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**CHOOSING DEATH, SHAPING DEATH:
ASSUMPTIONS ABOUT DISABILITIES, RACE, AND
DEATH**

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Introduction

This article considers two legal cases and the stories that developed around them. Both the cases and their stories involved issues of significance to the larger society – death and bias. Each concern has occasioned confusion and debate in its own right. When these issues are combined, confusion and debate are intensified. This Article examines the complicated interplay between bias and decisions about death and dying in the U.S. health care system. Further, it reviews intersecting claims about the importance, respectively, of autonomy and community in resolving disputes about the topics of death and dying.

Litigation can be lost or won on the basis of the underlying narrative reported to a court. When that narrative involves matters of interest to the public (as the two cases examined in this article do), it attracts the attention of public media. Media often embellishes upon legal narratives, offering stories that carry public messages. This article focuses on two such stories – that of Elizabeth Bouvia¹ who sought the right to die with hospital assistance in the 1980s, and that of Jahi McMath,² for whom a tonsillectomy, performed in 2013, led to a brain death diagnosis, and whose family refused to accept that diagnosis. These stories were separated in time by over three decades. Yet, each bears important similarities with one another—each involved bias. In the case of Bouvia, born with cerebral palsy, that bias reflected presumptions about people with disabilities.³ And in the case of McMath, an African American adolescent, bias reflected presumptions about race.⁴ Moreover, both Bouvia and McMath (or more accurately, perhaps, McMath’s family) attracted media attention, further exacerbated when both cases were selected for review by courts in California.⁵

¹ *Bouvia v. Superior Ct.*, 179 Cal. App. 3d 1127, 225 Cal. Rptr. 297 (Ct. App. 1986).

² *McMath v. California*, No. 15-CV-06042-HSG, 2016 WL 7188019 (N.D. Cal. Dec. 12, 2016).

³ *See generally Bouvia*, 179 Cal. App. 3d 1127.

⁴ *See generally McMath*, 2016 WL 7188019.

⁵ *McMath*, 2016 WL 7188019, at *1; *Bouvia*, 179 Cal. App. 3d 1127.

The next part of this article introduces the complicated array of issues occasioned by Elizabeth Bouvia and Jahi McMath's respective legal cases, and it begins to present the encompassing social stories of both Bouvia and McMath. Part III then reviews Bouvia's legal cases and her story in detail, focusing first, in Section A, on the court cases, and then, in Section B, on Bouvia's personal story. Part IV then reviews the legal cases involving Jahi McMath and public stories about her and her family. Section A of Part IV reviews relevant legal cases. Section B focuses on the notion of brain death. It aims to suggest the parameters and complex implications of a brain death diagnosis. Section C examines Jahi's personal and family stories. Part V reflects on the ideological context within which each case and its encompassing story developed the presentation of those stories in public media and the shifts in the public lenses through which each case was viewed by the larger society.

I. What Was at Stake: Death, Dying, Personhood, and Bias

Both the story of Bouvia and that of McMath frame the potential impact that bias and prejudice have on cases involving death and dying. Each reveals the significance that a party's personal and familial stories provide for the public's understanding of, and responses to, legal proceedings. For example, in Elizabeth Bouvia's story – a young woman sought the right to die because, as she framed the case, she could not live with her physical disabilities.⁶ However, once granted the right to die, Bouvia decided, instead, to live.⁷ In Jahi McMath's story, a black adolescent's family resisted the determinations of doctors and judges, who had ultimately concluded that the girl was brain dead.⁸ As a result of the family's efforts, the girl received ventilatory support and, eventually, nutritional support. Whether Jahi was brain dead or not depended on the lens through which one examines the nuances of brain death diagnoses.⁹

⁶ See *Bouvia*, 179 Cal. App.3d 1127.

⁷ See *id.*

⁸ See *McMath*, 2016 WL 7188019 at *4.

⁹ See *id.* at *4.

The specifics of each case differ significantly from one another. Bouvia wanted to die;¹⁰ McMath's family wanted her to live.¹¹ Bouvia lived with other people (in hospital facilities) but was not interested in communal engagement.¹² She depended on claims of privacy and autonomy in her pleas to public media and in court cases.¹³ In comparison, McMath's pro-active, committed family supported her, working together through each stage of the quest to keep McMath on life-sustaining care.¹⁴ Each story suggests the role underlying biases in judicial and medical assumptions about personhood and, correlatively, in understandings of death and dying.¹⁵ More specifically, each story shows the role bias and prejudice play in limiting healthcare options and in guiding judicial responses to disputed choices about death and dying.¹⁶ Further, media reports on the issues and people involved in each case reached broad audiences and affected the national debate surrounding death and dying.¹⁷

Both stories depended on narratives about young females: in one case a young woman, in the other, an adolescent in need of rescue from medicine and/or law. Bouvia's rescue story focused on Elizabeth, herself – a woman in her twenties, presumed to be seeking relief from disabilities and from a medical system that insisted on treating her despite her wish to starve to death.¹⁸ McMath's rescue story focused on Jahi, whose family members insisted to clinicians, to state judges, and to federal judges that the girl was not dead. Jahi's family prevailed through unrelenting insistence in having Jahi's life-

¹⁰ See *Bouvia*, 179 Cal. App.3d 1127.

¹¹ See *McMath*, 2016 WL 7188019.

¹² See *Bouvia*, 179 Cal. App.3d 1127.

¹³ See *id.*

¹⁴ See *McMath*, 2016 WL 7188019.

¹⁵ See *id.*

¹⁶ Importantly, that guidance is often not conscious; see, e.g., Mahzarin R. Banaji, *Blindspot: Hidden Biases of Good People* (2016).

¹⁷ Bouvia's story occurred before public media relied on the internet, and thus, almost certainly reached a smaller audience than did McMath's story. A search in Lexis+ (July 21, 2021) identified 555 news stories and 144 legal articles (for the search Elizabeth /3 Bouvia AND (death OR dying)); A Lexis+ search (July 15, 2018) for "Jahi McMath" AND brain /5 (dead OR death) identified over 2,000 news stories and over 42 articles in "Secondary Materials" that mentioned or discussed Jahi McMath's story.

¹⁸ See *Bouvia*, 179 Cal. App.3d 1127.

support sustained until she succumbed to a cardio-pulmonary death in 2018, over four years after she was declared brain dead.¹⁹

Although each case reflects biases,²⁰ the implications of those biases and the frameworks within which they operated differ between the two stories. A California appellate court granted Elizabeth Bouvia the right to be free from feeding through a nasogastric tube and to remain in a public hospital.²¹ The operative paradigm employed by the court that granted Elizabeth's request was that of autonomous individuality. The California appellate court that entertained the case contrasted with the state trial court which had reviewed an earlier, though similar, petition submitted by Bouvia.²² The trial court denied Elizabeth the right to starve to death in a public hospital.²³ The appellate court (in a separate action brought three years later) assumed that Elizabeth's choice made preeminent sense.²⁴ That assumption was based on the court's perspective regarding Elizabeth's everyday life. The court saw her as devastatingly limited in her life and it saw her options in life as consistently grim. In the court's view, Elizabeth's physical limitations severely restricted her opportunities to thrive and definitively precluded a full and desirable life in the present and the future.²⁵ Thus, the court concluded that Elizabeth's preference for death over life was entirely reasonable.²⁶

In contrast, the case of Jahi McMath, the adolescent girl declared brain dead but whose family insisted she was not dead, reflected the force of communal activism.²⁷ Jahi's autonomous individuality was not invoked by the courts that considered her situation. In part, this reflects Jahi's age; she was a child in the eyes of the law. It also

¹⁹ *See id.*

²⁰ *See id.*

²¹ *See id.*

²² *See* John H. Hews, *Bouvia v. Riverside, Trial Court Decision In Bouvia I*, 1 Issues L. & MED. 485 (1986); John H. Hews, *Bouvia v. Riverside, Trial Court Decision In Bouvia II*, 1 Issues L. & MED. 493 (1986).

²³ *See id.* at 490.

²⁴ *See id.* at 1145 (The court committed itself to providing a justification for Bouvia's decision).

²⁵ *See* Paul K. Longmore, *Elizabeth Bouvia, Assisted Suicide and Social Prejudice*, 3 Issues L. & MED. 167 (1987) [hereinafter Longmore, *Assisted Suicide*].

²⁶ *See Bouvia*, 179 Cal. App. at 1145.

²⁷ *See id.*

reflects Jahi's inability to have made medical decisions because she had lost – depending on perspective – all or much of her pre-surgical brain function. Even more, Jahi's family members, who resisted the brain death diagnosis given to the girl, presented themselves as a cohesive and competent community. The familial community was reinforced by active support from church groups and friends of Jahi's family members.

Legal proceedings in Jahi McMath's case do not reflect bias as transparently as do proceedings in the case of Elizabeth Bouvia. However, the family, which never succeeded in their efforts to have the courts order a revision of Jahi's California death certificate achieved a practical victory early on by gaining access to the child's body. In doing so, they were able to move Jahi to New Jersey where a brain death diagnosis was not necessarily determinative of death.²⁸ That victory reflects the commitment of Jahi's family – especially her mother, grandmother, uncle, and step-father – as well as that of her larger community, who prevented the hospital in which Jahi had been declared brain dead from withdrawing the tubes that allowed the girl to continue breathing and, later, to provide for Jahi to receive assisted hydration and nutrition.²⁹ The two cases present a sharp contrast between rights grounded on the presumption of autonomous individuality and the protections (often social as much as legal) that can come from a supportive community.

II. Elizabeth Bouvia: Competing Narratives

The California appellate court that granted Bouvia the right to be cared for in a public hospital—while she refused nutrition and hydration—constructed one vision of Bouvia's life.³⁰ It is a grim vision that encouraged the court to conclude that Bouvia's request to have hospital clinicians assist with her effort to die reflected the most rational response to a life with severe disabilities.³¹

²⁸ See *Winkfield v. Children's Hosp. Oakland*, No. 4:13-cv-05993-SBA, 2016 U.S. Dist. Lexis 8560, at *3-*4, (N.D. Cal. Jan 23, 2014).

²⁹ See *id.*

³⁰ See *Bouvia*, 179 Cal. App. at 1147.

³¹ See *id.*

The court did not leave room for alternative descriptions and explanations of Elizabeth Bouvia's situation. In fact, there are contrasting visions of Bouvia's life. Had the court attended to alternative understandings of Bouvia's situation, it would likely have re-shaped its reasoning, if not its holding.³² Several scholars and journalists belied the court's depiction of Bouvia's opportunities in life with the suggestion that that depiction flowed from a biased view of a life with disabilities. This part first considers the decisions rendered in two cases, each initiated by Bouvia. The first case, decided in 1983, held against Bouvia, denying her the right she sought. But in 1986, a California appellate court granted her that right. Each court opinion framed the court's conclusions in light of the judge's own vision of Bouvia's life and of her potential to enjoy that life.³³

a. Elizabeth Bouvia: The Legal Case

In the early 1980s, Elizabeth Bouvia sought legal assistance in order to gain the right to die.³⁴ At the time, Bouvia was living at a public hospital in Riverside County in California.³⁵ Bouvia was determined to stop eating and drinking; she explained that her life had become unbearable to her.³⁶ However, physicians at Riverside determined that clinicians would insert a nasogastric tube once Elizabeth's body weight fell below a set threshold. The tube, they explained, was necessary to "[keep] her alive through involuntary forced feeding."³⁷ The case raised novel questions. Barbara Miliken, an attorney for the hospital, reported that she was unable to find case

³² Ms. B v. An NHS Hosp. Trust, All ER (D)362, 449, para 95 (Mar. 22, 2002). (The court held for Ms. B and then declared: "I hope she will forgive me for saying, diffidently, that if she did reconsider her decision, she would have a lot to offer the community at large.").

³³ See Longmore, *Assisted Suicide*, *supra* note 25, at 150.

³⁴ See *Bouvia I*, *supra* note 22, at 485; *Bouvia II*, *supra* note 22. See also Rev. Robert Barry, *The Elizabeth Bouvia Case: Legalizing Euthanasia by Lethal Injection*, 53 THE LINACRE QUARTERLY, 13 (1986).

³⁵ See *Bouvia I*, *supra* note 22, at 488.

³⁶ *Id.*

³⁷ *Bouvia*, 179 Cal. at 1145.

law involving a patient requesting the right to stay in a public hospital while refusing assisted nutrition and hydration.³⁸

Bouvia's attorneys arranged for psychiatric evaluations of their client.³⁹ They engaged three psychiatric professionals—none with expertise in helping people with disabilities—who concluded that Elizabeth's desire to die was grounded only in her response to her disabilities, not society's failure to accommodate her or the series of life events that would have depressed most people.⁴⁰ In their view, her response was rational.⁴¹ But in the view of many disability rights activists, this reflected prejudice against disabled people.⁴² Paul Longmore, in a lengthy review of Bouvia's story, concluded that Bouvia suffered from depression, which he ascribed not to Bouvia's disabilities, but to society's failure to accommodate people with disabilities.⁴³

A California trial court refused Bouvia's request for an injunction. The injunction would have precluded the hospital from insisting that Bouvia receive nutrition and hydration through the use of a nasogastric tube or comparable device or procedure.⁴⁴ The trial court framed the issue in light of Bouvia's request for assistance in dying. The court wondered "whether or not a severely handicapped, mentally competent person who is otherwise physically healthy and not terminally ill has the right to end her life with the assistance of society."⁴⁵

Basing its decision "entirely upon the constitutional issue presented," the court determined that the right Bouvia sought was not extended to her by the law.⁴⁶ The constitutional issue at stake, the court explained, concerned "the unwritten right of privacy and self-determination recognized under the First, Fourth, Fifth, and

³⁸ Mary Johnson, *Right to Life, Fight to Die: The Elizabeth Bouvia Saga*, ELECTRIC EDGE (1997), <https://www3.dbu.edu/jeanhumphreys/DeathDying/Bouvia.htm>.

³⁹ See Longmore, *Assisted Suicide*, *supra* note 25, at 156.

⁴⁰ *Id.* at 157.

⁴¹ *Id.*

⁴² See *id.*

⁴³ See *id.*

⁴⁴ *Bouvia I*, *supra* note 22, at 485.

⁴⁵ *Id.* at 489.

⁴⁶ *Id.*

Fourteenth Amendments to the United State Constitution. . . .⁴⁷ More specifically, the court concluded that in light of Bouvia's situation, any right she might claim she had to terminate her life was "overcome by the strong interests of the State and society."⁴⁸

That the preservation of life is the strongest state interest involved. That our society values life. That Bouvia is not terminal and her life will be preserved. That none of the parties have cited any legal precedent which approves the proposition that a non-terminal person with the life 15 to 20 years who has a disabling but non-progressive physical condition should be allowed to terminate life because of a sincere desire to do so by reason of the disability.⁴⁹

Judge Hews, who presided in Bouvia's 1983 case, concluded his "Statement of Decision" by suggesting that Bouvia should "realize that there is hope in life and that now, because of the action by her, she can be a symbol of hope to others similarly situated if she changes her purpose."⁵⁰ The message, though presumably positive, suggests that Bouvia could find meaning in life only through effecting a heroic response – that, in effect, Bouvia could choose to be an object of pity (a position reflected openly in the decision of a state appellate court three years later) or a courageous "symbol of hope."⁵¹ In short, the court characterized Elizabeth Bouvia as either pitiable or heroic in the face of what the court imagined to be a terrible plight. Bouvia initiated an appeal but later dropped it.⁵²

Three years later, Bouvia sought court assistance for a second time, requesting the right to stay in a public hospital and to have a nasogastric feeding tube withdrawn and not re-inserted. Judge Beach for the California appellate court granted Bouvia the right she sought.⁵³ The appellate court focused on protecting Bouvia's right to autonomous decision-making concerning medical care. To justify its

⁴⁷ *Id.*

⁴⁸ *Id.*

⁴⁹ *Id.*

⁵⁰ *Id.* at 491.

⁵¹ *Id.*

⁵² See Belinda Stradley, *Elizabeth Bouvia v. Riverside Hospital: Suicide, Euthanasia, Murder: The Line Blurs*, 15 GOLDEN GATE U. L. REV. 407, 408 (1985).

⁵³ See *Bouvia*, 179 Cal. App. at 1146.

decision, the court displayed and re-enforced negative stereotypes of people with disabilities.⁵⁴ Near the start of his opinion, Judge Beach characterized what he viewed to have been the trial court's conceptual mistake:

By refusing petitioner the relief which she sought, the trial court, with the most noble intentions, attempted to exercise its discretion by issuing a ruling which would uphold what it considered a lawful object, i.e., keeping Elizabeth Bouvia alive by a means which it considered ethical. Nonetheless, it erred for it had no discretion to exercise. Petitioner sought to enforce only a right which was exclusively hers and over which neither the medical profession nor the judiciary have any veto power. The trial court could but recognize and protect her exercise of that right.⁵⁵

The court grounded that conclusion on a privacy right that incorporates “[t]he right to refuse medical treatment.” That conclusion assumes that the provision of nutrition and hydration is part of a patient's medical treatment.⁵⁶ The appellate court might seem to have been grounded on respect for Bouvia's personhood and her right to make her own medical decisions. However, the language through which the court supported and explained its decision reflected a deeply biased understanding of Bouvia's disabilities and of disabilities more generally.⁵⁷

Judge Beach constructed a narrative of Bouvia's life that, in his view, justified a preference for death over life.⁵⁸ The court contended that the trial court had erred in focusing on the length of time Bouvia would likely live if treated (15 to 20 years) rather than on the presumed “quality” of Bouvia's life – a matter, in the court's opinion,

⁵⁴ *See id.*

⁵⁵ *Id.* at 1135.

⁵⁶ *See Bouvia*, 179 Cal. App. at 1141 (noting that in March of 1986 the Council on Ethical and Judicial Affairs of the American Medical Association opined that “[l]ife prolonging medical treatment includes medication and artificially or technologically supplied respiration, nutrition or hydration.”).

⁵⁷ *See generally id.*

⁵⁸ *See id.* at 1145.

of more significance than the expected quantity of her life.⁵⁹ The court explained that determination:

[I]f force fed, petitioner faces 15 to 20 years of a painful existence . . . Her mind and spirit may be free to take great flights but she herself is imprisoned and must lie physically helpless subject to the ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness . . . It is incongruous, if not monstrous, for medical practitioners to assert their right to preserve a life that someone else must live, or, more accurately, endure . . .⁶⁰

The court assumed that the quantity of Bouvia's life paled in the face of its quality. Bouvia agreed.

In Elizabeth Bouvia's view, the quality of her life has been diminished to the point of hopelessness, uselessness, unenjoyability and frustration. She, as the patient, lying helplessly in bed, unable to care for herself, may consider her existence meaningless. She cannot be faulted for so concluding. If her right to choose may not be exercised because there remains to her, in the opinion of a court, a physician or some committee, a certain arbitrary number of years, months, or days, her right will have lost its value and meaning. Who shall say what the minimum amount of available life must be? Does it matter if it be 15 to 20 years, 15 to 20 months, or 15 to 20 days if such a life has been physically destroyed and its quality, dignity and purpose gone?⁶¹

In effect, Judge Beach grounded the decision on his sense that Bouvia's disabilities rendered her life unbearable and that those disabilities would render almost anyone's life unbearable. Thus, for Bouvia to die seemed to be a reasonable option. These conclusions harmonized with the growing emphasis in the second half of the twentieth century on the significance of autonomous individuality in a variety of contexts,⁶² including that of medical decision-making. By

⁵⁹ *Id.* at 1142.

⁶⁰ *Id.* at 1143.

⁶¹ *Id.* at 1142-43.

⁶² See Janet L. Dolgin, *The Family in Transition: From Griswold to Eisenstadt and Beyond*, 82 GEO. L.J. 1519, 1532 (1994). The domain of health care—in particular, the physician-patient

understanding Bouvia's life as unbearable, the court was able to explain the concrete decision in requiring the hospital to abide by Bouvia's wish to terminate nutrition and hydration.

Even more strikingly, the concurrence by Lynn Compton identified one of the "tragedies" of the case to have been the lengths to which Bouvia was compelled to go to gain "relief from her suffering."⁶³

Fate has dealt this young woman a terrible hand. Can anyone blame her if she wants to fold her cards and say "I am out?" Yet medical personnel who have had charge of her case have attempted to force Elizabeth to continue in the game. In their efforts they have been abetted by two different trial courts.⁶⁴

Later, Compton asserted that he identified with Bouvia's responses, that it was better to die than to continue living as Bouvia lived.⁶⁵

Importantly, Bouvia's attorneys presented a dismal portrait of her life and her future. Similar to the appellate court judge, Richard Scott⁶⁶ and other lawyers who participated in Bouvia's representation⁶⁷ painted Bouvia as hopeless and helpless.⁶⁸

Scott, one of the founders of the Hemlock Society,⁶⁹ explained while he was representing Bouvia, his client was "a tragically

relationship—was similarly reshaped in the last half of the twentieth century by a call for patient autonomy and a diminution of physician authority in choosing among medical options.

⁶³ *Bouvia*, 179 Cal. App. at 1146 (Compton, A., concurring).

⁶⁴ *Id.*

⁶⁵ Mike McKee, *Does Suicide Ever Make Sense: Some Doctors for the Terminally Ill Say Yes, but Not Everyone in the Medical Community Thinks It's Clear When a Patient's Choice to Die Is Rational*, THE RECORDER, p. 1 (Jan. 12, 1994).

⁶⁶ See Burt A. Folkart, *Richard S. Scott: Argued Right-to-Die Cases*, L.A. TIMES (Aug. 15, 1992), <https://www.latimes.com/archives/la-xpm-1992-08-15-mn-4791-story.html> (Scott committed suicide in 1992. Scott's wife told the media that her husband had "battled depression most of his life and 'some of the events in his practice (of dealing with the critically ill) had a strong bearing on his feelings.'").

⁶⁷ See *Bouvia*, 179 Cal. App. at 1133 (In addition to Richard Scott, Bouvia's attorneys, included Jacqueline Scheck, Griffith Thomas, Paul Hoffman, and Andrew Roth).

⁶⁸ Paul K. Longmore, *Urging the Handicapped to Die: Bouvia Decision Is Victory for Bigotry, Not Self-Determination*, L.A. TIMES (Apr. 25, 1986), <https://www.latimes.com/archives/la-xpm-1986-04-25-me-1395-story.html> [hereinafter Longmore, *Urging the Handicapped*].

⁶⁹ Derek Humphry, *Let Me Die Before I Wake: Hemlock's Book of Self-deliverance for the Dying* (Dell Publishing et al. eds., 1st ed. 1984); Patients Rights Council, *Assisted Suicide & Death with Dignity: Past, Present & Future – Part 1* (2013), <https://www.patientsrightscouncil.org/site/rpt2005-part1/>.

developmentally disabled person. She has come to realize she is completely unemployable.”⁷⁰ That view of Bouvia was readily appropriated by the court. Yet, other views were soon voiced in other settings, especially within the disability rights community. Paul Longmore, a disability rights advocate, characterized the court’s decision to reject Bouvia’s request to discontinue assisted nutrition and hydration to have been “pervaded with ignorance and bias.”⁷¹

b. Bouvia: A Life Story

In 1987, a year after the California appellate court rendered its decision in *Bouvia v. Superior Court*,⁷² Paul Longmore⁷³ narrated Bouvia’s story within a framework intended to advance social understanding of biases against people with disabilities.⁷⁴ Longmore’s article was particularly critical of Judge Beach’s 1986 decision that granted Bouvia the right to starve to death.⁷⁵ Longmore claimed that the court had “in effect, granted [Bouvia] a right to a judicially sanctioned, medically assisted suicide.”⁷⁶ Further, Longmore characterized the court’s opinion as “pervaded with ignorance and bias – thus rendering it “typical of discussions regarding disabled people and the right to die.”⁷⁷

In describing the suffering that Bouvia endured, the court explained that she had “degenerative and severely crippling

⁷⁰ Johnson, *supra* note 38, at 3.

⁷¹ Longmore, *Assisted Suicide*, *supra* note 25, at 157; Paul K. Longmore, *Famous (and not-so-famous) People with Disabilities*, DISABILITY SOCIAL HISTORY PROJECT (Sep. 15, 2010), http://www.disabilityhistory.org/people_longmore.html [hereinafter Longmore, *Famous*]. When the California appellate court decision in *Bouvia* was handed down (1986), assisted suicide was not legal anywhere in the United States. Its legalization, beginning in Oregon in 1994, would not have helped Bouvia. In states that have legalized assisted suicide, its use has been reserved for people with terminal illnesses and has been precluded for people with disabilities and not presumed likely soon to die. *See, e.g.*, Oregon Death with Dignity Act. § 127. 800 (2021).

⁷² *See generally Bouvia*, 179 Cal. App.

⁷³ *See* Longmore, *Assisted Suicide*, *supra* note 25.

⁷⁴ *See id.* at 141.

⁷⁵ *See generally Bouvia*, 179 Cal. App.

⁷⁶ Longmore, *Assisted Suicide*, *supra* note, 25 at 157. The Oregon Death with Dignity Act, passed through a ballot initiative, provides for physicians to assist patients in hastening death. *See* Janet Dolgin & Lois Shepherd, *BIOETHICS AND THE LAW*, 533-39 (4th ed. 2019).

⁷⁷ Longmore, *Assisted Suicide*, *supra* note 25, at 157.

arthritis.”⁷⁸ Longmore offered a correction: Bouvia had not, in fact, ever been diagnosed with arthritis.⁷⁹ Similarly, the court described Bouvia to have suffered from “severe cerebral palsy” which had “progressed to the point where she is completely bedridden.”⁸⁰ Longmore countered that “cerebral palsy . . . is not a progressive condition.”⁸¹ Perhaps, most stunning, Longmore corrected the court’s presumption that Bouvia would never be able to get out of bed. In fact, Longmore reported Bouvia had long been depressed, and that that depression, not physical disabilities, accounted for her inability to get out of bed.⁸²

Longmore described Bouvia’s own attorneys⁸³ to have based their presentation of her case to the court on distressing images of disability. These images facilitated the court’s pitying Bouvia for a life with disabilities and concluding that her preference for death over life was reasonable in light of her presumptive physical limitations. The court asserted,

“She lays flat in bed and must do so the rest of her life.” Her lawyers have assiduously propagated this distortion of the reality of her disability. In fact, she was never bedridden until four years ago, when, in her depressed state, she refused to get out of bed. She has been allowed to languish there ever since. When this case began, her lawyers told the court and the public that she required constant care. In fact, her in-home aides were never on duty more than six hours a day.⁸⁴

Bouvia’s personal history did not commence her opposition to the care she received in California public hospitals⁸⁵. Throughout the early years of her life, Bouvia suffered more from what Mary Johnson has called a “disabling environment” than from physical disabilities.⁸⁶ Bouvia’s family, the schools she attended, and

⁷⁸ *Bouvia*, 179 Cal. App. at 1136.

⁷⁹ Longmore, *Assisted Suicide*, *supra* note 25, at 157.

⁸⁰ *Bouvia*, 179 Cal. App. at 1135-36.

⁸¹ Longmore, *Assisted Suicide*, *supra* note 25, at 157.

⁸² *See id.*

⁸³ *See id.* at 162.

⁸⁴ *Id.* at 157.

⁸⁵ *Id.*

⁸⁶ *Id.*

eventually, she, herself, internalized society's most negative "construct of 'disability.'"⁸⁷ More specifically, "[p]eople never considered that the problems Bouvia faced might stem from an unadapted environment; that if her environment would change, her problems might lessen."⁸⁸

Elizabeth Bouvia's childhood relationships with close family seem to have been unfulfilling. When she was a young child, her parents separated and then divorced.⁸⁹ Her father, Ren Castner, moved away.⁹⁰ Five years later, Elizabeth's mother remarried and placed Elizabeth, then aged 10, in the Angel View Crippled Children's Foundation home in Desert Hot Springs, California.⁹¹ Between that time and her 18th birthday, she visited with her mother only two times.⁹² At 18, she was released from the facility, and aides, paid for by a California state program,⁹³ assisted Elizabeth with the activities of daily life.⁹⁴

Without familial assistance, Elizabeth put herself through college, first at Riverside Community College and then at San Diego State University.⁹⁵ She hoped to become a social worker but was precluded from completing a graduate program in social work because the hospital to which she was assigned for "fieldwork experience" did not make "reasonable accommodations" for her.⁹⁶ The social work program sought to find a placement for Elizabeth at a facility where her work would only involve other people with disabilities.⁹⁷ Elizabeth rejected the placement. One of Elizabeth's professors in the social work program said the program would have rejected her had

⁸⁷ *Id.*

⁸⁸ Johnson, *supra* note 38, at 4.

⁸⁹ *Id.*

⁹⁰ *Id.*

⁹¹ *Id.*

⁹² *Id.*

⁹³ *Id.* The program was expensive and yet "cost effective," according to Johnson: "If it hadn't existed, people like Bouvia would have been put in nursing homes, at a far higher cost."

⁹⁴ See Longmore, *Assisted Suicide*, *supra* note 25, at 153 (citing Hearn, *She's Had Enough Pity, Is Read to Die*, RIVERSIDE PRESS-ENTER., Oct. 9, 1983, at B1).

⁹⁵ See *id.* at 154.

⁹⁶ *Id.* The accommodations in question were mandated by federal law (Section 504 of the Rehabilitation Act of 1973).

⁹⁷ *Id.*

they know the extent of her disabilities and warned her that she was unemployable.⁹⁸

Robert Scott, in representing Bouvia, echoed the social work program's view of Bouvia as unemployable. Longmore, in contrast, saw the comment from the social work professor as "evidence of discrimination. Bouvia was in effect being told she was worthless."⁹⁹

Bouvia left the social work program. But she seemed already to have internalized the program's views of her worthlessness. "In fact, her disability in no way precluded her from fulfilling the requirements of the program or of her profession. People with more severe disabilities work productively. The professor's statements were not only biased, they were discriminatory, again violating her civil rights under federal law."¹⁰⁰ Even if Bouvia found employment, she would have forfeited state benefits when she reported an income.

[S]he would have quickly lost . . . the In-Home Supportive Services which made it possible for her to go to work in the first place and would be essential to her continuing to work. This is euphemistically called a "work disincentive." It is, in fact, a penalty imposed on disabled people who violate the pervasive social prejudice that they cannot productively contribute to the economy and community. . . .¹⁰¹

Additionally, Bouvia experienced a set of difficult challenges in her adult personal life. She married Richard Bouvia, became pregnant, and then miscarried. The marriage between Elizabeth and Richard did not last.¹⁰² As her marriage was failing, Elizabeth moved into her father's home. She told her father that Richard could not cope with her physical situation or with the couple's debt.¹⁰³ Soon after Bouvia moved to her father's home, he reportedly told Bouvia that

⁹⁸ *Id.*

⁹⁹ Johnson, *supra* note 38, at 6.

¹⁰⁰ Longmore, *Assisted Suicide*, *supra* note 25, at 154.

¹⁰¹ *Id.* at 154-55.

¹⁰² Interview by Mike Wallace, CBS co-host, with Elizabeth, CBS News (Sept. 7, 1997) [hereinafter Wallace, Interview]; Janet L. Dolgin & Lois L. Shepherd, *Bioethics and the Law* 86 (2d ed. 2009); Johnson, *supra* note 38, at 3.

¹⁰³ See Longmore, *Assisted Suicide*, *supra* note 25, at 156.

she was not welcome there; she found new accommodations.¹⁰⁴ Even more, Elizabeth's brother died in a drowning accident during Elizabeth's early adult years.¹⁰⁵

Within a two-year period, Elizabeth lost her marriage, her pregnancy, and her brother. She felt that she had been rejected by her father and saw the dissipation of her professional plans.¹⁰⁶ The last loss seems largely to have been attributable to biases that led her mentors to believe she was incapable of productive work. Unsurprisingly, Elizabeth was depressed. It is not unexpected that a person—able-bodied or disabled—who faced Elizabeth's challenges and society's insults to her personhood would become depressed. She voluntarily entered the Riverside County Hospital as a patient.¹⁰⁷ There, in the early 1980s, she asked the hospital to assist in helping her to die by starvation.¹⁰⁸

Mary Jane Owen, who worked for the President's Committee on Employment of the Handicapped as the Bouvia story was developing, also presented a very different view of Bouvia's situation than had the California courts and Bouvia's attorneys. Johnson's interpretation harmonized with that of Paul Longmore¹⁰⁹: "Were psychiatric students given the facts of the case of Elizabeth Bouvia, they'd quickly say she needed not suicide but help," . . . "Why," [wrote Owen in the *Disability Rag*] "does this bizarre story suddenly become logical when we add the information that Bouvia is severely disabled?"¹¹⁰ Virtually everyone involved in Elizabeth's legal cases—her lawyers, the court, Elizabeth herself—seemed to believe that Elizabeth Bouvia's disabilities made life unbearable.

To her attorneys, Bouvia's roadblocks weren't a reason to fight for her right to a job or help at home, but clear evidence as

¹⁰⁴ See Johnson, *supra* note 38, at 16. Bouvia's father later said that this claim was false. He contended that she rejected him; he did not reject her.

¹⁰⁵ See Longmore, *Assisted Suicide*, *supra* note 25 at 156 (citing 'Withdrawal' or Suicide?', N.Y. TIMES, Dec. 11, 1978, at E7, Col. 5).

¹⁰⁶ See *id.* at 156-57.

¹⁰⁷ *Id.*

¹⁰⁸ *Id.* at 156.

¹⁰⁹ *Id.* at 157.

¹¹⁰ Johnson, *supra* note 38, at 7 (Bouvia denied that her preference to die was related to her separation from her husband or her difficulties at school. Moreover, she asserted that counseling would not be useful. She explained that she was "aware of what's out there; I'm not stupid.").

to why the right to die was an important one for disabled people. It was “Whose Life Is it Anyway” in real life. It was all most people understood about severe disability. And it seemed to be the way Bouvia looked at it, too.¹¹¹

Disability rights activists concluded that Richard Scott, who headed Bouvia’s legal team and had helped create the Hemlock Society,¹¹² was “manipulat[ing]” Bouvia.¹¹³ Referring to Bouvia’s statements proclaiming that her interest in dying stemmed only from her disabilities and not from other difficult events in her life, these activists wondered about the source of her assertions and rhetoric: “[i]t sounded just a little too up on the right-to-die rhetoric in vogue just then, a little too pat.”¹¹⁴

Longmore declared that “[s]ociety had no business talking about a disabled person’s right to die before it had given them a right to live!”¹¹⁵ Activists attributed Bouvia’s depression and interest in death not to her body but to “what she thought of life in that body.”¹¹⁶ To Longmore, it was more worrisome still that the difference between granting disabled people a “right to die” and suggesting that such people *should* be ready to die could be mediated much too easily.¹¹⁷

Mary Jane Owen offered a psychological explanation of Bouvia’s wish to be permitted to starve to death.¹¹⁸ Society prevented Bouvia from succeeding and at the same time blamed her for that failure. She internalized the contradiction, seeing herself and her life as flawed.¹¹⁹ She could not obviate that flaw nor could she become comfortable with it. In consequence, she internalized her frustration and anger: “When we are afraid to express rage against others, it is common to turn that rage against ourselves.”¹²⁰

¹¹¹ *Id.*

¹¹² See Humphry, *supra* note 69 (characterizing Hemlock Society to have advocated for assisted suicide).

¹¹³ Johnson, *supra* note 38, at 17.

¹¹⁴ *Id.*

¹¹⁵ *Id.*

¹¹⁶ *Id.*

¹¹⁷ *Id.*

¹¹⁸ See *id.* at 7.

¹¹⁹ See *id.* at 8.

¹²⁰ *Id.*

Bouvia clearly internalized much of what the surrounding society assumed to be true of people with disabilities.¹²¹ Her expressed wish to die was openly grounded on self-pity: “Everything has to be done for me. At times it’s humiliating and disgusting. I choose to no longer do that.”¹²² “No one,” reported Mary Johnson, “seemed to notice that the woman who saw no reason to live came to court with makeup carefully applied.”¹²³

Although the California appellate court’s 1986 decision granted Bouvia the right she sought—to die through starvation¹²⁴—she did not take advantage of that right once it was offered to her.¹²⁵ In 1992, soon after the death by suicide of Bouvia’s attorney, Richard Scott,¹²⁶ Bouvia, 35-years-old and living at the County-USC Medical Center,¹²⁷ explained that she regretted not having been permitted to die through starvation in 1983 when she had first approached the court with that request. In her view, she would have been “strong enough” at that time and “ready to go through [with it].”¹²⁸ By this time, Bouvia had become a challenge for disability rights activists because she presented herself as helpless and agonized and did not

¹²¹ See Stradley, *supra* note 52, at 418 (citing Wolfenberger et al., *THE PRINCIPLE OF NORMALIZATION IN HUMAN SERVICE* 16-24 (Nat’l Inst. on Mental Retardation, 1972) (Belinda Stradley reports that one psychologist delineated phrases that underlie stereotypes about people with disabilities. These phrases include: “the Subhuman Organism, the Menace, the Unspeakable Object of Dread, the Object of Pity, the Holy Innocent, the Diseased Organism, the Object of Ridicule, the Eternal Child.”).

¹²² Johnson, *supra* note 38, at 9.

¹²³ *Id.*

¹²⁴ See *Bouvia*, 179 Cal. App. at 1145.

¹²⁵ See Beverly Beyette, *The Reluctant Survivor: 9 Years After Helping Her Fight for the Right to Die, Elizabeth Bouvia’s Lawyer and Confidante Killed Himself – Leaving Her Shaken and Living the Life She Dreaded*, L.A. TIMES (Sept. 13, 1992), <https://www.latimes.com/archives/la-xpm-1992-09-13-vw-1154-story.html> (In 1992 the L.A. Times published an article about Bouvia’s decision not to die). Photograph of Elizabeth Bouvia, IMGUR, (Feb. 28, 2018), <https://imgur.com/a/037gM> (an image of a seemingly contented woman in a wheelchair, available on Imgur, is identified as Elizabeth Bouvia).

¹²⁶ See Beyette, *supra* note 125, at 18 (noting that Bouvia’s principal attorney, Richard Scott, killed himself almost a decade after his representation of Elizabeth Bouvia).

¹²⁷ See Johnson, *supra* note 38, at 11 (a movement, started in California by Ed Roberts and other disabled people, focused on providing “independent living” accommodations for disabled people. While a student at UC Berkeley in the 1960s, Roberts and others developed the Center for Independent Living. The group favored disabled people living “like everyone,” not in a hospital or nursing home).

¹²⁸ Beyette, *supra* note 125, at 2.

connect those responses to a society that largely failed to accommodate the needs of people with disabilities.

In the 1992 interview, Bouvia expressed resentment about criticisms of her from disability rights activists.¹²⁹ At the time, she explained that she wished to be able to live with family – her father or one of her sisters. Griffith Thomas, the attorney who replaced Scott after Scott’s death, suggested that Bouvia had a fear of “being abandoned.”¹³⁰ Bouvia’s own statements and those of Thomas suggest that Bouvia—presumptively dedicated to independence from others and autonomy in medical decision-making—actually craved the opportunity to be part of a community.

In 1992, when Bouvia expressed continuing regret about not having had the wherewithal to affect her own death, had regained most of the weight she had lost in the early 1980s and told an L.A. Times reporter that she was physically well: “I’m feeling all right, fine, OK, I mean, I guess you could say I’m doing OK.”¹³¹

In a 1997 interview with Mike Wallace of CBS, eleven years after her court victory, Bouvia explained that “[s]tarvation is not an easy way to go.”¹³² Further, she said, “[y]ou can’t just keep doing it and keep doing it. It [i.e., starvation] really messes up your body. And my body was already messed up.”¹³³ Yet she described her continuing physical existence as a “burden to society” (financially and in other ways) – one that troubled her.¹³⁴

Again, it seems plausible to suggest that one of Bouvia’s primary motivations was a desire—a need—to be heard, to be witnessed. That need is familiar to most people. Bouvia’s history suggests that that need might have been particularly intense for her.

In sum, it is fair to conclude that Bouvia’s legal story and, ultimately, her medical story, were both grounded on a right to

¹²⁹ *See id.* at 4.

¹³⁰ *Id.* at 11 (Bouvia said at the time that her sisters were “still young” and would not be able to manage were she to move in with either of them. They were both in graduate school).

¹³¹ *Id.*

¹³² Wallace, Interview, *supra* note 102; Alicia Ouellette, Context Matters: Disability, the End of Life, and Why the Conversation is Still so Difficult, 58 NYLS L. REV. (213-14), at 387, n.84.

¹³³ *Id.*

¹³⁴ Wallace, Interview, *supra* note 102.

autonomous individuality, but that Bouvia's case also suggests the potential limitations of untrammelled patient autonomy. Indeed, Bouvia herself seemed to yearn for community.

The right to individual autonomy had become increasingly important in medical settings in the decades surrounding Bouvia's court hearings.¹³⁵ And Bouvia's legal case was among those that contributed to the increasing autonomy granted to patients, even with regard to decisions likely or certain to result in their deaths.

Yet, in granting Bouvia the autonomy she sought, the California Court of Appeals furthered Bouvia's prejudicial view of herself and her life – a view that had been presented to the court by Bouvia and her attorneys. To the extent that the right to autonomy in medical decision-making includes the right to make the “wrong” decision, the court's holding cannot be faulted. However, to the extent that Bouvia deserved more—a social and economic environment that would have shown her new options for a life well lived—the court's reasoning, if not its holding, is regrettable.

The second story, like Bouvia's, focused on an understanding of death and dying. Further, McMath's story reflects significant bias and perhaps prejudice. Beyond those similarities, however, the two stories, and the legal cases that determined significant elements of each story, diverged significantly.

Responses to Jahi McMath did not depend on respect for individual autonomy. Rather, the case suggests the strength of communal advocacy, both within and outside courts. Yet, at the same time, Jahi and her family faced significant biases that harmed everyone involved. In short, Bouvia—autonomous in the eyes of the law and alone in her personal life—was granted the right she sought – the right to die. McMath, a young, African American, declared brain dead by the hospital in which she had had surgery to correct sleep apnea, found little support from the law or from medicine, but

¹³⁵ Benjamin Moulton & Jaime S. King, *Aligning Ethics with Medical Decision Making: The Quest for Informed Patient Choice*, 38 J.L. MED. & ETHICS 85 (2012) (In 2012, Benjamin Moulton and Jaime King suggested that by that time, social and legal stress on autonomy had gone too far. Moulton and King hoped society would be able better to balance autonomy and clinician beneficence).

compelling and effective support from a tight-knit familial community, as well as from a larger church community.¹³⁶

III. Jahi McMath: Competing Narratives

As a young adolescent in California, Jahi McMath, the second of Nailah (Latasha) Winkfield's four children, suffered from sleep apnea.¹³⁷ Her doctors recommended that she undergo a tonsillectomy and related procedures.¹³⁸ Before the surgery, Jahi told her mother that she did not want the surgery. Nailah hoped that Jahi would have the surgery. When Jahi met the surgeon, she questioned him about his experience and his sleep during the night before her surgery. He reassured her.

The surgery—a tonsillectomy, adenoidectomy, and two additional procedures¹³⁹—took place on December 9, 2013, at Children's Hospital Oakland (CHO) in California.¹⁴⁰ The surgery took several

¹³⁶ See Rick Hurd, et al., *Jahi McMath: Family ready to move brain-dead girl to new facility; hospital may refuse surgery request*, SAN JOSE MERCURY NEWS (Dec. 26, 2013), <https://plus.lexis.com/document?crd=98f83369-4fb5-430b-b401-76401f4669e2&pdDocFullpath=%2Fshared%2Fdocument%2Fnews%2Furn%3AcontentItem%3A5B55-GMN1-DYT4-V55M-00000-00&pdSourcegroupingtype=&pdContentcomponentid=313960&pdmfid=1530671&pdisurlapi=true&cbc=0>.

¹³⁷ Rachel Aviv, *What Does It Mean to Die?: When Jahi McMath was declared brain-dead by the hospital, her family disagreed. Her case challenges the very nature of existence*, THE NEW YORKER (Jan. 29, 2018), <https://www.newyorker.com/magazine/2018/02/05/what-does-it-mean-to-die>.

¹³⁸ See *McMath*, 2016 WL 7188019, at *1 (describing related procedures).

¹³⁹ *Id.* (the surgery – intended to cure the child's sleep apnea – included an uvulopalatopharyngoplasty, removal of the child's soft palate and her uvula, as well as “a submucous resection of her bilateral turbinates.”). Complaint at 2, *McMath v. Rosen*, No. RG15796121 (Super. Ct. Cal., Dec. 9, 2015) (The case was filed by Milton McMath, Jahi's biological father. Milton McMath's complaint referred to these procedures, along with the tonsillectomy and adenoidectomy as “complex and risky surgery for sleep apnea.” The complaint further suggested that Jahi should first have been given a continuous positive airway pressure machine trial to see if that might have helped her sleep apnea and that, if surgery was still deemed necessary, the surgeon should have begun with a more limited procedure – including, at first, only a tonsillectomy and an adenoidectomy). The Hospital's name was later changed to UCSF Benioff Children's Hospital of Oakland. This complaint was filed for Milton McMath, Jahi's father.

¹⁴⁰ See *McMath*, 2016 WL 7188019, at *1 (note that the hospital's name was later changed). See Deborah Goldschmidt, *Jahi McMath, California Teen at Center of Brain-death Controversy, Has Died*, CNN (last updated, June 29, 2018), available at <https://www.cnn.com/2018/06/29/health/jahi-mcmath-brain-dead-teen-death/index.html>.

hours.¹⁴¹ During the night following the surgery, Jahi began to bleed profusely. Nailah and her husband, Marvin Winkfield, and later, her mother, Sandra Chatman, herself a nurse, continually asked for assistance from hospital clinicians. They were largely ignored by nurses and doctors who should have been attending to the girl. Apparently, hospital nurses told Jahi's family members that the girl's bleeding was "routine" and for the most part, refused to help stop the blood flow, leaving that task to Nailah and her mother.¹⁴² That night, Jahi suffered a cardiac arrest, and a code was called.¹⁴³ As a result, Jahi's breathing depended on ventilatory support.¹⁴⁴

On December 12, three days after Jahi's surgery, hospital clinicians told Jahi's mother and stepfather that Jahi was brain dead, and that life-sustaining care would be withdrawn.¹⁴⁵ This part considers the legal claims that followed these events. Then, Section B considers medical and legal understandings of brain death. Finally, Section C discusses Jahi's personal story – the story of a family and a community.

a. Jahi McMath: The Legal Case

In response to the hospital's diagnosis of Jahi as brain dead, Nailah Winkfield, Jahi's mother, secured an attorney and filed a claim in state court.¹⁴⁶ Nailah appealed to state and federal courts for help several times after this, and Jahi's biological father filed an action alleging malpractice in 2015.¹⁴⁷ These cases did not lead to a new law, however, they did bring public attention to the girl's story and thus to its many implications, including the meaning of brain death.

¹⁴¹ See Aviv, *supra* note 137, at 3.

¹⁴² See Matthias Gafni, *Jahi McMath: State Releases Report on Children's Hospital Oakland's Handling of Patients*, E EAST BAY TIMES (Mar. 12, 2014), <https://www.eastbaytimes.com/2014/03/12/jahi-mcmath-state-releases-report-on-childrens-hospital-oaklands-handling-of-patients> [hereinafter Gafni, *State Releases Report*].

¹⁴³ See *infra* note 292 and accompanying text.

¹⁴⁴ *Id.*

¹⁴⁵ Complaint at 5, *McMath v. Rosen*, No. RG15796121 (Super. Ct. Cal., Dec. 9, 2015).

¹⁴⁶ See *McMath*, 2016 WL 7188019 at *2 (citing Dkt. No. 69-2, Exh. A (*Ex Parte Petition*)).

¹⁴⁷ See Complaint at 9, *McMath v. Rosen*, No. RG15796121 (Super.Ct Cal., Dec. 9, 2015).

Further, the legal cases and the story that surrounded them stimulated some physicians to re-think the notion of brain death.¹⁴⁸

While Nailah did not succeed in convincing the court to preclude the county's issuing of a death certificate for Jahi, a negotiated agreement between Nailah, the hospital, and the county resulted in Nailah's being allowed to transport Jahi to New Jersey, a state in which she would be considered legally alive, despite the brain death diagnosis in California.¹⁴⁹ In short, the legal cases initiated by Jahi's mother and father did not upend state statutory provisions that defined brain death. However, these cases, and Jahi's story more broadly, received significant public attention – in large part a result of Jahi's family's efforts. This led to publications in scholarly journals and in the public media that have questioned the certainty of at least some brain death diagnoses.¹⁵⁰

Soon after CHO declared Jahi, brain dead, Nailah filed an ex parte application, seeking a temporary restraining order to ensure that her daughter would be kept on a ventilator.¹⁵¹ She wanted to keep Jahi's body oxygenated until she could arrange transfer to a facility that would agree to treat Jahi as a living child.¹⁵² On the day that Nailah filed her petition for the restraining order, the state court granted the temporary restraining order (TRO) that Nailah requested, thereby precluding the immediate withdrawal of ventilatory support for Jahi.¹⁵³

Subsequent to that order, the court heard testimony from two physicians who had reviewed Jahi's medical situation.¹⁵⁴ Neither physician was one who had treated Jahi.¹⁵⁵ Each concluded that, in

¹⁴⁸ See Ariane Lewis, Editorial, *The Legacy of Jahi McMath*, 29 *NEUROCRITICAL CARE* 519 (2018) [hereinafter Lewis, *The Legacy*].

¹⁴⁹ See *McMath*, 2016 WL 7188019, at *1 (considering agreement that allowed Nailah to gain custody of her daughter's body).

¹⁵⁰ See *infra* note 244-47 and accompanying text.

¹⁵¹ *McMath*, 2016 WL 7188019, at *2. See also *Winkfield*, No. 4:13-cv-05993-SBA at *1.

¹⁵² *McMath*, 2016 WL 7188019, at *1.

¹⁵³ *Id.* at *2.

¹⁵⁴ See Complaint at 6, *Winkfield v. Children's Hosp. Oakland*, No. 4:13-cv-05993-SBA, (N.D. Cal. Dec. 30, 2013).

¹⁵⁵ See *Winkfield*, No. 4:13-cv-05993-SBA, at *3 (one of these physicians, Dr. Paul Graham Fisher, Chief of the Division of Child Neurology at the Stanford University School of medicine, was appointed by the court).

light of medical standards defining brain death, Jahi was dead.¹⁵⁶ Largely on the basis of this testimony, supporting the conclusions of clinicians at CHO about Jahi's status, the trial court dissolved the TRO and concluded that Jahi was brain dead.¹⁵⁷

On December 26, 2013, the court issued a written statement that declared that Jahi was brain dead as defined by state law.¹⁵⁸ Judge Grillo for the trial court asserted, first, that Jahi was dead in compliance with California law,¹⁵⁹ and second, in consequence, that insertion of feeding and tracheal tubes “would arguably be medically ineffective or contrary to generally accepted health care standards, or could violate medical or ethical norms.”¹⁶⁰

In response, Jahi's mother sought relief in federal court.¹⁶¹ There, Nailah relied on the U.S. Constitution and federal statutory law¹⁶² to support her request that Jahi be provided with ventilatory support and assistance with hydration and nutrition, as well as other medical treatments until she could locate a facility willing to care for Jahi on

¹⁵⁶ See *id.* at *2.

¹⁵⁷ See *McMath*, 2016 WL 7188019, at *1, (citing Health and Safety Code sections 7180 & 7181); See *Winkfield*, No. 4:13-cv-05993-SBA, at *6.

¹⁵⁸ Plaintiff's Opposition To State Defendant's Motion to Dismiss at 5, *McMath v. Cal.* No. 3:15-cv-06042 HSG (N.D. Cal., May 12, 2016).

¹⁵⁹ *McMath*, 2016 WL 7188019, at *2 (noting that definition of brain death in the state was found in Health and Safety Code sections 7180 and 7181).

¹⁶⁰ *Id.* (in mid-January 2014, the same court denied Jahi's mother's renewed request for a tracheostomy for her daughter and a gastric tube).

¹⁶¹ See *Winkfield*, No. 4:13-cv-05993-SBA, at *7-10 (Judge Armstrong for the U.S. District Court for the Northern District of California, Oakland Division, explained in her opinion (regarding an order to show cause) that the action was brought by Nailah Winkfield and Jahi McMath, while a similar action, initiated by the same plaintiffs, was being considered in state court. The claims were somewhat different. However, Judge Armstrong questioned whether the federal district court had jurisdiction pursuant to the Rooker-Feldman doctrine. That doctrine precludes a lower federal court “from hearing de facto appeals from state court judgments[.]” Judge Armstrong further explained:

At a minimum, the claims herein appear to be “inextricably intertwined” with the state court action, thereby triggering application of the Rooker-Feldman Doctrine (*Doe v. Mann*, 415 F.3d 1038, 1041 (9th Cir. 2005) (where Rooker-Feldman applies, a federal court “must also refuse to decide any issue raised in the suit that is ‘inextricably intertwined’ with an issue resolved by the state court in its judicial decision.”)).

The federal court also considering issues of mootness and standing. It concluded by giving the plaintiffs “an opportunity to demonstrate why the instant action should not be dismissed for lack of jurisdiction.”

¹⁶² See *id.* at *3. (Nailah Winkfield invoked the First, Fourth, and Fourteenth Amendments of the U.S. Constitution as well as Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. Sec. 794 and the Americans with Disabilities Act, 42 U.S.C. Sec. 12101).

a long-term basis “in accordance with her religious beliefs.”¹⁶³ Nailah asserted that she was a Christian but did not seem to have provided additional information to the courts about her church and its specific views on brain death.¹⁶⁴ She did assert expressly, however, that her religious beliefs demanded that her daughter be treated as a living child.¹⁶⁵ Nailah’s claim to have had such religious beliefs appears to have been sincere.¹⁶⁶

On January 3, 2014, before the federal court opined on Nailah and Jahi’s request for relief regarding continuing medical care (including ventilatory support and support with nutrition and hydration), the parties framed an agreement to facilitate the transfer of Jahi to a facility that would care for her according to Nailah’s preferences.¹⁶⁷ The transfer was made three days later.¹⁶⁸ In consequence, the federal court found it “questionable” (even beyond issues raised by the concurrent cases in state and federal courts)¹⁶⁹ that a live controversy continued to exist.¹⁷⁰ The court gave Nailah an opportunity to explain why, in her view, the case was not moot.¹⁷¹ However, she agreed to dismiss the action.¹⁷²

Judge Armstrong of the U.S. district court further recommended that the parties enter into negotiations about transferring custody of

¹⁶³ *Id.* at *4; *See also McMath*, 2016 WL7188019, at *1 (citing Complaint at 5, *Winkfield v. Children’s Hosp. Oakland*, No. 4:13-cv-05993-SBA (N.D. Cal., Dec. 30, 2013)).

¹⁶⁴ Complaint at 4, *Winkfield*, No. 4:13-cv-05993-SBA (N.D. Cal., Dec. 30, 2013) (“Plaintiffs are Christians with firm religious beliefs that as long as the heart is beating, Jahi is alive...These religious beliefs involve providing all treatment, care, and nutrition to a body that is living, treating it with respect and seeking to encourage its healing.”).

¹⁶⁵ *Id.*

¹⁶⁶ *See* John M. Luce, *The Uncommon Case of Jahi McMath*, 147 *CHEST* 1144, 1147 (2015); *see also* Complaint at 4, *Winkfield*, No. 4:13-cv-05993-SBA (Winkfield based her objection to the brain death diagnosis on her “sincerely held religious beliefs.” She further explained:

Plaintiffs’ religious beliefs are also informed by Winkfield’s person knowledge of at least one person other than her daughter who had been diagnosed as brain dead, where the decision makers were encouraged to “pull the plug” yet refused, and thereafter their loved one emerged from legal “brain death” to a state where they had brain function).

¹⁶⁷ *See Winkfield*, No. 4:13-cv-05993-SBA at *4.

¹⁶⁸ *Id.*

¹⁶⁹ *Id.* at *6.

¹⁷⁰ *Id.* (The court ordered the parties to meet to discuss the issues at stake and to consider whether, in their views, the case in federal court had become moot).

¹⁷¹ *See id.* at *8.

¹⁷² *See McMath*, 2016 LEXIS 290, at *9.

Jahi's body to Nailah.¹⁷³ The Magistrate's office scheduled a settlement conference for 11 a.m. on January 3, 2014.¹⁷⁴ Earlier on the same day, the parties reached an agreement in state court that provided for the transfer of Jahi's body from the hospital to the county coroner and then to Nailah.¹⁷⁵ Details regarding these transfers of Jahi's body (or of Jahi, herself, depending on perspective) were further debated in conference with the Magistrate.¹⁷⁶ Eventually, an agreement was reached.¹⁷⁷ Details of the negotiations and consequent arrangements were complicated and exacerbated confusion about the implications of Jahi's medical condition.¹⁷⁸ In brief, Nailah agreed "under protest"¹⁷⁹ that the county coroner would sign a death certificate – though she denied that Jahi was dead. Issuance of a death certificate seemed necessary in order for Nailah to gain permission to be given custody of her daughter's body (which the county defined as dead and which Nailah viewed as alive).¹⁸⁰

The death certificate noted the "cause of death" as "pending investigation."¹⁸¹ But as a practical matter, the legal proceedings and negotiations among the parties in early 2014 resulted in honoring the hospital's demand that the child be declared dead,¹⁸² and at the same time, facilitating release by the Alameda County coroner of the child (or the child's body, depending on perspective) to the custody of her mother.¹⁸³ Nailah fought to have the county's death certificate for

¹⁷³ *See id.*

¹⁷⁴ *See Winkfield*, No. 4:13-cv-05993-SBA, at *4.

¹⁷⁵ *See id.*; *see also* Christina Q. Nguyen, *Comment: Death as Liberty*, 49 U.S.F. L. REV. 387, 388 (2015).

¹⁷⁶ *See Winkfield*, No. 4:13-cv-05993-SBA, at *4.

¹⁷⁷ *See id.*

¹⁷⁸ *See id.*

¹⁷⁹ Plaintiff's Opposition To State Defendants' Motion to Dismiss at 6, No. 3:15-cv-06042 -HSG (N.D. Cal. Dec. 23, 2015) (once a death certificate was issued, Nailah Winkfield was able to obtain a "disposition permit." Generally, such permits allow survivors to receive a body for preparation for internment or cremation).

¹⁸⁰ *Id.*; *see also* § 7.52. *Case histories – Jahi McMath*, NY ELDER L. AND SPECIAL NEEDS PRACTICE UPDATE, (N.Y. Elder L. and Special Needs Practice, N.Y.) June 2021, at 1.

¹⁸¹ Aviv, *supra* note 137, at 8.

¹⁸² *See McMath*, 2016 WL 718809, at *2.

¹⁸³ *See id.* at *2; *See* N.J. Declaration of Death Act, § 26:6A-3 (2021) (defining brain death); N.J. Declaration of Death Act, § 26:6A-5 (2021) (the statute includes a religious exception that allows someone with religious beliefs that oppose a diagnosis of death by neurological criteria to be defined as living).

Jahi overturned as late as 2018 when Jahi was declared dead in California.¹⁸⁴

Once the county issued the death certificate and Nailah gained custody of Jahi, the hospital disconnected Jahi's ventilator.¹⁸⁵ Nurses from an air-evacuation service-connected Jahi to a portable ventilatory device.¹⁸⁶ Even Nailah was unaware of the location to which her child would be sent. Her attorney was apparently "afraid that the hospital would find out and somehow thwart the plan."¹⁸⁷ That fear suggests the level of distrust that permeated relationships between Jahi's family and the Children's Hospital Oakland.

Jahi was transported to New Jersey¹⁸⁸ because, in that state, a law offered a religious exemption for those who would otherwise be declared brain dead. The law in question provided that a person's death:

shall not be declared upon the basis of neurological criteria...when the licensed physician authorized to declare death, has reason to believe, on the basis of information in the individual's available medical records, or information provided by a member of the individual's family or any other person knowledgeable about the individual's personal religious beliefs that such a declaration would violate the personal religious beliefs of the individual. In these cases, death shall be declared, and the time of death fixed, solely upon the basis of cardio-respiratory criteria . . .¹⁸⁹

¹⁸⁴ Goldschmidt, *supra* note 140.

¹⁸⁵ Aviv, *supra* note 137, at 8.

¹⁸⁶ *Id.* at 9.

¹⁸⁷ *Id.*

¹⁸⁸ *Id.* See Katie Nelson & Elisabeth Nardi, *Jahi McMath: Family Trying to Raise Money to Get 13-year-old Airlifted Out of State*, SAN JOSE MERCURY NEWS (Dec. 28, 2013), <https://www.mercurynews.com/2013/12/28/jahi-mcmath-family-trying-to-raise-money-to-get-13-year-old-airlifted-out-of-state-3/> (last updated Aug. 12, 2016, 9:46 AM) (expenses were covered, at least in part, through a Go Fund Me website that Nailah Winkfield created to pay for Jahi to be airlifted to a hospital outside California. Winkfield hoped to raise \$20,000). Jahi McMath Fund, <https://www.gofundme.com/f/jahi-mcmath> (last visited July 12, 2021) (in July 2021, after Jahi's death in New Jersey, the website for the fund noted that the family had raised \$65,100).

¹⁸⁹ N.J. Declaration of Death Act, § 26:6A-5 (2014) (the statute expressly provides for the continuation of health care and insurance for a person not declared brain dead by reason of religious belief); N.J. Declaration of Death Act §26:6A-7 (2013) ("No health care practitioner or other health care provider, and no health service plan, insurer, of governmental authority, shall deny coverage or exclude from the benefits of service any individual solely because of that

The legal proceedings and consequent responses of the parties created significant confusion. Public media augmented the confusion and consternation about Jahi's status by referring to her as dead but to her body as alive, or by referring to Jahi as dead but asserting that she was receiving life-sustaining care.¹⁹⁰ For instance, a California newspaper summarized a story reporting that the California state court had dissolved the restraining order that required the hospital to continue ventilatory support for Jahi.¹⁹¹ The newspaper article referred to the testimony of the two physicians whom the state court had appointed to review Jahi's neurological state.¹⁹² "Both [doctors] testified that the teen is brain-dead and that her body is alive only because of a ventilator hooked up to her since Dec. 12 [2013]."¹⁹³ To most people not familiar with brain-death diagnoses, that report may have suggested that Jahi was brain dead but that she was also "alive."

Nailah submitted several additional motions to the California trial court and to the federal court that had entertained Nailah's initial complaints. Among these later petitions, Nailah filed an action in the county trial court in October of 2014, asking to have the 2013 declaration declaring Jahi dead in California overturned; she referred to new evidence that Jahi was not dead.¹⁹⁴ After the court-appointed one of the same experts who had originally confirmed the position of hospital clinicians who opined that Jahi was brain dead in 2013, Nailah withdrew her petition.¹⁹⁵ In addition, Jahi's biological

individual's personal religious beliefs regarding the application of neurological criteria for declaring death.").

Winkfield, No. 4:13-cv-05993-SBA, at *10 (after transfer of the child to her mother's custody, Judge Armstrong, for the federal district court, concluded that the federal court had not had or "no longer [had] jurisdiction to consider the merits of Plaintiff's claims").

¹⁹⁰ See, e.g., Rich Hurd & David Debolt, *Jahi McMath: Judge Denies Petition to Keep Girl on Ventilator Past Dec. 30*, MERCURY NEWS (Dec. 24, 2013), <https://www.mercurynews.com/2013/12/24/jahi-mcmath-judge-denies-petition-to-keep-girl-on-ventilator-past-dec-30/>.

¹⁹¹ See *id.*

¹⁹² See *id.* See also Plaintiff's Opposition To State Defendant's Motion to Dismiss at 9, *McMath*, No. 3:15-cv-06042 HSG (referring to trial court appointment of two experts to examine Jahi).

¹⁹³ *Id.*

¹⁹⁴ See *McMath*, 2016 WL 718809, at *3.

¹⁹⁵ Plaintiff's Opposition To State Defendant's Motion to Dismiss at 9, *McMath*, No. 3:15-cv-06042 HSG (Nailah Winkfield disputed the claim that she withdrew the request. She reports that she asked the trial court judge to permit her to contact the expert who had been appointed by

father,¹⁹⁶ Milton McMath, initiated a malpractice action, naming the surgeon who had operated on Jahi and the hospital in which he operated as defendants.¹⁹⁷ That action sought, personal injury damages or, alternatively, wrongful death damages (depending on whether the child was considered alive or dead).¹⁹⁸

Milton McMath's complaint provided a detailed and lengthy list of actions deemed to have constituted negligent care. McMath alleged that Jahi's surgeon had neglected to inform hospital clinicians caring for Jahi after the surgery that the girl was at increased risk for bleeding due to an arterial condition.¹⁹⁹ Further, the complaint contended that hospital personnel, including medical clinicians and social workers, put pressure on Jahi's family to accept Jahi's death, to permit Jahi to be placed on an organ donor list,²⁰⁰ and to agree to the discontinuance of all care for Jahi.²⁰¹ At that time, Nailah is reported to have been pressured to withdraw life support even though, in her view, she had been given no explanation of what had happened to her daughter.²⁰² In the family's view, the hospital and its clinicians cared about having an organ donor but did not care about Jahi McMath.²⁰³

In light of the legal definition of brain death in California, the hospital's decision to withdraw life-support was justified. However, the timing and the manner in which the hospital and its clinicians

the court to examine Jahi and who concluded, in harmony with the hospital's conclusions, that she was brain dead. According to Nailah, the judge did not do that).

¹⁹⁶ See Matthias Gafni, *Jahi McMath: Biological Father Sues Hospital Claiming Botched Surgery*, MERCURY NEWS (Aug. 11, 2016), (<https://www.mercurynews.com/2015/12/14/jahi-mcmath-biological-father-sues-hospital-claiming-botched-surgery/>) [hereinafter Gafni, *Biological Father*] (Milton McMath and Jahi's mother, Nailah, never married. McMath was not an active part of Jahi's life before her surgery. McMath asserted that he was attempting to create a relationship with Jahi before the surgery). See *Winkfield*, No. 4:13-cv-05993-SBA (Marvin Winkfield, Nailah's husband and Jahi's stepfather, had been a plaintiff in an earlier lawsuit that raised similar claims. The judge concluded that Winkfield did not have standing to bring the case).

¹⁹⁷ *McMath*, 2016 WL 7188019, at *3.

¹⁹⁸ *Id.*

¹⁹⁹ *Family Says Hospital Pressured Them to Remove Patient From Life Support*, 10 No. 21 WL J. MED. MALPRACTICE 1 (2015).

²⁰⁰ *Id.*

²⁰¹ See *id.* See also Complaint at 4, *Winkfield*, No. 4:13-cv-05993-SBA (the claim that Dr. Durand said that Jahi was "Dead, Dead, Dead, Dead").

²⁰² See Complaint at 6, *McMath v. Rosen*, No. RG15796121 (Super. Ct. Cal Dec. 9, 2015).

²⁰³ See *id.* (noting response of doctor to Nailah Winkfield when she sought further explanations of her daughter's situation and requested the continuation of life-sustaining care).

responded to the family—a family shocked to learn that their recently healthy child was considered dead after a tonsillectomy, even as her skin was warm, and her heart was beating—raises concern. Nailah asked, simply, how can my daughter be dead?²⁰⁴

In late 2015, Nailah again asked the federal district court in California to acknowledge that Jahi (by then in New Jersey) was alive and that she thus enjoyed constitutional rights.²⁰⁵ At the time, Nailah hoped to bring Jahi back to California from New Jersey, where they had been since early 2014. Before that could happen, Nailah wanted to ensure that the girl's ventilatory support and assistance with hydration and nutrition would continue once they reached California.²⁰⁶ The action commenced with Nailah and Jahi as plaintiffs, was grounded on the claim that the child was alive and thus enjoyed the constitutional rights to life and to travel within the United States.²⁰⁷ The parties' motion explained that

[p]laintiff Nailah Winkfield, Jahi's mother, has traveled an exhaustive road seeking to obtain due process. What she seeks is to present undisputed medical testimony that, today, Jahi does not meet California's definition of brain death, no matter what her condition was on December 23rd 2013. Jahi shows numerous objective signs of brain activity, including: brain wave activity on an EEG, cerebral blood flow, intact brain matter, an ability to respond to her mother's voice as demonstrated by an increase in her heart rate and the ability to respond to her mother's request to move specific body parts.²⁰⁸

The action aimed to convince the court to review evidence that Jahi was alive, regardless of determinations regarding her status in 2013.²⁰⁹ Judge Hayward Gilliam, writing for the federal district court, concluded that Nailah's motion regarding the claim that Jahi "was

²⁰⁴ J.J. Paris et al., *Brain Death, Dead, and Parental Denial*, 23 CAMBRIDGE QUARTERLY 371, 378 (2014).

²⁰⁵ See *McMath*, 2016 WL 7188019, at *5.

²⁰⁶ See *Winkfield*, No. 4:13-cv-05993-SBA, at *3; see also *McMath*, 2016 WL 7188019, at *1 (invoking the Rehabilitation Act and the Americans with Disabilities Act).

²⁰⁷ See *McMath*, 2016 WL 7188019, at *4.

²⁰⁸ Plaintiff's Opposition To State Defendant's Motion to Dismiss at 1, *McMath v. Cal.*, No. 3:15-cv-06042 HSG (N.D. Cal., April 15, 2016).

²⁰⁹ See *id.* at 9.

incorrectly found to be brain dead on December 24, 2013” could proceed.²¹⁰ But the court stayed the action, waiting for a ruling from state courts addressing whether California brain death law provided guidance for overturning a brain death diagnosis as a result of subsequent evidence.²¹¹

At the same time, Jahi was deemed alive in New Jersey. This reflected one of the most confounding parameters of Jahi’s medical situation. Jahi McMath was deemed alive in one state—New Jersey—but dead in another – California, where a death certificate for her had been filed.²¹² The contention of Jahi’s family that the California death certificate was invalid,²¹³ rested, at least in part, on the fact that the certificate did not state a cause of death. Rather, it included the words “pending investigation.”²¹⁴

The varied responses of medicine, the law to Jahi’s situation, between the declaration of death in California in 2013 and living in New Jersey for more than four years then dying there in 2018, were confusing and distressing to many people. In part, these apparently conflicting responses reflect confusions in understandings of brain death. Brain death is the subject of debate even among experts.²¹⁵

In any event, after Jahi was taken to New Jersey in early 2014, that state’s law provided legal clarity as long as the girl was kept in New Jersey. There, state law allowed for Jahi to be treated by medical clinicians as a living child.²¹⁶ In 2018, more than four years after Nailah brought Jahi to New Jersey, the girl was declared dead according to cardio-pulmonary criteria for death. At first, the family continued its efforts to have the 2013 California death certificate

²¹⁰ *McMath*, 2016 WL 7188019, at *20.

²¹¹ *Id.* (citing relevant law: California Health and Safety Code Secs. 7180 and 7181).

²¹² *See id.* at *3 -*4. After Jahi was declared dead in New Jersey, the family’s attorney promised that he would continue to work pro bono to have the date of the child’s death in California listed as June 22, 2018, the date on which Jahi McMath was declared dead in New Jersey. *See* Goldschmidt, *supra* note 140.

²¹³ *See* Complaint at 6, *McMath v. Rosen*, No. RG15796121 (Super. Ct. Cal., Dec. 9, 2015). Further, the death certificate did not include a physician’s signature, certifying that Jahi had died. *Id.*

²¹⁴ *See* Plaintiff’s Opposition To State Defendant’s Motion to Dismiss at 6, *McMath*, No. 3:15-cv-06042-HSG.

²¹⁵ *See infra*, Section B. Medical and Legal Determinations of Death.

²¹⁶ *See* N.J. Declaration of Death Act, § 26:6A-3 (2021) (defining brain death), *supra* note 183 (noting relevant provisions in New Jersey law on brain death).

revoked. However, a year later, the family and the State agreed that the case should be dismissed without prejudice.²¹⁷

b. Medical and Legal Determinations of Death

Jahi McMath's story encouraged the re-examination of brain death determinations which had long been elusive and were sometimes openly challenged, in part because they were explicitly drafted, among other reasons, to provide for more organ donors.²¹⁸ In fact, now, most deceased organ donors are people who have received brain death diagnoses.²¹⁹ Although court responses to the litigation initiated by Jahi's family members did not directly result in policy changes regarding understandings of brain death, they had an indirect effect, in that Jahi's story stimulated challenges to state laws defining brain death.²²⁰ Those challenges have been accompanied by shifts in policy.²²¹

In the months immediately following Jahi's brain death diagnosis and her family's efforts to preserve ventilatory support and assistance with hydration and nutrition for Jahi, many experts in law, medicine, and bioethics were highly critical of the family for insisting on what these experts understood to be impossible; they were even critical of CHO for failing to preclude the family's resistance.²²² In 2014, John Paris defined "the fundamental problem" with Jahi McMath's case to

²¹⁷ See Notice of Stipulation and Dismissal Pursuant to FRCP 41(a)(1)(A)(ii) at 1, *McMath v. Cal.*, No. 4:15-cv-06042-HSG (N.D. Cal., Dec. 23, 2015).

²¹⁸ Thaddeus Mason Pope, *Brain Death Forsaken: Growing Conflict and New Legal Challenges*, 37 J. LEG. MED. 265, 288 (2017); see also Robert M. Veatch, *Would a Reasonable Person Now Accept the 1968 Harvard Brain Death Report? A Short History of Brain Death*, 48 HASTINGS CTR. REP. S6 (1918) (noting that the Harvard Ad Hoc Committee that crafted the definition of brain death in the late 1960s, believed, among other things, that the new definition would "address controversy over obtaining organs for transplant").

²¹⁹ See Jonah McKeown, *Proposed change to brain death laws draws criticism from some doctors, ethicists*, CATHOLIC NEWS AGENCY (May 18, 2021), <https://www.catholicnewsagency.com/news/247703/proposed-change-to-brain-death-laws-draws-criticism-from-some-doctors-ethicists>.

²²⁰ See *id.* (every state relied on the Uniform Determination of Death Act to provide for determinations of brain death, though sometimes with modifications in the model act's language).

²²¹ See *id.* (noting that legislation regarding brain death, introduced in Puerto Rico in 2017 explained that need for the bill was the result of "recent 'uncomfortable and painful' cases reported in the media.")

²²² See, e.g., Paris et al., *supra* note 204, at 379-80 (2014).

have been “the odd rulings of the trial judge and the corybantic activity of those who, despite the medical evidence and legal findings of brain death, insist that Jahi is not dead.”²²³ Paris argued that a brain death diagnosis should not be treated differently than any other death. In fact, he suggested that the very term “brain death” only leads to confusion and should be replaced with the word death.²²⁴ Similarly, Arthur Caplan, a bioethicist at New York University, declared that permitting Nailah to transfer Jahi’s body to a facility in a state where the girl would continue to receive ventilatory support and assistance with nutrition and hydration made no “medical or moral sense.” “What is being done to her corpse,” he said, “is wrong.”²²⁵

Yet, by the time Jahi was declared dead in New Jersey, more than four years after she was brought there, some experts faced doubts about Jahi’s status during the intervening years.²²⁶ Jahi McMath’s story requires some understanding of the term “brain death,” as defined in law and in medicine, and of challenges to the definition of brain death, originally proposed by a group at Harvard Medical School in 1968.²²⁷

Before the second half of the twentieth century, death was determined through reference to the cessation of cardio-pulmonary functions. Medical clinicians questioned this standard once respiratory and cardiac functions could be sustained with the use of mechanical ventilation.²²⁸ In 1968, an ad hoc committee at Harvard’s medical school published the “Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death.”²²⁹ The Report had implications for people on ventilators with severe brain injury, and it carried significance with regard to the availability of organs for transplantation. It was extraordinarily influential.²³⁰

²²³ *Id.* at 380.

²²⁴ *Id.*

²²⁵ *Id.* (quoting Arthur Caplan).

²²⁶ *See, e.g., Lewis, The Legacy, supra* note 148, at 519.

²²⁷ *See Pope, supra* note 218, at 270.

²²⁸ *See id.*

²²⁹ *See generally A Definition of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death*, 205 JAMA 337 (1968).

²³⁰ *See* Roberg D. Truog, et al., *Brain Death at Fifty: Exploring Consensus, Controversy, and Contexts*, HASTINGS CTR. REP, S2 (Nov.-Dec. 2018).

Implementation of the notion of brain death facilitated increased organs for donation. The organs of patients can be kept oxygenated until ventilatory support is withdrawn. In addition, though much less often noted, brain dead diagnoses preclude the costs of caring for people who will, presumably, never again achieve brain function.²³¹

By the early 1980s, the American legal system began to widely incorporate the brain death rule, which viewed brain death as an alternative form of death. The Uniform Determination of Death Act (UDDA), initially constructed by a presidential commission in 1981, gained approval from the American Medical Association in 1980 and from the American Bar Association in 1981. The UDDA defines death on the basis of either cardiopulmonary criteria or brain criteria.²³² The Act begins by defining the word death to refer to: “An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.”²³³

Every state provided for the determination of death on the basis of neurological criteria.²³⁴ About one-third of the states that promulgated the UDDA have modified the model act’s language.²³⁵ In 1995, about a decade and a half after the development of the Uniform Determination of Death Act and almost three decades after the Harvard Ad Hoc Committee proposed that death should be declared on the basis of the cessation of neurological activity, the

²³¹ This can be a form of rationing medical care and, as such, has been controversial. See Janet L. Dolgin *Re-Making the “Right to Die”: Give Me Liberty but Do Not Give Me Death*, 73 SMU L. Rev. 47, 57 (2020). It should be noted that, as a theoretical matter, rationing and futility can be distinguished, with rationing costs balancing against benefits. In contrast, futility decisions should be grounded in an investigation as to whether or not they will work. See Jeffrey P. Burns & Robert D. Truog, *Futility: A Concept in Evolution*, 132 CHEST, 1987, 1991 (2007).

²³² Uniform Determination of Death Act (UDDA).

²³³ Uniform Determination of Death Act § 1. The Act has provided a model for determining death in every state, though statutory specifics vary. See Ariane Lewis, et al., *Shouldn’t Dead be Dead?: The Search for a Uniform Definition of Death*, 45 J. L. MED. ETHICS 112, 113 (2017) [hereinafter Lewis et al., *Shouldn’t Dead be Dead?*].

²³⁴ See John M. Luce, *The Uncommon Case of Jahi McMath*, 14 CHEST 1144, 1147 (2015).

²³⁵ See Michael Cook, *UDDA and RUDDA: uproar over possible change in brain death criteria*, BIOEDGE (May 30, 2021), <https://www.bioedge.org/bioethics/udda-and-rudda-uproar-over-possible-change-in-brain-death-criteria/13816>.

Quality Standards Subcommittee of the American Academy of Neurology (AAN) crafted guidelines that summarized the components of a clinical exam for brain death and noted the limitations of the test.²³⁶ The AAN Subcommittee also delineated a set of exclusionary factors for a brain death diagnosis, including hypothermia and certain drugs. Further, they noted conditions that could be confused with brain death.²³⁷ In 2010, updating its 1995 guidelines, the Subcommittee reported that no one diagnosed as brain dead on the basis of the 1995 criteria had recovered brain function.²³⁸ This claim, voiced often, has been challenged by Jahi McMath's case.²³⁹

Efforts to update the UDDA are underway, and proposals for revision are being studied by the Uniform Law Commission.²⁴⁰ One proposal for a Revised Uniform Determination of Death Act responds to confusion about the medical standards for diagnosing brain death.²⁴¹ The proposal does not require that a patient tested for brain death show loss of all brain function.²⁴² Challenges to that proposal have focused precisely on the proposal's absence of mandated tests for the cessation of all brain function and on the suggestion that the word "all" be omitted from the current UDDA which requires "irreversible cessation of all functions of the entire brain" before brain death can be declared.²⁴³ In short, the proposed change would

²³⁶ Lewis et al., *Shouldn't Dead be Dead?*, *supra* note 233, at 114.

²³⁷ *Id.* (these conditions included "Guillain-Barre syndrome, organophosphate poisoning, high cervical spine injury, lidocaine toxicity, baclofen overdose, and delayed neuromuscular blockade clearance.").

²³⁸ *Id.*

²³⁹ See, e.g., Lola Butcher, *When the Line between life and death is "a Little Bit Fuzzy,"* SALON (May 16, 2021), https://www.salon.com/2021/05/16/when-the-line-between-life-and-death-is-a-little-bit-fuzzy_partner/.

²⁴⁰ See *id.*

²⁴¹ See McKeown, *supra* note 219 (among other things, the authors of the proposal (Ariane Lewis, Richard Bonnie & Thaddeus Pope) would allow declarations of brain death even in the presence of hypothalamic and pituitary activity).

²⁴² *Id.*

²⁴³ See *id.* (omission of the word "all" would facilitate brain death declarations despite the presence of hypothalamic and pituitary gland function); see also, D. Alan Shewmon, *Statement in Support of Revising the Uniform Determination of Death Act and in Opposition to a Proposed Revision*, THE J. OF MED. & PHILOSOPHY 4-5 (May 14, 2021), <https://academic.oup.com/jmp/advance-article/doi/10.1093/jmp/jhab014/6275576#247743303> (challenging proposal for revision of the UDDA). The Statement, prepared by Dr. Shewmon, was endorsed by more than

allow for brain death diagnoses despite some brain activity. Most often, this change is intended to allow for hypothalamic-pituitary function in people diagnosed as brain dead.²⁴⁴ Opponents of the proposal argue that its inclusion would facilitate false brain death diagnoses.²⁴⁵

Alan Shewmon, a pediatric neurologist who prepared a statement regarding revision of the Uniform Determination of Death Act—a statement endorsed by over 100 experts—has been an important voice in challenges to the proposal as well as to the central assumptions that undergird the UDDA.²⁴⁶ Shewmon’s Statement contends that the assumption that brain death is the “same physiological state as traditional (circulatory-respiratory) death” is erroneous. That contention upends the very notion of brain death as proposed in 1968:

Subsequent accumulated clinical experience with BD [brain dead] bodies proved this assumption [that brain death is no different than cardio-pulmonary death] to be false. BD bodies are physiologically equivalent not to traditional cadavers but to severely neurologically injured patients who are almost but not quite BD. BD is indeed an ‘irreversible coma’ (to use the infelicitous title term of the 1968 Harvard Committee report . . . – in fact, the most severe form thereof; but coma, whether reversible or irreversible, is not biological death. One cannot say with semantic correctness that a cadaver or corpse is comatose.²⁴⁷

These conclusions were supported by more than 100 physicians, legal scholars, bioethicists, and philosophers.²⁴⁸ This group concluded that people should be permitted to opt-out of a brain death

100 experts. The endorsers include physicians, social scientists, lawyers, philosophers, psychologists, and bioethicists, among others.

²⁴⁴ See Michael Nair-Collins et al., *Hypothalamic-Pituitary Function in Brain Death: A Review*, 31 J. INTENSIVE CARE MED. 41, 47 (2014), file:///C:/Users/JLD-LG-1/AppData/Local/Temp/PDF%20datastream.pdf (concluding that many patients declared brain dead “nonetheless maintain some brain function” and are thus “in a strict sense, . . . false positives”). The proposed changes would also allow clinicians to test for brain death without family consent. *Id.*

²⁴⁵ See McKeown, *supra* note 219 (referring to case of Jahi McMath, noting in particular, Jahi’s commencing menstruation while diagnosed as brain dead).

²⁴⁶ See generally Shewmon, *supra* note 243.

²⁴⁷ *Id.* at 5.

²⁴⁸ See Cook, *supra* note 235 (reporting on support for Shewmon’s statement).

diagnosis: “People have a right to not have a concept of death that experts vigorously debate imposed upon them against their judgment and conscience; any revision of the UDDA should therefore contain an opt-out clause for those who accept only a circulatory-respiratory criterion.”²⁴⁹ Were that proposal to be widely approved, stories such as that of Jahi McMath’s would not re-occur.

In short, despite the ubiquity of the Uniform Determination of Death Act (passed in some form in every state),²⁵⁰ definitions of death and methods for determining death remain murky. There is disagreement among medical clinicians about when brain death should be diagnosed, and concern because all hospitals do not employ uniform tests for assessing brain death.²⁵¹ Similarly, state courts and legislatures have adopted varying interpretations of brain death.²⁵²

Significant disagreement continues to shape discussions of Jahi McMath’s story and, in particular, shape discussion of whether she was alive during the years after she was taken by her family to New Jersey²⁵³ where—to use Alan Shewmon’s²⁵⁴ term—“she was statutorily resurrected.”²⁵⁵ Interestingly, Dr. Shewmon—who had diagnosed between 150 to 200 cases of brain death in his career²⁵⁶—concluded that Jahi McMath met the guidelines for a diagnosis of brain death in children (as well as the guidelines for determining brain death in adults) in late 2013.²⁵⁷ Yet, Shewmon concluded that later,

²⁴⁹ *Id.*

²⁵⁰ See Butcher, *supra* note 239.

²⁵¹ See *id.* Ariane Lewis suggested that Jahi’s case should lead to revision of the UDDA with a focus on the implications of the phrases “accepted medical standards” and the “entire brain.” Lewis, *The Legacy*, *supra* note 148.

²⁵² Butcher, *supra* note 239.

²⁵³ See *id.*

²⁵⁴ Dr. Shewmon is a pediatric neurologist and Professor Emeritus at the David Geffen School of Medicine of the University of California at Los Angeles. He is board certified in pediatrics, neurology, and clinical neurophysiology. See Declaration of D. Alan Shewmon, M.D. at 2, *Winkfield v. Rosen*, No. RG15760730 (Super. Ct. Cal., County of Alameda, Dec. 22, 2017) [hereinafter Declaration of Shewmon]. See Norman K. Swazo, *Jahi McMath and the Ethics of the Brain Death Standard*, 5 *Bangladesh J. Bioethics* 18, 19 (2014).

²⁵⁵ D. Alan Shewmon, *The Case of Jahi McMath: A Neurologist’s View*, HASTINGS CTR. REP, S74 (Nov-Dec. 2018), [hereinafter Shewmon, *The Case of Jahi McMath*].

²⁵⁶ See Declaration of Shewmon, *supra* note 254, at 2.

²⁵⁷ *Id.* at 3.

Jahi was not, in fact, brain dead.²⁵⁸ Clearly, the two conclusions, read together, challenge the notion of brain death. Shewmon explained,

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. . . . , as well as the adult guidelines, both regarded as the accepted medical standards. 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 conscious state."²⁵⁹

If Shewmon's analysis holds up, it offers support for those who challenge the conclusion that no one recovers after a brain death diagnosis.

Shewmon estimated that the shift in Jahi's consciousness occurred in the spring of 2014, three or four months after the catastrophic events that led to the brain death determination at the Children's Hospital in Oakland. Soon after Jahi was diagnosed as brain dead, her family (in particular, her mother) began to make videos of her. Nailah and other family members contended that Jahi responded to "simple commands."²⁶⁰ Shewmon reviewed 48 video recordings made by Jahi's family in order to show that the girl exhibited voluntary responsiveness. He acknowledged that before reviewing the videos, he "shared the general skepticism" about the family's reports that Jahi was capable of voluntary responses.²⁶¹ After watching the videos, Shewmon revised his initial conclusion that Jahi was unresponsive:

After countless hours studying the videos and taking a devil's advocate approach at every step, I cannot escape the conclusion that the alleged responses were genuine.

Some videos seem to demonstrate a surprising degree of comprehension. For example: extending the thumb upward after previously flexing it and being told to move it *up* instead; or

²⁵⁸ *Id.*

²⁵⁹ *Id.* at 3-4.

²⁶⁰ *Id.* at 4.

²⁶¹ Shewmon, *The Case of Jahi McMath*, *supra* note 255, at S74.

making a stronger repeat arm movement when told to “move it harder”; or, after a previous motor response when the digits and hand remained tense, relaxing them quickly upon being told to relax them . . . These demonstrations were not cherry-picked coincidences of spontaneous movements because such movements never occurred during baseline periods.²⁶²

In short, Shewmon concluded in 2017 that Jahi could not be diagnosed as brain dead. Rather, he described her to have entered a “minimally conscious state.”²⁶³ Shewmon’s conclusion—a result of Nailah’s efforts to prove that her daughter was alive—was stunning.

c. Jahi McMath: A Family Story

Jahi McMath’s story has encouraged re-assessments of the notion of brain death.²⁶⁴ However, her story was about more than that. Jahi’s story also speaks to a multitude of relationships – within families, between patients and clinicians, and between patients’ family members and clinicians. It speaks to the personhood of the girl, herself, and the family that loved her. And it speaks to understandings of individual autonomy as well as communal autonomy, to the notion of medical consent, medical assent (sometimes sought from a child), bias and prejudice in health care, and the role of the law in resolving complicated medical disputes.

At least three additional narratives about Jahi McMath’s situation supplement the narrative that focuses on the girl’s medical condition and the framework that that condition has provided for reconsidering diagnoses of brain death. Each of the additional narratives is important to an understanding of Jahi McMath’s life and story, and each speaks to important challenges in health care and in society, more broadly. One of these narratives focuses on Jahi’s personal story – the story of an African American teenager who reluctantly submitted to routine surgery, emerging from that surgery with a brain death diagnosis. Second, Jahi’s story includes a narrative about the

²⁶² *Id.* at S74-S75.

²⁶³ *Id.* at S75.

²⁶⁴ See Lewis et al., *Shouldn’t Dead be Dead?*, *supra* note 233.

power of the community to challenge and even, sometimes, to upend medical and legal determinations. And third, Jahi's story which includes elements of bias and prejudice—or at least the perception of bias and prejudice by members of the girl's family—includes a narrative about unequal treatment in health care. This third narrative focuses on how bias and prejudice shaped the tone of Jahi's story as well, perhaps, as its outcome. This Section considers each of these narratives, in turn.

i. Jahi, the person

Jahi was only 13 when she received a brain death diagnosis. But, even as a young adolescent, she had a distinct personality and character. Jahi told a classmate that she liked science, wanted to become a physician, to marry, and to have twins.²⁶⁵ She is described as having been considerate, friendly, and strong-willed.²⁶⁶ Even as a child, Jahi had a clear sense of her own preferences and was ready to make them known, when asked.²⁶⁷ One of Jahi's preferences, which haunted her mother later, was to avoid the proposed surgery which had been recommended to correct her sleep apnea.²⁶⁸ When Jahi met with the surgeon before the surgery, she queried him about his credentials and experience and asked if he had had adequate sleep during the night before her surgery.²⁶⁹

At the same time, according to her mother, Jahi was an anxious child who worried about matters such as wars coming to the United

²⁶⁵ Rachel Swan, *Outpouring of grief at Jahi's memorial; Oakland girl buried almost 5 years after being ruled brain-dead*, S.F. CHRONICLE (Jul. 7, 2018), <https://www.pressreader.com/usa/san-francisco-chronicle-late-edition/20180707/textview>.

²⁶⁶ See generally Aviv, *supra* note 137 (reporting that Jahi's school mates teased her for being "chunky," but "she absorbed the insults without protest.").

²⁶⁷ See *id.*

²⁶⁸ Scott Herhold, *At bottom, the Jahi McMath story is a tale of a mother's guilt*, THE MERCURY NEWS (Aug. 12, 2016), <https://www.mercurynews.com/2013/12/26/herhold-at-bottom-the-jahi-mcmath-story-is-a-tale-of-a-mothers-guilt/>. Nailah is reported to have said: "It was me. It was all me. . . .she didn't do it. She just followed what I said. So, I feel like it would be so wrong of me to let them pull that plug on her." *Id.*

²⁶⁹ Aviv, *supra* note 137.

States.²⁷⁰ She was shy,²⁷¹ and she submitted to teasing and bullying from schoolmates (mostly because of her weight) without any outward response.²⁷² Nailah worried that Jahi would let people take advantage of her.²⁷³ Thus, not unlike many adolescents, Jahi combined strength and fragility, and she combined the ability to challenge authority with a shy submissiveness.

Jahi attended a charter school in East Oakland, California. There, she hoped to become a cheerleader.²⁷⁴ Most of the students at the school came from low-income families, and most identified as Christian, as did Jahi's family.²⁷⁵ After Jahi's brain death diagnosis, the school's administration informed Jahi's schoolmates that she could well be alive.²⁷⁶ They responded by praying for her.²⁷⁷ Jahi's siblings attended the same school that she attended.²⁷⁸ Her siblings and friends characterized her as "quiet," yet always helpful.²⁷⁹ Her family called her "Mama Jahi" because she helped her younger siblings with their daily needs.²⁸⁰ Nailah declared that her daughter's name – Jahi – means "known by many."²⁸¹ Jahi's favorite color was purple. At her funeral in California in 2018, Nailah and other

²⁷⁰ See *id.*

²⁷¹ See Matthias Gafni, *Oakland: Emotional letter from Jahi McMath's mom to keep daughter 'warm,'* CONTRA COSTA TIMES (Dec. 21, 2013), https://web.archive.org/web/20141008045341/http://www.mercurynews.com/breaking-news/ci_24773831/oakland-emotional-letter-from-jahi-mcmaths-mom-keep?source=pkg [hereinafter Gafni, *Emotional Letter*].

²⁷² See Julia Prodis Sulek, *Jahi McMath: A mother's undeniable love is lost in divisive battle*, SAN JOSE MERCURY NEWS (Dec. 24, 2013), <https://www.mercurynews.com/2013/12/24/jahi-mcmath-a-mothers-undeniable-love-is-lost-in-divisive-battle/>.

²⁷³ See *id.*

²⁷⁴ Lisa Fernandez, *Friends Believe Jahi McMath, "Quiet Leader," is Alive*, NBC (BAY AREA) (Nov. 30, 2019), <https://www.nbcbayarea.com/news/local/jahi-mcmath-brain-death-tonsillectomy-ec-reems-academy-friends-believe-alive/79703/>.

²⁷⁵ Fernandez, *supra* note 274; Kat Chow, *Jahi McMath, Teen at Center of Medical and Religious Debate on Brain Death, Has Died*, NPR (June 29, 2018) <https://www.npr.org/2018/06/29/624641317/jahi-mcmath-teen-at-center-of-medical-and-religious-debate-on-brain-death-has-di>.

²⁷⁶ Chow, *supra* note 275.

²⁷⁷ *Id.*

²⁷⁸ *Id.*

²⁷⁹ Fernandez, *supra* note 274.

²⁸⁰ Sulek, *supra* note 272.

²⁸¹ Gafni, *Emotional Letter*, *supra* note 271.

mourners donned purple outfits.²⁸² The casket in which Jahi was buried was also purple.²⁸³

Any picture attempting to respond to questions about Jahi's personhood—the person at the center of this public narrative about a brain-dead child—must focus also on the girl's family. Much of Jahi's strength seems to have stemmed from within the supportive family and community where she was raised.²⁸⁴ After Jahi's brain death diagnosis, her family fought both the medical and legal establishments to have life-sustaining care continued.

ii. The Force of Community

Soon after Jahi was diagnosed as brain dead, her mother wrote a letter for public purview that sought communal prayer for Jahi.²⁸⁵ In that letter, Nailah pleaded with other mothers to pray for her daughter:

“Hold your children tight. Tell them you love them. I tell my daughter over and over. I know she can hear me. If she has any brain activity when they do the independent tests she will be kept alive. Pray for my daughter Jahi, pray that she will get better so they don't kill her. Pray for me, mothers, that my love can bring her life once more.”²⁸⁶

Nailah's proactive support for her daughter placed her in opposition to lawyers, hospital administrators, and doctors. In this, she was herself supported by strong family relationships and by support from her larger community and from strangers throughout the

²⁸² See Swan, *supra* note 265; see also Gafni, *Emotional Letter*, *supra* note 271.

²⁸³ See Angela Ruggiero & Alison Berg, *Jahi McMath: Funeral honors young teen whose brain death captured world's attention*, E. BAY TIMES (Jul. 6, 2018), <https://www.eastbaytimes.com/2018/07/06/jahi-mcmath-funeral-honors-young-teen-whose-brain-death-captured-worlds-attention/#:~:text=Jahi%20McMath%3A%20Funeral%20honors%20young%20teen%20whose%20brain%20death%20captured%20world's%20attention>.

²⁸⁴ See Rick Hurd et al., *Jahi McMath: Family ready to move brain-dead girl to new facility; hospital may refuse surgery request*, THE MERCURY NEWS (Dec. 26, 2013), <https://www.mercurynews.com/2013/12/26/jahi-mcmath-family-ready-to-move-brain-dead-girl-to-new-facility-hospital-may-refuse-surgery-request/>. Nailah Winkfield received significant support after Jahi's diagnosis from her Church community. That community participated in a prayer vigil for the girl soon after Jahi's diagnosis. See *id.*

²⁸⁵ See Gafni, *Emotional Letter*, *supra* note 271.

²⁸⁶ *Id.*

world. In February 2014, Nailah authored a second letter about her daughter's situation which, again, she made public.²⁸⁷ In this letter, Nailah noted the strong support she received within her family and from others:

It has been over a month since I have spoken about my life with Jahi to anyone outside a very small circle of family and friends. So many people have asked how we are doing . . . I have withdrawn for reasons of safety and privacy and to focus on my daughter and my role as her mother. However, I have not been alone. I have been surrounded by the love, support, and prayers of so many kind people.

. . . .

On the long hard days when I'm feeling down I think about all the people who are praying for me and Jahi and I feel so much better. I want you to know that I'm praying for you as well.²⁸⁸

Throughout, Nailah received support from her church group in Oakland. In the days following Jahi's brain death diagnosis, members of that community participated in protests outside the Oakland hospital in which Jahi had been declared brain dead. They chanted "'Don't pull the plug!'"²⁸⁹

In 2018, more than four years later, Jahi's funeral was held at the Acts Full Gospel Church in Oakland, California. About 200 people grieved with Nailah and other family members.²⁹⁰ At the funeral, congregants gave Nailah a standing ovation.²⁹¹ Nailah told the assembled mourners what she wanted to say to Jahi: "I am so proud of you. Because you did not let that hospital take you out, you left on your own."²⁹²

Nailah's language suggests the level of support that she and other members of Jahi's immediate family provided during the time

²⁸⁷ See Staff Reports, *Jahi McMath: Complete text of letter from brain-dead girl's mother*, THE MERCURY NEWS (Feb. 19, 2014), <https://www.mercurynews.com/2014/02/20/jahi-mcmath-complete-text-of-letter-from-brain-dead-girls-mother/>.

²⁸⁸ *Id.*

²⁸⁹ See Swan, *supra* note 265.

²⁹⁰ See Ruggiero, *supra* note 283.

²⁹¹ See *McMath's mom slams docs at funeral*, DAILY POST (Jul. 7, 2018), <https://plus.lexis.com/api/permalink/d9fb6b63-af12-4476-985f-df474c6ee546/?context=1530671>.

²⁹² Ruggiero, *supra* note 283.

between the girl's death in California and her death in New Jersey. Nailah and her husband, Marvin Winkfield (Jahi's stepfather) brought Jahi to New Jersey in early 2014. Nailah sold her home, gave up her job, and spent most of her days with Jahi between 2014 and Jahi's death, pursuant to New Jersey law, in 2018.²⁹³ Once Nailah arrived in New Jersey to be with Jahi, she lamented that she "had no plan, no place to live, no nothing," but in explanation, she described her commitment to Jahi: "'when it comes to my kid, I'm an animal.'" ²⁹⁴ Then, after Jahi's death, Nailah could not imagine a life without her daughter: "[E]verything I did revolved around Jahi" . . . "I want to paint her nails, and I want to comb her hair and brush her teeth and talk to her and watch TV with her and let her know what's on TV. And I can't do that no more"²⁹⁵

Jahi's uncle, grandmother, and siblings also actively helped care for Jahi after her 2013 surgery. And Milton McMath, Jahi's biological father, declared that he would never "give up on Jahi, period. . . I will pull a trigger on myself before I pull the plug on her."²⁹⁶

When Jahi experienced severe post-operative bleeding after the 2013 surgery, Nailah called her mother, Sandra Chatman, who was instrumental in notifying clinicians about Jahi's deteriorating condition – though to virtually no avail until the girl went into cardiac arrest. At that point, clinicians recognized that the girl was dying and initiated a Code.²⁹⁷ While resuscitation efforts were underway, a nurse on the unit is reported to have said to Sandra that she "knew this would happen," suggesting that Jahi's condition had not been attended to appropriately.²⁹⁸

²⁹³ See Joseph Geha, *Of Jahi McMath, mom says: 'That little black girl from Oakland made history'*, E. BAY TIMES (Jul. 4, 2018), <https://www.eastbaytimes.com/2018/07/03/of-jahi-mcmath-mom-says-that-little-black-girl-from-oakland-made-history/>.

²⁹⁴ Aviv, *supra* note 137.

²⁹⁵ *Id.*

²⁹⁶ Yanan Wang, *Jahi McMath: Family fights over 'healthy and beautiful' daughter legally dead since 2013; In legal terms, the 15-year-old girl is no longer alive, but on life support her organs continue to function*, THE INDEPENDENT (Mar. 24, 2016), <https://www.independent.co.uk/news/world/americas/jahi-mcmath-family-fights-on-over-healthy-and-beautiful-daughter-legally-dead-since-2013-a6950001.html>.

²⁹⁷ See Aviv, *supra* note 137.

²⁹⁸ Bay Area News Group, *Jahi McMath lawsuit: Timeline of events at UCSF Benioff Children's Hospital Oakland*, CHICO ENTER.-REC. (Apr. 21, 2018) <https://www.chicoer.com>

After Jahi's brain death diagnosis, Jahi's uncle Omari Sealey (Nailah's brother) slept in Jahi's hospital room while she remained at Children's Hospital Oakland, connected to ventilatory support.²⁹⁹ He feared that "the hospital could 'kill her off.'³⁰⁰ Omari was a former star athlete at a California state university. He had a substantial following on social media.³⁰¹ In a 2013 interview with CNN, Omari wore a purple t-shirt because Jahi loved the color. It read: "Team Jahi." Through his many contacts, Omari found Christopher Dolan, the attorney who represented the family pro bono until after Jahi's funeral in California in 2018.³⁰²

iii. *Bias and Prejudice*

Bias and prejudice form the third component of Jahi's story. This component involves both bias and prejudice toward Jahi and her family. Both aspects of this component are most likely to involve hospital healthcare professionals. Law professor Michelle Goodwin suggested that comprehending Jahi's story as a context for reevaluating brain death while "ignor[ing] the underlying medical treatment, which resulted in her dire status, is not only a folly but also renders her an object." "Arguably," continued Goodwin, "circumscribing Jahi McMath's life status to a question of brain death fails to acknowledge and respond to a chronic, if uncomfortable, bioethics problem in American health care – namely, racial bias and unequal treatment, both real and perceived."³⁰³

Clinicians' responses (or more accurately, non-responses) to Jahi's deteriorating condition in the period immediately following her

/2015/03/03/jahi-mcmath-lawsuit-timeline-of-events-at-ucsf-benioff-childrens-hospital-oakland/.

²⁹⁹ Samantha Schmidt, *Jahi McMath, The Calif. girl in life-support controversy, is now dead*, WASH. POST (Jun. 29, 2018), <https://www.washingtonpost.com/news/morning-mix/wp/2018/06/29/jahi-mcmath-the-calif-girl-declared-brain-dead-4-years-ago-is-taken-off-life-support/>.

³⁰⁰ *Id.*

³⁰¹ See Aviv, *supra* note 137.

³⁰² See Examiner Staff, *A personal story of Jahi McMath*, SF EXAMINER (Dec. 25, 2013), <https://www.sfexaminer.com/features/a-personal-story-of-representing-jahi-mcmath/?oid52658052>.

³⁰³ Michelle Goodwin, *Revisiting Death: Implicit Bias and the Case of Jahi McMath*, 48 *Hastings Cent. Rpt* S77, S78 (2018).

surgery are of particular concern. Both Nailah and Sandra wondered what role Jahi and the family's race played in the hospital's treatment and response to Jahi's post-surgery complications.³⁰⁴ Each matter—the care that Jahi received and clinicians' responses to the family—is described in detail in Milton McMath's complaint to a California state court, seeking, alternatively, damages for Jahi's compromised brain function or for the girl's wrongful death.³⁰⁵

As described in McMath's complaint, when Nailah was first permitted to see her daughter post-surgery, she found her child "coughing up blood."³⁰⁶ A nurse informed Nailah that this was not unusual. The nurse then told Nailah how to suction blood from the child's mouth. Nailah continued to suction blood for about an hour when a second nurse criticized her for potentially suctioning blood clots needed for healing.³⁰⁷ The child's bandages and material packing her nose became increasingly wet with blood. Nailah asked for a doctor to examine her daughter. No doctor came. As the child's bleeding grew more severe, Nailah's worry turned to fear. She contacted her mother, Sandra Chatman, a nurse. Chatman arrived at the hospital at about 10 p.m. She was "alarmed" by what she found.³⁰⁸

Chatman soon concluded that Jahi "was at risk of having serious medical complications from the loss of blood and the lack of medical care."³⁰⁹ She called for help when Jahi's complications grew more worrisome still.³¹⁰ McMath reported that no one responded or considered Chatman's concerns real.³¹¹ She continued to meet with a lack of concern from the nursing staff.³¹² No physicians arrived to examine the child.³¹³ One doctor who stood in the pediatric intensive

³⁰⁴ See Aviv, *supra* note 137.

³⁰⁵ See Complaint at 4, McMath v. Rosen, No. RG15796121 (Super. Ct. Cal., Dec. 9, 2015).

³⁰⁶ *Id.* at 3.

³⁰⁷ See *id.*

³⁰⁸ *Id.* at 4.

³⁰⁹ *Id.*

³¹⁰ *Id.*

³¹¹ See Richard Alleyne, *EXCLUSIVE - 'It hurts so Bad': Devastated grandmother reveals the last words of Jahi McMath before routine tonsil operation left her brain dead*, MAIL ONLINE (Jan. 1, 2014), <https://www.dailymail.co.uk/news/article-2532210/I-told-OK-Grandmother-devastated-final-words-teenager-moments-routine-tonsil-operation-left-life-support.html>.

³¹² See Complaint at 4, McMath v. Rosen, No. RG15796121 (Super. Ct. Cal., Dec. 9, 2015).

³¹³ See *id.*; see also Aviv, *supra* note 137.

care unit at the time ignored Sandra and told the on-duty nurse not to change Jahi's robe so that the amount of blood loss could be discerned.³¹⁴ To Sandra, this doctor appeared to be "all frowned up with his arms crossed. . . It was like he thought we were dirt."³¹⁵ Sandra's efforts to get clinical help for her granddaughter were effective only after the girl suffered a cardiac arrest and was clearly dying. Then, a Code was called.³¹⁶ At that time, a physician finally came to Jahi's bedside. Sandra heard him say, "Shit, her heart stopped." Attempts to revive the child left her in a severely compromised condition; two days later she was declared brain dead.³¹⁷

The nurse responsible for Jahi during the night following the girl's surgery entered a note in the child's chart which read: "This writer was informed there would be no immediate intervention from ENT or Surgery. Brain tests administered during the course of the following two days indicated "severe brain damage."³¹⁸ On December 12, three days after the tonsillectomy, hospital personnel informed Jahi's mother and stepfather that the hospital had put the girl on a donor list and that life support would be withdrawn by the following morning.³¹⁹

Nailah reported that her questions about her daughter's situation were left unanswered.³²⁰ Yet, she faced increasing pressure to consent to Jahi's becoming an organ donor. The family requested another medical opinion. The hospital's Chief of Pediatrics rejected the request and reportedly exclaimed: "What don't you understand? She is dead, dead, dead." By this point, Nailah had lost faith in the Oakland's Children's Hospital and in its clinicians. Christopher Dolan, Nailah's attorney, quoted her to have explained:

"I brought her in here for a simple operation, I trusted you. Now you tell me she is dead. I can touch her, she is warm and soft. She is not cold and stiff like death. She smells good and

³¹⁴ See Aviv, *supra* note 137.

³¹⁵ *Id.*

³¹⁶ See Complaint at 4, *McMath v. Rosen*, No. RG15796121 (Super. Ct. Cal., Dec. 9, 2015).

³¹⁷ See *id.* at 5.

³¹⁸ *Id.*

³¹⁹ *Id.*

³²⁰ See *id.*

when I rub her feet she pulls away. I know my daughter, she's not dead. She needs time, I need time. She is my baby, you can't take her. You did this to her, you owe her some time to get better."³²¹

The hospital administration reportedly had security guards follow Jahi's family members after the hospital challenged the diagnosis of brain death. At the same time, hospital personnel continued to pressure the family to consent to the child's becoming an organ donor.³²² Chatman concluded that the hospital clinicians were simply "heartless."³²³

There are almost no public documents that definitively confirm the accuracy of the claims in Milton McMath's complaint. But there is nothing that contradicts them.³²⁴ Even if some of the facts reported could be interpreted variously, Mr. McMath's assertions suggest the family's understanding of what had happened to them and to 13-year-old Jahi and its deep discontent with the manner in which hospital personnel had treated them.³²⁵

By the time that the hospital declared Jahi brain dead, the family did not believe that hospital administrators or clinicians could be trusted. Sandra reported that an African American physician, who had asked the hospital to provide Jahi's family with a little more time, requested an opportunity to speak privately with Sandra. She reportedly told Sandra that the child would look bad at her funeral if left on the ventilator much longer. "You know how we are," Sandra reports her having said.³²⁶ Sandra wondered to whom the "we" referred:

³²¹ Examiner Staff, *supra* note 302.

³²² See Complaint at 6, *McMath v. Rosen*, No. RG15796121 (Super. Ct. Cal., Dec. 9, 2015) (the complaint further reports that requests to Nailah Winkfield for Jahi's organs for donation were made to her even as she sat in the hospital chapel, praying for her daughter's life).

³²³ Alleyne, *supra* note 311.

³²⁴ In a *New Yorker* article, Rachel Aviv reported on interactions in the hospital between Jahi's family members and hospital clinicians and other personnel on the day or two following Jahi's surgery. Her account harmonizes with that of Mr. McMath's complaint. The *New Yorker* article does not provide footnote support for the account offered. See Aviv, *supra* note 137.

³²⁵ See *id.* (note ways in which actively involved hospital ethicists could have responded to the family's concerns).

³²⁶ *Id.* (Aviv reports that the physician in question did not accept Sandra's characterization of their discussion).

“We African Americans? I felt so belittled. Yes, a lot of black children die in Oakland and people do have funerals for their children—but that don’t mean all of us are like that. Do you think we’re supposed to be used to our children dying, that this is just what black people normally go through?”³²⁷

Jahi’s mother later told a *New Yorker* reporter that she wondered what lay behind the hospital’s responses to her child: “No one was listening to us, and I can’t prove it, but I really feel in my heart: if Jahi was a little white girl, I feel we would have gotten a little more help and attention.”³²⁸ The family felt that they received no compassion from the hospital administration or clinicians.³²⁹ Jahi’s story demanded the attention of hospital ethicists who would, ideally, have discussed the family’s concerns with them and would have facilitated communication between Jahi’s family and her clinicians. That seems not to have happened. A hospital Medical Ethics Committee did apparently review the hospital’s decision not to continue life-sustaining care for Jahi and concluded that that decision was appropriate. The Committee also concluded “that accommodating the family’s requests [for continuing care] raised “significant concerns of justice and fairness” and could establish “a troubling precedent for the future.”³³⁰ These conclusions did not bridge the painful gap that had developed between Jahi’s family and her clinicians and did not help the family respond to their shock and grief in the weeks following Jahi’s brain death diagnosis. Well-trained ethicists, ready to devote the time needed to this case might even have precluded the subsequent litigation between Jahi’s family and the hospital. Indeed, Sandra wondered, later, whether the family “would . . . have fought so much” if they had been treated with more respect by hospital personnel.³³¹

In addition, the family’s loss of trust in hospital personnel may have been exacerbated by knowledge of a long history of disrespect within the medical and scientific establishments for African

³²⁷ *Id.*

³²⁸ *Id.*

³²⁹ *See id.*

³³⁰ Christopher M. Burkle et al., *Why brain death is considered death and why there should be no confusion*, 83 *NEUROLOGY* 1464, 1467-68 (2014).

³³¹ *Aviv, supra* note 137.

American patients and research subjects. In the United States, African Americans had often been used and abused as experimental subjects, frequently without consent.³³² Moreover, bias and prejudice have affected medical care in clinical settings.³³³ Yolanda Wilson, a philosopher at Howard University, believes that this history helps explain the incredulity of Jahi's family about the level of medical care that the girl received, about hospital responses to them after Jahi's brain death diagnosis, and about motivations behind that diagnosis.³³⁴ In Wilson's view, the discriminatory treatment to which the family believed that it had been subjected, increased their pain and grief.³³⁵

A history of distrust, in John Paris's words, was "on full display at community-organized demonstrations outside Oakland Children's Hospital"³³⁶ in the days following Jahi's final diagnosis there: "Accusations were made that the hospital disrespected the family, portrayed the parents as 'ignorant,' and 'wanted a quick end to Jahi's life' to limit malpractice costs. The fact that the oxygenated body appeared 'warm and alive' rather than 'cold and dead' created a problem of perception."³³⁷

IV. The Law and the Media: What Made a Difference for Elizabeth Bouvia and Jahi McMath?

The legal cases initiated by Bouvia and by McMath's family were at least as significant as pivots around which media reported these stories of death and dying as they were in directing the course of events for either Elizabeth Bouvia or Jahi McMath. In some part, this media attention may have reflected the appeal of "damsels in

³³² See Yolonda Wilson, *Why the case of Jahi McMath is important for understanding the role of race for black patients*, THE CONVERSATION (Jul. 12, 2018), <https://theconversation.com/why-the-case-of-jahi-mcmath-is-important-for-understanding-the-role-of-race-for-black-patients-99353> (referring to the gynecological experiments of J. Marion Sims in the nineteenth century, to the decades-long Tuskegee study, sponsored by the U.S. Public Health Service, and to the robbery of bodies from cemeteries in which African Americans were buried, among other matters).

³³³ See *id.* (noting that this has resulted in "patient anxiety, as well as lower engagement in health care decision-making between patient and provider").

³³⁴ See *id.*

³³⁵ See *id.*

³³⁶ Paris, *supra* note 204, at 378.

³³⁷ *Id.*

distress.” Both Bouvia and McMath were young—the first a young woman, the second a teenager—and both (or more accurately, Bouvia and McMath’s family) refused to live or die in a manner expected of them by the law and by medicine.

a. Practical, Social, and Ideological Implications of Legal Holdings Regarding Bouvia and McMath

The first time that Elizabeth Bouvia asked a court to order clinicians to withdraw tubes supplying her with nutrition and hydration and thus to facilitate Bouvia’s expressed wish to die, the court refused to do that.³³⁸ But three years later, when Bouvia went to court for a second time, a California appellate court granted her the right to exercise her preference for death over life, understanding the withdrawal of food and water by hospital clinicians while Bouvia remained a patient in the hospital, as tantamount to any patient’s refusing to accept recommended medical care.³³⁹

Bouvia and her attorneys had re-shaped her claims to facilitate this understanding. When she first sought judicial assistance in the early 1980s, Bouvia stated that she hoped to die from starvation. In 1985, when she went to court for a second time, she claimed that she wanted only to make medical decisions for herself, including decisions about assisted hydration and nutrition.³⁴⁰ The shift in language mitigated focus on the implications of asking clinicians to assist in Bouvia’s death.

In 1985, when Elizabeth Bouvia attempted for the second time to gain legal authorization to stay in a public hospital while refusing life-sustaining care, American society had begun seriously to contemplate

³³⁸ See *supra* notes 44-52 and accompanying text.

³³⁹ See *supra* notes 53-57 and accompanying text.

³⁴⁰ See Marcia Chambers, *Woman Who Fought To Die Is Back In Court*, N.Y. TIMES (Feb. 9, 1986), <https://www.nytimes.com/1986/02/09/us/woman-who-fought-to-die-is-back-in-court.html>;

legalizing a right to assisted suicide.³⁴¹ The appellate court's 1986 decision seemed to support arguments in favor of that right.³⁴²

However, for Bouvia, herself, the court's decision did not lead to her death. She decided not to take advantage of the right that the court extended to her.³⁴³ Yet, the many news articles about Bouvia's request and the courts' responses brought significant public attention to the so-called "right to die" with physician assistance.³⁴⁴

Bouvia's legal cases also brought public attention to social understandings of people with disabilities. That attention defined conflicting visions of disability. The courts that entertained Bouvia's cases tended to view her situation as calling for heroism or pity.³⁴⁵ But disability rights activists contended, in sharp contrast, that that view was deeply biased and harmful to people with disabilities.³⁴⁶

The legal proceedings that surrounded Jahi McMath's case did not change state law.³⁴⁷ However, the public media presentations and scholarly analyses of the case that reported on and interpreted the legal proceedings did influence some lawmakers and medical clinicians to reconsider the implications of a brain death diagnosis.³⁴⁸ They also focused attention on the perception of Jahi's family that they, and Jahi, had been the targets of biased responses, particularly from hospital personnel.³⁴⁹

³⁴¹ See also *How Death with Dignity Laws Work*, DEATH WITH DIGNITY (last accessed Sep. 28, 2021), <https://deathwithdignity.org/learn/access/> (Oregon first granted the right to assisted suicide through a voter initiative in 1994. By 2021, other states that had passed laws providing for physician assistance with dying include California, Colorado, the D.C., Hawaii, Maine, New Jersey, New Mexico, Oregon, Vermont, and Washington).

³⁴² *Bouvia*, 179 Cal. App. at 1147 (Compton, J., concurring).

³⁴³ See *supra* Section III (A) and accompanying text. This is not to contend that the legal case held no consequences for Bouvia, only that it held no consequences insofar as the law which she contested had precluded her from starving to death, but when given that right, she turned it down. It is possible, if not likely, that Bouvia gained a great deal from the legal proceedings that she initiated – in particular, the fact of having been witnessed.

³⁴⁴ Bouvia's story occurred before the Internet. Thus, there were fewer avenues for discussion of her story than were available when McMath was declared brain dead. Still, however, there were scores of news stories and law review articles that discussed Bouvia's case. See *infra* Section V(B) (noting results of search).

³⁴⁵ See *supra* notes 78-84 and accompanying text.

³⁴⁶ See *supra* note 42-3 and accompanying text; *infra* notes 373-380 and accompanying text.

³⁴⁷ See *supra* subsection IV(A) (discussing legal proceedings relevant to Jahi McMath).

³⁴⁸ A July 2021 search (July 20, 2021) revealed thousands of relevant studies about Jahi McMath's situation; see *supra* note 17; see also Section V.

³⁴⁹ See *supra* notes 323-337.

For Jahi McMath's family, the law was not directly helpful except insofar as courts encouraged a negotiated agreement,³⁵⁰ which made a significant practical difference for Jahi's family. That agreement resulted in Jahi's mother gaining custody of Jahi's body for transport to New Jersey.³⁵¹ In the years during which Jahi was in New Jersey, her story was reviewed again and again. That attention did make a difference in views of brain death.³⁵²

When Jahi was initially transferred to New Jersey, the facility's website declared that Jahi "has been defined as a deceased person, yet she has all of the functional attributes of a living person despite her brain injury."³⁵³ Robert Truog, a bioethicist and pediatrician, noted the comment of one "prominent bioethicist [who] quipped: 'You can't really feed a corpse.'"³⁵⁴ Truog added: "This is correct, of course, but given that McMath and other brain-dead patients can not only be fed, but can digest the food, excrete wastes, and grow and develop, he [the bioethicist] was unwittingly undermining his own position."³⁵⁵

Soon after McMath's surgery and the declaration that she was brain dead, a number of bioethicists criticized the family and others who insisted on treating Jahi as a living child. Lawrence McCullough at the Center for Medical Ethics and Health Policy at Baylor College of Medicine in Houston commented that the medical facility that had accepted Jahi's body must have been suffering from "disordered" thinking "from a medical point of view . . . There is a word for this:

³⁵⁰ That agreement was facilitated by state and federal courts. See *supra* notes 149-80 and accompanying text.

³⁵¹ In the eyes of the family, they gained custody of Jahi, herself – a living child. See *supra* note 173-189 and accompanying text.

³⁵² Law review articles looked to McMath's situation to suggest an ambiguity at the center of the notion of brain death. See, e.g., Ben Nipper, *Comment & Note, Legislating Death: A Review and Proposed Refinement of the Uniform Determination of Death Act*, 17 HOUS. J. HEALTH L. & POL'Y 429, 453 (2017); Seema K. Shah, *Article: Piercing the Veil: The Limits of Brain Death as a Legal Fiction*, 48 U. MICH. J.L. REFORM 301, 306 (2015); Robert D. Truog, *Symposium: Science Challenges for Law and Policy: Defining Death: Getting It Wrong for All the Right Reasons*, 93 TEX. L. REV. 1885, 1897 (2015).

³⁵³ Truog, *supra* note 352, at 1895.

³⁵⁴ *Id.* at 1896.

³⁵⁵ *Id.* (citing Margaret Lock, TWICE DEAD: ORGAN TRANSPLANTS AND THE REINVENTION OF DEATH, 243-44 (2002)).

crazy. “³⁵⁶ Arthur Caplan opined that the girl’s physicians in New Jersey were “trying to ventilate and otherwise treat a corpse. “³⁵⁷ By 2018, when Jahi was declared dead in New Jersey, according to cardio-pulmonary criteria, scholarly discussion and legal debate had, in some part, shifted gears on the matter of brain death.³⁵⁸ Law professor Thadeus Pope contented in 2018 that critics of the notion of brain death had begun to

us[e] the courts to successfully challenge prevailing and long-standing brain death principles. In other words, what has long been an intellectual and scholarly debate is now increasingly framed as a question of law and public policy. The legal status of brain death is no longer merely a subject for more scrutiny and deliberation. It is now a target for fundamental reassessment of settled practices.³⁵⁹

Yet, for the McMath family, their ability to transport Jahi to New Jersey was a matter of central importance. In New Jersey, Jahi was fed and ventilated for more than four years. This arrangement was the result of the family’s concerted and pro-active insistence that Jahi’s brain had been injured, but that she was not dead.³⁶⁰

b. Autonomy and Community

The contrast between Elizabeth Bouvia’s separation from community sharply distinguishes her story from that of Jahi, whose family stressed community rather than autonomy. Together, these cases present a challenging stage on which to consider the comparative importance of autonomy and community in bioethical debate. Perhaps too often, bioethicists have invoked the notion of individual autonomy in describing and responding to patients’ ethical

³⁵⁶ Liz Szabo, *Ethicists criticize treatment of brain-dead patients*, NAT’L. CATH. REP. (Jan. 10, 2014).

³⁵⁷ *Id.*

³⁵⁸ See, e.g., Pope, *supra* note 218, at 267-68 (noting that in the previous couple of years “the slow simmer of an academic debate” about brain death had “begun to boil over into a legal conflagration.”).

³⁵⁹ *Id.* at 268.

³⁶⁰ See *supra* notes 28-29 and accompanying text.

challenges. Failure to understand the power of community as a balance to autonomy has limited bioethical debate.

Even as hospital bioethicists have stressed the patient's right to autonomy in clinical care, they have noted the potential conflict between autonomy and clinician beneficence – the obligation of clinicians to serve their patients' best interests. One law professor, himself a physician and an attorney, asserted that "at some point" the two values are bound to conflict with each other.³⁶¹ Perhaps underlying the conflict between autonomy and beneficence sits a more profound divergence between autonomy and community. The implications of this underlying conflict reflect shifts in the Western social order, beginning during the second half of the twentieth century.

Before the 1960s, American culture largely separated everyday life into two domains – the marketplace and the personal arena (e.g., the family).³⁶² Different values governed and characterized each domain. At work, people functioned as autonomous individuals, free (often in theory more than in fact) to negotiate and re-negotiate the terms of their employment. At home, people valued a social hierarchy, organized in terms of status and attendant roles. As society viewed money to govern at work, so it viewed love to define the home and hearth.³⁶³ That social order began openly too far apart by the 1960s, and by the start of the twenty-first century, the values that once separated work from home had largely merged.³⁶⁴ The intimate community that once characterized (or more accurately, was expected to characterize) the family had been replaced—at least with regard to adults—with negotiated arrangements that endured only as long as the parties involved chose to stay connected.³⁶⁵ Yet, the values of the traditional family have not disappeared entirely, and there remains a significant yearning for the presumptive trust, shared values, and

³⁶¹ Brian Liang, *Bouvia v. Superior Court: Quality of Life Matters*, 7 ETHICS J OF THE AMA (Feb. 2005).

³⁶² See Janet L. Dolgin, *The Family in Transition: From Griswold to Eisenstadt and Beyond*, 82 GEO. L.J. 1519, 1525 (1994) (the domain of family was often conflated with that of church).

³⁶³ See *id.* at 1551.

³⁶⁴ See Janet L. Dolgin, *The Constitution as Family Arbiter: A Moral in the Mess?*, 102 COLUM. L. REV. 337, 347-348 (2002).

³⁶⁵ See *id.* at 340.

support offered by the community. At least to some extent, Elizabeth Bouvia's story stands for autonomy and Jahi McMath's story stands for community.

As an adult, Bouvia lived alone, largely without strong communal associations, but surrounded by hospital clinicians and staff. That seems to have been her preference.³⁶⁶ In court, she asked for the right to have her "choice" to die with the assistance of hospital clinicians respected by the law and thus by her treating clinicians. In a statement that Bouvia released through Richard Scott, her attorney, she declared that "as an individual," she had "the right to make an individual choice with regard to [her] own future."³⁶⁷ Bouvia expressly rejected the opportunity to become involved with members of the disability rights community:

"I am aware that many disabled people volunteered to come to Riverside to talk to me about my decision and about other options. While I appreciate those offers, I do not wish to accept them. I wish to re-emphasize that I reviewed my alternatives, and that I now simply wish to be left alone. This is a personal and very private decision, which I have made after long and careful thought."³⁶⁸

Autonomy does not necessarily suggest aloneness. In bioethical discourse, autonomy is only rarely connected expressly with aloneness or loneliness. Yet, American society has witnessed increasing stress on autonomy, especially in family life and in healthcare relationships, in the last six decades, and at the same time, communal relationships have become less accessible to many people.³⁶⁹ Jahi McMath's story defies this pattern. The power of the familial community and of the larger community that surrounded and supported Jahi's family go far toward explaining the family's success in arranging for Jahi to receive life-sustaining care for over four years

³⁶⁶ At any rate, Bouvia claimed that this was her choice. See generally Johnson, *supra* note 38.

³⁶⁷ Johnson, *supra* note 38.

³⁶⁸ *Id.* (quoting from statements that Elizabeth Bouvia gave to Richard Scott).

³⁶⁹ See Robert D. Putnam, BOWLING ALONE: THE COLLAPSE AND REVIVAL OF AMERICAN COMMUNITY, 252 (Simon and Schuster, 2000) (examining disengagement of Americans from communal activities since start of 1950s).

after the girl was declared brain dead in California.³⁷⁰ Public media focused on the notion of brain death, on conflicts between one family and the medico-legal establishments, and on Jahi's unrelenting family support. This brought widespread attention to the family's cohesive commitment to, and success in, sustaining Jahi's care between late-2013 when she died in California, and mid-2018 when she died in California. Aspects of Jahi's story present a model that bioethicists might heed. Autonomy needs to be balanced not only against beneficence but, as well, against the preservation of communal relationships within the society and, more specifically, within the world of health care.

c. Law, Medicine, Media, and Bias

Both the story of Elizabeth Bouvia and that of Jahi McMath have informed lawmakers, medical clinicians, and the public on the implications of withdrawing life-sustaining care – in the first case for a patient who requested the cessation of such care, and in the second case, for a patient deemed brain dead whose family resisted that diagnosis. Each case has stimulated public debate about death and dying and about the role of bias in the context of decisions about death and dying.

Several dozen subsequent legal cases³⁷¹ have cited *Bouvia v. Superior Court*, decided in 1986, often for the proposition that a competent patient has the right to refuse recommended medical treatment.³⁷² Further, the stories about Bouvia that supported and then developed out of the legal cases have stimulated continuing responses from disability-rights activists.³⁷³ News stories about

³⁷⁰ See *supra* Section IV(C) and accompanying text.

³⁷¹ See *e.g.*, *Compassion in Dying v. Washington*, 85 F.3d 1140, 1144 (9th Cir. 1996) (O'Scannlan, J., dissenting); *Cruzan v. Dir., Mo. Dep't. of Health*, 497 U.S. 261, 270 (1990) (citing *Quinlan* for proposition that competent patient "generally possesses the right not to consent, that is, to refuse treatment"); *Conservatorship of Drabick*, 245 Cal. Rptr. 840, 846 (Cal. App. 6d 1988) (citing *Bouvia* for proposition that clinicians are obliged to respect the refusal of care if requested by a competent patient).

³⁷² *Bouvia*, 179 Cal. App.3d at 1141.

³⁷³ See William R. Macklin, *Disability-rights activists answer right-to-die comment with protest: Members fighting to show they aren't a drain on society*, DALL. MORNING NEWS (Sep. 26, 1999), <https://1.next.westlaw.com/Document/10cb92c00fb6d11dab681e9ec8c7fd03c/View>

Bouvia's legal cases appeared when she first sought assistance in court and continued for years after that.³⁷⁴ Early on, Bouvia appeared on the evening news and was the subject of many news articles.

Many of these stories reflected a significant bias toward people with disabilities. A number of stories about Bouvia's situation, published in the 1980s, appeared under disconcerting headlines (e.g., "Quadriplegic Loses in Court Again,"³⁷⁵ "Suicide Banned for Quadriplegic"³⁷⁶ and "Life of Agony"³⁷⁷). In 1984, a law review article about Bouvia's story reported that public presentations about Bouvia often reflected serious biases:

The manner in which the story was presented reflected attitudes the general public holds toward disability. . .

Rather than address the social or political implications of the case, . . . media coverage merely reflected images many nondisabled people have about what it would be like to be disabled. Society still sees disability as a very unfortunate situation, in fact, it is often seen as one of the worst things that can happen to an individual. Society feels sorry for Bouvia, the generic pity that it feels for all disabled people.³⁷⁸

Yet, some stories about Bouvia in the years after she brought her case to court aimed to reveal the biases that undergirded responses to her and to encourage society, generally, to rethink biases about people with disabilities. A 1984 story (written between Bouvia's first court case and her second) described her as living in "Southern California," "taking regular nourishment," and "waiting for a better opportunity" to stop eating.³⁷⁹ The piece noted that disability rights activists

/FullText.html?transitionType=UniqueDocItem&contextData=(sc.Default)&userEnteredCitation=1999+WLNR+7721289&reason=1011&OWSessionId=5d77baab90a94de99ef4df0485785d76&firstPage=true&bhcp=1&ignorebhwarn=IgnoreWarns&CobaltRefresh=13216.

³⁷⁴ See Stradley, *supra* note 52, at 422.

³⁷⁵ Murray Dubin, *Quadriplegic Loses in Court Again Calif. Supreme Court Rejects Starvation Suicide*, PHILA. INQUIRER (Jan. 20, 1984), available in WestLaw Edge at 1984 WLNR 160824.

³⁷⁶ United Press International, *Suicide Banned For Quadriplegic*, PHILA. DAILY NEWS (Jan. 20, 1984), available in WestLaw Edge at 1984 WLNR 10021.

³⁷⁷ See generally Stradley, *supra* note 52, at 422.

³⁷⁸ *Id.*

³⁷⁹ Jay Arnold, *Elizabeth Bouvia, the quadriplegic who quietly left a hospital seven months after a futile battle for the right to starve to death, is in failing health waiting for "a better*

claimed that assisting Elizabeth in a wish to die was “criminal and dangerous,” particularly because she had not been given a chance to live a full and dignified life.³⁸⁰

Over a decade after the California appellate court granted Elizabeth the right to refuse assisted nutrition and hydration (in 1986),³⁸¹ Diane Coleman, founder of Not Dead Yet (a disability-rights organization), traced her own pro-active stance in the protection of people with disabilities back to Bouvia’s case, explaining that the appellate court decision “paved the way for abuse.”³⁸² A news article, printed a year earlier, also referencing Bouvia’s case, focused on the fear of members of Not Dead Yet that a “‘right’ to die can become a ‘duty’ to die.”³⁸³ Some people working to advance the disability rights platform viewed Bouvia as “a sort of reverse poster child” for disability rights advocates.³⁸⁴

Similarly, Jahi McMath’s story received widespread attention in public media. Stories about Jahi’s evolving situation brought renewed attention to the challenging implications of brain death diagnoses. Some media stories also focused attention on the role of biases in health care. In Jahi’s story, bias has been identified not so much in judicial responses to the family’s requests, but in responses from hospital clinicians and administrators to Jahi and to the girl’s family in the days following the brain death diagnosis.

As reported by family members, that treatment lacked compassion. As the girl began to bleed profusely and Jahi’s family members sought assistance for her, nurses were lackadaisical and almost no doctors responded at all.³⁸⁵ One physician, on the other side of the ICU from Jahi’s bed, hardly responded to Sandra’s queries. To

opportunity to die,” her attorney said., AP ONLINE (Nov. 12, 1984) (quoting Bouvia’s attorney, Richard Scott).

³⁸⁰ *Id.* (quoting Disability Rights Coordinating Council).

³⁸¹ *Bouvia*, 179 Cal. App.3d, at 1144.

³⁸² Macklin, *supra* note 373 (Macklin references alternative views. Prof. Andrew Batavia, himself disabled, viewed the positions of Not Dead Yet as paternalistic, saying that disabled people should be allowed to decide whether to live or die, much as everyone else).

³⁸³ Erin Hoover Barnett, *Not Dead Yet Wants to Expand Suicide Debate*, THE OREGONIAN (Aug. 1, 1998), [https://www.westlaw.com/Document/I8f140e10e02c11daabafec86ceb66b1c/View/FullText.html?transitionType=Default&contextData=\(sc.Default\)&VR=3.0&RS=cbt1.0](https://www.westlaw.com/Document/I8f140e10e02c11daabafec86ceb66b1c/View/FullText.html?transitionType=Default&contextData=(sc.Default)&VR=3.0&RS=cbt1.0).

³⁸⁴ Beyette, *supra* note 125.

³⁸⁵ See *supra* Section IV and accompanying text.

Sandra, “[i]t was like he thought we were dirt.”³⁸⁶ Then, after Jahi’s brain death diagnosis, family members were pressured to consent to the withdrawal of care, but no one explained to the family what had happened that resulted in a tonsillectomy leading to brain death; family members were not permitted to see the girl’s medical records; no one at the hospital apologized, despite requests from the family. Even more disturbing to the family, social workers pressured the family to agree to the withdrawal of ventilatory support for Jahi and asked them to consent to the donation of the girl’s organs.³⁸⁷ Several days after the brain death diagnosis, the hospital’s chief medical officer dismissed the family’s request that the hospital provide Jahi with a feeding tube; a clinician asked the family what they failed to comprehend, but clearly not expecting to be queried or to respond to the family’s questions, he continued: “What is it that you don’t understand. . . . She’s dead, dead, dead.”³⁸⁸

These responses, assuming that the family’s reports were accurate, failed to attend to the needs of a grieving family. They were inappropriate, at best. Whether such responses to the family reflected frustration, impatience, or bias is not clear, but the family certainly thought that the hospital’s responses were grounded in bias or prejudice. They openly wondered whether the treatment provided to Jahi would have been different—more attentive, more caring—were Jahi not Black.³⁸⁹ Whatever the explanation—and Nailah’s explanation (that Jahi and her family’s skin color shaped responses) may be the right one³⁹⁰—the treatment that the hospital and its clinicians reportedly offered to this girl and her family was harsh, even unseemly.

³⁸⁶ Aviv, *supra* note 137.

³⁸⁷ *Id.* (Marvin Winkfield, Jahi’s stepfather, thought, when the family was asked to donate the girl’s organs that the request was unacceptable in light of the lack of information that had been given to the family. He reported later: “We were like. . . , ‘Nah’ . . . First tell us what happened to her.”).

³⁸⁸ *Id.*

³⁸⁹ *See id.*

³⁹⁰ *See id.*

Conclusion

Both Elizabeth Bouvia and Jahi McMath (through her family) refused to follow social and medical expectations about how and when to die. In the early 1980s, a California trial court expected Bouvia to show heroism in submitting to a life with disabilities.³⁹¹ By 1986, expectations had changed with a change in social presumptions as well as in court and judge: now, Bouvia gained the right to die and her situation was understood to justify her preference for death over life.³⁹² Almost no one involved in the case asked whether Bouvia was depressed for reasons only indirectly connected to her disabilities and whether that depression might have found relief in proper treatment.

Jahi McMath's family similarly defied expectations. The family refused to agree to the withdrawal of ventilatory support. One physician even contended that the family should accept Jahi's death sooner rather than later so that her body would look good at her funeral.³⁹³ The Winkfield and McMath family insisted that Jahi had not died despite the conclusions of her doctors and the provisions of state law.

Legal decisions for³⁹⁴—and against³⁹⁵—Bouvia reflected bias against people with disabilities. These biases—in particular, that disabled people could not thrive, could not live full, vibrant lives, and should, instead, be pitied—were deeply ingrained in the society. Bouvia's legal cases and the stories that surrounded them and that followed in their wake brought some of those biases to light. These stories were used by the fledgling disability rights movement to frame social biases against people with disabilities and the implications of those biases.

Courts' responses to cases initiated by Jahi's family were more circumspect, revealing less about the judges' perspectives than was true of court responses to Bouvia's claims.³⁹⁶ Yet, for McMath, as for

³⁹¹ See *Bouvia I*, *supra* note 22, at 491.

³⁹² *Bouvia*, 179 Cal. App.3d, at 1144.

³⁹³ See *Aviv*, *supra* note 137 (noting disclaimer).

³⁹⁴ See *Bouvia*, 179 Cal. App.3d, at 1144.

³⁹⁵ See *Bouvia I*, *supra* note 22, at 491.

³⁹⁶ To some extent, the express appearance of bias in Bouvia's case reflects social presumptions at the time. The courts, the lawyers—Bouvia herself—did not seem to understand

Bouvia, bias was part of the underlying story. Whether clinicians and hospital administrators' treatment of Jahi and of her family were grounded in bias and prejudice is not clear from available reports but is suggested by some of those reports.³⁹⁷

Ironically, Bouvia, herself, did not perceive what others saw as bias, while McMath's family perceived bias when others did not seem to recognize it. At least some clinicians and/or attorneys who should have cared for these patients/litigants seem, instead, to have responded to them through lenses colored by social biases. Many of their reported responses were callous, unthoughtful, and, for McMath's family, at least, profoundly painful.³⁹⁸

Had these cases not invoked complicated social debates about death and dying, the two stories—that of Bouvia and that of McMath—might not have been told in public settings. Had they not involved two compelling patients, they also might have been less compelling to the public and received less attention or stimulated fewer responses. That they were widely considered and reported has helped society clarify its understandings of death or dying, while raising new and challenging questions about autonomy, community, and bias. Indeed, each story has identified deeply ingrained biases and, arguably, more explicit prejudice in medical and legal settings.

Through these stories, even as they are uneven and often contradictory, society has been encouraged to make sense of social responses to the issues occasioned by the Bouvia and McMath stories and to contemplate whether and how to re-shape its responses. More specifically, challenges occasioned by the stories of Elizabeth Bouvia and Jahi McMath have pushed society more carefully to consider the shape of death and the force of bias in medical and legal deliberations.

that their view of disabled people was grounded in bias, even if that bias is transparent from a contemporary perspective.

³⁹⁷ See, e.g., Aviv, *supra* note 137; Wilson, *supra* note 332; Goodwin, *supra* note 303.

³⁹⁸ See Wilson, *supra* note 332.