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“Philosophical Treatises on Life and Death”:Newspaper Coverage of a Controversial Brain Death Case

Khadija Ejaz

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“PHILOSOPHICAL TREATISES ON LIFE AND DEATH”: NEWSPAPER COVERAGE
OF A CONTROVERSIAL BRAIN DEATH CASE

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DEDICATION

To the past five years that forced me to trust that little voice within for science and follow it again and again and again. That is not how women are raised.

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My dissertation was a stage, and many actors played a part in that production. The lead role was played by my spouse Sonal Mehta who first told me about Jahi McMath. I continue to learn about the world and about myself from him constantly.

I am also indebted to my committee for helping me birth this project. Dr. Leigh Moscovitz, thank you for accepting the job offer here and agreeing to let me be your graduate assistant. Thank you for staying through the crises you faced with your homes. Thank you to Dr. Robert McKeever for your encouragement. Thank you, Dr. Kenneth Campbell, for showing me that it possible to be kind and have a career. And thank you, Dr. Daniela Friedman, for always being so quick with emails!

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My interviewees always surprised me with their sincerity and generosity. I thank them for bothering with a project sight unseen for nothing in return.

But most of all, I cannot forget the McMaths and their daughter whose lives formed the foundation for my project. I would rather that Jahi had not died and that her loved ones had not gone through any of the things they are still dealing with. I always tried to remember that somewhere underneath all this science were real people.

ABSTRACT

The central concern of this multi-method research project was to investigate newspaper coverage of the controversial brain death case of Jahi McMath. This represents the first study of sense-making of the case in the news media, positioning it at the intersection of science communication and critical qualitative inquiry. First, framing theory was used to guide a textual analysis of 81 newspaper articles from high-circulation newspapers in California. This revealed four frames that first created uncertainty about brain death, thereby permitting two competing frames of Jahi being alive and also being dead to co-exist before merging into a frame that further lay blame for the confusion on science itself. These findings were then used to inform in-depth interviews with two groups of people: the journalists who had written these news articles, and the experts who had been quoted in those articles. Their responses provided insight into the factors that influenced the creation of the previously identified frames – the involvement of multiple journalists, the dynamic of conflict, financial and professional pressures, outside influences, suspicions of racial and economic oppression, and a perception of scientific disagreement about brain death. The interviews also allowed experts to weigh in on the coverage and gave both experts and journalists a chance to describe their relationship with each other in this case. Experts did not all agree about the newsworthiness of the story, perceived the coverage as haphazard, and discussed the impact of the story on expertise. Experts and journalists also expressed asymmetrical need of and satisfaction with each other but remained aware of their relationship. These findings are important

because they highlight the effect that the coverage of complex scientific concepts such as death has on the communication of science and its status in a society mounting increasing resistance to expertise and journalism.

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CHAPTER 1

INTRODUCTION

“You can be dead in London but alive in New York.”

This statement has stayed with me ever since I first heard it in early 2016.

At the time, I was still a first-year doctoral student. I had only been married for a little over three years, but all my time was now taken up by my studies. Most evenings, my spouse Sonal and I would spend time in the television room with him *actually* watching television and my not really being mentally present but consumed with some sort of work on my laptop, my backpack nearby, a ubiquitous pile of printed-out research articles scattered about me.

But one night, Sonal was also working on his laptop. He is a neurologist, and he was preparing slides for an upcoming presentation. His topic was brain death, and he wanted to practice his presentation on me.

I put my own work aside and began to listen to him talk about a topic of which I had pretty much no understanding. I had only heard about brain death in passing and had never really given it much thought.

But then Sonal said that one could be dead in London and alive in New York. He talked about how the concept of brain death was only a few decades old and that the rules about it could be applied inconsistently by different doctors in different places. I normally have a high tolerance for ambiguity, but even this idea, that dying isn’t like a binary on-off switch that is always very clearly marked, began to make me feel uneasy. I knew I

would want people to be one hundred percent sure before they disposed of my body. Can people feel things when their state of existence is debatable between, say, London and New York? What if I felt that I was alive but the people who got to make the decision for me said I was dead? The idea that what death is has changed over time made me feel anxious almost immediately. Did this mean that the century in which a person was born determined whether they were considered alive or not, whether the so-called plug was pulled on them or not? How can this be? All of these thoughts began to spring up in me all at once, sprouting menacingly like unnatural flora from the dark, silent soil of my panic.

Sonal continued his presentation. On top of the lack of knowledge about brain death in the general public, he said, media often inject confusion about it. My ears pricked; I was studying mass communication after all, and that semester I was enrolled in a seminar about science in the media. In fact, one of the research papers that was probably in the scattered piles around me mentioned how scientists are often less than satisfied with how journalists convey scientific ideas in their writing. My spouse appeared to be one of them. He showed me a slide that had examples of news stories where journalists had not written about brain death accurately. He also mentioned the name of a girl – Jahi McMath. She had died from total brain failure, but the fact of whether she was dead or not was still in dispute. Jahi was from a poor black family in California, a state where the law recognized her as dead; at the same time, her body was connected to mechanical support machines in New Jersey where she was legally considered alive.

You can be dead in California but alive in New Jersey?

What if that happened to me?

I didn't want that to happen to me.

Over the next couple of years, I would talk about Jahi to many people in my department. I told Dr. Robert McKeever who was teaching my science and media seminar about what my spouse, a scientist, felt about how journalists covered cases of brain death. I spent a lot of time talking to Dr. Leigh Moscovitz, whom I was working for as a research assistant, about the case. I had worked on a project with her that analyzed news coverage of gay male athletes in the major leagues in the United States, and I was familiar with her work that used framing theory to analyze news coverage of same-sex marriage in the United States. At some point in my third year as a doctoral student, it occurred to me that I could do something like that except with news coverage of the controversy in Jahi's story. This project – my dissertation – is the culmination of my thought processes over the past few years.

For how people make sense of pain and suffering, or of death, are vitally important to their experience of them. In fact, the cases of death and suffering present are some of the strongest arguments for the variety and importance of sense-making practices. (McKee, 2003, p. 20)

The ending of Jahi McMath's life forms the core of this study. Much attention has been given in the United States as well as other parts of the world to the question of when life begins (Ball-Rokeach, Power, Guthrie, & Waring, 1990; Carmines, Gerrity, & Wagner, 2010; Feree, 2003; Kumar, Hessini, & Mitchell, 2009; Pollock, Robinson, & Murray, 1978; Purcell, Hilton, & McDaid, 2014; Rohlinger, 2002, 2006; Taracena, 2002; Wilson & Lynxwiler, 1988). This study relocates the debate to another point, that is, its

end. Further, a rich tradition of academic research exists around the communication of various controversial scientific topics (Barry, Jarlenski, Grob, Schlesinger, & Gollust, 201; Bonfadelli, Dahinden, & Leonarz, 2002; Dudova, 2010; Hart, 2010; Holton, Weberling, Clarke, & Smith, 2012; Lore, Imungi, & Mubuu, 2013; Menashe & Siegel, 1998; Mula, 2007; Nisbet, Brossard, & Kroepsch, 2003), but limited attention has been given to this particular case. The idea of death is of significance to every person. I, therefore, wanted to explore how this deeply personal experience was framed for the public through newspapers. My research rested upon four research questions that, while briefly introduced here, I address in greater detail later in this chapter.

Popular media, including newspapers, help the audience understand various issues (Boyce, 2006; Nisbet et al., 2002; Trench, 2007). The nature of Jahi's story – a case literally of life and death – and how it is presented to news audiences by journalists informs citizens as well as legislators (Albaek, Christensen, & Togeby, 2003; Boykoff, 2009; Hotz, 2002; Miller, 2004; Young & Matthews, 2007). It has the potential to influence the legal definition of death in different states, impact organ donations, and determine the cost of maintaining patients such as McMath for an extended period of time (Luce, 2015). This was the driving force behind my first two research questions, the first of which specifically sought to tease out the frames that journalists used – consciously or otherwise – to construct the narrative of this case in newspapers in California. I aimed to achieve this through a systematic qualitative textual analysis of state newspaper coverage of Jahi's case in California, textual analysis being appropriate for understanding the meaning in any text (McKee, 2003). This research question, however, only addressed the proverbial tip of the framing iceberg; what remained below

the surface was the subject of my second research question that attempted to reveal the different factors that influenced how those frames were created and disseminated. In order to answer this question, I interviewed the people who birthed those frames, that is, the journalists who had written those news stories. I also interviewed the very experts – physicians, surgeons, lawyers, and bioethicists – who had been cited in the news stories. In doing so, this project shed light on the various ways that journalists attempted to make sense of the case for the public.

My dissertation also informs the practice of healthcare professionals and journalists. The former can gain a deeper understanding of the issues underlying the idea of brain death and be able to convey it better to patients and their families, and the latter would be made aware of the effects of their actions with regard to how they frame such issues as part of their work. In addition, both healthcare professionals and journalists would be able to derive insights into the professional culture of the other party and ideally use that knowledge for the goal of communicating better with each other. My last two research questions directly addressed these concerns. In the first question, I tried to understand how the scientific experts that were cited by journalists in their coverage of Jahi's story in California thought about how this case was covered. My last research question explored the relationship between these experts and the journalists whom they interacted with for news stories about the case.

My overall goal with this project was to inform the scholarship in the areas of media and science communication by offering insight into the relationship between scientists and journalists. I also expected to learn how scientific knowledge is conveyed and perhaps transformed as it is disseminated by experts through journalists. The critical

cultural perspective that informed this project helps highlight underlying dynamics of power between various individuals and institutions as they played out in Jahi's controversial yet human story. Ultimately, this project's goal was to reveal the underlying narratives that contributed to the public understanding of an ongoing medical controversy surrounding death, perhaps laying the groundwork for how this controversy and others like it could be resolved.

I begin this first chapter of my dissertation by providing context to the topic of the study, specifically by introducing the specific case within which this particular debate about brain death has been set. I also present an overview of how death and dying have been understood in human society; this is followed by an introduction to the study of scientific controversies and the place that the media occupies within them. The next section seeks to strengthen the argument for this project by justifying my multi-method research approach and the research questions, concluding with the assumptions upon which my dissertation is based. The chapter ends by introducing the layout of the rest of my dissertation through a brief summary of the chapters that follow.

Woven throughout this project is a debate over the line between life and death. Recognizing this, I have made certain choices regarding nomenclature in the interest of clarity and consistency. Throughout this manuscript, I use Jahi's name and pronouns like "she" when referring to her in general as the person at the center of my dissertation. I do the same when talking about her before she died in California. In the context of the events after her death in California, I refer to her in terms of her body, using phrases like "Jahi's body" and "it." While these choices on my part appear to reflect the official position of the state of California, I do not take any particular side in the story. My goal,

as stated earlier, is to be as clear as possible as I write about this complicated and unusual story.

I also refer to various members of Jahi's family through this manuscript - her grandmother Sandra Chatman, her mother Nailah Winkfield, her uncle Omari Sealey, her stepfather Marvin Winkfield. Even though they don't all share the same last name, I use Jahi's last name when I talk about her family as one unit, saying "the McMaths" or "the McMath family." This choice, like the one in the previous paragraph, I also made for clarity and consistency.

1.1 HOW JAH MCMATH DIED...TWICE

When my spouse Sonal first told me about Jahi, she was considered dead in California but alive in New Jersey. She had died in Oakland, California, on December 12, 2013, from complications from surgeries that were supposed to ease her apnea and help her breathe better (Gostin, 2014; Johnson, 2016; Luce, 2015; Paola, 2014). At the time, she was 13 years old (Johnson, 2016; Luce, 2015; Paola, 2014). Her surgeries had been performed at the Oakland Children's Hospital and Research Center, which is now known as the University of California – San Francisco Benioff Children's Hospital (Johnson, 2016; Luce, 2015). Jahi had undergone these procedures on December 9, 2013, and they had initially been deemed successful with her having been transferred to the pediatric Intensive Care Unit (ICU) for observation (Johnson, 2016; Luce, 2015; Paola, 2014).

Things, however, soon took a turn for the worse. Jahi began to bleed from her nose and her mouth and suffered a heart attack (Johnson, 2016; Luce, 2015). While the doctors were able to restore her heartbeat through cardiopulmonary resuscitation (CPR) and her breathing with a mechanical ventilator, they were not able to detect any electrical

activity in her brain (Luce, 2015). Jahi never regained consciousness, and three days after her surgery, she was declared dead according to neurological criteria (Johnson, 2016; Luce, 2015; Paola, 2014). In other words, she was brain dead (Gostin, 2014; Paris, Cummings, & Moore, 2014).

The McMath family, however, did not accept this diagnosis. They began posting updates about Jahi's health on a Facebook page ("Keep Jahi McMath on Life Support," n.d.) and moved her body across the country to the state of New Jersey where it was put on mechanical support. According to the McMaths, Jahi was alive – she had never died. They based this decision on their Christian beliefs and their observations of her body, that her heart was beating, her lungs were breathing air, and she felt warm to the touch (Gostin, 2014; Johnson, 2016; Magnus, Wilfond, & Caplan, 2014). Their Facebook posts echoed these beliefs with statements like "Jahi is alive and is not going anywhere" and that she had "flawless skin." They did not appear to be alone in believing that Jahi was still alive – their Facebook page itself attracted over 50,000 followers, and the top comments often expressed strong support for the family's stance. In the meantime, Jahi's body continued to physically grow and take on the characteristics of a child going through puberty while in what merely looked like a state of unconsciousness. In this way, Jahi was just another young teenage girl – her family would make sure her hair was braided, her nails done, and they celebrated her birthday every year. News about these otherwise typical events were shared by the family with their supporters on Facebook.

Jahi's doctors, however, disagreed with the McMath family. According to them, Jahi's outward signs of life were only due to the machines that were providing her mechanical support (Luce, 2015; Paris, Cummings, & Moore, 2014). Without those

machines, her heart and other bodily functions would stop (Luce, 2015). They predicted that, even with those machines, Jahi's body would become difficult to maintain over time – her organs would begin to fail, and her body would start disintegrating (Luce, 2015).

Both parties in this conflict, that is, the McMath family and the staff at the Oakland hospital, continued to maintain their respective positions over the years. The controversy escalated when the McMath family filed legal suits against the hospital in California, their main goal to force the state to recognize Jahi as alive so that they could bring her back from New Jersey and have her body maintained at the state's expense (Swan, 2018).

The events in this case were routinely covered by the news media, particularly in the state of California, ever since Jahi's complications and death in the Oakland hospital in 2013. Journalists approached the case in different ways, such as the need for a miracle around the holidays, a predatory approach toward organ donation, and pitting the black McMath family against the elite of American society (Kilcullen, 2015; Luce, 2015). Jahi's story was unique. Cases of brain death are not very common, and when they do occur, the patients' bodies don't last very long even on mechanical support; eventually their organs, including their hearts, give way. In this case, the patient's body not only continued to hold on mechanical support, but it also developed physically as it went through puberty.

Jahi's story took a turn in the summer of 2018 when her liver failed in New Jersey and she was declared dead there, too (Swan, 2018). At the time, I was firmly immersed in the process of collecting data for my dissertation and interviewing journalists who had written about the controversy in California. In fact, it is through them that I learned about

this turn of events; some of them emailed me about this development in the story the day it happened.

Jahi's body was soon returned to her home state of California where it was buried (Swan, 2018). She now has two death certificates that have been issued in states on two coasts and separated by four years (Swan, 2018). The lawsuits continue as does coverage of the story by news media (Swan, 2018).

1.2 WHAT DOES IT MEAN TO DIE?

At the heart of the controversy in Jahi's story lies conflict over what it means to be dead. Death certainly is a universal human experience. In the words of the American band The Flaming Lips, "everyone you know someday will die" ("The Flaming Lips lyrics," n.d.). Magnus, Wilfond, and Caplan (2014) describe the determination of death as a "highly significant social boundary" (p. 894), one that is tied to the recognition of personhood and the various legal and constitutional rights that it entails, including its effect on the execution of wills and testaments.

Despite the universal belief in death, however, not everyone understands death – and life – in the same way. Indeed, according to Benton (1978), "no one has ever understood death" (p. 1). Different strains of experts – medical doctors, lawyers, philosophers, religious scholars – approach the study of death from different angles (Benton, 1978). According to Kellehear (2007), "...the nature of dying today is an amalgam of features we have inherited from past traditions – urban, rural and prehistoric – but also the current economic, political and public health pressures exacted by our own time and societies" (p. 3). Death is understood to be a construct that is assigned meaning by the culture – "myths, mysteries, and more" (Irish, Lundquist, & Nelsen, 1990, p. 187)

– within which it occurs, including religion, social factors, technology, ethnicity, race, and available options for dying (Backer, Hannon, & Russell, 1994; Davies, 2005; Field & Cassel, 1998; Hayslip & Peveto, 2005; Kellehear, 2007). In Asian countries, for example, like India, Pakistan, and China, death is a public event in which the family of the deceased is expected to grieve openly, while those from European countries consider death to be a private event where the show of emotion is discouraged (Laungani & Young, 1997; Parkes, Laungani, & Young, 1997). Sharp, seemingly incompatible distinctions may emerge as in Rosenblatt's (1990) assertion that "in many cultures people are counted as dead whom most Americans would consider alive, and people are counted as alive whom most Americans would consider dead" (p. 14). Hindus, Buddhists, and Jains believe in reincarnation; Christians and Muslims believe in a resurrection; but Spiritualists and Christian Scientists deny the fact of death, forbidding their followers to mourn those who have died (Backer, Hannon, & Russell, 1994; Benton, 1978). Most people see death as a transition where the essence of a person – the spirit or the soul – survives the destruction of the body, but humanists believe that death results in extinction:

Afterlife expectations are more prominent among the less powerful and oppressed than among the privileged, who tend to focus more upon this life. Historically that has been the case for African Americans in the United States, but oppression has not been the only factor. Traditional Latin Americans, Buddhists, and Muslims also have prominently focused on after-death expectations. Islam strongly prepares for the next life as a process; and Buddhists seek perfection for a state of Nirvana. Jews, Quakers, and Unitarians tend to stress the here and now. The

Lakota assume that an afterlife is automatic for every tribal member, not something that needs to be earned. (Irish, Lundquist, & Nelsen, 1990, pp. 184-185)

In Kellehear's (2007) view, the construct of death evolved in tandem with the development of human civilization, going through three primary phases. The earliest conception of death occurred when humans lived as hunter-gatherers; at the time, death was perceived as not disconnected from life. This is because, in those days, life was short and often ended abruptly, mostly because of accidents. When human beings began settling into towns and cities, they began to live longer. This gave them the chance to witness the arrival of death as bodies aged and contracted various diseases. This created a culture in which people developed practices to prepare for the end of their lives; death began to take on the characteristics of an experience that was both of this world as well as the next. The current era of globalization, however, brings confusion to living and dying because there is no one meaning of life and death. This leads to much mismanagement of death, which together with longer lifespans has lent an aura of shame to dying. This arises partly because people don't talk about death as much compared to the past when mortality rates were higher, death was a very visible part of life, and people had to confront it with an attitude of "resignation and acceptance" (Backer, Hannon, & Russell, 1994, p. 2).

Some scholars study our changing relationship with death via an examination of the roles that ghosts have played in human imagination over time. This is an important avenue for the study of the construction of death since a belief in spirits of the dead has been a feature of almost every society in history (Rosenblatt, 1997). In small-scale

societies, ghosts were believed to communicate with the living on their journey into the next life, indicating a belief in death as a process that takes time, requiring “a series of steps on the way to some other state” (Rosenblatt, 1997, p. 49). Prior to the European Reformation, ghosts were more frequently represented as intervening in the lives of the living, whereas in modern times they are “ethereal creatures that float, or who appear only as sounds or invisible ‘poltergeists’, providing proof of an alternative reality to that described by science but no longer exercising moral regulation over the living” (Seale, 1998, p. 52). As the personification of death, ghosts reveal to us the presence we assign to the dead in society; according to Seale (1998), the living are distancing themselves from the dead.

Death is not what it used to be. For most of human history, medicine could do little to prevent or cure illness or extend life, and living to an old age required considerable good fortune. Dying – like being born – was generally a family, communal, and religious event, not a medical one. Because many deaths occurred at home, people were likely to care for dying relatives and, thus, to have a fairly personal and direct experience with dying and death. (Field & Cassel, 1997, p. 33)

This distancing of death is a typical feature of the modern world. Western countries in particular such as the United States have been described as “death denying” (Backer, Hannon, & Russell, 1994, p. 1). Such a culture is often attributed to developments in science and technology that prolong death to the extent of giving the impression that it is possible to conquer death entirely (Backer, Hannon, & Russell, 1994; Field & Cassel, 1997; Laungani & Young, 1997). Whereas people once used to die in their home, now most die in hospitals; as a result, first-hand knowledge and experience of

dying is not widespread, which results in anxieties about death (Backer, Hannon, & Russell, 1994; Field & Cassel, 1997; Laungani & Young, 1997). At the other end of the spectrum, this absence of visible death in society has also led to a counter culture of “pornography of death” (Laungani & Young, 1997, p. 222) that makes death the subject of jokes and fascination (Parkes, Laungani, & Young, 1997).

This is not to say that attitudes about death are uniform across the United States. While the dominant culture of the country can be described as “Western (or European-American) and Judeo-Christian” (Field & Cassel, 1997, p. 47), beliefs vary from community to community (Hayslip & Peveto, 2005; Kalish & Reynolds, 1976; Rosenblatt, 1990). Jahi McMath was from a large African American community in Oakland, California; Kalish and Reynolds (1976) described being black in the United States as being “part of a history told in terms of contact with death and coping with death” (p. 103).

...the attitudes and behaviours of African Americans toward death need to be understood with reference to the struggle, violence, suppressed anger, and exploded aggression that have followed African Americans since the earliest days of slavery. Preoccupation with violence and death is found in Black folklore, music, literature, art, and poetry. (Kalish & Reynolds, 1976, p. 31)

In fact, the hospital, which has become the epicenter of the modern ritual of dying in the United States, has taken on a symbolic role in the black community there – “‘going to the hospital’ has come to signify dying for many middle- and lower-class blacks” (Perry, 1990, p. 63). This is complicated by the prevalence of medical mistrust among African Americans, which stems from a history of medical abuses and experimentation

on their community, and may serve as a barrier to receiving healthcare (Ball, Lawson, & Alim, 2013; Matthews, LaVeist, Nickerson, & Bowie, 2000; Selligren, Manfredi, & Williams, 2002). Such mistrust not only influences the decisions African American adults may make about their own health but also those of children under their care (Moseley, Freed, Bullard, & Goold, 2007). Turner (1990) recommends healthcare providers being sensitive to the cultural beliefs of African Americans in situations involving death and dying, much of which involve religion and the church community (Hayslip & Peveto, 2005). These recommendations gain urgency in light of Laurie and Neimeyer's (2008) research that reveals higher levels of complicated grief symptoms in African Americans when compared to Caucasian Americans by virtue of:

...more frequent bereavement by homicide, maintenance of a stronger continuing bond with the deceased, greater grief for the loss of extended kin beyond the immediate family, and a sense of support in their grief, despite their tendency to talk less with others about the loss or seek professional support for it. (p. 173)

1.3 BRAIN DEATH IN THE MODERN WORLD

The predominant perspective of death in the United States is now secular, but a "tension between Christian ideas and secular, rational beliefs" (Walter, 1997, p. 185) remains. Parkes, Laungani, and Young (1997) consider doctors and nurses the "new priests and acolytes" (p. 4) of this new secular medicalized perspective of death.

In the eighteenth century death came to be seen as a natural process instead of a spiritual passage; by the twentieth century it had become a medical problem.

Doctors, hospital administrators, life support machines and bereavement

counsellors have displaced the priest and the praying family. (Walter, 1997, p. 186)

This modern medical understanding of death has evolved over time. Until 1968, death was thought to occur with the irreversible failure of the heart and the lungs (Michael, 2014), the “hallowed means of specifying death” (Benton, 1978, p. 8). It is now possible to keep the cardiac and respiratory functions going by means of technology (Paris, Cummings, & Moore, 2014). The current definition of death now also includes a neurological aspect, i.e. death from irreversible damage to the brain, and it arose from a series of developments that took place in the mid-twentieth century (Johnson, 2016; Michael, 2014). This is what is called brain death (Wijdicks, 2002).

In 1947, Claude Beck performed the first successful defibrillation of a human heart; according to the definition of death at the time, this brought some patients back from death (Michael, 2014). Positive pressure ventilation was developed a few years later in 1950, and the first mass-produced ventilator hit the market in 1955 (Michael, 2014). These developments raised questions about the meaning of life and death and the ethics concerning treating patients who were transgressing those boundaries.

In 1954, the neurologist Robert Schwab became the first to consider a comatose patient with a beating heart but an inactive brain dead (Michael, 2014). This was termed “death of the nervous system” (Michael, 2014) and for the first time gave consideration to the brain in the determination of death. This outlook was formalized by two documents in 1968: “A Definition of Irreversible Coma” by the Ad Hoc Committee of the Harvard Medical School (Brenningstall, 2014; Johnson, 2016; Michael, 2014; Truog & Miller,

2014b; Magnus, Wilfond, & Caplan, 2014), and the Declaration of Sydney at the 22nd World Medical Association (Michael, 2014).

By the 1970s, the new standards for recognizing death as proposed by these two documents began to be legally incorporated, although some debate persisted in various circles (Johnson, 2016; Michael, 2014). The President's Commission of 1981 created the Uniform Determination of Death Act (UDDA), which presented a whole-brain approach to death and placed death by neurological criteria on the same footing as death by cardiovascular criteria (Gostin, 2014; Michael, 2014; Truog & Miller, 2014b). In 1994, the American Academy of Neurology standardized the neurological criteria for death by stating that brain death included "coma or unresponsiveness, absence of brainstem reflexes, and apnea" (Michael, 2014). By the new millennium, a President's Council on Bioethics had recommended that the term "total brain failure" be used instead of "brain death" and framed death with the "cessation of the fundamental vital work of a living organism – the work of self-preservation" (Michael, 2014).

As of 2016, all 50 states in the United States of America have adopted the two criteria for death from UDDA, i.e. the irreversible loss of all functions of the entire brain, including the brainstem, and the irreversible loss of all circulatory and respiratory function (Johnson, 2016). This means that a person meeting either criteria is considered dead (Johnson, 2016). Over 80 countries subscribe to this standard as well (Breningstall, 2014).

Not everyone, however, accepts the neurological definition of death – Orthodox Jews, Buddhists, and some Native Americans accept the circulatory-respiratory definition of death over the neurological one (Johnson, 2016; Luce, 2015). This has led to the

creation of what Johnson (2016) refers to as a “conscience clause” (p. 106) that directly translates to reasonable accommodation of moral and/or religious objections to neurological death (Johnson, 2016). This has only been implemented in the state of New Jersey where the law states that, when patients or their families disagree with neurological death, the healthcare providers have to use the alternate idea of circulatory-respiratory death (Gostin, 2014; Johnson, 2016; Paola, 2014; Magnus, Wilfond, & Caplan, 2014; Wijdicks, 2002). By contrast, the law in California requires that healthcare providers accommodate the personal beliefs of the patients and their families, but it does not permit the rejection of the neurological basis of death (Gostin, 2014; Luce, 2015; Paola, 2014). The conflict between the two states lies at the heart of the McMath controversy.

Confusion over the meaning of death and the point at which it occurs continues to linger in the general population (Michael, 2014). Johnson (2016) believes that this is because the circulatory-respiratory outlook of death is more intuitive than the neurological one; the former is “traditional” (p. 106) and part of “common-sense notions of life and death” (p. 106). According to this argument, it is not surprising that families cannot believe that their brain-dead loved one is dead when they can see that the patient’s body – officially a corpse but supported by machines – is warm, moving spontaneously, and performing essential biological functions (Johnson, 2016; Magnus, Wilfond, & Caplan, 2014; Paris, Cummings, & Moore, 2014). These functions include but are not limited to “digestion, waste excretion, homeostasis, thermoregulation, hormonal and immunological functions, and spinal reflexes” (Johnson, 2016). Even wounds can heal

while a patient's body is in such a condition (Johnson, 2016; Magnus, Wilfond, & Caplan, 2014).

Family members, informed that a catastrophic event has occurred, are probably confused to find their loved one in the ICU, warm, with beating heart and breathing with the assistance of a ventilator. Surely this person cannot be dead because that is not what dead people look like. (Bresnahan & Zhuang, 2012, p. 3)

Contributing to the general uncertainty of issues of death are other seemingly similar medical states and concepts. In a survey of university students, Bresnahan and Zhuang (2012) found varying levels of uncertainty about deep coma, persistent vegetative state, and brain death. Students with higher levels of knowledge about these three conditions were found to be more comfortable with the idea of organ donation. This relates to what is known as the Dead Donor Rule, a fundamental concept of transplant ethics that requires that patients not be killed by the removal of vital organs necessary for life (Brenningstall, 2014; Magnus, Wilfond, & Caplan, 2014; Truog & Miller, 2014). In other words, donors must be dead before any organs can be retrieved from their bodies. This practice complicates the matter of brain death even further – uncertainty in the public or even on behalf of the healthcare provider about the status of a patient as one who is living or dead can have strong effects on organ donation. In fact, Brenningstall (2014) argues that the controversies surrounding death would disappear if organ donations did not exist.

There have also been some cases in which patients who were brain dead continued to “live” with the help of mechanical support machines (Johnson, 2016). Some rare cases of children have seen them go on for years on mechanical support (Johnson,

2016) and also grow as if they were alive (Magnus, Wilfond, & Caplan, 2014). There have even been highly-publicized cases in which pregnant women who were brain dead were kept on mechanical support long enough to give birth (Johnson, 2016; Magnus, Wilfond, & Caplan, 2014). One such case occurred in the same year as Jahi's but only lasted three months, which was not long enough to make the story as newsworthy as Jahi's (Lewis et al., 2016, p. 1083). This particular case involved Marlize Munoz, a 33-year-old pregnant woman from Texas who was kept on mechanical support by a hospital in Fort Worth for two months despite having been declared brain dead in November 2013 (Hellerman, Morris, & Smith, 2014). Her husband had found her unconscious and lying on the floor at their home; she had been 14 weeks pregnant at the time (Hellerman, Morris, & Smith, 2014). After being declared dead by the hospital, her husband had wanted her to be removed from mechanical support, but the hospital disagreed with him, citing a state law that provided life-sustaining treatment for pregnant patients (Hellerman, Morris, & Smith, 2014). Munoz's body was only released to her family after her husband won a lawsuit against the hospital that claimed that the "statute does not apply in cases of brain death, infringes his wife's right to make treatment decisions, and violates equal protection of the laws by treating pregnant women differently than other patients" (Gostin, 2014, p. 2014).

According to Magnus, Wilfond, and Caplan (2014), the United States is a society which is tolerant of individual lifestyles and perspectives. The scholars discuss whether that tolerance should extend to who is considered an authority on death. In their view, this individualism creates difficulties for public policy. The scholars go to the extent of saying that, in this specific case, allowing family members to determine what death is

undermines the very basis of the institutions of law, medicine, and ethics. Siding with these institutions, however, conflicts with the bioethical value of autonomy, i.e. an individual's right to accept or decline treatment (Gostin, 2014). This debate is further complicated by patients' apprehensions about the qualifications and competence of healthcare providers (Wijdicks, 2002).

Further, the definition of death implies that being alive and being dead are not two mutually exclusive states of existence. Instead of a binary state that functions like an on/off switch, dying is believed to be a process (Benton, 1978; Magnus, Wilfond, & Caplan, 2014), giving rise to the debate of "which dies first, the cell or the whole person?" (Benton, 1978, p. 4). This idea is derived from the 1968 Declaration of Sydney that said that "the point of death of the different cells and organs is not so important as the certainty that the process has become irreversible" (Michael, 2014, p. 675). Truog and Miller (2014) compare this to being legally blind and argue that the biological aspect of brain death and the legal aspect are different (Truog & Miller; 2014b), a situation they describe as "legal fiction" (Truog & Miller, 2014).

1.4 SCIENTIFIC CONTROVERSIES IN THE MEDIA

What attracted me to Jahi's story was the persistent level of controversy it had sustained over the years. As I've discussed earlier, the constructs of death and especially brain death have invited some discussion and debate as they've evolved over time. Such scientific controversies reveal a conflict "between the scientific search for universal, generalizable knowledge, and more localized forms of understanding, which are rooted in individual experience" (Moore & Stilgoe, 2009, p. 3). One way to conceptualize scientific controversies is by classifying them based on the information that may be able

to provide a resolution (Hines, 2001). Such a classification rests upon the importance of knowing the issues underlying the controversies; it is through the acquisition of this knowledge that an attempt can be made toward the resolution of a controversy.

Informational controversies, for example, are based on the lack of information about the topic at hand. Such controversies can expect to be resolved simply by gathering more information. Decisional controversies also arise due to limited information, but a resolution must still be enacted despite the lack of information. Ethical controversies, however, are not a matter of information per se; rather, they rest upon perceived conflicts of morality, ethics, or values (Saner, 2001).

It is important to aim for a resolution in scientific controversies particularly as they rise in the media; not doing so contributes to the degradation of trust between scientists and the general public (Hines, 2001). Supplying additional information or conducting more research may address the issues at the heart of informational controversies, but they may not be the best method to untangle controversies that are decisional or ethical (Saner, 2001). Such controversies are best tackled through participation, specifically that of the people whose lives are affected by the decisions that are made by scientists and politicians. Particularly in cases of ethical controversies that rest upon a foundation of ethical and moral issues, a simple scientific resolution will not be able to help what appears to be discord over preferences.

This approach to gaining resolution on scientific controversies rests upon the central tenet of controversy studies, according to which “the conflict and debate in a controversy allow hidden features of the social aspects of scientific practice to become more visible” (Brossard, 2009, p. 258). Individuals interested in resolving such

controversies would therefore be well-advised to, in a way, read between the lines of the discourse that arises out of a controversy and attempt to address the issues that are unearthed by such an analysis. One of the ways in which this kind of analysis can be performed is by focusing on how the controversy has been framed, the power of which still overwhelmingly rests with journalists (Dearing, 1995).

Controversy exists wherever one party disagrees with another. It may be that modern controversies ignite faster and spread more widely than those in centuries past because the media is more developed now than then. And the border-free, self-published attributes of the Internet only serve to speed up the tempo and breadth of the debate. (Hines, 2001, p. 188)

The media play an important role in scientific controversies (Brossard, 2009; Dearing, 1995). Journalists are seen as “information brokers” (Hinnant & Len-Rios, 2009, p. 85) in the space they occupy between scientists and the lay public. As part of this role, journalists perform one of two functions within the realm of a scientific controversy (Dearing, 1995): translation, in which journalists attempt to convey the facts of the controversy as they are to a lay audience but by using simpler language; and transformation, in which journalists choose to highlight the controversy in a way that heightens its newsworthiness rather than represent a balance of scientific opinion. These functions may be performed without journalists being aware of their own actions (Hinnant & Len-Rios, 2009).

Framing theory is based on the idea that news stories are created within certain larger social, political, and economic structures (Boykoff, MT, 2009). Journalists work within these structures in order to bring personalization, dramatization, novelty,

authority-order bias, and balance to their stories (Boykoff, MT & Boykoff, JM, 2007). These structural factors are related to the social constructivism paradigm of media effects, within which framing theory is located (McQuail, 2014). According to this paradigm, the media have a potentially strong influence on how their audience defines reality. This phenomenon of meaning-making relies upon both the consumers of such media and the individuals who create it, such as journalists (Gamson & Modigliani, 1989). An analysis of frames in the media, particularly in news stories, can therefore allow researchers to better understand how journalists construct frames about any topic and create reality for those who consume those frames (Graber, 1989). Nisbet (2010) extends the applicability of such research to “understanding the dynamics of science debates and their relationship to public opinion, media coverage, and policy decisions” (p. 59).

According to Gamson (1985), “news frames make the world look normal” (p. 617). This normalcy is achieved by various decisions that newsmakers make about the elements that comprise the structure of the story, specifically what is included, what is left out, and what is emphasized. These include images, stereotypes, metaphors, actors, and messages (Mathes, 2009). Entman (1993) has identified five traits of media texts that set a certain frame: importance judgements; agency, or the answer to the question; identification with potential victims; categorization, or the choice of labels for the incidents; and generalizations to a broader national context. Social norms and values, organizational pressures and constraints, pressures of interest groups, journalistic routines, and ideological or political orientations of journalists can influence the frames that journalists use to frame the narrative of their stories (Shoemaker & Reese, 1996;

Tuchman, 1978). Neither the journalists nor the audience may be aware of the presence of frames per se in the media; nevertheless, they do internalize the effects of these frames, unwittingly taking for granted the reality of the reporting and not considering that the narrative is a construction (Gamson, 1985). According to Wallack (1993), a common frame found in American media places the flaw not in “the fabric of society but in the loose thread of the individual” (p. 69).

The media typically frames scientific controversies based on the different factions that are portrayed as in conflict with one another (Brossard, 2009; Liebler and Bendix, 1996). Different stories might result from how two newspapers choose to depict the same issue by emphasizing different interest groups (Jensen & Hurley, 2012). Mikulak (2011) also considers the journalistic norms of conflict, balance, and human interest as further obfuscating scientific issues. How a newspaper chooses to frame a scientific controversy could ultimately influence public opinion with media consumers relying on mental shortcuts present in the media in order to form value judgements about a complex scientific controversy (Brewer & Ley, 2011; Ho, Brossard, & Scheufele, 2008; Liu & Priest, 2009). Liu and Priest (2009) use this argument to study stem cell research “because of the complex mixture of ethical and religious, scientific and medical arguments that are involved, creating for some a difficult maze of considerations through which to navigate” (p. 705). This argument can also be made for the controversy around brain death that arises in the Jahi McMath case.

1.5 OVERVIEW OF RESEARCH QUESTIONS AND METHODOLOGICAL APPROACHES

The study of death and dying in the media forms a small but established area of research. Most studies examine the representation of other forms of death, such as dying alone (Seale, 2004), violent deaths (Gerbner, 1980), and physician-assisted suicide (Haller & Ralph, 2001; Kalwinsky, 1998). Lewis, Lord, Czeisler, and Caplan (2016) performed a quantitative content analysis of newspaper coverage of two controversial brain death cases, including that of Jahi McMath, including up until the year 2015 and reported descriptive statistics such as mentions of the patients being “alive” or on “life support.” What these studies have in common, however, is an underlying belief in the role of the media in shaping the parameters for public understanding – in this case, about death – and a desire to decipher the various meanings that are attached to death in the process of reality creation. These meanings are surprisingly not limited to medical interpretations (Seale, 2004). Death is often represented as “the outcome of an undesirable personal character, either of the deceased or of onlookers, or involving the failings of society at large” (Seale, 2004, p. 967). Gerbner (1980) viewed the representation of death in television as dictated by power relations; he viewed it as “just another invented characterization, a negative resource, a sign of a fatal flaw or ineptitude, a punishment for sins or mark of tragedy” (p. 66).

This study will examine newspaper coverage of the Jahi McMath case in order to understand the mediated narratives that drive the controversy. Even though Jahi is dead now in both California and New Jersey, the case is still ongoing. The controversy circles around the legal definition of death in California, which is why this study focuses on how

the news media in that state frame the narrative of the case. Not only does this project examine how brain death has been framed by journalists, but it also seeks to reveal how a complicated scientific concept such as brain death is communicated by scientific experts to the journalists, most of whom are not scientifically trained (Reed & Walker, 2002; Tanner, 2004). The ongoing nature of the medical controversy surrounding Jahi suggests that the concept of brain death is not well-understood by the general public or journalists. While a body of work has interrogated how media frame scientific and medical issues, minimal attention has been given to news constructions of death and especially this particular case.

Brain death, with its relation to living and dying and all the institutions it draws upon as a concept, is a core component of the management of human health. It is crucial to understand how messages about such health issues are constructed. These messages – nonverbal or verbal – can affect our perceptions, beliefs, and behaviors directly and indirectly (Witte, 1994). Media messages “help to create the unarticulated assumptions and fundamental beliefs that underlie personal decisions, public policies, and clinical practices” (Nelkin, 1996, p. 1603). While these effects are believed to occur in the context of health campaigns, they can also be seen to apply to newspaper coverage of health issues, which create a sense of reality for those who consume such media (McQuail, 1994).

Of particular importance is how media messages about any given topic are framed (Witte, 1994). Frames may not always be implemented consciously by content creators such as journalists (Witte, 1994), a fact that raises the urgency of an examination of the various narratives employed in news stories about health matters. Frames may be created

by decisions as seemingly small as word or source choice, which could ultimately have the effect of emphasizing a certain aspect of the message over another (Dearing, 1995; Witte, 1994). Content creators who “do not consciously or strategically consider their word choices may inadvertently produce harmful outcomes” (Witte, 1994). These outcomes become even more concerning in health messages about the nature of death and, by extension, life. Every single living thing, including human beings, dies at some point, and many individuals find themselves in the position of having to make a decision about the life of a relative in a hospital setting.

This analysis will also address Salmon’s (1989) concerns about the institutions that determine the nature of health communications. The power to influence the selection and construction of health messages has traditionally resided “disproportionately with government, corporations, and other institutions possessing legitimacy, social power, and resources and access to the mass media” (Salmon, 1989, p. 25); not considering these dynamics in a study of the framing of health issues such as brain death may further empower those institutions at the expense of the patients they are intended to serve (Witte, 1994). These concerns feed into Hawkesworth’s (2012) claims that science is has never been objective and value-free with scientists having traditionally pursued research from a position of power and bias.

One approach to these concerns would be to determine the salience of a health issue from the perspective of the community (Witte, 1994), reflecting updated approaches in healthcare. Traditionally, the doctor-patient relationship has been paternalistic, that is the doctor was always the center of authority and the patient the source of non-compliance. Scholars now reject this view as narrow and argue for a broader conception

of health delivery that is based on a holistic understanding of the patient's world, including social cultural norms of health and wellness (Muturi, 2005; Sligo & Jameson, 2000). A critical cultural lens with its emphasis on power and hegemonic practices (Mann, 2013) would allow for the interrogation of this dimension in an examination of the frames present in the narrative of brain death in the Jahi McMath case. Further, a qualitative approach is best suited for performing a deep study of this understudied area, particularly with respect to the "embeddedness of these phenomena within social structures" (Kreps & Maibach, 2008, p. 739) that has seen limited exploration by quantitative work in this area.

This research project, therefore, addresses several gaps in extant research. Not only does it fill the need for more research in death and dying as represented in the media, but it does so qualitatively, which is an emerging area in the field of health communication (Kreps & Maibach, 2008; Lindlof & Taylor, 2011). The study will also examine power relations as related to the various interpretations of brain death that are represented in news coverage about the Jahi McMath case. This approach contributes to the growing area of research in health communication that seeks to reduce the power disparity between healthcare providers and patients. Ultimately, because of the ongoing nature of this controversy, this study aims to shed light on the underlying issues that are continuing to keep this conflict alive and to, by extension, show the way towards a reconciliation around this tragic event in the life of the McMath family. Controversies also threaten the functional standing of the institution of science (Von Schomberg, 1993); it is my goal to alleviate this threat and perhaps reconcile the so-called ivory towers of

science with lay audiences whose lives are affected by the decisions made by the occupants of those distant towers.

As outlined earlier, death may not exist as a simple medical state for most lay people in society; rather, it is imbued with various meanings. Brain death, in particular, is a new phenomenon that has arisen due to various technological developments that occurred in the field of medicine over the past few decades. Its recency may be contributing to the public understanding of the Jahi McMath case. In this case, analyzing newspaper coverage of the case may provide insight into the meanings that are attached to brain death. As a researcher, I am interested in understanding how this poorly understood diagnosis is taking shape in American society, particularly in the state of California, which is the epicenter of the case. I do this by using framing theory, which helped me tease out the frames that journalists have been using to build the narrative of this case. This was the goal of my first research question.

RQ1: What frames have been used in newspaper coverage of the Jahi McMath case?

My review of the framing literature also highlighted the different factors that influence journalists as they create frames as part of their fact-gathering and story-writing process. As a critical cultural researcher, I was particularly interested in the social, political, and economic structures (Boykoff, MT, 2009) within which the journalists that have been covering the Jahi McMath case work. Prior research alerted me to the fact that these factors may be related to social norms and values, organizational pressures and constraints, pressures of interest groups, journalistic routines, and ideological or political orientations of the journalists (Shoemaker & Reese, 1996; Tuchman, 1978). My second

research question, therefore, tried to capture the complexity of this frame-building process.

RQ2: What factors influenced the way journalists framed the Jahi McMath case?

The legal battles in the Jahi McMath case are between two parties, that is the McMath family and the medicolegal scientific establishment of California. My first two research questions addressed how news organizations and journalists made sense of Jahi's story. Brain death, however, is a complex scientific concept, and I also wanted to know how its experts perceive the way that journalists have been covering the case and, by extension, the non-medical lens through which the lay audience views brain death. As it currently stands, brain death has been defined by scientists, and it is according to their criteria that Jahi McMath is considered to be dead in California although not in New Jersey. The case, however, is complicated by the existence of a conscience clause that allows patients or their families to disregard the concept of brain death if they do not believe in it. My third research question explored the conflicts and negotiations, if any, that may exist between the general public and scientific experts like neurologists when it comes to the understanding of brain death. This conflict forms the heart of this case.

RQ3: What do experts feel about the coverage of the Jahi McMath case?

As a mass communications scholar, I viewed the journalistic act of covering the Jahi McMath case as central to the controversy surrounding this long-running issue. I was specifically concerned about how information about the case and the diagnosis of brain death was conveyed from experts to journalists, parties whose professional norms often conflict and whose members come from vastly different professional backgrounds. As I discuss in detail in Chapter 4, previous research has indicated a contentious relationship

between scientists and the media, and I was concerned about whether this had an influence on the newspaper articles that were produced from their relationship for the consumption of general society. My fourth and final research question, therefore, examined the relationship between the two groups in detail.

RQ4: How do experts and journalists feel about communicating with each other in the Jahi McMath case?

In order to answer the research questions above, I approached this study qualitatively and through a critical cultural lens. Such approaches are well-suited to the topic of brain death, which as an area in mass communication has received minimal academic attention. Not only will qualitative analysis permit an exploration of the various narratives as they are constructed in the media, but a critical cultural approach will provide context to those findings. Understanding the various interpretations of brain death as mediated by mainstream news organizations and gauging the social structures within which those interpretations are created will allow a deeper understanding of the various issues that underlie this controversy. Insight into those factors, as highlighted earlier in this chapter, will permit a greater understanding of the controversy surrounding brain death and provide new pathways for journalists and scientists alike as they continue to inform the public about cases like Jahi's.

As detailed in Chapter 2, this project will first analyze newspaper articles that have been written in the state of California about the Jahi McMath case. This data will be supplemented with interviews of the journalists from the dataset made up of the newspaper articles analyzed previously and also with interviews of experts on brain

death. Textual analysis and interview data will be analyzed inductively, and I will use concepts in the literature review to sensitize myself during analysis.

An analytical approach such as this will allow for an in-depth reading of this specific topic, which is the intent of this study. Qualitative research that falls within the critical paradigm does not aim to produce research whose results are replicable or generalizable, goals which critical researchers do not subscribe to. Rigor will therefore be incorporated into the analysis and interpretation of the data by means of self-reflexivity, negative case analysis, member validations, and member reflections.

This study is based on a number of assumptions from previous scholarship. First, scientists and journalists occupy professional cultures that function according to different sets of values (Colson, 2011; Conrad, 1999; Dunwoody, 1992; Eide & Ottosen, 1994; Peters, 1995; Reed, 2001). Second, scientific concepts such as brain death are transformed and given meaning when conveyed to the general public via media such as newspapers. This assumption is based on the limited knowledge that the public holds about the condition of brain death (Michael, 2014) and the various non-medical meanings that are attributed to death and dying in the media (Gerbner, 1980; Seale, 2004). The third assumption makes the case for a critical cultural paradigm by building off of work that shows how science is value-laden and not objective; it is subject to “false universals, biological determinism, essentialism, a colonizing gaze, heteronormativity, and insensitivity to race, class, ethnicity, disability, nationality, and other critical markers of difference” (Hawkesworth, 2012, p. 113). An examination of the communication of scientific objectives may thus not only reveal different interpretations of the scientific concepts under study but also a hegemonic ideology preferred by the scientific

establishment. Finally, this study is based on McQuail's (1994) social constructivist approach according to which the media, particularly newspapers, help shape reality for its audiences.

1.6 OUTLINE OF DISSERTATION

This dissertation contains five chapters. Following this first introductory chapter, the second chapter provides details about my methodological approach. I then present my findings across two chapters that I have organized around the topics of framing and science communication, respectively. The last chapter in this study concludes by examining how this work contributes to the scholarship on science communication, framing, and death and dying.

Chapter Two, "Methodology," contains an overview of and a justification for the methodological decisions I made in this project. I approach the topic of this study from a critical cultural perspective and argue for qualitative data collection within that particular paradigm. At its core, my arguments are based on the need for more communications research on the many intersecting topics in this project, including death, brain death, and the case of a minor like Jahi McMath. The chapter also includes step-by-step details about how I collected and analyzed my data that included 81 newspaper articles from California about Jahi's story, 13 in-depth interviews with the journalists who wrote those articles, and 11 in-depth interviews with the medical experts that they cited in their stories.

Chapter Three, "Framing: Text and Process," is the first of the two chapters in which I present results from my data analysis. This chapter is solely dedicated to framing theory and how it explains the creation of the journalistic narrative used in Jahi's story in

Californian newspapers. The findings in this chapter are based on a qualitative textual analysis of 81 newspaper articles about Jahi's story from California, which allowed me to extract and explain the different frames present in the narrative. I was also able to describe the framing process of the story in detail; these themes were derived from an analysis of the 24 in-depth interviews with the authors of those articles and the experts that they cited in their work.

In Chapter Four, "The Science in the Story: Experts and Journalists," I continue to present my findings; these are also based on the 24 in-depth interviews with the journalists and the experts. This chapter, however, differs from the previous one in its emphasis on science communication. The findings are presented thematically; the first set of themes reveal what the experts on brain death think about newspaper coverage of Jahi's story in California, and the second set is dedicated to describing various aspects of the relationship that existed between journalists and experts while the former reported on the Jahi's story.

As the last chapter of my dissertation, Chapter Five, "Discussion," functions as an overall conclusion of this project. My goal in this chapter is to make sense of the findings from this study and explain what they mean in the context of the extant literature in the relevant areas, thereby illustrating the significance of this project in the broader academic fields of media studies and science communication. I also offer practical interdisciplinary recommendations based on my findings. I then outline important future avenues for study that my project creates going forward within the constraints that it was limited by.

CHAPTER 2

METHODOLOGY

One of the first things I did the night that Sonal educated me about brain death in our basement television room was look up studies about Jahi McMath. While he was talking, I searched for any research that may have been done about her case or brain death. I saw plenty of research in the fields of philosophy, medicine, and law; most of these studies mentioned the media in a peripheral way, but I did not see any work centrally devoted to approaching how her story was framed or given meaning from within my field of media studies. This surprised me, and it also did not surprise me. I was surprised because this highly unusual case had been covered by the media for years even by 2016; the story itself had long graduated to playing out across the breadth of the country. Part of me, however, was not surprised that the case had not been the subject of academic interest in my field because it was about such a highly specialized and admittedly dark subject, the brain death of a minor. After all, it took my being married to a teaching neurologist to even hear about it. Clearly, I saw a need for media research to understand Jahi's story, and over the next few years, I was able to put together a plan of the different research methods I could use to understand how the controversy about how Jahi's life ended – and whether it ended at all – had been covered by the media in her home state, the battleground for the narrative of her life and her death. This chapter talks about that part of my research. These findings are expected to offer insight into the

controversy of brain death as is currently playing out in the Jahi McMath case without being limited to this single instance.

This chapter is organized to inform and justify to readers the methodological approaches I took in my dissertation. In the following sections, I describe in detail the qualitative research design and the critical cultural research tradition that I have undertaken in this study. These are followed by details on the overall research design, IRB approval, data collection and analysis methods. I also include a section on ethical and trustworthiness considerations that I undertook in this project, concluding with methodological limitations.

2.1 RATIONALE FOR QUALITATIVE RESEARCH DESIGN

A qualitative approach best suits this exploratory study because of the scarcity of literature about brain death in the field of mass communication. More exploratory research, therefore, is needed to examine discourses about brain death as they are constructed in the media. Given the complex history and often-misunderstood nature of brain death, it is important to understand how, as a concept, it is portrayed by journalists and why. These frames, the first of their kind in this case, are best determined by qualitative means (Haller & Ralph, 2001). Lindlof and Taylor (2011) make specific mention of the usefulness of qualitative research in health communication, especially in its ability to examine the “role of gender, class, and racial identities in the co-construction of profound – and often conflicting – cultural meaning for embodied conditions of illness, pain, suffering, and death” (p. 19).

Qualitative research is based upon the assumption that any human society and the rules and concepts along which it functions are created by its members (Christians &

Carey, 1989). Such research allows us to become “aware of the categories in which we think and to analyze and critique such models” (Christians & Carey, 1989, p. 346). Qualitative research, therefore, focuses on how humans interpret various experiences. The question is not “how do the media affect us?” but rather “what are the interpretations of meaning and value created in the media and what is their relation to the rest of life?” (Christians & Carey, 1989, p. 347). This is the central question in my dissertation as examined through the lens of the construction of brain death.

Meaning can be determined qualitatively by immersing oneself in the situation under study and making use of naturalistic observation, contextualization, maximized comparisons, and sensitizing concepts (Christians & Carey, 1989). This process involves paying special attention to the vocabulary and symbolic imagery specific to the situation under study; these allow researchers to provide a rich description of underlying rules and structures upon which discourse and meaning is negotiated (Christians & Carey, 1989).

It was possible for me to approach my dissertation with a quantitative approach like content analysis. This, however, would not help me reveal the various levels of meaning in the data (Gill, 2006) – according to Gamson (1989), “to identify frames, the informational content of news reports is less important than the interpretive commentary that surrounds it” (p. 158). This would run contrary to my goals in this study, especially considering its novelty. Without first determining the frames, it would not be possible to quantify them. A qualitative approach employing textual analysis is an important first step in identifying structures of meaning. In addition, in-depth interviews are an important tool of qualitative inquiry as they permit insight into experiences not directly observable by researchers (Lindlof & Taylor, 2011).

2.2 RATIONALE FOR CRITICAL CULTURAL RESEARCH

The morals of the dominant ideology have surfaced. But whose morals are reflected? (Kalwinsky, 1998, p 103)

I have based this study on the critical cultural tradition, specifically its postmodernist adaptation (Lindlof & Taylor, 2011; Tracy, 2013). This approach is inherently interpretive but additionally concerned with questions about the negotiation of power. This means that in addition to discovering the various meanings that are created in communication texts, critical cultural researchers are interested in what those texts can tell us about the hegemonic ideology within which such texts are created. This involves the study of not just a dominant culture in any given society but also various oppositional identities that resist the dominant ideology (Kellner, 2011). These overlap with Gramsci's (1971) notions of hegemony and counter hegemonies, respectively. Such a critical lens has been used in several studies that examined death and dying portrayed in the media, as discussed in the previous chapter.

Cultural studies are particularly useful in the study of media culture because of their influence on how people build their worldviews, shape their behaviors, and even forge their identities (Kellner, 2011). According to Kellner (2011), media culture is "a site of intense struggle between different races, classes, genders, and social groups" (p. 12). Staiger (1992) defines these groups along several intersections, including the self, gender, age, family, class, nation, ethnicity, and sexuality. Kellner (2001) recommends a thorough examination of "each dimension of ideological domination across representations of class, race, gender, and sexuality, and other forms of domination and subordination and to show how specific narratives serve interests of domination and

oppression, contest it, or are ambiguous” (p. 13). Such an analysis is intended to ultimately empower subordinate groups and transform society (Kellner, 2011). In Tracy’s (2013) words, ‘Research from a critical paradigm asks not only “what is?” but “what could be?”’ (p. 43).

Asking questions not just about who produces the discourse but also which social groups or social worlds they are about can uncover political and ideological power relations that “are often unknown or at least unacknowledged by those producing the discourse” (Mann, 2013, p. 688). At the same time, researchers do not assume a position of objectivity; rather, they conduct their study while in a constant state of self-reflexivity (Christians & Carey, 1989; Darling-Wolf, 2004; Parameswaran, 2001). This allows them to acknowledge their own biases and possession of power in relation to the object of their study.

Kellner (2011) outlines the three components of a critical cultural studies project: production and political economy, textual analysis, and audience reception and use of media culture. Production and political economy refer to an analysis of the social structures within which the text under study is produced and, in the process, coded with the relations of power and domination. Interpreting or reading such cultural texts informs the second component, that is, textual analysis. It is important to note that textual analysis in this case refers to one of any number of analytical methods, both qualitative and quantitative (Zhou & Sloan, 2015). In order to avoid one-sided interpretations of texts, critical cultural studies also call for an analysis of how the recipients of media texts make meaning from the media they use. This forms the final component of critical cultural studies. Interestingly, these elements of critical cultural studies resonate with work in

science communication that advocates for research that goes beyond media effects and media content and into the realms of production and audience reception (Hansen, 2009; Leach, Yates, & Scanlon, 2009).

Journalism by its very nature can function as an ideal cultural text. Not only does the practice seek to provide information to the public and curtail any problematic exercise of power in society's various institutions, but it also functions as a "mediator of meaning" (Zelizer, 2008, p. 89). Seale (2004) has described journalists as "bearers of moral messages and guardians of the community, aligned with an official morality about how such a society ought to behave" (p. 973). In this light, journalism emerges as a form of culture which provides "a web of meanings, rituals, conventions, and symbol systems, with journalists, who provide different kinds of discourse about public events, as its facilitators" (Zelizer, 2008, p. 88). It is these meanings that I aimed to tease out as related to the topic of brain death in the Jahi McMath case. As recommended by Kellner (2011), I performed a textual analysis of newspaper articles about this case in order to discover how journalists have been framing this controversy. Further, I used framing theory to bring to light the hegemonic forces that create media frames that appear natural and function "as persistent patterns of cognition, interpretation, and presentation of selection, emphasis, and exclusion" (Gitlin, 1980, p. 7).

2.3 REFLEXIVITY IN THE RESEARCH PROCESS

Matthes (2009) stresses upon the need for framing researchers to provide generalizable results, determining antecedent and consequences of frames, and demonstrating reliability. Qualitative researchers recognize the positivistic origins of concepts such as these and objectivity and therefore question them (Hawkesworth, 2012;

Lindlof & Taylor, 2011; Tracy, 2013). As concepts, objectivity and reliability are challenged in qualitative research by the nature of the instrument, which in qualitative research are the researchers themselves (Tracy, 2013). Moreover, the findings from a study such as this are specific to the context and cannot be replicated in the traditional sense (Tracy, 2013). This point also addresses the issue of theory-building and generalizability, which are not the purpose of a study such as this (Lindlof & Taylor, 2011; Tracy, 2013) but as I discuss in Chapter 4, find room in Scheufele (1999).

I, however, attempted to meet various criteria as set forth by Tracy (2013) in order to achieve rigor and validity when designing this project. I practiced reflexivity at every step of the project and presented the findings in relation to its specific context via thick description. I am a fourth-year doctoral student and the sole researcher on this project. As I discussed in Chapter 1, my spouse is a neurologist, and it is from him that I initially learned of the concept of brain death and its problematic reception in the media. While I don't consider myself an expert on the matter of brain death as a neurologist would, I don't see myself as a member of the lay public, either. I feel that I have gained more than what is considered a normal level of knowledge about brain death than the average non-expert because of my close relationship to a neurologist and the process of conducting the literature review for this study. I also have professional experience in journalism; I spent a year as a staff writer and photographer at the university newspaper at Oklahoma State University and another year at an apprenticeship at New Delhi Television in India. I believe that my relationship with both the fields of neurology and journalism benefited me at every step of this project, especially in understanding the perspectives of members of each field while interviewing them.

I also sought to strengthen my analysis by performing negative case analysis, member reflections, and member validations. Negative case analysis involved my incorporating conflicting information as it emerged from my data while I was creating my codes and categories (Lindlof & Taylor, 2011). In order to perform member reflections, I shared my initial findings with the interviewees and incorporated their reactions into further analysis (Tracy, 2013). Member validations were conducted towards the end of the study when I shared my findings with the interviewees and discussed whether they found my interpretations valid and accurate (Lindlof & Taylor, 2011).

2.4 OVERVIEW OF RESEARCH DESIGN

The following list summarizes the steps that I used to carry out my research:

1. Preceding the actual collection of data, I conducted a selected review of the literature to study the contributions of other researchers and writers in the broad areas of death, brain death, controversy studies, science journalism, and framing theory. I paid particular attention to critical and qualitative approaches to the study of these topics. I began to assemble these as part of my dissertation proposal that I successfully defended on December 4, 2017.
2. Starting February 18, 2018, I began constructing the first set of data that consisted of newspaper articles from California about the Jahi McMath case.
3. From February 2018 to May 2018, I conducted a qualitative textual analysis of the dataset above using framing theory. Two graduate students coded a subset of the data with me from March 1, 2018, to March 29, 2018.

4. I created and submitted an Institutional Review Board (IRB) request at the University of South Carolina (USC) in order to gain approval for the next step of the study, that is, gathering interview data. I submitted my request on April 19, 2018, and received approval on May 1, 2018.
5. On June 7, 2018, I began to contact the journalists who wrote the articles in the dataset above and invite them to be interviewed. At the same time, I began to do the same for the experts who had been cited by those journalists in their news stories.
6. I conducted interviews with the journalists and the experts from June 10, 2018, to July 12, 2018. They all consented to having their interviews recorded. I later transcribed the interviews myself.
7. I analyzed the interview transcripts.
8. The findings from all the methods mentioned above were synthesized and interpreted. The complete draft of my dissertation was submitted to my chair on January 7, 2019, who returned a reviewed version of the manuscript on February 22, 2019. I incorporated her suggested changes into my writing and submitted the final document to my committee on March 10, 2019.

2.5 ETHICAL CONSIDERATIONS

According to Tracy (2013), qualitative research addresses ethics in the following areas: procedural rules and procedures, the specific ethics of the context under study, and the ethics of working with participants. Ethics were observed at every point of this project and included IRB approval as outlined in the relevant section earlier. I maintained a transparent and honest demeanor with interviewees and informed them about the

voluntary nature of the study, allowing them to withdraw their participation at any time. In addition, I gave them the option of confidentiality. If they chose it, I honored it by assigning them a pseudonym. I also informed them about their interviews being recorded as audio files so as to aid in transcription later; if they chose to not consent to being recorded, they were not, although none of them denied my request to record. I was also proactive when interacting with interviewees and did not treat them as objects but rather as full people. Part of this process involved informing the participants about the sensitive nature of the topic of brain death and treating them with caution and respect.

2.6 IRB APPROVAL

Analysis of newspaper articles does not involve human subjects and therefore did not require IRB approval. This is not the case with interviews involving human subjects, so for this phase of the study, I submitted the relevant material to the USC IRB on April 19, 2018, before conducting the interviews. I received approval from IRB on May 1, 2018, and only then proceeded to reach out to participants and conduct the interviews.

2.7 DATA COLLECTION METHODS

2.7.1 NEWSPAPER ARTICLES

The sample of newspaper articles was assembled using the Newsbank database at USC's Thomas Cooper Library. Newsbank isn't the only database at the library that allows one to search for newspaper articles; Lexis Nexis is another popular database that I have used in the past to look for news stories. I decided to use Newsbank for this study because it appeared to carry a bigger and more varied collection of state-level newspaper articles than Lexis Nexis did. My dissertation exclusively focused on Californian newspapers, so Newsbank fulfilled my data collection needs better than Lexis Nexis did.

I made the decision to limit the sample to the state of California because of the issue at the heart of this controversy, that is, the legal status of Jahi McMath in California as a person who may be dead or alive. This geographic factor makes it important to understand how the case is presented to the people in California because it is in that state that the law determining brain death was being challenged by the McMath family. State newspapers are best suited for an analysis of this nature because of their focus on local issues, such as state government, justice, crime, and human interest stories (Wackowski, Lewis, Delnevo, & Ling, 2013). Coverage of Jahi's story in California, therefore, would be important to understand how the case is presented to local, regional, and national news audiences, especially since the people who can influence the case – voters, legislators, judiciary, and jury members – will be drawn from that population.

Analyzing newspaper articles as texts that represent “material culture” (Lindlof & Taylor, 2011, p. 218) have several benefits. Such texts are rich in the information they contain, which allows the researcher to consider history, language, and cultural assumptions (Lindlof & Taylor, 2011). Newspaper articles in particular are widely available and disseminated online and through social media and do not change once they have been published or disseminated (Lindlof & Taylor, 2011). Researchers, however, must take care to familiarize themselves with the culture from which the texts under study are produced so as to ensure a highly contextualized interpretation as possible (Lindlof & Taylor, 2011). I was able to familiarize myself with the issue and professional cultures by conducting a literature review for this study as well as conducting interviews with the journalists who created the texts I was analyzing and the experts who had been cited by those journalists in those texts.

I began collecting my data on February 18, 2018, when I used the keyword “Jahi McMath” in Newsbank to search for newspaper articles that had been published in the state of California about the Jahi McMath case. This initial search resulted in a list of 1,019 newspaper articles from across California. In order to narrow the search, I selected those articles that had been published in the top daily newspapers in California by circulation (“Top 10,” 2016). This limited my sample to 148 newspaper articles from the following publications: *San Francisco Chronicle*, *The Mercury News*, *The Sacramento Bee*, and *The San Diego Union-Tribune*. I compiled those articles into a Microsoft Word document and proceeded to remove duplicates and those articles that only briefly referenced the Jahi McMath case. I also removed letters to the editor and op-editorials because the scope of my study was limited to mainstream traditional news reporting. I removed editorials because they are usually not attributed to individual journalists but rather reflect the stance of a publication. News briefs were also removed because they did not center exclusively on this one case.

These selection criteria reduced the number of articles in the *San Francisco Chronicle* from 70 to 32, in *The Mercury News* from 67 to 46, in *The Sacramento Bee* from 8 to 1, and in *The San-Diego Union-Tribune* from 3 to 2. My final sample, therefore, contained 81 newspaper articles from California about the Jahi McMath case that spanned the entire timeline of the case from its inception in December 2013 to February 2018 when I started collecting my data.

The final selection of newspapers in my sample represented prestigious publications with wide circulation throughout the state. The newspapers spanned both northern and southern California; three out of the four newspapers were from the north –

San Francisco, San Jose, and Sacramento – and based around Oakland where Jahi’s story is rooted. The northern newspapers in my sample were the *San Francisco Chronicle*, *The Sacramento Bee*, and *The Mercury News*. The Pulitzer-Prize-winning *Chronicle* was founded in 1865 and is “the largest newspaper in Northern California and the second largest on the West Coast” (“San Francisco Chronicle,” n.d.). The *Sacramento Bee* also describes itself as the largest newspaper in the region; it is based in the Northern Sacramento Valley, also covering some surrounding areas such as the San Francisco Bay Area (“About Us,” n.d.). The newspaper was founded in 1857 and, like the *Chronicle*, has won six Pulitzer Prizes (“About Us,” n.d.). *The Mercury News*, which is based in San Jose, is affiliated with the *Contra Costa Times* and the *Oakland Tribune* and in 2013 was the seventh most circulated Sunday newspaper in the United States (Carey, 2013). In the same year, the newspaper was almost ranked the fifth most circulated daily in the country; according to Carey (2013), “year-over-year comparisons could not be made due to a change by several affiliated newspapers, which dropped Monday home delivery two years ago.” In southern California, *The San Diego Union-Tribune* describes itself on its website as “the region’s most trusted and comprehensive source of local news and information” by its ability to reach over 96% of all households in San Diego County every week (“About the Union-Tribune,” 2017).

2.7.2 INTERVIEW TRANSCRIPTS

I also collected interview data for this project; this dataset was constructed from interviews with the journalists who had been covering the case in California and the experts who were cited in their coverage. I expected this data to yield insights into the dynamics between scientific experts and journalists as they attempted to convey complex

concepts to the public. I was also interested in learning about the larger framing process that had influenced the narratives created about Jahi's story in California's newspapers. In addition, I hoped to understand what experts thought about the way that journalists had written about the controversy. My approach reflects Lindlof's and Taylor's (2011) understanding of the purpose of an interview, that is, to gather "information about things or processes that cannot be observed effectively by other means" (p. 173) and understand "the social actor's experience and perspective through stories, accounts, and explanations" (p. 173). Interviews also permit the collection of data about visual cues, which during phone interviews, may be compromised (Lindlof & Taylor, 2011). In-person interviews also make it easier for the interviewer and interviewee to establish rapport and to limit distractions during the process (Lindlof & Taylor, 2011). While I made a strong effort to conduct the interviews in person and, when possible, using Skype, all participants preferred to speak to me over the phone instead.

I identified both the journalists and the experts from the sample of newspaper articles that were included in the textual analysis. These respondents sampled were therefore purposive, drawing from those who had an active voice in the media coverage of this controversial issue. I managed the sampling list by creating a Microsoft Excel document that had two sheets – one for each sample – and added the names, titles, and contact information about each person in these stories as I came across them in the newspaper articles. I added more information for each person by searching for their expertise and contact information on the Internet; this was especially useful while trying to locate contact information. I also used the Excel sheets to record my interactions with each person.

The interview guides that I used to conduct the interviews were developed by me based on the literature review and my findings from the textual analysis of the newspaper articles (see Appendices F and G). Before seeking IRB approval for the interviews, I pre-tested the interview guides with my advisor (who is also my dissertation chair) and a colleague who used to be a journalist and had recently also conducted interviews with journalists for her own master's thesis. I incorporated their suggestions into my interview guides prior to submitting it for IRB approval.

I began reaching out to the people in my sample on June 7, 2018, by sending them short invitations by email and through social media like Facebook, Twitter, and LinkedIn (see Appendices B and C). I continued following up with them until one of the following happened: I was able to secure an interview, they declined to participate, or I didn't hear back from them after several follow-ups. Once participants agreed to be interviewed, I also sent them a document that contained additional information about my project, including the interview process and consent (see Appendices D and E). While I was able to find contact information for many participants on my own, I also relied on those who did interview with me to help me get in touch with other potential participants.

Ultimately, I was able to interview 13 journalists from a sampling frame of 38 and 11 experts from a sampling frame of 27 (see Appendices H and I). The time frame for the interview data collection was from June 10, 2018, through July 12, 2018. In that time, I recorded 16.38 hours' worth of interviews. Journalist interviews spanned 21.02 minutes to 58.55 minutes with an average of 38.81 minutes; taken together, I interviewed journalists for 8.41 hours. Expert interviews lasted from 22.23 minutes to 68.3 minutes; the average length for these interviews was 43.46 minutes with a total time of 7.97 hours.

Each interview was recorded using a voice recorder as well as a secure sound recording app on my cell phone. I used these audio recordings to transcribe each interview in as much detail as possible, transcribing not just words but also non-verbal elements like laughter, pauses, hesitations, and the like, and using italics to indicate emphasis. After transcribing all the interviews, I had 223 single-spaced pages worth of interview data with 112 pages for journalist interviews and 111 for expert interviews. To enhance the study's validity, I emailed each transcript to the relevant respondent for review and made any necessary factual corrections and amendments based on the respondent's feedback.

2.8 METHODS FOR DATA ANALYSIS AND SYNTHESIS

In interpreting my data, I strove for what Geertz (1973) calls thick description. This concept refers to interpreting meanings within the context in which they occur.

As interworked systems of construable signs (what, ignoring provincial usages, I would call symbols), culture is not a power, something to which social events, behaviors, institutions, or processes can be causally attributed, it is a context, something within which they can be intelligibly – that is, thickly – described... (Geertz, 1973, p. 316)

My approach to providing thick descriptions, therefore, was motivated by a need to create second-order interpretations, which Tracy (2013) calls “meaning that researchers construct explanations for the participants’ explanations” (p. 5). In other words, I wanted to go beyond simply describing my findings to providing explanations for them. I did this by trying to put myself in my subjects’ shoes so that any interpretations that I made would have made sense from their perspective. This allowed me to gain “access to the conceptual world in which our subjects live so that we can, in

some extended sense of the term, converse with them” (Geertz, 1973, p. 320). Some of the things I paid attention to during this process were “supplanted meanings, historical context, ideological stances, questions of authorial voice, examination of communication processes, and how dominant and negotiated meanings interact” (Kalwinsky, 1998, p. 95).

2.8.1 NEWSPAPER ARTICLES

I analyzed the first set of data using textual analysis. The simplest way to understand this method is as an “educated guess” about the meanings in a text (McKee, 2003, p. 1). This method is best suited to this study because of how McKee (2003) defines a text as “something we make meaning from” (p. 1). That is the goal of this study as a qualitative project, to determine the narratives that are created in this case in the first data set (newspaper articles). I expected analysis to reveal meanings and sense-making strategies about Jahi’s story at all levels, from the superficial to those that “challenge our very foundations for thinking about what reality is and how it works” (McKee, 2003, p. 5).

Different sense-making cultures disagree over whether death is a desirable, or an undesirable, experience. Death of the body doesn’t necessarily mean death of the person. It need not be something to be feared. It may, quite reasonably, be seen as desirable. (McKee, 2003, p. 21)

I followed Miles, Huberman, and Saldana’s (2014) approach to textual analysis. Their approach is based on grounded theory and follows a constant comparative method (Lindlof & Taylor, 2011). At the same time, I used framing theory and various sensitizing concepts present in the literature while considering all aspects of the text, such as “story

sources, direct and indirect quotes, language/terminology, pro or con narratives, and missing perspectives about the issue” (Haller & Ralph, 2001, p. 408). These elements constitute manifest content as well as latent content.

I analyzed my sample of newspaper articles in multiple steps; I performed this data analysis from February 2018 to May 2018. In the first pass, I read all the newspaper articles in my sample in their entirety while creating a list of recurrent themes or codes as I saw them emerging. I also wrote analytical memos to myself so as to capture my thought process, which would be useful while articulating my results (Saldana, 2016). In order to be able to detect the things that I was looking for as per the critical paradigm, I asked myself the following questions while reading through the sample (Zhou & Sloan, 2015, pp. 318-319):

- Which discourses are privileged over others?
- Which social and economic interests are served by these discourses?
- Whose/what point of view, feelings, and experiences are readers invited to identify with in this text by virtue of editing, narrative structure, and conclusion (i.e., in what subject positions do the discursive and dramatic narrative elements place the viewer)?
- Who is the ideal reader, who is hailed or addressed by the text?
- What does the text invite the ideal reader to regard as normal, natural, or enjoyable?
- Through what formal or technical strategic and codes is the point of view conveyed?

- Do the roles, values, actions, images, and words in the text maintain, deconstruct, or reconstruct dominant cultural discourse on this topic?

At the same time, I recruited two of my colleagues – a white female doctoral student from the United States of America and an Arab female master’s student from the State of Kuwait – to conduct the analysis with me. This technique was used to strengthen my own analysis by enhancing its validity (Bloomberg & Volpe, 2016; Intemann, 2012). Because the paradigm that this study is situated in assumes the existence of different realities, the presence of multiple researchers from diverse backgrounds permits a richer set of results to emerge. In other words, multiple sets of analytical eyes from different backgrounds are helpful in the decoding of the multiple realities that may be encoded in texts such as newspaper articles.

With this goal in mind, I scheduled a training session on March 1, 2018, with my two colleagues in which I introduced them to my study, shared my sample with them, and showed them how to analyze it. I also asked them to analyze the first 10 articles, that is, 12.5 percent of the sample. We met again on March 29, 2018, and discussed the codes we had seen emerging and the range of possible meanings that could be attributed to them. I incorporated their analyses into mine wherever relevant and continued to analyze the sample by reading it several times as I fine-tuned the list of codes.

In the second pass of textual analysis, I collapsed the codes into categories which would ultimately become the news frames I was looking for in my sample (see Table

J.1). During this process, I also selected excerpts from the sample that could be used as exemplars and convey the essence of each frame (Lindlof & Taylor, 2011).

2.8.2 INTERVIEW TRANSCRIPTS

The second set of data, that is the interview transcripts, were analyzed as laid out by Brennen (2013), according to whom, interpretation of interviews begins while the interview is actually taking place. I, therefore, asked clarifying questions during the interviews in an attempt to address any “issues, concerns, and contradictions” (p. 37) that I may have noticed as arising.

After the interviews were transcribed, I inductively identified important insights and information, key concepts, opinion, patterns, and themes as they emerged during my readings of the transcripts. These were guided by various sensitizing concepts from my literature review as well as the findings from the analysis of the first dataset. These resulted in sets of codes that were also collapsed into categories (see Tables J.2, J.3, and J.4).

2.9 LIMITATIONS

While I arrived at my methodological choices because of the unique combination of strengths and how it would help me tackle my research questions, I was aware of the weaknesses inherent in these approaches, too. No methodological approach is without its limitations. In this section, I present certain limitations that were related to the methodology methodologies I chose for this dissertation. Some of the limiting conditions arise from the study’s research design while others address the common critiques of qualitative research.

Framing theorists encourage the study of various processes that occur during framing; these include processes at the audience level and refer to individual level frames as independent variables. As highlighted earlier in this chapter, critical cultural studies also emphasize audience reception of texts in a manner similar to framing theorists. This study does not address how audiences interpret texts; this is beyond the scope of this project but can serve as the objective of another study. At best, the experts and the journalists who were interviewed can be considered as part of the audience of the news stories that were analyzed in this project.

Also, the textual dataset that forms part of the analysis in this article is limited to newspaper articles. Images are not included in that data set. Further, the newspaper articles are limited to those published in the state of California. Future studies should aim to include a wider variety of data, perhaps television transcripts and magazines from across the country, and include visuals as well. The McMath family maintains a public Facebook page whose content could also form the basis of another study.

Finally, the design, execution, data analysis and findings from this study are grounded in me as the researcher. Qualitative research considers the researcher as the instrument and therefore acknowledges the subjective position that the researcher occupies with respect to the entire life cycle of a research project. This issue is of particular salience to data analysis and interpretation, which may not necessarily be replicable. A detailed literature review that serves as the basis of the sensitizing concepts used to analyze the data as well as an active attempt to be transparent while exercising self-reflexivity can help reveal the researcher's subjective position and provide context to the results of the study. I have attempted to do this at every step of the research process,

including the writing stage, where I wrote purposively in the first-person. My goal for using this technique was to remind not only the reader but also myself of my presence in this project as a researcher and that every aspect of this project occupies a position relative to mine in some way or the other.

CHAPTER 3

FRAMING: TEXT AND PROCESS

Back in that basement in 2016, Sonal was concerned about the way in which brain death was covered by journalists. He didn't like how journalists sometimes confused brain death with other neurological states like coma and vegetative state. He was also worried about the use of religious terminology and narratives – miracles and prayers – in descriptions of scientific phenomena in the news. The way that brain death was written about by journalists sometimes made trained experts look like they had no credibility or knowledge.

Ever since we got married and I started socializing with more physicians, I've noticed that doctors in the United States worry about these things while dealing with patients. They are especially nervous about dealing with families who have been told that their loved one has died because one can never predict how the families will process this information and if they will sue the hospital and its staff. Healthcare providers are wary of lawyers who take on these cases. They are not-so-lovingly referred to as “ambulance chasers” by many in medicine. Situations of life and death such as these are obviously very complex in how they involve the different, very specialized fields of medicine and the law, and from what I understood from Sonal's presentation about brain death, journalists may at the very least struggle to grasp the complexity of these situations and convey it to their audiences.

All of these concerns made me curious about how journalists had written about Jahi McMath. As I've mentioned in earlier chapters, brain death as a concept is a new arrival on the cultural scene and is not well-understood by the public. Disagreements may crop up among experts depending on their intellectual approach to the topic. As I discussed in the first chapter, the media performs an important role of informing the public about various issues. I decided upon framing theory, a powerful tool used by mass communication researchers to analyze newspaper articles (Matthes, 2009), to help me make sense of this drawn-out controversy as it played out in California's newspapers. This chapter presents the findings of my first two research questions, both of which relied upon framing theory to help me unpack journalistic narratives as they may have been constructed about Jahi's story.

Before I introduce my findings, I describe framing theory in detail, talking about its history as well as its current place in academic circles. I discuss how I used the tenets of the theory to inform my research questions. The rest of the chapter is dedicated to the answers I found to these research questions. This part is divided into two main sections – the first presents the findings from my textual analysis of newspaper articles from California, while the second presents themes from interviews with journalists and experts on brain death. Each of the frames and themes are described in detail. An overall summary of the findings across both methods is also offered at the end of the chapter.

3.1 FRAMING THEORY

Framing theory has had a comparatively shorter lifespan than some other theories used in mass communication, yet as a framework it has seen a considerable amount of

discussion with regard to its explication. At the same time, framing theory has experienced a resurgence in use over the past several years (Matthes, 2009).

Framing theory traces its roots from the traditions of sociology and psychology (Scheufele, 1999; Scheufele & Tewksbury, 2007; Cacciatore, Scheufele, & Iyengar, 2016). Psychologists have traditionally viewed frames on the basis of “how a given piece of information is presented to an audience, rather than differences in what is being communicated” (Cacciatore et al., 2016, p. 10). In other words, frames are differently worded choices for what are essentially equivalent options (Cacciatore et al., 2016). They demonstrate that “human choice is contingent on the description of choice problems, how information is contextualized, rather than the expected utility of those options” (Cacciatore et al., 2016, p. 10). Because the emphasis here is on presentation and not the actual content, these frames are called equivalence frames.

Sociologists trace their use of frames to scholars such as Goffman (1974), Gamson, and colleagues (Ferree, Gamson, Gerhards, & Rucht, 2002; Gamson, 1985, 1992; Gamson & Modigliani, 1987, 1989) who conceptualize frames as tools that people use to organize their experiences of life. Gamson and Modigliani (1987) called frames as a “central organizing idea or story line that provides meaning to an unfolding strip of events” (p. 143). This concept of frames is based on the idea that human beings are always struggling to make sense of the world around them (Goffman, 1974). Such frames are called emphasis frames because they are constructed by emphasizing certain aspects of reality over others (Cacciatore et al., 2016; Scheufele & Tewksbury, 2007). The most popular description of frames that is used by researchers comes from this tradition (Matthes, 2009), that is, framing is “selecting some aspects of a perceived reality and

make(ing) them more salient in a communicating text, in such as a way as to promote a particular problem definition, causal interpretation, moral evaluation, and/or treatment recommendation” (Entman, 1993, p. 52).

Scholars continue to wrestle with many aspects of framing theory. One of these aspects relates to the very nature of the theory, specifically the underlying mechanism of the framework (Cacciatore, Scheufele, & Iyengar, 2016; Scheufele & Tewksbury, 2007). Scholars such as McCombs have clumped framing theory with others from the same paradigm as agenda setting and priming, both of which are based on the network memory model. According to this outlook, all of these theories are based on the concept of salience or accessibility (Cacciatore et al., 2016; Scheufele & Tewksbury, 2007). This means that they function by making concepts in the media content accessible to the audience. When seen from this angle, framing theory is merely an extension of agenda setting and priming and is often referred to as second-level agenda setting. Other scholars like Cacciatore et al. (2016) argue against this conceptualization of framing theory. According to them, framing theory rests upon the assumption of the existence of interpretive cognitive schemas within each individual in the audience. When frames in the media are received by the individuals in the audience, they only produce a framing effect when they are matched by comparable frames in the individuals. In this case, the effects produced by framing theory are not a matter of salience but applicability.

Another area of discussion within framing theory has been the great variability in the way that researchers continue to explicate frames in their research (Cacciatore, Scheufele, & Iyengar, 2016; Matthes, 2009; Scheufele, 1999; Scheufele & Tewksbury, 2007). Such a conceptualization of frames “captures a wide range of media effects, which

has little to no actual explanatory power and which provides little understanding of the mechanisms that distinguish it from other media effects concepts” (Cacciatore et al., 2016, p. 9). Concepts that such studies have used to refer to frames in an almost interchangeable way include themes, schemas, and scripts (Cacciatore et al., 2016). Scholars recommend that researchers be clear about their research goals and discuss the conceptualization of framing theory that they then turn to in order to achieve those goals. Not doing so would further contribute to the debate about the status of framing theory as a unified conceptual framework.

Scheufele (1999) offers a solution to the problems associated with framing theory as discussed above. He proposes a four-cell typology within which framing studies can be classified; this classification rests upon distinguishing different levels of frames and also the causal location of frames. Ideally, scholars who use this typology would abandon the use of generic terms like frames and be more specific when describing the kinds of frames they are going to operationalize. Not only would this four-cell typology permit the categorization of extant framing research and permit comparisons between them that so far have been difficult, but it would also allow theorists to examine how each type of framing research as divided into each cell is developing. Finally, the typology would also make it possible over the long term to contribute to theory building in a structured manner that has not been possible with framing theory so far.

The typology (see Figure 3.1) rests upon two dimensions as mentioned above, one of which is the level of the frame. On this axis, frames can be either macro-level media frames or micro-level individual frames. Media frames refer to the frames that are embedded in the media, while individual frames are those that are part of the cognitive

schema of the individuals in the audience. The latter can be of two types: long-term political beliefs and short-term issue-based frames. The other dimension in the typology views frames as variables and classifies frames into those that are independent and dependent. Independent frames usually examine the effects of media frames on the audience, and dependent frames are those that are constructed in the media.

Scheufele (1999) also alerts framing researchers to pay attention to not just the inputs and outputs of the framing process as is laid out in their typology but to also explore the processes between them (see Figure 3.2). He categorizes these processes into four types: frame building, or how media frames are constructed; frame setting, or how media frames and individual frames interact; individuals-level effects of framing, or the behavioral and attitudinal effects produced by individual frames; and journalists as audience, or how journalists are affected by frames as the consumers and creators of media frames themselves.

My project is limited to a single topic, that is news coverage of Jahi's story, rendering the frames under study of the issue persuasion. Given the close connection that Jahi's story has to brain death, this approach permitted me to gain an understanding of the narratives around brain death that are present in the culture within which the journalists who have been covering this story function (Bird & Dardenne, 1997). This approach has also been used in other framing studies that examine controversial scientific issues like climate change (Hart, 2010), vaccinations (Holton, Weberling, Clarke, & Smith, 2012), tobacco use (Menashe & Siegel, 1998), childhood obesity (Barry, Jarlenski, Grob, Schlesinger, & Gollust, 201), biotechnology (Bonfadelli, Dahinden, & Leonarz, 2002),

stem cell technology (Nisbet, Brossard, & Kroepsch, 2003), abortion (Dudova, 2010), and genetically modified crops (Lore, Imungi, & Mubuu, 2013; Mula, 2007).

At the same time, I depart from the traditional approach taken by most framing theorists who take a strong media effects and theory-building approach to framing studies. My dissertation uses the theory more akin to the tradition of qualitative analysis:

Qualitative researchers can benefit from being familiar with theories, because theories serve as sensitizing concepts that help direct attention to meaningful data – helping determine what to observe, take notes on, or ask questions about.

Although theories should not be viewed as strict recipes, they provide guidance and potential organizational frameworks. (Tracy, 2013, p. 50)

A qualitative analysis is well-suited to a study like mine, being especially suitable for the study of a single topic such as brain death because of the ability of qualitative analysis to provide rich, context-based results (David, Atun, Fille, & Monterola, 2011; Haller & Ralph, 2001). An in-depth, multi-dimensional analysis as required in this project also allows for the discovery of both manifest and latent content. As outlined by Babbie (1989), manifest content refers to specific words or terminology, and latent content aligns more closely with reading between the lines in an attempt to uncover the meanings within communication.

Of the few studies that examine the representation of death in the media, two use framing theory to guide their analysis, and both use qualitative textual analysis to make sense of their data, which was composed of newspaper articles. In their study of the framing of physician-assisted suicide, Haller and Ralph (2001) found six narrative frames that fell into either one of two types: mainstream frames that devalued the disabled, and

oppositional frames that challenge the mainstream frames. They further expressed their conviction in qualitative analysis as an appropriate approach in studies that examine the frames in news texts. Kalwinsky's (1998) analysis also concerned physician-assisted suicide, although it revolved around the controversial case of Jack Kevorkian, the American physician who was jailed for helping patients suffering from acute conditions die. His analysis presents a detailed contextual treatment of several frames, such as the frame of individuality that portrayed Kevorkian in the "traditional myth of the intelligent, rugged individual attempting to provoke a hypocritical society into realizing its inherently faulty stance" (p. 98), the frame of individual rights "under the Fourteenth Amendment, intercalating the concerns of health and its relation to individual autonomy as a primary North American value" (p. 98), and religious frames that opposed physician-assisted suicide.

A critical approach to this analysis is crucial to understanding the conflict between the McMath family and what they may perceive as the elite scientific establishment. Giannino (2013) uses such an approach in his analysis of editorials about the representation of Italian Americans on the reality show *Jersey Shore*. He scours through the editorials for frames concerning stereotypes about Italian Americans, supporting his analysis with the belief that frames are tools that are used by dominant segments of society to spread hegemonic ideologies. Moscovitz, Billings, Ejaz, and O'Boyle (2018) also conceive of frames in this way in their qualitative framing analysis of print and broadcast stories about the coming out of athletes Michael Sam and Jason Collins. They conclude that "the role of media and the visibility it affords emerges as a double-edged sword: providing a platform for potential change while also actively

reinforcing power relations undergirding the coming-out narrative” (p. 15). This is also an assumption that forms the basis of this study, particularly when seen in light of Hawkesworth’s (2012) claim that science is value-laden and may contains biases.

The Jahi McMath case, unusual as it is because of how long Jahi’s body had maintained on mechanical support, has elevated to the level of a controversy, one that appears to rest not on a lack of information on the side of the McMath family but on underlying moral and ethical issues. Such controversies, as I discussed in Chapter 1, are best approached with an aim toward the resolution of those issues (Hines, 2001). Framing theory is an appropriate choice to reveal those issues, specifically by analyzing the frames that journalists have been using to construct the narrative of the case. According to the four-cell framing typology mentioned earlier, these would be media-level dependent frames that would examine the frame building process. Analyzing newspapers is a common approach in framing analyses (Matthes, 2009).

Framing theory is a framework of media effects. It appears to arise from positivism, something I detected by the insistence of scholars on cause-and-effect, deduction, generalizability, and reliability (Cacciatore, Scheufele, & Iyengar, 2016; Matthes, 2009). Qualitative research is concerned with a deep, rich analyses of specific cultural meanings (Lindlof & Taylor, 2011; Tracy, 2013), which are not primarily intended for generalization, causal analyses, and theory building. Qualitative researchers make no claims to objectivity or reliability; rather, they claim that there can be no such thing because researchers always carry biases and have some sort of relationship with the things they study (Hawkesworth, 2012). The only claim that I, as a researcher attempting a qualitative study, can make to objectivity is to attempt to disclose my own position by

means of self-reflexivity throughout my dissertation, as well as to include member validations and member reflections as part of my study (Tracy, 2013). However, I do feel that using the four-cell typology and the processes model indicated earlier allows my study to still contribute to the need of framing theorists for structure and theory-building. In addition, qualitative research can be conducted inductively, especially in cases where the topic is as understudied as brain death. According to Christians & Carey (1989), such an approach, especially when coupled with maximized comparisons, sensitization, contextualization, and naturalistic observation, can reveal general underlying structures which could be used to fulfill the requirements of framing theorists for generalizability. It is in this space that my study occupies a unique position within framing theory and qualitative approaches.

3.2 FRAMES IN NEWSPAPER ARTICLES

This section presents my findings from a qualitative textual analysis of newspaper coverage of the Jahi McMath case in California. Some of the questions that arose in my mind related to how newspapers, specifically in California, had been covering the case. How had journalists, many of whom are not trained in science and frequently avoid science courses while in school (Reed & Walker, 2002; Tanner, 2004), been covering a case that dealt with such a complex concept such as brain death? How were they interpreting the story for news audiences? Based on the social constructivist paradigm of media effects, newspaper coverage not only informs people about various issues, but it constructs reality for them (Quail, 1994). I explored these concerns via the following research question:

RQ1: What frames have been used in newspaper coverage of the Jahi McMath case?

I conceived of the frames as emphasis frames along the lines of what they suggested the controversy was about (Gamson & Modigliani, 1987). Untangling these various interpretations of brain death not only gave me a deeper understanding of the underlying issues that have elevated brain death cases such as Jahi McMath's to the level of a controversy, but I hope that they will allow experts to better address those issues as part of an effort to make brain death a less controversial topic (Hines, 2001). A key assumption of this study is the value-laden nature of science (Hawkesworth, 2012); I also aimed to uncover various meanings of brain death that could be beneficial to experts as they continue to refine the definition of death and reconcile it with the lived experience of death and dying within the social landscapes of their patients and their families.

My textual analysis of 81 newspaper stories in prominent California newspapers revealed the presence of the following frames as they were used to construct the narrative of Jahi's case in the news in California: "Uncertainty About Death," "Legal Exploitation," "A Conspiracy," and "Blame the Science" (Figure 3.3). While I was expecting the second frame, "Legal Exploitation," because it advocated for the current standards of the determination of death, I was surprised by the presence of the others which presented alternative and conflicting narratives about the case when compared to the second frame. The first frame, "Uncertainty About Death," appeared to cultivate a sense of doubt about what is scientifically understood to be certainty about the determination of death; this appeared to make it possible for the next two otherwise conflicting frames – "Legal Exploitation" and "A Conspiracy" – representing the two

irreconcilable sides of the controversy to coexist. As if in need of relief from this state of conflict, the two frames appeared to give rise to the fourth frame in which various features of the two frames preceding it attempted to combine. The fourth frame, “Blame the Science,” thus represented a negotiation between conflicting narratives and ultimately incompatible versions of reality in this long-running and emotionally charged controversy, perhaps as a form of epistemological cognitive dissonance.

The case, however, is still very much active, and the fourth frame, which represents the middle ground between scientific certainty and an attack on scientific principles, continues to feed into the first frame, further creating uncertainty about death by continuing a conversation about it between scientists and the lay public.

3.2.1 UNCERTAINTY ABOUT DEATH

This frame addresses the uncertainty that media storytellers created around the determination of death. This uncertainty persisted throughout my sample of newspaper articles about this case in California and grew in strength over time. It highlighted the fact that death is not a static condition, such as in the headline of *The Mercury News* article “Technology alters views about death” (Krieger & DeBolt, 2013); rather, it is a matter of debate and disagreement not just between scientific experts but also between scientists and non-scientists and amongst members of the general public.

Declaring death used to be simple: The deceased turned blue and stiff. The heart became inaudible, the pulse faded and the chest stilled. That’s not Jahi McMath’s story. The 13-year-old Oakland girl’s skin is still soft and warm. Her pulse is still strong. And her lungs fill with air. (Krieger & DeBolt, 2013)

One of the ways in which uncertainty about death was highlighted was by describing death and brain death as complex issues that are difficult to understand, requiring moral questions that “have a million answers” (Lee, 2014a). Court arguments about the case were described as involving “philosophical treatises on life and death,” with questions such as the following being asked: “why are we focusing so much on death? On the flip side is life; life is not static” (Gafni, 2015). This complexity extended to the Jahi McMath case as well, the establishing events of which were presented in *The Mercury News* as “not immediately clear” (DeBolt & Hurd, 2013b) and shrouded in mystery despite a state investigation into the matter.

Several articles were dedicated to explaining the complexities of death and brain death, such as in Jones (2013a) who described in the *San Francisco Chronicle* the determination of the end of life as “a difficult decision” and “a struggle.” She further described death as more complicated than it used to be in the past, which has ignited debates over the issue and resulted in the determination of death on an individual basis. The complex nature of death today was described as being difficult for families to understand, with family members disagreeing with doctors as to the definition of death because their “loved ones can die but still be breathing” (Jones, 2013a).

Newspaper reports also centered on the debates within the medical establishment over when life ends, such as in the case of Dr. Paul A. Byrne who believes that “brain death is not true death, a belief that contrasts with the majority of the medical establishment” (DeBolt, Hurd, & Oakley, 2013); retired professor of health law and medical ethics Marjorie Shultz who confessed to “turmoil about the definition of death and whether the brain is or is not functioning” (Jones & Egelko, 2013); Catholic doctors

who volunteered to assist the McMath family with providing long-term care for Jahi's body; and an unnamed pediatrician "who has seen Jahi who has sworn that she is not dead" (DeBolt, Alund, & Ivie, 2013). Disagreement within the medical community was also expressed prominently in the headline of the *San Francisco Chronicle* article "Doctor challenges medical consensus" (Johnson, 2017). Jahi's grandmother, Sandra Chatman, who had also had a career as a nurse, also reported that Jahi was alive. This pattern fully manifested towards the end of the sample in the case where Jahi – while still deemed dead in California – was being treated as alive by other doctors and nurses after being moved to New Jersey, a situation that was in direct opposition to the law in California. So powerful was the dissenting opinion expressed by Jahi's new medical team that it convinced the judge overseeing her case in California to accept it as admissible expert testimony even as it contradicted California law and the opinion of the staff at the Oakland hospital.

Death was also presented as not a single condition but one of varying kinds. Death was especially shown to have been traditionally determined by the law and medicine, or as the ear, nose, and throat surgeon who operated on Jahi was quoted in the *San Francisco Chronicle* as saying, "by statute, and by science and medicine" (Egelko & Colliver, 2015). While Jahi was sometimes simply described as "dead" (Jones, 2013b), she was also described as "legally, morally, and ethically" deceased (DeBolt, Bender, & Alund, 2013), thus implying that death can be legal, moral, or ethical. Brain death was limited in *The Mercury News* to "the equivalent of the end of life in the medical field" (Debolt, 2014a), while in the *San Francisco Chronicle* the determination of death was extended to being dependent on "culture, religion, family dynamics" (Lee & Jones,

2013). In the words of elder attorney and former social worker Kathleen Day-Seiter (Lee & Jones, 2013), “In some cultures, you don’t give up, no matter what. You don’t give up until the person is gone, gone...plus, you’re dealing with the emotions of losing a loved one. It can be very complicated.”

This perspective of dying gave rise to the question of which kind of death should be recognized. Bioethicist Ryan Holmes was quoted as championing the need for “hard lines” in the determination of death, a need that became more urgent because he believed that the Jahi McMath case was setting a dangerous precedent, specifically that of questioning healthcare professionals in such situations (Gafni & Alund, 2013). Lawrence Nelson – lawyer, bioethicist, and associate professor of philosophy – echoed a similar sentiment, bemoaning the confusion that he believed that Jahi’s legal case could cause in lay circles.

Journalists further appeared to use certain terminology inconsistently, such as describing Jahi as “brain dead” in both the headlines (DeBolt & Hurd, 2013a) and the body of the news articles (DeBolt & Hurd, 2013a), thus suggesting that it was only her brain that had died while the rest of her body and person might still be alive. Also, the terms “life support” (DeBolt, Bender, & Alund, 2013; DeBolt & Hurd, 2013a), “mechanical support” (Fimrite, 2013), “artificial support” (Krieger & DeBolt, 2013), and “organ support” (DeBolt, 2014a) were used interchangeably; according to Nelson in the *San Francisco Chronicle*, the first term indicates an assumption that Jahi is alive and “further confuses the situation...the single worst consequence of this...people may think death is not uniform, that’s it not the same thing for all of us” (Colliver, 2014), while the second term is preferred by professionals

who believe that Jahi is dead. The third term, however, indicated a deeper question – if Jahi’s organs need to be supported, then does her life reside in her organs? Who is it that died – Jahi or her body? This idea is reflected in narrative that separates Jahi from her body, such as in a quote by the McMath family’s lawyer Christopher Dolan who described the McMath family as “going to have that body surrounded so that nobody can touch Jahi” (Lee, 2013a) and who declared that Jahi’s “medical condition, separate from the brain issue is not good” (Krieger & DeBolt, 2014) and the headline “Jahi’s organs slowly dying, expert asserts – lawyer has said Oakland teenager’s health is improving” (DeBolt, 2014a). Neurologist and chief medical officer Dr. Neal E. Slatkin further emphasizes that “her organs are alive, but she’s not alive” (DeBolt, 2014a).

In addition, some journalists used incorrect terminology to refer to Jahi, such as calling her comatose, which is a condition in which patients are alive. Further, the facility where Jahi was taken to in New Jersey was described as a “brain injury treatment center” (Gafni, 2014a), which implied that Jahi had a brain injury instead of complete brain failure and was therefore living. The facility is also described in its own words as a “state-of-the-art outpatient facility designed to provide rehabilitation, management and recovery for community members with traumatic brain injury, physical disabilities, cognitive disabilities or dementia” (Bender, 2014a), all of which are conditions in which patients have some level of brain activity and are therefore considered alive. The Terri Schiavo Life & Hope Network also officially referred to Jahi as suffering from a brain injury. All of these things ultimately further bolstered the argument that the matter of whether Jahi is alive or not is, at best, still undetermined and, at worst, is moot because she is alive.

Closely tied to the issue of multiple perspectives of death was the issue of the struggle over picking a single kind of death over others and how that affects the rights of the individual. The matter of the rights of the individual, such as Jahi's right to life and privacy, as well as those of parents to determine the lives and deaths of minor children were raised by Dolan in *The Mercury News*:

Who gets to make these choices regarding children and healthcare and this most intimate fundamental choice – will you live or die? Was it the family who brought the child into the world? Or was it the hospital, who may have made the mistake that's taken her life? I would fight just as hard if they were making the decision to take Jahi off a respirator. This is about choices. No matter how they try to characterize it, it's about empowerment, choices and the rights of the people.

(DeBolt, Alund, & Ivie, 2013)

Religious freedom was also touted by mentioning that hospitals were required to reasonably accommodate a patient's religious beliefs and that in New Jersey one's religious beliefs could be used to override the law regarding brain death by rejecting it altogether. The court case centered on Jahi was described as being about "the rights of families – not doctors, lawyers or politicians – to determine a loved one's death, based on religious or personal beliefs" (Jones, 2013b). Dolan's concern, as expressed in a direct quote in *The Mercury News*, is that "if (the government) decides when life ends, they also may try to decide when life begins" (Gafni, 2014b). This quote begins to tie the Jahi McMath case – one of end-of-life – to another more established and controversial issue, that of when life begins, that is, abortion rights. Shultz, too, recommended seeking the input of family members in the determination of death.

Other cases deemed to be similar to Jahi's were discussed in an effort to show that this has been a pressing concern for some time and needs to be addressed because the problem will only continue to grow in the future. Some of these cases involved brain death patients whose bodies had been returned to their families or kept on mechanical support, strengthening the position of the McMath family while weakening the stance of Oakland hospital and California. Shultz's own story was shared in the *San Francisco Chronicle*, that of a mother "not being able to believe doctors" over the determination of the status of her son who had been deemed to be in a minimally vegetative state but who ultimately "now lives on his own and has bachelor's and master's degrees" (Jones & Egelko, 2013). "It makes you question everything," one of the parents of a 23-month-old boy, Hiram Lawrence, who had died due to complete brain failure was quoted as saying in *The Mercury News* (Krieger & DeBolt, 2013).

Jahi's case, therefore, is positioned as not unique, but at the same time, it is described as groundbreaking and making news around the country and the world. Bender (2014b) cites experts calling for independent testing, especially considering the unusual situation that Jahi's body is in and has lasted so long. Ultimately, this frame hopes that Jahi's case will "change how California determines when death occurs" (Gafni, 2014b) or at least set legal precedent for similar cases in the future, inspiring "other families to question brain death determination of their loves ones" (DeBolt, 2017), which according to Dolan, is "a very important, significant legal debate that has been started" (Gafni, 2014b).

What it means to be determined dead is a scary thought for most people...we are going to have to move in that direction and revisit it, legally and collectively. We

will continue to learn more about what is going on in the brain of people who are minimally conscious, or something in the twilight zone between unquestionably dead and unquestionably alive. (Johnson, 2017)

Uncertainty, however, persists even at this point with Shultz who, having previously expressed little confidence in healthcare providers, predicted “chaos if it were up to each individual to determine death” (Gafni, 2014b). Thaddeus Pope, director of the Hamline University’s Health Law Institute, echoed this sentiment in *The Mercury News*, calling the controversy around the determination of death in Jahi’s case a “big house of cards” (DeBolt, 2014f). The public response to Jahi’s case is described as similarly varied with her family portrayed as receiving support and also criticism.

3.2.2 LEGAL EXPLOITATION

Another narrative framing device that structured the story of Jahi McMath was based on the legal consequences of her actually having died; this narrative placed the hospital in the right and reaffirmed the authority of healthcare professionals to determine death. This frame also lent credence to the concept of brain death and acknowledged its legitimacy. The controversy around Jahi’s status as a person, therefore, was attributed to her family being misled and manipulated by others, particularly their lawyer, Christopher Dolan.

Jahi was presented as being dead in many ways. Journalists did this through their own words outside of quotes attributed to someone else. For example, many clearly described Jahi as “dead” (Lee, 2013b) or having suffered “death” (Bender, 2013) instead of only calling her brain dead, which, as extant literature has established, gives some lay people the impression that brain death is not complete death, may be reversible, or

considered temporary as compared to cardiac death. Journalists also dedicated a considerable amount of space in their writing to explain what brain death was and why it meant that Jahi was dead. Dr. Neal Slatkin, a neurologist and chief medical officer, for instance, was quoted in *The Mercury News* saying that “the brain controls pretty much everything in the body...without it, everything begins to break down” (Krieger & DeBolt, 2014). The journalists also regularly mentioned the fact that Jahi had been issued a death certificate in California and that her body was deteriorating while on mechanical support.

The tissues under her skin were losing their elasticity, and her muscles were contracting. Her blood pressure spiked but was gradually declining. Blankets were needed to maintain a constant temperature. This deterioration became inevitable the moment she died...additional and more dramatic signs of the body deterioration will continue to manifest over time, regardless of any procedures and regardless of any heroic measures that any facility might attempt. (Krieger & DeBolt, 2014)

The journalistic reporting established that Jahi was dead by presenting the hospital as firm in its stance. Journalists cited various individuals who represented the hospital, such as the Chief of Pediatrics at the Oakland hospital Dr. David Durand and hospital spokesperson Melinda Kriegel. The hospital’s lawyer Douglas Strauss was also quoted saying that “Ms. McMath is dead and cannot be brought back to life” (Bender & Alund, 2013) and that she is a “deceased person” (Lee, 2013b). The hospital also consistently referred to Jahi as a body, even in direct quotes such as the one from Strauss that referred to her as “Jahi’s body” (Gafni & Alund, 2013) and dispelled theories of life

by, for example, labelling any movements in Jahi's body as involuntary movements – the Lazarus Effect – that were not unusual in a dead body.

The hospital's position was also shown as being supported by the majority of the scientific community, including experts on brain death like author Nancy Berlinger from the Hastings Center, Stanford professor David Magnus, bioethicist Ryan Holmes, and Arthur Caplan from the New York University Langone Medical Center. These testimonials bolstered the hospital's credibility and presented a unified scientific front in the controversy around Jahi's status as a person. "When they turn off the ventilator, she will not die," Magnus was quoted as saying in the *San Francisco Chronicle*. "She already died" (Colliver, 2014). According to Lawrence Nelson, a bioethicist and associate professor of philosophy: "There's no choice to be made here. She is gone" (Colliver, 2014). Slatkin had another term for Jahi's body being on mechanical support – "organ support" (DeBolt, 2014a). "Dead is dead," he was quoted as saying in *The Mercury News*. "There aren't grades of dead. Anything that (the attorney) or the family may perceive as improvement does not indicate that she is alive in any way" (DeBolt, 2014a). Further, Wade Smith, director of a neuroscience intensive care unit, was quoted as issuing a final stamp in the case by declaring that he knew of "no recorded cases of a brain-dead patient recovering brain function" (DeBolt, 2014b). Thaddeus Pope, director of the Health Law Institute at Hamline University agreed; according to him, the revocation of a death certificate in a case like Jahi's had "never happened, ever, on Earth" (DeBolt, 2015a).

Scientists were not the only individuals who were portrayed as thinking of Jahi as a dead person. Jahi was also talked about by her own family and supporters as if she was

dead. Jahi's uncle, for instance, initially was quoted referring to her in the past tense – "she was my baby...she was the sweetest girl. She always smiled. All she did was smile and laugh" (DeBolt & Hurd, 2013b). Jahi's mother, Nailah Winkfield, was quoted from a letter she had written asking all mothers to pray to "bring life" (Sulek, 2013) to Jahi; a similar prayer was offered by Jahi's godfather and pastor, specifically praying for God to "breathe life" into Jahi, indicating an underlying assumption on his part that Jahi was dead (DeBolt, Hurd, & Oakley, 2013). Even Dolan, who later criticized the hospital for refusing to call Jahi by her name and simply referring to her as a "body" (Gafni, 2013a), was quoted as doing so himself early into the case.

In this narrative, the hospital was portrayed in a positive light. It was reported as following the rules of care and meeting medical regulatory standards. Bleeding after tonsillectomies was described as "relatively common" (Sisson, 2013), and Jahi's death was attributed as an "unanticipated outcome" (DeBolt & Hurd, 2013) of her surgeries. The hospital itself was portrayed as law-abiding, only unwilling to retain and perform procedures on Jahi's body because of concerns about violating ethical and legal norms, a situation that was described as "grotesque and unprecedented" (Gafni, O'Brien, & Alund, 2014) by the hospital's attorney. In this way, the hospital was cast in a righteous light with nothing to hide and open to investigations.

The hospital itself was shown as being deeply sympathetic to the McMath family and accommodating them in various ways, including "repeated meetings with medical staff, support from social workers and the hospital's chaplain, special accommodations for visits, a room for the family to meet away from Jahi, and space in the facility's Family House" (Bender & Alund, 2013). Their willingness to work with the McMath

family in dealing with Jahi's death was expressed in direct quotes from Durand in the *San Francisco Chronicle*:

Our hearts go out to family and friends of Jahi McMath. This is a tragic situation. We implore the family to allow the hospital to openly discuss what has occurred and to give us the legal permission – which it has been withholding – that would bring clarity, and we believe, some measure of closure and deeper understanding of this medical case. (Lee, 2013a)

Durand's emphasis on clarity and understanding in his words above reflected the assumption that the controversy around whether Jahi was truly dead or not was the result of some unspecified sources creating "misperceptions" (DeBolt & Hurd, 2013b). For example, he questioned the claims of a consumer advocacy group that was reported calling for criminal and medical investigations as "unsubstantiated and inflammatory" (Bender, 2013) and "replete with errors" (Bender, 2013); interestingly, the consumer advocacy group referred to Jahi as dead. Sam Singer, a public relations expert hired by the hospital, further questioned the credibility of the consumer group by calling its allegations "fraudulent and misleading, based on conjecture and not on the facts" (Matier & Ross, 2014) and its attorneys "dishonest, disreputable and heartless" (Matier & Ross, 2014).

Singer also squarely placed the blame of the controversy and the prolonged suffering of the McMath family on their lawyer Dolan who was accused of creating "false impressions that brain dead is not dead" (Nelson & Nardi, 2013). He was further criticized in *The Mercury News* by CNN legal analyst Jeffrey Toobin as "preying on the false hope of the family" (Mintz, 2014). Singer also questioned Dolan's motives by

pointing out that Dolan had been “criticizing the very hospital that all along has been working hard to be accommodating to this grieving family” (Tucker, 2013). He called Dolan “heartless” (Mintz, 2014) and described his crusade as the most “reckless disregard for the truth” (Mintz, 2014) that he had ever seen.

Sadly...Mr. Dolan is not being truthful to the public or his clients...when he says his ‘medical team’ wants to feed her body so her brain will have the optimum nutrients, he is either being purposely deceptive or ignorant. In either case, he is perpetuating a sad and tragic hoax on the public and the McMath family.

Tragically, this young woman is dead, and there is no food, no medical procedures and no amount of time that will bring back the deceased. (DeBolt, Bender, & Hurd, 2014)

Many people from the public at large, while not identified by name or given individual quotes in coverage of the case, were also cast as critical of the McMath family. Their opposition was so extreme as to have warranted death threats against the family. A news story that reported on reactions to a New York facility allegedly asking for donations for Jahi garnered public criticism on Twitter, including the creation of the hashtag #scamfam, alluding to less than honest intentions in the McMath family and casting doubt upon their agenda.

Ultimately, this frame implies that that the only way to resolve the controversy is for the family to accept that Jahi is dead and to bear “some recognition that the situation is not going to change” (Nelson & Nardi, 2013). In the words of Strauss, the hospital was “empathetic to their reluctance to get closure here and the difficulty that everybody is having in coming to grips with a tragic situation” (Lee, 2013b).

This, however, does not imply that the hospital and ultimately the greater scientific community are against the McMaths; rather, the hospital is portrayed as a victim of Dolan's legal scam – both the family and the medical team are suffering on his account. This is particularly evident by the decision of *The Mercury News* to include the comments from an emotional Strauss during a conversation with journalists outside a courtroom on a day of a hearing between the hospital and the McMath family; he is described as distraught, as “nearly in tears” (Gafni, O’Brien, & Alund, 2014) and “choking up” (Gafni, O’Brien, & Alund, 2014), lamenting Jahi's death and expressing sorrow at the predicament that the McMaths face. He is clear about this suffering, which humanizes him, as well as the otherwise impersonal hospital and the normally far-removed scientists that it represents: “... Wouldn't it be great if they were able to come to terms with a terrible tragic event and that I didn't have to stand in front of you all time after time” (Gafni, O’Brien, & Alund, 2014).

In fact, the hospital, with its supportive stance toward the McMaths, is shown as acting against its own best interests. Taking care of patients who were already deemed as dead was described as “traumatizing” (Krieger & DeBolt, 2013) and “demoralizing” (Gafni, O’Brien, & Alund, 2014) for the hospital staff, and according to Holmes, “the hospital is in the unfortunate position that any time they set those standard, it can be perceived as cold and unsympathetic, and it's a very hard place to be put in” (Gafni & Alund, 2013). In this way, the hospital, attempting to follow the law and conscious of its “responsibility to ensure that we don't create hope where there is none” (Gafni, 2013a), emerges as the weary protector of the McMaths, their last bastion against those who seek

to misguide them, and brain death is reinforced as equivalent to cardiac death in its finality.

3.2.3 A CONSPIRACY

This frame dramatically shifts the journalistic narrative of Jahi's story from that of the previous frame. According to this version of "what happened," Jahi never died; she is still alive but needs to be saved from the hospital that wants to kill her in order to protect itself. This frame especially differs from the previously described one in how the narrative is hinged on the characterization of the McMath family's lawyer Christopher Dolan and the hospital – here Dolan is their ally, promising in *The Mercury News* to "go down swinging" because Jahi's mother asked him to "save her kid from being killed" (Mintz, 2014), while the president of a nonprofit calls the hospital "heartless" (Matier & Ross, 2014) in the *San Francisco Chronicle* because they want to "call a patient who is breathing a corpse in order to vindicate themselves" (Matier & Ross, 2014). Because Jahi is considered alive in this frame, brain death is challenged as a concept and the McMaths are portrayed as engaged in a crusade against a system that seeks to oppress them. The family, however, doesn't engage in this struggle alone; they have support from the rest of the mortal world as well as the metaphysical one.

The seeds of the idea that there is a conspiracy against the McMaths or that something just isn't quite right are sown early in the story. The McMaths are shown as in disbelief over Jahi's death because her time at the hospital was "supposed to" (DeBolt & Hurd, 2013a) only last for one night and that she had otherwise appeared to be fine after the surgery:

When Jahi came out of surgery, she appeared healthy and alert, and was eating a Popsicle, her mother said. The girl was talking and reading notes before blood began pouring from her nose and mouth, she said. Jahi later went into cardiac arrest and was pronounced brain-dead by Thursday, the family said. (DeBolt & Hurd, 2013b)

Sandra Chatman, Jahi's grandmother, is quoted in *The Mercury News* suggesting the idea of some unspecified person or group of persons out there having done something bad to her family: "they took away my granddaughter" (DeBolt & Hurd, 2013a). Her words, that she felt that she had been stabbed in the heart, express an unusual degree of active mal intent towards herself and her family. Jahi's uncle, Omari Sealey, also expresses a certain degree of suspicion when he is quoted saying that "there was a lack of urgency" (DeBolt & Hurd, 2013a) and that "it was not immediately clear" (DeBolt & Hurd, 2013b) how the decision to take Jahi's body off mechanical support was made by the hospital. DeBolt, Bender, & Alund (2013), in fact, indicate that "distrust of medical staff" (DeBolt, Bender, & Alund, 2013) could be contributing to this controversy; Lee (2013a) later provides evidence of this distrust on behalf of the family in his own article in the *San Francisco Chronicle*.

At first, the McMaths are simply portrayed as unhappily going along with the hospital's declaration that Jahi is dead. They are portrayed passively, as lacking agency, that the "hospital made the decision for the family" (DeBolt & Hurd, 2013b) and that they had not been receiving detailed information from the "obstinate and rude" (DeBolt & Hurd, 2013b) staff at the hospital about how Jahi had unexpectedly died. They are described as "searching for answers" (DeBolt & Hurd, 2013a) and "feeling helpless"

(DeBolt & Hurd, 2013b) while dealing with the hospital which has “asked family to leave the facility and have refused the family’s request to meet with hospital administration” (DeBolt & Hurd, 2013b).

It is only later in the story – by the fourth article in my sample dated December 18, 2013 – that I began noticing clear references to a conspiracy of some sort at the hospital. This idea is lent credibility through the words of a pediatric ear, nose, and throat surgeon who is quoted in *The Mercury News* expressing doubt over the results of Jahi’s surgeries, calling death from such procedures “very unusual” (Bender & Alund, 2013). Doubt is further cast upon why these surgeries were performed in the first place considering that, according to Gafni (2013b), there is no clear agreement within the scientific community on the effectiveness of these procedures. This disagreement is further highlighted through the mention of other scientists who disagree with the practice of declaring brain death and believe that Jahi is alive, such as a “pediatrician who has seen Jahi who has sworn that she is not dead” (DeBolt, Alund, & Ivie, 2013).

Lee and Jones (2013) express this possibility succinctly in the *San Francisco Chronicle* when they use the subtitle “Cover-up feared” in their writing, although they attribute this idea to Jahi’s mother who “feared the hospital would ‘cover up’ what happened” to Jahi. She describes how she was stopped from entering Jahi’s room by hospital staff and was told by them that Jahi’s bleeding was normal, the word normal itself being placed in quotes by Gafni (2013a) in *The Mercury News*, suggesting that maybe it was not normal. Jahi’s mother is further quoted as knowing that Jahi “wants to scream out and tell me something.” The feeling that the hospital is hiding something is

bolstered by journalists who mention that the staff there refused to release Jahi's medical records to her family and continue to decline discussing the details of the case:

...Jahi's mother, Nailah Winkfield, had asked the hospital for her child's records.

A clerk initially agreed to give her the records but a senior hospital staff member intervened, saying the records were "not final" and that "the doctors needed an opportunity to review their records to see if there were any 'errors' or any additional information that needed to be provided"... (Bender, 2013)

This, according to others like advocacy groups and Dolan, is evidence enough of potential negligence in Jahi's time at the hospital and grounds for a medical malpractice suit. A California consumer advocacy group, for instance, suggests that hospitals which make mistakes like those that are being alleged in Jahi's case prefer that those patients die so as not to be burdened by negligence claims that can shortchange hospitals up to \$250,000. This eventually transforms into clear accusations that the hospital is trying to kill Jahi, "trying to end her life" (Lee, 2013a), wanting to "pull the plug" (Gafni, 2013a), and "hell-bent on this girl going out in a box" (Hurd, DeBolt, & Parr, 2013). According to Dolan in *The Mercury News*, "the hospital wants to block every opportunity for Jahi to leave" (Hurd, DeBolt, & Parr, 2013), going to the extent of suggesting that potential care facilities are choosing not to help Jahi for fear of risking their relationship with the hospital. Even a state investigation into the hospital's handling of Jahi's case that reveals no negligence is dismissed by Dolan, who argues the McMath family was not contacted during the investigation. He considers the investigation a further indication of a conspiracy at the highest levels, calling it "doctors covering for other doctors" (Gafni, 2014c) and an example of "the fox guarding the henhouse" (Alexander, 2014a). DeBolt

(2015b) highlights concerns about the hospital wanting to harvest Jahi's organs, describing how "hospital officials hounded her mother to sign off on donating Jahi's organs...they allegedly went so far as to approach her as she prayed in a hospital chapel."

Jahi's uncle remains confident, though, that "what's done in the dark, will come to light"; fears, however, about the perceived conspiracy against Jahi remain. Jahi's mother's words – "I won't let you take her" (Jones, 2013a) – are aimed at her perceived oppressors, and Alexander (2014a) maintains that the report did not address the important details about Jahi's case. Dolan further confirms these fears in *San Francisco Chronicle* (Lee, 2013a):

"They're afraid," Dolan said. "Could the hospital go in and try to do something? I think it would be absolutely foolish. But in their eyes she's no longer a person. She's dead. So they're not looking at her like it was your daughter or my daughter, they're looking at her like they've got to get her out of there quickly."

The underlying assumption here is that Jahi is alive; she is often referred to as "disabled" (Lyons, 2017), "comatose" (Lyons, 2017), and in a "minimally responsive" (Lyons, 2017) or "vegetated state" (DeBolt, 2014c), all of which as conditions distinct from brain death imply that Jahi is alive and that she will regain consciousness. This assumption underlies the rest of the frame concerning what the family wants, who they think their allies are, and who they think their enemies are. This claim, however, is in direct opposition to the assumptions in the frame described previously where Jahi is considered dead. Once this frame makes evident its assumption in the sample that Jahi is alive, the McMaths are clear in what they want, that is to find a facility that can "provide her with care and support and treat her as if she's a living person" (Hurd, DeBolt, & Parr,

2013) and that the state of California annuls her death certificate. The hospital, according to them, wants the opposite, that is, for Jahi to leave “in a body bag” (Hurd, DeBolt, & Parr, 2013). The assumption that Jahi is alive is especially strengthened by moments in the narrative where Jahi’s health is depicted as improving after being released from the hospital to a facility where she is being cared for. Such a moment is created through Dolan’s words in the *San Francisco Chronicle*:

Doctors are optimistic that her condition has stabilized and that her health is improving from when she was taken from Children’s Hospital Oakland. I can confirm the trach and g-tube procedure on Jahi McMath was a success and she is doing very well and now getting the treatment she should have gotten 28 days ago. (Jones, 2014b)

Through this statement and others, Jahi is presented as alive in various ways. One of the ways in which this effect is achieved is by journalists’ use of the term brain-dead to describe Jahi, which, as previous literature has pointed out, could suggest to some that Jahi was somehow not completely or permanently dead. Rather, she is frequently described in the journalists’ own words as being in a sleeping state rather than being dead, describing the whole controversy as resting on the “hope that she may one day wake up” (DeBolt, Alund, & Ivie, 2013). Even Jahi’s family describes her in this way, such as when her mother says that “Jahi looks like she’s sleeping” (Jones, 2013a) and that she has “faith that my daughter will wake up” (DeBolt, 2013). Fraley (2015) cites one of their posts from their Facebook page in *The Mercury News* that describes Jahi as “our little sleeping angel.” Jahi’s uncle Omari Sealey sums up the family’s goal in this case,

that they want to “give her another fighting chance to wake up” (Hurd, DeBolt, & Parr, 2013).

Another way that Jahi is described as being alive is by being on “life support” (DeBolt & Hurd, 2013a) and requiring “treatment” (Lee, 2013b) and “care” (Hurd, DeBolt, & Parr, 2013). She is also regularly described in quotes – both direct and indirect – and in the words of the journalists themselves as exhibiting traditionally understood signs of life, such as being “warm” (Lee, 2013b), “soft to the touch” (Lee, 2013b), and “tossing and turning” (Alexander, 2014b). “If you rub her foot, her foot curls in,” Dolan adds (Lee, 2013b). “The mother has yelled in her ear, and the daughter has lifted up her arms.” Sulek (2013) even uses these symptoms at the beginning of her article in *The Mercury News* to set the tone for the rest of her writing: “On Christmas Eve, Nailah Winkfield held vigil on her daughter’s hospital room, caressing the girl’s warm hand, kissing her soft cheeks, feeling her pulse and telling her she’s sorry for promising that everything would be OK.” According to this description, Jahi feels like a person who is alive, a person who is healthy and can hear and speak. Elsewhere also Sulek (2013) paints a picture of Jahi as a typical living teenager – wearing lip gloss, Victoria’s Secret moisturizer, and listening to music on an iPod – and not a dead body as she is considered in her home state of California. DeBolt, Bender, and Hurd (2014) also quote Dolan on his claim that Jahi is alive because she exhibits traditionally understood signs of life: “Her kidneys function, she regulates her temperature and her body moves now more than ever.” Jahi is also described as entering puberty, developing breasts, and having her first period all the while considered brain dead.

These signs are tied to a functional heart and suggest the legitimacy of the heart over the brain when it comes to the determination of death. In fact, the McMaths are frequently quoted as prioritizing cardiac death over brain death such as when they say “as long as she has a pulse, we want her on life support” (DeBolt & Hurd, 2013a) and “it’s so hard for me because her heart is still beating” (DeBolt & Hurd, 2013b). Jahi’s mother, in fact, expresses this point clearly when she says, “She’s alive to me. She’s not dead. She still has a heartbeat” (DeBolt, Bender, & Alund, 2013). Journalists also appear to make this statement in their own words when they write that “Jahi continues to draw breath and her heart continues to beat” (DeBolt, Bender, & Alund, 2013) and that her family “believes that if the heart is still beating, there’s still a chance” (DeBolt, Bender, & Alund, 2013).

Jahi is also consistently referred to by journalists by name and as a “girl” (DeBolt, Bender, & Alund, 2013) even after she has been issued a death certificate, such as in the headlines “Girl, 13, to stay on life support” (Bender & Alund, 2013) and “Hospital will let family take girl” (Lee, 2014b) and within the body of the articles like “...an independent expert to examine the girl” (Hartlaub, 2013) and “...send the girl to a long-term care facility...” (Gafni & Alund, 2013). Using Jahi’s name is a particularly important point for the McMaths who filed part of their lawsuit against the hospital in Jahi’s name and also criticize the hospital for not using Jahi’s name while referring to her as a body. References are also made to her age, such as the fact that she is (still) a teenager as is seen in many headlines in my sample: “Teen will be taken off life support – family pleads for answers, prepares to say goodbye” (DeBolt & Hurd, 2013b), “Hospital releases Jahi to mother – 13-year-old girl moved by ambulance to unknown site”

(DeBolt, Bender, & Hurd, 2014). Journalists also keep track of her body's age – Jahi was 13 years old when she died in California, but she continues to be referred to in that way, like “Jahi, 13, is...” (Jones, 2014b), even after issuance of a death certificate in California. She also continues to age throughout the sample and not just in the words of those on her side of the conflict, such as her family attorney Andrew Chang who referred to her in as “...now 14-and-a-half years old...” (Gafni, 2015) and her family as turning “15 in a few days” (Fraley, 2015), but also in the words of the journalists themselves, who write about her 15th birthday being celebrated by her family and also refer to her as 15 years old. These techniques give the impression that Jahi is alive because she continues to accrue years of life as someone who is living.

Many journalists also talk about Jahi in the present tense, such as in the very first article in my sample in which she had already been determined to be dead, but DeBolt & Hurd (2013a) write that Jahi “has been looking forward to spending the holidays with family and attending an eight-grade dinner dance” at her school. Other examples of the present tense giving the indication that Jahi is still among us in the world of the living include a quote from her teacher saying that “she is a wonderful girl” (DeBolt & Hurd, 2013b), her mother saying that “she’s a beautiful young lady” (Jones, 2013a), “she is at St. Peter’s Children’s Hospital in New Brunswick, New Jersey” (DeBolt, 2014b), and even a headline like “Jahi McMath remains on life support” (Bender, 2013).

Jahi, since this time last year, has shared a two-bedroom apartment in Somerset, New Jersey, with her mother, her stepfather, Marvin Winkfield, and her 6-year-old sister, Jordyn. Jahi spends her days with Beyonce playing on her iPod, a TV in the background, and calls from relatives and friends, who are put on speaker

phone net to her bed, her family said. Her mother said that Jahi has no bed sores or illnesses and that her vital organs are still functioning. (DeBolt, 2015b)

Jahi's presence is also constructed at various places in the sample where she is given a voice in the form of direct quotes after her death in California through notes that she wrote after her surgery – “Am I OK?” (DeBolt & Hurd, 2013b), “Is this blood?” (Gafni, 2013a), and “Why am I bleeding so much?” (Gafni, 2013a) – and via the memories of others, such as her mother remembering the last few things that Jahi had told her: “I am scared, Mommy” (Gafni, 2013a), “I am afraid I won't wake up” (Gafni, 2013a), “Mom, don't cry” (DeBolt & Hurd, 2013b). The possibility of Jahi speaking in the future is also addressed in *The Mercury News* by a judge according to whom Jahi may walk in to court and say “Hi, I'm here” (Gafni, 2015), thereby reinforcing the idea that she is still alive.

Perhaps the most glaring assertion that Jahi is still alive is in instances where journalists literally say as much, such as in the headlines – “Family Fights to Keep Girl Alive” (DeBolt, Bender, & Alund, 2013), “Alive Through The Holiday – Judge Grants Family More Time with Teen Declared Brain-Dead” (DeBolt, Hurd, & Oakley, 2013), and “Girl losing battle for survival, family says – Brain-dead teen's body is rapidly deteriorating, lawyer acknowledges” (Krieger & DeBolt, 2014) – and in the body of newspaper articles by saying that her family would “keep her alive” (Lee, 2013a). Jahi's mother is quoted in the *San Francisco Chronicle* as saying “...can my daughter just live for a few more days?” (Lee, 2013a); Dolan makes the case for her tracheotomy by saying that without it “she will die” (Jones, 2014a) and that he doesn't know “if she's going to make it” (Krieger & DeBolt, 2014). Gafni (2015) also appears to expose his assumption

that she is alive when he writes the following words, according to which Jahi is presented as suing the hospital even if she is dead: “If McMath is alive, she could sue her surgeon and hospital for millions of dollars, legal experts say. If she is dead, she can sue for a medical malpractice wrongful death, but the damages cap in California at \$250,000.” All of these constructions further suggest that journalists are treating Jahi as alive even in their own words when they are not quoting others who take more of a stand in this controversy.

Overall, the disagreement between the McMaths and the hospital over Jahi is portrayed as a binary, one that only has two sides. Further, it is portrayed as an unequal one. “I am just one woman fighting a whole corporation” (Gafni, 2013a), Jahi’s mother was quoted as saying in *The Mercury News*. She also acknowledges that she knows that “the odds are stacked against us” (Nelson & Nardi, 2013) as they are “struggling to control the fate” of Jahi (DeBolt, Alund, & Ivie, 2013). The relationship between the McMaths and the hospital is described using fighting words, like “struggle” (Bender & Alund, 2013), “battle” (Lee, 2014b), “wrenching conflict” (Krieger & DeBolt, 2013), and “heated” (Gafni & Alund, 2013) that leaves the family “shattered” (Gafni, O’Brien, & Alund, 2014) and “scrambling” (Nelson & Nardi, 2013). The McMaths are portrayed as facing ruin as a family, both financially and emotionally, having “fled” California (DeBolt, 2015b) but still choosing to persist in their struggle:

If I didn’t fight for her, they’d say ‘That mother is no good, she didn’t fight,’ and now I’m fighting for her, and now they say ‘She’s doing too much.’ So the only thing I can do is what I know how to do and what my mother taught me how to do, and that’s to fight for your children. Because my daughter can’t fight for

herself right now – I’m her voice. My brother’s her voice. Everybody who’s praying for her – all of those people are her voice. (DeBolt, Alund, & Ivie, 2013)

Despite the unequal nature of the struggle described against the single McMath family and entire scientific establishment, the family is not portrayed as standing alone. They have reinforcements in the form of religion, which is set up by journalists as binarily opposed to science. This is expressed through religious language such as the McMaths hoping for a “Christmas miracle” (DeBolt & Hurd, 2013a) and “divine intervention” (Lee & Jones, 2013) that suggest that religion can rescue people from the tyranny of the scientific establishment, further reinforcing the notion that the two institutions are natural opposites. DeBolt, Bender, and Alund (2013), writing for *The Mercury News*, do appear to set up this dichotomy in the debate over brain death when they acknowledge that strong religious beliefs can convince believers “that cardiac death is death and that a patient should be cared for until the heart stops, regardless of what the brain is doing.” The McMaths are also frequently depicted making references to religion as their refuge in this battle against the hospital because Jahi’s life “should be in the hands of God, not in the hands of doctors” (DeBolt, Bender, & Alund, 2013). Pastors are also presented as exercising their communal authority by amplifying the McMaths’ demands that the hospital accepts its mistakes and that those responsible be punished. “Is not Jahi worthy of the highest amount of medical treatment?” one of them demands (DeBolt, 2013). Even law professor Thaddeus Pope refers to this case as one of “religions versus medicine” (Gafni, 2014b).

At other points, however, the secular and the divine appear to negotiate new space, as is evident through the use of the term “medical miracle” (Bender & Alund,

2013). This is also seen when journalists mention that Catholic doctors are willing to work with the McMath family. This is attributed to the reason that the doctors' religious affiliation makes them friendly to the McMaths because of their belief that "brain death is not true death, a belief that contrasts with the majority of the medical establishment" (DeBolt, Hurd, & Oakley, 2013). This negotiation between the religious and the scientific is also created by articles that mention that the facilities that are reaching out to the McMaths in order to accept Jahi "believes in life" (Peele, 2013).

The McMaths are also seen as being supported by the larger religious community through prayer vigils not just in their local community but from "people from around the world pledged on social media to pray for Jahi" (Bender, 2013). Others visit them in the hospital with "prayer rugs and statues and incense and all these directions of how to wake her" (Sulek, 2013). Jahi's mother is depicted as having a direct connection to the Christian god through her ability to talk to him, further convincing her that "God will wake her up" (Lee & Jones, 2013) and that "there's still time for a miracle. Christmas is tomorrow. It would be great if she woke up" (DeBolt & Hurd, 2013c), evoking once again the assumption that Jahi is not dead but merely asleep.

Support is also seen as coming from the families of other patients who have been in similar situations and the organizations – alternate systems to scientific establishments such as hospitals – who fight these battles for them. Several families are described as having had similar experiences with the hospital. Journalists, for example, use the mother of Hiram Lawrence, a 23-month-old boy who had also died due to brain failure but kept on mechanical support to "keep his heart beating long enough to celebrate his second birthday and the holidays" (Krieger & DeBolt, 2013), to describe her experience with the

hospital in combative terms. Interestingly, she calls her son “sick” (Krieger & DeBolt, 2013), implying that he too like Jahi was alive. Journalists describe Hiram as being taken off of mechanical support against the family’s will and, according to the family pastor, moved to a room that was like a “death row gas chamber” (Krieger & DeBolt, 2013) where his heart took more than an hour to stop beating. This “raised more doubt within the family that he was truly gone before” (Krieger & DeBolt, 2013), a feeling directly expressed by his aunt who said that “it’s heart-wrenching for them to turn the machine off and watch him living” (Krieger & DeBolt, 2013). Shultz also described a “harrowing encounter with the system” (Jones & Egelko, 2013) in the *San Francisco Chronicle* in which she fought “like hell against judgements that were made prematurely” about her son who was in a coma and then in a vegetative state, conditions which, it is important to note, are different from brain death. Suspicions about a conspiracy at the hospital to kill patients and steal their organs is supported by referencing a 2014 case in which a family sued the hospital based on similar allegations.

Other organizations that are depicted as coming to the aid of the McMaths are the New Beginnings Community Center, a nonprofit based on the idea of “preserving life and treating brain-injured patients” (Gafni, 2014a) and the Terri Schiavo Life & Hope Network who are directly quoted as supporting the McMaths in their conviction that Jahi is alive because her heart is beating. The latter further offer support to the idea of a conspiracy against the McMaths by calling hospitals corporations and saying that they have a “vested financial interest in discontinuing life” (Lee, 2014a). Lee & Jones (2014) describe these organizations as generally Catholic or right-to-life.

Another course of support for the McMaths is depicted as coming from the world at large. People are not only depicted as offering support through prayers but also by attending rallies and engaging through social media, especially in the form of fundraising and advice. The assumption that Jahi is alive can be seen in these cases as well, such as through the mention of signs saying “Keep Jahi Alive” (DeBolt, Hurd, & Oakley, 2013) at a rally and the name of the family’s Facebook page “Keep Jahi McMath Alive” (Hartlaub, 2013). Others show up in the hospital to offer their support to the family:

But for the Winkfields, the lobby has been a chaotic and sometimes unscrupulous place, where throngs of well-wishes bring cards and flowers, pastors pray and bring Bible verses and strangers show up offering incense and oils and demand to lay their healing hands on Jahi. They speak in tongues on the sidewalk. Some say they’re the girl’s uncle or grandmother and somehow get into the hallways of hospital’s third floor. One woman waited in the corridor for 10 hours. “I want to see your daughter and touch her,” the woman told Winkfield. When Winkfield said no, the woman replied, “Then I want to be close to you.” She watched Winkfield sleep. (Sulek, 2013)

Ultimately, this frame delegitimizes the finality of brain death by presenting it as a way for the scientific establishment to manipulate lay people. This frame positions the general public of the U.S., if not the world to question brain death by learning about Jahi’s case and turning to science’s natural ally – religion – to fight back against scientific persecution. This movement is supported by the belief that determining death, especially that of a child, is a personal matter that cannot be dictated by doctors. The case is further elevated to the larger political debate in the Western world by linking it to the

“concept of life” (Alexander, 2013) or “abortion rights” (Gafni, 2014b). Death, like life, is connected to the larger Conservative American agenda of limited government, civil rights, and freedoms of religion and privacy, all issues which sit at the core of this “fight heard around the world” (DeBolt, 2015b). The McMaths, too, are aware of the implications of this frame:

We know the darkness that likely lays ahead for us, for Jahi. We have heard the criticisms that we are harming Jahi and we need to just let go...we are working every minute to preserve our rights and Jahi’s existence. It is our fundamental, constitutional right as it would be yours should this horror ever befall you; something I do not wish on anyone, ever. (Nelson & Nardi, 2013)

3.2.4 BLAME THE SCIENCE

Roughly three quarters the way into my sample and about 10 months after the case attracted the attention of journalists, I noticed a new frame emerge, one that reorganized the nature of the conflict over Jahi by combining elements from the previous two frames. In this narrative, Jahi was initially misdiagnosed as dead, but the hospital is not vilified for this mistake because blame is placed on the mis-conceptualization of death itself. Specifically, this frame states that brain death is a reversible condition that Jahi initially had but doesn’t anymore, stoking the idea that brain death is not permanent death but rather is temporary. “Everybody, even the plaintiffs, agrees that Jahi was (brain) dead in December 2013,” says Professor Thaddeus Pope in the *San Francisco Chronicle* (Johnson, 2017), “What her family is saying is that she is not dead now.” According to this narrative, the hospital and the McMaths are not enemies at all. In fact, the scientific community is depicted as being open to reconsidering brain death as a

concept. In this way, the frame suggests that the matter can be resolved not by fighting the system but by working within it, a recommendation that is opposite to that in the previous frame where the system was positioned as the enemy.

In the previous frame, the McMaths wanted California to revoke Jahi's death certificate because according to them, Jahi had never died and had been alive the whole time. This frame is also centered around the revocation of Jahi's death certificate, but it argues for this in a slightly different way – Jahi only appeared brain dead in the beginning because her brain was swollen, but she has since regained electrical activity in her brain and is therefore “alive again” (Lagos, 2014). She continues to be presented by journalists as alive using the same techniques that were outlined in the previous frame, such as referring to her by name, age, symptoms of life, etc.

In this way, the McMaths do not reject the idea of brain death but suggest modifications to it. These suggestions are made on the basis of evidence offered by the McMaths of electrical activity in Jahi's brain, like “an MRI, a brain test that records electrical activity of the brain” (DeBolt & Bender, 2014) together with video clips showing Jahi responding to her mother's commands as established in the previous frame.

In the first video Dolan showed Thursday, Jahi, who has been on various machines giving her nutrients and oxygen since December, is shown on a hospital bed with signs posted on wall. Her toenails are painted. Except for her head and feet, she is covered in blankets. Her mother, Nailah Winkfield, is at her side and asks Jahi to move her foot.

“Kick your foot Jahi,” Winkfield said. “Move your foot. Come on, Jahi, we are watching. I see you wiggling your toes. Come on, Jahi you can do it. Try your hardest. I see you move your toes.”

About 40 seconds later, her right foot twists upward.

“Very good Jahi. I’m proud of you,” her mother can be heard saying. (DeBolt, 2014c)

The McMaths do not appear to blame the hospital for Jahi’s condition in this frame. In fact, unlike the previous frame, they appear to express a certain degree of understanding toward them. Dolan says as much in when he claims that the initial tests done by the hospital “were not wrong” (DeBolt, 2014d) and that the McMaths are not trying to question the legitimacy of the original tests that were performed on Jahi because her brain swelling “would have given the impression of brain death at that time” (Lagos, 2014).

There is no question that in December 2013 at Oakland Children’s Hospital, Jahi McMath fulfilled the widely accepted pediatric guidelines for determining brain death,” Shewmon wrote in his Alameda County Superior Court declaration.

“There is equally no question in my mind that she no longer does, for the single reason that the first of the three cardinal findings in brain death – coma, absence of brainstem reflexes, and apnea – is not fulfilled. Rather, she is intermittently responsive, placing her in the category of ‘minimally responsive state.’ (Lyons, 2017)

This frame expresses the desire of the McMaths to resolve the controversy around Jahi’s state of consciousness through collaboration and “an open and transparent dialogue

between health professionals” (Lagos, 2014). This choice of words in the *San Francisco Chronicle* proposes a solution to this controversy that is located within the scientific community itself.

While Jahi’s brain dead status was described firmly in previous frames, this frame portrays some room for doubt and negotiation on this matter even within the scientific community. Scientists are shown as willing to revise the idea of brain death as an irreversible condition, as illustrated by Jahi’s improving condition. For example, Paul Fisher, the Stanford pediatric neurologist who performed the original tests on Jahi in the hospital, is quoted in *The Mercury News* as expressing less certainty in his position than what he had originally held: “I’m not saying they are wrong; they may be able to prove this. They just have not collected the evidence in a systematic way” (DeBolt, 2014f). Lawyer and associate professor of philosophy Lawrence Nelson also expresses room for argument in this case: “Many of us might disagree with what they are doing, but if she’s alive, then she’s a person, and she has the rights of any other living person” (DeBolt, 2014f). Doubt is further sown by Wade Smith, director of a neuroscience intensive care unit, according to whom “there’s still a lot of information that’s not there to look at and be comfortable with” (DeBolt, 2014f). While David Magnus, director of the Stanford Center for Biomedical Ethics is quoted as saying that brain death is not reversible, he is also described as being surprised by how long Jahi’s body has lasted on mechanical support while brain dead. Medical ethicist Arthur Caplan acknowledges that claims of recovery of Jahi’s brain would “force us to re-examine the whole nature of death in America” (DeBolt & Alund, 2014), which would mean that “what people believe they

know about brain death based on decades of experience and evidence would turn out to be false” (Johnson, 2017).

The possibility that the McMaths’ claims are correct is further bolstered by mention of how they are supported by other scientists. This group includes “certified neurologists, pediatric neurologists and a prominent world expert on brain death” (DeBolt & Bender, 2014), such as Phillip DeFina, the chairman of the International Brain Research Foundation, who believes that Jahi is in “some other state” (DeBolt, 2014c) rather than dead and Cuban neurologist Calixto Machado from Rutgers University in New Jersey who, after reviewing the results of an MRI and EEG test, concluded that Jahi showed some brain function. Johnson (2017) also cites a scientific expert on brain death in the *San Francisco Chronicle*, professor emeritus of pediatrics and neurology Dr. Alan Shewmon, who opposes its current standards in his scholarly publications and does not believe that Jahi meets its criteria.

Experts, however, express hesitance about these claims until a series of official tests are performed on Jahi to confirm the claims of her medical team. Jahi’s medical team is criticized as not being specialized in neurology, and electrical activity is not sufficient proof of a functional brain, according to Caplan, who states that “I can get electrical activity out of Jell-O” (DeBolt, 2014d). Fisher, too, concurs, although Dolan delegitimizes his credibility by indicating that he has a conflict of interest and a legal bias in this case.

This frame also differs from the others described earlier in that it contains minimal references to the legitimacy of cardiac death and religion, suggesting that the

McMaths are not really challenging science at all but seeking to make room for religious perspectives within science.

This frame ultimately places Jahi's case as "groundbreaking" (DeBolt, 2014f), the first of which has the potential to overturn the idea of brain death as is currently understood by the medical and legal establishments. Dolan describes her as "Patient No. 1" (DeBolt, 2014f) and entering "unchartered territory" (DeBolt, 2014f). This idea, that this case is abnormal and likely not one of true death, is strengthened by it being described as "one of the very strangest (cases in recent memory)" (DeBolt, 2014f) and one in which "oddities and possible firsts abound" (DeBolt, 2014f). The very idea of Jahi being "no longer brain dead" (Johnson, 2017) is interesting down to the choice of words because according to current definitions of brain death, it is a permanent condition, a suggestion that the specific excerpt contradicts by suggesting that one can stop being brain dead. This argument is the essence of this frame, presenting Jahi as a person who "currently fulfills neither the standard diagnostic guidelines for brain death nor California's statutory definition of death" (Johnson, 2017). Her case ultimately defies the current conceptualization of brain death and recommends reworking by scientists, mirroring the sentiment of a moment in the *San Francisco Chronicle* when, in response to her mother asking her to move the "bad finger" (Johnson, 2017), "...Jahi appears to slowly flex her middle finger..."

3.3 THE LARGER FRAMING PROCESS

This section presents my findings from a qualitative thematic analysis of the 24 interviews I conducted with the journalists who have written about this case in California as well as the scientific experts they cited in their stories. Scheufele's (1999) emphasis on

framing processes alerted me to issues that formed the basis of my second research question.

RQ2: What factors influenced the way journalists framed the Jahi McMath case?

Put simply, I was interested in how the frames were constructed. Were journalists aware of the frames they were constructing for their audience? What factors influenced the way they framed the narrative in this case? Were they influenced by the frames that other journalists had already set for this case in the media? How did they view brain death? Was it along the same lines as the brain death experts? In other words, I was interested in both media-level and individual-level independent frames in the agenda-building, agenda-setting, individual-level effects, and journalist-as-audience processes.

Using Scheufele's (1999) processes-based framing model, I was able to peek behind the framing curtain and gain insight into the various factors that gave rise to the frames that I had previously articulated as part of my first research question. Six main processes emerged from my analysis, and I attempted to describe the mechanics of each so as to clearly convey the impact that it had on the way that Jahi's story was ultimately framed and even whether it was covered at all. Journalists were influenced by many factors, including the involvement of many journalists over time, the fact that the story was based on conflict, newsroom dynamics that played out under the shadow of financial difficulties in the business, the activity of people with special interests, the racial identities of the parties involved in the story, and a perception that the verdict was not quite out on the science of brain death. Clearly, the framing process was influenced by many considerations besides just reporting the facts.

3.3.1 MULTIPLE JOURNALISTS WORKED ON THE STORY

One of the reasons for the varying and sometimes contradictory narrative of the Jahi McMath case in newspapers was the professional norms that dictated the story itself was often covered by more than one journalist. This happened for several different reasons.

First, journalists tended to work in teams while covering the story. These teams were not limited to the staff within a newspaper; coverage was also provided by teams working across different newspapers. Julia Prodis Sulek (2018), for example, described her newspaper and *The Mercury News* as “sister newspapers” who covered the story together.

Teams were assembled in different ways. “I didn’t flesh out the what is brain death aspect of that story,” said Doug Oakley (2018). “It might have been Matthias or Dave DeBolt.” David DeBolt (2018) relied on a science writer at his newspaper who had experience covering end-of-life issues. “I had a question, I needed something,” he said, “I’d give her a call, and she’d always take the time to kind of walk me through things.” Rick Hurd (2018) described how he split his assignment with another reporter (emphasis was added by me through the use of italics):

... at *one* point of the *proceedings* I’m helping to write, I’m helping to craft the *words*, you know, for the story. I’m working with another reporter on that. She may have actually been doing the typing, but I was helping craft, you know, so I sort of felt like I was part of the writing process...

The case was initially covered as a “straight up news story” (Jones, 2018) with journalists assigned to “feed in to” the story (Oakley, 2018). Not all journalists, however,

had a background in science, and over time, journalists were brought on based on a match between their specific skills and the aspect of the story that needed to be fleshed out at any given time. Lisa Krieger (2018) and Victoria Colliver (2018), for example, covered the story from a medical perspective, writing “step back stories” to explain certain topics to readers (Krieger, 2018). Dr. Nancy Berlinger (2018) expressed support of such stories, what she called Q&As and explainers, mentioning how she recommends reporters write glossaries and sidebars in such stories. Legal reporters like Egelko (2018) were brought on to provide legal insight into the case, while Daniel Willis (2018) was onboarded for research-based stories that relied on his skills with data journalism. Some of the decisions that were made about the development of the story occurred in conversations between the reporters and editors. One such conversation was initiated by Sulek (2018) who, sensing a lack of explanation of the McMath family’s side in the news, volunteered to work on the story. She credited her identity as a mother to giving her this insight.

Ultimately, the story developed according to each journalist’s unique perspective and background. This contributed to the development of the story in many ways besides its legal and scientific aspects.

...it’s more the matter of how stories are *covered*, like some people take a story from a really *emotional* level and the *family*, it kind of, a legal person would really focus on the *legal* aspect of it, yeah, that’s another case that this helps in, a healthcare reporter might look at things too and understand the *physician* responsibility and the *hospital* aspect of this and the *science* of it... (Colliver, 2018)

Second, the story lasted many years, and most of the journalists in my sample were only assigned to it for some part of that time. Only one journalist – DeBolt (2018) – stayed with the story through its lifetime, and he expressed a certain degree of ownership over it. This emerged as unusual in my sample – the common practice for journalists appeared to be covering many stories at the same time and not being able to keep track too much of the work they may have done in the past.

Third, the longer the story persisted, the more journalists and indeed experts were able to marinate on it and revisit it, further leaving the narrative open to change. In Dr. Olivia Evans' (2018) words, "journalism is writing the first draft, but it's not, you know, there are *other* stories that have to be very deeply *reported* that are going to probably come a bit *later*." This often involved consulting the work of other journalists on this story. This was especially the case with bigger publications like the Wall Street Journal, New Yorker, and even *ProPublica* that had more resources – time, reporters, and fact-checkers – to dedicate to the story when compared to smaller newspapers.

...the New Yorker and the Wall Street Journal, this is a *major* story for them, right, like, they, I don't know how much other stuff they are doing, but they're putting a *lot* of time into this one story, while The Mercury News guys, they probably have to do five other stories the same day. I don't know about their numbers, but you know what I mean. They don't, they want to get some quotes, they want to check things real quick, but they want to move on. (Pope, 2018)

Many of my interviewees – both journalists and experts – specifically referred to a 2018 article about this case that was written by Rachel Aviv for the New Yorker; many remarked upon how its narrative had been affected by the fact that it had been written

later in the lifetime of the case. Others like Dr. David Magnus (2018) felt like the fact that Jahi McMath's body had maintained longer than expected had "led to a *shift* in the media coverage from skepticism to being supportive." This is important considering that somatic survival of a body isn't uncommon.

3.3.2 THE NATURE OF CONFLICT

Perhaps the way the story of Jahi McMath was framed was affected by the fact that the story had its roots in conflict, that is, a disagreement between the McMath family and the Oakland hospital that ultimately graduated to a cross-country legal battle. The journalists in my sample appeared to recognize this foundational aspect of the case. Egelko (2018), for instance, perceived the story to be "two sides of a lawsuit represented by attorneys," a sentiment echoed by Krieger (2018) who described the setup as a "giant pissing match between the family and the hospital."

The perception of the story being about a conflict bolstered the reporters' journalistic desire for objectivity. This translated into news coverage that sought to emphasize facts over emotions – even the journalists' own – in a bid to represent all sides of the conflict, which in this case was the hospital and the McMath family. For Henry Lee (2018), this meant that he had to "make sure you get *all* sides of the story, give them *equal weight if possible*, and then lay it all down for the reader." During this process, he aimed to "keep my emotions in a box." The emphasis on objectivity was also driven by what the journalists perceived to be the purpose of journalism – to offer information to readers so that they could make up their own mind about the issue. Journalism, according to Krieger (2018), was the "first draft of history" and a "really crowded, cloudy crystal ball." Peter Fimrite's (2018) approach to journalism rested upon his sense of

“responsibility and purpose in informing people and exposing injustice and helping the underdog.”

Objectivity did not come easily. Many journalists confessed to it being a struggle, especially in a case as controversial and rife with emotions such as Jahi’s. Landon Brand (2018) faced difficulty reconciling the two sides in this story, which he is wont to typically do in his work. Hurd (2018) had concerns about the perception that one of the sides had to be wrong and another had to be right. According to him, the different sides in a story don’t always line up because of varying perceptions about the issue at hand; this, in his opinion, makes it more difficult to determine the facts in a story. Krieger (2018) built on this observation when she said that both sides in the story were correct in that “the family wanted to keep her going, and they *succeeded*, and the hospital couldn’t bring her back to...any semblance of a normal life...they were right about that *too*...”

Difficulties with access to information presented a challenge to the journalists in their quest for objective reporting. Hurd (2018) was involved in the story in its early stages, and he faced obstacles while seeking to make contact with the McMath family:

...I don’t want this to come across as a racist sounding thing, I really don’t, but it’s like, okay, well, the daughter is African American, and I’m hearing stories, oh, here’s, well, okay, the father is *not* African American, and then I’m hearing, well, the father *is* African American and the mother is African American and heavy and so it’s like, you know, you go to a hospital and you’re trying to track down people, that’s a hard thing to do, you know what I mean, it’s, so *that* was a challenge I faced was, you know, how do you know whether to approach a person, and once you approach that person, how do you ask...

Overall, however, the McMath family was described as being more forthcoming than the hospital; Carolyn Jones (2018) remembers their sending press releases and “making a big fuss.” Krieger (2018) described having difficulty accessing information on both sides of the issue; according to her, the family would only be accessible at press conferences where reporters weren’t able to ask them questions, and the hospital wasn’t allowed to disclose a lot of information because of HIPAA restrictions. Oakley (2018) attributed the hospital’s hesitance to their “really watching their words carefully because they were worried about the, you know, the coming lawsuit.” On the other hand, Sulek (2018) felt that news coverage did not adequately represent the McMath family because “when you’re sitting out there waiting for them to come out to the microphone to the press conference, you know, you *get* what you *get*.” She also described difficulties getting Jahi’s family to trust her.

Many times, this happened because of logistical issues and not because the sources were trying to withhold information; however, both the family and the hospital seemed to recognize how this made them look in the newspapers, and they attempted to outdo each other in “dueling press conferences” while interacting with journalists (Jones, 2018). “As the family volunteered information,” Hurd (2018) explained, “the hospital gave up more information.” Kristen Bender’s (2018) approach to handling issues of access was to “try to be very *clear* in stories that, you know so-and-so *declined to comment* or so-and-so was not *available for comment* or so-and-so could not be reached on the telephone or the email or the Facebook, whatever the case may be.” This, according to her, conveyed an effort toward objectivity for the reader.

Framing the story along a conflict between sides continued as the family recruited scientific experts, which transformed the conflict from one between the hospital and the family to one solely between experts. This appeared to create a sense of doubt in the science itself by highlighting the gray area between life and death, an “in-between area” in Jones’s (2018) words “where you can be kind of dead, kind of alive,” thus creating a narrative in which it was possible to challenge experts. Dr. Berlinger (2018) stated this dynamic in her own words: “...there’s the fact of, well, is the family *right* about her diagnosis rather than *refusing* to accept her diagnosis because there *are* these differing neurological opinions about *how* her brain state should be described.” Many journalists acknowledged how this perceived debate between experts imparted credibility to the story.

Some discussion, however, emerged from my sample about how highlighting the debate between experts appeared to grant legitimacy to both parties in the conflict. Dr. Berlinger (2018) mentioned debate amongst journalists about the 50-50 rule of journalism, giving equal time to the various sides in a story. Brand (2018) embodied this debate in his struggle over whether to empower fringe beliefs or marginalize them, an issue that he felt journalists who covered other scientific controversies like abortion and flat-earthism also shared. “It’s nice to present both sides,” he said, “but if one side still believes that the world is flat, you don’t necessarily want to, you know, present that like it’s a true thing when you know that the world is not flat...” This opinion was shared by the experts I interviewed who extended their criticism of coverage of the McMath case to controversies such as climate change, evolution, and even the Raelians, a group that believes that all life started from aliens. “There aren’t two sides,” Dr. Magnus (2018)

said. “*Here’s* the scientist, and *here* are the quacks.” On his end, Dr. Ryan Holmes (2018) envisioned science journalism as “*reflective of the facts and the science as best as known*, but also, you know, paint a fair picture to both sides essentially.” In the end, despite the best intentions of the journalists to objectively present equal and oppositional sides in the story of Jahi McMath, the experts felt that reporting ended up otherwise one-sided. Chapter 4 provides a deeper look into this sentiment.

3.3.3 FINANCIAL DIFFICULTIES IN THE NEWS BUSINESS

Some journalists attributed economic realities in the news business to how the story of Jahi McMath was covered. They further expressed feeling a lack of control over their work in the face of the financial needs of their employers. Much of these discussions emerged from interactions with editors.

There was overall agreement among journalists that Jahi’s story was unique. This translated into a perception of public interest and what Bender (2018) believed was editors’ interest “in keeping in the public eye.” Newspapers were described as going through financial difficulties, so journalists also believed that news coverage was influenced by the possibility of high readership. “The industry is *struggling*,” Willis (2018) said. “If we’re getting the page views on something, then we’re going to keep following the story.” Egelko (2018) understood this as an effect of working for a “commercial enterprise” whose interests lay in attracting advertisers, “so of course other values are going to intervene.” Hurd (2018) wondered if it was “just a matter of we know it will get us a lot of clicks.”

...it was *real* desperate times at this company, and they were trying to increase the number of hits on the website because the advertising revenue for the printed

product was just falling like off a cliff, and they were trying to get the web traffic up... (Oakley, 2018)

Editors appeared to play a significant role in the negotiation of the coverage with journalists, dispelling any notions of news creation being solely based on the journalists' judgement. The story was often developed in a "kind of a little *huddle* with an editor" (Colliver, 2018). Even Dr. Berlinger (2018), someone who regularly interacts with journalists, mentioned hearing about this "background newsroom tension" from journalists in this case. As a source, she understood why journalists may end up complying with the desires of editors. "Your editor is maybe controlling your access to stories," she said, "or, you know, giving you permission to do something special or whatever may be."

Journalists mostly described their relationship with editors in this story in contentious terms. According to Oakley (2018), "there are arguments every day over what *is* news and what should be on the front page and what should be buried, you know." Egelko (2018) confessed to not always being able to tell the "full story." "Either my employer or the editor or somebody else has *other priorities* too," he said. "Either they don't think the story is *important enough* or they want a different *angle* or it's not our story."

At its most basic level, editors and journalists battled over whether the story needed to be covered at all. Oakley (2018) felt that Jahi's death had just been an accident and that news coverage had sensationalized it. Hurd (2018) remembered not being convinced about the public interest aspect of the story because of concerns with privacy and discussing it with his supervisor. Willis (2018) too had his doubts later on in the

coverage that he felt was becoming exploitative. “There just comes a point you need to step out of it and let this family deal with their situation,” he said, “but I’m not the editor. I didn’t make that call.”

Some of the arguments revolved around allegiance, which Kreiger (2018) described as naturally falling on the side of the McMath family. Jones (2018) provided more details about that negotiation with the McMath case:

...at *one* point my editor was saying, well, *wait* a second, what if this girl *is* alive, we need to cover this story *as if she’s alive*, the *family* thinks she’s alive, *that’s* good enough for us, *we* need to cover it like she’s alive, and the hospital really *screwed* up here, and we need to *totally change* the way we cover this. And I was like, well, I don’t know, we don’t really know if she’s alive or not <laughs>...

Hurd (2018) expressed frustration with the degree of control that editors had over the writing process:

...we’ve got higher up editors that are standing over our *backs* literally, you know, literally critiquing us *word for word for word for word* as we go, and that’s a hard way to work also, I mean, that’s just a *really* hard way to work, and you know one of those situations where you would like to be able to turn back and look at your editor and go, why don’t *you* sit down and do it, you know what I mean...

At the end of the day, editors appeared to emerge the more powerful party in the relationship with journalists. The journalists’ feeling of lacking agency was further exacerbated by the financial downturn in their industry. Willis (2018), who had been let go by his employer, described the newspaper business as “failing financially.” He

considered himself lucky though because some of his co-workers who had also been laid off had not been able to find another job. Hurd (2018) described witnessing two-thirds of his industry get laid off; the staff at Oakley's (2018) newspaper too had shrunk from 300 to 10. These uncertainties in the industry manifested as a feeling of powerlessness in the relationship with editors; journalists knew that they could be let go from their jobs at any expression of resistance to the editor. Oakley (2018), for example, was conscious of his position as not "one of the star reporters." "They can say, well, don't come back in tomorrow, you know what I'm saying?" he said. "You can't *really* say no."

At the same time, however, Dr. Berlinger (2018) offered insight into the role of an editor, resulting in perhaps a more balanced and humanized face of what otherwise was perceived as a negative if not villainous entity in the news production cycle:

I *do* know from working in an organization that also publishes *journals* that an editor has, is, *has* to think about not just the individual story and the credibility of the story and being the *guarantor* of the story in a way, you know, making sure that it *stylistically* works and setting, you know, the *policy* for how it'll be *fact-checked* and things like that, whatever it is, you know, at a particular place, but also they are thinking about the *entire publication* or the entire *section* of the publication, so they're thinking about not just the story that *you're* writing but the *other* stories and how these things fit together...

3.3.4 OUTSIDE INFLUENCES

For journalists, the fact-gathering process was more complex than it would seem on paper; journalists did not simply look for the facts of the case out in the world at large and then go back to write up their stories. Rather, journalists were aware of the

controversial nature of this case and that some people would try to use it for their own purposes. Journalists spoke about hidden agendas that they detected in many people, including the family and its lawyer, and tried to expose them in their stories or simply keep them from influencing their narrative. Knowledge of such agendas was also expressed by experts who tried to counter it indirectly by attempting to influence the journalists.

Many journalists understood the need for skepticism as part of their job. “You find a lot of noise like that around any kind of big news story,” DeBolt (2018) said. “You got to kind of just, you know, sort of put your blinders on and stay focused on what the story is.”

It’s just when *private* people’s tragedies are elevated and magnified in the public sphere, *any* reporter would have to be *just a little bit* watchful to see what’s being used, how much truth is being told, and how much is simply being blown up for ulterior motives, and *that* I confess was my, kind of, *early* reaction to this case... a healthy dose of skepticism is a good idea whenever an individual case gets thrust into the public spotlight. *Cui bono*, as they say, who benefits. (Egelko, 2018)

Journalists were aware that all parties in this case had an agenda. As far as the McMaths were concerned, journalists knew that the family stood to gain a large sum of money at the end of the legal case, a fact that may have been motivating them to argue that their daughter was still alive in order to keep the case going. “Is it the money,” said Oakley (2018), “or is it keeping their *daughter* alive or are they just *saying* they want to keep their daughter alive, but they *really* want the money, you know?” He spoke about

encountering the family's lawyer in person who told him about the law that lifted the cap on damages that the McMaths could claim for malpractice if they could "keep her alive." "*That just killed it for me,*" Oakley (2018) confessed. The family had also been releasing short clips of Jahi's body moving, but because they lacked detail, DeBolt (2018) remained skeptical about the family's stance.

The McMath family's lawyer was the object of particular suspicion. Journalists were wary of his intentions and wondered if he was using this case to generate attention for himself.

I remember once, you know, their attorney Chris Dolan, you know, he held a press conference, he was talking *on and on and on* about *oh, she's menstruating*, you know, Jahi, she's *menstruating*, she lifted her left *pinkie* yesterday, something like that, and I said, well, can I go *see* her, can you allow reporters to go *see* her, and he said no, absolutely not, and I said, well how do we know that you're telling the truth, and he wouldn't, and the fact that he wouldn't let anyone *see* her and wouldn't say where she *was*, and I just, it made me really suspicious. I thought, *I don't know what this guy is doing, I don't know why he's doing this to this family, I don't know what his angle is in all this...* (Jones, 2018)

At the same time, journalists recognized that the McMaths had suffered a tragedy and were vulnerable and that others may be trying to take advantage of them. These others – "snake oil salesman and everything else" (Sulek, 2018) – were described as "circling" the family (Jones, 2018). These included attorneys, publicists, religious groups, and other organizations like the Terri Schiavo Foundation.

Not only did interest groups attempt to influence journalists directly, they also sought to influence one another. One of DeBolt's (2018) expert sources, a "kind of a small-time guy locally," was threatened with a boycott by what he described as a group with Al Sharpton who wanted him to stop talking to DeBolt. Dr. Magnus (2018) mentioned receiving similar threats from the McMath family's lawyer, "unbelievable emails at three or four in the morning during the *height* of the initial case," that were also sent to other experts who were speaking to the media on behalf of the Oakland hospital. The lawyer, in fact, was known to some of the experts I spoke to. Dr. David Faigman (2018) called him "bombastic," "an attorney who is very good in front of the microphones." To Dr. Magnus (2018), the lawyer was "quite a piece of work" and "a vicious pit bull." He attempted to counter the lawyer by instructing a columnist on the sort of questions to ask the lawyer, an attempt Magnus (2018) perceived as allowing the columnist to bypass the "smoke and mirrors" at a press conference. "So he actually asked that question," Magnus (2018) said, "and Dolan *went off* on him. He told me afterward that he just *went off* on him, and then anyway, and then he wrote a *story* about it... which I thought was excellent, yeah."

3.3.5 SUSPICIONS OF RACIAL OPPRESSION

Oakland, where the McMaths are from, is home to a large black community whose members are acutely aware of institutional racism. The McMaths are an underprivileged black family, and some of the narrative in the coverage of Jahi's story appeared to be influenced by these factors. These concerns were also raised about the quality of care that Jahi may have received and in the way that her family may have been perceived as more hostile toward the hospital than a white family would have. This theme

is important because it raises the question of whether the story would have been framed differently if the McMaths were from a different demographic group. Many journalists and experts highlighted “a lot of racial undertones and overtones” in this story (Colliver, 2018). Some of it stemmed from concerns that Jahi’s treatment and the events that followed in the case may have been influenced by the fact that she was black. “I think the fact that people’s perceptions that this was something that shouldn’t even have happened at *all* colored things,” Dr. Magnus (2018) said.

Yeah, I think this family got *piss-poor care*. I think it’s not irrelevant, they are a black family. We know that *black* patients, African American patients, don’t do as well in medicine as others. I think they were dealt with *cavalierly*, I think they were not dealt with *truthfully*, and I think that medicine needs to do better on dealing *with*, providing care for, and telling the truth *to* African American families. (Evans, 2018)

This is not to say that all the people I interviewed believed that racism was at play in Jahi’s story, but rather that the perception it could have been was strong and contributed to the persistence of public interest in the story.

I think in Oakland there’s a tendency for people to pull the race card when it’s not an appropriate time to pull it, and maybe they *need* to do that because there is, you know, they need to do that because there *is* institutional racism. They need to let the world know it, but in *this* case, it didn’t occur to me that that was the case. (Oakley, 2018)

The racial dimension of this story called upon an established mistrust of the scientific establishment in the black community that seemingly created a recurring

narrative of suspicion about the hospital and misuse of power against a black child. Jones (2018) remembered “the family saying *oh*, the doctors wouldn’t *listen* to us, they kind of said it was a *racial* issue or a *class* issue or an *education* issue or something...” The family viewed the hospital as “an accomplice” in Jahi’s death (Krieger, 2018), adding to the understanding that patients and their families often see the hospital “as the *Man* and themselves as the victims” (Oakley, 2018). These suspicions gained credibility by many journalists’ belief that the procedures were routine and that there had to be something dubious about what had happened to Jahi.

In contrast to the value of detached objectivity, some journalists were especially predisposed to feeling compassion for the family, a feeling compounded by the idea of exposing justice through news reporting. Journalists described this aspect of their job in various ways, such as serving as a watchdog, helping the underdog, exposing corruption, and revealing the culprit.

...I think as journalists, our instincts are always to *listen* to the family and give them their day in court to say, you know, to make their case, and I think any of us who’s been a *parent* would want to give the family the benefit of the *doubt*, and if the family is saying they’re still *alive*, then we sort of, you know, we all *want* her to be alive, right, and to be honest with you, I think our allegiances at least *initially* are listen to the family, and you really *want* to turn this case around, you really *want* this 13-year-old to pull through, so then when the hospital said she’s *not*, then that’s why the editors said *well*, you know, why *not*, so that’s I think how we approached it, and *because* the family came to us first, and the hospital was playing *defense* at that point, I think that’s why they, and as I recall, I didn’t

have a chance to go back and look at all of our coverage, I think our coverage *initially* started out saying, you know, essentially family fighting for the rights of their child, and it was very sympathetic... (Krieger, 2018)

Families rejecting the recommendations of experts is not the norm, and a black family from Oakland standing up to experts added an “interesting narrative” (Krieger, 2018) and made for “gripping stories” (DeBolt, 2018). The framing of the news coverage along a racial axis therefore added newsworthiness to the story in the form of a challenge to the powers-that-be. “Here you had a family that has *no* medical background, and people were *questioning their judgement*,” Colliver (2018) said, “and they just stood up and said, we don’t *believe* you.”

3.3.6 THE PERCEPTION OF UNRESOLVED SCIENCE

News coverage about the Jahi McMath case also appeared to be influenced by the perception of journalists that experts disagreed with one another about the science of brain death. These differences, as expressed by the experts in my sample, ranged from subtle nuances to opposition. These stances affected how experts spoke to journalists and whether they believed that Jahi was alive or not. The 11 experts I interviewed attributed some confusion in the coverage of the case to these technical opinions within the scientific community. Journalists relied on experts for coverage of the case, so any perceived inconsistency in the science on behalf of the experts contributed to the narrative that challenged the concept of brain death and extended the stay of the story in newspapers. “I think *that* really, really turned the tide,” said Dr. Magnus (2018).

Both journalists and experts mentioned the fact that life and death were not mutually exclusive binary states but rather that dying was a process and that death was

determined by placing a line in an “in-between area where you can be kind of dead, kind of alive” (Jones, 2018). While this insight was common knowledge to most experts, especially the ones who specialized in brain death, it was something that journalists had to learn as part of the process of covering the story. “The idea that it was like a diagnosis or determination of brain death rather than a yay-nay kind of sums up I think is what really resonates,” said Colliver (2018).

...throughout human history, death was something that happened really *quickly*, right, you know, you *fell* off a horse, you *hit* your head, you *fell* off a tractor, you *got* pneumonia, heart failed, *boom*, you’re dead, and end of story, and then it was very much *around* us, and we were really familiar with it, and it happened within hours, days at the most, so this whole *really* grey area of defining death has been *delivered* to us thanks to improvements in clinical care and medicine... (Krieger, 2018)

Some experts expressed a basic agreement within science about brain death. Any perceived disagreements were designated as philosophical enough that “it doesn’t really make *much* difference to the public” (Holmes, 2018).

...doesn’t make sense for doctors to talk to patients and explain to them, you have the flu, and you need to take Tamiflu. They don’t then say, but I need to *explain* to you that you learn some philosophy of medicine to understand that my nosology or the classification system is *partially* conventionally defined rather than entirely determined by and or any kind of natural kind. You don’t do that. You just say you’ve got the flu, and in a *way*, you really have the flu, you just don’t *really, really* have the flu, so, and so I would say that same thing about

death, so when you're brain dead, you're really *dead*, you're just not *really, really* dead... (Magnus, 2018)

Dr. Magnus (2018) believed that the line of death is “drawn in the right *spots* for the *right* reasons, for *good* solid reasons.” The point at which this determination becomes difficult is when it has to be implemented. Experts who share the same basic understanding of brain death but have different philosophical approaches could communicate their position to reporters very differently, appearing as if they held a different position. Dr. Holmes (2018) elaborated on the implementation of brain death by separating it into its clinical and social aspects. According to him, experts try to assign values to “all these in-between neurological conditions” between life and death that at its core are about evaluating the value of a human life. The different values that a scientist may ascribe to such a state as compared to those ascribed by loved ones or religious people is where brain death begins to emerge as a social construction. Neurologists, for instance, would base their determination of death on the cerebral cortex. People like neurologists “generally *don't* regard permanently vegetative patients as having expired even though we might say the *person* they were has ceased to exist” (Magnus, 2018). Dr. Evans (2018) believed that many physicians don't understand brain death well enough, saying things like “your person is dead but is being kept alive on machines.” Some discrepancies also exist between the clinical practice of brain death and the UDDA.

...I think *sometimes* the understanding of what *tests* are appropriate and what those tests *mean* are not necessarily clear when you go from intensive care unit to intensive care unit. There *are* national *standards*, but there are also sort of, you know, so sometimes they do like a brain flow test or a blood flow test of the brain,

or sometimes they do a EEG that tests electrical activity, which are *not* necessarily standard tests for *brain* death *because* they give false positives for certain, you know, movements in the brain, so there's a lot of *blurring* in science when alone in media about those kinds of things... (Holmes, 2018)

Others expressed more serious concerns with the idea of brain death, specifically that it's anything but permanent irreversible death. Reservations ranged from a desire for further research in the area to suspicions about the origins of the concept of brain death. Scholars mentioned in this vein were Robert Truog and Joseph Fins. Robert Truog's position on brain death was put across by Dr. Evans (2018) as that of not being dead but "very sick." "The brain death criterion is *up* for grabs," she said as she described Fins' work on minimal consciousness, admitting that he had not yet found support for brain dead patients being capable of minimal consciousness.

The name of the neurologist Dr. Benjamin Teague also emerged in conversations with both journalists and experts. According to Dr. Holmes (2018), Dr. Teague had "*literally* flip-flopped on, you know, *either* end of the spectrum on this one." DeBolt (2018) described Dr. Teague as "pretty respected" and taking "a cautious approach, you know, about, maybe she is improving, maybe we need to look at this, rethink this criteria and have a greater discussion about or revisit this (inaudible) report from 50 years ago." Dr. Teague (2018) himself called the concept of brain death "incoherent," stating that the concept of brain death was created for organ transplantation and later justified as a way of diagnosing death. Dr. Evans (2018) echoed Dr. Teague's thoughts, describing brain death as "a *convenience* established because of the need to get viable organs for *transplantation*, but it was *packaged* as *death* to get around the issue of murdering the

patient.” Dr. Teague’s (2018) perspective on brain death casts it not as “a *biological* form of death but a legal fiction.” In his opinion, Jahi was not brain dead. He based his opinion on the videos that the McMath family released of Jahi’s body intermittently responding to commands, attributing it to preservation of her brain structure from potential blood flow to the brain that has escaped early detection. According to this reasoning and the unusually long survival of Jahi’s body, Dr. Teague (2018) considered the possibility of misdiagnosis of brain death, which he expressed to journalists on behalf of the McMath family. “I think there’s a tremendous amount to be *learned* from the case,” he said, “and hopefully results in an improvement in the diagnostic criteria.”

3.4 CONCLUSION

Jahi’s story first began in 2013 with her death in California. At the heart of her story lay the idea of brain death, a highly complex concept that is not commonly understood by members of the general public. Most journalists can be considered part of that public as well. This chapter was dedicated to understanding how those journalists wrote about Jahi and her association with brain death. I used framing theory to help me with this task; this chapter presented the results of that analysis.

Analysis was not just limited to determining the frames that guided the narrative of Jahi’s story in newspapers in California but also involved illuminating the processes at work that gave rise to those frames. Scheufele’s (1999) recommendations for framing studies helped me understand what I was looking for. Investigating media frames in newspaper articles also corresponded with the textual analysis portion of critical cultural studies, while teasing out the processes that gave rise to the frames provided insights into the production aspect of a critical cultural project. This dovetailing of the positivistic

framing theory and critical cultural studies is one of the strengths of this project. Another strength is its application of Scheufele's (1999) recommendations for framing studies, especially its emphasis on extending framing reach beyond the text itself.

Textual analysis was performed qualitatively on 81 newspaper articles about Jahi's story from California, revealing the narrative framing devices that were used by journalists since 2013 to make sense of the events starting with the end of Jahi's life. I presented detailed descriptions of various frames in an attempt to provide a deep, contextual interpretation in the line of Kalwinsky's (1998) work on physician-assisted suicide. The most significant finding in this portion of the study was the presence of completely contradictory frames – Kellner's (2001) “intense struggle” (p. 12) – that is, one frame that appeared to present Jahi as dead and being exploited by a manipulative lawyer and another frame that assumed that Jahi was alive and being persecuted for her very life by a murderous elite hospital. These two frames represented the different sides in the conflict between the McMath family and the Oakland hospital. But Jahi cannot be both dead and alive, and the contentious co-existence of these frames appeared to be made possible by the emergence of a frame that highlighted disagreement within the scientific community over the concept of brain death and, by extension, what had happened to Jahi. The impossibility of the contradictory frames existing at the same time gave way with the fourth frame that emerged from my analysis; this frame recast the controversy in a way that Jahi could be both alive and dead, specifically by having initially appeared to be dead but not being dead anymore. This frame relieved the hospital of the blame for Jahi's “condition,” relocating blame to the imperfect nature of the science of brain death itself. While this frame appeared to offer a resolution to the

controversy, one that would appeal to all parties involved in the conflict, it inadvertently fed the frame that presented the scientific consensus about brain death as unstable.

The framing analysis in this chapter continued by my taking a step back from the media frames present in the text, that is, the newspaper articles, and attempting to decipher the various processes that potentially contributed to the creation and use of these frames. Six factors emerged from my analysis of 13 in-depth interviews with the journalists who had written those news stories and 11 in-depth interviews with the experts who they had cited in their work. These helped me understand the values and symbols around which the narrative about brain death had been constructed by journalists (Bird & Dardenne, 1997). One of these processes involved Jahi's story being crafted by multiple journalists over time. The fact that the coverage initiated as that of a two-sided binary conflict between the McMath family and the hospital also contributed to the narrative that the story ended up acquiring. Financial difficulties in the newspaper industry enervated some of the agency that journalists possessed when it came to making decisions about the newsworthiness of Jahi's story and how it would be covered; this particularly left them feeling powerless in the face of the financial needs of their employers. Outside parties also attempted to influence journalists as they gathered facts in Jahi's story; journalists were not always conscious of all the individuals and organizations that wanted to affect how they wrote about Jahi. Jahi was black, too, and that gave newsmakers pause while weighing the facts of the story, if not outright framing the racial dynamics of the controversy in the news articles. There also appeared to be a general perception that the science around brain death was not quite as certain. All of these factors contributed to the creation and evolution of the media frames that I had

earlier discussed in the chapter as emerging from a textual analysis of the news stories about Jahi in California.

The unveiling of the processes that led to the creation of the media frames in journalistic discourse about Jahi provide additional levels of insight. For example, the journalistic desire for balanced reporting, especially in a story like Jahi's that began as a conflict, perhaps explains the co-existence of the frames that position Jahi as alive at the same time as her being dead. The fact that the story begins as a conflict and continues to be framed that way indicates the persistence of media frames once they have been set. Each of these frames, as I've outlined earlier in this chapter, present entirely different narratives about what happened to Jahi. While these contradictory versions of reality are expected in the courtroom where much of the coverage was derived from, they may inadvertently have a different effect on the lay audience that consumes these conflicting narratives as constructions of reality. These two frames, taken together with the other frames that sow doubt about the science of brain death, may further obscure the issues for news audiences, which may include jury members, judges, lawyers, politicians, and voters. This confusion may also extend to the journalists who read the same news stories, influencing the narratives that impact their future work.

The general perception about the unresolved nature of the science of brain death further supports the preponderance of these conflicting media frames, which appear to create doubt about the science behind brain death. This is bolstered by the fact that the two competing frames about Jahi's status as a person who is alive or dead correspond to arguments for the cardiac and neurological perspectives of death, respectively, pitting the two against each other scientifically when they both stand on equivalent footing in the

eyes of the UDDA in California. The frame that appears to argue for the legitimacy of cardiac death even reflects Jahi as being alive by virtue of her body showing symptoms of a functioning heart (Bresnahan & Zhuang, 2012; Johnson, 2016; Magnus, Wilfond, & Caplan, 2014; Paris, Cummings, & Moore, 2014). They also reflect findings from previous scholars that the framing of health information is often condensed into a struggle between the rights of the individual versus the requirements of policy. In this case, the frame that depicts Jahi as alive represents the perspective of the individual, that is, her family's personal beliefs, and the frame that depicts Jahi as dead stands in for the perceived oppression of policy.

My analysis also indicates that while journalists are dedicated to being objective, they do not function in a vacuum. At the very least, they are affected by other journalists around them, whether they work with them directly or follow their work from the outside. The reality, in this case at least, is that journalists had to navigate pressures coming at them from all directions. The pressure could be arising from the system they work in, specifically the requirements of their employers and the people who manage them. Journalists also had to circumvent various interest groups who wanted to influence the framing of Jahi's story. In addition, journalists were not always aware of every person who was trying to affect what they wrote. It is not unreasonable, then, to connect the systems within which the journalists worked and the frames that they ultimately produced and disseminated in their news stories.

Complicating the norm of objectivity was the revelation that journalists felt called to stand on the side of social justice as part of their professional responsibilities. Jahi was African American, and her family had approached the news media first, and this appeared

to make journalists at least consider whether the controversy had arisen from racism on behalf of the Oakland hospital, a place that most African Americans associate with dying (Perry, 1990). At the same time, the journalists struggled to remain objective within their desire to stand up for the oppressed; their struggle was obvious with their constant negotiation of reality attempted to report the facts for their readers. This struggle appears to be reflected in the existence of the conflicting media frames that represent a reality where Jahi's death was not unusual and the other reality where Jahi was the target of a conspiracy to kill her. The question that arises, though, is how the story would have been framed if Jahi had not been from a minority community but rather from the majority white community. Would the story have then been framed as one about a hospital that potentially wanted to kill her? African American beliefs about death frequently involve religion and the church community (Hayslip & Peveto, 2005), and these elements are depicted as allies of the McMaths in their fight against the elite hospital conspiring with other healthcare providers to oppress the family. While the question of *how* the framing would be different had Jahi had not been black is beyond the scope of this study, this chapter has revealed that race did play a role in how the story was framed.

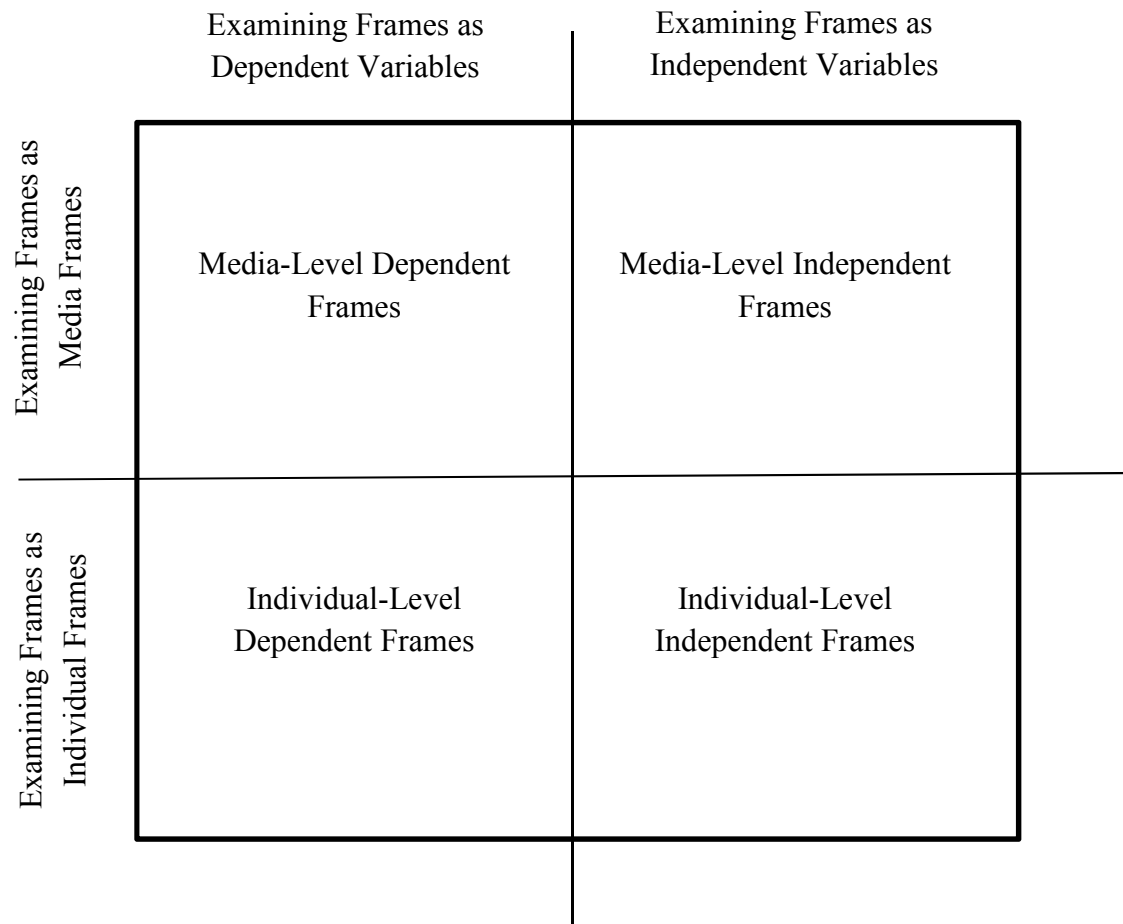


Figure 3.1 Typology of framing research. Adapted from “Framing as a Theory of Media Effects,” by D. A. Scheufele, 1999, *Journal of Communication*, 49(1), p. 109. Copyright 1999 by the International Communication Association.

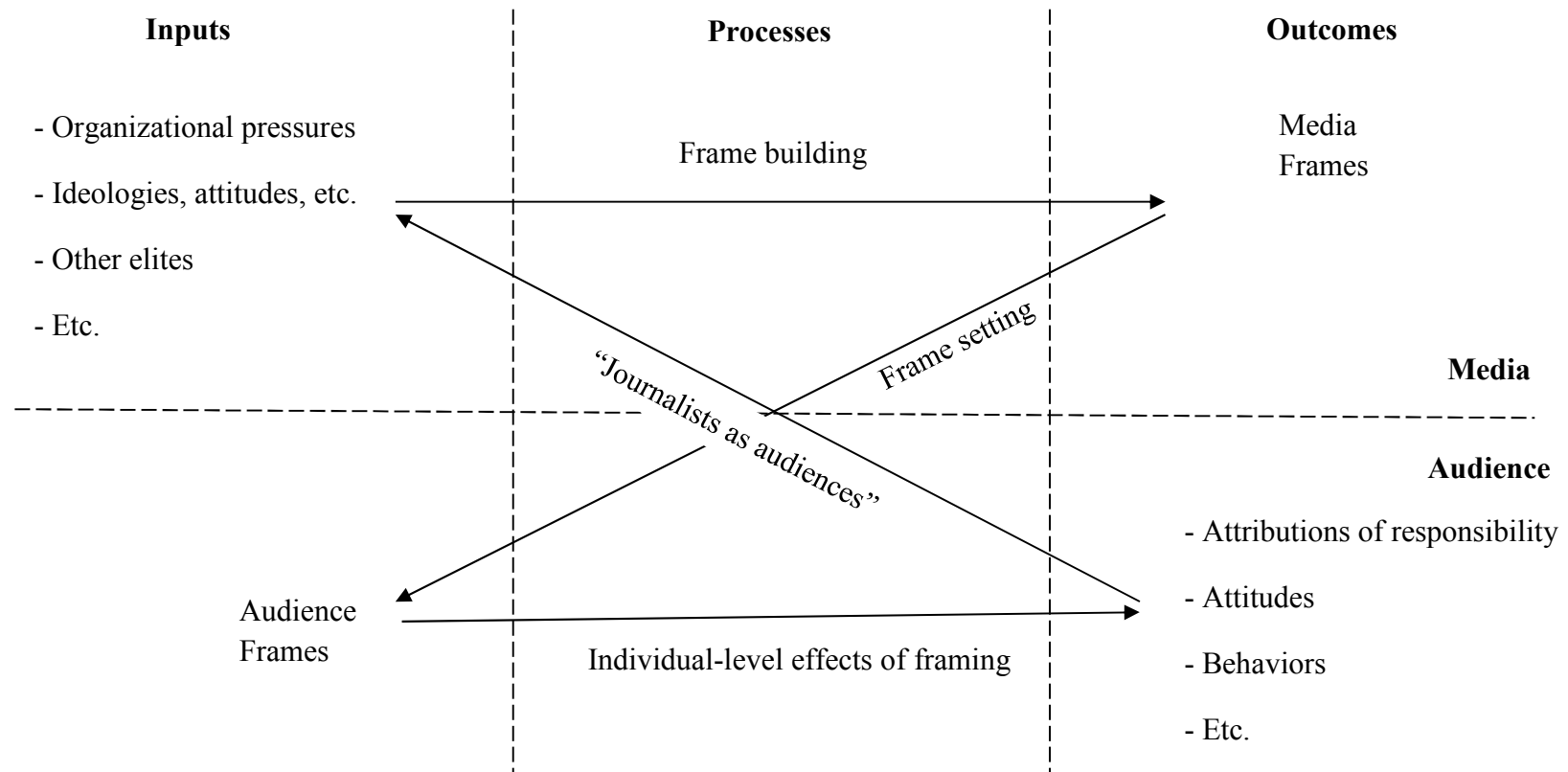


Figure 3.2 A process model of framing research. Reprinted from "Framing as a Theory of Media Effects," by D. A. Scheufele, 1999, *Journal of Communication*, 49(1), p. 115. Copyright 1999 by the International Communication Association.

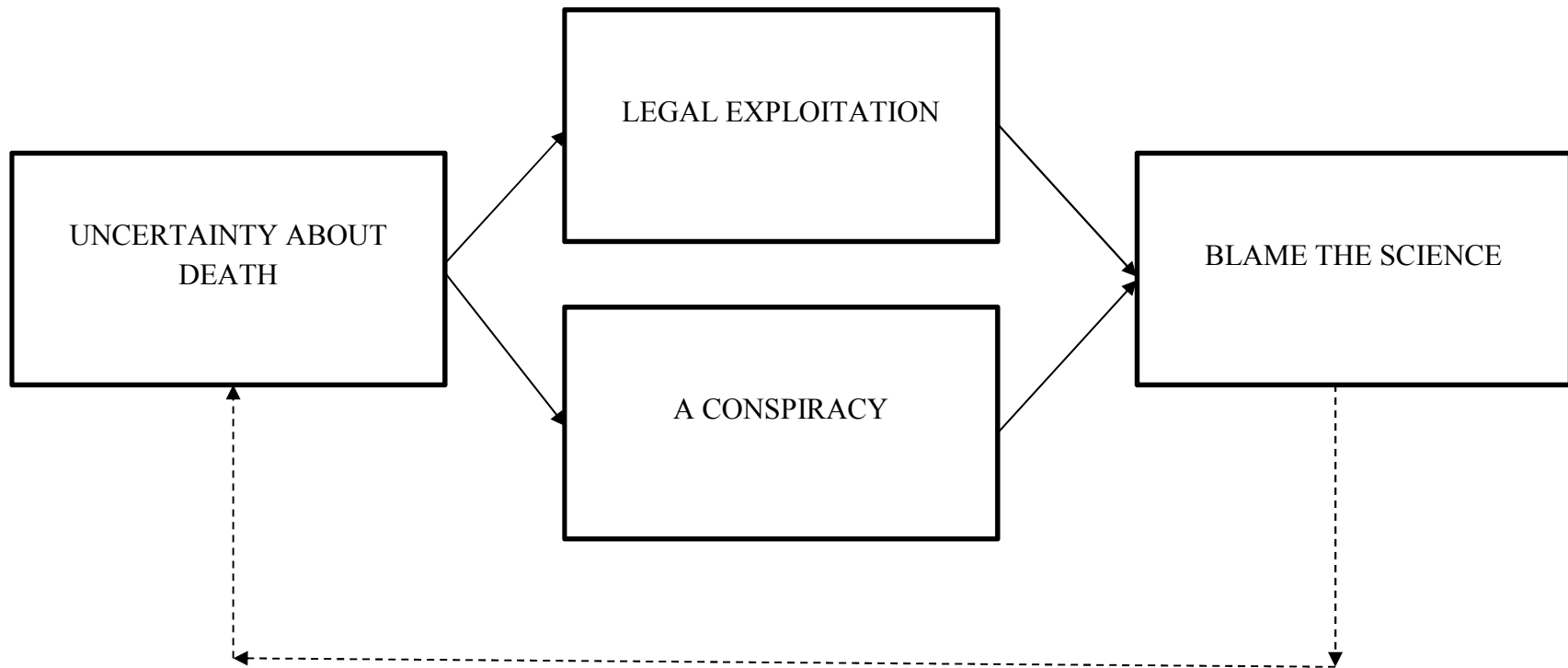


Figure 3.3 Frames in newspaper coverage of the Jahi McMath case in California

CHAPTER 4

THE SCIENCE IN THE STORY: EXPERTS AND JOURNALISTS

Recall back to that night in 2016 when I first heard about brain death and Jahi McMath from my spouse, Sonal. Some of his ire was reserved for how journalists caused further confusion about brain death by how they covered such stories. I remember his showing me a slide that had screenshots of news stories that confused various aspects of brain death cases and even conflated them with other conditions such as coma and vegetative state. I wondered what someone like Sonal would think of how Jahi's story had been covered.

Laungani and Young (1997) refer to the mediated representation of death in the media as a “contemporary pornography of death” (p. 222). This term refers to the Western “obsession” (p. 221) with death in the media – “a virtually inexhaustible diet of violence and death in its gory and graphic detail” (p. 221) – coexisting together with the culture of the denial of death. I introduced this denial of and distancing from death in the first chapter of this project; such a culture leads to an unfamiliarity with the reality of death that tends to create an increased reliance on its culturally mediated representation (Seale, 1998). These representations, however, may not necessarily serve as the ideal source of education about death and dying.

Certain patterns follow the representation of death as it is presented in the media. Portrayals frequently focus on deaths arising due to violent death, natural disasters, and grief (Seale, 1998) or attributing it to poor care resulting from:

...arrogance and callousness rather than from flaws in general systems of care or from uncertainties about the prognoses for gravely ill patients, the consequences of alternative treatments, the preferences of patients and families, and the applicable ethical and legal standards for care. (Field & Cassel, 1997, p. 15)

News reports especially can mislead the public by selecting a greater number of violent and shocking modes of death that do not correspond to their true numbers in society, frequently presenting them without much social or personal context (Combs & Slovic, 1979; Field & Cassel, 1997; Lazarsfeld & Merton, 1948; Lichtenstein, Slovic, Fischhoff, Layman, & Combs, 1978). Such news reports also focus on violent or sudden death, young death, and dramatic medical resuscitations that in reality do not work (Field & Cassel, 1997). At least some of these are present in Jahi's story.

This chapter was inspired by Sonal's criticism of news coverage of brain death and provides the results of my exploration into that very concern. I also went one step further and tried to understand what the relationship between experts like Sonal and the journalists who had written about Jahi in California had been like. Before I present my findings for the aforementioned areas, I discuss the literature in the area of science communication and its relationship with the media. I then introduce the results for my last two research questions, that is, what experts think about news coverage of Jahi's story in California, and what the relationship between these experts and the authors of news stories about Jahi in California had been like. I conclude the chapter with an overall summary of my findings.

4.1 A HISTORY OF SCIENCE AND THE MEDIA

The relationship between science and the media is an old one and has evolved with developments as they took place in both domains (Bucchi, 2008). Science as we currently know it has only existed since the time of the European Renaissance (Vickery, 2000); indeed, the first recorded use of the word scientist can be traced back to the mid-nineteenth century (Vickery, 2000). The practice of recording one's knowledge and specialized skills, however, dates back to the ancient civilizations of Egypt and Mesopotamia when doctors, builders, and metal workers were known to generalize from their observations and techniques (Vickery, 2000). These early specialists did not openly share their knowledge, a trait that was also shared by Renaissance scientists. According to Crawford, Hurd, and Weller (1996), "science originally emerged as a form of very serious and highly competitive activity with much concern for discovery, but little concern with communication" (p. v). These early scientists were often funded by the wealthy – rulers, clerics, landowners, and merchants – but later began to rely on personal family wealth that was unconnected to science (Vickery, 2000).

The Renaissance saw the arrival of the printing press, an invention that permitted previously unforeseen levels of recording and dissemination of knowledge (Vickery, 2000). Scientific knowledge, too, was part of this phenomenon; the first scientific material was printed in 1469 (Vickery, 2000). Moreover, of the over 35,000 editions that were printed in the fifteenth century, around 3,000 were scientific and represented over 650 authors (Vickery, 2000). Two centuries later, Henry Oldenberg published *Philosophical Transactions* of the Royal Society that would move news of discovery to scientists in a reasonably quick way, was openly available, and assured authors of

enduring identification with their discoveries. This marked a turning point in the culture of science, which until then, had not placed emphasis on communication as part of its work (Crawford, Hurd, & Weller, 1996). In this period, science became a public activity, and “secrecy, private ownership, and personal knowledge were outlawed” (Gregory, 2009, p. 4). Scientists eventually began to migrate to classrooms as teachers and, with the advent of the nineteenth century, entered the industry and the government in larger numbers and as specialists and professionals (Vickery, 2000). Science’s new military and commercial value in the eighteenth and nineteenth centuries respectively saw an increase in scientific publication and the creation of abstracts (Crawford, Hurd, & Weller, 1996). By the nineteenth century, the first independent forms of scientific association – academies and societies – were established as were discipline-specific journals arising from these associations (Hurd, 1996; Vickery, 2000). In the years since, technological changes have transformed the nature of science. Modes of communication have especially evolved as people progressed from riding horse-drawn coaches to flying in airplanes, allowing a greater availability of science to the world and transforming it from the domain of a few to “as unevenly distributed among the world’s peoples as any other cultural or material good” (Vickery, 2000, p. xxii).

Attitudes toward the public communication of science continue to evolve. For the most part, scientists have lived a “monastic existence” (Farago, 1976, p. 9), in Anglo Saxon countries at least. In the late nineteenth century, scientists viewed the popularization of science as part of their job, but higher rates of specialization and professionalization in the twentieth century created a distance from the public (Bucchi, 1998; Dunwoody, 2008). Many scientists also did not receive any government or industry

support for public communication (Farago, 1976). “Too much investment in popularization,” wrote Dunwoody (2008), “could ruin a scientist’s career” (p. 16).

The trend towards public communication continues to shift with scientists once again being encouraged to interact with the public, giving rise to the field of public understanding of science (PUOS) in the 1980s (Brossard & Lewenstein, 2010; Bucchi, 2008; Gregory, 2009). PUOS examines improving public understanding of science and exploring the interaction of the public and science (Brossard & Lewenstein, 2010). The traditional approach to the public communication of science was linear, pedagogical, and paternalistic – scientists assumed a deficit of knowledge in the public and attempted to fill it with one-way communication (Brossard & Lewenstein, 2010; Farago, 1976; Irwin, 2009). In recent times, emphasis has shifted toward the consideration of context, extant local knowledge, and public dialogue (Brossard & Lewenstein, 2010; Farago, 1976; Irwin, 2009; Leach, Yates, & Scanlon, 2009; Redfern, 2009). Two-way communication is now encouraged (Bucchi, 1998; Farago, 1976).

One of the channels for science communication has been the media (Bucchi, 1998; Dubeck, Moshier, & Boos, 1988; Dunwoody, 2008; Krieghbaum, 1967; Peters, 2008; Weingart, 2012) – citizens learn about science from “mediated channels, those ubiquitous packagers of information for large numbers of readers, listeners and viewers” (Dunwoody, 2008, p. 15). The availability of information about science to the public is important because science is now part of contemporary society (Farago, 1976; Krieghbaum, 1967). Science communication is crucial to the functioning of a democratic society, taxpayers being the main supporters of scientific research and development and an informed population forming the basis of a well-functioning democracy (Crawford,

Hurd, & Weller, 1996; Franzen, Weingart, & Rödder, 2012; Krieghbaum, 1967; Ransohoff & Ransohoff, 2001; Weingart, 2012). Much of this science helps provide solutions to practical problems and can also be used to teach in the classroom (Farago, 1976; Krieghbaum, 1967). Scientists also may use mass media like newspapers, radio, television, and web-based news media in order to impart legitimacy to science in the eyes of the public and bolster public support for their work (Franzen, Weingart, & Rodder, 2012). Public knowledge of science in today's world, it seems, is a "democratic, personal and cultural asset" (Irwin, 2009, p. 4), and the science communicator in the media a "bridge between two communities, a catalyst of new attempts at improving the society he inhabits" (Farago, 1976, p. 6). Science communication, thus, acts:

...as the scientific advisory service to those not privileged enough to possess their own. It should attempt to point out both the glories and the dangers of science. It should insist on the cultural and historical importance of science. It should allay fears but draw attention to future consequences. But above all it should act a bridge between the thoughts, ideas, and ordering processes of science and those of non-scientific culture, both being facets of our common humanistic traditions. (Farago, 1976, p. 5)

Past research, however, has indicated a sense of dissatisfaction about the quality of science communication (Farago, 1967). Scholars have attributed a certain degree of responsibility to the popular media for causing confusion about scientific issues (Kilcullen, 2015). This phenomenon is further exacerbated by the rise of the Internet, which makes it harder for readers to gauge the reliability of scientific information (Colson, 2011; Boykoff, 2009; Peters, 1995; Trench, 2007). The needs of such readers

gain even more importance when they seek information about issues that can affect their quality of life (Trench, 2007). Research into how social media platforms fit into this communication landscape, particularly as used by clinicians, is only in the early stages (Von Muhken & Ohno-Machado, 2012).

The coverage of science in the media is further complicated by the way the general public perceives scientists. Research in the area of popular media like Hollywood films reveals that the dominant fear about scientists involves the “creation and manipulation of life” (Weingart, Muhl, & Pansegrau, 2003, p. 286). They are portrayed as gaining knowledge by violating ethical boundaries, particularly in medical research (Weingart, Muhl, & Pansegrau, 2003). Most films about science belong to the horror genre (Weingart, Muhl, & Pansegrau, 2003) with scientists on television being described as “sinister” (p. 586), “powerless” (p. 586), “geeks” (p. 587), “elite” (p. 587), and even “priests” (p. 587) (Nisbet et al., 2002). These reservations are often based on the view that science changes long-held belief systems too quickly (Miller, 2004; Nisbet et al., 2002) and that it can conflict with religious beliefs (Miller, 2004). All these concerns naturally influence the perception of a topic like death.

4.2 NEWS COVERAGE OF SCIENCE

One of the byproducts of the continuous dovetailing of science communication and the media is the creation of the science journalist, a position that is overwhelmingly seen in print news (Bucchi, 1998; Dunwoody, 2008). The job of a science journalist is to provide science news that is timely and about a social or human problem (Farago, 1976). Kriehbaum (1976) considers Benjamin Harris the first science journalist. Harris published a story on September 25, 1690, in the *Publick Occurrences* that informed

Massachusetts colonists of prevailing “Fevers” (p. 19). His writing emphasized public health and medicine, local angle, progress, and ties to the military. Health and medicine continue to dominate in the popular list of topics in science journalism (Badenshies & Wormer, 2012; Dunwoody, 2008; Hansen, 2009). Reflecting on his experiences working on science programs at the British Broadcasting Corporation, Redfern (2009) considered the biggest science news stories to be those that – like Jahi’s story – involved debates about consciousness and religion. Dunwoody (2010) attributes this to the “life-or-death quality” (p. xi) of science and health issues like Jahi’s that makes them compelling and globally critical.

Much of the coverage of science in the past 50 years has focused on specific controversies rather than a sweep of the various topics in science as based on publications (Hansen, 2009; Redfern, 2009). Further, coverage is now more critical than the celebratory position it used to take towards science in the past (Allan, 2009); this is because of the nature of “mass democracies whose publics and political leaderships no longer recognize and accept the professional elites’ privilege of virtual accountability” (Weingart, 2012, p. 24). At the same time, however, the agenda continues to be primarily set by the sources, that is, the scientists and the scientific community (Hansen, 2009).

Scientists and journalists, however, express a sense of dissatisfaction when it comes to the coverage of science in the news (Leask et al., 2010). Science journalism is often blamed for its promotion of “scare stories” (Dubeck, Moshier, & Boss, 1988; Farago, 1976, p. 4; Redfern, 2009, p. 185), or its “attempts to dramatize and vulgarize the solid if unremarkable achievements of scientists” (Farago, 1976, p. 4). The narrative of health stories especially often emphasizes individual autonomy as being restricted by

policies (Wallack et al., 1993). Newspapers in particular are accused of sensationalism (Blok, Jensen, & Kaltoft, 2008; Burchell, 2007; Krystallis, 2007; Witte, 1994), being influenced by non-scientific vested interests (Meyer, 2006; Trench, 2007; Young & Matthews, 2007), fostering confusion about the various facets of an issue (Besley & Tanner, 2011; Boykoff, 2009; Wilkes, 2002), and oversimplifying issues in an attempt to communicate information to a lay audience (Colson, 2011; Dunwoody, 1992; Logan, 1991; Peters, 1995; Ransohoff & Ransohoff, 2011; Shuchman, 2002). Scientists use specific terminology to refer to very sharply boundaried concepts (Krieghbaum, 1967), but how journalists understand and convey such language may leave scientists unhappy with the level of accuracy in the journalism (Dunwoody, 2008).

The public wants to know the truth with respect to scientific issues. And scientists want to tell the public the truth about the issues that concern them. Unfortunately, trying to distill the messy realities of scientific research into immutable bullet points (which generally seems to be what the public wants) often undermines the whole notion of understanding. (Hines, 2001, p. 186)

Dunwoody (1999) has described the relationship between scientists and journalists as a “complicated dance” (p. 59) in which both parties struggle to shape narratives about scientific concepts according to their own perspective. This metaphor is based on a perceived disconnect between the cultures of the two professions (Allan, 2009; Dunwoody, 2008; Krieghbaum, 1967; Leach, Yates, & Scanlon, 2009; Peters, 1995; Weingart, 2012). This disconnect results from difficulties that scientists and journalists experience while transmitting meaning to each other, prejudices and stereotypes that they may believe in about the other group, and differences in professional

conventions. The relationship between scientists and journalists can also be understood through the lens of time, power relations, and organization (Reed, 2001). These refer to the differences in turnaround time between scientific fields and media organizations, the struggle between scientists and journalists for control over the communication process, and the structural forces that shape the two arenas, respectively.

Journalists and scientists approach communication differently (Pearce, Romero, & Zibluk, 2010). Journalists care about news values and questioning, while scientists see communication as public relations or public education and need the media to bolster support for their research or influence policy (Pearce, Romero, & Zibluk, 2010). Most scientists view public science communication as split between two separate arenas, that of internal scientific communication and public communication (Peters, 2013). They see the media as part of the latter and consider them outsiders. Medical professionals in particular have described their interactions with the media in negative terms – not only do they feel powerless and overwhelmed by such experiences, but they fear being misquoted and also worry about what their colleagues may think of their media presence (Kutner & Beresin, 1999). Scientists are not traditionally rewarded on the basis of their interactions with the media but by their peers on the basis of their professional achievements (Dunwoody & Scott, 1982). Indeed, scientists are primarily trained to communicate with their peers (Nelkin, 1995).

Journalists, on the other hand, often opt out of science courses during the course of their professional training and education (Reed & Walker, 2002) and are trained to distrust authority figures such as scientific experts in any subject (Dearing, 1995). Their responsibilities include gathering information from scientists and also translating it for

the lay public (Farago, 1976; Kriehbaum, 1967; Pearce, Romero, & Zibluk, 2010). In the absence of the ability to determine what is true, reporters opt for objectivity by going into “neutral transmitter” mode and focusing not on validity but on accuracy (Dunwoody, 2008, p. 20), in effect telling the reader, “the truth is in here somewhere” (Dunwoody, 2008, p. 21). Part of this process is the selection of expert sources, a process that is based on journalist perceptions of relevance, visibility, accessibility, and media appropriateness (Peters, 2008). This expertise may not necessarily reflect pure scientific knowledge, rather is defined by its reference to social problems, decision-making, and action (Peters, 2008). Thus journalists, by virtue of their profession, not only communicate scientific expertise but may also create it (Peters, 2008). A side effect of this process may be poorly balanced reporting that may result in the rise of pseudoscience (Dubeck, Moshier, & Boss, 1988; Hansen, 2009).

Research has revealed many other factors that affect how science is conveyed in the media. Kriehbaum (1967) classifies these factors into those internal to the assignment itself and those external or imposed from the outside. Internal barriers include translating scientific language and the ability to generate scientific sophistication. External barriers include governmental and corporate censorship, authoritarian and over-zealous bureaucracy, and the pleadings of special-interest groups. The principles of science and journalism are often at odds with each other, with the traditional news format not being ideal for the conveyance of science (Dunwoody, 2008; Farago, 1976). Dunwoody (2005) particularly questioned the traditional journalistic norms of objectivity and balance in science reporting, introducing the concept of weight-of-evidence reporting in their place, calling on journalists “not to determine what's true but, instead, to find out

where the bulk of evidence and expert thought lies on the truth continuum and then communicate that to audiences” (p. 90). Moreover, science news, which is patterned after science itself, is often not interesting enough to meet the traditional expectations of news values that are ideally more suited to carry general and political news (Allan, 2009; Badenschier & Wormer, 2012; Dunwoody, 2008). The result is a “compromise between personal, economic, and political pressures” (Farago, 1976, p. 29) with the science journalists being described as treading a “tightrope between the concerns of the public and those of the scientists, especially when, as it frequently happens, there is a genuine and sincerely felt antithesis” (Farago, 1976, p. 12). Walking this tightrope renders science journalists into “slightly contorted” (Farago, 1976, n. p.) figures, especially as they add into the negotiation other actors like politicians, industrialists, and editors. Science journalists have to be aware of working in a hierarchy that is different from science, one that is composed of editors and management that often have different motivations – often monetary – from the science specialist (Dunwoody, 2008; Farago, 1976). Science journalists, in fact, have been decreasing in number over the years (Farago, 1976; Kriehbaum, 1967); most journalists are not specialists because those are expensive (Dunwoody, 2008). Thus, “even in the best of times, most media organizations do without them” (Dunwoody, 2008, p. 17).

As modern society becomes more saturated with various forms of media (Brown, 1998), the general population continues to turn to the media for scientific ideas (Boyce, 2006; Malone et al., 2000; Nisbet et al., 2002). This population includes voting citizens as well as legislators (Hotz, 2002; Miller, 2004). One of the ways that the media can fulfill this function is by focusing on the relationship between scientists and journalists,

which is necessary for the healthy functioning of the political and economic systems of the United States (Hartz & Chapell, 1997). Ultimately, the nature of the interaction that scientists have with the media determines the position that science occupies in society (Trench & Miller, 2012). This relationship continues to change with scientists becoming more media savvy and journalists' interactions with their audience becoming more two-way (Dunwoody, 2008).

4.3 THE EXPERT PERSPECTIVE ON NEWSPAPER COVERAGE OF THE JAHİ MCMATH CASE

In this section, I present my findings from a qualitative thematic analysis of the 11 interviews I conducted with the scientific experts who were cited in news coverage of the Jahi McMath case in California. I used this method to answer the following research question:

RQ3: What do experts feel about the coverage of the Jahi McMath case?

My conversations with the experts fell into three broad categories. First, not all experts agreed about whether Jahi's story had any news value at all. Second, experts did not feel that the news coverage was technically consistent. Finally, the experts felt that reportage had an impact on how people perceived the idea of expertise.

4.3.1 DISAGREEMENT ABOUT NEWSWORTHINESS OF THE STORY

I interviewed experts from a wide variety of fields – neurology, bioethics, otolaryngology, law, etc. – and they disagreed about whether the Jahi McMath case even warranted news coverage.

The experts who felt that the story was not newsworthy overwhelmingly based it on their opinion of tonsillectomies, that is, the procedure that Jahi underwent before she

died in California. According to them, the case was not unusual because tonsillectomies were not routine and bore a certain level of known risk, “an irreducible rate of post tonsillectomy bleeding, usually around 1% in the world” (Lakowski, 2018). Jahi was also obese, a fact that added further levels of risk to her case. Her case, therefore, was one that was inherently risky and thus not unique, but “the fact that the child had the *complication* was made to be something *extraordinary* and something that should *not* have happened” (Lakowski, 2018). Dr. David Tunkel (2018) concurred with this perspective, expressing that the controversies in Jahi’s case were not new; rather, they had been going on “all throughout modern medicine.” His hope, in fact, was that news coverage of Jahi’s story would educate people about the “extreme consequences” inherent in the procedures she went through.

...we know that in this *country* there can be up to half a million tonsillectomies done each *year*, and so if that’s the case, there are several deaths each *year*, and I *am* aware of death after tonsillectomies, some of which were much lower *profile* than the case that you’re *talking* about, so this wasn’t news to *me* that a child could have a terrible outcome after a tonsillectomy, and *because* of that, it’s important that as surgeons we really assess risk, figure out what the risk is for a child. We also assess indications, meaning is this surgery really *needed* as something that’s going to *help* more than *hurt*, and then we develop communication skills that we can *somehow* explain that to parents and caregivers who may be under the *impression* that a tonsillectomy is very *routine*, *mild* operation with complications that are never *seen*. (Tunkel, 2018)

Other experts believed the story to be newsworthy, also evaluating it along the line of risk. Dr. David Goodman (2018) believed the procedure to be a “straightforward, simple, safe *procedure*.” This gave rise to Dr. Nancy Berlinger’s (2018) query – “how did a relatively healthy child go in and for this, for an elective procedure, and die as a consequence?”

Another newsworthy aspect of the case was the fact that it lasted as long as it did. This was unexpected and, according to Dr. Benjamin Teague (2018), “*very* remarkable.” “I mean, if she *lasted* that long,” said Thaddeus Pope (2018), “they know that there’s something the matter with it, right, they *know* that there’s something the matter with the brain death diagnosis.” According to him, the family’s claim that Jahi was not dead suggested “that something very unprecedented has happened.”

One is what the *family* is saying is historic because there’s never been a case ever reported where somebody correctly determined to be dead was later no *longer* dead, so that’s, that, *that* would be miraculous and historic, and it would *also* show that there’s something seriously problematic with the way that we measure *brain* death because that should, if the diagnosis was really *solid*, *that* wouldn’t happen because the thing you’re supposed to be measuring is that it’s irreversible cessation, and if it *reverses*, then you’re not measuring what you’re supposed to be measuring... (Pope, 2018)

The story became even more newsworthy because of the fact that it involved a child. Jahi had not been asked to consent for her procedures; she had only been able to assent to a decision made by others like her mother, so the fact that those procedures led to extreme complications brought up continuing issues of the consent of minors.

...to have Jahi say, *I don't want to go do this procedure, oh, no baby, we should, it's going to be okay*, then this sort of abhorrent thing happens where the *bleeding* happens and no one pays *attention* or doesn't *seem* to pay attention or doesn't pay *sufficient* attention or *whatever*, and then, you know, then the state comes in, then the *hospital* comes in and tells her she's *dead, dead, dead*, you know, what was it, I think it was in the New Yorker article where the, one of the physicians came in and said, oh, you know how we *are*, and sort of she feels like she's *patronised*. *All* of that treatment I think read through their *eyes*, which is basically how it's reported, is *very* compelling to I would say *anyone* but *certainly* people with children, and that's a very sympathetic *case*, so I think that that *all* has played into why it's gotten such attention and why it's been so controversial if that's what you want to call it. (Holmes, 2018)

The fact that Jahi was black and concerns about whether race played any role in the decision to take her body off mechanical support gave the story "some *legs*" (Magnus, 2018).

Thaddeus Pope (2018) summed up the overall news value of Jahi's story as one that was "worth thinking about" because of the lessons it could offer to medicine and public policy. Dr. David Faigman (2018) extended the case to the family of scientific controversies such as evolution, climate change, and reproduction rights, which in his view is based on "tension between the individual uses of science, understanding of science and establishment uses of science and understanding of science." "I think I *see* it evolving in as a continuing story of how you reconcile *religion* and *personal* views and *medical* choices as against the medical establishment and find scientific wisdom," he

said. He further called it “a perfect storm of actors, of uncertainty, *perceived* uncertainty because of different perspectives on what constitutes death between science and *religion* all magnified by an attorney who is very good in front of the microphones.” Ultimately, Dr. Teague (2018) agreed. “It’s a case that *generates* a lot of public interest,” he said, “and so there *should* be news coverage *of* it.”

4.3.2 PERCEPTION OF COVERAGE AS HAPHAZARD

Experts expressed varying degrees of satisfaction with the overall coverage of the Jahi McMath case. Dr. Faigman (2018) and Dr. Ryan Holmes (2018) used phrases like “mostly accurately” and “relatively reasonable” with regards to the quality of the coverage. David Magnus (2018), too, described the coverage as “*heterogeneous*” and that it “ebbed and flowed,” adding that the stories that came later in the lifetime of the case were “mostly very misleading.” Others were satisfied with the consistent coverage that the case received over time and the facts that it attempted to convey.

I think that the journalist’s *primary* role is translating *complex* subjects that...have important public policy implications in a way that the average person can appreciate the depth and complexity of the *issue* and form an opinion about, you know, the best path forward, so I think that, for example, *some* of the press did a good job in explaining why it was necessary to have a *fairly clear* definition of brain death because of, you know, issues surrounding transplant opportunities...but I do think that part of the job of the journalist is to make clear the full *range* of consequences of choosing one policy versus another policy.

(Faigman, 2018)

The main criticism that was levied against the coverage was that it lacked depth. “There are *never easy answers*,” said Dr. Lakowski (2018), “but of course, that’s not the way you newspapers work. Headlines are as short as possible, lack complexity as possible.” Some of these problems stemmed from the limited amount of time and space that experts felt they were given by journalists to explain complicated scientific issues. Many experts described speaking to journalists over the telephone in brief conversations. Dr. Marjorie Shultz (2018) felt that she had been “*skimpily* quoted” with the journalist she had spoken to only using one or two sentences of what she had said. “I said much *more* than came *through* in the story,” she said.

I *don’t* think that news coverage went *into* the kinds of issues I’ve tried to go into in talking to *you* about *splits* within the medical community that have emerged over the last 10 years about whether our current criteria for death or non-recovery are adequate, including a reconsideration by a presidential bioethics committee of whether the laws adopted in the nineties are appropriate or should be revised. I *don’t* think anybody in journalism had the capacity to dig *deeper* than saying *here’s* a family that insists their child isn’t dead even though doctors say she is. (Shultz, 2018)

Experts were particularly concerned about the inconsistent use of terminology in the coverage. Most of this concern was tied to use of the term “brain death,” which experts described as being hard to understand for laypeople. “People *often* think it means something else,” said Dr. Berlinger (2018). Brain dead was described as a catch-all phrase that can mean anything from being tired to being developmentally delayed or neurologically compromised to being dead. “I think the public doesn’t understand the

difference between brain death, vegetative state, coma, minimally conscious state, and (inaudible) brain damaged,” Magnus (2018) said. He applied this criticism to journalists as well whom he also criticized as misleadingly linking the case to Terri Schiavo’s. “I don’t think I talked to a reporter who understood the difference until I talked to them,” he said.

Terri Schiavo did *not* have brain death. She has persistent *vegetative* state, which is a *different* kind of injury, and *her* injury, and *hers* was particularly challenging because she had things like sleep wake cycles, so her eyes would open during the *day*, her eyes would *close* at night. She seems to have some interaction when in fact there wasn’t really any purposeful movement or purposeful *interaction*, but people *see* that, and they’re like, *oh*, is *that* what you mean by brain death? No, that’s *not* what we mean by brain death, but that’s sometimes a hard distinction to make. (Holmes, 2018)

Experts pointed out other inconsistencies in journalistic terminology. The most common issue according to Dr. Teague (2018) was saying “in *one* breath that Jahi is brain dead and (inaudible) kept alive,” which is a contradiction according to established law. He also mentioned use of the term “life support,” a point of criticism also raised by Thaddeus Pope (2018):

...so if you say she’s been kept *alive* on life support, right, or do you say she’s being *sustained* on life support, because you don’t, the very question at *hand* is *is* she alive or dead, so you don’t want to write it in a way that, you know, it, you don’t want to write it in a way that suggests that she’s *alive* because that’s not, well, we don’t *know* that or not, so I think some people are more careful about the

specific verbs, adverbs, and nouns that they use because they're especially important here because she's being kept alive on a ventilator, a mechanical ventilator. Would you call that, normally that's called a form of life support, but when you're talking about *her*, it's not *really* a form of life support because she's not *alive*, so can't support somebody's life if they don't, if they're dead, *so* I think some reporters are more *careful* at that level of word choice than others.

At the same time, experts acknowledged that some of the confusion on behalf of the journalists was rooted in the experts themselves. Different experts would use terminology differently. "The way a neuroscientist would use certain terminology," said Dr. Berlinger (2018), "is not the way a doctor talking to a *family* would definitely, would definitely use the terminology." Experts too could make mistakes like saying, "your person is dead but is being kept alive on machines" (Evans, 2018).

Another reason for the variance in the perceived technical quality of the coverage appeared to be that different newspapers were able to dedicate different amounts of resources to the story. Local and regional newspapers were described as merely reporting the developments of the case, while larger national news publications like the *New Yorker*, *Wall Street Journal*, and *ProPublica* were described as covering the case more in depth in order to "explain to the readers why this matters to them or why they should care about it" (Pope, 2018). Dr. Shultz (2018), however, felt that only a handful of modern newspapers "can *invest* sufficient resources and reporter time to get below the surface of something like this." Magnus (2018) felt like journalists covered the story differently based on their personal opinions:

I was doing a segment on the *Today Show*, and the reporter who was talking about it just *clearly* was *so* sympathetic to the mother. It's like, *oh*, you know, she's still *breathing*, so even if it's through the *machines*, so as long as the machine's breathing for her and her skin is still warm and she loves her kid, let her have what she wants, which is an understandable response, but so a lot, so *really*, I saw a *lot* of very different narratives with some reporters thinking like this is crazy and really angry at Chris and helped telling *that* story. Other reporters sympathetic to the mother, thinking that this is just *wrong* and this poor woman and why don't they just let her say that she's *alive*, and you've seen both of those things.

4.3.3 THOUGHTS ABOUT THE IMPACT OF THE COVERAGE ON THE PERCEPTION OF EXPERTISE

Dr. Shultz (2018) described the role of an expert as making “visible to people varying points of views about issues which were subjects of public attention and controversy.” Experts, however, appeared cognizant of the impact that news coverage of the Jahi McMath case may have on their roles as scientific experts. Many expressed an awareness of the degradation that the idea of expertise has faced over the years, a phenomenon that they felt was strengthened by how the coverage was framed as a challenge to experts and empowering non-experts, the latter not only including patients in this case but also pseudo-experts. Experts varied their opinions over what this means, some decrying the decreasing trust in science while others welcomed the levelling of power relations between patients and experts.

Many experts saw the coverage of Jahi's story as a conflict between the McMaths and the Oakland hospital as a narrative that challenged expertise and revolved around

“disparities of *power*” (Goodman, 2018), particularly the ultimate power of the state to determine life and death for an individual. Dr. Holmes (2018) described this narrative as one in which the McMaths had been patronized by the hospital, a narrative that “brought up issues for *some* folks, the idea that, you know, either someone with authority is telling her whether someone’s alive or dead.” Dr. Shultz (2018) personally viewed the story as a David versus Goliath conflict in which Jahi’s “family has fought like hell to prevent her basically abandoned and declared dead.”

Few families have the wherewithal to *fight* a major medical establishment, okay, I mean, it just doesn’t *happen*...they had some kind of spiritual or religious beliefs and *family strength* to *fight* one of the most *elite* hospitals in the country and do so for a *long* period of time under a *great* deal of pressure to stop. I think it also became visible because it *was* a nationally known high-status hospital and the consultant that the hospital called *in* was from *Stanford*, so you had *two*, you had experts from *two enormously prestigious medical locations* who said she’s dead, right, and yet the family refused to accept that. (Shultz, 2018)

Framing the story as a valid challenge to experts, in the opinions of the respondents I interviewed, devalued the concept of expertise, a phenomenon that many acknowledged as already occurring in the current political climate of “fake news” as touted by President Donald Trump. “*Used* to be that expertise had some *value* in society,” said Dr. Lakowski (2018). “It seems recently that that type of value has significantly *declined* in its *worth*.” He described feeling intense fear of the media after facing a recent complication in a case similar to Jahi’s. “I’m thinking, *oh my God*,” he said, “Oakland all over again.” He also lamented the negative effect that news coverage of Jahi’s story had

had on the surgeon involved in the case, a “*well-trained and capable man*” with whom he had trained in the past.

Further doubt was cast upon expertise by journalists’ inclusion of a pseudo-scientist from the International Brain Research Organization who represented the McMath family in the conflict, claiming to have a cure for brain death. Magnus (2018) described him as a quack with a correspondence degree in psychology from a dubious school:

He is a *quack*. I think he is a *complete disreputable quack*. If you, and so it does *not* take long to look into it to see that this is a *complete* snake oil salesman, and *yet* the media, but you know, *anybody tomorrow* could get a correspondence degree. It’ll take you *two* weeks to have some kind of diploma, and tomorrow you could create something called the Stem Cell Institute for Curative, you know, and say *I* can cure anything. Anybody can do that *any* time that they want to, and there are *tons* of quacks out there...and *that* makes it really hard because as hard as I’m trying to educate them, I have a *quack* who’s also disinforming them, and the media just have *no* ability to tell the difference between, you know, the guy who is the head of neurology at *Yale* who’s now at *Boston* and somebody who’s got a, you know, a certificate that you get with *Box Tops*, and yeah. (Magnus, 2018)

Other reasons why experts described people doubt them included prior bad experiences, belief in one’s ability to understand the needs of a loved one better than an expert’s, misunderstanding and misinterpreting scientific literature, and outright rejection of neurologic death over circulatory death.

I mean, look at *Jahi*, she, they said, everybody said she's dead, she's not dead anymore, so why would we stop treating my loved one, so I think it's done a lot to confuse and really, and I don't know that that's coverage in the way that the specific coverage has happened but just sort of that this case has *gotten* coverage, right, so that's a distinction. I think it's really confused a lot. (Holmes, 2018)

Mistrust of expertise has grown “over the last five years in part because of the Jahi McMath case” (Pope, 2018). This is reflected in the growing number of families that contest brain death diagnoses and the need for tonsillectomies for their children, which ultimately hurts the health of those children. According to Dr. Lakowski (2018), “they’re *curious*, and they’re *scared*, and they want to know is this going to happen to *my* child”:

I probably do three to 500 tonsils a year <laughs> along with the other things I do, but there *hasn't* been a clinic that a parent hasn't asked me about the case and how that's going to, and the *number* of kids whose surgeries have been put *off* because of that has been enormous, and this has been the *worst* impact of the, all of this news articles scared the *shit* out of parents about having their kids properly treated *when* indeed the kids need the treatment. (Lakowski, 2018)

At the end of the day, experts were concerned about a highly complex case like Jahi's ending up as a debate between experts and non-experts. Dr. Holmes (2018) expressed some concern about the case being taken out of the hands of experts and presented to laypeople in a jury, a scenario that “has the potential to *really blow* this whole thing up.” His fears are reflected in Dr. David Tunkel's belief in the need to trust science:

It has to be trusted because you want people to *accept* the concepts that may *improve* their health. You also want people who are in, have the ability to *support* medical science, and then lots of, well, in lots of ways. *Taxpayers* support medical science through the *NIH* and through lots of *things*, and also there's, you want *philanthropists* to be able to have *confidence* that they give *money* to people who are *producing*, you know, *truthful* work that's of benefit to people... (Tunkel, 2018)

4.4 THE EXPERT-JOURNALIST RELATIONSHIP IN THE JAHİ MCMATH CASE

This section presents my findings from a qualitative thematic analysis of the 24 interviews I conducted with the scientific experts who were cited in news coverage of the Jahi McMath case in California and the journalists who included them in their stories. I used this method to answer the following research question:

RQ4: How did experts and journalists feel about communicating with each other in the Jahi McMath case?

My analysis revealed that experts and journalists did not need each other in the same ways. They also did not feel equal levels of satisfaction with the relationship. Despite these disparities, however, both experts and journalists were aware of the fact that they were connected in some way to each other when it came to reporting of Jahi's story.

4.4.1 UNEQUAL NEED OF EACH OTHER

One of the themes that emerged from my conversations with journalists and experts related to their perception of reliance on each other. While both parties expressed

a need for the relationship, journalists overwhelmingly appeared to rely on experts; experts, on the other hand, seemed to diminish the value of their relationships with journalists.

Journalists considered reaching out to experts as part of their job, that is, to inform the public about any given issue. They were able to make contact via different channels, including through the experts' media offices or through a professional organization. Journalists also made direct contact with experts after having read about them elsewhere in other publications or from personal meetings at conferences and lectures.

According to *The Mercury News's* Rick Hurd (2018), "you've *received* the word *from* the experts and now you're passing along that word along." This is what also happened in the coverage of the Jahi McMath case; Daniel Willis (2018), also from *The Mercury News*, believed that "...a lot of what we did is just relayed from doctors information about that." Journalists appeared to rely upon experts for this transmission of information because journalists did not consider themselves to be subject matter experts, especially in the case of Jahi McMath; most of the journalists who wrote about the case that I spoke to did not have a background in science or specialize in science writing. In fact, many of the journalists considered themselves at par with laypeople in their audience as far as knowledge about the intricacies of brain death in Jahi's story. Hurd (2018) "felt like I *don't know* enough about this topic to really have a *dog* in the show, you know, a *dog* in the fight so to speak in terms of what I think."

...as a reporter you've got to take all this really incomplete information and go to outside experts, you know, bioethicists and other clinicians, and then say, you know, what do *you* think, what do you, given this mess of information, this

incomplete information, what do you take from, what, you know, what would you advise, what do you take from this... (Berlinger, 2018)

Therefore, the need that journalists primarily directed toward experts was that for subject matter experts and a desire to be guided by them. This was one of the first things David DeBolt (2018) from *The Mercury News* did when he started covering the Jahi McMath case, finding experts who “held my hand a little bit, who kind of break things down.” Willis (2018) described these experts as “doctors who spend some ungodly amount of time in medical school to learn about this.” Robert Egelko (2018), a reporter with the *San Francisco Chronicle*, considered experts to be a neutral party in the newswriting process, echoing the standard norm of objectivity.

You *need* a neutral *set of eyes*, a pair of eyes and a brain to evaluate what you’re being told, so to put it in perspective, so you’re not just hearing partisan versions on one side or another, which is just somebody out there that said, *here’s* the context, *here’s* how to compare it to past cases, *here’s* what the *law* says, or here’s how the medical industry and the medical profession treats these things...I try to go to *reliable, relatively* neutral and informative experts. I mean, you know, they have *opinions*, but I usually believe I can count on them to tell me here’s what the law is or here’s what standard practice is or here’s what this language that you may not understand means. (Egelko, 2018)

Others who were more familiar with the concept of brain death also attributed their knowledge to having interacted with experts in the past. “We have been long trained,” Henry Lee (2018) of the *San Francisco Chronicle* said, “that once there’s no brain *activity*, that you are considered *dead*, and that any *movements* might be just

reactions of the body not to *stimuli* but to *different* things to *different* reasons.” According to Egelko (2018), “I’m used to seeing neurosurgeons or whoever go in to make the determination that a person is irreversibly brain dead, or maybe that’s a redundancy, simply brain dead, and that’s the end of it.”

Underlying this reliance on expertise is a sense of trust toward experts. “If I get hurt,” Willis (2018) said, “I don’t want my mom treating me. I would much rather go to a hospital <laughs>.” Journalists continued to express this sentiment even after news coverage appeared to challenge the hospital and the idea of expertise itself. Journalists described this seemingly tenuous position in a variety of ways. The *San Francisco Chronicle*’s Landon Brand (2018), for example, said, “I’m not saying that they’ve *changed* my, *changed* my personal views in anyway, but they’ve sort of expanded my horizons.” DeBolt (2018) preferred to describe himself as undecided on the debate at the heart of Jahi’s story, adding however that like many other journalists whom I interviewed, “I...*tend to trust* the medical establishment.”

They don’t just come up with this off the top of their *head*. There’s a *lot* that goes into it. There’s *testing*, there’s *studies*, there’s *peer* review, there’s *double* blind, you know, I, so because of that, I *trust* scientists, you know, especially scientists who publish a paper and publish their results and *show* me, show their *work* essentially...I tend to trust that experts know what they’re doing, and if they’re later proven wrong, they will come back and say so. That’s the way it’s worked for hundreds of years now. (Willis, 2018)

While the experts I interviewed were aware of journalists’ needs, the former were more discerning on whether they spoke to the latter or not. Their attitudes toward being

interviewed varied. Some like Dr. Olivia Evans (2018), an expert in bioethics, did not actively seek media interactions. “If I have something to say, I’ll say it,” she said, “and if not, I’ll tell them to go elsewhere.” Others did not see talking to journalists as part of their job unless of course their job required them to interact with the media. Often their other professional responsibilities – research, teaching, or practice – took precedence over talking to journalists. Some experts, however, viewed their talking to journalists as an extension of their roles as intellectuals, especially given the perception of confusion in the public about brain death and Jahi’s case:

When you’re doing a (inaudible) report or you’re doing a short thing on TV, it’s just like a student asking questions when you’re teaching a class. In fact, it’s not *that* dissimilar. You’re just trying to convey something. When you’re writing an op-ed piece, it’s a way of writing a very *short* piece, but that’s just written for a much broader audience... (Magnus, 2018)

At the same time, bioethicist Magnus (2018) did not feel like he benefited from such interactions in a substantial way. “It’s not clear what the payoff is,” he said, adding that he didn’t get paid for spending time explaining his area of expertise to journalists in interviews. “I’m only going to get *10* words of a quote,” he said, “and it might not even be a great quote.” Experts were also wary of journalists who sought out interviews in order to support their pre-established agenda or who were only able to touch upon the expert’s knowledge in a superficial way. Dr. Goodman (2018), a pediatrician, encountered negative feedback from other physicians after his interview with a journalist:

...I *do* recall that after that story that there was a physician or two, this came out of California as I recall, is that right, *yeah*, who *wrote* me and were *furious* at me.

They were very *angry* that I would engage in a journalist and talk about sort of the state of the evidence of tonsillectomies...

Experts could be motivated to engage with journalists if they represented bigger, more prestigious news publications like *The New Yorker* or the *Wall Street Journal*. Not only were experts attracted to the fact that such publications reach national audiences, but those journalists frequently have the resources to give an in-depth treatment to a story. This attracts experts because interacting with those journalists may make them feel as if they are also learning from the experience.

4.4.2 UNEQUAL LEVELS OF SATISFACTION WITH EACH OTHER

Journalists and experts also expressed varying levels of satisfaction with their interactions with each other. Overall, journalists appeared confident in their ability to communicate with experts; not only did they feel that they could understand what the experts said but that they could also represent those professional opinions accurately in their news writing. This was particularly the case with those journalists who had a scientific background.

...the advantage of having some *background* is that you're not having to figure it out in real time quickly, and that if you *are* familiar with the material, you have some good *follow up* questions because you're not learning it from scratch...

(Krieger, 2018)

Even those journalists who did not have a background in science felt that they could decipher information from experts easily. Kristen Bender (2018), a reporter for the *San Francisco Chronicle*, for example, said that she had never struggled with having to ask experts for clarification. "I have no problem telling a person, I don't understand what

you're saying," she said, "you need to repeat it or you need to say it in a different *way* or you need to explain it further," adding that experts are usually willing to accommodate journalists in whatever way is needed. In fact, such journalists considered their limited exposure to science a strength that allowed them to present themselves as laypeople in front of experts, encouraging experts to speak to them in simple terms for the benefit of the audience.

Well, like when someone starts talking about photosynthesis, you know, I have a *general* idea what it is, but could I explain it to somebody else? *No*, and so I have to ask them to explain it to *me* in such a way that *I* in turn would be able to explain it to, say, like, a fourth grader <laughs> (Jones, 2018)

...a *big* part of being a reporter I found is you kind of have to swallow your pride and admit you don't know anything, and if someone uses a word you *don't* know, you just kind of stop them and say, *hey*, excuse me, I have *no* idea what you just said, can you dumb that down by a *lot*, generally in fancier terms but that's, you know, what I mean, so yeah, I mean, there *was* a lot of *that* early on with a lot of these, a lot of these sources that weren't *really used to* talking to people outside of their field about this. Okay now, step back a little bit and please tell me what you just said but in English <laughs> (Willis, 2018)

Ultimately, all journalists felt confident about the quality of their interactions with experts. Experts, however, did not all feel the same way towards journalists or their reporting abilities. Some experts felt satisfied with their relationship with journalists in the coverage of the Jahi McMath case. Others raised many issues with that relationship,

revealing a certain dissatisfaction with the relationship between the two parties.

According to the health law and bioethics professor Thaddeus Pope (2018), the matter was one of control. “Generally nobody writes it the way that I would write it *myself*,” he said, “so I’m *never* fully satisfied.”

I said much *more* than came *through* in the story, so that’s *always* the frustration of academics talking to journalists, and I’m sure journalists get frustrated <laughs> with talking to academics because they think they’re too long-winded or don’t understand their, the journalist’s *time* pressure or space limits or whatever... (Shultz, 2018)

In contrast to the ease of access that characterized how journalists spoke about their relationship with experts, some experts viewed journalists with a certain degree of mistrust. This feeling arose partly from past poor interactions with journalists, such as being used to support a pre-established press agenda or for a superficial quote. Some experts even talked about being treated rudely by antagonistic journalists and having their comments misconstrued. Dr. Lakowski (2018), a pediatric otolaryngologist, described one journalist who had tried to interview him in the past: “*goodness gracious*, I wouldn’t want him at a party in my house. He was (inaudible) as a bulldog, *that’s* all...*He* was just aggressive and unpleasant.” According to him, journalists “cover the *full* gamut of human character, both *virtuous* and *sinful* and *evil*.” Dr. Tunkel (2018), also a pediatric otolaryngologist, extended his hesitation about talking to journalists to me for this project:

I mean, I’ll tell you quite frankly, when I heard from you, I did at least a rudimentary search and, okay, just to find out a little bit *about* you, and I *also*,

when I get asked to deal with *media*, unless it's very *straightforward*, some of it I'll ask to see the written *proof* just to make sure it's *accurate*, and usually people are willing to do that because email is so *efficient* now...

Interactions in the Jahi McMath case also fueled mistrust of the media for some experts. Dr. Lakowski (2018) described coverage of Jahi's story as "overblown and underinformed" and an example of the media creating "false news" and circulating "false information."

In *our* field, *each* time I see a child and I need to make a decision about operating, I get *paid* for the surgery that I do, and there's *somehow* a incentive for me to operate, but one needs to *resist* that, and in the same way, the *press* needs to resist the urge to make money over doing what's right. <pause> *That's* what I have to say about *this* case. *They* didn't do what's right on this one. They *dramatized* it, and they made it into good, you know, *good* guys, and *bad* guys when there was just a *sick* child who got hurt as a consequence of *known* complications and a *difficult, difficult* anatomy. (Lakowski, 2018)

Some experts felt that journalists were not able to identify relevant experts for their stories. Dr. Tunkel (2018) described expertise as real or perceived. "My hope," he said, "is *real* that they're looking for." The bioethicist Dr. Holmes (2018), however, confessed to feeling "*pushed*" by journalists to offer a medical perspective on the case when his background was bioethics. Magnus (2018) also felt that journalists could not tell the difference between "the guy who is the head of neurology at *Yale* who's now at *Boston* and somebody who's got a, you know, a certificate that you get with *Box Tops*." He attributed such issues to a lack of understanding amongst most journalists about the

elements of science in the case, which he tried to alleviate by spending time educating journalists about the different neurological states like coma, brain death, and vegetative state. He also noticed that many journalists assumed that Terri Schiavo had been brain dead, which was not true. According to him, this was because most modern journalists were generalists in that they covered a variety of stories and that just because they were covering a science story like Jahi's did not mean that they were familiar with the basics of the relevant science. "You should assume that they don't know *anything* of what they're writing about," he said.

...I spent a *lot* of time trying to get to the aha moment, when they said, *aha*, *clinically and legally dead*, now I get it, and it would be this click where they're saying, *oh*, and then they're like, well, then, *why* are they still doing this, *why* are they giving life support on a dead body, and then it's like, okay, *now* you get it... (Magnus, 2018)

Experts also expressed some knowledge about the fact that journalists did not work in isolation and that they are increasingly reporting in teams and under the influence of editors. This knowledge helped Dr. Berlinger (2018), an ethics expert, realize that "the thing *I'm* getting upset about may not reflect something the reporter may have *control* over." Even then, Magnus (2018) felt that some journalists were not able to be purely objective while reporting on the case. In other words, they approached the story based on whether they thought Jahi was alive or not.

...I saw a *lot* of very different narratives with some reporters thinking like this is crazy and really angry at Chris and helped telling *that* story. Other reporters sympathetic to the mother, thinking that this is just *wrong* and this poor woman

and why don't they just let her say that she's *alive*, and you've seen both of those things. I think the New Yorker piece definitely led to a *shift* in coverage in the fact that she's, that somatic survival of the body for so long. (Magnus, 2018)

4.4.3 AWARENESS OF THE RELATIONSHIP WITH EACH OTHER

Despite the differences that journalists and experts expressed in the need for each other and the quality of their relationship, both parties agreed that their interactions as they occurred in the coverage of this case yielded important effects. Both articulated a similar understanding of the role of journalism, that of presenting the facts as they related to every side in a story for the reader. They expressed an appreciation for the role that journalism was supposed to play in a democratic society, often describing news stories as the first draft of history. "You really have to *know your laws*," said *The Mercury News* reporter Hurd (2018), "and *know* what you have the right to *see* and *know* what information is the public's right." Part of this was described by the paediatrician Dr. Goodman (2018) as revealing events "that are important that would otherwise be hidden from *view*, that has, that are important to *people* and should be *part* of the, you know, public debate and discourse."

Some journalists and experts described the journalist as an intermediary between experts and readers. Egelko (2018) from the *San Francisco Chronicle* referred to himself as a "go-between." Dr. Tunkel (2018) described a journalist as a "connector" that according to the ethicist Dr. Berlinger (2018) helps mediate messages she may have for the public "because I'm not going around and talking to every single human being who might be interested in a topic even if it's happening right in their community." At the same time, Krieger (2018) from *The Mercury News* expressed frustration with what she

perceived to be “a huge disconnect” between scientists and her readers, a gap she felt could be closed by the commitment of journalists.

As intermediaries, journalists were not only understood as conveying information but also translating it in a way that made the information both understood and relevant to the readers. In the case of Jahi’s story, this was conceived making the story “meaningful to someone who is just picking up the morning paper at their coffee table or whatever and translating it in a way that is *reflective* of the *facts* and the *science as best as known*” (Holmes, 2018). Not only was this important in building an understanding of and trust in science, but “*ultimately*,” said law expert Dr. Shultz (2018), “*public opinion is important in adopting laws and in supporting or resisting judicial decisions that control things as important as life and death.*”

According to my conversations with journalists and experts, news coverage of Jahi’s story appeared to be in line with the expectations of science reporting as outlined above. In other words, news coverage was determined to have fulfilled the purpose of informing readers about the details of Jahi’s case. DeBolt (2018) from *The Mercury News* described the effects of the news stories as creating a previously unseen “awakening” in the general public about brain death – “the Jahi McMath Effect” – a phenomenon that was confirmed when families in nearby hospitals began to question brain death determinations. Many experts also told me about this movement, including Dr. Holmes who admitted to the case having affected the way he approached similar situations in his professional life. Dr. Tunkel viewed this as a step in the right direction, specifically that of the case having created opportunities for frank conversations between patients and

healthcare providers. “I think it’s actually been a way to *get* in a conversation,” Dr. Holmes (2018) said.

...all medicine is now about shared decision making. It’s not this *paternalistic* thing where the surgeon comes out and tells you what you *need*, and parents that just say yes. Parents usually come in pretty *informed* about the medical condition. They sometimes have had first and second *opinions* before they *see* you, and they do some research *online*, and they talk to their primary care providers. That’s *all* good, okay, because it allows for *two*-way communication, and if, you know, if there’s anything that may come out of a tragedy like this is that it may help people understand that there are *extreme* consequences, thank *God*, very rare but extreme consequences of these decisions that lets us have very forthright communication and conversations. (Tunkel, 2018)

Other experts disagreed about the value of the “Jahi McMath Effect.” Their arguments rested upon the assumption that families of patients like Jahi McMath were withholding beneficial treatment from their loved ones and that their decisions were based on unjustified suspicions about healthcare providers and procedures like tonsillectomy. “They’re *curious*, and they’re *scared*,” said Dr. Lakowski (2018), “and they want to know is this going to happen to *my* child, and what’re you going to tell them.” Pope (2018), a health law and bioethics expert, attributed the reporting of Jahi’s story to causing conflict and mistrust between patients and their healthcare providers:

There’s going to be kids who are going to drown in swimming pools, just to, you know, just to use an example, because it *happens*, right, and then that’s *one* source, that’s *one* way in which kids become brain dead. Some of those parents,

most of those parents are just going to, you know, follow the clinician recommendations, but *some won't*, and that number is higher today than it used to be... (Pope, 2018)

While much of the discussion around the role of a journalist appeared to assume a unidirectional flow of information from experts to readers, my interviews also indicated that coverage affected experts, too. Many experts expressed an awareness of news reporting on topics related to their professional interests. Dr. Shultz (2018), for example, talked about reading news articles where she learned about how patients' families consulted with healthcare providers about when to withdraw mechanical support – “after three days, a week, two weeks” – and about “a lengthy *New Yorker* article by Gary Greenberg about his experiences at an international conference, and the responses of a non-responsive boy who was examined at a medical conference there.” She also credited first learning about the speciality of bioethics in legal studies through newspapers, using news coverage of such articles in her early courses as an instructor.

Some experts kept up with the developments in Jahi's story through its news coverage. “I read about it the way everybody read about it,” said Dr. Tunkel (2018), “in the press or on television.” Many experts brought up a recent *New Yorker* article about the case; bioethicists especially talked about how this specific article was circulated in their professional circles and inspired much discussion. “It was just discussed for weeks,” Dr. Berlinger (2018) said. Dr. Teague, a paediatric neurologist, attributed media coverage of the case to inspiring him to reach out to the family directly. Dr. Evans (2018) was even aware of an upcoming “big expose” scheduled for publication in the *Washington Post* about “the ineffectiveness of the transplantation system.” Pope (2018) admitted to relying

on journalists who covered stories in his area of expertise for help in gaining access to information and resources.

...it *might* have happened I think with one of the San Francisco people is *I'm* doing my own research, right, as a writer, and they might have said something like referenced something like a *document* or something, and I would go to *them* asking *them* for help, like, *oh*, you must *have* this, can I get a copy, so or you talked to so-and-so, did he say anything *else*...

News coverage of the case also drove new scholarly activity. Pope (2018) attributed this to legitimization via media coverage, making brain death a “real *happening, active, live*, you know, *hot* topic” and a more “worthwhile topic of academic inquiry.” This led to “more *talks, more* conferences, *more* journal articles,” ultimately affecting the trajectory of his academic career. For example, the annual meeting of the Association for Healthcare Journalists hosted sessions about the reporting of Jahi’s story. Harvard Medical School, too, recently held a conference on brain death in which one session was entirely dedicated to the Jahi McMath case. “It was interwoven into other presentations as well,” said Dr. Berlinger (2018).

...people were reflecting on the *reporting* about the case, what we know about the case, how the case *confounds* the definition of brain death, and is it *possible* that, and this is *very* much open to, for debate right now, is it *possible* that that was a misdiagnosis in the case, and is it *possible*, there *are* neurologists who will say her diagnosis is something else... (Berlinger, 2018)

Experts also mused on the extreme silencing effects of news stories about Jahi’s case. According to Dr. Lakowski (2018), awareness of the case through the news had

made him self-conscious about his own performance as a pediatric otolaryngologist in cases similar to Jahi's; he confessed to feeling "*terrified* frankly of the press" in such situations. Dr. Shultz (2018) felt that news coverage of the case could even persuade the hospital to "settle the case if they can to prevent more bad publicity and general uproar." Magnus (2018) predicted long-term policy changes at hospitals that could adversely affect the well-being of the families of patients determined to have died due to brain failure:

...we might not give families as much time as we otherwise would have, so when they get the bad news, and they need some time to sort of deal with the grieving before we withdraw (inaudible) support, where I think *before* we might have said to them was to take a few days to a week to get over it, let's give them the time, *now* knowing that they can go to court and get a court injunction that would stop that, I think we're *less* inclined to do that.

4.5 CONCLUSION

As I detailed earlier in this chapter, science news has often been criticized for focusing more on controversies and scares than science "as it happens" as released through publications (Dubeck, Moshier, & Boss, 1988; Farago, 1976; Redfern, 2009). Jahi's story falls squarely in that category – in this case, brain death is communicated through the unique circumstances of a single incident rather than as informational reporting about the scientific developments of brain death as they happen.

This chapter was the second of the findings-based chapters in this dissertation. While the first findings chapter, that is, Chapter Three, presented a framing analysis of coverage of Jahi's story in California's newspapers, this chapter focused on the science

communication aspect of this case. Since the story was so centered on a complex scientific concept like brain death, I wanted to interrogate the aims, strategies and challenges experts in brain death face in my dissertation. The chapter began with an overview of the literature in the area of the communication of science in the media before presenting my findings.

In-depth interviews with 11 experts on brain death formed the basis of the first research question I attempted to answer in this chapter. These experts were drawn from those that had been cited in news articles about Jahi in California. I wanted to know what these experts thought about the way journalists had covered Jahi's story. Their responses were mixed – experts did not agree on the newsworthiness of the story, and they felt that journalists had written about it in a haphazard fashion. Experts also expressed mixed feelings about the effect that the coverage would have on the perception of expertise.

The second part of the chapter shed light on the complex relationships between the experts and the journalists who wrote about Jahi McMath in California. This analysis was based on the 11 expert interviews and the 13 journalist interviews. Both groups of respondents expressed an awareness of the relationship between them as it developed within the confines of Jahi's story, but they expressed an asymmetrical need of each other and an asymmetrical level of satisfaction with the relationship.

These two sets of findings could be connected to each other. The fact that Jahi's story was covered at all indicates that the story was deemed newsworthy by the journalistic establishment, both in California and on a national scale. The fact that not all experts agreed on the news value of the story reflects the mixed relationship that appeared to exist between the experts and the journalists in this case when it comes to

need of each other and satisfaction with each other. This resonates with previous scholarship in this area that reflects some turbulence between scientists and journalists in the communication of science to the public.

Journalists appeared satisfied with their coverage of the story and their interaction with scientists, but scientists differed with the journalists on this point. They considered the coverage haphazard, reflecting prior research on coverage of science topics in the news (Farago, 1976; Kilcullen, 2015). Perhaps this sentiment arose from the fact that the experts did not feel as much need of the journalists as the journalists did of the experts. Some experts spoke about not having any incentive to speak to the media, reflecting Farago's (1976) assertion about scientists having limited support for the public communication of their work. This unequal need for each other may also have caused unequal satisfaction with the relationship with one another as part of the reporting of Jahi's story.

Both journalists and experts were, however, aware of the relationship that exists between them; they were both aware of the bridge-like function that journalists serve in the process of the communication of science (Farago, 1976). Some experts also used science reporting to teach (Farago, 1976; Kriegbaum, 1967). Experts' concerns about the effect that the coverage, less than perfect as they deemed it to be, affected the perception of expertise mirrored similar previously revealed findings of public anxieties about scientists (Nisbet et al., 2002; Weingart, Muhl, & Pansegrau, 2003). The experts I interviewed appeared to be aware of how contemporary science reporting may criticize experts and challenge their authority (Allan, 2009; Peters, 2008). They also expressed the fear of being misquoted in news stories (Kutner & Beresin, 1999). Closely tied to this

fear was their frustration with journalists' limited familiarity with science (Reed & Walker, 2002) and the effect that this had in the creation of expertise where they perceived to be none and the introduction of pseudoscience in the complex discussions at the heart of the story (Dubeck, Moshier, & Boss, 1988; Hansen, 2009).

At the same time, the experts echoed Dunwoody's (2008) assertion that scientists are becoming more adept at interacting with journalists. In addition to being aware of the effect of news coverage on the perception of expertise, they also had insight into how news coverage of certain topics can be used to justify scholarly work and bolster one's professional agenda (Franzen, Weingart, & Rodder, 2012). Others welcomed the discussion that coverage of Jahi's story initiated between patients and healthcare providers, reflecting a departure from the one-way paternalistic model of the public communication of science in favor of more recent patient-centric championed techniques (Brossard & Lewenstein, 2010; Bucchi, 1998; Farago, 1976; Irwin, 2009; Leach, Yates, & Scanlon, 2009; Redfern, 2009). An awareness of these effects, together with concerns about unsatisfactory coverage of brain death, may increase how much experts rely on journalists who write about their areas of expertise.

CHAPTER 5

DISCUSSION

As I write these words, it has been over three years since Sonal first told me about Jahi McMath. Many things have happened in the time since then: I decided to do my dissertation on her story, I interacted with many people who have met her family and are the voices in the news stories about her. Jahi died a second time while in New Jersey and was buried back home in California.

Her story hasn't ended, though.

The McMaths continue to pursue their legal fight. Other cases like hers – the most recent being Payton Summons in Texas – continue to crop up in the news. What these cases have in common is the fact that they all make reference to Jahi, whose name has joined the ranks of others like Karen Ann Quinlan in the universe of the study of brain death.

No human activity occurs in a vacuum, and I cannot forget to mention the zeitgeist within which I worked on this project. The year 2016 was not just the year in which I first heard about Jahi. It was also the year in which the U.S. presidential elections closed with the election of Donald Trump, a candidate whose campaign was based on persistent attacks on the field of journalism and the misinterpretation of scientific research in many fields such as climate change, gun violence, and mental health. These continued into his presidency and strongly affected my day-to-day life as a mass communications doctoral student who not only did research but also taught both research

methods and journalism courses to undergraduate students. I don't think I will ever forget how, while interviewing one expert over the phone for this project, I learned about the mass murder of the Capital Gazette journalists in Annapolis, Maryland, from the CNN website open on my laptop's Internet browser. A few days later, I learned that that newspaper also employed an alumnus of my department, which brought the tragedy even closer to home. Long-term exposure to Trump's reported misogyny also made it difficult for me, a married woman in a doctoral program, to passively listen to one expert who, while now retired from a long academic career, began her career being rejected from a doctoral program in history because she had been married and who was later denied tenure as a law professor because of her gender. This political climate also appeared to affect many of the reporters and experts that I interviewed as was evident from their concerns about the mounting hostility against journalists and the dwindling respect for expertise. It is important that readers view my findings within this turbulent time in American history in which we – myself and my participants – all lived our personal and professional lives.

Finally, I want to mention that no matter whom I interviewed, everyone expressed deep sympathy for Jahi and her family.

This dissertation represents the first attempt to analyze the controversy around Jahi McMath through a study of media discourse. In this chapter, I will present an overall discussion of my findings within the context of extant literature in the areas of science communication, framing theory, critical cultural studies, and brain death. These findings offer insight into the controversy of brain death as it evolved in Jahi's story. Not only do the findings allow the scientific establishment to understand the underlying factors that

elevate this case to a controversy, it will perhaps encourage them to revisit the still evolving nature of brain death so as to accommodate a wide variety of perspectives about life and death. The findings will also be of use to journalists who are tasked with conveying complicated scientific concepts such as (but not limited to) brain death from experts to non-experts and will hopefully allow them insight into what otherwise both conscious and unconscious processes that guide their construction of narratives in the news. I will then outline the limitations of my project and offer suggestions for further research in the area that this project occupies.

5.1 A PANIC ABOUT POWER

In this study, I took a critical cultural approach to examine newspaper coverage of the Jahi McMath controversy in California. My goal was to bring to form “hidden features of the social aspects of scientific practice” (Brossard, 2009, p. 258) - “the complex mixture of ethical and religious, scientific and medical arguments” (Liu & Priest, 2009, p. 705) – by analyzing the media discourse of Jahi’s continuing controversial story. Not only was I interested in the content of this media, which I analyzed using framing theory, but I also wanted to take one step back and understand the processes that gave rise to the media content in the first place. Interviews with the journalists who had composed those news stories as well as with the experts they had quoted provided the data for the science communication component of my project. In other words, framing theory told me what to look for, qualitative methods did the looking, and critical theory told me what it meant.

While the previous two chapters presented the findings for my research questions, my goal in this chapter is to provide second-order interpretations for those findings

(Tracy, 2013). What do these findings mean when taken together across the years since 2013 until today? We know that frames create multiple realities for audiences (Graber, 1989), including both the journalists and scientific experts I spoke to for this project. These framed realities are the result of an unconscious or conscious selection and arrangement of facts from a universe of available narratives; regardless, the final narrative(s) make the world appear normal (Gamson, 1985). This constructed normalcy represents the efforts of the dominant segments of society who use frames as tools to spread their hegemonic ideology (Giannino, 2013; Moscovitz et al., 2018). So, what complex meanings have been created by the way that newspaper journalists wrote about Jahi's story in California, and whose preferred sense of normal do those ideological tools reflect?

Despite prior research that established the dominance of powerful institutions in crafting media messages, particularly in healthcare (Hansen, 2009; Salmon, 1989), I found that the frames used by journalists did not completely reflect that power. It is not unreasonable to assume that if traditional dominant ideologies had been reaffirmed in news stories, the frames would have been grounded in the assumption that the Oakland hospital was in the right and that Jahi had died in 2013. While this narrative was presented by journalists in California, it was countered by another frame that completely contradicted the first's reality. According to this second version of reality, Jahi had not died in 2013 and her family was struggling to keep her alive in the face of a hostile elite institution. The picture of normalcy that was presented by this frame was that hospitals oppressed people like the McMaths in their quest for their individual freedoms. The frame rejected the neurological criteria for death in favor of the cardio-respiratory one.

This was in contrast to the first frame according to which it was normal for hospitals to make decisions about life and death for society at large, which in this case legitimized neurological death. The presence of these contradictory frames and the mutually incompatible realities that they represent suggests a struggle over meaning; in this case, this struggle is between the different factions in the debate, that is, the hospital and the McMath family, calling to mind Kellner's (2011) conceptualization of media culture as a struggle between different social groups. The fact that the other frames highlight uncertainty about the science behind the determination of death and create doubt about it further strengthens the reality perceived by the McMath family, perhaps at the cost of the authority of hospitals, experts, and science as otherwise presented in the frame.

According to my analysis, it appears that not only is the scientific perspective not the dominant one crafted in newspaper coverage of Jahi's story in California, but the whole controversy about how and indeed whether she died in 2013 is presented as one between two parties – a hospital and a patient's family – with equivalent credibility. Newspaper coverage of Jahi's story appears to fall in the same vein as that of other scientific controversies, one of different factions in conflict with each another (Brossard, 2009; Liebler & Bendix, 1996); in this case, it reflects a conflict between generalized rules of science and individual knowledge (Moore & Stilgoe, 2009) and between policy and the individual (Gostin, 2014; Magnus, Wilfond, & Caplan, 2014). Newspaper coverage of Jahi's story in California, therefore, does not reflect the dominance of traditional authority figures as I had been expecting to find. By equating the credibility of scientific experts with that of the McMath family and raising questions about the science behind brain death, coverage of Jahi's story in California newspapers may ultimately weaken the

institutions behind that science, reinforcing the tendency for scientific controversies to degrade public trust in science (Hones, 2001; Von Shomberg, 1993). At the same time, the group that is traditionally considered to be oppressed in the science-public relationship – in this case, the McMath family – emerges as at least as powerful as the experts, perhaps reflecting Weingart’s (2012) assertion that scientific experts do not have the unquestioned credibility that they once had. In the “tension between Christian ideas and secular, rational beliefs” (Walter, 1997, p. 185), the former appears to be holding strong if not overcoming the latter at least in the battleground of the media in this controversy. This was surprising considering how much the journalists I interviewed valued the knowledge of experts and did not in any way seek to criticize them as has become common in modern science reporting (Allan, 2009).

Perhaps this very asymmetrical reliance can explain my conclusion about the unexpected power dynamics between the hospital and the McMaths. As I found during the course of this project, many journalists from various backgrounds worked on Jahi’s story in California; a minority of those journalists had specialist knowledge about brain death. This lack of subject-matter knowledge may have contributed to the journalists going into “neutral transmitter” mode (Dunwoody, 2008, p. 20), presenting the facts of the controversy based on accuracy rather than validity. The journalists interviewed for this project expressed a strong belief in the journalistic practice of objectivity and balance, which also contributed to the creation of a narrative of a valid conflict between experts and lay people. The combination of the lack of knowledge about the science behind brain death, the reliance on experts, and the professional norms of conflict-driven news frames may have also led to journalists quoting people who are considered outside

of the general scientific community as experts, creating an aura of expertise where there may have been none (Peters, 2008). As criticized by the experts I spoke to, this practice legitimized pseudoscience by its inclusion in journalistic discourse, and in the process, hurt the perception of science.

The McMaths also appeared to benefit from the journalists' belief in the social justice function of their profession and its role in checking the problematic exercise of institutions in power (Zelizer, 2008). Many of the journalists and even some of the experts raised the fact that the McMaths were African American; this had given journalists some pause at least about the claims that the McMaths were making given the history of scientists hurting communities of color (Hawkesworth, 2012; Kalish & Reynolds, 1976; Perry, 1990). The fact that news coverage was initiated by the McMaths also alerted the journalists and their supervisors to the possibility of medical maltreatment of the McMath family because of their racial and economic identities. This may have spurred journalists to empower the traditionally oppressed by portraying their reality and its challenge to neurological death on equal footing with the reality of the institutions that were being contested.

While the journalists sought to translate the complexities of brain death from the experts to the general public, the financial difficulties that the news industry has been going through also transformed their work (Dearing, 1995). Some of this transformation was unintentional and even resisted by some of the journalists who did not see news value in Jahi's story. Their supervisors, as my data showed, felt otherwise and covered the story anyway because they knew its potential to attract readers and ultimately generate revenue. This negotiation of newsworthiness between journalists and the

business-tuned members of their organizations has been documented by prior research as well (Dunwoody, 2008; Farago, 1976). In the end, editorial veto power permitted the news stories about Jahi to be framed the way that they ultimately were as an inadvertent challenge to science. This, however, was not the intention as it appeared to be motivated by profit, at least as perceived by the journalists I interviewed.

Where did this leave the scientific experts, then? Their reactions were mixed with some decrying the misrepresentation of science in news stories about Jahi and others welcoming the opportunity for public conversation and education about brain death. The latter represent modern approaches in the public communication of science (Brossard & Lewenstein, 2010; Bucchi, 1998; Farago, 1976; Irwin, 2009; Leach, Yates, & Scanlon, 2009; Redfern, 2009). Experts did express a feeling of distance from – and even terror of – the media and the general public as has been articulated in the past (Bucchi, 1998; Dunwoody, 2008; Farago, 1976), but some also exhibited a more recently developed media savviness and understanding of the place of journalism in the communication of science, especially in the role that media coverage of various scientific issues may have on their own careers (Dunwoody, 2008; Franzen, Weingart, & Rodder, 2012). News coverage of Jahi's story, even as it was deemed to have issues with accuracy (Farago, 1976; Kilcullen, 2015), educated the experts themselves about the details of the controversy, inspired academic discussions from informal conversations with colleagues to the level of conferences at Harvard, and directed the experts to revisit and further explore areas of debate as they had been highlighted in news stories about various elements in Jahi's story and brain death. Experts were also motivated by problem areas in the reporting of topics like brain death to develop a closer and more nuanced relationship

with journalists. In this way, news stories about Jahi in California assuaged some of the difficulties that journalists and experts have frequently experienced while communicating with each other. In the end, this represented an attempt of experts to swing back the power pendulum towards the traditionally dominant institutions of science, an attempt motivated by a narrative in Californian newspapers that was increasingly challenging scientific expertise with lay perspectives. These concerns appeared to be on everyone's mind, including my own, as we all learn to find our way through a larger public anti-science and anti-journalistic discourse that is reverberating across the country and around the world as we speak. My findings reveal these tensions, adding to the body of scholarly work on the public communication of science, death, and controversy studies.

Specifically, they reaffirm the criticism that has been directed towards scientific expertise (Allan, 2009; Weingart, 2012) but also serve as a reminder of the relationship between science and the media in a democracy (Crawford, Hurd, & Weller, 1996; Franzen, Weingart, & Rödder, 2012; Krieghbaum, 1967; Ransohoff & Ransohoff, 2001; Weingart, 2012), energizing recent calls for the two-way communication of science that considers context, extant local knowledge, and public dialogue (Brossard & Lewenstein, 2010; Bucchi, 1998; Farago, 1976; Irwin, 2009; Leach, Yates, & Scanlon, 2009; Redfern, 2009).

5.2 APPLICATION OF FINDINGS

This project performed a deep study of a specific situation while drawing upon the extant body of work in the areas of framing theory, brain death, science communication, and controversy studies. The previous section discussed the findings of this project from the perspective of basic research, that is, for the purpose of scientific

knowledge. In this section, I seek to extend my findings into the realm of applied research by offering practical recommendations. I derive these suggestions from what my research revealed about the belief of both journalists and experts in journalism as a crucial intermediary in the communication of science. My recommendations, therefore, are intended to ameliorate the imbalance in need of and satisfaction with this relationship between journalists and experts as was revealed in this project.

I encourage scientific experts and journalists to learn more about each other's professional worlds. This mutual education can be achieved in many ways. Experts can undergo training so as to understand the landscape of the media industry. This would help them understand the conditions within which media professionals such as journalists and editors have to perform and what they need from experts in order to do their jobs. Journalists can also gain exposure to the world of scientific expertise by seeking out science courses early.

While the suggestions I made above can be initiated by and pursued at the level of the individual, there are certain structural acts that may make it easier for journalists and experts to reach their goals. Scientists have not been traditionally rewarded in their careers for their media-related activity; offering to recognize such work as a condition for advancement in one's career may encourage experts to need journalists more than what my findings indicated. Media training can also be incorporated across all programs at colleges and universities where scientific experts are trained in the foundations of their chosen fields; in this way, the principles of interacting with the media would be inculcated in them at the earliest stages of their careers. Similar structural initiatives can also be undertaken for journalists. For example, journalism programs can offer to help

students train specifically in science journalism. This can range from offering a single course in the subject all the way to an entire degree dedicated to training science journalists. Many journalists learn about framing theory in journalism school, but not all journalists have such degrees, so it is important that the basics of framing theory and weight-of-evidence reporting and their implications on the journalistic principle of objectivity as outlined in this project are discussed in the workplace as well as a form of continuing education. Institutions of higher education can also offer platforms for the discussion of science journalism where experts and journalists can both congregate, ideally on a regular basis. Further, media organizations can seek to hire and retain dedicated science journalists whose numbers were described as falling by many of the people I interviewed for this project. As what appears to be a dwindling population, science journalists may also benefit from the creation of unions that advocate for their need in democratic society.

5.3 LIMITATIONS

As is the case with every research project, my dissertation is not without limitations. Jahi's story lasted many years, and this long timespan affected how much my interviewees were able to recall about the case. Also, the story was covered by more than one journalist, and many of those journalists had not stayed with the story for its entire duration. They, therefore, were only able to offer me their perspective as it related to certain periods in the story's timeline.

I also was not able to speak to every single journalist and expert in my sampling frames. Of the 37 journalists, I was only able to interview 13, and of the 26 experts, I was

only able to interview 11. My findings, therefore, could have been different had I ended up speaking with a different selection of interviewees.

Of the experts that I did interview, only a handful shared the McMath family's perspective. My sampling frame of experts included more experts who "represented" the family; perhaps if more had agreed to let me interview them, my findings may have been different.

5.4 FUTURE DIRECTIONS FOR RESEARCH

As I've detailed earlier in this project, critical cultural studies projects in the field of mass communication focus on any combination of the following: production of media, media content, and audience reception of media. In this dissertation, I touched upon all of these components, but each still offers room for further study.

According to many of my participants, much of the media coverage was driven by – and initiated by – the McMath family and its lawyer. I, however, did not interview them for this study, a shortcoming that was beyond the scope of this study and can be addressed in future studies. Including their perspective of news coverage of Jahi's story may prove to be valuable for a deeper understanding of the dynamics of the news production process in the case of this specific story. My findings revealed editors to have played an important role in the production of news stories about Jahi; future studies would benefit from including editors in analyses of news production. Findings also included attempts by interest groups to intervene in the production of news and, in this case, the communication of science. This could also serve as another avenue of study.

While Jahi is now considered dead by both the hospital and her family, the controversy over when and how she died continues to drive the legal battle between the

two parties involved in the case. My dissertation only analyzed news stories about Jahi's story until February 2018; journalists, however, kept covering the case beyond that date. Future studies, therefore, can analyze a more current and comprehensive sample of news stories. I also only focused on print news in California. Future studies could seek to include a non-print perspective perhaps by including broadcast and digital news sources. Stories could be sought from beyond California to include more states or to focus on national and even international news. Analysis can be expanded to other forms of media as well, such as social media, magazines, and images.

The audience reception component of my project represented the perspectives of journalists and experts. Future studies could probe these populations in more detail to understand how they resist, accept, or negotiate the media narratives of the Jahi McMath case. Similar studies can also be conducted for other groups of people who form the audience for Jahi's story. These could include the general audience of the specific media under study or more specific individuals like judges, jury members, and politicians.

I want to make special mention of the Facebook page run by the McMath family. Critical cultural studies are concerned with the study of power and often includes the perspectives of those with a limited reserve. The McMath family's Facebook page offers the chance to study an alternative perspective of Jahi's story and especially one that represents the lay person who is typically understood to not hold as much power in the production of journalistic discourse as compared to the elites of society. Many elements of the page can be studied, such as the posts, many of which contain images and videos that can be further subject to visual analyses. With an active community of followers who number in the thousands, the page garners comments from followers in response to the

posts made by the family; these can be further mined – perhaps with an initial textual analysis and then with in-depth interviews – to gain insight into the space that the page occupies in the lives of its followers.

I also recommend a more thorough analysis of this specific case as it relates to methodology. As I described in detail earlier in this project, I selected a qualitative approach so as to explore this understudied case in detail. Critical cultural studies projects, however, are not limited to qualitative research, and I recommend the use of quantitative research methods such as content analysis, experiments, and surveys in order to answer other questions – especially those related to media effects – in the study of media coverage of Jahi's story. These can also be used to explore the various areas of study that I've suggested above in this section.

The conclusion of this specific project should not be equated with the conclusion of media research of brain death. Jahi McMath is not the only name tied to brain death controversy; there are many other cases that have arisen in this context in the past, and some, as has been indicated by the people I interviewed for this project, will continue to arise in the future. These cases, both in the past and in the future, merit research not only of the strain performed in this dissertation but also of the variety suggested in this section itself.

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APPENDIX A – DEFINITIONS OF KEY TERMINOLOGY

Death: a state of being in which a person experiences irreversible loss of all functions of the entire brain or the irreversible loss of all circulatory and respiratory function. The former refers to the neurological criteria for death, while the latter refers to the cardiovascular criteria. This definition of death is tied to the cessation of self-preservation, which is the fundamental characteristic and vital sign of a living organism.

Brain Death: a term used to refer to dying according to the neurological criteria for death. “Total brain failure” is the technical term for this condition, and it includes coma or unresponsiveness, absence of brainstem reflexes, and apnea. This definition is based on a whole-brain approach.

Frames: storytelling techniques that are, consciously or otherwise, used to build a narrative from a universe of all possible constructions of an event. Particularly in journalism, frames can be detected by an analysis of importance judgements; agency, or the answer to the question; identification with potential victims; categorization, or the choice of labels for the incidents; and generalizations to a broader national context. These can include images, stereotypes, metaphors, actors, and messages.

Critical cultural studies: a tradition within social science research that is based on a sensitization to the presence of dominant ideologies within communication texts. The three components of a critical cultural project is production and political economy, textual analysis, and audience reception and use of media culture. The goal of such research is to empower subordinate groups and transform society.

APPENDIX B – INTERVIEW INVITATION EMAIL FOR JOURNALISTS

Subject: interview request

Dear [name],

My name is Khadija Ejaz, and I am a doctoral candidate at the University of South Carolina. I am currently working on my dissertation which examines how the Jahi McMath case has been covered in newspapers in California. You have written at least one article about this case, so I would like to interview you for my dissertation. Please let me know if you will be willing to speak with me; the interview will take around 30 minutes and will be conducted over the phone or through Skype. I will follow up in the next week to find a time that works with your schedule.

I look forward to hearing from you – thank you!

Khadija Ejaz

Doctoral candidate

School of Journalism and Mass Communications

University of South Carolina, Columbia

APPENDIX C – INTERVIEW INVITATION EMAIL FOR EXPERTS

Subject: interview request

Dear [name],

My name is Khadija Ejaz, and I am a doctoral candidate at the University of South Carolina. I am currently working on my dissertation which examines how the Jahi McMath case has been covered in newspapers in California. You have been cited as an expert source in at least one article about this story, so I would like to interview you for my research project. Please let me know if you will be willing to speak with me; the interview will take around 30 minutes and will be conducted over the phone or through Skype. I will follow up in the next week to find a time that works with your schedule.

I look forward to hearing from you – thank you!

Khadija Ejaz

Doctoral candidate

School of Journalism and Mass Communications

University of South Carolina, Columbia

APPENDIX D – INTERVIEW INFORMATION FOR JOURNALISTS

Thank you for agreeing to let me interview you for this research project. I am a doctoral student at the Department of Journalism and Mass Communications at the University of South Carolina (USC), and I am studying newspaper coverage of the Jahi McMath brain death case for my dissertation. I am reaching out to you because you have written at least one news article about this story. I am particularly interested in your experiences as a journalist covering this case.

The interview will be conducted over the phone or on Skype and will take around 30 minutes. Unless you give me permission to use your name, your name will not appear in any report resulting from this study; anonymous quotations may also be used in the report. I will ask you for permission to use your name at the end of the interview, and you may decline and choose to withhold your name.

There are no known or anticipated risks to you as a participant in this study. Participation in this study is voluntary. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences by informing the researcher. With your permission, the interview will be tape-recorded to facilitate collection of information and later transcribed for analysis. Shortly after the interview has been completed, I will send you a copy of the transcript to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish.

I am very excited about the chance to interview you about your experiences as a journalist covering Jahi McMath's story. I very much look forward to speaking with you and thank you in advance for your help with my dissertation. Please contact me at kejaz@email.sc.edu or 314-413-8524 if you have any questions.

APPENDIX E – INTERVIEW INFORMATION FOR EXPERTS

Thank you for agreeing to let me interview you for this research project. I am a doctoral student at the Department of Journalism and Mass Communications at the University of South Carolina (USC), and I am studying newspaper coverage of the Jahi McMath brain death case for my dissertation. I am reaching out to you because you have expertise on brain death and have been cited as a source in news coverage about the Jahi McMath case. I am particularly interested in your experience talking about brain death to lay people such as journalists.

The interview will be conducted over the phone or on Skype and will take around 30 minutes. Unless you give me permission to use your name, your name will not appear in any report resulting from this study; anonymous quotations may also be used in the report. I will ask you for permission to use your name at the end of the interview, and you may decline and choose to withhold your name.

There are no known or anticipated risks to you as a participant in this study. Participation in this study is voluntary. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences by informing the researcher. With your permission, the interview will be tape-recorded to facilitate collection of information and later transcribed for analysis. Shortly after the interview has been completed, I will send you a

copy of the transcript to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish.

I am very excited about the chance to interview you about your perspective of brain death and the Jahi McMath case. I very much look forward to speaking with you and thank you in advance for your help with my dissertation. Please contact me at kejaz@email.sc.edu or 314-413-8524 if you have any questions.

APPENDIX F – INTERVIEW GUIDE FOR JOURNALISTS

Thank you for agreeing to let me interview you. My name is Khadija Ejaz, and I am a doctoral candidate at the University of South Carolina. My overall goal is to understand what your experiences have been like while covering the Jahi McMath case. I am asking you because you are a journalist who has written at least one news story about the case.

However, I want to remind you that participating in this interview is strictly voluntary. If you are okay with moving forward, I would like to get your consent to record this conversation on tape. This is only for the purpose of the research. Only I will listen to the tape. No names or personal information will be used in the report unless you give me permission to do so at the end of the interview. Please say “yes” if I have your consent to begin the interview. [start recording]

So, tell me about yourself.

1. What inspired you to become a journalist?
2. What kind of stories do you typically cover?

Let’s now start talking about the Jahi McMath case.

3. How did you first hear about the case?
4. Why do you think this case is newsworthy and has persisted in the news?

5. How familiar were you with brain death, personally and professionally, before covering this case?
6. What do you think is the general public's knowledge about brain death?
7. How did you choose the angle for this story?
8. What challenges did you face while covering this story?
9. What was it like talking to the experts on brain death for this case?
10. What sort of feedback have you received on your coverage of this case?
11. What do you think your role as a journalist has been in this case?
12. How do you think news coverage of this case has impacted the community?
13. How did this case affect the way you feel or think about brain death?
14. How do you see this case evolving in the future?

We are now toward the end of the interview. I just have a few closing questions.

15. Is there anything else you would like to add that you think I should know but haven't asked?
16. Can you recommend another journalist whom I can interview for this project?
17. Do you mind if I use your name in my report?

Alright, well, let me be the first to say thank you for your honest opinions – you were tremendously helpful at this very early but very important stage. Your input from today will help me better understand how news is constructed.

Again, thank you very much for your participation today.

APPENDIX G – INTERVIEW GUIDE FOR EXPERTS

Thank you for agreeing to let me interview you. My name is Khadija Ejaz, and I am a doctoral candidate at the University of South Carolina. My overall goal is to understand your perspective of media coverage of the Jahi McMath case. I am asking you because you have some expertise in the area of brain death and have been cited in newspaper articles in California as an expert.

However, I want to remind you that participating in this interview is strictly voluntary. If you are okay with moving forward, I would like to get your consent to record this conversation on tape. This is only for the purpose of the research. Only I will listen to the tape. No names or personal information will be used in the report unless you give me permission to do so at the end of the interview. Please say “yes” if I have your consent to begin the interview. [start recording]

So, tell me about yourself.

1. How did you arrive at your line of work?
2. What do you think is your role as a scientific expert?
3. How do you think lay people perceive scientific experts such as yourself?
4. What is your understanding of brain death?
5. What do you think is the general public's knowledge about brain death?

Let's now start talking about the Jahi McMath case.

6. Why do you think the case has become so controversial?
7. What do you think about news coverage of this case?
8. What do you think is the role of a journalist?
9. Can you tell me about how you became a source in this case?
10. What has your experience interacting with journalists in this case been like?
11. How do you see this case evolving in the future?
12. How do you wish to see this case evolve in the future?
13. How do you think news coverage of this case has impacted the community?
14. How has this case affected you personally?

We are now toward the end of the interview. I just have a few closing questions.

15. Is there anything else you would like to add that you think I should know but haven't asked?
16. Do you think there are other experts on brain death that I can talk to?
17. Do you mind if I use your name in my report?

Alright, well, let me be the first to say thank you for your honest opinions – you were tremendously helpful at this very early but very important stage. Your input from today will help me better understand how news is constructed.

Again, thank you very much for your participation today.

APPENDIX H –LIST OF JOURNALIST INTERVIEWEES

Table H.1 List of journalist interviewees

Name/Pseudonym	Newspaper	Interview Details
Bob Egelko	<i>San Francisco Chronicle</i>	Sunday, June 10, 3 p.m. EST
Carolyn Jones	<i>San Francisco Chronicle</i>	Wednesday, June 13, 4 p.m. EST
Danny Willis	<i>The Mercury News</i>	Wednesday, June 20, 4 p.m. EST
David DeBolt	<i>The Mercury News</i>	Monday, June 11, 2 p.m. EST
Doug Oakley	<i>The Mercury News</i>	Sunday, June 10, 11 a.m. EST
Henry K. Lee	<i>San Francisco Chronicle</i>	Monday, June 18, 7:30 p.m. EST
Julia Prodis Sulek	<i>The Mercury News</i>	Monday, June 11, 3:30 p.m. EST
Kristin J. Bender	<i>The Mercury News</i>	Thursday, June 13, 3 p.m. EST
Landon Brand		Monday, June 11, 7 p.m. EST
Lisa M. Krieger	<i>The Mercury News</i>	Thursday, June 21, 1 p.m. EST
Peter Fimrite	<i>San Francisco Chronicle</i>	Wednesday, June 20, 6 p.m. EST
Rick Hurd	<i>The Mercury News</i>	Tuesday, June 19, 4 p.m. EST
Victoria Colliver	<i>San Francisco Chronicle</i>	Thursday, June 21, 12 p.m. EST

APPENDIX I –LIST OF EXPERT INTERVIEWEES

Table I.1 List of expert interviewees

Name/Pseudonym	Expertise	Interview Details
Benjamin Teague	Pediatric neurology	Friday, June 29, 1 p.m. EST
David Faigman	Law	Thursday, July 12, 1 p.m. EST
David Goodman	Pediatrics	Thursday, July 18, 1:30 p.m. EST
David Magnus	Biomedical ethics, pediatrics	Monday, July 9, 1 p.m. EST
David Tunkel	Pediatric otolaryngology	Monday, June 25, 8 p.m. EST
Marjorie Shultz	Law	Thursday, June 29, 4 p.m. EST
Nancy Berlinger	Ethics	Monday, June 25, 4 p.m. EST
Olivia Evans	Bioethics	Friday, July 20, 12 p.m. EST
Quinn Lakowski	Pediatric otolaryngology	Thursday, June 29, 7 p.m. EST
Ryan Holmes	Bioethics	Wednesday, June 27, 1 p.m. EST
Thaddeus Pope	Law	Monday, July 2, 1 p.m. EST

APPENDIX J –CATEGORIES AND CODES

Table J.1 Categories and codes for RQ1 that examined the frames present in news coverage of the Jahi McMath case

Category	Code
Uncertainty about death	Starts physical, then using scientific and legal language, What is death? (heart or brain), Kinds of death: legal, medical, tactile, Types of death (legal, medical, religious, familial), What is death (cellular, physical, visible), Who defines death? (power), Who died/is alive? Jahi or her body?, Scientists against scientists, Families left out of health determination - > paternalistic, Child's right? Parents determine, Religion, Religious language at first, replaced by legal language, Maintenance or treatment?, Other conditions (coma, vegetative, terminal = end of life) same/different?

Legal exploitation	“the body”, Purposeful deception by lawyer, Doctors are supportive
A conspiracy	Siding with family for sure, Not technically dead, Challenging doctor’s standards, Medical/legal rejected, Evidence yet story continues, Disability??, Sleeping (not dead), “brain” dead (declared “brain dead”), Brain dead = not fully dead?, As if she’s alive (name, tense present, not “deceased person”, etc.), “life support”, Using Jahi’s name, Jahi is dead but given a voice via direct quotes, Description of life (breath, warm, heart), Time running out?, Religious words, Religion versus science, Religion as a civil force (what about the religion of the doctors) against the secular institutions?, Community/support, Becoming part of institutions and networks, Ground breaking , Pro-life movement?, Civil rights, Freedom of religion, Other cases

Blame the science	Distrust of hospital/authorities, Doesn't seem to believe hospital, Hospital is not very forthcoming, System is the problem, Conspiracy against Jahi, Malpractice, "seemed fine", Fighting official language, David and Goliath, Maternal figures (motherhood), Female puberty, Degradation of female body, Saving the female body, Femininity, Family sources, More family than scientists
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Table J.2 Categories and codes for RQ2 that explored the factors that influenced the framing of the Jahi McMath case

Category	Code (Journalist Interviews)	Code (Expert Interviews)
Multiple journalists worked on the story	duration, news development, teamwork, journalist knowledge, ownership, confusion, other reporters	bigger papers, duration, journalist knowledge, lacking depth, story development, terminology, time crunch
The nature of conflict	court case, sides, objective, access, expert debate,	challenge experts, degradation of experts,

	inform, story initiation, line of death	drama, framing, power, sides
Financial difficulties in the news business	editors, industry, doubt	editor
Outside influences	interest groups, skepticism, religion, other cases	religion, control, guided interaction, influencing journalists, lawyer, source conflict
Suspensions of racial oppression	race, challenging experts, mistrust, power, routine procedure, child, compassion, justice	children, location, race
The perception of unresolved science	line of death, rely on experts	expert debate, experts rely on experts, confusing concepts, rely on expertise, confused journalists, routine, newsworthy, unusual, not unusual, not routine

Table J.3 Categories and codes for RQ3 that outlined the experts' opinion of news coverage of Jahi McMath

Category	Code
Disagreement about newsworthiness of the story	newsworthy, children, duration, location, race, religion, routine, unusual, not routine, not unusual
Perception of coverage as haphazard	mistrust of media, control, bigger papers, confused journalists, confusing concept, journalist knowledge, lacking depth, mixed coverage, drama, terminology, story development, expert debate
Thoughts about the impact of the coverage on the perception of expertise	challenge experts, degradation of expertise, power, what is an expert, trust in science, effect on practice, personal effects, science journalism, effect on patients, framing

Table J.4 Categories and codes for RQ4 that examine the interaction between experts and journalists in the Jahi McMath case

Category	Code (Journalist Interviews)	Code (Expert Interviews)
Unequal need of each other	choice, confusion, doubt, expert debate, inform, interest groups, journalist knowledge, line of death, other cases, rely on experts, scientific controversies, uncertainty, objectivity, sides	bigger papers, confused journalists, confusing concept, expert debate, no incentive, personal media practices, rely on expertise, science journalism, terminology
Unequal levels of satisfaction with each other	how experts talk, story structure, challenging experts, degradation of expertise, frames, justice, power	control, drama, editor, framing, good experience with media, influencing journalists, journalist knowledge, lacking depth, lawyer, talking to reporters, time crunch, challenge experts, degradation of expertise, mistrust of media, mixed coverage, past bad experiences,

		power, press agenda, what is an expert
Awareness of the relationship with each other	effect on families, role of a journalist, science journalism, simplify	effect on patient, effect on practice, effect of journalism, how scientists learn, inform, personal effects, role of journalist, simplicity, trust in science