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# Don't Pull the Plug on Bioethics Mediation: The Use of Mediation in Health Care Settings and End of Life Situations

AMY MOORKAMP\*

## I. INTRODUCTION

Theresa Marie “Terri” Schiavo was a woman who suffered cardiac arrest in 1990 which left her in a persistent vegetative state.<sup>1</sup> Terri Schiavo’s case made headlines in 2005 in a well-publicized right-to-die case.<sup>2</sup> The controversy festered in the clashing of opinions voiced from both Schiavo’s husband (her legal guardian) and Schiavo’s parents.<sup>3</sup> Schiavo’s husband argued that his wife would not have wanted prolonged artificial life support without the prospect of recovery, and advocated for removal of her feeding tube.<sup>4</sup> Conversely, Terri Schiavo’s parents advocated for a continuation of artificial nutrition and hydration for their daughter.<sup>5</sup> This well-documented conflict amounted to an array of legal challenges, ultimately involving state and federal politicians alike, including President George W. Bush.<sup>6</sup> The result was a seven-year delay before eventual removal of Terri Schiavo’s feeding tube.<sup>7</sup>

A hefty decision, such as the life or death of a loved one, requires more than a few minutes of deliberation and a handful of outside consultations. Delicate, emotional, and potentially contentious medical decisions compel a structured, compassionate approach to produce quality and well-informed results. Due to the magnitude of the decision being made, as well as the abundance of other considerations, (emotional, religious, historic, financial, etc.) the case for a creative, problem-solving process of dispute resolution, such as mediation, is ripe.

This Comment will explore the use of mediation in bioethical disputes. In Part II, the Comment will give an overview of bioethics and examine its inherent nuances and complexities. Part III will examine mediation and its application in health care settings. Finally, Part IV will advocate for increased use of mediation in bioethics disputes in recent, applicable scenarios and cases.

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\* B.A., University of Missouri 2015, J.D. Candidate, University of Missouri School of Law 2018. I would like to thank the editorial board of the *Journal of Dispute Resolution* for their careful and considerate edits to this Comment. I would also like to thank my family and friends for their unwavering encouragement of all my pursuits. I would especially like to thank my late grandfather for his consistent support and for unknowingly lending valuable insight to this Comment.

1. Jennifer Frey, *Terri Schiavo’s Unstudied Life*, WASH. POST, Mar. 25, 2005, at C01.
2. *Id.*
3. *Id.*; Brad Smith, *Schiavo Videotapes Offer Powerful But Misleading Evidence*, TAMPA TRIB. (Mar. 20, 2005), <http://news.tbo.com/news/MGBQ67CTI6E.html> [<https://archive.li/5RPkW>].
4. Frey, *supra* note 1, at C01; Smith, *supra* note 3.
5. Frey, *supra* note 1, at C01; Smith, *supra* note 3.
6. Frey, *supra* note 1, at C01.
7. *Id.*

## II. BIOETHICS

## A. An Overview

Ethics is the philosophical study of principles of morality and human behavior—good and bad, right and wrong.<sup>8</sup> Bioethics is the meshing of fields—ethics with medicine and healthcare.<sup>9</sup> More often than not, ethicists and bioethicists create relevant questions and inquires rather than forming sure and certain answers.<sup>10</sup> One integral question in the field of bioethics is whether or not physicians, patients, or families *should* preserve life “on its margins” when modern advances in medicine have provided the ability to do so.<sup>11</sup> Relationships, namely between caregiver and patient, give rise to a set of four main ethical principles.<sup>12</sup> The first principle is patient autonomy, which focuses on helping a capable patient exercise independence.<sup>13</sup> The second principle is beneficence, honing in on furtherance of the patient’s best interests while insulating them from potential harms.<sup>14</sup> The third principle is nonmaleficence, which fixates on evasion of any wrongs being done to the patient.<sup>15</sup> The fourth and final principle is distributive justice, a principle which attempts to evenly distribute the “benefits and burdens related to health care delivery.”<sup>16</sup>

Bioethicists ask questions in the context of modern medicine and strive to promote public awareness of moral philosophy and relevant advances in healthcare.<sup>17</sup> Changes in medical technology significantly affect the way populations experience the meaning of health and illness, and, ultimately, life and death.<sup>18</sup> The field of bioethics is composed of contributions from many disciplines, as it blends “philosophy, theology, history, and law with medicine, nursing, health policy, and the medical humanities.”<sup>19</sup> Over the past forty years, these diverse groups of scholars worked to identify “shared values that provide the basis for normative principles and rules.”<sup>20</sup> Major issues of care have emerged that simply did not exist prior to modern technological advances. As technology and health care experienced metamorphosis, so too did the body of principles and rules that guide these advances.<sup>21</sup>

When the term “bioethics” was first coined,<sup>22</sup> it may have been representative of the mere union of biology with humanistic knowledge.<sup>23</sup> Today, however, the

8. *What is Bioethics?*, THE CTR. FOR PRAC. BIOETHICS, <https://practicalbioethics.org/what-is-bioethics> (last visited Apr. 6, 2017).

9. *Id.*

10. *Id.*

11. *Id.*

12. NANCY N. DUBLER & CAROL B. LIEBMAN, *BIOETHICS MEDIATION: A GUIDE TO SHAPING SHARED SOLUTIONS* 8 (Vanderbilt Univ. Press, rev. & expanded ed. 2011) (2004).

13. *Id.*

14. *Id.*

15. *Id.*

16. *Id.*

17. *What is Bioethics?*, *supra* note 8.

18. *Id.*

19. *Id.*

20. DUBLER & LIEBMAN, *supra* note 12, at 8.

21. *Id.*

22. Some say the term was first coined by University of Wisconsin professor Van Rensselaer Potter, while others say it was coined by fellows of the Kennedy Institute in Washington, D.C. *What is Bioethics?*, *supra* note 8.

23. *What is Bioethics?*, *supra* note 8.

field of bioethics encompasses a full range of concerns.<sup>24</sup> These concerns range from tough private medical decisions, to controversies spawned by stem cell research, to repercussions of reproductive technologies, to more broad concerns such as international human medical research, to health care policies generally, and to the distribution of scarce resources.<sup>25</sup> These concerns can be reduced to four main groups: Aging and End of Life, Clinical and Organizational Ethics, Life Sciences, and Disparities of Health and Healthcare.<sup>26</sup> Due to the private nature of many medical concerns, real case studies can be few and far between. The end of life cases are somewhat more accessible,<sup>27</sup> (due to their sometimes more controversial nature) and provide a thought-provoking foundation for discussion, thus the end of life cases will be the practical focus of this article.

### *B. Purpose*

Defining bioethics is helpful, but understanding what the field accomplishes is essential to comprehension of the law's close encounters with bioethics. As this area changes, bioethics has become a prominent player in legislation, public policy, and other everyday applications of principles and values.<sup>28</sup> Considered a more recent discipline, bioethics "has a burgeoning literature, with journals and publishers . . . [and] hundreds of vocational specialists in clinical ethics consultation, and others in bioethics departments within traditional academia."<sup>29</sup> Today, "[i]t would be difficult . . . to find a health care institution of any quality that does not have an ethics committee addressing staff education, policy protocols, and at the very least, retrospective case consultation or review."<sup>30</sup>

In 1992, the Joint Commission on Accreditation of Healthcare Organizations established "a new standard that required all accredited institutions to have the capacity to address ethical issues in medical care and practice."<sup>31</sup> In the formative stages, most bioethics committees "engaged in retrospective analysis as a way of

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24. *Id.*

25. *Id.*

26. *Id.*

27. *See generally, In re Martin*, 538 N.W.2d 401 (Mich. 1995) (end of life case where prior oral statements made by patient did not rise to clear and convincing level of evidence required to show that patient would not have wanted to receive life-sustaining treatment while incompetent but conscious); *In re K.I.*, 735 A.2d 448 (D.C. App. 1999) (end of life case where the best interest of child standard applied to DNR determination for neglected child); *Matter of In re Guardianship of L.W.*, 482 N.W.2d 60 (Wis. 1992) (end of life case where a guardian sought authority to consent to withdrawal of all life-sustaining medical treatment, including artificial nutrition and hydration, from incompetent patient who was in persistent vegetative state. The Supreme Court of Wisconsin held that: (1) incompetent individual in persistent vegetative state has right to refuse life sustaining medical treatment, including artificial nutrition and hydration, and (2) court-appointed guardian may exercise such right on patient's behalf without obtaining prior authority of court, although decision may be reviewed by court at instance of parties in interest); *In re Doe*, 37 N.Y.S.3d 401 (N.Y. Sup. Ct. 2016) (end of life case where incapacitated person's end-of-life wishes could not be reasonably ascertained and the Supreme Court in Kings County, New York held, among other things, that withdrawal of life support was in the incapacitated person's best interests); *Conservatorship of Wendland*, 28 P.3d 151 (Cal. 2001) (end of life case where clear and convincing proof was needed to deny life-sustaining treatment to conscious conservatee).

28. *What is Bioethics?*, *supra* note 8.

29. *Id.*

30. DUBLER & LIEBMAN, *supra* note 12, at 8.

31. *Id.*

educating themselves about the conflicts that exist in clinical practice.”<sup>32</sup> However, as some bioethics committees have developed, or spawned into actual specific consultant services, they have “increasingly become involved in real-time discussions that affect the outcome of patient care decisions under way.”<sup>33</sup> Intervention in decisions involving the withdrawal of treatment or the limitation of care ought to be made by an individual with adequate training and skills, who is guided by governing principles to ensure professionalism and structure in an intervention.<sup>34</sup>

### C. Clinical Ethics Consultation

Clinical Ethics Consultation (CEC) is a service administered by an individual, consultant team, or committee with a focus on ethical issues involved in any given clinical case.<sup>35</sup> Clinical ethics consultation is the current standard of practice that must be implemented, at a minimum, in hospitals.<sup>36</sup> The main purpose of a CEC program is to improve patient care by attempting to flag and understand ethical issues as they arise.<sup>37</sup> CEC is a service within the hospital that “provides an additional resource for difficult decisions and a conduit for complex communication among patients, their families (relatives, significant others, close friends and appointed surrogates), and the care team.”<sup>38</sup> A well-structured CEC does the following: (1) conducts programs focused on the relevant content and history of bioethics; (2) provides education on the ethical dimensions in medicine;<sup>39</sup> and (3) frequently mediates conflicts between medical professionals or staff and patients or loved ones.<sup>40</sup> It is necessary for the clinical ethics consultant to intervene and act promptly in a manner that helps empower patients and families.<sup>41</sup>

Clinical ethics consultation regularly involves mediation. However, CEC is distinguished from bioethics mediation because a bioethics mediation can be viewed more as a clinical intervention which balances the unique qualities of healthcare disputes (described below) with the demands of a medical setting.<sup>42</sup> Conversely, a CEC may inadequately weigh the desires of the patient when attempting to perform a consultation.<sup>43</sup>

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32. *Id.*

33. *Id.*

34. *Id.* at 9.

35. Nancy N. Dubler et al., *Charting the Future: Credentialing, Privileging, Quality, and Evaluation in Clinical Ethics Consultation*, 39 HASTINGS CTR. REP. 23, 25 (Nov.-Dec. 2009) [hereinafter *Charting the Future*].

36. *See id.*

37. *Id.*

38. *Id.* at 23.

39. *Id.* at 25 (e.g., directing conversations riddled with uncertainty, spelling out the ethical issues, explaining ethical viability of options, negotiating decisions to be made in complex medical scenarios).

40. *Id.* at 26.

41. *Charting the Future*, *supra* note 35, at 26.

42. DUBLER & LIEBMAN, *supra* note 12, at 16.

43. Armand H. Matheny Antommara, *Alternative Dispute Resolution and Pediatric Clinical Ethics Consultation: Why the Limits of Ethical Expertise and the Indeterminacy of the Best Interests Standard Favor Mediation*, 23 OHIO ST. J. ON DISP. RESOL. 17, 43 (2007) (citing AM. SOC’Y FOR BIOETHICS & HUMANITIES, CORE COMPETENCIES FOR HEALTH CARE ETHICS CONSULTATION 3, 9 (1998) [hereinafter ASBH]). “The [ASBH] contends access to ethics consultation should be open to patients, families, and surrogates and notes disagreement regarding which health care providers or others may request consultation. . . . The report, however, limits notification of patient to ‘situations where their participation in

### III. MEDIATION

Mediation is a form of alternative dispute resolution that is distinguishable from one of its counterparts, arbitration, chiefly because of its consensual nature.<sup>44</sup> Mediation is a process which aims to help parties reach an agreement where conflict exists.<sup>45</sup> Mediators are neutral third persons who facilitate negotiation between parties in conflict, assisting to find solutions that meet respective interests and needs.<sup>46</sup> A mediator possesses skills in communication, negotiation, and is well versed in conflict management.<sup>47</sup> The mediator “works with the parties, helping them identify their goals and priorities, generate and explore options, and exchange information that may be necessary for formulating a solution.”<sup>48</sup> Mediators are dissimilar from judges or arbitrators, because a mediator does not possess the authority to enforce any result on the involved parties.<sup>49</sup> The mediator helps parties to understand each other’s desires, values, and emotions.<sup>50</sup> Likewise, a mediator will “lay the groundwork to repair damaged relationships” and incite creative options for resolution.<sup>51</sup> It is common for the mediator to arrange meetings between disagreeing parties.<sup>52</sup> The mediator ideally listens, empathizes, encourages emotional outbursts when productive, urges the parties to face facts, urges them to listen, and lauds their efforts to accommodate.<sup>53</sup>

In sum, mediation can be a helpful tool in solving disputes. Participation in a meditative process may give participants the “opportunity to exchange information, clarify goals, and explore options that will aid in finding resolution in some other forum.”<sup>54</sup>

### IV. BIOETHICS MEDIATION

#### *A. The Nature of Health Care Settings*

The unique and delicate nature of health care disputes calls for a tailored approach to managing conflicts. Bioethics mediation has many specialized approaches to conflict management, providing a productive forum for dispute resolution in medical environments. Bioethics mediation has the potential to increase the independence of the patient, encourage the shared values of patient and family, and clarify and reinforce the agreed-upon values of medical care to be provided.<sup>55</sup> Sometimes, a bioethics mediation will conclude in the parties’ decision to execute

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decision-making is ethically required,” and permits consultations to proceed, in some cases, in spite of the patient’s refusal to participate.” *Id.*

44. SARAH R. COLE ET AL., *MEDIATION: LAW, POLICY AND PRACTICE* § 1:1, Westlaw (updated Dec. 2016).

45. MARK D. BENNETT & SCOTT H. HUGHES, *THE ART OF MEDIATION* 3 (2d ed. 2005).

46. DUBLER & LIEBMAN, *supra* note 12, at 11.

47. BENNETT & HUGHES, *supra* note 45, at 3.

48. DUBLER & LIEBMAN, *supra* note 12, at 11.

49. BENNETT & HUGHES, *supra* note 45, at 3.

50. *Id.*

51. *Id.*

52. *Id.*

53. COLE ET AL., *supra* note 44, § 1:1.

54. DUBLER & LIEBMAN, *supra* note 12, at 15.

55. *Id.* at 13.

a mutually-agreed upon plan, but such ultimate cohesion is not always accomplished.<sup>56</sup> Irrespective of the end result, the most central goal of mediating bioethics disputes is to increase the chance that a conscientious decision will be made in a manner which is appropriate for those involved.<sup>57</sup>

One key characteristic of bioethics mediation is creating a neutral location, or a more even playing field in light of the power dynamics inherent to the medical field.<sup>58</sup> A more neutral environment is attempted by the presence of a mediator who is unaffiliated with the instant health care team or family.<sup>59</sup> Importantly, the individual has not been intertwined in the prior discussions which proceeded poorly enough to necessitate a bioethics mediation.<sup>60</sup> However, unlike its counterpart, traditional mediation, where the mediator is presumably unbiased and without any pre-existing connections to any of the parties, the bioethics mediator will probably be employed by the hospital or institution at which the dispute arose.<sup>61</sup> This may not be the best practice, as this could stack the deck in favor of the health care provider in a process built on the oversight of a neutral, third party mediator.<sup>62</sup> Nevertheless, the bioethics mediator “brings a distinct set of concerns and skills to the meetings with providers, patients, and families and must be impartial to the situation at hand.”<sup>63</sup>

Bioethics mediation is essential to the creation of an environment characterized by equal opportunities for patients and family members to be heard.<sup>64</sup> This opportunity is crucial because oftentimes, in contemporary health care settings, patients’ or their family’s voices feel muted, if not lost, and their capability to emphasize the patient’s interests can be overpowered.<sup>65</sup> There are many sources from which this inequity of power in modern medical facilities originates.<sup>66</sup>

Medical professionals and hospital staff possess increased knowledge and expertise about available treatments than do most patients or family members.<sup>67</sup> The hospital setting is one which can be highly technical, foreign, and intimidating to family members and patients in comparison to those who work in the hospital on a daily basis.<sup>68</sup> The interests of the patients and the treatment team members are appropriately deemed “imperfectly aligned.”<sup>69</sup> Another consideration contributing to inequity is the weight of physical and emotional stress intrinsic to all loved ones involved in cases with patients with serious illnesses.<sup>70</sup> Patients in settings necessitating bioethics mediation are usually quite sick. Their “cognition, understanding, and judgment” can all be impacted by their illness.<sup>71</sup> Depending on the patients’

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56. *Id.*

57. *Id.*

58. *Id.*

59. *Id.*

60. DUBLER & LIEBMAN, *supra* note 12, at 13.

61. *Id.*

62. BENNETT & HUGHES, *supra* note 45, at 3.

63. DUBLER & LIEBMAN, *supra* note 12, at 13.

64. *Id.*

65. *Id.*

66. *Id.*

67. *Id.*

68. *Id.*

69. DUBLER & LIEBMAN, *supra* note 12, at 13.

70. *Id.*

71. *Id.*

status—be it progressing or diminishing—families can fall anywhere on a stress spectrum, from mildly stressed to tremendously stressed.<sup>72</sup>

Certain diagnoses are more stressful than others. Likewise, some diagnoses are more difficult to comprehend. For example, in end of life cases, one issue that may arise is brain death. Brain death can be a challenging diagnosis to receive as a family member not only because of the finality and gravity of the diagnosis but also because of the gray area that exists in understanding what exactly brain death means. It is not uncommon for the patient to still be attached to various life-sustaining mechanisms; thus, the patient exhibits signs of life rather than death. The Uniform Determination of Death Act was enacted to attempt to standardize the requirements for brain death.<sup>73</sup> Confusion can fester when visually a family member or loved one appears to be alive and breathing, yet has received a brain death diagnosis. The requirements for brain death must therefore be enumerated precisely and consistently to aid in comprehension for all involved.

The first attempt at a standardized set of brain death regulations was the Uniform Brain Death Act, promulgated in 1978.<sup>74</sup> However, due to confusion about the criteria of the act, the Uniform Law Commission replaced the Uniform Brain Death Act with the Uniform Determination of Death Act of 1980 (UDDA).<sup>75</sup> The UDDA states that “[a]n 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.”<sup>76</sup> The UDDA and other attempts to encapsulate a set of regulations have been accepted as the majority rule throughout the United States.<sup>77</sup> This Act lends understanding to the phenomenon of brain death as legal death even when anatomical and physical signals suggest liveliness.<sup>78</sup>

Families under stress are likewise “at a disadvantage in medical settings because they have a bad collective reputation among health care professionals.”<sup>79</sup> This is because the families may be perceived as “disruptive, hard to manage, and at odds with staff.”<sup>80</sup> In reality, there is no actual data which proves families are difficult to manage or disruptive.<sup>81</sup> It is commonplace for families to feel their concerns and desires are ignored or not given merit.<sup>82</sup> Families believe they are viewed as an inactive, non-essential component of the decision-making process by the medical staff.<sup>83</sup> Thus, sometimes an opportunity for families to communicate in an environment where their beliefs are valued can be more worthwhile than reaching the

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72. *Id.*

73. *In re Guardianship of Hailu*, 361 P.3d 524, 528-29 (Nev. 2015).

74. *Id.* at 528.

75. *Id.*

76. *Id.* (citing UNIF. DETERMINATION OF DEATH ACT § 1, 12A U.L.A. 781 (2008)).

77. *Hailu*, 361 P.3d at 528; see LESLIE C. GRIFFIN & JOAN H. KRAUSE, PRACTICING BIOETHICS LAW 106 (2015) (“Thus all fifty states define brain death as legal death even if the heart continues to beat.”); Eun-Kyoung Choi et al., *Brain Death Revisited: The Case for a National Standard*, 36 J.L. MED. & ETHICS 824, 825 (2008) (stating that the UDDA “provides the national legal framework for defining death”).

78. *Id.*

79. DUBLER & LIEBMAN, *supra* note 12, at 13.

80. *Id.*

81. *Id.*

82. *Id.*

83. *Id.*

conclusion for which they had originally advocated.<sup>84</sup> When families feel they are being heard, they are more attentive to medical staff and more open to working with them to find the best treatment option available for the patient.<sup>85</sup>

A beneficial aspect of employing bioethics mediation is the malleable nature of the process.<sup>86</sup> The overall structure of this type of mediation can be modified and adjusted to best align with the interests and needs of the participants.<sup>87</sup> However, the foundational principles are always the same: “respect for the patient, the family, and the care providers and an impartial stance regarding what the outcome should be in any particular case.”<sup>88</sup> A feature inherent and important to bioethics mediation is, “the process is a key part of the product.”<sup>89</sup> A significant step forward in the ethical process is accomplished when a decision is examined by an experienced medical group as well as the interested parties who wish to put forth relevant information and considerations.<sup>90</sup> When so many people are attuned to a dispute it is much more difficult to evade ethical norms.<sup>91</sup> Bioethics mediation is valuable because a dispute will be analyzed by an increased number of trained professionals, mounting opinions and experiences that initiate “multidisciplinary discussion.”<sup>92</sup> This type of procedure also reduces the chances that the previously discussed clinical ethics consultant will be overshadowed by some of the more powerful medical professionals present.<sup>93</sup> A chief element of success of the meditative process is its open, collaborative nature.<sup>94</sup> The significance of that element cannot be understated when its alternative in a health care setting tends to be “secret, hidden, authoritarian, and private decision making that emerges only as a progress note or a consultant script in the medical chart.”<sup>95</sup>

Decision-making, especially that which occurs in end of life situations, requires the presence and incorporation of many voices. Patients may voice their desires through advance directives, but in the absence of such enumerated requests, families must assume the role of proscribing their wishes.<sup>96</sup> The forum for disagreement is ripe and teeming with conflict.<sup>97</sup>

This forum for disagreement may include situations like the one described below. It is relevant to the legal lens of this Comment to discuss exactly how much weight may be given to the statements by family members articulating what their loved one would have wanted. A 1988 Missouri Supreme Court decision was granted certiorari by the U.S. Supreme Court, producing the 1990 decision, *Cruzan*

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84. *Id.* at 13-14.

85. DUBLER & LIEBMAN, *supra* note 12, at 14.

86. *Id.*

87. *Id.*

88. *Id.*

89. *Id.*

90. *Id.*

91. DUBLER & LIEBMAN, *supra* note 12, at 14.

92. *Id.*

93. *Id.*

94. *Id.*

95. *Id.*

96. PRESIDENT’S COMM’N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMEDICAL & BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 1 (1983).

97. John M. Sue & Douglas P. White, *The Pressure to Withdraw Life-sustaining Therapy from Critically Ill Patients within the United States*, 175 AM. J. RESPIRATORY & CRITICAL CARE MED. 1104, 1104-07 (2007) (noting that disagreements between families and clinicians on end-of-life care are commonplace in the United States).

by *Cruzan v. Director, Missouri Department of Health*.<sup>98</sup> Seven years prior to the Supreme Court's holding, twenty-five-year-old Nancy Cruzan was involved in a serious automobile accident in Jasper County, Missouri.<sup>99</sup> The attending physician diagnosed Nancy Cruzan with a probable brain injury "compounded by significant anoxia (deprivation of oxygen)."<sup>100</sup> It was estimated that Nancy Cruzan's oxygen deprivation to the brain was for a period between twelve and fourteen minutes.<sup>101</sup> The trial judge concluded that "a deprivation of oxygen to the brain around six minutes would result in permanent brain damage."<sup>102</sup> Cruzan remained in a coma for around three weeks.<sup>103</sup> Nancy Cruzan's eyes wandered around the room, but was in what doctors refer to as a persistent vegetative state.<sup>104</sup> Her lower brain (brain stem) was functioning.<sup>105</sup> The brain stem controls heartbeat, breathing and reflexes.<sup>106</sup> Cruzan's upper brain suffered harm which significantly impaired its normal functioning abilities.<sup>107</sup> This portion of the brain controls thinking, feeling, and the ability to move purposefully.<sup>108</sup> So, even though Cruzan still maintained sleep and wake cycles and her eyes could wander around her room, doctors maintained she was unaware of her environment.<sup>109</sup> At some point in her life, Nancy Cruzan expressed to a former housemate that she would not wish to continue her life if sick or injured unless she could live at least halfway normally.<sup>110</sup>

Nancy Cruzan's parents brought declaratory judgment action seeking judicial sanction of their wish to terminate artificial hydration and nutrition for their daughter, after hospital employees refused to carry out their wishes.<sup>111</sup> The Circuit Court in Jasper County directed state employees to carry out the requests of Cruzan's parents.<sup>112</sup> The Circuit Court found that a person in Cruzan's condition has a fundamental right under the State and Federal Constitutions to direct or refuse the withdrawal of death-prolonging procedures.<sup>113</sup> Because the Circuit Court's holding involved a provision of the Missouri Constitution, when an appeal was made, it went to the Missouri Supreme Court.<sup>114</sup> The Missouri Supreme Court reversed.<sup>115</sup> The U.S. Supreme Court affirmed the holding of the Missouri Supreme Court.<sup>116</sup> The Court rejected the argument that Cruzan's parents were entitled to order the termination of her medical treatment, concluding that "no person can assume that choice

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98. 497 U.S. 261 (1990).

99. *Cruzan v. Harmon*, 760 S.W.2d 408, 411 (Mo. 1988), *aff'd sub nom. Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990).

100. *Id.*

101. *Id.*

102. *Id.*

103. *Id.*

104. *Id.*

105. Virginia Young, *The Right to Die -- Legal, Ethical Issues of The Cruzan Case Far From Resolved*, ST. LOUIS POST-DISPATCH, Dec. 27, 1990, at 12.

106. *Id.*

107. *Id.*

108. *Id.*

109. *Id.*

110. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 268 (1990).

111. *Cruzan v. Harmon*, 760 S.W.2d 408, 410 (Mo. 1988) (en banc), *aff'd sub nom. Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990).

112. *Id.*

113. *Id.*

114. MO. CONST. art. V. § 3.

115. *Harmon*, 760 S.W.2d at 410.

116. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 287 (1990).

for an incompetent in the absence of the formalities required by the Living Will statute or clear and convincing evidence of the patient's wishes."<sup>117</sup> Relevant to the scope of this Comment, it is important to recognize that although families must assume the role of proscribing the wishes of their loved ones, such desires are not necessarily guaranteed legal enforcement.

### B. Bioethics Mediation

To reiterate, a touchstone of meditative bioethics intervention is its flexible nature.<sup>118</sup> Structure, though, is a necessity to guide the process. The process has been divided up into eight stages: (1) Assessment and preparation, (2) Beginning the mediation, (3) Introducing the patient, (4) Presenting and refining the medical facts, (5) Gathering information, (6) Problem solving, (7) Resolution, and (8) Follow-up.<sup>119</sup> Although these stages appear clear-cut and linear, most mediators deviate from these distinct categories.<sup>120</sup> In any given case, "steps might occur in a different order and some steps might be eliminated entirely."<sup>121</sup>

Like mediation, bioethics mediation utilizes the intervention of a third party who seeks to help the parties on how to talk and listen to one another in new and meaningful ways. The following is a description of the process which guides a bioethics mediation dispute.

#### 1. Pre-Mediation

Pre-mediation investigation is necessary to get up to speed on the issues at play. As with a civil claim or community dispute, pre-mediation investigation may not be as important as it is in bioethics mediation.<sup>122</sup> Here, though, the mediator needs to become familiar with the patient's medical chart, make initial assessments about patient competency (i.e., whether it is an issue in the case), figure out which family members, if any, are available, and start to collect relevant medical facts.<sup>123</sup> There is a heavy emphasis on knowledge and understanding of medical facts, bioethics norms, and much more information not necessarily possessed by all mediators.<sup>124</sup> The American Society for Bioethics' Task Force Report acknowledges bioethics mediators should possess a strong background in: moral reasoning and ethical theory; bioethical issues and concepts; health care systems, clinical context, knowledge of the local health care institution where consultation is occurring; the local health care institution's relevant policies; beliefs and perspectives of the patient and staff

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117. *Id.* at 269 (quoting *Cruzan v. Harmon*, 760 S.W.2d 408, 425 (Mo. 1988) (en banc)).

118. DUBLER & LIEBMAN, *supra* note 12, at 43.

119. *Id.*

120. *Id.*

121. *Id.* at 44.

122. Ellen Waldman, *Bioethics Mediation at the End of Life: Opportunities and Limitations*, 15 CARDOZO J. CONFLICT RESOL. 449, 452 (2014).

123. *Id.*

124. *Id.*

population; relevant codes of ethics and professional conduct; guidelines of accrediting organizations; and relevant health care law.<sup>125</sup> In addition, the mediator must study and become familiar with the “decision history” of the case.<sup>126</sup> This process would include searching for the answers to the following questions: (1) How often has the patient been in the hospital lately? (2) Who typically deals with the patient in these situations? (3) Is there someone in the hospital who is familiar with this patient’s medical and family history? (4) Has any major event occurred that affects the conflict at issue currently?<sup>127</sup>

The significance of obtaining information regarding the “narrative arc of a case” is especially high when there have been previous interactions between the patient and the health-care provider which have been characterized by disagreements and lack of satisfaction.<sup>128</sup> In these sorts of cases, the mediator’s understanding of the case history is essential to regain the trust of the patient, or family members, in the health-care system.<sup>129</sup> Pre-mediation meetings with the clinical staff can produce important insights into the patient’s medical status, how future care should proceed, and psychosocial aspects of the case.<sup>130</sup> Following the initial meeting with the clinical team, the mediator ought to attempt to arrange a pre-mediation meeting with the patient and their family if at all possible.<sup>131</sup> Should the patient be healthy enough to participate in one of these meetings, the mediator can ask about the patient’s diagnosis and her specific preferences.<sup>132</sup> Unfortunately, it is more common that the patient is not functioning adequately to have such a meeting and the mediator will inquire about the desires of the patient with the family.<sup>133</sup> Frequently, family members are vaguely attuned to the patient’s status and diagnosis, so a pre-meeting is a beneficial time to allow the mediator to get a sense of what the family knows and understands about the patient’s health and path for the future.<sup>134</sup>

## 2. Conflicts of Interest

Once the mediation commences, it is important to address certain conflicts of interest that may arise. As previously mentioned, the bioethics mediator is likely employed by the health-care institution at which the mediation takes place. Mediators in different types of disputes maintain that they do not have any prior dealings with mediating parties and are indifferent as to the resolution of the dispute solving process.<sup>135</sup> However, the bioethics mediator is frequently associated and more in-tune with the clinical staff than with the family of the patient purely because the staff and the mediator share the same employer. Most likely, “the mediator works

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125. *Id.* at 458 (citing AM. SOC’Y FOR BIOETHICS & HUMANITIES, ASBH TASK FORCE ON ETHICS AND HUMANITIES EDUCATION IN UNDERGRADUATE MEDICAL PROGRAMS (2009), <http://asbh.org/uploads/publications/Report%20on%20Ethics%20%20Humanities%20in%20Undergraduate%20Medical%20Programs.pdf>).

126. *Id.* at 452-53 (quoting DUBLER & LIEBMAN, *supra* note 12, at 51).

127. *Id.* at 453.

128. Waldman, *supra* note 122, at 453.

129. *Id.*

130. *Id.*

131. *Id.* at 454.

132. *Id.*

133. *Id.*

134. Waldman, *supra* note 122, at 454.

135. *Id.* at 458.

in-house and is seen as valuable precisely because of her familiarity with the political currents and rip-tides of the organization.”<sup>136</sup> From the perspective of the health care provider, the mediator being in-house is reassuring because he or she best comprehends the inherent complexities of the setting and the needs of the participants.<sup>137</sup> From the perspective of the family, though, the mediator’s association with the health-care institution is more likely to produce discomfort and apprehension.<sup>138</sup> So, while the bioethics mediator offers an advantageous familiarity with the institution and is able to speak the clinical staff’s language, the tradeoff is the possible compromise of neutrality and a lack of trust.<sup>139</sup>

### 3. Conclusion & Follow-Up

Regardless of the mediation concluding in an agreement or not, the bioethics mediator must compose a progress note in the patient’s chart.<sup>140</sup> The patient’s chart ends up serving dual functions as both a medical device and a legal document.<sup>141</sup> The contents of the chart encompass physicians’ signatures, psychological interviews, vital signs, social work reports, and more.<sup>142</sup> The mediator must “chart the consult,” or report that a mediation occurred and include the issues discussed and any potential decisions that were made.<sup>143</sup> If the mediation concluded without a decision, the mediator should communicate with the family the likely next steps in terms of the institution.<sup>144</sup> Because various next steps could result (such as review by a full ethical committee if one exists, or the case being passed along to the legal department for potential judicial intervention), it is imperative for the mediator to adequately describe each possibility and their potential repercussions.<sup>145</sup> Although the mediation may be complete, the mediator’s role is not.<sup>146</sup> The mediator should conduct subsequent meetings with the parties and offer support to both family and caregivers.<sup>147</sup> The possible outcomes differ widely—from providing care that is contrary to the medical opinions of staff to withholding or termination of treatment for a family’s loved one.<sup>148</sup> Regardless, the mediator “should be available to provide a sympathetic ear or to make referrals to other departments that might provide

136. *Id.* at 459.

137. *Id.* at 452 (citing DUBLER & LIEBMAN, *supra* note 12, at 40).

138. *Id.* at 459.

139. *Id.* & n.32 (“This issue is addressed elliptically in [AM. SOC’Y FOR BIOETHICS & HUMANITIES’ TASK FORCE REPORT ON ETHICS CONSULTATION, CORE COMPETENCIES (1998)], under a section devoted to Conflicts of Interest. The Report does not state that ethics consultants employed by health care entities face a conflict by virtue of their employment status, but it does recognize the possibility that consultants may be subject to competing pressures. *Id.* The report notes, ‘There is a potential conflict of interest whenever the ethics consultant is employed by a healthcare institution (whether the institution pays the ethics consultant specifically to perform HCEC services, or employees of the institution perform HCEC as part of their other professional activities). Giving advice or otherwise acting against what is in the institution’s financial, public relations, or other interests will test the strength of the consultant’s fiduciary relationship to the parties in the consultation.’ *Id.*”).

140. Waldman, *supra* note 122, at 460.

141. *Id.*

142. *Id.*

143. *Id.*

144. *Id.*

145. *Id.*

146. Waldman, *supra* note 122, at 460.

147. *Id.*

148. *Id.*

assistance.”<sup>149</sup> Ceasing treatment for a loved one, although it may be the right thing to do in the scenario, is devastating and distressing for everyone involved.<sup>150</sup> As such, it is appropriate for the mediator’s role to encompass post-mediation attempts to aid the family to accept and come to terms with the unfortunate reality and weight of the decision.<sup>151</sup>

#### 4. *Alternative Approaches—STADA*

Another approach, described by Carol Liebman and Nancy Dubler, authors of the book *Bioethics Mediation: A Guide to Shaping Shared Solutions*, is a method known by the acronym, STADA (Sit down, Tell me about [the patient], Admire, Discuss, Ask).<sup>152</sup> STADA is a less intricate checklist than other procedures,<sup>153</sup> but it “is a good reminder of where [a mediator is] in a mediation and what comes next.”<sup>154</sup>

The first step in the STADA approach is to request the patients and family members sit down together.<sup>155</sup> Hospital staff and medical professionals busily enter and exit patient’s rooms day and night.<sup>156</sup> When a mediator requests the family and patients sit down together, this provides a more private environment, one which “offers some assurance of focus and attention.”<sup>157</sup>

Equally significant to diagnoses is the empowerment of patients and families. This may be accomplished by requesting that families tell the mediator about their loved one.<sup>158</sup> By engaging the family as experts at the beginning of the conversation, the family is viewed as equals to the medical team.<sup>159</sup> This is something not typically seen in a usual hospital setting.<sup>160</sup> Mending the imbalance of power is a crucial step in enabling families to openly discuss their loved ones.<sup>161</sup> When a mediator requests the family to lay out their opinions and concerns first, “the mediator validates their place in the power dynamic of the discussion.”<sup>162</sup>

“Stroking” is one of the tools mediators employ to increase “participants’ sense of being recognized and appreciated.”<sup>163</sup> Stroking helps medical professionals understand that participants’ opinions, viewpoints, desires, and schedules are important.<sup>164</sup> It is essential that a family member’s opinion on the patient’s status or condition is admired and appreciated.<sup>165</sup> This is because medical professionals

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149. *Id.*

150. *Id.*

151. *Id.*

152. DUBLER & LIEBMAN, *supra* note 12, at 74-75.

153. *Id.* at 74 (“STADA is less complicated than those that govern interventions in . . . complex surgical cases.”).

154. *Id.*

155. *Id.* at 75.

156. *Id.*

157. DUBLER & LIEBMAN, *supra* note 12, at 75.

158. *Id.*

159. *Id.*

160. *Id.*

161. DUBLER & LIEBMAN, *supra* note 12, at 75.

162. *Id.*

163. *Id.*

164. *Id.*

165. *Id.*

themselves recognize they are strangers to the patient.<sup>166</sup> Thus, family members and friends are the ones who know the patient best and can help discover what he or she would have wanted for their care.<sup>167</sup> If opinions or stories about the patient are disregarded rather than appreciated, an essential decision may be made without a full understanding of what the patient actually would have wanted.<sup>168</sup>

In discussion, the medical staff introduces the patient's background medical information.<sup>169</sup> This is important to the dispute resolution process because medical facts (including diagnoses) tend to change as the data changes.<sup>170</sup> Alternative interpretations may result when another individual views and interprets facts through varying filters or historical lenses.<sup>171</sup> In short, medical facts are less rigid than they may appear to non-medical participants.<sup>172</sup>

At this point, it is necessary for the medical staff to ask, "what would the patient have wanted?" It is crucial for family to be involved in deciding what the patient would want if the patient could tell everyone.<sup>173</sup> This discussion ought to be an expansion of the "lifestyles, values, and preferences" of the patient in relation to the options available.<sup>174</sup>

To conclude, STADA is merely one potential approach to mediating bioethics disputes. In these disputes, the mediator is continuously "gathering information, testing tentative hypotheses, and summarizing what participants have said."<sup>175</sup> Summarizing what has been said is a crucial skill that cannot be overused.<sup>176</sup>

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166. *Id.*

167. *Id.*

168. *See id.*

169. *Id.*

170. DUBLER & LIEBMAN, *supra* note 12, at 75.

171. *Id.*

172. *Id.*

173. *Id.*

174. *Id.*

175. *Id.*

176. DUBLER & LIEBMAN, *supra* note 12, at 75.

## V. CASE STUDY AND APPLICATION

*A. The Case of Jahi McMath*

Jahi McMath is now a 16-year-old girl.<sup>177</sup> At the age of 13, McMath had a tonsillectomy<sup>178</sup> and adenoidectomy<sup>179</sup> on December 9, 2013 at the Children's Hospital Oakland in California.<sup>180</sup> Although the two procedures were supposed to be "routine", tragedy struck after the surgeries.<sup>181</sup> Jahi McMath lost significant amounts of blood, yet hospital staff repeatedly told Jahi's mother (Ms. Winkfield) that this was "normal."<sup>182</sup> Eventually, Jahi suffered cardiac arrest due to the significant blood loss during post-operative care.<sup>183</sup> Due to the sudden and serious amount of blood loss, Jahi experienced brain swelling which manifested into a severe brain injury.<sup>184</sup> On December 12, 2013, doctors at the hospital declared Jahi "brain dead."<sup>185</sup>

Following a brief, but intense legal battle, a California Superior Court judge ruled on December 23, 2013, that Jahi McMath met the criteria for Brain Death under California Health and Safety Code 7180.<sup>186</sup> This ruling meant that Ms. Winkfield's requests to keep Jahi alive with a ventilator and feeding tube were dismissed.<sup>187</sup> Ms. Winkfield then filed an appeal in addition to a federal lawsuit in the U.S. District Court for the Northern District of California.<sup>188</sup> A negotiation ensued, but the end result was to implement a plan for Jahi's removal from the hospital.<sup>189</sup>

However, before Jahi was to be removed from the ventilator, Ms. Winkfield and her attorneys worked to have Jahi moved to a health care facility in New Jersey.<sup>190</sup> New Jersey state law allows for a religious exemption to brain death.<sup>191</sup> Jahi

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177. See Complaint for Declaratory and Injunctive Relief at 2, *McMath v. California*, No. 4:15-cv-06042 (N.D. Cal. Dec. 12, 2016). Jahi McMath was 15 at the time the petition was filed on December 23, 2015.

178. "[T]he surgical removal of the tonsils, two oval-shaped pads of tissue at the back of the throat — one tonsil on each side. A tonsillectomy was once a common procedure to treat infection and inflammation of the tonsils (tonsillitis). Today, a tonsillectomy is usually performed for sleep-disordered breathing but may still be a treatment when tonsillitis occurs frequently or doesn't respond to other treatments." *Tonsillectomy*, MAYO CLINIC (July 17, 2015), <http://www.mayoclinic.org/tests-procedures/tonsillectomy/basics/definition/prc-20019889>.

179. "Adenoid removal, also called adenoidectomy, is a common surgery to remove the adenoids. The adenoids are glands located in the roof of the mouth, behind the soft palate where the nose connects to the throat. The adenoids produce antibodies (white blood cells) that help fight infections. Typically, the adenoids shrink during adolescence and may disappear by adulthood. Doctors often perform adenoid removals and tonsillectomies (removal of the tonsils) together. Chronic throat and respiratory infections often cause inflammation and infection in both glands." Sandy Calhoun, *Adenoid Removal*, HEALTHLINE (Oct. 8, 2015), <http://www.healthline.com/health/adenoid-removal#Overview1>.

180. Complaint, *supra* note 177, at 2.

181. *Id.*

182. *Id.*

183. *Id.*

184. *Id.*

185. *Id.*

186. *Id.*

187. *Id.*

188. *Id.*

189. Complaint, *supra* note 177, at 4.

190. *Id.*

191. *Id.*

and her family now reside in New Jersey where she receives minimal in-home support.<sup>192</sup>

### *B. Bioethics Mediation Applied Retrospectively*

Bioethics mediation cannot reverse the tragedy of Jahi McMath's case. In Jahi McMath's case, the disintegration of the care team, the complexity of the scenario, the reluctance of medical staff to talk about death, and the unrealistic hopes of her mother combined to produce a conflict about the best plan of care.

Here, Ms. McMath brought her daughter into the hospital with likely expectations of a brief procedure and a prompt return to normal life. Errors, miscommunication, and tragedy occurred. Although it is impossible to retroactively determine what would have made the McMath family *feel better*, there were steps that could have been taken to clarify medical procedures, discover available opportunities, and cultivate a resolution which best reflected Ms. McMath's values and satisfaction.

As a non-present party to the circumstances which occurred, it is impossible to authoritatively remark on what did or did not happen. The following are simply recommendations based on research of pertinent bioethics mediation studies.

First, if a medical error actually occurred, one way in which physicians can respond is with an apology.<sup>193</sup> Apologies—statements that acknowledge an error and its penalties, take responsibility, and communicate regret for having caused harm—can decrease blame, decrease anger, and increase trust.<sup>194</sup> Further, apologies have the potential to *decrease* the risk of a medical malpractice lawsuit and may help settle claims by patients.<sup>195</sup> Patients indicate they expect communications that explain and apologize after medical errors.<sup>196</sup> Physicians also indicate a desire to apologize, but may in fact, provide minimal information after medical errors and infrequently offer complete apologies.<sup>197</sup> The reason most cited for this lack of communication or apology is fear about potential litigation.<sup>198</sup> Despite this fear, incorporating an apology into conversations between physicians and patients/families “can address the needs of both parties and can play a role in the effective resolution of disputes related to medical error.”<sup>199</sup>

Based on Jahi's case, a bioethics mediation session would have been beneficial. If the mediator had followed the STADA method, relations and sentiments *could have* improved. Sitting the parties down in the same room may have potentially broken down some of the barriers resultant from the differentiation in power between the physicians and the McMath family members. Next, Ms. McMath may well have been empowered by a level playing field, and been provided an open forum to articulate her daughter's livelihood and desires. Subsequently, an acknowledgment of the difficulty of the situation, and the effect it had on Ms. McMath

192. *Id.* at 5.

193. See Jennifer K. Robbenolt, *Apologies and Medical Error*, 467 CLINICAL ORTHOPAEDICS & RELATED RES. 376, 376-77 (2009).

194. *Id.* at 376.

195. *Id.*

196. *Id.*

197. *Id.*

198. *Id.* at 379 (“[I]n part because physicians and other potential defendants fear their apologies might be interpreted as evidence tending to prove legal liability, over two-thirds of the states have enacted evidentiary rules that make some apologies inadmissible in court as evidence of liability.”).

199. *Id.*

may have provided some gratification and sense of worth to Jahi's mother in this extremely undesirable situation. Next, Jahi's case involved brain death, which can be a difficult concept for some to wrestle with. This is because the qualifier *brain* can be confusing to families, suggesting that only one organ of the patient is dead.<sup>200</sup> A conversation where the clinicians express the unfortunate realities of the case, or consider other options for Ms. McMath may have been fruitful here, where legal battles and a cross-country move were ultimately pursued. Alternative interpretations from various physicians, discussed in a meaningful way, may have concluded either the finality of the situation, or various options that may have been available. Finally, at some point, it was necessary for the medical staff to ask, "what would Jahi have wanted?" Although this may seem off-beat to inquire about a thirteen-year-old girl, it is essential to keep the patient at the epicenter of the discussion. A mediator could have given value to Ms. McMath's grief, confusion, anger, and miscommunications with the medical staff. This would not have fixed the possible medical mistakes which occurred with Jahi, but it may have provided a forum founded on respect and understanding, creating a more compassionate comprehension of this unfortunate case. Likewise, a mediator could have provided post-mediation support to help the McMaths come to terms with the weight and reality of the decision ultimately made.

## VI. CONCLUSION

Challenging, complex, and emotionally taxing medical cases which unfold and create disputes are ever-present. The need for a caring, respectful, communicative environment to explore these disputes is pressing. Bioethics mediation is one worthwhile tool to help resolve and explore such disputes. Bioethics mediation provides a forum of open communication, acknowledgement of varying viewpoints, and ultimately, an ethical lens through which to mediate difficult disputes. It also allows for comprehensive solutions to problems which may not typically even be discussed, providing a patient and their family a chance to be adequately respected to best initiate a restorative process of healing.

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200. Mike Nair-Collins, *Death, Brain Death, and the Limits of Science: Why the Whole-Brain Concept of Death Is A Flawed Public Policy*, 38 J.L. MED. & ETHICS 667, 670-71 (2010).