a valuable and tangible illustration of political theory and the formation of public policy. Despite national media attention and the infamous case's lengthy court proceedings, the Terri Schiavo saga failed to make any legitimate national policy changes. The author examines how public policy's Process Model, despite the case of Terri Schiavo and subsequent national concern, contributed to the stagnation of euthanasia legislation on a federal, state, and local level.

## Introduction

### *History*

Early one cold February morning in 1990, Terri Schiavo's wellbeing took a catastrophic turn. At the young age of 26, Schiavo suffered from what the Terri Schiavo Hope and Life Network refers to as a "mysterious cardio-respiratory arrest for which no cause has ever been determined" ("Terri's Story"). At the time of the incident, Schiavo had not executed a living will or designated power of attorney. Several months later, following her admission to the hospital, Schiavo was diagnosed by Dr. Garcia J. DeSousa to be in a persistent vegetative state.

On June 18<sup>th</sup>, 1990, four months after the incident, the court appointed Terri's husband, Michael Schiavo, as her legal guardian. Terri's parents, Robert and Mary Schindler did not object to the court's decision. Eight years later, after almost a decade of failed rehabilitation efforts, Michael Schiavo, as Terri's legal guardian, petitioned to have her feeding tube removed. Schiavo's petition was met with opposition by the Schindlers and, after reviewing both arguments, Judge Richard Pearse suggested denying Michael Schiavo's petition to remove the feeding tube, citing that Schiavo's request may have been influenced by his potential inheritance upon her death.

In January of 2000, Michael Schiavo again petitioned to withdraw life support. The 2000 court case was heard by Judge George Greer in Pinellas-Pasco's Sixth Judicial Circuit. Over the course of the hearing, Michael Schiavo, along with his two siblings, testified that Terri had told them in the mid 1980's that she would not want to be kept alive in the event that life support was needed. Her parents, on the other hand, argued that their daughter was a devout catholic and would never want to be kept alive by artificial means. Judge Greer found Schiavo's testimony to be convincing and ruled that Terri's feeding tube be removed.

On April 21<sup>st</sup>, 2001, Florida Suncoast Hospital removed Terri Schiavo's feeding tube. Nearly three days later, new evidence emerged, raising suspicion of Michael Schiavo's testimony in the case heard the year before. The evidence was the result of a private phone conversation had between Terri's father and Michael Schindler's ex-girlfriend from 1991 in which she claimed that, "(Michael) had no idea what Terri's wishes were" ("Timeline," 2015). Sixty hours following the removal of the feeding tube, Judge Frank Quesada, finding the newly presented evidence to be credible, issued an injunction requiring Florida Suncoast hospital to resume Terri's nourishment.

Following this bizarre turn of events, media saturation of the situation intensified. According to a Tyndall Report, prior to Judge Quesada's decision there were "fewer than ten (online) references a day to Terri Schiavo." Following his decision there were "more than 4,000 every day" ("The Schiavo Case ", 2005). The same report stated that CBS, NBC, and ABC all devoted 22 minutes of their 60 minute nightly broadcasts to covering the Schiavo saga.

In 2002, Judge Greer heard Terri's medical evidentiary trial. Following the trial, Greer ruled in favor of Michael Schiavo and once again ordered that Terri's nutrition be halted, and set October 15<sup>th</sup>, 2003 as date for the removal of the feeding tube. On that day, hundreds of people gathered outside of the hospital in which Terri resided. By the end of the day, "at least 180,000 signed a petition to Governor Jeb Bush of Florida to invoke Florida's Adult Protective Custody statutes based on allegations of neglect" ("Timeline"). Five days later, an emergency session of the Florida Legislature was held in which both the House and the Senate passed "Terri's Law," a law giving Governor Jeb Bush the authority to reinstate Terri's nutrition. One year later, Judge Baird of Florida's 6th Circuit court ruled that "Terri's Law" was not constitutional and ordered the removal of Terri Schiavo's feeding tube for a third and final time.

The Schindlers scrambled to make final attempts to plea for their daughter's life. Both the Florida Supreme Court and the United States Supreme Court denied to hear the Schindler's appeals. On March 18<sup>th</sup>, 2005, Terri Schiavo's feeding tube was again removed. Fourteen days later, after two weeks of no food or water, Terri Schiavo died from severe dehydration and malnutrition.

### *Theory*

The Terri Schiavo case gripped the attention of the public on a national level. According to Terence Smith, "76 percent of the public polled (said) that they (were) following (The Terri Schiavo case) either very closely or somewhat closely" (Cosgrove-Mather, 2005). Even with such vast public awareness, today there is absolutely no federal legislation. Euthanasia has been deemed a state matter (only four states have legalized euthanasia in the last 20 years ("New Health Guide").

A 2007 Gallop poll of approximately 1,000 adults (though the statistics are approximately eight years old, it is unlikely that the results are not still fundamentally representative of public opinion as there was little variation in responses over course of the six year study) found that Americans are relatively evenly split with regard to the acceptability of doctor-assisted suicide (**Table 1**).

Table 1. 2007 Gallop Poll: Moral acceptability of doctor-assisted suicide.\*

		Morally acceptable	Morally wrong	Depends/ not an issue/ no opinion
May 10-13, 2007	Overall	49%	44%	7%
Partisan views	Republicans (including "leaners")	39%	54%	N/A
	Democrats (including "leaners")	59%	36%	N/A
Churchgoers' views	Attend weekly	23%	71%	N/A
	Attend almost weekly/ monthly	45%	48%	N/A
	Seldom/ never attend	67%	24%	N/A
May 8-11, 2006*		50%	41%	8%
May 2-5, 2005*		49%	46%	5%
May 2-4, 2004*		53%	41%	6%
May 5-7, 2003*		45%	49%	6%
May 6-9, 2002*		50%	44%	6%
May 10-14, 2001*		49%	40%	11%

\* Opinion Polls/Surveys - Euthanasia

According to the Process Model of public policy, principal key actors (the people, i.e. the voters) have identified a problem. Many secondary actors (i.e. interest groups) have long set agendas for euthanasia policy creation. Even so, the Process Model has failed in leading to the formation of right to die legislation. After the agenda setting phase of the 'process', euthanasia legislation has gone seemingly stagnant, impacting sick Americans, their families. The implementation of policy would effectively end deliberation, instating direct results of a centuries long paradigm debate.

#### Literature Review: Reoccurring Themes from Research

##### *Public Policy Theory: The Process Model*

The Process Model can perhaps be described best as public policy as a result of political activity. At its core, the Process Model identifies key actors/stakeholders. Scholars from oxford refer to these actors as "individuals, groups, (or) organizations that have a stake in" the outcome of a policy or are directly impacted by the influence of potential legislation (Trousset, "Degrees

of Engagement"). In the context of this case study, the American public (i.e. voters), euthanasia interest groups (The Terri Schiavo Life and Hope Network, The American Medical Association), and legislators are stakeholders.

Continuing laterally with the process, the subsequent step is identifying a problem, a relatively minute phase by comparison, and to set an agenda. The media plays a chief, necessary role in this step, a function that will later be discussed.

The final step for our case study is the formulation and implementation of policy. Currently, no euthanasia legislation is active in the United States on a federal level. This is where the Process Model has halted any real progress.

### *Persistent Vegetative State*

Euthanasia is a superficially taboo subject of discussion in the realm of American politics. For this reason, the Terri Schiavo case is especially valuable. Few, if any, other cases have lead to such varied public opinion on such a massive scale. Nearly the entirety of the euthanasia literature used for this research was directly grounded in the case of Terri Schiavo. A case study by Joshua Perry, Larry Churchill, and Howard Kirshner (2005) was the first to introduce a reoccurring theme of Terri being in a persistent vegetative state (PVS). That is, she was unaware of herself and her environment and was deemed to be non-cognitive and incapable of conscious experience (Coleman, 2005). According to one source, PVS is characterized by “periods of wakefulness with no apparent awareness or response to any stimulus” (Koninklijke, "The Terri Schiavo Case in a Comparative Perspective"). Many of the articles and other publishing’s used in this research made mention of PVS and grounded their research on the media’s lack of understanding of the diagnosis, a mistake discussed later in depth.

### *The Role of Media in the Terri Schiavo Case*

A school of thought that constantly reemerged while conduct research was the concept of the media's role in the formation of public policy. The media has long been referred to as the "gatekeepers" of knowledge for the American people. As in all topical news, the media reports heavily and densely on an issue at the height of its relevance. The Terri Schiavo case undoubtedly was at the time an all time high for the discussion of euthanasia practices. The media reported forcefully for weeks, acting as the sole source of information on euthanasia for many citizens. However, many scholars argue that the media could potentially be to blame for the stagnation of euthanasia policy/reform.

According to a recently published journal, broadcasters were allegedly guilty of "inadequate explanation of end-of-life issues, insensitivity to stakeholders, (and) inconsistency in terminology," (Kenney, "An Ethics of Caring"). In fact, that same study completed textual analysis for over 1,500 media sources in Florida from 2005 and found that "neutral medical terms, such as "persistent vegetative state (PVS)" and "inserted a tube," were used almost interchangeably (used) with judgmental language such as "half-life," "interfered," and "starved to death"." Scholars have stressed the importance of fully understanding PVS when forming a general opinion on euthanasia. The study went on to further mention that "terminology was often imprecise, such as in the use of "life support" and "sustenance," which don't identify accurately a particular care or treatment" (Kenney, "An Ethics of Caring").

The American Academy of Neurology conducted a study and textually analyzed 1,141 articles published from 1990 to 2005 from a sample comprised of publishing's from *The New York Times*, *The Washington Post*, *The Tampa Tribune*, and *St.-Petersburg Times*. The study analyzed how the various sources described Schiavo's neurologic condition. A miniscule 34%



referred to Terri Schiavo as being in a persistent vegetative state. Other articles referred to Schiavo as being “brain dead” or in a “coma” instead of being in a PVS (**Table 2**). This research proved that the media was woefully ignorant and/or misinformed of the medicine behind the case. So much so in fact, 71 of the articles (6%) blatantly denied the PVS diagnosis (Racine, 2008).

Scholars agree that the media should always strive to report news in an unbiased and professional model, just as they should have done in this case. However, most academics have come to the conclusion that when “facing daily and even hourly deadlines at the end of Terri Schiavo’s life, journalists seemed overwhelmed by the volume of voices clamoring to be heard” (Kenney, "An Ethics of Caring and Media Coverage of Terri Schiavo"). This fault is likely to blame for the oftentimes chaotic, prejudiced reporting.

**Table 2. Description of Schiavo's neurologic condition in print media coverage\***

Description of neurologic condition	Affirmation (%)	Refutation (%)	Equivocal (%)
Persistent vegetative state	392 (34)	71 (6) <sup>1</sup>	28 (2)
Brain damage	316 (28)	0 (0)	0 (0)
Vegetative state	148 (13)	17 (1) <sup>2</sup>	5 (0)
Severe brain damage	145 (13)	1 (0)	1 (0)
Coma or coma-like*	106 (9)	18 (2)	0 (0)
Brain destroyed	82 (7)	7 (1)	0 (0)
Permanent vegetative state	26 (2)	8 (1) <sup>3</sup>	0 (0)
Brain is gone	23 (2)	2 (0)	0 (0)
Brain injury	23 (2)	0 (0)	0 (0)
Irreversible brain damage	20 (2)	2 (0)	1 (0)
Extensive brain damage	18 (2)	0 (0)	1 (0)
Brain death	12 (1) <sup>4</sup>	16 (1)	0 (0)
Minimally conscious state	10 (1) <sup>5</sup>	4 (0)	6 (1)
Irreversible vegetative state	9 (1)	2 (0)	1 (0)
Critical brain damage	5 (0)	0 (0)	0 (0)
Massive brain damage	4 (0)	0 (0)	1 (0)
Permanent unconsciousness	4 (0)	0 (0)	0 (0)
Devastating brain injury	3 (0)	0 (0)	0 (0)
Severe irreparable brain damage	3 (0)	0 (0)	0 (0)
Drastic brain damage	2 (0)	0 (0)	0 (0)
Irreversible coma*	1 (0)	0 (0)	0 (0)
Permanent brain damage	1 (0)	1 (0)	0 (0)
Persistent coma-like state*	1 (0)	1 (0)	0 (0)

\*Reference 12: American Academy of Neurology

### *The Role of Ethics in Research*

Yet another reoccurring theme that emerged on the course of the research process was the concept of ethics in the Terri Schiavo case. An obvious point of discord over the course of the hearings was whether it was ethically right to remove Schiavo's nourishment when she had no living will. Most scholars agree that this was an ethical choice and was the right thing to do, morally speaking. The University of Washington's Tom Preston (2006) argues "the use of a feeding tube inserted directly in to the stomach constituted artificial treatment" and that Schiavo's "treatment prolonged biological life but (would not have) lead to a cure (nor) restore (her) health." Other scholars agreed that removing Schiavo's nutrition was ethically sound, arguing that though the probability of a patient in a persistent vegetative state for three months was 1%, the probability of a patient in a persistent vegetative state for 6 months or more was 0%. Terri Schiavo was in a persistent vegetative state for over 15 years (Joshua, Churchill, and Kirshner, 2005).

Many religious scholars, however, argue that because of Schiavo's roots as a devout Catholic, she would not have condoned any euthanasia-centered practices and the decision to remove her sole source of nutrition was not only unethical, but also inherently wrong. Nevertheless, most scholars agree that she would rather have died peacefully than for her parents to assume the "financial and emotional burden of her care" (Gellman, 2005). Regardless of one's moral reasoning, all scholars can agree on one thing: ethics, no doubt, play the foremost role in public's formation of an opinion on right-to-die legislation.

### *The Role of Government Sources in Research*

Unsurprisingly, few to no governmental research documents were made readily available when researching euthanasia. This research relied heavily on scholarly articles and other forms

of information. The lack of governmental publishing's is largely due in part to lack of discussion among the major players in American Politics. Currently, the United States has taken no formal stance on the issue, and it is still widely debated amongst politicians, political parties, and states.

### Research Design

Euthanasia is still a relevant debate. As recently as November of last year, right-to-die coverage has sparked debate on a national scale. In Spring of 2014, Brittany Maynard of Portland, Oregon was diagnosed with stage-four cancer and given just six months to live. In November of that same year, after succumbing to frequent seizures and being left with stroke-like symptoms, Maynard ended her life with the help of a physician (Eleftheriou-Smith, 2014).

In addition to its relevancy, this research poses an original question and is compiled of existing information to confront an unaddressed issue. Namely, why, despite the national media coverage and debate following the saga of Terri Schiavo in the early 2000's, has the United States not implemented even the most basic of public policies concerning euthanasia practices? The research amassed in this case study is not only important, but also significant as it is likely the first of its kind (i.e. the first to attribute the lack of policy to a failed phase of the process model). This case study is unique in that it argues that Process Model helps one to understand the relationship between the Terri Schiavo case and the lack of euthanasia-oriented policy.

### Methodology Used in Research

For this purpose of this research, a case study is the most suitable approach when analyzing how the Process Model relates to the case of Terri Schiavo. According to researcher Robert K. Yin, scholars use the case study investigative method when “contemporary real-life

situations ... provide the basis for the application of ideas and extension of methods” (Yin, 1984). In this research, the Terri Schiavo case was the “contemporary situation” that was heavily examined and public policy’s Process Model was the theory used to analyze the event. A case study was appropriate for this research because it is the first of its kind. Few, if any, scholars have published any literature evaluating the relationship between euthanasia legislation and the case of Terri Schiavo using the Process Model. Other research designs would not have been appropriate given the case’s specific nature.

The unit of analysis for social research can best be defined as, “The what or whom being studied” (Babbie, 2013). The unit of analysis for this compilation of research is the case of Florida’s Terri Schiavo. Schiavo’s case was the first, and practically only of its kind. The public nature of the case allows for in-depth analyzation of the events that transpired and makes it possible to directly apply political theory to better understand the relationship between the case and the lack of public policy enacted following the cases conclusion.

Data was almost entirely collected from specifically selected scholarly sources. Sources were carefully chosen and the research within the publishing’s was thoroughly examined before being applied to this case study. When examining research, factors such as the time frame in which data was collected, the population from which data was collected, and the and the size of the sample from which the data was collected were all considered.

Textual analysis and time series analysis were both major sources of evidence for this case study. Textual analysis was implemented to examine how newspaper articles from specified years (1990, the year Schiavo was first admitted to the hospital, to 2005, the year of Schiavo’s death) referred to Schiavo’s condition. Four newspapers were carefully selected to be analyzed for the research. Two national newspapers (*The New York Times* and *The Washington Post*) were

chosen to demonstrate how the case was being described nationally, and two regional newspapers (*The St.-Petersburg Times* and *The Tampa Tribune*) were selected to express how the case was being written about at a local level.

The careful selection process used to vet previously published research helps to validate the claims made in this study. The use of triangulation, defined by Norman Denzin (1978) as “the combination of methodologies in the study of the same phenomenon,” incorporates mixed methods (both quantitative analysis and qualitative analysis) to strengthen the substance of this research. In an effort to reduce bias, information was collected from a plethora of scholarly sources (both in favor and against the courts decision to remove Schiavo’s nutrition) as well as from the Terri Schiavo Life and Hope Network and from email correspondence with Bobby Schindler, brother of Terri Schiavo.

The sources and data used in this case study were selected for the purpose of better understanding not only the case of Terri Schiavo, but also how the media portrayed the case and subsequently how the public interpreted the case. Knowing how the public interpreted the Schiavo saga was crucial in understanding where the process model failed to make legitimate policy changes.

## Findings

The findings of this research are that the media’s defective reporting is likely to blame for the stagnation of euthanasia policy. Data collected from numerous sources concluded that the media was guilty of what many scholars refer to as “media malpractice.” Statistics show that the Internet and television cannot be used in place of official medical sources. Media outlets

butchered medical jargon and misdiagnosed Schiavo for almost 15 years. A report from the American Academy of Neurology reported that articles published referring to Terri Schiavo as “brain dead” were written primarily by journalists and the mainstream media. The articles referring to Schiavo as in a persistent vegetative state were commonly written by medical professionals. As most Americans receive their topical information from the evening news rather than from recent medical journals, that’s over a decade of inaccurate information being fed to the public.

This case study revealed that reliable, valid information is critical for the Process Model to produce implementable public policy. The processes first phase is for key actors to identify the problem and to set and an agenda. This initial step likely can impede the progression of the model when stakeholders are ill informed. It is no doubt difficult for stakeholders to create an appropriate agenda when they do not fully understand the issue(s) at hand.

Additional findings of this research indicate that, though Americans are aware that euthanasia is a critical issue in politics today, further literature needs to be created addressing the issue. Most searches for “euthanasia” in a scholarly article database returned publishing’s addressing foreign euthanasia policy in the Netherlands and Australia and provided data that was not applicable for the purpose of this case study.

In an effort to address the seemingly inactive discussion on euthanasia policy, an email correspondence with Bobby Schindler, brother of Terri Schiavo, was opened in which he was asked “What, if anything at all, (had) changed since (his) sisters death in 2005.” Schindler responded, writing, “Yes, things have changed – they’ve gotten worse.” Schindler’s response addressed a reoccurring revelation that though the debate on euthanasia rages on today, just as it did in 2005, little to no action is being taken politically to address the problem.

## Conclusion

On February 25, 1990, the life of Terri Schiavo took a calamitous turn, leaving an incredible impact on not only the lives of the Schindler's and Michael Schiavo, but also on the nation. The case's abrupt and unprecedented nature captured national attention as its events unfolded on a world stage. Following the first reinsertion of Terri Schiavo's percutaneous endoscopic gastrostomy feeding tube, fervent media attention heightened to intense degree, becoming a hallmark of the solemn case. The overwhelming surge of reporting, however, likely came at an unnecessary cost.

This research presents the extent of the misinformation being presented to the public and identifies this issue as a likely obstruction in the process of forming public policy. Among other inaccuracies, the media repeatedly misdiagnosed Terri Schiavo, referring to her as "brain dead" and in a "coma-like state." The medical community has highlighted that Schiavo was in a persistent vegetative state, a diagnoses most reporters failed to mention. Outlets even went so far as to counter medical professional's opinions asserting that Schiavo was "not in a persistent vegetative state."

The media's erroneous reporting has been identified as a likely source for the lack of euthanasia policy today. Public policy's Process Model has several distinct, sequential phases, the first of which requires the public to identify a problem and to take action. Misperception on behalf of the confused public likely has decelerated the pace of progress, and is likely to blame for the lack of policy today.

It is essential that discussion continue on euthanasia policy. Scholars must strive to explore and research on the area in an effort to inform and educate. Specifically, as accurate public awareness of the topic increases, advancement in policy formation will follow.

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