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Patient Agency, Terministic Screens, and The Role of the Public in the Cases of Karen Ann Quinlan and Terri Schiavo

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PATIENT AGENCY, TERMINISTIC SCREENS, AND THE ROLE OF THE PUBLIC IN
THE CASES OF KAREN ANN QUINLAN AND TERRI SCHIAVO

by

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DEDICATION

This thesis is dedicated to Drew Walker for believing in me and for his unwavering support throughout all of my endeavors. This thesis is further dedicated to Anna and Jim Moore for teaching me to work hard and believe in myself.

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I would like to thank my thesis director, Dr. Kevin Brock, for his support, guidance, and pragmatism. His feedback and suggestions have challenged me to transform a fleeting idea into a thesis that reflects my abilities as a scholar. I would also like to thank my second reader, Dr. Byron Hawk, for helping me understand our academic field and making me feel welcome within it.

ABSTRACT

Humanity has always been fascinated with death, and in recent history, has attempted to delay or suspend death through life-preserving technologies. These advancements in artificial life support, such as ventilators and feeding tubes, have contributed to tenuous and controversial situations in which the dividing line between life and death is unclear. In this thesis, I interrogate two case studies in order to analyze how the various medical, legal, and public discourses have grappled with the ambiguous space between life and death regarding patients in persistent vegetative states. The case of Karen Ann Quinlan from 1975 and the case of Terri Schiavo from the 1990s and early 2000s serve as my case studies for this examination. In particular, these two cases demonstrate how the ambiguous question of brain death, and what it means to exist between life and death, empowers a variety of groups to make significant decisions on behalf of a patient. These influential parties, including physicians, attorneys, family members, and the general public, each approach the issue of brain death from a unique perspective. My analysis is influenced by Kenneth Burke's notion of terministic screens; in particular, I examine the various medical, legal, familial, religious, and public screens and how each one influenced the outcome of both cases. My primary focus in examining these various terministic screens is the issue of patient agency, including how the patient's wishes are interpreted, how guardianship is determined and challenged, and how various parties assert their own influences in an attempt to control the patient's agency and the case's ultimate outcome.

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CHAPTER 1

INTRODUCTION

As a collection of mortal beings, humanity has always been fascinated with death. For thousands of years, human beings have taken measures to avoid death as we fear the unknown, worshipped gods that promise a life after death, and more recently, developed technologies to delay or suspend the moment of death. These attempts at reconciling life, death, fear, and curiosity have led to unprecedented and complicated situations in which the separation between life and death is tenuous and unclear. Physicians, legislators, and rhetoricians alike have attempted to confront the issues presented by advancements in life-preserving technology, including matters of patient rights, legal limitations in cases involving artificial life support, and questions of responsibility and agency when the patient can no longer speak for herself. Two particular cases in recent history, those of Karen Ann Quinlan and Terri Schiavo, represent some of our deepest questions and deliberations of death. In both cases, a young woman in a comatose state is kept alive by artificial life support technologies, and she is surrounded by doctors and lawyers who struggle to determine whether or not their patient is truly alive and are grappling with the complexities that life support technologies bring to the situation. The Quinlan case occurred in the 1970s at the cusp of life-preserving technologies, and as a result, focused heavily on the ethical questions of removing her from such support and who had the responsibility and power to make such a decision. The Schiavo case, in contrast, came to a head in the early 2000s, although it still centered on similar questions of patient agency,

guardianship, and the added complexities of artificial life support. What makes these two cases stand out among the rest is the intertwining of medical and legal arguments, particularly as they center on the patient's personal agency and decision-making abilities for herself, as well as the way the public is involved in the patient's story. In this paper, I will examine the unique ways in which artificial life support, definitions of life and death, and the clash of the medical, legal, and public spheres come together within these compelling and significant cases. Each influential entity in these cases approaches the issue of brain death from a unique perspective, formed and influenced by different theoretical backgrounds, understandings of brain death as a physical and spiritual concept, and relationships to the patient. The collision of these various influences is compounded when the patient's personal agency is considered. In order to examine these various influences and how they come together to create the unique situations that allow these two cases to become as complex as they are, it is important to first understand the historical and theoretical background of brain death and humanity's attempt to understand it.

With examinations of human death inevitably come questions of personhood and identity. Christine Quigley, a scholar of death and mortality, argues in *The Corpse: A History* that it is nearly impossible for a human being to come in contact with a corpse without reflecting on his own impending death and subsequent disappearance of his soul or essence; in fact, "when we die, we relinquish our individuality" and become nothing more than "meat that remains after the spirit is gone" (9-10). The belief that the physical body, once deceased, no longer contains the person who once lived inside of it seems to be a relatively universal idea across centuries of humanity, as demonstrated in

Hinduism's concept of reincarnation, Christianity's understanding of the soul and Heaven, and Islam's notion of the soul leaving the body through the throat upon death.¹ Despite these similar beliefs across humanity's history, it is the moment of the person's spiritual departure from that body that remains uncertain. When does a corpse cease to be the person who formerly lived inside the body? When, and how, does that person's essence of selfhood leave the material body behind? As Quigley notes, many cultures throughout history follow a variant of a "cleansing" procedure for the body after death, generally performed by a religious leader; this procedure is often followed in order to prepare the deceased to move into the afterlife (49). For example, the ancient Egyptians mummified their dead with great care, as the "integrity of the mummy ensured entry into the next world" (11). In ancient Greece, the laying out and preparation of the dead was a sacred task for female relatives of the deceased, who washed the body and anointed it with oils and spices (52). In a similar manner, the anointing of the dead in Christianity, particularly Roman Catholicism, has been performed with holy oils since at least the fifth century (49), and was completed in order to cleanse the body of mortal sin in preparation for the afterlife.² If the bodies of the dead were not prepared correctly for the afterlife, it is apparent that the soul or essence of the person would not arrive there successfully; this

¹ See Susan Thrane's "Hindu End of Life: Death, Dying, Suffering, and Karma" in which she describes the concept of reincarnation as "The body is like a set of clothes that the soul removes before putting on new clothing. From a Hindu viewpoint, one can be born as a human, an animal, an insect, or even a plant" (337); Ecclesiastes 12:7 "Then shall the dust return to the earth as it was: and the spirit shall return unto God who gave it" (King James Bible); and The Quran 56:83-85 "Then why, when the soul at death reaches the throat / And you are at that time looking on / And Our angels are nearer to him than you."

² This anointing procedure, used both for dying and deceased patients, is outlined in the Bible: "Is any sick among you? Let him call for the elders of the church; and let them pray over him, anointing him with oil in the name of the Lord: And the prayer of faith shall save the sick, and the Lord shall raise him up; and if he have committed sins, they shall be forgiven him." (King James Version; James 5:14-15)

preparation calls into question when the person leaves their body behind, whether at the moment of death, or sometime later, after the body has been properly prepared.

The Roman Catholic Church has grappled with such questions in recent history, particularly with medical advancements and technologies that blur the line between living and dead. Perhaps most notably, Pope Pius XII addressed an international group of anesthesiologists in 1957 in order to attempt to clarify the confusion regarding anointing a body just before death (also referred to as extreme unction) and after death: was anointing after the person has died still valid? The Pope's conclusion was as follows: "If, as in the opinion of doctors, this complete cessation of circulation means a sure separation of the soul from the body, even if particular organs go on functioning, Extreme Unction would certainly not be valid, for the recipient would certainly not be a man anymore. And this is an indispensable condition for the reception of the sacraments." However, he does acknowledge that if the separation of the soul from the body is "doubtful" in the eyes of the doctors present, it is still possible for the sacrament to be valid. The Pope continues on to address the question of whether a person is defined as dead after "grave trauma of the brain" or "only when there is complete arrest of circulation" by responding that "the answer cannot be deduced from any religious and moral principle and, under this aspect, does not fall within the competence of the Church... But considerations of a general nature allow us to believe that human life continues for as long as its vital functions – distinguished from the simple life of organs – manifest themselves spontaneously or even with the help of artificial processes" (Pope Pius XII). It seems the Church, while not entirely certain of the moment in which a person has died and leaves his body, was attempting to declare a position that brain death

(while the body and organs still survive) was not a barrier to the bestowing of final sacraments as the person could still be considered to be a man. Pope Pius XII's 1957 address marks the first time the Catholic Church publicly acknowledged the ways in which life-preserving technologies could affect the traditional Catholic understandings of and procedures for human death. This declaration set the precedent for the Catholic Church's future interactions with cases involving artificial life support and the potential for death by asserting that the person remains inside the body even when the body is being kept alive by artificial means. This understanding of personhood in the face of death heavily influenced the Church's 1980 "Declaration on Euthanasia," which maintains that patients being kept alive by life-preserving technology are still alive and states that "when inevitable death is imminent ... it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life" (Sacred Congregation). In other words, while the Church continues to renounce any form of active euthanasia of human beings, here it officially acknowledges that it is ethically acceptable for the patient to deny certain forms of life-preserving treatment. This 1980 declaration remains the standard viewpoint of the Church today regarding extraordinary measures of keeping a patient alive, although the lack of specificity in this declaration in terms of what constitutes "precarious and burdensome prolongation of life" has become a cause of concern in recent cases in which the patient is Catholic, including both the Quinlan and Schiavo cases.

1.1 THE ORIGINS OF "BRAIN DEATH"

In order to explore the current controversies regarding medical "brain death" and the ethics of determining death within a still-living body in more detail, one must

recognize the technological advances that served as a catalyst for the shift in conversation from understanding death as determined solely by loss of heart and lung function to considering death as determined by some measured loss of brain function. Predecessors to the modern medical ventilator, such as the iron lung, have existed since the early 20th century, but Forrest Bird's invention and production of the Bird Universal Medical Respirator in 1955 marked the beginnings of the use of ventilators to extend human life beyond the natural trajectory by circulating oxygen through the patient's body after the body itself becomes unable to do so. This new capability to keep human bodies clinically functioning after those bodies would have otherwise ceased to function led to an immediate concern among medical experts regarding the ethics behind artificial extension of life and the uncertainty that accompanied the declaration of death on a body that is not entirely dead. To combat these concerns, French neurologists Pierre Mollaret and Maurice Goullon crafted the term *coma dépassé* (translated roughly to "beyond coma" or "over-coma") in 1959, which they used to describe patients who had lost all brain function. This definition came in contrast to previous understandings of a coma as a possibly temporary state and insinuated that *coma dépassé* was irreversible. Patients who were declared to be *coma dépassé* were considered to be beyond the help of medical professionals and were generally not recommended for extended ventilator-assisted care. *Coma dépassé* as a permanent and irreparable medical condition created the opening for doctors and family members to decide to remove a patient from a ventilator with the belief that it was in fact the more ethical choice. The introduction of *coma dépassé* as a medical diagnosis only two years after Pope Pius XII's address on it is perhaps not a coincidence; it is certainly possible that Mollaret and Goullon were attempting to

reconcile the ethical implications of removing a patient from life support with the very public stance from the Catholic Church on personhood and comatose patients.

The medical community's definition of brain death changed further in the late 1960s as physicians began to anticipate additional ethical and legal concerns regarding the introduction of new life-preserving technologies and comatose patients. In 1968, Harvard Medical School's Ad Hoc Committee published a groundbreaking report titled "A Definition of Irreversible Coma" in which they expanded on the medical definition of "irreversible coma" as a "new criterion for death" (85). The committee's opening declaration of "an organ, brain or other, that no longer functions and has no possibility of functioning again is for all practical purposes dead" (85) is followed by four requirements for determining irreversible brain death: unreceptivity, no movement or breathing (without the aid of a ventilator), lack of reflex movements, and a blank electroencephalogram (EEG), which measures brain activity (85-86). The committee recommends that such patients, once declared, should be disconnected from any artificial medical life support; this recommendation is followed by a strong emphasis on following standard procedure for declaration of brain death as a matter of legal protection for the physicians involved.

The report's criteria for brain death have become the standard in the United States, endorsed both legally and in the medical profession. The criteria have been reviewed and endorsed by two presidential commissions, in 1981 and more recently in 2008.³ These commissions, staffed by a wide array of scholars from philosophy, law, medicine, political science, psychology, and other various fields, work to advise the

³ See the President's Commission on Ethical Problems in Medicine and Biomedical and Behavioral Research (1981) and the President's Council on Bioethics (2008).

President on “ethical issues related to advances in biomedical science and technology” (President’s Council on Bioethics).⁴ Additionally, these criteria have reviewed and adopted by the American Neurological Association, made up of academic neurologists and neuroscientists in 1995 and again in 2010. In the more recent 2010 review of brain death criteria, “Evidence-based Guideline Update: Determining Brain Death in Adults” led by Eelco F.M. Wijdicks, M.D. et al., the Association notes that physicians must determine “the presence of unresponsive coma, the absence of brainstem reflexes, and the absence of respiratory drive after a CO₂ challenge” in order to conclude that a patient has lost all function of the brain (1914). While the Association acknowledges that there is not sufficient evidence to adopt a recommended observation time to allow for patients to potentially recover from brain death (1912), the report concludes that the criteria “have not been invalidated by published reports of neurologic recovery in patients” (1914); in other words, there has not been a published account of a patient recovering from medically-confirmed brain death using the criteria first outlined by the Ad Hoc Committee.

Although the essential characteristics of brain death appear to be relatively standard, the diagnostic criteria for declaring brain death are not consistent around the world. A 2002 global study, led by E.F.M. Wijdicks, collected and analyzed the brain death guidelines for adults across 80 countries covering every continent. While “all the recommended guidelines required strict definition of brainstem reflexes,” the diagnostic methods varied greatly; for example, 44% of guidelines required at least one physician’s diagnosis, 34% required two, 16% required between three and four, and 6% did not

⁴ For more information on the members of these commissions, see Georgetown University’s Bioethics Archive, particularly the citation referenced above regarding the 2008 council members.

specify how many physicians must make the decision to determine brain death (21). Additionally, throughout Europe alone, the observation period for brain death diagnosis varies greatly from no required observation to a period of 48 hours; in Georgia, a physician must have five years of experience in the neurosciences before earning eligibility to determine brain death; in Bangladesh, at least one of the three required physicians must be at least an associate professor in academia; and in South America, confirmatory tests for brain death are optional in the majority of countries surveyed (21-24). The legitimacy of brain death as a medical diagnosis appears to be widely accepted, but it is the methodology and understanding of death as a more complex experience that continues to create controversy.

1.2 MEDICAL AND LEGAL IMPLICATIONS IN PRACTICE

With the recognition of brain death came the problematic issue of when (and even if) the person in question has actually died. Despite the relatively uniform guidelines regarding the characteristics of brain death, in practice, the medical community is divided on this concept of a “moment” of death, and it is at this point that medical and legal conversations are so closely intertwined that it is impossible to separate them. Medical professionals are required to record an official time of death for each patient, which is typically recorded for brain-dead patients as the moment when the body, disconnected from the ventilator, ceases to live on its own via cardiorespiratory function. The requirement of an official medical and legal time of death complicates the notion of brain death and death alongside life-support technologies, leading scholars and professionals to disagree on whether or not determining a moment of death is even possible. There are two principal viewpoints that are in contention with one another: that a person’s death

only occurs when the physical body has ceased to function, and conversely, that a person's death can occur before his or her physical body has ceased to function.

Thinkers who adhere to the first viewpoint are, unsurprisingly, quite against the notion of brain death and the removal of supposed brain-dead patients from ventilators as their bodies are still living. While scholars who support this viewpoint are dwindling in number, it is still important to examine this perspective in order to better understand the alternatives. One of the primary works that represent this standpoint is A.M. Capron and L.R. Kass's "A Statutory Definition of the Standards for Determining Human Death: an Appraisal and a Proposal." Published in 1977, Capron and Kass's work reflects the tensions of the time period as witnessed by a law professor and a physician; only a mere decade after Harvard's Ad Hoc Committee supported the notion of brain death as a legal cause for death, many medical professionals and scholars alike were concerned with the potential legal consequences of declaring a person dead who may not truly have died. Capron and Kass recognize the loss of cardiorespiratory function as an acceptable definition of death, positing that "the determination that a person has died is to be based on an evaluation of certain vital bodily functions, the permanent absence of which indicates that he is no longer a living human being" (119). While they do acknowledge that artificial means of life support do complicate matters, they still hold cardiorespiratory function as a key determiner in human death.

The second viewpoint, that a person can die and leave the physical body behind before the body itself ceases to function, comes in direct contrast to the first. James Bernat (et al.), a physician and neurologist, responded in direct contention to Capron and Kass in their 1981 response "On the Definition and Criterion of Death" in which they

accept Capron and Kass's definition of death as a suitable test for loss of brain function, but consider the loss of brain function to be the true moment of death regardless of continuing bodily functions: "A person will be considered dead if ... he has experienced an irreversible cessation of all brain functions. ... Death will have occurred at the time when the brain functions have irreversibly ceased" (393). Bernat et. al. put increased emphasis on the function of the brain as the true sign of human life, rather than function of the heart or lungs. This distinction is significant when thinking about the spiritual aspect of death and the concept of a soul.

Bernat et. al. support the notion that death occurs in a "more or less definite time," arguing that viewing death as a process complicates death with the processes both of dying and of post-death disintegration (389). Instead, they insist that death be viewed as the singular moment between those two processes and not as a process itself. This viewpoint of death as a moment in time is generally supported by legal definitions of brain death, such as in *Defining Death*, the study conducted and published by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in 1981; this study defines death as a moment in time in the proposed definition of death, clarifying that "although it assumes that each dead person became dead at some moment prior to the time of diagnosis, the statute does not specify that moment. Rather, this calculation is left to 'accepted medical practices' and the law of each jurisdiction" (77). *Defining Death* directly informed the Uniform Determination of Death Act (UDDA), which was approved that same year and currently serves as the guidelines for determining brain death in 37 U.S. states, the District of Columbia, and the

U.S. Virgin Islands.⁵ The UDDA's key statement on death is that "an individual who has sustained either 1) irreversible cessation of circulatory and respiratory functions, or 2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards," (5) and this statement was approved by both the American Medical Association and the American Bar Association upon publication (1). This statement includes both physical death through disaster or disease, but also brain death, adhering to the concept of total brain death and leaving determination of death open for interpretation and varying state medical standards.

1.3 THE INTERSECTION OF BRAIN DEATH AND RHETORIC

Medical and legal scholars are clearly divided on how to navigate the elusive "moment" of death, particularly when artificial life support is involved. It is within this divide in the conversation that rhetoricians, who are more removed from actually working with patients and families in any sense, can bring their own perspectives in order to cast a different light on some of these cases, including Quinlan's and Schiavo's. In particular, rhetoricians can offer methods and terminology to examine the ways in which different perceptions of death, life, and agency are formed within both the medical and legal spheres; these contentious conversations are without doubt already rhetorical in nature, but rhetoricians can do more to interject into these discussions by examining how similar language is used differently in various discourse communities, particularly

⁵ As listed by the Uniform Law Commission's "Legislative Fact Sheet - Determination of Death Act," although some states have adopted the UDDA with additions or revisions. Texas, for example, stipulates that "death must be pronounced before artificial means of supporting a person's respiratory and circulatory functions are terminated" (Determination of Death 671.001). Florida requires two physicians to determine brain death; one must be the "treating physician, and the other physician shall be a board-eligible or board-certified neurologist, neurosurgeon, internist, pediatrician, surgeon, or anesthesiologist" (Recognition of Brain Death under Certain Circumstances 382.009).

medical and legal communities. When considering how to best combine rhetoric with the medical and legal conversations surrounding the Quinlan and Schiavo cases, Kenneth Burke's notion of "terministic screens" seems particularly useful when examining the ways in which the different parties involved in the Quinlan and Schiavo cases portrayed the situation and delivered their arguments; by using Burke's concept of the terministic screen, we can examine not only how each party's perspective was formed, but also how each party utilized their perspective to create an argument. Burke describes his terministic screens as ways in which attention is directed regarding a particular subject. To clarify, Burke likens terministic screens to color filters on a photograph; the same photograph, when altered with a filter, can look quite different and seem to actually portray a different image. As Burke describes in "Language as Symbolic Action," "here something so 'factual' as a photograph revealed notable distinctions in texture, and even in form" (1035). The same understanding, Burke asserts, can be applied to a variety of other situations. In particular, he attributes a similar phenomenon to our choice of terminology when describing a situation: "much that we take as observations about 'reality' may be but the spinning out of possibilities implicit in our particular choice of terms" (1035). Depending on our word choices and the perspectives from which we view a situation, our understanding of that situation could differ drastically. Burke's notion of terministic screens can be used to examine not only how the public viewed Karen Ann Quinlan's and Terri Schiavo's stories, but how the parties directly involved viewed their situation as well. If one party viewed the patient as truly alive inside her body, such an understanding would lead that individual to very different beliefs of the situation and

possible solutions, particularly when compared to someone who viewed the patient as being kept only artificially supported in all matters of life.

Tod Chambers, former president of the American Society for Bioethics and the Humanities, addresses the current lack of crossover between the humanities, medicine, and bioethics in “The Virtue of Incongruity in the Medical Humanities.” Chambers acknowledges the possible gains to be made by increasing the interdisciplinary conversations between the humanities and medicine, relying heavily on Kenneth Burke’s “perspective by incongruity”; while Burke argues that terministic screens are an unavoidable necessity in understanding our world, he also warned that “every way of seeing is also a way of not seeing” (qtd. 152). Chambers advocates for a greater interdisciplinary effort to bring in vocabulary and perspectives from the humanities in order to gain different insights into current medical and bioethical questions.

While we are not to the point of interdisciplinary work that Chambers calls for, some rhetoricians have begun to build a field of medical rhetoric in which more rhetorical terminology and other humanities-specific discourses are being used to create a new understanding of the medical sphere. Robert Wade Kenny, a rhetorician with a background in psychology, uses Burke’s work with terministic screens and the importance of particular terminology in “A Cycle of Terms Implicit in the Idea of Medicine” to examine Karen Ann Quinlan as an icon who played a role in shaping the American public’s understanding of life support, euthanasia, and medicine. In particular, Kenny looks at the various portrayals of Quinlan both in the courtroom and in news media in order to piece together an understanding of how such portrayals led to the rise of “life-sancity advocates” and right-to-die supporters within the United States. Political

theorist Russell Keat makes a similar move to intersect the humanities with medical studies in “The Human Body in Social Theory: Reich, Foucault, and the Repressive Hypothesis,” this time using the works of Wilhelm Reich and Michel Foucault to construct an argument against the understanding of human bodies as belonging to the biological world; relying primarily on Foucault’s “repressive hypothesis” as an example of Foucault’s rejection of human bodies as simply biological beings, Keat argues that there is indeed something distinctive that separates human beings from the biological world we reside in, allowing for a nuanced understanding of human beings as they are viewed within the medical sphere as perhaps something more than simply a biological body to be maintained or returned to the natural world.

The work of philosophers, social scientists, and rhetoricians can perhaps be most often found in the intersection between medical studies and social and public communications. Rhetoricians are interested in how the public views medical procedures and patients, which has led to some very recent and fascinating interdisciplinary work. John Sutton Baglow’s “The Rights of the Corpse” made waves in the interdisciplinary journal *Mortality* by asserting that corpses indeed have limited rights due to social obligations to respect the dead. In particular, Baglow argues that the dividing line between living and dead is tenuous and unclear, and as a result, it is impossible to determine a singular moment in which a human body ceases to have rights. As his assertions relate to cases such as Quinlan’s and Schiavo’s, in which the families of the patients attempt to take ownership of those rights, Baglow’s claims that “in claiming the corpse of a family member, is actually carrying out an obligation to that corpse, rather than asserting rights or ‘ownership’ over it” (236) create an interesting perspective on

family members making decisions on the behalf of someone who cannot speak for themselves. Megan Foley tackles the issue of agency of a body that cannot speak in “Voicing Terri Schiavo,” examining the public outcry for this “woman without a voice” (qtd. 382). In this piece, Foley argues that Terri’s voiceless body became a symbol to the American public that created anxiety and fear over self-representation in the United States. She opens with Michel Foucault’s notion of biopower, or “the right to make live and to let die” (qtd. 383), using this understanding of biopower to investigate the legal and legislative involvement in the Schiavo case. As Terri could not speak for herself, others had to make legal decisions to either keep her living or allow to her die, but both of these options required someone else to forcibly overstep Terri’s sovereignty as a citizen and make a decision one way or the other, rather than protecting her right to decide for herself. Indeed, the question of personal agency and voice became one that spurred the American public into a frenzy in both the Quinlan case and the Schiavo case as everyday people became outraged and terrified at the thought of a comatose patient being considered “dead,” and being treated as such, in any form other than physically.

In this piece, I plan to make use of rhetoric’s current attempts to intersect the medical and legal conversations surrounding brain death, patient agency, and public perceptions of death as they relate specifically to Karen Ann Quinlan and Terri Schiavo. In particular, I will use the work of Kenneth Burke to continue to examine the significance of various terministic screens in the medical, legal, and public perspectives on each of these cases, as the differing terminology and understanding of such terminology heavily influences the ways in which the different parties create and build their arguments. In the Quinlan case, the argument made by her physicians that she was

not brain-dead by any definition is certainly colored by the language of medical documents of the time period, and it will be valuable to examine how the medical discourse surrounding Karen Ann and her diagnosis helped to shape the outcomes of her case as well as future cases, including Terri Schiavo's. For the Schiavo case, it is the legal discourse that deserves more significant examination; in particular, the relentless arguments regarding patient agency and legal guardianship by both family members and the courts are certainly shaped by the language of the legal discourse community both in how laws would be written and interpreted and how future decisions would be made.

CHAPTER 2

KAREN ANN QUINLAN

The case of Karen Ann Quinlan can be regarded as one of the landmark cases that has influenced the “right to die” movement and the rhetoric regarding medical patients in comatose and persistent vegetative states. Her story was used as a reference point throughout the Terri Schiavo case, including as evidence by Mary and Robert Schindler in their argument that their daughter should not be removed from artificial life support. Despite the similarities between the Quinlan case and the later Schiavo case, the key distinction between the two seems to be where the rhetorical argument was centered.⁶ While the controversy in Terri’s case occurred primarily in the legal sphere through endless court appeals, Karen Ann’s case was centered in the medical sphere due to confusion and disagreement over how her medical condition affected her rights as a patient and others’ capacities to make medical decisions on her behalf. While Karen Ann’s parents, their lawyer, and the attending physician all agreed that she was not “brain dead” despite her persistent vegetative state, the central conflict became a question of who was responsible to make decisions on Karen’s behalf and whether or not removing Karen from her ventilator would qualify as homicide. In particular, it will be useful here to examine how the opinions and testimony of the medical experts involved in this case

⁶ In order to clarify between the patients and their families, I will refer to the patients by their first names: Karen Ann and Terri, respectively, from this point forward.

affected the legal conversation surrounding the issue of patient agency, guardianship, and decision-making. Kenneth Burke’s notion of “terministic screens,” as mentioned previously, can serve as a valuable tool for understanding the perspectives of each of the different parties involved in this case, including their perceptions of Karen Ann and her agency as well as the limitations of these perceptions.

Karen Ann Quinlan was born in 1954 and adopted shortly after by Julia and Joe Quinlan; the Quinlans raised their daughter as a Catholic, similarly to Terri Shiavo’s later upbringing. Karen fell into a comatose state after attending a party in 1975 at the age of 21. While official court documents retain that the cause of her collapse “remains unclear” (In Re: Quinlan), Julia Quinlan acknowledges in *My Joy, My Sorrow* that Karen Ann’s friends reported fast-dieting as well as heavy amounts of alcohol and possibly some drugs (38). Dr. Robert Morse, the leading neurologist involved in the case, testified in court that the patient’s EEG was “abnormal but it showed some activity and was consistent with her clinical state,” referring along with other physicians to her condition as a “chronic persistent vegetative state” (In Re: Quinlan). Considering Karen’s “sleep-wake” cycles in which she remained unaware of her surroundings but opened her eyes and cried out, her neurologists testified that they “believed with certainty that Karen Quinlan is not ‘brain dead’” (In Re: Quinlan), citing the Harvard Medical School’s 1968 Ad Hoc Committee report’s requirements that a patient must lack reflexive movements and have a blank EEG in order to qualify as suffering from brain death, which Karen’s condition did not match. The Ad Hoc Committee’s report specifically describes the blank EEG as being “of great confirmatory value,” stating that “when available it should be utilized” (85-86); this language places significant weight on the EEG as a determining factor, creating a

situation for Karen Ann's physicians that made it impossible for them to declare her to be brain dead in any capacity.

Karen Ann's loved ones all seem to have approved of her medical diagnosis, including the assertions that she was not brain dead. In her memoir, Julia Quinlan consistently refers to her daughter as still living, describing the family's decision to remove her from the ventilator as something they "knew Karen would want, had she been able to express her feelings" (44) and that the family "wanted her to die peacefully" (52). However, the Quinlans found themselves in a legal battle over whether or not to remove Karen from her artificial life support. After the family gave the hospital permission to discontinue the life support, the hospital rejected the decision, arguing that at the age of 21, the patient was of legal age and her parents could not make such a decision on her behalf without going to court to pursue legal guardianship. Joe Quinlan requested legal guardianship of his daughter later in the year of 1975; the first legal verdict, that Joe Quinlan would not be granted guardianship, was issued by Judge Muir on November 10, 1975 with the conclusion that "there is always the dilemma of whether it is the conscious being's relief or the unconscious being's welfare that governs the parental motivation" (261); Muir was concerned that Mr. Quinlan's personal desire for a resolution to his grief would cloud his decision-making abilities in reference to his daughter's life. Joe Quinlan appealed Muir's decision, ultimately earning guardianship of his daughter in 1976 when the Supreme Court, led by Chief Justice Hughes, decided that Muir's concerns regarding Mr. Quinlan's ability to make decisions for his daughter in the face of his grief and personal emotions were unfounded, writing that "his strength of purpose and character far outweighs these sentiments and qualifies him eminently for guardianship of the person as

well as the property of his daughter” (36). Despite Judge Muir’s initial concerns about Mr. Quinlan’s ability to discern between his own desires and what might be best for his daughter, the courts eventually appointed him to be Karen Ann’s guardian, favoring his status as the patient’s father. The American legal system has an established history of providing parental guardianship over children as a fundamental right; a precedent set by the 1925 *Pierce v. Society of Sisters* establishes and protects a parent’s fundamental right to the care and management of his child under the due process clause of the Fourteenth Amendment, referring to children as not “mere creature[s] of the state” but instead as citizens under the primary authority and responsibility of their parents.⁷ The establishment of legal precedents in the American justice system directs future court decisions, guiding (and limiting) the possible perspectives for the courts to take. This particular screen through which immediately family (and particularly parents) are valued as responsible guardians certainly colored the courts’ perception of Mr. Quinlan’s guardianship case, and as a result, Mr. Quinlan’s capabilities as a parent ultimately went unquestioned.

The Supreme Court’s overturning of Muir’s initial decision allowed the Quinlans to move forward with their wishes, but St. Clare’s Hospital continued to refuse to remove Karen Ann’s ventilator even after the Supreme Court ruled that “the ensuing death would not be a homicide but rather expiration from existing natural causes,” as quoted in Julia Quinlan’s memoir (52). While her doctors eventually carried out the court’s decision to allow her ventilator to be removed, St. Clare’s pressured the Quinlans into finding a different hospital or location in which their daughter would presumably die shortly after

⁷ This court case struck down an Oregon law requiring parents to enroll their children in public schools (*Pierce v. Society of Sisters*, 268 U.S. 510).

in order to sidestep any responsibility for her death (54-56). From the perspective of a medical facility that was directly affiliated with the Catholic Church, St. Clare's was undoubtedly concerned about the potential for legal and ethical ramifications of a patient like Karen Ann being removed from a ventilator and dying under their supervision. In fact, Pope Pius XII's declaration on personhood and life support technology less than two decades earlier maintains that "human life continues for as long as its vital functions ... manifest themselves spontaneously or even with the help of artificial processes," which certainly would mean that Karen Ann remained a living person so long as the ventilator kept her alive. It is not unlikely that Pope Pius XII's language here shaped the terministic screen through which St. Clare's viewed this situation and led the hospital to conclude that removing her from her ventilator would still constitute the murder of a living person, regardless of what the courts had previously determined. St. Clare's battled against the removal of Karen Ann's ventilator for six weeks before reluctantly agreeing to allow for the removal as long as she was immediately moved to a different location afterward. Karen Ann was weaned off her ventilator in May of 1976, and much to everyone's surprise, she did not die when the ventilator was removed; in fact, she lived for nearly another decade with the assistance of a feeding tube, dying of pneumonia complications on June 11, 1985 (53-54; 106).

2.1 MEDICAL DISCOURSE IN THE QUINLAN CASE

Karen Ann's case is unique in part because of the kairotic positioning of her story in the history of medical advances in life support technology. Her collapse and subsequent hospitalization came at a time when life-preserving technology and definitions of death were still tenuous at best. Harvard's Ad Hoc Committee had only

released their new criterion for death a mere seven years previously; one of the report's new requirements for a diagnosis of brain death was a blank EEG, which Karen Ann did not have. The report also stressed the importance of doctors and hospitals protecting themselves legally when treating patients who may be considered to be brain-dead, something that Karen Ann's hospital took very seriously when regarding her case. Based on statistics regarding heart transplants in the United States, some argue that the Ad Hoc Committee's report was released simply to protect doctors performing such transplants, rather than to be used as evidence in a case like Karen Ann's.⁸ Additionally, much of the life-preserving technology in use in the 1970s was still quite new, causing confusion and ethical concerns regarding whether or not it was the correct thing to do to artificially keep someone alive who would otherwise die. Essentially, Karen Ann's collapse came at a time when no one, including physicians, were certain of how to handle such a situation. It is nearly impossible to delve into procedures and outcomes of previous comatose patients who came before Karen Ann, perhaps because the life-support technology simply had not been developed or implemented in order to cause controversy for physicians and families; without readily available technology to preserve the life of a comatose patient, that patient would simply die. Timeliness is one of the most significant reasons as to why Karen Ann's story became so widely known; it is one of the first to carry on long enough for anyone to battle over its outcome.

The physicians involved in Karen Ann's case were quite open with their beliefs regarding whether or not their patient was still alive inside her body; although no one can

⁸ See Jill Lepore's "The Politics of Death": "The first heart transplant was conducted in 1967; in 1968, doctors transplanted more than a hundred hearts. Brain death, which is something between a medical fiction and a legal one, was meant to facilitate organ transplant; it had little to do with the kind of decision the Quinlans faced."

be certain of their motives, it is possible that they merely sought to protect themselves and their profession as cautioned by the Ad Hoc Committee. Regardless of reasoning, Karen Ann’s physicians maintained throughout their medical and legal discourse that she was not dead at all, causing complications in the Quinlans’ attempt to remove her from the ventilator. As Julia Quinlan explains, the authorization papers that Joe Quinlan signed at the hospital granting permission to discontinue all “extraordinary means” of care were rejected by the hospital two days after the signing, stating concern over a potential homicide charge (44). This concern was not unfounded; not only did the Ad Hoc Committee express concern over the legal protection for doctors, but there was legal precedence to hold doctors responsible for preserving life. In the first court hearing regarding Joe Quinlan’s petition for guardianship, one physician testified that “to terminate the respirator would be a substantial deviation from medical tradition” (In Re: Quinlan); Judge Muir confirmed this precedence, stating that the refusal of Karen Ann’s physicians to move forward with her family’s requests matched “the then existing medical standards and practices,” citing the 1964 Schueler v. Strelinger case in which it was determined that a doctor is required to “exercise ... the degree of care, knowledge, and skill ordinarily possessed and exercised in similar situations by the average member of the profession practicing in his field” (In Re: Quinlan). As evidenced by Muir’s written response, he seems to have focused heavily on the question of whether or not Karen Ann was “alive” within her artificially-supported body, ultimately concluding that “Karen Quinlan is by legal and medical definition alive. She is not dead by the Ad Hoc Committee of Harvard Medical School standards nor by the traditional definition, the stoppage of blood circulation and related vital functions” (In the Matter of Karen

Quinlan). The belief that Karen Ann was still alive seems to have been a strong motivating factor in Muir's final decision to not allow her father, who wanted to remove her ventilator, to become her legal guardian. In particular, the physicians' strong assertions that the patient was not brain-dead despite her persistent vegetative state are striking; besides their reference to the recent Ad Hoc Committee declarations on brain death, their statements were grounded not in medical discourse, but in personal beliefs. The physicians also agreed that Karen Ann would not improve and was medically incompetent, and yet refused the removal of her ventilator due to their beliefs about the preservation of life. The language of the Ad Hoc Committee's recent report, which privileged the EEG over other perhaps more subjective requirements, such as observation of patient response to light and sound, certainly created a particular terministic screen through which the physicians involved in this case viewed the patient and situation. As the report specified that a blank EEG should be used as confirming evidence of brain death above other observational evidence, rather than equal alongside it, the physicians' perspective of Karen Ann's situation was consequently shaped by the Committee's choice of language. For example, despite observations by the physicians and family that Karen Ann was unable to consistently respond to light and sound, such as people speaking to her, the language of this defining report restricted the ways in which the physicians could understand and interpret their patient's diagnosis as either brain-dead or not. Examining the medical language used to guide the physicians' decisions through the understanding of terministic screens sheds a new light on the rhetorical influence of language that might otherwise seem straightforward and unambiguous.

It is important to note that the legal battle over the fate of Karen Ann Quinlan also escalated in part due to confusion over whether or not Karen remained in control of the medical procedures performed on her body even while unable to physically speak for herself. Additionally, if she lost her autonomy due to her physical and mental condition, who was responsible for speaking for her, and how much weight should their words hold? Rhetoricians have begun to tackle this question primarily through the examination of rhetorical power present in human corpses. To return to Baglow's "The Rights of the Corpse," rhetoricians have begun to interrogate the tenuous space between a living person with autonomous rights over his own body and a corpse that can no longer speak for itself in any capacity. While Baglow argues that the corpse retains its previously-human rights and that guardians simply carry out those rights, rather than taking over those rights, James Stacey Taylor and Aaron Spital take up a directly opposing argument in "Corpses Do Not Have Rights: A Response to Baglow" in which they focus on the definition of rights as "tools that persons may use to protect their interests" (285). Taylor and Spital maintain that corpses, as inanimate objects, have no interests to protect and therefore do not have any use for rights. Interestingly, this argument leads Taylor and Spital to conclude that "if rights are generated by obligations concerning the treatment of corpses, it is the surviving relatives and friends, not the corpses, who hold those rights" (285), providing an alternative understanding of the rights of the family when a patient has been declared to be in a persistent vegetative state. This particular argument creates an uncertain space for people like Karen Ann, who is in some respects "inanimate" in that she cannot speak for herself; if this is the case, then it would seem entirely plausible to pass along her rights to those who surround her hospital bed, including her family.

In 1975, only eight states had adopted any sort of laws defining brain death; the Quinlans' state of New Jersey was not one of them (Lepore), meaning that the legal definitions of Karen's situation were even more uncertain. Despite her family's attempted documentation of her reported beliefs on artificial life support, the legal system ultimately ruled that such statements did not hold legal ground and could not be considered as evidence. Such conclusions contrast sharply with what the Hastings Center Project on the Termination of Treatment and Care of the Dying, directed by leading bioethics and medical professionals, lists in *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* as the four central values of Western medical practices, which are beneficence, professional integrity, justice, and personal autonomy (6-8). Jon Eisenberg, appellate lawyer who worked with Michael Schiavo, acknowledges in "The Continuing Assault on Personal Autonomy in the Wake of the Schiavo Case" that these values are considered equal, although he argues that personal autonomy has the most significant support in medical practice as well as American law. As Eisenberg outlines, personal autonomy can be traced back as far as 1891's *Union Pacific Railway Co. v. Botsford* in which the Supreme Court supported "the right of every individual to possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law" (qtd. Eisenberg 102). More recently, Eisenberg notes the 1990 *Cruzan v. Director, Missouri Dept. of Health* as supporting "bodily integrity [and] the right to refuse medical treatment" (102). While it seems clear on the surface that Americans have a right to make medical decisions for their own bodies, it becomes nearly impossible to determine a clear decision when the patient in question is incapable of physically speaking for themselves.

The Hastings Center Project acknowledges that the vast majority of Americans do not have advance directives on file that clearly state instructions for future medical care, and they maintain that the next step in the decision-making process on behalf of the patient should be “substituted judgment” in which a surrogate decision-maker relies on the patient’s known values or preferences; the third option to follow, attempting to decide in the patient’s “best interests” as an objective decision-making process, is only to be used as a last resort (27-28). These guidelines seem to clearly indicate that Karen Ann’s known values and statements on life as described by her family should have taken precedence over a “best interests” route led by outsiders to her case, and yet her previous statements on life and death were marginalized.

For Karen, her supposed statements and beliefs were ultimately determined to be inapplicable to her case because the courts ruled that her statements were not indicative of her actual situation, but rather, the situations of people around her. Additionally, while her Catholic beliefs were considered via Pope Pius XII’s statements and the support of her parish priest Father Trepasso, the Catholic Church’s viewpoint on artificial life support was not strong enough to warrant influence on the court’s decision. When the original decision regarding Joe Quinlan’s guardianship status was overturned, the Supreme Court did acknowledge Karen Ann’s constitutional right to privacy, including under that broader right that “citizens could make decisions that profoundly affect their own lives” (Quinlan 51) and that, as Karen was incompetent to assert that right for herself, a guardian could do it for her. Even so, there was no legal acknowledgement of Karen Ann’s personal agency over her body. When the courts granted Joe Quinlan legal guardianship of his daughter, there was no stipulation that he be required to respect or

adhere to her personal wishes or values; rather, the courts determined that he was a suitable judge of her fate, following what the Hastings Center Project describes as the last possibility for making a decision on behalf of an incapacitated patient. In fact, Chief Justice Hughes focused his verdict on Mr. Quinlan's "strength of purpose and character" (36) as a reflection of his ability to make respectable decisions on behalf of his daughter. By passing responsibility on to her father, her agency was essentially erased as the courts allowed someone else to make decisions for her.

2.2 PUBLICITY IN THE QUINLAN CASE

Media coverage of Karen Ann Quinlan's story created a tragic account of a young girl's mysterious collapse and heartbreaking comatose state. What made her story so uniquely moving for so many people amidst the other tragedies that could have captured their attention instead? In order to explore the possible answers to this question, it is useful here as well to continue to interrogate Kenneth's Burke's notion of terministic screens, this time to examine the limiting effects they can have on the public's understanding of a news story as portrayed through various media.

It is easy for news sources to capitalize on a story that is unique or otherwise unprecedented, such as Karen Ann's. News media serves as an art form for many, and as Burke contends in *The Philosophy of Literary Form*, art forms are capable of providing symbolic resolutions to the difficulties that many people face in their daily lives (304). However, as other art forms are limited, news media (particularly newspaper headlines and nightly news channels, which were the most prevalent forms of news media in the 1970s) is limited in the lenses or screens through which it can provide its audiences with information. Quite often, news media take a tragic or dramatic approach to storytelling in

order to hook their audience, but such an approach has a larger effect on the general public. When describing the murder of Matthew Shepard in “The Politics of Negotiating Public Tragedy,” Brian Ott and Eric Aoki argue that “the news media’s tragic framing of that event works rhetorically and ideologically to relieve the public of its social complicity” (271), and a similar perspective can be taken here. The public, anxious and unhappy with the confusion surrounding artificial life support and specifically Karen Ann’s situation, were able to reconcile its distress through the transformation of Karen into a tragic and symbolic martyr.

In the 1970s and 1980s, technology still largely limited the general public to the information and images that the family was willing to release, and coverage of Karen Ann’s story was almost entirely limited to word-of-mouth discussion and written text. Eleanor Clift notes in *Two Weeks of Life* that the Quinlans never allowed their daughter’s photo to be taken while she was in the hospital, and no video was ever released of Karen Ann from either before or after her collapse (95). A school photo from Karen’s high school years was used so often by the media that it assisted in turning her into an icon for the public.



Fig. 2.1 Karen Ann Quinlan's high school photo.

Due to the lack of updated photos or video footage of Karen Ann, the media and the general public had to be creative with their representations of her. As Julia Quinlan describes in the 1977 *Karen Ann: the Quinlans Tell Their Story*, in the midst of the media hysteria surrounding her daughter, “most of the artists drew beautiful sketches, because the public wanted to think of her as a ‘sleeping beauty.’ They always painted her with long hair. They didn’t know her hair was cut short. And they made her face very thin, drawn. They couldn’t know that it was more full and round than it had ever been when she was healthy” (222). The news media capitalized on the “sleeping beauty” epithet as it created the perfect tragic character for the public to react to; bioethics historian M.L. Tina Stevens perfectly describes the circumstances that created the sensationalism that surrounded Karen Ann in *Bioethics in America: Origins and Cultural Politics*: “her youth, gender, and comeliness, the mysterious origin of her unconsciousness, and the grotesque condition in which she was left gave Karen’s tragedy a romantic, mythic

quality” (110). As Burke writes when describing terministic screens, “even if any given terminology is a *reflection* of reality, by its very nature as a terminology it must function also as a *deflection* of reality” (emphasis original; *Language as Symbolic Action* 1035). The term “sleeping beauty” may serve to reflect the image that the public longed to see, but it also by necessity deflects the public’s perception and line of sight away from the truth. Although Karen Ann was indeed in a comatose state, she was not the graceful, serene “sleeping beauty” the public longed to believe in; to the contrary, she often seemed to be in pain, repeatedly fell ill, and continued to lose weight until her death at only 65 pounds (Quinlan 40-41). However, all the public required was the simple, romantic notion of an innocent girl struck by tragedy, and the media-created “sleeping beauty” persona combined with a lack of evidence to the contrary was more than enough to satisfy the public’s need for a martyr to pray for and mourn over, and many did. In addition to news articles and talk show discussions, Karen Ann’s story spurred a television movie, all of which stimulated public interest in the case and led to vigils and letters sent to her family. As Julia Quinlan describes, most of the correspondence was sympathetic, as “parents across the country saw our family as being similar to their own. They saw our tragedy as something which could easily happen in their own homes” (74). The ease of which American families could identify with the Quinlans’ story allowed for the highly emotional responses to Karen Ann, her court cases, and her fate; if every set of parents can imagine their child lying in a hospital bed and themselves at odds with the court system over whether or not to release their child from pain, it becomes impossible for Karen Ann’s story to not incite an emotional frenzy among the general public.

Indeed, Karen Ann almost immediately became an icon of the burgeoning “right to die” movement in the United States. The 1970s were a time of significant change in life-preserving technologies and procedures, and for the first time, a significant number of Americans were dying in hospitals or in hospice situations, aided by the new medical technologies available. Derek Humphry is often credited with jumpstarting the right-to-die movement in 1980 with the founding of the Hemlock Society, an organization which campaigned for law reform regarding assisted dying; these same organizations refer to Karen Ann and her case as the catalyst for Humphry’s actions.⁹ In response to the confusion over who had the right to speak for Karen Ann once she could no longer speak for herself, organizations such as the Hemlock Society began to campaign for advanced care directives, or methods through which people could document their medical and healthcare wishes for a future time when they may not be able to speak for themselves. Although attorney Luis Kutner first proposed the idea of a living will as a way for patients to declare their wishes for the future in her 1969 “Due Process of Euthanasia,” advanced directives were not universally acknowledged until the adoption of the Patient Self Determination Act of 1990, which required medical providers to “inform such individuals of an individual's rights under State law (whether statutory or as recognized by the courts of the State) to make decisions concerning such medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advanced directives” (H.R. 4449). Right-to-die organizations such as the Hemlock Society used the story of Karen Ann Quinlan, and her national fame, as a catalyst to call for political change, such as what eventually became the Patient Self Determination Act. The

⁹ See the Final Exit Network’s “Questions and Answers” and Death With Dignity’s “Chronology of Assisted Dying.”

American public, who could not reconcile Karen Ann’s perceived innocence with her heartbreaking condition, were eager for change that might prevent themselves from falling into a similar situation, as parents or as the victim herself. The tragic and dramatic story of the nation’s “sleeping beauty” created the perfect atmosphere in which to incite change. In *Attitudes Toward History*, Burke refers to the different frames through which an event can be represented as “symbolic forms”; he divides these different forms into “forms of acceptance” and “forms of rejection” (3). Tragedy, the frame that best fits Karen Ann’s story as told through news media at the time, falls under the forms of acceptance, which allow people to ultimately accept a situation or event. While it may seem as though a tragedy like Karen Ann’s would, and did, spur the public to demand effective change, Ott and Aoki argue that tragic framing “brings about symbolic resolution without turning the event into a lesson for those involved.... the public achieves resolution *in this instance*, but does not substantively alter its character to insure that future instances are less likely” (281, emphasis original). While legislation like the Public Self Determination Act required physicians to make patients aware of their options regarding advanced directives and the right to refuse medical treatment, this particular law and others like it have arguably failed to create a significant and lasting change in the medical and legal landscapes of the United States. One of the most recent and controversial examples of the continued tension and uncertainty regarding a patient’s “right to die” and her guardian’s right to follow her wishes is the story of Terri Schiavo, who collapsed into a persistent vegetative state in 1990 and remained alive with the assistance of a feeding tube for more than fifteen years while a legal battle waged around her.

CHAPTER 3

TERRI SCHIAVO

Theresa “Terri” Schiavo collapsed in 1990, was determined to be in a persistent vegetative state, and was then kept alive through a feeding tube until her death more than a decade later in 2005. Her case is distinctive from similar past cases largely because of the significant legal hostility between her parents, Robert and Mary Schindler, her husband, Michael Schiavo, and eventually a variety of governmental agencies from Governor Jeb Bush to the Supreme Court. While modern communicative technology, such as the Internet, certainly played a role in the national and international attention garnered by this case, it is also significant to note how each involved party played a unique role not previously seen in similar cases. While earlier cases, including Karen Ann Quinlan’s, relied heavily on medical discourse regarding a PVS patient, the Terri Schiavo case was ultimately fought and determined through the legal system. Although there were certainly disagreements between Michael, the Schindlers, and Terri’s physicians in regards to how severe Terri’s brain damage truly was, it was concerns of legal guardianship and patient agency that came to the forefront of the ensuing legal battle. For Terri’s case, it is important to question how and why there was a conversational shift not only from the medical sphere to the legal sphere, but also into the public sphere; returning to Kenneth Burke’s terministic screens, we can examine how the many participants in Terri’s case interpreted her situation and how particular nuances in

language regarding both guardianship and the patient's voice helped to shape the outcome of Terri's story.

Terri collapsed in the apartment she shared with her husband Michael in the early morning of February 25, 1990 in St. Petersburg, Florida. The official police report marks the 911 call from Michael at 5:40 AM with paramedics arriving at 6:33 AM where they found Terri to be unresponsive; she was transported to Humana Northside Hospital where she was placed on a respirator (St. Petersburg Police Department). Neurologist Ronald Cranford, who examined Terri in 2002, contributes Terri's collapse to cardiac arrest, noting in "Facts, Lies, and Videotapes" that she remained in a comatose state for approximately one month, which "then evolved into a vegetative state" (364). Cranford notes that Terri's initial CT scan upon hospital admission was "normal" but that subsequent CT scans showed "a progression of widespread cerebral hemisphere atrophy, eventually resulting in CT scans of 1996 and 2002 showing extreme atrophy," leading to the clinical diagnosis of a "permanent vegetative state" or PVS (364-65).

Michael Schiavo almost immediately petitioned the courts for legal guardianship of Terri in order to hold power of attorney and be able to speak for her legally, in addition to approving her healthcare treatments as her legal husband; in June 18, 1990, Michael was officially appointed as Terri's guardian. At this point, the Schindlers did not object to this decision, as is confirmed by both parties' separately published books.¹⁰ According to Judge George Greer, who worked heavily with the Schiavo case, "during the period of

¹⁰ See Schiavo's *Terri: The Truth* and the Schindlers' *A Life That Matters: The Legacy of Terri Schiavo—A Lesson for Us All*. Michael maintains that the Schindlers "never voiced any objection [and] didn't even come to the hearing in court" (31), while the Schindlers write that, although they did sign the necessary documents, "we didn't realize [in] our naïveté ... that we had essentially given Michael power of attorney" as well as that "we had no idea that such a hearing was held, nor did we know its outcome" (41-42).

time following the incident of February 25, 1990, the parties worked together in an attempt to provide the best care available for Terri Schiavo. On February 14, 1993, this amicable relationship between the parties was severed” (In Re: the Guardianship of Theresa Marie Schiavo). Both parties acknowledge that the tension and anger was caused by the financial settlement from a malpractice lawsuit that Michael had recently won against some of Terri’s former physicians for not noticing possible signs of an eating disorder such as bulimia, which may have contributed to her collapse.¹¹ With the downfall of Michael and the Schindlers’ relationship came the beginnings of a legal battle over Terri that would last over a decade and would come to involve Florida governor Jeb Bush, the United States Supreme Court, and even Pope John Paul II. Judge Greer called for the removal of Terri’s feeding tube in January of 2000, but countless appeals by the Schindlers prevented the removal from actually happening. The feeding tube was briefly removed in April of 2001, only to be reinserted four days later in the face of more appeals. These appeals continued over the next few years, preventing Terri’s feeding tube from being removed for more than a few days at a time before another legal move would have it reinserted. Eventually, Terri’s feeding tube removed for the final time on March 18, 2005, and she officially died on March 31, 2005 (Schiavo Timeline, Part 2). In what the Associated Press describes in “Even in Death, Acrimony over Schiavo” as Michael’s final calculated move, Terri’s gravestone marks her death as the

¹¹ The Schindlers describe the event in an emotional narrative in which they approach Michael about how the money from the lawsuit will be used to pay for Terri’s care, only to have Michael respond, “There’s no money ... This has nothing to do with you ... As far as I’m concerned, you will never see your daughter again—that is, if I have anything to do with it” (53-54). Meanwhile, Michael insists in his book that Robert Schindler was obsessed with the money and asked, “How much am I going to get?” to which Michael responded, “Y’know something? I’m just going to give it all to Terri” (77-78). According to Michael, Robert’s response to this statement was, “This isn’t right. This is my daughter. I deserve money ... I’m going to take over this guardianship” (79).

night she collapsed in 1990 and the 2005 date as the day she was “at peace” along with the inscription, “I kept my promise” (See Fig. 3.1 below).



Fig. 3.1. Terri Schiavo’s gravestone.

3.1 MAPPING THE TERMINISTIC SCREENS IN THE SCHIAVO CASE

Terri’s case, which spanned more than a decade, was complicated by the divisive and disparate perspectives of the parties involved. To return to Kenneth Burke’s notion of terministic screens, “every way of seeing is also a way of not seeing” (qtd. Chambers 152); by incorporating Burke’s understanding of how language can shape and alter perception of a situation, we can examine more closely how the conflicting medical, familial, religious, legal, and public perspectives each played an important role in the outcome of Terri’s story.

One might expect a case such as Terri’s to involve some sort of medical dispute over her condition and whether or not she might improve, but remarkably, all of the

neurologists and attending physicians who examined Terri were in agreement regarding her persistent vegetative state and the prognosis that she would not improve, and there are no court records of opposing testimony. It is significant that there was essentially no medical debate at all regarding Terri's PVS diagnosis; this lack of medical conflict comes in sharp contrast to the Quinlan case, in which the physicians shared strong opinions that she was not "brain dead" by any means and therefore could have some potential to improve. Without any dissent among the medical community, the discussion of Terri's fate moved into the legal sphere, where there was perhaps more to consider. The 2000 Florida Statutes on Healthcare Advance Directives, which were used heavily in this case, define "persistent vegetative state" as "a permanent and irreversible condition of unconsciousness in which there is: (a) The absence of voluntary action or cognitive behavior of any kind. (b) An inability to communicate or interact purposefully with the environment" (765.101). As there is no "or" present between (a) and (b), as exists within other definitions within this section, it can be inferred that both are required for this definition to be applied to a patient. Even within the specific linguistic confines of this statute, the testimony of Dr. James Barnhill, assisting neurologist, and Dr. Vincent Gambone, Terri's attending physician, "conclusively establishes that [Terri] has no hope of ever regaining consciousness and therefore capacity," leading the court to find "beyond all doubt that Theresa Marie Schiavo is in a persistent vegetative state" as determined by Florida Statutes Section 765.101 (6).

In the face of medical agreement that Terri could not improve, the Schindlers would continue to believe that their daughter was not in a persistent vegetative state under the basis that she could indeed respond to their presence; they argued that she was

merely disabled, but otherwise still mentally and spiritually present within her body. Their refusal to accept Terri's prognosis displayed a tenuous relationship between the opinions of medical experts and strong personal beliefs. In contrast, Michael fought to remove all methods of artificial life support for Terri in acceptance of her prognosis, presenting an argument regarding the notion of birth family versus marital family. Despite the medical consensus regarding Terri's condition, the Schindlers uphold to this day their belief that the PVS diagnosis was incorrect, which became a partial catalyst for their legal battle against Michael Schiavo as he attempted to take steps toward removing all artificial life support and allowing Terri (or Terri's body, depending on the perspective) to die.¹² Their denial displays a particular limiting screen as the immediate family of the patient, and particularly as the parents; as they raised Terri from birth and protected her from harm on countless occasions, the notion that it might be impossible to take care of her in this instance no doubt colored their perception of the situation, particularly in regards to guardianship decisions. The Schindlers' position as the parents of the patient calls to mind Judge Muir's initial concerns from the Quinlan case: "there is always the dilemma of whether it is the conscious being's relief or the unconscious being's welfare that governs the parental motivation" (In Re: Quinlan 261). In fact, Judge Greer made a similar comment in 2002: "the court is not unmindful that perceptions may become reality to the person having them," referring to the Schindlers' insistence that their daughter was fully able to see and hear them (In Re: the Guardianship of Theresa Marie Schiavo). It is undoubtedly very difficult for parents to face the notion that their

¹² See the Terri Schiavo Life and Hope Network's "About Us" page: "Michael lost interest in caring for his brain injured, but otherwise healthy, young wife. Terri was not dying, and did not suffer from any life-threatening disease. She was neither on machines nor was she 'brain dead.' To the contrary, she was alert and interacted with friends and family."

child may never improve and will continue to live in a vegetative state, and it is easy to see why the Schindlers, viewing the situation through such the familial screen, were unable to come to terms with Terri's PVS diagnosis. The Schindlers' inability to accept their daughter's bleak prognosis drove them to attempt to assert their power as Terri's immediate family in order to keep her alive.

The central question became one focused on how much weight Terri's wishes and values had, and most importantly, who had the right to speak on her behalf if her wishes could not be clarified. The Schindlers first petitioned the courts to remove Michael as Terri's guardian in July of 1993, but their suit was dismissed (Schiavo Timeline, Part 1). The details regarding this early lawsuit are unknown, but we can examine the later court case that revived the guardianship debate after Michael first attempted to have Terri's feeding tube removed. Richard L. Pearse, Jr. was appointed guardian ad litem in 1998 to assess the situation after Michael petitioned for the removal of Terri's feeding tube.¹³ Here, it is important to examine why Michael was appointed as Terri's guardian without much question in the first place. The simple answer is that Michael, as Terri's legal husband, was held to a higher position of power than Terri's immediate family members in the language and perspective of the law. According to the Florida state statutes at the time, if an incapacitated patient had not issued an advance directive or deliberately named a surrogate to speak for her, "health care decisions may be made for the patient by any of the following individuals, in the following order of priority ... (a) The judicially appointed guardian of the patient, who has been authorized to consent to medical treatment, if such guardian has previously been appointed ... (b) The patient's spouse; (c)

¹³ Such a guardian only represents an incapacitated or otherwise voiceless person for the duration of a legal proceeding.

An adult child of the patient ... (d) A parent of the patient,” and the list continues, all the way down to the seventh in line, a “close friend of the patient” (765.401). Unless there is a different guardian appointed by a judge, the spouse is the primary person with authority over the patient; in the eyes of Florida law, Michael was considered to be notably more significant in his ability to make decisions for Terri than the Schindlers were, who are listed fourth in line behind an adult child of the patient. Here, Florida law held significant power in determining the outcome of this case; Florida law viewed Michael as immediately trustworthy as Terri’s guardian simply because he was married to her, he was granted the power to make decisions for her, which displays another limiting screen through which to view this case. Regardless of how much the Schindlers loved their daughter or felt that Michael’s decisions were inappropriate, they had very little legal leverage to gain control of Terri’s guardianship. Through the terministic screen of the law, they were valued quite a bit less than they believed they should be, which no doubt caused significant tension. As he concludes his report, Pearse notes that a potential financial conflict of interest (who would take control of Terri’s estate if she were to die) made it impossible to determine whether or not the supposed statements made by Terri could be trusted, and acting on Terri’s behalf, determined that the feeding tube should not be removed (In Re: the Guardianship of Theresa Marie Schiavo). However, Pearse notably does not conclude that Michael is an unsuitable guardian, focusing instead on his own responsibility to represent Terri as fairly as possible. With no legal means to take on guardianship of their daughter, the Schindlers had to turn their attention to fighting against Michael’s decisions for her.

The legal proceedings regarding Terri's wishes and her agency as a patient began in January of 2000. Whereas the court system in the Quinlan case rejected the evidence provided by Karen Ann's family regarding her values and beliefs as not substantial enough to be considered true evidence of her wishes for herself without much opposition, Terri Schiavo's purported statements and wishes for herself were weighed heavily in the court proceedings as potential evidence. According to Pearse's 1998 report, the Schindlers acknowledged that Terri had never specifically declared her wishes for herself if she were to become incapacitated, but also denied any knowledge that she had shared such wishes with anyone else, whereas Michael maintained that she had specifically told him that she would not want to be kept alive (In Re: the Guardianship of Theresa Marie Schiavo). However, in the 2000 trial with Judge Greer presiding, the Schindlers used media coverage of Karen Ann Quinlan's case from 1976 as evidence that Terri would not want to be removed from life support if she was ever in a similar situation. Mary Schindler testified that she had conversations with Terri about the Quinlan case when it was in the news, and that Terri "said just leave her alone. Leave her. If they take her off, she might die. Just leave her alone and she will die whenever" (373). Michael Schiavo, however, testified that Terri had made multiple statements to the contrary. According to Michael, Terri made the following statement about her ailing grandmother: "If I ever have to be a burden to anybody, I don't want to live like that" (31). Additionally, Michael testified that Terri had made similar comments when watching television documentaries about people on life support, such as "Don't ever keep [me] alive on something artificial" (35).

Similarly to the Quinlan case, the teachings of the Catholic Church and Terri's Catholic upbringing also came into play, this time more divisively as the two opposing parties attempted to illustrate how Terri's religious beliefs (or lack thereof) may have affected the decisions she would make for herself if she were able to. The Schindlers struggled to balance their own religious beliefs with the possibility of allowing Terri to die. They strongly opposed removing Terri's feeding tube in part because of their Catholic beliefs as described by Terri's brother Bobby: "I know that to remove my sister's feeding tube deliberately to cause her death is euthanasia and is forbidden by the Church" (Schindler 82). Bobby's use of the term "euthanasia" points directly to Pope Pius XII's 1957 address to anesthesiologists as well as the Church's 1980 "Declaration on Euthanasia," both of which maintain that patients in vegetative states retain their personhood, and the latter of which acknowledges a patient's right to refuse treatment but deems all other refusals of treatment to be a form of immoral euthanasia of a human being. The Schindler's use of the cold and distant term "euthanasia" to describe what Michael was fighting for on behalf of Terri certainly demonstrates how such language influenced their perspective on the situation. The Schindlers also argued that Terri was still a practicing Catholic, placing emphasis in their book that Terri insisted on a Catholic wedding (30) and describing her as a "devout and pious Catholic" (183). Mary and Robert Schindler were the ones who raised Terri as a Catholic, and believed that they knew her best; from this perspective, it was impossible for Michael's statements regarding Terri's beliefs to be representative of the truth.

In contrast to the Schindlers, Michael maintained in his testimony that Terri was not an active Catholic at the time of her collapse in that she did not take communion or

participate in confession (36). Father Murphy, a Catholic priest, testified in court that Terri would not be considered a practicing Catholic if she had not been taking communion (Testimony of Father Gerard Murphy). Additionally, referencing Pope Pius XII's 1957 statements on life support, Father Murphy confirmed that removing Terri's feeding tube "would be consistent with the teaching of the Catholic church" (Testimony). The question then became whether or not the teachings of the Catholic Church could be used to determine Terri's wishes for herself. Through a religious screen, Terri's beliefs would have been extremely significant to her wishes for herself in the face of death. If Terri was a practicing Catholic, then it would make sense for the Catholic Church's beliefs to be applied as her own; however, Michael testified that Terri had abandoned her Catholic beliefs, reviving the competing influences of immediate family against marital family.

Just as in the Quinlan case, Terri's religious beliefs were ultimately not considered relevant to the decision at hand as it was simply not possible to determine how such beliefs may have affected her wishes for herself; there was no testimony that she had ever directly connected any religious beliefs to the notion of death. In contrast, Terri's supposed statements on life and death as shared by both Michael and the Schindlers became the deciding factor in the 2000 court case, primarily due to a 1990 legal precedent set forth by *In re: Guardianship of Estelle M. Browning*. This case centered on whether or not Ms. Browning's living will was still valid once she was incapacitated, and the court upheld her right to privacy and "the sole control of [her] person" (qtd. In Re: the Guardianship of Theresa Marie Schiavo). In response to this case, most likely in order to prevent any similar confusion, the Florida Supreme Court

created a list of three requirements which must be fulfilled when a guardian attempts to make decisions on an incapacitated person's behalf: the evidence of the patient's "oral declaration" must be "reliable," it must be proven that the patient does not have a "reasonable probability of recovering competency" in order to speak for herself, and any "limitations of conditions expressed" by the patient must be "carefully considered and satisfied" (qtd. 7-8). Judge Greer concludes in his court decision that, as Terri was only 11-12 years old at the time of the statements she made regarding Karen Ann Quinlan, those statements do not "truly reflect upon her intention regarding the situation at hand," while the statements she made to Michael Schiavo as an adult reliable and "[rise] to the level of clear and convincing evidence to the court" (9). Judge Greer's focus on Terri's age at the time of her statements, and his conclusion that her statements were invalid, display a notable limitation within the terministic screen of the law. In the legal sphere, those under the legal age of consent as adults are viewed as much less capable of making decisions for themselves. Based on the evidence provided in relation to the language of the legal precedent, as well as his own preconceptions and considerations of age as a factor in decision-making, Judge Greer ultimately ordered that Michael was authorized to proceed with the removal of all forms of artificial life support as it was determined by the court that such a decision accurately reflected Terri's personal wishes.

When compared to the Quinlan case in which Karen Ann's personal statements were essentially disregarded, it is remarkable that Terri's past voice held so much weight in the eyes of the legal system. While the recent legal precedent certainly provided additional support that did not exist at the time of the Quinlan case, the language there is still relatively vague; it only requires that a patient's verbal declarations are considered

“reliable,” which is incredibly objective and determined by the presiding judge. For Judge Greer, statements made by Terri at a young age and about someone other than herself were not considered reliable evidence, which mirrors the decision in the Quinlan case regarding statements that Karen Ann had previously made regarding various relatives. However, unlike in the Quinlan case, there was also testimonial evidence that Terri had spoken personally, as an adult, about her own wishes for her own body if she were to ever require artificial life support. Judge Greer perceived these words as more reliable due in part to Terri’s age at the time; she was not a minor and was consequently, at the time of the statements, fully responsible for herself in the eyes of the law. Additionally, this element of testimony came directly from Michael Schiavo, Terri’s legal guardian and the most reliable person to make decisions for her according to Florida law.

The Schiavo case was also complicated by the additional influences of a public screen. While Karen Ann Quinlan’s case garnered quite a bit of national attention, Terri’s story rose to an unprecedented level of national fame through increased levels of technology, including the internet and digital video. Whereas supporters of Karen Ann had only one high school photo to examine and use in their campaigns, Terri’s supporters had access to numerous photos and videos of Terri, shared almost entirely by her parents. As the Schindlers were the ones sharing almost all information about Terri with the public, the public perception of her was largely one of an innocent victim of horrific attempts to end her life unjustly, and much of the general public supported the Schindlers in their attempts to keep Terri alive. The public attention brought to the Schiavo case is something to examine more closely, particularly in terms of how the public came to

understand Terri as a victim and how public outcry became a terministic screen through which state and national legislatures viewed her case.

3.2 PUBLICITY IN THE SCHIAVO CASE

To return to Ott and Aoki's work mentioned previously, "how a story begins is crucial to how a story develops" (273). While the Schindlers used photographic and video examples of Terri both as legal evidence in the 2000 court case and beyond, they were also eager to use the attention of the general public in order to support their cause, and as a result, Terri's story quickly became one of the most emotionally gripping news stories of the early 2000s.

Perhaps the most well-known example of the use of the general public as support for the Schindlers' keeping Terri alive is a video referred to as the "balloon incident" in which Terri appears to show her responding to the movement of a balloon as evidence that she was not brain-dead at all. Neurologist Robert Cranford was asked to examine Terri in 2002, which he did in the presence of Michael, the Schindlers, and George Felos, Michael's attorney. It was during this examination that the now-infamous balloon incident occurred, which Cranford maintains was the only "minor clinical feature during my examination [that] raised any question about the diagnosis of PVS" (A Common Uniqueness 115). The video footage of Dr. Cranford's balloon test, in which he waves a balloon back and forth and Terri appears to follow it for roughly 15 seconds, caused quite a stir among the American public and is still used by the Schindlers today, now through their Terri Schiavo Life & Hope Network, as key evidence that their daughter was not in a persistent vegetative state after all. Here, the Schindlers insisted that Terri's apparent ability to respond to stimuli was evidence of her personal agency. As she could respond

to them, she could not possibly be brain dead, and could potentially have the ability to speak for herself after all.



Fig. 3.2. Still frame from the Schindlers' "Dr. Cranford Examination of Terri Schiavo (Part 1 of 2)."

In the instance of the balloon video, the public's first and immediate understanding of the situation came from the way in which the video was framed. While the video footage of doctors examining Terri totaled roughly four hours, the videos released to the public by the Schindlers via their website (then terrisfight.org) totaled only four minutes and 20 seconds over six short segments (Nohlgren). To return to Burke's notion of deflection, in that "even if any given terminology is a *reflection* of reality, by its very nature as a terminology it must function also as a *deflection* of reality" (1035), these video clips showed the public presumably all of the moments in which one might believe to see a glimmer of purposeful response of reaction from Terri. The brevity and conciseness of these clips allowed the general public to consume them in one minute or less, and the rise of the internet ensured that anyone who may have missed one of these clips on the evening news could watch it online and share it with a friend. Additionally,

modern technology allowed for further editing of the footage from the balloon video, such as the photo seen in Fig. 3.3, taken directly from the Schindlers' Life and Hope Network web page and used as evidence of Terri's cognitive awareness and abilities.



Fig. 3.3. Photo from the examination, from the Schindlers' Life and Hope Network web page.

While these clips do indeed display Terri's actual physical movements as they happened during the examinations, they by necessity deflect much of the truth from the eyes of the general public. Dr. Cranford acknowledges his hesitation during the balloon test, but he concluded during his examination that the occurrence "did not in any way constitute sustained visual pursuit" and "could have been a random response"; in fact, Cranford insists that "attempts to reproduce these same eye movements with the balloon later in my examination were unsuccessful" (114). Not only do these shot video clips prevent the public from seeing the examination as a whole (and the hours of time in which Terri does not respond to trials such as the balloon), but they also create a sense of "tunnel vision" through which the public only sees Terri without realizing the larger medical and legal context of the situation.

W. Lance Bennett, political science and communications scholar, refers to this focused personalization of news media in which a single person is made the center of the story as "downplaying institutional and political considerations that establish the social context for those events" (qtd. Ott and Aoki 274). The general American public was not

privity to the legal proceedings of the Schiavo case, including physicians' testimonies and other medical information regarding Terri's prognosis and situation. Additionally, internet archives were not as advanced as they are today, making it much more difficult for the average person to research documents such as *In re: Guardianship of Estelle M. Browning* and the Florida statutes regarding patient guardianship. While Terri was alive, neither Michael's nor the Schindlers' books had even been published; as biased as they are, these publications were among the first lengthy and detailed representations of Terri's story. The public was significantly limited in what they had access to and how the story was presented to them, creating a unique public screen that served as yet another possible window into the Schiavo case. The emotional fervor surrounding the videos of Terri exploded so instantaneously that it did not make much of a difference to the public for Dr. Cranford to explain that the videos were not an accurate representation of Terri's capabilities, or even to testify as such in court. As a result, it was surprisingly easy for the public to respond instantly and emotionally to what was billed as definitive evidence of Terri's capabilities as a patient without pausing to consider medical evidence or legal precedents.

Public outcry served as its own form of agency in this case; just as Michael, the Schindlers, physicians, lawyers, legislators, and religious leaders attempted to speak on Terri's behalf, now the public was doing so as well. The emotional reaction of the general public was strong enough to draw the attention of state and national political leaders. Once the video clips reached the Florida legislature, there was an almost instant political reaction; one Florida state representative, Republican Frank Attkisson, was quoted as saying, "I said, wait a minute, that's not my definition of somebody in a comatose

situation” (Nohlgren). When Terri’s feeding tube was removed by court order on October 15, 2003, the public clamored for someone to step in. On October 21, six days later, the Florida state legislature passed what is commonly known as “Terri’s Law,” a one-page bill that was signed into law by Governor Jeb Bush within less than 24 hours (Bousquet). Terri’s Law grants the governor the authority to “issue a one-time stay to prevent the withholding of nutrition and hydration from a patient” if, by October 15, 2003, the patient had no advance directive, was found to be in a persistent vegetative state, has had nutrition and hydration withheld, and if a relative of the patient was challenging the withholding of nutrition (House Bill No. 35-E). While Terri’s Law was later determined by the Supreme Court to be unconstitutional on the basis of separation of executive and legislative branches (Phillips), the bill accomplished its immediate goal of requiring Terri’s feeding tube to be reinserted as well as temporarily pacifying Florida constituents.



Fig. 3.4. A protestor using an image from the Schindlers’ video footage (Bellafante).

The influence of the public’s outcry for Terri did not stop at the United States government. According to Mary Schindler, many Catholics approached the family to offer support, and she continually asked them to “get people to write letters to Rome,”

going so far as to write two letters herself and sending them to the Pope's secretary's fax number (182). The Catholic Church and Terri's possible religious beliefs came back into play on March 20, 2004 when Pope John Paul II delivered an address titled "Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas." In this address, the Pope seems to controversially push directly against Pope Pius XII's previous address concerning extraordinary acts of preserving life as well as the Church's "Declaration on Euthanasia," stating:

I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a *natural means* of preserving life, not a *medical act*. Its use, furthermore, should be considered, in principle, *ordinary* and *proportionate*, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.

[Emphasis original]

While Pope John Paul II does not mention Terri Schiavo by name, considering the levels of publicity that her story reached as well as the supporters attempting to contact the Pope directly, it seems quite likely that he was consciously referencing her case. In particular, his pointed emphasis on the artificial administration of food and water as ordinary and "not a medical act" takes a strong position against the notion that forms of life-preserving technology (such as a feeding tube) are medical treatments that a patient can deny, which pushes directly against the "Declaration on Euthanasia," which allows the denial of "burdensome" forms of treatment. The Schindlers, and undoubtedly many of their Catholic supporters, took the Pope's statements to be "a blessing from God" (Schindler

183), even if “to [the courts], Terri’s religious beliefs were meaningless” (184).

Additionally, Pope John Paul II’s use of the qualifier “always” leaves absolutely no room for extenuating circumstances, inherently dismissing all other arguments against keeping Terri alive. His statements created a wave within the general public, particularly Terri’s Catholic supporters; in addition, the Schindlers used his words as new evidence that Terri’s religious rights were being denied in yet another appeal. The Schindlers lost this appeal as well, and ultimately would appeal to the United States Supreme Court, only to have their case denied only days before Terri died.¹⁴ Protesters continued to demonstrate outside of Terri’s hospice for weeks following her death; the final protestor, Lisa Wilson, remained nearly two months after Terri’s death (LaPeter) with a sign that read, “Never again.”

¹⁴ To note, the entirety of the Supreme Court’s refusal document reads: “The application for stay of enforcement of judgment pending the filing and disposition of a petition for writ of certiorari presented to Justice Kennedy and by him referred to the Court is denied” (Order 544 U.S., March 24, 2005).

CHAPTER 4

CONCLUSION

Examination and analysis of both the Quinlan case and the Schiavo case, particularly through the notion of Burke's terministic screens as a lens in itself, can provide a potentially more comprehensive insight into how each of these cases, and our interpretation of brain death cases on a larger scale, are shaped by the language we choose to use and our positions within the story. While it is not possible to ever grasp a complete understanding of these cases, as according to Burke, "every way of seeing is also a way of not seeing" (qtd. Chambers 152), it is essential to continue to investigate how language can both provide and limit power and agency, particularly in cases of brain death, in order to further understand the effects of language (medical, legal, and public) on outcomes of future cases.

For both Karen Ann and Terri, their stories set medical and legal precedents that will have a lasting impact on similar cases in the future, particularly in terms of how patient agency is interpreted and influenced. The Quinlan case was one of the first brain-death cases to gain national attention, inciting the right-to-die movement and contributing to medical and legal frameworks that would begin to shape our understanding of voiceless patient agency, legal guardianship, and how artificial life support technologies play a role in diagnosis and decision-making. The Schiavo case invited legal conversations to be further intertwined with medical expertise, allowing the Schindlers to take their fight almost entirely into the legal sphere, and in turn, the public sphere as well.

Modern technological advances, including digital video and the internet, further complicated the potential power the general public can wield in high-profile cases.

However, the issues present in each of these cases that made them so complex are far from resolved, and in many ways, these cases only created additional concerns. For example, the Schiavo case only exemplifies the continued confusion surrounding brain death diagnosis and patient agency, despite the Quinlan case making legal progress in terms of determining guardianship in situations in which the patient cannot represent herself. Even now, the procedures for determining guardianship when the patient herself is incompetent are problematic; as evidenced by the Schindlers' battle for guardianship of their daughter, it is not always clear who is most capable to speak on behalf of another individual. While Florida law recognized Michael Schiavo as presumably the most qualified representative for his wife, her family disagreed with legitimate concerns as the people who had known her all her life. Additionally, there is still little legal protection for the patient's personal wishes for herself; without an advance directive, such wishes are nearly impossible to prove, and the courts must rely on hearsay and testimony in order to piece together an image that they can only hope is accurate.

Rhetoricians, as well as medical and legal experts, should pay close attention to the effects that advance directives may have on similar cases in the future. It will be interesting to study whether or not a patient's written word truly holds up in court against opposing family testimony, potential legal precedents, or the wishes of the patient's physicians or hospital. In particular, it will be worthwhile to consider the various terministic screens through which such a document can be viewed including medical, legal, and familial, among others; other contributing factors, such as the date the directive

was written and the potential for ambiguous language, will also be important to consider. In fact, physicians have already acknowledged that with the introduction of advance directives comes the issue of language and interpretation, noting that patients often use terms such as “terminal” and “no hope of recovery,” which in their lack of specificity can be barriers to implementation of the directive (Spoelhof and Elliott 463). As in both the Quinlan and Schiavo cases, it seems that ambiguity of language continues to be a concern regarding patients with bleak prognoses, and the various ways in which language is interpreted could have a profound impact on future cases.

Rhetoricians have made strides to intersect the dialogues surrounding medical studies and communications, and we should continue to contribute to these conversations, especially as they relate to the public’s involvement in cases like Karen Ann’s and Terri’s in terms of public agency. In the Schiavo case in particular, new technological tools aided not only in the public’s perception of the case, but in how the public was able to actually influence the movements and progress of the case. In many ways, the public’s involvement in Terri’s case was unprecedented; community outcry managed to reach Florida’s state legislature as well as the Pope, pressing them to make statements regarding the case when they had otherwise remained largely uninvolved. Rhetoricians need to continue to study the public’s influence on high-profile cases, particularly as we continue to see the rise of technology as a tool to shape stories as they develop.

As much as Terri’s final protestor insists that a similar case should never happen again, due to the continued controversy regarding patient agency and guardianship as well as the uncertain influence of medical consensus in the face of the law, we most certainly will continue to see similar struggles in brain-death cases, particularly when

issues of patient agency or wishes are unclear. Looking back at previous cases as well as looking toward the future, the use of terministic screens as a lens through which to view these cases can help us better understand how they are shaped and where the power of influence truly lies.

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