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RESOLVING HEALTH CARE CONFLICTS: A COMPARATIVE STUDY OF JUDICIAL AND HOSPITAL RESPONSES

JANET L. DOLGIN†

I. INTRODUCTION

In 1976, Chief Justice Hughes of the Supreme Court of New Jersey ("SCNJ") suggested in In re Quinlan1—a case involving a life and death decision for a patient without capacity—that comparable cases would be more appropriately handled by hospital "Ethics Committee[s]" than by courts of law.2 Such committees were understood, even in 1976, as interdisciplinary bodies "composed of physicians, social workers, attorneys, and

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2. Id. at 668–69. Justice Hughes opined that the "practice of applying to a court to confirm such decisions would generally be inappropriate... because that would be a gratuitous encroachment upon the medical profession's field of competence" and "because it would be impossibly cumbersome." Id. at 669. This article concurs with Justice Hughes's suggestion that such cases generally are better handled (at least initially) by ethicists within hospitals (either as members of an ethics committee or as part of an ethics consult service), though for somewhat different reasons than Justice Hughes delineates. See infra Part II (discussing the roles that ethics committees and courts play in similar cases).
theologians” that responded to health care conflicts within hospitals and other health care facilities. When the SCNJ rendered its decision in Quinlan, few hospitals housed such committees. That is no longer the case. Within a few decades after Quinlan, ethics committees and consult services began to proliferate in the United States. By 2007, they could be found or were being developed in ninety-five percent of U.S. hospitals. Justice Hughes’s decision in Quinlan may have encouraged that development.

This article supports Justice Hughes’s preference that ethics consultations or committees, (depending on the scope of each in a particular institution) rather than courts of law, should respond, at least initially, to bioethical disputes within hospitals. But that support comes with a confounding caveat: there is a continuing and significant need for court review—especially appellate court review—of cases occasioned by health care conflicts. That court review serves needs that cannot be similarly served by ethics committees or consultants.

3. The phrase “health-care conflicts” was used by Rita Charon. See ARTHUR W. FRANK, THE WOUNDED STORYTELLER 155 (2d ed. 2013) (quoting Rita Charon, Narrative Contributions to Medical Ethics: Recognition, Formulation, Interpretation, and Validation in the Practice of the Ethicist, in A MATTER OF PRINCIPLES?: FERMENT IN U.S. BIOETHICS 260, 260 (Edwin R. DuBose et al. eds., 1994)).


5. In the early 1980s, only a small percent of hospitals in the U.S. had established ethics committees or consult services. See Charity Scott, Ethics Consultations and Conflict Engagement in Health Care, 15 CARDOZO J. CONFLICT RESOL. 363, 365 (2014) [hereinafter Charity Scott] (noting a significant increase in the percent of hospitals with ethics committees between the early 1980s and the 2000s).

6. Id.

7. See infra Part II.B (defining ethics committees and ethics consultation services).

8. Charity Scott, supra note 5, at 365.

9. Id.


11. Ethics committees and ethics consult services may differ from each other, depending on the institution in which they were shaped. See infra Part II.B (considering ethics committees and ethics consult services).

12. See Annas & Grodin, supra note 10, at 554 (arguing that ethics committees “do best when they stick to clinical ethics and leave legal questions to a hospital’s attorney and the courts”); infra Part IV (reviewing the comparative advantages and disadvantages of responses to health care conflicts within hospitals through the assistance of an ethics consult service with resolution of similar cases in courts of law).
The availability of court review—the option for disgruntled stakeholders in a health care conflict to take their case to court—is an important, perhaps essential, adjunct to the work of ethics committees and ethics consult services. Additionally, appellate court review of cases presenting bioethical challenges shapes and re-shapes jurisprudential frames within which ethicists (as well as trial court judges) consider and respond to bioethical conundrums in hospitals and other health care settings. Ironically, given Justice Hughes’s plea that such cases should be entertained outside of courtrooms, the SCNJs decision in Quinlan demonstrates the potential effectiveness and far-reaching benefits of appellate court review in such cases. In Quinlan, Justice Hughes developed an influential model to which courts and health care institutions look to in considering cases involving surrogate decision-making about end-of-life questions for patients without capacity. Appellate court decisions in other cases that involved a wide variety of bioethical conundrums have been similarly consequential for the development of bioethics as a field of study and as a frame within which to shape clinical responses.

The cases reviewed in this article—some decided by ethics consultants and some by courts—illustrate the limitations of court review compared to the review of ethics consult services in

13. See Norman L. Cantor, Quinlan, Privacy, and the Handling of Incompetent Dying Patients, 30 Rutgers L. Rev. 243, 243 n.2 (1977) (arguing that while “a court should probably not be involved in individual termination decisions, questions of the legality of withholding or withdrawing life-preserving care are constantly lurking in hospitals and would inevitably surface in the courts, whether through homicide, malpractice, or life insurance litigation. The law must eventually fix decisionmaking responsibility and criteria.”).


16. See Annas & Grodin, supra note 10, at 554. Interestingly, Dr. Fred Plum, who testified in the Quinlan case, was one of two scientists who proposed the term “persistent vegetative state,” in the same decade in which Quinlan was decided. Lawrence K. Alman, Fred Plum, Neurologist Who Helped Coin ‘Persistent Vegetative State,’ Dies at 86, N.Y. Times (June 12, 2010), https://www.nytimes.com/2010/06/13/health/13plum.html.

satisfactorily resolving individual cases raising bioethical dilemmas within hospital settings.¹⁸ Yet, comparing these cases also highlights the significance of court review, including the role courts can play in crafting legal and social responses to bioethical challenges.¹⁹ Thus, although this article agrees with Justice Hughes that, as a general matter, bioethical disputes are best entertained by ethics bodies created within health care facilities, it also concludes that court review can be essential in the development of bioethical theory and practice. Court review can also encourage society more generally to reflect on and sometimes reshape deeply ingrained assumptions about personhood and relationships.

This article examines two categories of ethics consult cases²⁰ and compares them with "matching cases" decided by courts.²¹ The first category of cases involves pregnant patients.²² The second category involves newborn babies and infants.²³ Prior to beginning research, the hypothesis for this article was that the comparative benefits and disadvantages of review by ethics consultants within hospitals, on the one hand, and by judges, on the other hand, would vary with the issues at stake in the cases. In fact, few differences emerged in the responses of ethics consultants to the two categories of cases examined—the few subtle differences that did emerge²⁴ do not justify the conclusion that ethics consultants are more adept at handling one category of cases compared to another.²⁵ However, significant differences

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¹⁸. See infra Part IV (comparing the advantages and disadvantages of resolution by ethics consult service with resolution of similar cases in courts of law).
¹⁹. See id.
²⁰. A third category of cases, focused on issues surrounding death, dying, and patients with very serious medical conditions, is expected to be the subject of an article offering a similar comparison to that offered in this article between the work of ethicists in hospitals and the work of courts in resolving bioethical conflicts.
²¹. The phrase "matching cases" refers to cases that were occasioned by similar health care conflicts.
²². See infra Part II.
²³. See infra Part III.
²⁴. The consultants were more directive in the cases involving pregnant women than in those involving neonates. This difference was subtle. Further, the number of cases is too small to draw any general conclusions.
²⁵. The identity of the particular ethicists working within any one hospital may also affect the committee or ethics consult service's responses to various sorts of cases. Since the ethics reports considered in this article all stem from the work of one ethics consult service, no general claim can be made about ethics review with regard to differences in responses to various sorts of conflicts within hospital and other health care settings.
between ethics consult review and court review—beyond the most obvious differences—became apparent in the comparison between the two. Those differences are delineated and analyzed throughout this article.

Part I of this article describes the scope of the research underlying the article’s analysis. It then reviews the development and operation of ethics committees and ethics consult services in hospitals in the United States in the last several decades. Part II focuses on health care conflicts between pregnant women and clinicians or hospital administrators, and Part III examines cases involving conflicts about the care of seriously ill neonates and infants. Parts II and III compare matching cases considered by hospital ethics consultants and by judges. Finally, Part IV of this article compares the advantages and disadvantages of responses to health care conflicts within hospitals through the assistance of an ethics consult service with resolution of similar cases in courts of law. Part V offers a conclusion to this article.

II. SCOPE OF THE PROJECT: ETHICS COMMITTEES, ETHICS CONSULTATION SERVICES, AND COURTS

This Part delineates the scope of the analysis described in this article. In Section A, it suggests a need for caution about generalizing the article’s conclusions to all ethics consult services or all courts. Then, Section B offers a summary of the character of ethics consult services and ethics committees in hospitals and reviews their development in the U.S. Section B also reviews differences in professional presumptions among those working in law, medicine, and bioethics, and suggests the importance of developing methods for those working in each realm to communicate more robustly with those in the others. This may involve collaborative relationships between ethics consult services, a hospital’s legal department, palliative care, social work, and chaplaincy, among others.

A. Scope of the Project

The ethics cases analyzed in this article arose at a large urban hospital in the Northeast, referred to in this article as
“Brookside.” Each case was summarized by an ethics consultant in a written report. Almost all of Brookside’s ethics consultations included several ethicists, one of whom was almost always a Fellow, working alongside a more seasoned bioethicist with professional training in nursing, medicine, or law. In addition to the ethics consult service, Brookside has several ethics committees. At Brookside, the consult service responds to cases involving individual patients, and the ethics committees review cases, including cases already reported on by the consult service. In addition, ethics committees may examine and make suggestions about hospital policy regarding bioethical issues and undertake educational activities. At other hospitals, these tasks may be distributed in a different manner or the ethics committee may be responsible for both sets of tasks.

The analysis offered in this article depends on qualitative assessment of texts. In comparing the work of ethicists to the work of courts in responding to the conflicts at issue, this article suggests that ethics consultants offer an important alternative to court deliberations and often should be preferred to court review in response to health care conflicts within hospitals.

26. This article considers ethics consult reports written between the start of 2012 and the first week of October 2017. Research for this article relied on de-identified reports. Sometimes even the gender of stakeholders had to be assumed. That was not always the case, however, as in cases involving pregnant patients. Almost each review of an ethics case in this article involved some changes in detail in order to make it less likely that a patient, clinician, or other stakeholder could be re-identified.


28. See id.

29. Pregnancy Case P20123, supra note 27.

30. See id.

31. Id.

32. See Judith Hendrick, Legal Aspects of Clinical Ethics Committees, 27 J. Med. Ethics i50, i51 (2001) (identifying “three main functions” of clinical ethics committees as “education, policy development and case review”).
B. Ethics Committees and Ethics Consultations

In 2011, a task force of the American Society for Bioethics and Humanities ("ASBH") identified "core competencies" that should be required of all bioethics consultants: "skills, knowledge, and attributes" needed "to perform competently."\(^{33}\) The task force's report defined a "health care ethics consultation" as "a set of services provided by an individual or group in response to questions from patients, families, surrogates, healthcare professionals, or other involved parties who seek to resolve uncertainty or conflict regarding value-laden concerns that emerge in healthcare."\(^{34}\)

The great majority of U.S. hospitals and nursing homes now include ethics committees and/or ethics consult services (or have access to such services).\(^{35}\) A slew of factors—some internal to health care facilities, some social, cultural or economic, and some legal—have pushed these facilities to develop ethics committees and ethics consult services.\(^{36}\) Until the late 1980s, their creation was voluntary everywhere in the U.S.\(^{37}\) In 1986, Maryland lawmakers mandated for the first time in the U.S. that hospitals develop an ethics committee or similar body.\(^{38}\) In 1992, the Joint Commission, a non-profit accrediting group, amended its standards for hospital accreditation to mandate the presence of an ethics committee or another in-hospital group that would respond to ethical challenges within the hospital.\(^{39}\) That accreditation

33. AM. SOC'Y FOR BIOETHICS & HUMANITIES, CORE COMPETENCIES FOR HEALTH CARE ETHICS CONSULTATION 19 (2d ed. 2011) [hereinafter ASBH, CORE COMPETENCIES].

34. Id. at 3 (some critics bemoaned the definition's vagueness); see, e.g., Giles R. Scofield, What Is Medical Ethics Consultation?, 36 J.L., MED. & ETHICS 95, 97 (2008).


36. See id. at 550 (noting relevance of developments in technology, moral issues, "clashes between values in a pluralistic context, and relative time-pressure for decision-making," as factors calling for services of ethics consultants).

37. See id. at 548–49.


39. Legal Briefing, supra note 38, at 76 (citing JOINT COMMISSION, COMPREHENSIVE ACCREDITATION MANUAL FOR HOSPITALS: THE OFFICIAL HANDBOOK § LD.04.02.03 (2011)).
requirement was significant to all U.S. hospitals.\textsuperscript{40} By the end of the twentieth century, virtually every hospital in the U.S. with at least 400 beds offered ethics consult services, often through ethics committees.\textsuperscript{41}

The ASBH Task Force on core competencies described "ethics facilitation" as the most appropriate approach for ethics consultants in responding to health care conflicts.\textsuperscript{42} This approach asks ethics consultants to "elucidate issues, aid effective communication, and integrate the perspectives of the relevant stakeholders."\textsuperscript{43} The task force identified the key attributes of the ethics facilitation approach as "(1) identifying and analyzing the nature of the value uncertainty, and (2) facilitating the building of a principled ethical resolution."\textsuperscript{44}

The ASBH Task Force rejected two alternative approaches to ethics consultation.\textsuperscript{45} An "authoritarian approach" defines the consultant's moral values as privileged.\textsuperscript{46} This approach precludes the "process that respects the rightful decision-making authority" of those affected by the health care conflict (including the patient).\textsuperscript{47} At the opposite end of the continuum, the task force posited a "pure consensus approach."\textsuperscript{48} This approach aims to "forge agreement" regardless of the issues at stake.\textsuperscript{49} This approach "fails to incorporate the importance of ethically justified norms or values."\textsuperscript{50}

The task force’s description of the preferred approach to ethics consultations ("ethics facilitation") suggests clear differences between the key aims of ethics consultants and of courts of law in responding to cases occasioned by health care conflicts.\textsuperscript{51} Moreover, significant debate has surrounded questions

\textsuperscript{40} Id.
\textsuperscript{41} Aulisio, supra note 35, at 546. In addition to large hospitals, Aulisio reports that federal hospitals and hospitals that belonged to the Council of Teaching Hospitals also had ethics committees or consult services. Id.
\textsuperscript{42} ASBH, CORE COMPETENCIES, supra note 33, at 6.
\textsuperscript{43} Id. at 7.
\textsuperscript{44} Id. The work of the Brookside ethics consult service reflects those attributes.
\textsuperscript{45} Id. at 6.
\textsuperscript{46} Id.
\textsuperscript{47} Id. at 7.
\textsuperscript{48} Id.
\textsuperscript{49} Id.
\textsuperscript{50} Id.
\textsuperscript{51} Id.
about the relationship between the work of ethics consultants and that of courts in such cases:

[A]lmost every possible arrangement of courts and committees has been suggested. Thus some commentators have advocated case consultation as a way of trying to keep cases out of court. Others have argued that consultation should actually substitute for judicial review. Given these divergent views, it is not surprising that American judges have also failed to be consistent in their approach. Thus in one case the courts treated a committees’ determinations as highly persuasive “evidence”... [T]he court seemed to use the committee’s documentation for assurance that the doctor and experts had come up with the right answer, and that the appropriate procedure would yield that answer. But in other cases the courts have virtually ignored a committee’s recommendations or have ordered some kind of future committee process.52

That description suggests a need for more consistency in shaping the relationship between ethics committees and courts. More particularly, in cases entertained first by ethics consultants and then by judges, institutionalizing processes that would encourage or even require communication between ethics consultants and judges might lead to more satisfactory results for stakeholders, including patients, their family members, and clinicians.53

This would require the capacity to translate the presumptions held by discrete professional domains into terms that make sense within other domains, and thus, it would require

52. Hendrick, supra note 32, at i52 (citations omitted).
53. See infra Part V (recommending this sort of communication). In a hospital, such as Brookside, this encourages its legal staff to work with its ethics consult service; such collaboration can be invaluable to the more far-reaching development of channels of communication between ethics consultants and courts. Id.
the softening of lines separating professional silos. The scope of such translation can be discerned by comparing identities bestowed on patients in the stories told about them by law, medicine, and bioethics.

The stories that courts narrate are grounded in a notion of legal facts—discrete representations of some event, situation or act in the world to which truth is attributed. Connecting legal facts produces legal stories. Those stories, constructed in the context of explicit rules and procedures, are encompassed within a frame of reference that speaks about justice or justice-gone-wrong. Although less single-mindedly than was once the case, medicine, in contrast, assumes patient identities, and thus, patient stories in light of diagnoses and within the frame of a professional hierarchy. Ethics consultants are often clinicians, and ethics consult services are part of the medical enterprise. Yet, they deviate from medicine’s approach to patient stories. The stories told by ethics consultants are far more likely to facilitate patients or their surrogate decision-makers in reclaiming a position of responsibility in patients’ care. Yet, even as they acknowledge the patient-as-person, they aim as well to acknowledge the clinician-as-person. Not all ethics consultants’ work reflects this

55. See infra Parts II and III.
56. See Facts, BLACK’S LAW DICTIONARY (Online 2nd ed.) https://thelawdictionary.org/fact.
58. See id.
59. See ARTHUR FRANK, THE WOUNDED STORYTELLER 59–68 (2d ed. 2013) (analyzing patients’ stories). The twentieth-century American sociologist Talcott Parsons described the “sick role” in the 1950s. See TALCOTT PARSONS, THE SOCIAL SYSTEM (1951). A central parameter of that role involved the patient’s acceptance of the doctor’s diagnosis. Id. Even now, almost three-quarters of a century after Talcott Parsons identified the significance that a patient’s diagnosis plays in his or her submission to the medical domain, medicine continues to subsume patients’ stories within a diagnostic frame. Id.
61. See id. at 1109.
62. See id. Again, not all ethics consultants follow the model delineated here. On the whole, those working at Brookside do follow this model. This approach reflects Arthur Frank’s call to help patients reclaim their pre-diagnosis selves. FRANK, supra note 59.
understanding of the ethicist’s work, but many do. 64 Part II of this article has illustrated that vision of ethics consultations through the work of one large ethics consult service. 65

III. Disputes Between Pregnant Women and Clinicians or Hospitals

The ethics and legal cases considered in this Part involve health care conflicts between pregnant women and their clinicians or the hospitals in which they were patients. Section A considers disputes about cesarean sections, and Section B considers disputes about blood transfusions. Each section examines matching cases, reviewed, respectively, by Brookside's ethics consult service and by a court of law. 66

A. Compelled Cesareans

By the 1980s, new imaging techniques gave clinicians access to fetal development. 67 That technology and other new technological developments in obstetrical care facilitated medical organizations' and clinicians' “bestow[ing] upon the fetus the status of a patient.” 68 This led to confusion about the identity of the obstetrician’s patient, and it resulted in more obstetrical interventions, including cesarean sections. 69

Most women consent to a cesarean if it is recommended by their doctor. 70 But some do not. 71 Refusal to consent to a cesarean may be grounded in religious beliefs, fear of surgery, a

64. See, e.g., id. (Charon’s work presents the narrative about relationships between patients and family members differently than Frank’s work.).
65. See supra notes 26, 28–30 and accompanying text.
66. Supra note 21. The matching cases reflect similar conflicts and patient populations. They are not, however, necessarily connected each to the other, in any other manner.
69. Id. (noting that imaging allowed revelation of placenta praevia, slow uterine growth, as well as whether a fetus is likely to be born feet-first. Each of these conditions may call for a cesarean). Electronic fetal monitoring (available in the 1970s) can reveal abnormalities in a fetus’s heart rate, which may indicate need for a cesarean. Id. at 1957.
70. Id. at 1959.
71. Id.
commitment to "natural childbirth," or something else. This section compares the process of decision-making by a hospital ethics consult service with the process of decision-making by courts of law in cases involving women who refused cesareans recommended by their clinicians. Subsection i of this Section considers a case handled by Brookside's ethics consult service about a patient who refused a cesarean. Subsection ii considers two matching cases, decided by judges.

i. An Ethics Consultation Involving a Patient's Refusal to Submit to a Cesarean Section

In 2012, a Brookside obstetrical resident ("Dr. R.") sought an ethics consult, while caring for a pregnant woman ("CO"). At the time, CO was about twenty-five weeks pregnant and was hospitalized at Brookside. Dr. R. sought the consult because CO refused to consent to a cesarean section that was recommended by one of the hospital's attending obstetricians. That recommendation followed CO's diagnosis with gestational diabetes and hypertension, as well as evidence that the fetus she carried was in distress. Changes in the fetus's condition during the thirty-six hours before Dr. R. asked the ethics consult service to participate in resolving the conflict about CO's care led Dr. R. to conclude that the fetus's condition was deteriorating and that a cesarean should be performed as soon as possible.

72. Id.
73. See Pregnancy Case P20122, supra note 27. The ethics consult reports reviewed in this Part were selected from among a total of eight consult reports describing cases occasioned by healthcare conflicts about treatment for a pregnant woman. Each of the eight cases arose between the start of 2012 and October 2017. Of the eight cases, some have not been reviewed here as the reports do not provide easy comparison to legal cases, because no matching legal cases could be identified, or for some other reason.
74. See id. The report has been de-identified and a few facts about the patient's diagnosis or care have been altered. Similarly, potentially identifying facts about clinicians (e.g., gender) have sometimes been altered as well. Finally, all patients and clinicians referred to in this article are referred to by initials that do not reflect the actual first letters of the parties' first and last names.
75. Id.
76. Id.
77. Id.
78. Id.
The ethics consult team met and discussed the situation with CO and with hospital clinicians responsible for CO’s care.\textsuperscript{79} CO was very positive about being pregnant and looked forward to giving birth with joy.\textsuperscript{80} She had not refused the recommended cesarean on religious grounds or for any other moral reason.\textsuperscript{81} Rather, as reported by an ethics consultant, she preferred to allow things to go their way in order to “give the pregnancy more time.”\textsuperscript{82} In effect, her choice reflected her understanding of the medical facts.\textsuperscript{83} CO mentioned that one of her cousins was similarly situated to CO during the last trimester of her pregnancy.\textsuperscript{84} CO reported that her cousin was placed on bed rest and delivered at term with no harm to herself or to the infant to whom she gave birth.\textsuperscript{85} She saw her cousin’s positive experience as powerful evidence that she too could avoid a cesarean so early in her pregnancy and could successfully carry her baby to term or, at least, could give the fetus more time to develop in utero before its birth.\textsuperscript{86}

CO conducted online research of her own and had concluded, based on that research, that the risks of delivering a fetus at twenty-five weeks were greater than the risks of harm to herself or the fetus should the pregnancy continue.\textsuperscript{87} The ethics consultant, herself a physician, described CO as “very intelligent and well-reasoned.”\textsuperscript{88} An important aspect of this case was the willingness of the ethics team and in the end, the obstetrician who had recommended an emergency cesarean, to consider CO’s conclusions and to acknowledge the extent of the medical uncertainty underlying decisions about CO’s obstetrical care.\textsuperscript{89}

Dr. R. openly talked with the ethics consultant about her own growing uncertainty about the best form of care for CO and her fetus.\textsuperscript{90} The concern of CO’s clinicians about the risks to CO

\begin{flushleft}
\textsuperscript{79} Id.
\textsuperscript{80} Id.
\textsuperscript{81} Id.
\textsuperscript{82} Id.
\textsuperscript{83} See id.
\textsuperscript{84} Id.
\textsuperscript{85} Id.
\textsuperscript{86} Id.
\textsuperscript{87} Id.
\textsuperscript{88} Id.
\textsuperscript{89} See id.
\textsuperscript{90} Id.
\end{flushleft}
and about the possible effects of CO's condition on fetal development did not abate; they continued to recommend a cesarean. 91 However, the clinicians also acknowledged that the risks of very early delivery were not definitively less significant than the risks to the fetus of postponing the cesarean and allowing the pregnancy to progress. 92

Moreover, CO told the ethics consultant that she would agree to a cesarean should her clinicians tell her that her own health was at risk or that the condition of the fetus had deteriorated such that the risks of postponing delivery clearly outweighed the risks of a premature delivery. 93 The willingness of CO's clinicians to acknowledge the value of the patient's own informal research about her condition and to address the medical uncertainty at the center of CO's case, as well as CO's agreement to reconsider her decision should the clinicians report a shift in the medical situation for her or the fetus, frame the success of this ethics consult. 94

An additional component of the ethics consult report deserves note. In addition to talking with most, if not all, of the stakeholders involved in CO's care, the ethics consult service identified relevant medical literature about decision-making in obstetrical care. 95 The consult team pointed to one article, in particular, that focused on medical uncertainty (such as the uncertainty surrounding decisions about the best care for CO). 96 The authors of the article recommended attaching significant weight to the conclusions of the pregnant woman in situations of medical uncertainty. 97 The identification of medical uncertainty as a specific and important component of ethical deliberations in cases resembling CO's helped shape responses from most of the stakeholders involved in CO's care. 98

91. Id.
92. Id.
93. Id.
94. See supra notes 79–92 and accompanying text.
95. Pregnancy Case P20122, supra note 27.
96. Id. (citing L. B. McCULLOUGH & F.A. CHERVENAK, ETHICS IN OBSTETRICS AND GYNECOLOGY (1994)).
98. See Pregnancy Case P20122, supra note 27.
Thus, the ethics team—noting the uncertainty embedded in efforts to assess comparative risks facing CO and the fetus—concluded that CO's choice to forgo the recommended cesarean should be respected.99 That recommendation, as is the case with all such ethics consultants’ recommendations at Brookside, was precatory and unenforceable.100 The ethics team did not want or expect its recommendation to be coercive.101 In short, the ethics consultant leading the consult team respected the attending obstetrician’s preference for an immediate delivery by cesarean but concluded that CO’s autonomy should outweigh the physician’s medical conclusions, especially since the physician acknowledged that CO’s case involved significant medical uncertainty.102

The ethics team’s own conclusions were not imposed on the parties.103 Rather, the clinicians accepted the ethicists’ recommendation and agreed to continue to share information with CO about her medical condition as it stabilized or changed over time and information about the condition of the fetus.104 The ethics team’s report concluded by applauding CO’s clinicians for their “honest transparency” and thoughtful treatment of CO.105

This ethics consult was successful for all of the stakeholders. It illustrates some of the most compelling benefits of involving ethics consultants in hospital cases that involve health care conflicts. A reasonable medical accommodation was reached.106 The process safeguarded each stakeholder’s personhood. And the health care conflict that led to the call for an ethics consult was abated.107 Not all ethics consults are as successful.108 Some less successful consults are addressed in latter sections of this article.

99. Id.
100. Id.
101. Id.
102. Id.
103. Id.
104. Id.
105. Id.
106. See id.
107. See id.
108. See infra Part III.B.2.
ii. Legal Cases Involving Patients Refusing to Submit to a Recommended Cesarean

This Subsection focuses on two legal cases; each is similar to CO’s case, because each case involved a pregnant woman who refused to consent to a recommended cesarean. In each of these cases, a judge authorized the cesarean that had been recommended by the patient’s clinicians even though in both cases the pregnant woman objected to having a cesarean performed. Moreover, in each of these cases, an appellate court reversed the lower court’s decision. In neither case did the appellate court’s decision preclude the cesarean section to which the patient had objected because both appellate court decisions were reached after the cesarean sections had been performed. In *In re A. C.*, the pregnant woman died two days after the cesarean and her baby died within a few hours of its birth. In *Burton v. State*, the fetus, delivered by cesarean, was born dead.

Neither appellate court decision absolutely precluded coerced care. The *en banc* decision of the D.C. Court of Appeals in *A.C.*—identified as a woman named Angela Carder—shaped a jurisprudential frame on which future courts (and ethics consultants) might rely in responding to cases involving similar disputes. *Burton*, in contrast, did not re-shape existing state law regarding limitations on a pregnant woman’s right to make her own medical decisions even though the appellate court did not support the lower court’s order. For that reason, the appellate court decision in *A.C.* will be reviewed in more detail in this article than that in *Burton*. A tripartite comparison of the work of the ethics consult service, the decision-making of the lower court judges, and the opinions of the two appellate courts in *A.C.* and *Burton*, respectively, suggest that appellate court review of bioethical disputes can offer an important complement to

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110. *In re A.C.*, 573 A.2d at 1237; *Burton*, 49 So. 3d at 264.
111. *In re A.C.*, 573 A.2d at 1253; *Burton*, 49 So. 3d at 266.
112. *In re A.C.*, 573 A.2d at 1237; *Burton*, 49 So. 3d at 264.
113. *In re A.C.*, 573 A.2d at 1241.
114. *Burton*, 49 So. 3d at 264.
115. See *In re A.C.*, 573 A.2d at 1241-42.
116. See *Burton*, 49 So. 3d at 266.
decision-making on the ground (whether in courts or by hospital ethics consult services).  

iii. In re A.C.

Carder's story has been told by courts and by commentators. Unfortunately, there seems to be no public record of the trial court proceedings in the case. Thus, the account here of that court's decision-making reflects information provided by the appellate court and secondary sources. Carder's story—an emotional and sad story—seeks a "thick" description. Judges focus on legal facts, and in cases occasioned by health care conflicts, that can be a significant factor in limiting trial courts' attention to stakeholders' underlying concerns and relationships. Generally, that precludes them from offering nuanced narratives.

Court accounts of Carder's story offer only a thin narrative. Accounts of Carder's story presented in scholarly and popular articles and through public media enhance one's understanding of the stakeholders, their preferences, and their values. In short, such extra-judicial sources facilitate a clearer

117. See infra Part II.A (noting limitations of trial court decisions in these cases but benefits of some appellate court decisions). The Burton court relied significantly on earlier state court decisions regarding the rights of pregnant women to make medical decisions. See Burton, 49 So. 3d at 265–66; see also id. at 267–68 (Berger, J., dissenting) (noting that Burton was not a "case of first impression").

118. In re A.C., 573 A.2d 1235.


120. In re A.C., 573 A.2d at 1235.

121. See, e.g., Curran, supra note 119, at 489–90; Spruce, supra note 119, at 239.

122. See Curran, supra note 119, at 239. See generally Curran, supra note 119; Remnick, supra note 124.

123. See BLACK'S LAW DICTIONARY, supra note 56 (considering meaning of "legal facts").


125. In re A.C., 573 A.2d at 1263–64; Remnick, supra note 124, at W12.

126. See Spruce, supra note 119, at 239. See generally Curran, supra note 119; Remnick, supra note 124.
understanding of Carder’s voice (largely absent from the courts’ decisions).127

As a young adolescent, Carder was diagnosed with cancer.128 After surgery and chemotherapy, her condition went into remission.129 When Carder was in her early twenties, the cancer recurred—diagnosed at that time as osteogenic sarcoma.130 Treatment included amputation of her left leg and part of her pelvis.131 Carder later married and soon thereafter became pregnant.132 During the twenty-fifth week of the pregnancy, Carder’s physicians diagnosed her with terminal cancer.133 Carder opted to receive palliative treatment, and hoped, along with her clinicians, that she would live until the twenty-eighth week of the pregnancy.134 Carder’s clinicians expected that by that time, the fetus’s prognosis would have improved significantly.135 However, soon after Carder was diagnosed, her condition deteriorated dramatically.136 Intubation soon became necessary to ease Carder’s breathing.137

George Washington University Hospital sought a court order to decide “what [the hospital] should do in terms of the fetus, whether to intervene [by Caesarean section] and save its life.”138 When Carder’s case was brought to court, there had been significant pressure to reach a decision quickly in light of Carder’s worsening condition.139 The legal proceedings during the last days of Carder’s life were expeditious.140 Judge Emmet Sullivan, convened a trial court hearing in the hospital.141 Carder, who was

127. See, e.g., Spruce, supra note 119.
129. Id.
130. See Spruce, supra note 119, at 239.
131. Id.
132. In re A.C., 533 A.2d at 612.
133. Id.
135. Id.
136. Id. at 1239.
137. Id.
138. In re A.C., 533 A.2d at 612.
139. See id. at 613 ("In retrospect, we must acknowledge that any attempt to use rules on stay procedures places appellate form over substances. No appeal in this case could mature.").
140. Id. (describing the hastily-put-together nature of the appellate proceeding).
141. The trial court proceedings are not available, but that court’s decision is reviewed by the appellate court. See In re A.C., 573 A.2d at 1238.
intubated at the time, was not present. After the hospital hearing, Judge Sullivan authorized the hospital to proceed with "a Cesarean section on [this] terminally ill woman who was in extremis." At that time, some of Carder’s clinicians believed that she was capable of making medical decisions and that she had made it clear, even though intubated, that she did not want the cesarean performed. Carder’s parents agreed that their daughter did not want a cesarean. After Carder’s death, her mother, Nettie Stoner, expressed deep regret about her daughter’s having been subjected to a compelled cesarean: “I thought we had the right to choose what we were going to do with our bodies . . . Angela should have had the choice. And Angela did not have the choice.”

Before the cesarean was performed, Carder’s counsel requested that the appellate court stay the lower court’s order. Judge Nebeker of the D.C. Court of Appeals declined to issue the requested stay. Later, the same court, hearing the case en banc, vacated Judge Nebeker’s refusal to stay the trial court order and established a new frame for considering medical decision-making for and by pregnant women. By that time, Carder and her baby, who lived for about two hours, had both died. Carder’s death certificate noted the cesarean to have been a “contributing cause” of her death.

In 1990, after Carder and the fetus died, the D.C. Court of Appeals suggested a framework for responding to cases such as

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142. Id. at 1240 (noting that the clinicians “discouraged” the judge from moving the hearing). The judge did not question one of the hospital clinicians who opined that the proceedings should not be moved to Angela’s bedside. Id.
143. In re A.C., 533 A.2d at 611.
145. Id.
146. Id. at D3.
147. In re A.C., 533 A.2d at 611.
148. Id. at 611–12. Judge Nebeker wrote for the panel. Id. at 611.
149. Id. at 611.
150. See generally In re A.C., 573 A.2d 1235 (D.C. 1990) (en banc).
151. Id. at 1241.
152. Id. at 1238.
153. See Curran, supra note 119, at 490.
that posed by Carder’s situation. The appellate court introduced its opinion with a brief statement about the court proceedings that occurred while Carder was alive and pregnant. The summary is stark. It contrasts tellingly with the engaged report of the hospital ethics consult service regarding CO. Judge Terry, for the court en banc wrote in Carder’s case:

This case comes before the court for the second time. [The first time], a three-judge division denied a motion to stay an order of the trial court which had authorized a hospital to perform a caesarean section on a dying woman in an effort to save the life of her unborn child. The operation was performed, but both the mother and the child died. A few months later, the court ordered the case heard en banc and vacated the opinion of the motions division. Although the motions division recognized that, as a practical matter, it “decided the entire matter when [it] denied the stay,” the en banc court has nevertheless heard the full case on the merits.

The fateful significance, for Carder and her fetus, of the lower court proceedings has been elided by the attention given to the jurisprudential approach constructed by the appellate court. The appellate court rendered that decision two years after Carder and her baby’s deaths. The jurisprudential significance of the court’s en banc decision does not gainsay the unfortunate consequences of the earlier court proceedings for Carder and the baby in the last days of Carder’s life. The legal proceedings in this case, however one assesses the significance of the appellate court’s

154. In re A.C., 573 A.2d at 1237.
155. Id. at 1238.
156. See id.
157. See Pregnancy Case P20122, supra note 27.
158. In re A.C., 573 A.2d at 1237 (citations omitted).
159. Even if Carder and the fetus would not have died, the trial court’s decision shaped the last days of Carder’s life. Carder, herself, might well have preferred a different end-of-life experience, both for herself and for her fetus.
160. See In re A.C., 573 A.2d at 1235.
161. See id.
decision after the patient’s death, did not serve Carder.\textsuperscript{162} To some extent, the appellate court echoed that conclusion in vacating Judge Nebeker’s refusal to stay the trial court’s order.\textsuperscript{163}

Judge Terry explained that Judge Nebeker, unsure about Carder’s views regarding a cesarean, did not attempt to discern what Carder would have preferred.\textsuperscript{164} The appellate court, reviewing the case en banc, thus accepted Judge Nebeker’s conclusion that Carder’s views were essentially unknowable when it authorized the hospital to perform a cesarean.\textsuperscript{165}

What a trial court must do in a case such as this is to determine, if possible, whether the patient is capable of making an informed decision about the course of her medical treatment. If she is, and if she makes such a decision, her wishes will control in virtually all cases. If the court finds that the patient is incapable of making an informed consent (and thus incompetent), then the court must make a substituted judgment. This means that the court must ascertain as best it can what the patient would do if faced with the particular treatment question. Again, in virtually all cases, the decision of the patient, albeit discerned through the mechanism of substituted judgment, will control.\textsuperscript{166}

Thus in vacating Judge Nebeker’s decision, the D.C. Court of Appeals concluded that Carder had the right to make medical decisions for herself.\textsuperscript{167} The court accepted the conclusion that Carder’s own views were unknowable, but it held that the trial court should have followed a substituted judgment procedure.\textsuperscript{168} That would have obliged the court to discern what Carder would have wanted, while she continued to enjoy capacity.\textsuperscript{169} In effect, in the view of the D.C. Court of Appeals, pregnant women were not

\begin{itemize}
\item \textsuperscript{162} See \textit{id}.
\item \textsuperscript{163} \textit{Id.} at 1258.
\item \textsuperscript{164} \textit{Id.} at 1252.
\item \textsuperscript{165} \textit{Id}.
\item \textsuperscript{166} \textit{Id}.
\item \textsuperscript{167} \textit{Id.} at 1235.
\item \textsuperscript{168} \textit{Id.} at 1247.
\item \textsuperscript{169} \textit{Id}.
\end{itemize}
to be treated differently than other patients—at least in the great majority of situations—and therefore, they were entitled to decision-making autonomy regarding medical care.\footnote{170} In the case of a pregnant woman without capacity, her preferences while still capable should serve as a substitute for the exercise of contemporaneous autonomy.\footnote{171} The court explained:

> It would be an extraordinary case indeed in which a court might ever be justified in overriding the patient’s wishes and authorizing a major surgical procedure such as a caesarean section... \footnote{172} We have stressed that the patient’s wishes, once they are ascertained, must be followed in “virtually all cases...unless there are truly extraordinary or compelling reasons to override them”... Indeed, some may doubt that there could ever be a situation extraordinary or compelling enough to justify a massive intrusion into a person’s body, such as a caesarean section, against that person’s will.

The appellate court’s opinion in this case, which contrasted with earlier cases involving pregnant women refusing cesarean sections,\footnote{173} shaped subsequent approaches—both in courts and in hospitals—to competent pregnant women refusing recommended care.\footnote{174} In short, the court proceedings were of potential value to others, but none to Carder or her fetus.\footnote{175} The significance of the A.C. ruling is suggested by a statistical noted in an article published in the same year as the en banc appellate court decision in A.C.: in cases brought by clinicians or hospitals involving pregnant women refusing recommended cesareans,

\begin{itemize}
  \item [170. \textit{Id.} at 1242-47.]
  \item [171. \textit{Id.} at 1237, 1249.]
  \item [172. \textit{Id.} at 1252.]
  \item [173. See Curran, \textit{supra} note 119, at 489–90 (describing the \textit{en banc} appellate court decision in A.C. to have broken with a “trend”).]
  \item [174. See Spruce, \textit{supra} note 119, at 245.]
  \item [175. See \textit{id.} at 241; see, e.g., D.R. by A.F. v. Daughters of Miriam Ctr. for the Aged, 589 A.2d 668 (N.J. Super. Ct. Ch. Div. 1990) (relying on \textit{In re A.C.}, 573 A.2d 1235, to rule that when available, a court must consider prior wishes of an incompetent patient from any time that they were competent to make medical decisions).]
\end{itemize}
judges ordered that a cesarean be performed against the pregnant woman's wishes in eighty-six percent of the cases.176

Carder's case was and remains haunting for many reasons.177 Among those reasons is the failure of the courts to give Carder an opportunity to tell her story as she would have wanted it told.178 Tracey Spruce, offering a thicker version of Carder's story than did any of the courts, intoned:

This story is not the same one you are likely to hear from the judges, the doctors, or the lawyers involved in the Angela Carder case. It might be close to the one Nettie Stoner [Angela's mother] tells, but it probably is not the one Rick Carder [Angela's husband] would tell. Dan Stoner, Angie's father, would simply tell you a story about how a judge killed his daughter. The two opinions issued by the D.C. Court of Appeals tell a story that tries to avoid criticizing the trial judge's conduct in the hospital hearing.179

In any event, the appellate court accepted the trial court's findings of fact180 and thus failed to listen for Carder's voice, something a hospital ethics consultant might have done.181 Spruce, noting the plethora of transformations of Carder's story, suggested

176. Curran, supra note 119, at 489 (citing Veronica E. B. Kolder et al., Court-Ordered Obstetrical Interventions, 316 N.E.J.M. 1192 (1987)). Curran further reports distressing bias in that "in 81 percent of the cases of court-ordered cesarean sections, the women were black, Hispanic, or Asian. Twenty-five percent did not speak English as their primary language." Id. at 489.

177. For other examples of haunting cases, see COMPLEX ETHICS CONSULTATIONS: CASES THAT HAUNT US (Paul J. Ford & Denise M. Dudzinski eds., 2008). A forward to this book, authored by Albert R. Jonsen, described it as "a summons to realism in clinical ethics." Id. at xv. The cases described in the book, he further notes, are "hard cases," that can lead to "emotional discomfort" and "intellectual puzzlement." Id. at xix.

178. See Spruce, supra note 119, at 241.

179. Id.

180. Judge Terry explained: "We reiterate that we cannot find the facts in this or any other case. That is the function of trial judges, who can view the witnesses and discern from their demeanor and testimony, rather than a cold written record, what the facts are." In re A.C., 573 A.2d 1235, 1251 (D.C. 1990) (en banc).

181. See Scofield, supra note 34, at 97 (quoting ASBH, CORE COMPETENCIES, supra note 33).
that there might have been fewer transformations had Carder been heard—had she ever gotten “to tell her side of it.”

iv. Burton v. State

Burton v. State, a Florida case occasioned by a woman’s refusal to submit to prenatal care, including a cesarean section recommended by physicians, is less significant than A.C. as a jurisprudential matter. Unlike A.C., Burton did not establish a legal framework to which future courts and hospitals might look in responding to disputes between pregnant women and clinicians. The decision did, however, reverse a trial court order that failed to take the patient’s needs and preferences into account.

a. Trial Court Order

Samantha Burton, the mother of two children, was twenty-five weeks pregnant when she voluntarily sought care at Tallahassee Memorial Hospital. Hospital clinicians recommended that Ms. Burton stay in the hospital for medical supervision. She preferred to go home. The hospital asked the state to prohibit Burton from leaving the hospital, arguing that continued hospitalization was necessary to safeguard the fetus’s life. Florida’s Attorney General appointed the hospital’s outside counsel to serve as a “special assistant state attorney.” In response to a petition from that “state attorney,” a state circuit court judge spoke with Burton on the telephone and with a hospital physician and then ordered that Burton remain in the hospital subject to the care of hospital clinicians who were:

182. Spruce, supra note 119, at 241.
184. Compare In re A.C., 573 A.2d at 1252, with Burton, 49 So. 3d 263.
185. See Burton, 49 So. 3d 263.
187. Id.
188. Id.
189. Burton, 49 So. 3d at 264.
191. Wevers, supra note 186, at 436.
...authorized to provide such medical care and treatment to Samantha Burton and her unborn child as in their reasonable professional judgment is necessary to preserve the life and health of Samantha Burton’s unborn child, including but not limited to restricting Samantha Burton to bed rest, administering appropriate medication, postponing labor, taking appropriate steps to prevent and/or treat infection and/or eventually performing a cesarean section delivery of the child at the appropriate time. Samantha Burton is ordered to comply with the attending physician’s orders with regard to such medical care and treatment.¹⁹²

Not only was Burton compelled to submit to medical care that she did not want, but she was effectively imprisoned in a hospital for the duration of her pregnancy.¹⁹³ A cesarean was performed two days after the court issued its order.¹⁹⁴ The fetus had already died.¹⁹⁵

The trial court order—unusual in cases such as this one in being available to the public¹⁹⁶—illuminates the limitations of judicial responses to bioethical disputes about patient care, especially in cases in which the patient and/or family members of the patient are opposed by clinicians and the hospital.¹⁹⁷ Leon County Circuit Court Judge John Cooper, referring to Burton’s fetus as “the unborn child,” relied on the testimony of what he described as “the unborn child’s attending physician.”¹⁹⁸ Asserting that “as between parent and child, the ultimate welfare of the

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¹⁹⁴. Id.
¹⁹⁵. Id.
¹⁹⁸. Id.
child is the controlling factor," and that Burton "exhibited behavior since her admission to [the hospital] in contradiction to the health care providers' instructions and recommendations." Judge Cooper authorized the hospital and its clinicians to provide any care to Burton that they deemed appropriate and denied Burton's request to move to a different hospital for the sake of the "child's best interest." Even more, he authorized the hospital to notify the state's Department of Children and Families about "Samantha Burton's condition."

In short, the trial court judge defined Burton as a non-compliant patient who "exhibited behavior" that contravened the clinicians' recommendations, including continuing to smoke during her pregnancy. Her interests and preferences were ignored or displaced for the presumptive sake of the fetus she carried. Burton was deprived of virtually all choice in deciding about her own care, including the right to find a hospital willing to provide care that met with her preferences for continuing her pregnancy and for giving birth. The trial court's order did not serve Burton, and although Judge Cooper could not have foreseen the fetus's death that occurred two days after he issued the court's order that order did not serve the fetus either.

b. Appellate court decision in Burton

As in A.C., the appellate court in Burton agreed to grant an appeal concluding that the issues at stake were "capable of repetition" and might "evade review" in a subsequent case due to the rapidity with which medical events can unfold in such cases. As a general matter, the appellate court, relying on state precedent, agreed that the right of a pregnant woman to make her own medical decisions can—in contrast with the rights of almost every other competent adult—be outweighed by the state's

199. Id.
200. Id.
201. Id.
202. Id.
203. Id.
204. Id.
205. See id.
interest in safeguarding the life of a viable fetus.²⁰⁹ However, the court reversed the trial court's order on two grounds.²¹⁰ First, the viability of the twenty-five week fetus had not been established:

Because there is no statutory or precedential presumption of viability, in terms of the stage of pregnancy or otherwise, there must be some evidence of viability via testimony or otherwise. Only after the threshold determination of viability has been made may the court weigh the state's compelling interest to preserve the life of the fetus against the patient's fundamental constitutional right to refuse medical treatment.²¹¹

Second, the state must "establish a compelling state interest" in order to "override the pregnant woman's constitutional right to the control of her person."²¹² The court explained that "where the state does establish a compelling state interest... the state must then show that the method for pursuing that compelling state interest is 'narrowly tailored in the least intrusive manner possible to safeguard the rights of the individual.'"²¹³

v. Comparison of CO's case with those of Angela Carder and Samantha Burton

Judge Terry, who wrote the opinion for the en banc appellate court in A.C., expressed discomfort at trial court judges hearing cases, such as Carder's.²¹⁴ "We observe... that it would be far better if judges were not called to patients' bedsides and required to make quick decisions on issues of life and death."²¹⁵ Judge Terry suggested instead that an alternative "tribunal" be

²⁰⁹. Id. at 265–66.
²¹⁰. Id. at 266.
²¹¹. Id. But see id. at 268 n.2 (Berger, J., dissenting) (opining that "we must presume there was sufficient evidence to support the trial judge's decision, e.g., that viability was determined").
²¹². Id. at 266 (majority opinion).
²¹³. Id. (citations omitted).
²¹⁵. Id.
created that would entertain cases such as that involving Angela Carder, "with limited opportunity for judicial review."  

A comparison of court responses in A.C. and Burton with those of the Brookside ethics consult service in CO's case supports Judge Terry's concern about the limitations of judges responding to health care conflicts, such as those that faced CO, Carder, and Burton. The ethics consultants were able to attend to the patient's voice and to encourage the patient's clinicians to respond with the patient's voice in mind. Communication with the patient and her clinicians facilitated important dialogue. Moreover, the ethics consultants understood the significance of the medical uncertainty at the center of CO's care. In contrast, the trial judges in both A.C. and Burton elided the medical uncertainty at the center of both Carder's and Burton's cases.

a. The Pregnant Woman Voice, Personhood, and Conversation

The trial court judge never entered the hospital room where Carder was being cared for. Although she was intubated, she was alert and able to respond to questions competently. Carder's voice was rendered mute by the appellate court because

216. Id. While firmly deeming the "trial court's findings of fact" as "binding" on the appellate court, Judge Terry noted the limitations placed on the trial court, obliged to hear the case expeditiously given Carder's rapidly declining health. Id. at 1248.

217. See supra Part II.A.1 (describing CO's experience) and Part II.A.2 (describing Carder's and Burton's experiences).

218. See Pregnancy Case P20122, supra note 27.

219. See id.

220. See supra Part II.A.2 (describing Carder's and Burton's experiences).

221. In re A.C., 573 A.2d at 1238.

222. Id. at 1241.
all of the courts that entertained her situation were unable to “hear” her. One of Carder’s treating physicians explained to the superior court judge:

[Angela] does not make sound because of the tube in her windpipe. She nods and she mouths words. One can see what she’s saying rather readily. She asked whether she would survive the operation. She asked [Dr.] Hammer if he would perform the operation. He told her he would only perform it if she authorized it but it would be done in any case. She understood that. She then seemed to pause for a few moments and then very clearly mouthed words several times, I don’t want it done. I don’t want it done. Quite clear to me.

Yet the appellate court concluded that Carder’s voice could not be discerned. That, according to one commentator, was “the easy way out.” The commentator added: “If [the judges] had really listened, they would have heard a dying woman begging to be allowed to die with her baby.” Carder’s voice disappeared in a medley of other voices that shaped the courts’ assumption that Carder was not capable of expressing her dying wish to avoid a cesarean. Perhaps, as Tracey Spruce suggested, the court’s inability to hear Carder’s voice allowed them to preserve a vision of Carder as a “good mother.” In the myth of the good mother, self-sacrifice for one’s child (or one’s fetus) is essential. Had Carder been understood to reject a cesarean because of the possibility that it would shorten her life (as seems to have been the

223. Id. Judge Terry noted that “[c]ounsel for A.C. now maintain that A.C. was competent and that she made an informed choice not to have the caesarean performed.” Id. at 1238. He then concluded that “the evidence, realistically viewed, does not support [that].” Id. Further, the court noted its role to preclude “findings of fact . . . unless clearly erroneous.” Id. at 1242.
224. Id. at 1241.
225. Id.
226. Spruce, supra note 119, at 241.
227. Id.
228. See id. at 255.
229. Id. at 256.
230. Id. at 253.
Thus, from one perspective, the Carder case reflects a progressive appellate court, vacating a trial court order that compelled a pregnant woman to submit to a cesarean. The case was applauded by feminists. But from a second perspective, the appellate court’s decision resembled the trial court’s decision in that it failed to heed or hear the pregnant woman’s voice.

Burton’s story, like that of Carder, is sad. When Burton was twenty-five weeks pregnant she was effectively confined to a hospital where she did not want to be. According to one author, who focused on components of Burton’s story that the courts ignored, “[Burton] remained alone in a dreary hospital room until the fetus died and was surgically removed.” Burton’s situation was likened to “solitary confinement” in a prison. Unlike Carder, Burton survived.

After the death of Burton’s fetus and the compelled cesarean, the American Civil Liberties Union brought an appeal. Michele Goodwin suggests that the success of Burton’s appeal was “symbolic.” Burton had already been subjected to “three days of involuntary confinement and a forced cesarean section.” In Burton’s and Carder’s cases, the voice of the patient was muted and elided. The Florida trial court’s treatment of

231. See Curran, supra note 119, at 489–90 (reporting that Carder’s death certificate noted that cesarean as a “contributing cause” of her death).

232. Spruce, supra note 119, at 246–47.


235. See In re A.C., 573 A.2d at 1243 (noting appellate court’s obligation to accept lower court’s findings of “fact” “unless clearly erroneous”).

236. See supra Part II.A.2 (describing Carder’s and Burton’s experiences).

237. Id.


239. Id. at 800.

240. Id. (stating that the fetus died, but not indicating that the mother had as well).

241. Id. at 805.

242. Id.

243. Id.

244. See supra Part II.A.2 (describing Carder’s and Burton’s experiences).
Burton openly disdained this woman’s voice and her personhood.\textsuperscript{245} While Carder was portrayed as a “good mother,” Burton was portrayed as a “bad mother.”\textsuperscript{246} The trial court judge characterized Burton as a difficult patient, “exhibit[ing] behavior” that conflicted with the recommendations of hospital clinicians\textsuperscript{247} and concluded that the state’s interest in Burton’s fetus displaced Burton’s “privacy interests.”\textsuperscript{248} Further, the trial court authorized the hospital where Burton was confined to notify the state’s Department of Children and Families “of Samantha Burton’s condition so that the Department or other appropriate agency may monitor and provide any necessary assistance to Samantha Burton and her children.”\textsuperscript{249} This order assumed Burton was a neglectful or abusive mother.\textsuperscript{250}

Despite distinct and often contrasting portraits painted in Carder’s and Burton’s respective court proceedings, both women were deprived of their personhood.\textsuperscript{251} Although the Burton appellate court reversed the trial court’s order, its decision offered no commentary on the trial court’s portrait of Burton.\textsuperscript{252} For Carder and Burton the trial court decisions were reversed, but the consequences could not be.\textsuperscript{253} Both women’s preferences and needs were largely disregarded in the stories the courts told about them.\textsuperscript{254}

In contrast, CO’s case report placed the patient’s voice and personhood at the center of the consultation and strived to encourage and sustain communication between the patient and her clinicians.\textsuperscript{255} The ethics consult service report reflected the

\textsuperscript{245} Goodwin, supra note 238, at 801.
\textsuperscript{246} Goodwin noted that that the court ordered the Tallahassee Memorial Hospital to notify the Department of Children and Families to “intervene as necessary in the monitoring of Samantha Burton’s children.” Id. at 802; see also supra note 239 and accompanying text.
\textsuperscript{248} Id.
\textsuperscript{249} Id.
\textsuperscript{250} Fla. STAT. § 39.201(2)(a) (2018) (requiring reports of child abuse, abandonment, or neglect).
\textsuperscript{251} See supra Part II.A.2 (describing Carder’s and Burton’s experiences).
\textsuperscript{252} Burton v. Florida, 49 So. 3d 263, 266 (Fla. Dist. Ct. App. 2010).
\textsuperscript{253} See supra Part II.A.2 (describing Carder’s and Burton’s experiences).
\textsuperscript{254} See id.
\textsuperscript{255} See supra Part II.A.1 (describing CO’s experience).
concerns of both CO and her treating clinicians. Further, the report identified the chief bioethical principles at stake to include respect for the patient’s autonomy and concern that the physicians’ professional responsibility (grounded in obligations of beneficence and non-maleficence for the patient) be respected as well. The consultant’s involvement with most of the stakeholders allowed her to mediate between the obstetrician’s wish to perform a cesarean as soon as possible and the patient’s wish to prolong the pregnancy as long as possible in the hope that the fetus would be allowed to develop while not suffering increased harm while in utero.

At the heart of this successful mediation sat the ethics consultant’s focus on the medical uncertainty that surrounded stakeholders’ conflicting conclusions about a course of action that would best serve CO and her fetus. Uncertainty about the best treatment options was also at issue in the cases of Carder and Burton. However, the fact of medical uncertainty was handled quite differently in those cases. In CO’s case, medical uncertainty was rendered explicit and became the fulcrum around which discourse and eventually agreement were developed.

256. See id.


258. See supra Part II.A.1 (describing CO’s experience).

259. See id.


261. See In re A.C., 573 A.2d at 1252; In re Unborn Child of Samantha Burton, 2009 WL 8628562 at *2.

262. Pregnancy Case P20122, supra note 27.
b. Uncertainty at the Center

CO’s obstetrician concluded that an expeditious cesarean would best serve CO and her fetus. She disagreed. She felt that she could continue the pregnancy safely, giving the fetus more time to develop before its birth. Yet, in communicating with the ethics consultant, both CO and the clinicians acknowledged uncertainty about the outcome for CO and for the fetus regardless of the course followed. The uncertainty was not masked or elided. The ethics consultants picked up on the parties’ readiness to recognize the uncertainty surrounding medical choices in CO’s care in order to define an area of agreement between CO and her clinicians. Forging that area of agreement included participation of the obstetrician who favored an immediate cesarean but who later concurred with CO that that option was not risk-free and that her care had to be shaped in light of the medical uncertainty at its center.

In sharp contrast, the uncertainty that attended medical conclusions in Carder’s and Burton’s cases was ignored or displaced. In part, that process would seem to reflect the trial court judges’ goal of reaching a clear-cut decision about whether or not to authorize a cesarean despite the refusal of the pregnant women to undergo that surgery. Had the trial court judge focused on the probability that the surgery would serve neither mother nor fetus, he might well have “heard” Carder’s voice and refrained from authorizing surgery. Instead, it would seem, he opted to try to save the fetus even if Carder could not be saved. However, the hope that the fetus would be saved may have displaced a more clear-sighted understanding of the odds facing

263. Id.
264. Id.
265. Id.
266. Id.
267. See id.
268. See id.
269. Id.
271. See In re A.C., 573 A.2d 1235; Burton, 49 So. 3d 263.
272. In re A.C., 573 A.2d at 1240.
the twenty-six week fetus in the 1980s, a fetus already compromised by Carder’s failing medical condition.273

Uncertainty also colored medical decision-making for Burton and her fetus.274 And that was also largely disregarded by the trial court.275 The trial court authorized a cesarean, presumptively to serve the fetus.276 Two days later, that surgery was performed.277 The fetus was born dead.278 Yet, the responses of the Florida court differed from those of the D.C. court in that the circuit court judge in Burton concluded that Burton’s fetus was a “child” and that the welfare of that child superseded Burton’s health and welfare.279 That conclusion further limited the court’s capacity to focus on the uncertainty of the medical situation for Burton and her fetus.280

In fact, the decision to perform a significantly pre-term cesarean often involves medical uncertainty about potential benefits to a woman and/or her fetus.281 Such medical uncertainty can shape the decision-making process.282 The circuit court did not acknowledge that reality.283 Its only concession to medical uncertainty was a request to the hospital lawyer (delegated to serve as a special assistant state attorney) to describe “any change in the circumstances surrounding [Burton’s] pregnancy,” after the court issued its order.284 That never happened: Burton’s fetus died and was “delivered by Cesarean.” “Two days after entry of the [circuit court’s] order.”285

Medical clinicians often make treatment decisions despite uncertainty.286 That challenge is central to medicine.287 Yet, it has

273. See id. at 1239.
274. See Burton, 49 So. 3d at 263.
275. See id.
276. Id. at 264.
277. Id.
278. Id.
279. Id. at 265.
280. Id. at 263.
281. See Corney, supra note 144.
282. See id.
283. See generally Burton, 49 So. 3d 263.
285. Burton, 49 So. 3d at 264.
been suggested that “doctors tend to dwell on the upside.”

If so, that may reflect an attempt to minimize the discomforts of uncertainty. Had the courts and the clinicians involved in Carder’s legal and medical cases known that the compelled cesarean would result in a dead baby, perhaps they would have allowed Carder to die in peace, without surgery, and without the knowledge that her baby had died a few hours after its birth. That was not knowable. But greater readiness to acknowledge and respond to the medical uncertainty at the center of care decisions for Carder would likely have re-shaped the trial court’s understanding of the case. Similarly, had the courts and clinicians responding to Burton known that the fetus would die in utero two days after the court authorized a cesarean, despite Burton’s refusal to consent, perhaps the cesarean that delivered the dead fetus might not have been forced on Burton. In CO’s case, there were similar uncertainties. However, they were acknowledged and discussed openly. That acknowledgment shaped decisions. CO herself, as well as attentive clinicians, including CO’s obstetricians and the ethics consult team, recognized those uncertainties and discussed them—an important step in their interactions with CO. The recognition of the uncertainty that undergirded decision-making about CO’s care became the modus vivendi, as it were, for agreement among the stakeholders. Recognizing that uncertainty expressly, the clinicians agreed that CO’s preference to preclude or at least postpone a cesarean deserved respect.


289. Id. (noting two sorts of uncertainty in medicine—the “uncertainty of evidence” and the “uncertainty of outcome”; the first, Khullar suggests, “is an information problem,” while the second “is a prediction problem”).

290. Pregnancy Case P20122, supra note 27.

291. Id.

292. See id.

293. Id.

294. See id.

295. Id.
B. Pregnant Women Refusing to Submit to Blood Transfusions

The cases considered in this Section resemble those considered in Section A of this Part in that they involve the responses of hospitals, clinicians, bioethicists, and courts to pregnant women refusing care recommended by their clinicians. However, the decisions at issue in this section differ from the type of decision at issue in Section A. Each of the cases considered here involves women who refused a blood transfusion for herself, her fetus, or her just-born infant on religious grounds.

Specifically, each of the cases involves a pregnant Jehovah’s Witness. Jehovah’s Witnesses accept medical and surgical care, but are prohibited from accepting blood transfusions. For a Jehovah’s Witness, doing so violates biblical law and results in excommunication and “eternal damnation.” Thus, the consequences for a Jehovah’s Witness who consents to a blood transfusion are very serious.

A competent Jehovah’s Witness has the right—as do all competent adults—to consent to or refuse recommended care even if refusing that care is likely to have dire consequences, including death. Although standards for assessing whether a patient has been provided with adequate information differ from state to state, all standards allow competent adult patients to refuse recommended care.

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297. Id.
301. LEXISNEXIS FIFTY-STATE SURVEYS, HEALTHCARE LAW – MEDICAL TREATMENT: INFORMED CONSENT (Sept. 2016) (some states apply a “physician standard,” others apply a “patient standard,” and a few apply a hybrid standard). Broadly, informed consent laws require clinicians to inform patients about the benefits and risks of recommended medical treatment and procedures (including diagnostic tests), as well as alternatives to those recommendations. See, e.g., MINN. STAT. §§ 144, 651 (2018). The definition of clinician may be supplied by state law. New York, for instance, includes “medical, dental or podiatric practitioner[s]” among those required to provide patients with information.
Yet, courts have sometimes compelled capable pregnant women to submit to care recommended for the welfare of a fetus even though the woman has refused that care. A number of these cases occurred before development of the modern informed consent doctrine in the early 1970s. However, a patient's right to consent or refuse health care, even if not predicated on information provided by a physician, antedated that development.

One might expect the First Amendment to offer further protection to Jehovah's Witnesses refusing blood transfusions. But invocation of First Amendment rights has generally not safeguarded pregnant Jehovah's Witnesses from recommended blood transfusions. In authorizing blood transfusions to a pregnant Jehovah's Witness in 1964, the SCNJ explained:

We have no difficulty in...deciding [to compel a blood transfusion] with respect to the infant child. The more difficult question is whether an adult may be compelled to submit to such medical procedures when necessary to save his life. Here we think it is unnecessary to decide that question in broad terms

before seeking patient consent to (or refusal of) care. N.Y. PUB. HEALTH § 2805-D (Consol. 2018).

302. LEXISNEXIS FIFTY-STATE SURVEYS, supra note 301 (providing citations to relevant state laws in every state). State statutes do not require patient consent in cases involving emergencies where the patient's condition precludes informed consent if care is to be given in time to help the patient. Raphael J. Leo, Competency and the Capacity to Make Treatment Decisions: A Primer for Primary Care Physicians, 1:5 PRIMARY CARE COMPANION J. CLINICAL PSYCHIATRY 131, 137 (1999).


304. See, e.g., Appl. of Pres. & Dir. of G'town Coll., Inc., 331 F.2d 1000 (D.C. Cir. 1964).

305. Paula Walter, The Doctrine of Informed Consent: To Inform or Not to Inform?, 71 ST. JOHN'S L. REV. 543, 543, 555, n.54 (noting existence of common law consent rules and noting that the informed consent statute, N.Y. PUB. HEALTH § 2805-D, entailed codification of aspects of common law). A few of the legal cases noted in this subsection involving pregnant Jehovah's Witnesses refusing blood fit within the category of court-identified exceptions to informed consent laws. Id.


307. See, e.g., Appl. of Pres. & Dir. of G'town Coll., Inc., 331 F.2d 1000 (compelling Jehovah's Witness patient to receive blood even though she raised a constitutional claim); see also Raleigh Fitkin-Paul Morgan Mem'l Hosp., 201 A.2d 537 (authorizing that pregnant Jehovah's Witness receive blood transfusion for sake of "unborn child").
because the welfare of the child and the mother are so intertwined and inseparable that it would be impracticable to attempt to distinguish between them with respect to the sundry factual patterns which may develop. The blood transfusions (including transfusions made necessary by the delivery) may be administered if necessary to save her life or the life of her child, as the physician in charge at the time may determine.308

In short, legal limits on the right of pregnant women to make autonomous medical decisions in cases involving compelled care have been imposed in the name of fetal health and welfare despite consent rules that presumptively safeguard the patient’s right to refuse recommended care.309 Sometimes that imposition has been constructed with reference to a more general vision of limitations on the right of parents to refuse medical care deemed necessary for newborn children, as well as for older children.310 Courts have ordered that blood be transfused to very ill children when recommended by the children’s clinicians, even in cases in which the children’s parents refused on religious grounds to consent to the procedure for their child.311 These cases are part of

308. Raleigh Fitkin-Paul Morgan Mem’l Hosp., 201 A.2d at 538.


310. See, e.g., State ex rel. Angela M.W. v. Kruzicki, 541 N.W.2d 482 (Wis. Ct. App. 1995), rev’d, 561 N.W.2d 729 (1997) (concluding that viable fetus is a “child” within the meaning of the [state’s] juvenile law and allowing internment of pregnant woman who used drugs during pregnancy in order to place fetus in protective custody); see also In re Fathima Ashanti K.J., 558 N.Y.S.2d 447 (N.Y. Fam. Ct. 1990). The New York Family Court opined: “The State through the Family Court has inherent power to protect and promote the welfare of young children under the parens patriae doctrine. The State authority to protect the viable fetus has its origins in Roe v. Wade.” Id. at 449.

311. Karen L. Diaz, Rights of Parents: Refusal of Medical Treatment Based on Religious Beliefs, 16 J. CONTEMP. LEGAL ISSUES 85, 86 (2007). In these cases, lower courts often invoke the Supreme Court’s decision in Prince v. Mass, which notes that “[p]arents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full discretion when they can make that choice for themselves.” Prince v. Mass, 321 U.S. 170 (1944). In 1991, Massachusetts’s highest court ruled in separate cases that a child could be given blood transfusions deemed medically necessary to restore her to good health despite the objections of her Jehovah’s Witness parents, and that an adult Jehovah’s Witness, refusing blood transfusions recommended to deal with a bleeding ulcer had the right to refuse recommended medical care. AP, Court Says Ill Child’s Interests Outweigh
a broader paradigm that authorizes medical care deemed necessary for children even in cases in which parents refuse to give their consent.\textsuperscript{312}

Further, a mid-twentieth century court conditioned a mother's right to refuse a blood transfusion on religious grounds on her obligation to stay alive for the sake of her young children.\textsuperscript{313} Subsequently, courts have noted that rule—though they have generally not followed it—in cases involving pregnant women refusing transfusions.\textsuperscript{314} Even so, cases involving pregnant women who are Jehovah's Witnesses continue to occasion interpretational dispute.\textsuperscript{315} Increasingly, however, such cases similar to others that involve proposed medical interventions during pregnancy respect the pregnant woman's right to exercise decisional autonomy in consenting to or refusing recommended care.\textsuperscript{316}

Subsections i and ii of this Section consider cases occasioned by a pregnant Jehovah's Witness refusing a blood transfusion. Subsection i considers a case reviewed by the ethics consult service at Brookside Hospital. Then, Subsection ii considers cases involving similar facts that were resolved in courts of law. Subsection iii compares the process, focus, and resolution of the two sets of cases.

i. An Ethics Consult for a Pregnant Jehovah's Witness Refusing a Recommended Blood Transfusion

JT's case was brought to the ethics consult service by a clinician who sought the service's assistance in responding to a


312. \textit{See infra} note 323 and accompanying text.

313. \textit{Appl. of Pres. \& Dir. of G'town Coll., Inc.}, 331 F.2d 1000 (D.C. Cir. 1964).

314. \textit{See, e.g., In re Dubreuil}, 603 So. 2d 538 (Fla. 4th Dist. Ct. App. 1992) (concluding that pregnant women who were parents already should not “neglect [the] fundamental duty ‘to their children’ on the basis of ‘religious beliefs’”), \textit{quashed}, 629 So. 2d 819 (Fla. 1993) (noting that existing children would not be left parentless if mother died since father would be available as parent); Rosamund Scott, \textit{Autonomy and Connectedness: A Re-evaluation of Georgetown and its Progeny}, 28 J.L. MED. \& ETHICS 55, 55 (2000) (finding the right of a woman's infant to be raised in a two-parent family to outweigh the woman's right to refuse a blood transfusion).

315. \textit{See Gribow, supra} note 296, at 182–86.

316. \textit{See id.} at 179.
conflict between a pregnant patient and the medical team. JT had arrived at Brookside in labor, though only twenty-five weeks pregnant. She gave birth on the day of her arrival at the hospital. Thus, as it played out, the case focused on reaching a medical decision for both JT and her newly delivered infant. The baby’s doctors concluded that a blood transfusion was medically necessary to safeguard the baby’s welfare, and perhaps to save its life. JT, a Jehovah’s Witness, refused to consent to a blood transfusion for the newborn baby. While still pregnant, JT had requested all medical care deemed important for the baby—once-born except for a blood transfusion.

Called by an obstetrical nurse on the day of JT’s admission to Brookside, the ethics consult team was quickly informed about JT’s medical condition, as well as that of the fetus. Before the baby’s delivery the ethics consult team spoke with JT and her clinicians (including an attentive obstetrical nurse and an obstetrician). That nurse and physician had already talked with JT about the baby’s likely need for a transfusion, once born. They had informed JT that hospital policy provided for giving blood transfusions to a minor in need of blood, even if the parent or parents objected, upon the consent of two physicians who had concluded that a transfusion was necessary to protect the child. The ethics team reported that JT was fearful and felt vulnerable for herself and for the fetus.

JT was not given a blood transfusion while pregnant, but as hospital policy dictated, JT’s baby was given a transfusion soon after his birth. After she delivered the baby, JT was informed that the infant had been resuscitated and that he had been given

317. Pregnancy Case P20123, supra note 27.
318. JT’s membranes had ruptured prematurely several weeks earlier. Id.
319. See id.
320. Id.
321. Id.
322. Id.
323. See id.
324. Id.
325. Id.
326. Id.
327. Id.
328. Id. at 1–2.
329. Cf. id.
330. Id. at 1.
blood. The ethics consult team sought the help of a Jehovah’s Witness liaison from the Watchtower Society in order most effectively to communicate with JT about her religious needs and preferences. The liaison spoke with JT and her clinicians, helping to mediate among them. JT reported to the ethics Fellow who was serving with the ethics consult team that she had spoken with the Watchtower Society liaison and with her clinicians about the transfusion given to the child and that she accepted the hospital’s decision to provide blood to her baby. Despite that, she hoped that more blood would not be given to the infant. However, the baby received an additional transfusion.

The ethics team defined the key bioethical principles at issue in JT’s case as a conflict between JT’s autonomous right to make medical decisions for herself and her young children and the clinicians’ obligation to provide beneficent, non-harmful care, to both JT and the newborn infant. The team expressly differentiated between the right of the patient to make decisions for care while pregnant and her more limited right to refuse care deemed medically necessary for the infant. Further, the team placed great value on sustained communication between JT and her clinicians. That was understood as an essential component of beneficent care for JT. The team noted the central importance of providing continuing support to JT during the early months of her child’s life, support that respected JT’s religious beliefs, even as it was deemed important to bypass those beliefs in providing care for JT’s infant baby. JT responded with gratitude that her baby was well-treated. Yet, she expressed regret about the need to transfuse the child.

331. Id.
332. Cf. id.
333. Id.
334. Id.
335. Id.
336. Id.
337. Id. at 1–2.
338. Id.
339. Cf. id. at 1.
340. Id.
341. See id.
342. Cf. id.
343. Cf. id.
JT’s acceptance of the hospital decision, modulated by her regret about the need to give blood to her baby, seemed to have been grounded in her trust for one clinician who supported JT throughout her hospitalization at Brookside.\textsuperscript{344} As reported by the ethics consult service, JT felt that she was “heard.”\textsuperscript{345} In fact, JT’s very premature baby did well, and JT, who might have been deeply angered had she not enjoyed the respect and attention of hospital clinicians and of the ethics consult service, continued to seek medical care at Brookside and at its clinics in the years following the baby’s birth.\textsuperscript{346}

The ethics team, with the support and assistance of the mother and the baby’s clinicians, had access to and understanding of the medical issues at stake.\textsuperscript{347} Further, the team framed its own deliberations and responses with its determination that JT’s case, and that of her newborn baby, involved a conflict among (1) respect for the mother’s right to make autonomous medical decisions, both for herself and her child; (2) the need to protect the life of a minor, even in the context of parental dissent (an obligation of beneficence); and (3) an obligation to support JT and to show respect for her religious beliefs.\textsuperscript{348} In addition, they shaped the process of responding to JT’s needs and those of her infant in light of relevant law.\textsuperscript{349} The team’s continuing communication with JT during the period of her baby’s hospitalization and the team’s involvement and guidance from the liaison from the Jehovah’s Witness Watchtower Society were important components of a successful ethics consultation.\textsuperscript{350}

ii. Legal Cases Involving Pregnant Jehovah’s Witnesses

This Subsection reviews two legal cases, each involving conflicts similar to those at the center of JT’s case. The first legal case involves a trial court decision rendered at a time during which there were few appellate decisions of relevance to which the

\textsuperscript{344} See id.
\textsuperscript{345} Cf. id.
\textsuperscript{346} Cf. id.
\textsuperscript{347} Id.
\textsuperscript{348} Id.
\textsuperscript{349} Id.
\textsuperscript{350} Id.
The second case, an Illinois appellate court decision, offers a useful framework from within which to consider the ethics consult service’s work with JT and *In re Jamaica Hospital*. The right defined by the Illinois appellate court was respected fifteen years later by the hospital and clinicians involved in caring for JT.

a. *In re Jamaica Hospital*

Jamaica Hospital in New York City initiated *In re Jamaica Hospital* in order to compel a Jehovah’s Witness, eighteen-weeks pregnant, to submit to a blood transfusion deemed medically necessary for the woman and the fetus. Justice Lonschein noted that when called by a hospital lawyer, he was “getting dressed for a dinner engagement;” he then instructed the hospital’s lawyer to call the justice then assigned to “special term,” but he agreed to conduct the hearing upon learning that the justice in question could not be located. Given the patient’s serious medical condition, Justice Lonschein “dispense[d] with the ‘usual formalities’” including “assignment of counsel, notice to [the patient’s] family and testimony in a courtroom setting with stenographic record.”

Justice Lonschein asked the patient if she would consent to a transfusion; she refused. Justice Lonschein then appointed an attending physician as “special guardian for the unborn child,” authorizing that doctor to compel the patient to undergo a transfusion if that seemed necessary to save the life of the fetus. Justice Lonschein opined that if the patient’s “life were the only one involved here, the court would not interfere.” He further

353. *Id.* (finding that a woman has a right to make medical decisions for herself while pregnant and after delivery, but not as broad a right to make medical decisions for her infant child).
354. *In re Jamaica Hospital*, 491 N.Y.S.2d 898.
355. *Id.* at 899.
356. *Id.* at 898.
357. *Id.* at 899.
358. *Id.*
359. *Id.*
360. *See id.*
361. *See id.* at 900.
362. *See id.* at 898.
acknowledged that the "unborn child" was not yet viable and that abortion would still be possible under the framework established in Roe v. Wade. Yet, he referred to the fetus as a "potentially viable human being in a life-threatening situation." Justice Lonschein wrote:

While I recognize that the fetus in this case is not yet viable, and the State's interest in protecting its life would be less than "compelling" in the context of the abortion cases, this is not such a case. In this case, the State has a highly significant interest in protecting the life of a mid-term fetus, which outweighs the patient's right to refuse a blood transfusion on religious grounds.

The patient appeared to have had almost no role in the proceedings. Her personhood was barely acknowledged, and the court showed no interest in her needs and values. The decision contrasts sharply with the approach of the hospital ethics consultants in JT's case.

b. People v. Brown (In re Brown)

Almost a dozen years later, a circuit court judge in Illinois reached a decision at odds with In re Jamaica Hospital. The court appointed a hospital administrator as "temporary custodian of Fetus Brown" and authorized that administrator to consent to a blood transfusion for Darlene Brown, who was about

363. See id. at 900.

364. Id. at 899-900 (acknowledging that "the State's interest in protecting [the] life [of the fetus] would be less than 'compelling' in the context of the abortion cases, [but] this is not such a case").

365. See id. at 899.

366. See id. at 900.

367. See id. at 899-900.

368. See id. The emergency in In re Jamaica Hospital was time sensitive, but so was that of JT, which was considered by Brookside's ethics consult service. See id.; see also Pregnancy Case P20123, supra note 27.

369. Compare In re Jamaica Hospital, 491 N.Y.S.2d 898 (appointing a guardian to act in the interests of the fetus), with Pregnancy Case P20123, supra note 27.


371. Id. But see In re Jamaica Hospital, 491 N.Y.S.2d at 900.
thirty-four weeks pregnant. A transfusion was administered to Brown that evening for the sake of Brown’s fetus. Brown “tried to resist the transfusion and the doctors ‘yelled at and forcibly restrained, overpowered and sedated’ her.” Although the trial court “closed the case,” after she gave birth and was discharged from the hospital with her infant, Brown appealed the court’s decision to appoint a custodian who was given authority to order that Brown receive a transfusion against her wishes.

Limitations of the trial court proceedings in this case again suggest that trial courts are not equipped to respond to medical crises. From Brown’s perspective, that seemed abundantly clear. Yet, the appeal that she initiated resulted in a higher court’s re-shaping state law for women in the future who might find themselves in Brown’s situation.

Brown’s appeal encouraged the appellate court to respond to a question that had been expressly left open by an earlier Illinois court, precluding clinicians from performing a procedure “as invasive as a cesarean section,” but that queried whether that conclusion should apply in the context of a transfusion. In that earlier case, Baby Boy Doe, the court commented by way of dicta that a transfusion (presumably in comparison to a cesarean) is “relatively noninvasive and risk-free.” That claim, as the appellate court in Brown suggested, is not accurate from a medical

372. In re Brown, 689 N.E.2d at 399–400.
373. Id. (emphasisizing the doctor’s medical opinion that the only way to get oxygen to the placenta was through the mother’s blood).
374. See id. at 400.
375. Id.
376. See id.
377. See infra notes 378–94 and accompanying text (discussing the limitations of the trial court’s decision in In re Brown).
378. See In re Brown, 689 N.E.2d at 399–401.
379. See id. at 400–02.
380. See, e.g., People v. Tinisha L.-B (In re Harriett L.-B.), 50 N.E.3d 1222, 1236–37 (Ill. App. Ct. 2016) (citing In re Brown, 689 N.E.2d at 405) (“[r]espondent is correct that a woman, even one who is pregnant, has the right to refuse medical treatment.”); Order at 21–22, Major v. City of Cook, 2014 IL App (1st) 123632-U, ¶ 51 (citing In re Brown, 689 N.E.2d at 405) (“The state may not override a pregnant woman’s competent treatment decision, including the refusal of recommended invasive medical procedures, to potentially save the life of the viable fetus.”).
381. In re Brown, 689 N.E.2d at 401–02 (citing People v. Doe (In re Doe), 632 N.E.2d 326 (Ill. App. Ct. 1994)).
383. In re Brown, 689 N.E.2d at 401 (quoting In re Doe, 632 N.E.2d at 333).
point-of-view, but even more, blood transfusions carry significant risk from the perspective of a believing Jehovah’s Witness. The trial court in Brown had seemed unaware of, or uninterested in, that risk.

In responding to the challenge raised by Brown’s appeal, the Illinois appellate court noted first that common law, as well as the United States and Illinois Constitutions, protect a competent adult’s right to refuse recommended medical care. However, the court also explained that in certain cases, the state’s interest may “outweigh the interests of the patient in refusing medical treatment.” In that regard, the court identified the “ultimate issue” in Brown’s case as the state’s “interest in protecting the viable fetus.”

In analyzing that issue, Judge Theis rejected the suggestion that compelling pregnant women to submit to blood transfusions may not carry the same concerns raised by compelling a pregnant woman to submit to a cesarean. Brown’s decision to refuse the recommended blood transfusion, despite her clinicians’ concerns, should have been respected.

The State may not override a pregnant woman’s competent treatment decision, including refusal of recommended invasive medical procedures, to potentially save the life of the viable fetus. We disagree with the Baby Boy Doe court’s suggestion that a blood transfusion constitutes, a “relatively noninvasive and risk-free procedure,” and find that a blood transfusion is an intrusive medical procedure that interrupts a competent adult’s bodily integrity. We thus determine that the circuit court erred in

384. Id. at 405 (considering implications of blood transfusion for Jehovah’s Witnesses).
385. See id. at 402–03.
386. Id. at 402.
387. Id.
388. Id. at 404.
389. Id. at 405 (relying on two previous Illinois cases. In re Doe, 632 N.E.2d 326 (Ill. App. Ct. 1994); Stallman v. Youngquist, 531 N.E.2d 355 (Ill. 1988)).
390. Judge Theis distinguished the case from cases involving abortion or maternal substance abuse as well as from a case involving refusal to allow a blood transfusion for a minor. Id.
ordering Brown to undergo the transfusion on behalf of the viable fetus. 391

This decision established a legal framework for subsequent cases in which pregnant hospital patients refused blood transfusions deemed medically necessary to safeguard the health or life of the mother and/or the fetus and offered a model that other states could follow. 392 The challenge that faced the appellate court was clearly distinct from that which faced the trial court that first heard Brown’s case and from that which faced the ethics consult service that participated in JT’s care. 393 In that vein, the next Subsection compares In re Brown and In re Jamaica Hospital with JT’s case. 394

iii. Comparing JT’s Case with In re Brown and In re Jamaica Hospital

Both the decision of the court in In re Brown, 395 and of the trial court in In re Jamaica Hospital, 396 contrast with the work of the Brookside ethics consult service in JT’s case. 397 As a general matter, a court proceeding initiated by the hospital providing care to a patient poses a patient’s clinicians and hospital administrators as antagonists to the patient. 398 That situation will almost inevitably affect the patient and her clinicians and hospital personnel quite differently than an ethics consult.

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391. Id. (citations omitted).
392. See In re Harricut L.-B., 50 N.E.3d 1222, 1236–37 (Ill. App. Ct. 2016) (citing In re Brown, 689 N.E.2d 397, for the proposition that a pregnant woman has the right to refuse medical treatment).
394. Ethics consult decisions are not mandatory or enforceable. Alessandra Gasparetto et al., The Notion of Neutrality in Clinical Ethics Consultation, 13:3 PHIL., ETHICS, & HUMAN. IN MED. 1, 1 (2018).
396. In re Jamaica Hospital, 491 N.Y.S.2d 898.
397. See supra notes 317–50 and accompanying text (discussing the facts of JT’s case).
398. See In re Jamaica Hospital, 491 N.Y.S.2d at 899 (describing the doctor’s testimony that the patient’s unborn child would die without a blood transfusion which the patient objected to due to her religious beliefs).
Court proceedings constrain interaction among the parties. They limit those permitted to participate, and they compel those involved to follow legal rules about when to speak and what to say. These rules can easily render a patient voiceless. The patient can become a character for whom decisions are shaped by experts—those ‘knowing better’—rather than a person with needs, beliefs, and preferences, often sensible, even as the patient’s preferences conflict with the preferences of medical and legal experts. An ethics consult may or may not lead to results that a patient or that patient’s clinicians applauded; yet, the patient, as in JT’s case, may still feel “witnessed.” In contrast, the patients whose preferences were overridden by the N.Y. court in *In re Jamaica Hospital* and by the Illinois circuit court in *In re Brown* were marginalized, unheard, and unwitnessed.

The ethics consult service at Brookside had experience responding to the needs of Jehovah’s Witnesses before JT was admitted to Brookside and was able to contact an expert from the Watchtower Society to assist with the consult processes by serving as a liaison between the patient and the clinicians and to support JT. The presence of another Jehovah’s Witness who is an expert in the matters at issue would be likely to reassure any Jehovah’s Witness patient that the nurses, doctors, and hospital respected his or her beliefs and values. In JT’s case, the presence of the Watchtower liaison harmonized with the approach of the ethics consult team that sought JT’s views as well as those of her

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401. Id.

402. See *In re Jamaica Hospital*, 491 N.Y.S.2d at 899-900 (explaining that the judge found the unborn child to be regarded as a human being and therefore appointed the doctor to do what was necessary to save its life, including giving the mother a blood transfusion that was expressly against her religion).

403. For cases in which a patient lacks capacity, the patient’s proxy or surrogate (often a dear friend or family member) will sit in the role of patient and speak for the patient.


doctors. The involvement of an expert from JT’s religious group facilitated respectful discussion among the stakeholders.

Nothing in the court records suggests a similar accommodation for the patient at Jamaica Hospital or for Brown. In the end, JT’s continued use of the hospital’s services in the years subsequent to the birth of her baby may suggest her comfort with and appreciation of the process of the ethics consult and her respect for the clinicians, despite their disagreement with her choice and, remarkably, despite the decision to give her baby a blood transfusion without her consent. In contrast, Brown went to court again after the birth of her baby in order to appeal the trial court’s order. That suggests a very different response to her clinicians than JT’s response to hers. The case of the patient in Jamaica Hospital was not appealed, and there is no record suggesting anything about the patient’s response beyond her refusal to submit to a transfusion on religious grounds. Even the absence from the record of such information is telling. The patient’s responses, it would seem, were of minimal concern to the court.

A comparison of JT’s case with Brown and the patient at Jamaica Hospital is especially significant because each of these women was compelled to accept a blood transfusion for herself or her newborn baby. JT’s baby was given a transfusion despite her refusal; Brown and the Jamaica Hospital patient were given transfusions while still pregnant, despite their refusal to consent. Yet JT accepted what had transpired and may well have been grateful for the discourse encouraged between her and hospital

406. See id.
407. See id.
408. See In re Brown, 689 N.E.2d 397; In re Jamaica Hospital, 491 N.Y.S.2d 898.
409. See supra note 346 and accompanying text.
410. Pregnancy Case P20123, supra note 27.
411. See In re Brown, 689 N.E.2d 397.
412. See In re Jamaica Hospital, 491 N.Y.S.2d 898.
413. See id.
414. See supra notes 317–50 and accompanying text (discussing JT); supra notes 354–69 and accompanying text (discussing the patient at Jamaica Hospital); supra notes 370–94 and accompanying text (discussing Brown).
415. See supra notes 317–50 and accompanying text (discussing JT); supra notes 354–69 and accompanying text (discussing the patient at Jamaica Hospital); supra notes 370–94 and accompanying text (discussing Brown).
clinicians, a process initiated by the ethics consult service.\textsuperscript{416} Her clinicians, hospital administrators, clergy, and others attended to her situation and respected her religious values even though her newborn infant was given a transfusion.\textsuperscript{417} Brown was patently displeased with the court proceedings.\textsuperscript{418} One can assume—though again there is no record from which to be certain—that the Jamaica Hospital patient was distressed by the proceedings of the New York court that issued the order to authorize a transfusion despite her choice not to receive blood products and without attending even minimally to her concerns, beliefs, and needs.\textsuperscript{419}

Furthermore, the ethics consult cases—in sharp contrast with the court cases—are generally marked by concern to identify or respond to the moral distress of nurses and physicians in the context of health care conflicts.\textsuperscript{420} Such distress can have significant personal consequences for clinicians who face moral dilemmas about patient care, but are constrained from effecting the treatment that seems best to them.\textsuperscript{421} This can result in practitioners experiencing emotional suffering.\textsuperscript{422} The ethics consultants, working within Brookside, were keenly aware of the potential for the clinicians caring for JT to experience moral distress and worked openly to respond to clinicians’ needs as well as those of the patient.\textsuperscript{423} The moral distress of clinicians in cases such as those of Brown and the patient at Jamaica Hospital was not a component of the issues to which the courts were asked to respond and was thus not addressed by—and perhaps not even contemplated by—the courts that rendered decisions in these cases.\textsuperscript{424}

\textsuperscript{416} See Pregnancy Case P20123, supra note 27.
\textsuperscript{417} See id.
\textsuperscript{418} See In re Brown, 689 N.E.2d 397 (Ill. App. Ct. 1997).
\textsuperscript{419} In re Jamaica Hospital, 491 N.Y.S.2d 898 (N.Y. Sup. Ct. 1985).
\textsuperscript{420} See supra Part I.
\textsuperscript{422} Elizabeth Dzeng et al., Moral Distress Amongst American Physician Trainees Regarding Futile Treatments at the End of Life: A Qualitative Study, 31 J. GEN. INTERN. MED. 93 (2016).
\textsuperscript{423} See Pregnancy Case P20123, supra note 27.
\textsuperscript{424} See In re Brown, 689 N.E.2d 397 (Ill. App. Ct. 1997); In re Jamaica Hospital, 491 N.Y.S.2d 898.
IV. Disputes About Medical Decisions for Neonates and Babies

Once, parental decisions about appropriate care for very sick newborn babies were a private matter, entertained between parents and clinicians. Increasingly, that is not the case. Such decisions may now include the participation of hospital administrators, social workers, bioethicists, attorneys, and judges and may also be described in public media. In short, decision-making and conflicts about decisions for neonates have entered the public domain. Medical, legal, and ethical uncertainties shape such decisions and the conflicts they engender. Further, these conflicts often reflect broader ideological debate within the nation.

Importantly, a number of discrepant ideological positions about responses to treatment for critically ill neonates have emerged. Some stem from, and often share in, the volatility of discourse about abortion in the United States and the difficulties stakeholders may face in attempting to distinguish between neonates, especially those who are very premature, and fetuses. Another perspective, however, views parents who seek the continuation of life-sustaining care deemed “futile” by physicians as emotional, misguided, and/or unrealistic. Each of these situations can engender confusion and anger among the stakeholders.

Moreover, conflicts about the appropriate care for seriously ill neonates, including babies born very prematurely, almost

426. Id. at 1104-06.
427. See id.
428. Id.
429. See id. at 1103.
430. See id. at 1104-06.
431. See id. at 1106.
432. See id. at 1123 (noting the connection between religious views and the position that all “human biological existence” is valuable and thus medical care should never be abandoned).
433. Id. at 1117-19.
434. See id. at 1120.
435. Id. at 1114 (categorizing babies born between twenty-two and twenty-seven weeks as “extremely premature”).
always involve significant medical uncertainty. Certain factors suggest better outcomes, but statistically better (or worse) outcomes may involve significant uncertainty in particular cases. In addition to questions about survival, it is almost impossible to predict long-term neurodevelopmental outcomes. George Annas has suggested one response to that uncertainty as dependence on "trials of therapy that can be ended when reasonable clinical goals cannot be achieved." Annas added:

More data are unlikely to provide a yes-or-no answer to whether resuscitation should be attempted at birth. Life is not always preferable to death, as was made clear by the exceptions to the old Baby Doe regulations (which pertained to refusals of treatment for disabled, not premature, newborns) and by the entire series of so-called right-to-die cases.

Furthermore, clinicians' individual responses to risk-taking and individual assessments of the value that they place on aggressive medical care that is likely to result in only a small percent of infants surviving among those treated can play a role in clinicians' treatment recommendations to parents.

Legal cases involving medical care for seriously ill newborn babies generally reflect a conflict among the stakeholders, often between a baby's parents and his or her clinicians. The law authorizes parents to make medical decisions for their children.

436. See id. at 1114.
437. Id. at 1115 (noting relevance of baby's sex, multiple fetuses, weight at birth, and exposure or to antenatal corticosteroids to likelihood of successful outcome for an extremely premature baby).
438. See id. at 1118.
439. Id. at 1116.
441. Id.
442. Conway, supra note 425, at 1118–19 (noting that some neonatologists recommend treatment even if there is only a ten percent chance for "profoundly disabled survival," while others prefer not to treat babies with less than a "fifty percent chance of intact survival").
443. Id. at 441.
That right can be lost should a parent be found abusive or neglectful.\textsuperscript{445}

An abuse or neglect determination against the parent of an ill child is a matter for courts, not hospitals.\textsuperscript{446} States vary in their definitions of medical neglect and medical abuse.\textsuperscript{447} Broadly, medical neglect or abuse refers to a parent’s failure to provide medically necessary care or a parent’s administering unnecessary and potentially harmful treatment to a child.\textsuperscript{448} A hospital administrator or clinician’s medical abuse accusation against a parent can be a powerful deterrent to parents who disagree with clinicians’ recommendations and would otherwise want to have their child treated in a manner not recommended by a hospital’s clinicians.\textsuperscript{449} In short, such accusations against parents can, themselves, be abusive.\textsuperscript{450}

In contrast, many Brookside cases involving medical decision-making for such babies reflect uncertainty among all of the stakeholders more often than they reflect outright disputes.\textsuperscript{451} In many of these cases, the ethics consult service began its work before potential conflicts were clearly identified and before disagreements hardened.\textsuperscript{452} Even in cases that involved differences

\textsuperscript{445} Maxine Eichner, \textit{Bad Medicine: Parents, the State, and the Charge of ”Medical Child Abuse,”} 50 U.C. DAVIS L. REV. 205, 317 (2016) (concluding that “outside of [a] narrow range of abuse and neglect cases, decisions about medical care should be the parent’s, not the doctor’s or the state’s”).

\textsuperscript{446} Id. at 318.


\textsuperscript{448} Id.; Eichner, \textit{supra} note 445, at 210 (reporting on the use of medical abuse statutes by hospitals to “coerce parents to accept care plans drafted by the hospitals’ doctors, even when the parents do not believe these plans are in their children’s best interests”).

\textsuperscript{449} See Eichner, \textit{supra} note 445, at 210.

\textsuperscript{450} Id. at 233 (reporting that most states do not provide information on the percent of abuse cases against parents that involve medical abuse but that there may be as many as 1,600 reports of medical abuse in the U.S. each year).

\textsuperscript{451} See generally Pregnancy Case P20123, \textit{supra} note 27; Pregnancy Case P20122, \textit{supra} note 27; Infant Case 120171, \textit{supra} note 27; Infant Case 120138, \textit{supra} note 27; Infant Case 120124, \textit{supra} note 27.

\textsuperscript{452} See generally Pregnancy Case P20123, \textit{supra} note 27; Pregnancy Case P20122, \textit{supra} note 27; Infant Case 120171, \textit{supra} note 27; Infant Case 120138, \textit{supra} note 27; Infant
in treatment preferences between an infant’s parents and the infant’s health care team, the ethics consult service reports generally do not frame the cases centrally as conflict cases.

Rather, the reports suggest responses that respect the preferences of all of the stakeholders. In significant part, that may reflect the character of the Brookside ethics consult service and may not be widely generalizable as an assessment of ethics consults at other hospitals.

For both courts of law and ethics consult services faced with health care challenges or outright disputes involving neonates determining the appropriate decision-maker or decision-makers can be central. Courts seem often to favor clinicians when determining whose view of appropriate care for an ill neonate should govern. Brookside’s ethics consult service favors involvement of all the stakeholders and potentially mediation among them. Many of the service’s reports involving care for neonates proclaim that decision-making should belong to parents.
and clinicians working as a team. Successful mediation can produce that result, but not all mediation has been successful.

A. Births at Twenty-Three Weeks Gestation

The ethics consultations at Brookside regarding neonates and infants in the study period differ from those regarding pregnant patients—especially in cases involving conflict or incipient conflict—in that the responses of the children’s parents (the patients’ surrogate decision makers) were colored by deep uncertainty about the implications of options for care of their children. This uncertainty shaped the responses of parents who agreed with their child’s clinicians and those who disagreed. Several parents appealed to the miracles of God or put responsibility for the infant in God’s hands. The parents who referred to God’s miracles had often chosen a path that conflicted with the path recommended by their child’s doctors, but the parents who described their child’s medical future as simply being in God’s hands, one way or the other, had generally accepted the clinicians’ assessments and recommendations.

i. The Case of Baby Female, “AB”

In late 2012, Brookside’s ethics consult service was asked to assist the parents and the clinicians of a neonate born two days earlier at twenty-three weeks of gestation. AB weighed 620 grams

458. See generally Infant Case I20171, supra note 27; Infant Case I20138, supra note 27; Infant Case I20124, supra note 27.
459. See Autumn Fiester, Bioethics Mediation & the End of Clinical Ethics as We Know It, 15 CARDOZO J. CONFLICT RESOL. 501, 508 (2014).
460. See id. (noting that mediation is a failure in a situation in which one party to the mediation “has no conversational space in the dialogue”); Annas, supra note 440, at 2118 (noting that “[a]dvances in neonatology have far outpaced decision-making practices in the neonatal intensive care unit”).
461. Compare Pregnancy Case P20123, supra note 27; Pregnancy Case P20122, supra note 27, with Infant Case I20171, supra note 27; Infant Case I20138, supra note 27; Infant Case I20124, supra note 27.
462. See generally Infant Case I20171, supra note 27; Infant Case I20138, supra note 27; Infant Case I20124, supra note 27.
463. See Infant Case I20138, supra note 27; Infant Case I20124, supra note 27.
464. See Infant Case I20138, supra note 27; Infant Case I20124, supra note 27.
465. Infant Case I20124, supra note 27.
466. See generally Pregnancy Case P20123, supra note 27; Pregnancy Case P20122, supra note 27; Infant Case I20171, supra note 27; Infant Case I20138, supra note 27; Infant Case I20124, supra note 27.
at birth.\textsuperscript{467} A chart note entered by one of AB's ethics consultant declared that birth at twenty-three weeks gestation is "extreme prematurity."\textsuperscript{468} The ethics consult service offered a statistical assessment (which does not, of course, serve as a tool for prognosticating the course of development for AB or any other specific infant).\textsuperscript{469} The team reported that three-quarters of the children born after only twenty-three weeks of gestation are not alive eighteen to twenty-two months later.\textsuperscript{470} Over ninety percent are either dead or "profoundly impair[ed]" within that timeframe; the report further noted that extreme prematurity involves radical uncertainty about a baby's prognosis.\textsuperscript{471}

AB's father wanted his daughter to receive every form of care that might have helped her.\textsuperscript{472} The mother agreed about all forms of care except one.\textsuperscript{473} She was a Jehovah's Witness and therefore did not want the child to receive additional blood transfusions.\textsuperscript{474} The mother ("BB") knew that her daughter had already received two transfusions despite her refusal to consent.\textsuperscript{475} BB, reporting a series of events in her own life that she characterized as miraculous, expressed confidence that her child would survive if God willed it.\textsuperscript{476} That was the case, she opined, whether or not the child received a blood transfusion.\textsuperscript{477}

AB's case challenged the ethics consult team, as well as the baby's parents and her clinicians, because of the multiplicity of problems that can interfere with the health and developmental progress of a child born as early in the gestational process as was AB.\textsuperscript{478} The case also required the ethics consultants and the child's clinicians to respond to parents who enjoyed equal decision-making authority under the law and who did not share a religion

\begin{footnotes}
\begin{itemize}
\item \textsuperscript{467} Infant Case 120124, supra note 27. 620 grams is equivalent to about 1.3 pounds.
\item \textsuperscript{468} Id.
\item \textsuperscript{469} Id.
\item \textsuperscript{470} Id.
\item \textsuperscript{471} Id.
\item \textsuperscript{472} Id.
\item \textsuperscript{473} Id.
\item \textsuperscript{474} Id.
\item \textsuperscript{475} Id.
\item \textsuperscript{476} Id.
\item \textsuperscript{477} Id.
\item \textsuperscript{478} See id.
\end{itemize}
\end{footnotes}
or a culture and did not agree with each other about all aspects of AB's care.\footnote{479} The medical uncertainty at the center of decisions regarding AB's care and prognosis shaped the ethics consult team's review of the ethical principles ("beneficence," "non-maleficence," and "autonomy"),\footnote{480} defined as relevant for those making decisions about this child's care.\footnote{481} Frequently in their hospital reports, the ethics consultants rely on relevant medical or bioethical literature in explaining a case and responses to it.\footnote{482} In its report about AB, the ethics consult team studded the text with references to legal, bioethical, and medical authorities.\footnote{483} The report invoked a court decision,\footnote{484} a state statute,\footnote{485} a federal regulation,\footnote{486} and the \textit{Guidelines on Forgoing Life-Sustaining Medical Treatment} from the Committee on Bioethics of the American Academy of Pediatrics\footnote{487} and referred to articles by attorneys, physicians, and bioethicists.\footnote{488} It may be that the ethics consultants included this plethora of references to laws, ethics opinions, and general commentary in an effort—perhaps not entirely

\footnote{479} Id. AB's father was the child of immigrants and spent time during his childhood outside the U.S. Id. AB's mother was an American by birth and socialization. Id. BB opposed blood transfusions, while AB's father did not. Id.
\footnote{480} See supra note 257 (summarizing the history of these principles in American bioethics).
\footnote{481} Infant Case 120124, supra note 27.
\footnote{482} See generally Pregnancy Case P20123, supra note 27; Pregnancy Case P20122, supra note 27; Infant Case 120171, supra note 27; Infant Case 120138, supra note 27; Infant Case 120124, supra note 27.
\footnote{483} Infant Case 120124, supra note 27.
\footnote{484} Montalvo v. Borkovec, 256 Wis. 2d 472 (Wis. Ct. App. 2002).
\footnote{485} Family Health Care Decisions Act, ch. 8, N.Y. PUB. HEALTH § 29-CC (2010).
\footnote{488} See Infant Case 120124, supra note 27, at 2–3.
conscious—to offer some balance to the uncertainty that surrounded AB’s prognosis that each of the stakeholders had acknowledged.\textsuperscript{489}

The ethics consult service’s report about this baby’s care did not focus on the conflict between the baby’s parents or on that between her mother and her clinicians.\textsuperscript{490} Instead, the report focused on the difficult path that lay ahead for the infant and her parents and on the challenge that medical uncertainty about this baby’s future presented to all of the stakeholders.\textsuperscript{491} The ethics consult service expressed continuing readiness to communicate with and support the child’s parents and her clinicians and, if called for, to mediate among them.\textsuperscript{492} That approach seemed to serve everyone involved in caring for AB and participating in decisions about her health care.\textsuperscript{493} Although AB’s mother remained uncomfortable about her daughter receiving blood transfusions, she accepted that decision, one supported by both the baby’s father and her health care professionals.\textsuperscript{494}

The ethics consult report about AB’s care delineated scholarly and legal references and considered many of the issues more deeply than is typical of the service’s reports.\textsuperscript{495} These references did not resolve the challenges at issue in AB’s case, in part because they reflected varying positions about withdrawing life-sustaining care from seriously ill neonates.\textsuperscript{496} These references included a 2002 Wisconsin case, \textit{Montalvo v. Borkovec}.\textsuperscript{497} The report described the court in \textit{Montalvo} as having denied an infant’s

\begin{itemize}
\item \textsuperscript{489} See id.
\item \textsuperscript{490} See id. at 2.
\item \textsuperscript{491} See id.
\item \textsuperscript{492} Id. at 2–3.
\item \textsuperscript{493} See id.
\item \textsuperscript{494} See id. at 1.
\item \textsuperscript{495} See id. at 2–3.
\item \textsuperscript{496} See id.
\item \textsuperscript{497} Montalvo v. Borkovec, 647 N.W.2d 413 (Wis. Ct. App. 2002). \textit{Montalvo} involved allegations that a hospital and its doctors were liable for having failed to provide an infant’s parents with the opportunity to consent to life-sustaining care for their child. \textit{Id.} at 415–16. A careful review of \textit{Montalvo} supports the conclusion that the physicians involved in the care of Nancy Montalvo’s baby were facing a medical emergency. Kellie R. Lang et al., \textit{Gavels in the Nursery: An Appellate Court Shuts Out Parents and Physicians from Care Decisions}, 16 ANN. HEALTH L. 263, 267–68 (2007). That—and not the presence or absence of treatment alternatives—can alone justify the failure to have provided the parents with an opportunity to consent, on the basis of appropriate information, to the care provided to their child. \textit{Id.} at 268.
\end{itemize}
parents the right to decide whether to withdraw or withhold life-sustaining care. The report also discussed Guidelines composed by the Committee on Bioethics of the American Academy of Pediatrics ("AAP"), which provided that parents may consent to withholding or withdrawing life-sustaining care from an infant if the infant's survival is deemed very unlikely. The two views—that of the Wisconsin court in Montalvo and that of the AAP's Bioethics Committee—reflect alternative responses to parents refusing recommended life-sustaining care for a neonate. These references suggested that the medical uncertainty that surrounded AB's care and prognosis was complemented by legal and moral uncertainty. The ethicists did not note a preference for one choice over others. Instead, the report focused on serving those involved in AB's care rather than on the conflict among them. The consultants' final recommendation noted the importance of ensuring that AB's parents would be privy to continuing information about their infant's shifting medical condition.

ii. Montalvo v. Borkovec

Emanuel Vila, the son of Nancy Montalvo and Brian Vila, and AB were both born in the twenty-fourth week of gestation. Both births and the babies' progress in the weeks after their births were

498. Montalvo, considered in Subsection ii, has rarely been invoked in subsequent cases (in Wisconsin or elsewhere), but see Disability Rights Wis. v. Univ. of Wis. Hosp. & Clinics, 2014 Wisc. App. LEXIS 994, at *17–19 (2014) (distinguishing Montalvo for involving right of parent to be given information about "refusing life-sustaining treatment for a child, and ... not expressly address[ing] a doctor's obligation to provide the treatment"). Montalvo has been criticized by law review commentators. See, e.g., Lang et al., supra note 497, at 265.

499. See Guidelines on Forgoing Life-Sustaining Medical Treatment, supra note 487.

500. The report did not address the apparent conflict between its view of the court's conclusion in Montalvo, 647 N.W.2d 413, and the position taken in the Guidelines on Forgoing Life-Sustaining Medical Treatment, supra note 487.


502. See id.

503. See id.

504. Id. at 3.

505. Montalvo, 647 N.W.2d 413; Infant Case I20124, supra note 27, at 1.

506. Montalvo, 647 N.W.2d 413; Infant Case I20124, supra note 27, at 1.

507. Infant Case I20124, supra note 27, at 1 (noting AB's birth weight as 620 grams at birth); Montalvo, 647 N.W.2d 413 (noting that when Emanuel's mother was in labor an ultrasound revealed that the fetus's weight was estimated at 679 grams).
surrounded by significant medical uncertainty, as well as uncertainty about the law’s perspective and the most fitting ethical responses.508 Emanuel’s story resembled that of AB in that the adult stakeholders in both cases disagreed about the proper course of treatment for the newborn babies. However, Emanuel’s story differed from that of AB and her parents because the conflict among the stakeholders in Emanuel’s case intensified in the weeks following his birth.509 Acrimony soon defined, and quickly undermined, the relationship between Emanuel’s parents and his clinicians.510 Emanuel’s parents eventually initiated legal action.511

Nancy Montalvo and Brian Vila brought suit against the physicians who treated Emanuel and against the hospital in which Emanuel was born and cared for after his birth.512 They alleged that they had not given informed consent for the care provided to the infant after his birth and thus that the hospital did not have proper authorization for providing that care.513 The trial court dismissed the complaint.514 The appellate court affirmed the dismissal.515 Judge Wedemeyer, writing for the appellate court, concluded that an informed consent obligation would have been superfluous as there was no choice to be made. The court stated that “requiring the informed consent process here presumes that a right to decide not to resuscitate the newly born child or to withhold life-sustaining medical care actually existed. This premise is faulty.”516 The court, invoking both state and federal law, offered several reasons for its conclusion that the law required that Emanuel be resuscitated after birth and that he receive life-sustaining treatments.517 In the court’s view, the absence of an

508. See Montalvo, 647 N.W.2d 413; Infant Case 120124, supra note 27.
509. See Infant Case 120124, supra note 27; Montalvo, 256 Wis. 2d 472.
511. Montalvo, 647 N.W.2d 413.
512. Id. at 415.
513. Id. at 416. The plaintiffs originally sued the obstetrician who performed the cesarean on Nancy but did not appeal the trial court’s conclusion that there was no claim against this physician “upon which relief could be granted.” Id. at 417.
514. Id. at 416.
515. Id. at 416, 421.
516. Id. at 418.
517. See id. at 417–21.
alternative made informed consent unnecessary. Further, the court viewed Emanuel's care within the "emergency exception" to the informed consent rule.

At Emanuel's birth "an emergency arose requiring an immediate response, which occurred." At age three, Emanuel had neurological difficulties. He was unable to speak, eat, or drink and was fed through tubes. When Emanuel was two-and-a-half-years-old his parents described their deflated hopes and continuing fears:

We cannot help but know the difference between what is and what should have been. And what future lies ahead for our severely disabled son when we pass away or cannot cope any longer? Most likely it will be the brutality of an institutionalized existence... When people are faced with such tragedies they often try to find comfort by speaking of "miracle babies" and "God's will." However, back when God played God, babies such as our son died quickly and mercifully at birth.

The parents queried why Emanuel's clinicians felt "compelled to 'torture to life' an infant who will never have a chance at a normal life?... All we know is, it was not done because it was in our son's best interests or in ours."

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518. First, the court opined that life-sustaining care could be withheld or withdrawn only for patients in a persistently vegetative state, Id. at 418–19 (relying on Edna M.F. v. Eisenberg, 563 N.W.2d 485 (Wis. 1997)). Second, the court concluded that pursuant to the U.S. Child Abuse Protection and Treatment Act (CAPTA) of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (codified at 42 U.S.C. § 5101 et seq.), the state did not permit withholding "medically indicated treatment from a disabled infant with a life-threatening condition." Montalvo, 647 N.W.2d at 419. Each of these explanations is severely criticized in Lang et al., supra note 497, at 266–68.

519. Montalvo, 647 N.W.2d at 420. The emergency exception was recognized as early as 1914 by Justice Cardozo in Schloendorff v. Soc'y of N.Y. Hosp., 211 N.Y. 125 (1914). It is now incorporated in informed consent statutes. See, e.g., Lang et al., supra note 497, at 268–70.

520. Montalvo, 647 N.W.2d at 420.


522. Id.


524. Id.
Emanuel’s parents were angry and deeply regretful about Emanuel’s birth and the care he received in the months after his birth.\textsuperscript{525} AB’s parents were not angry or deeply regretful, even though AB was given a transfusion despite her mother’s objection.\textsuperscript{526} Some part of that difference may be attributed to the work of Brookside’s ethics consult service in mediating the needs and values of the stakeholders involved in AB’s care.\textsuperscript{527} However, the confusion and animosity that defined relationships among the stakeholders who cared for Emanuel cannot, in turn, be attributed simply to the responses of the Montalvo courts.\textsuperscript{528} Emanuel’s case might not have been brought to court were it not for an apparent failure of the ethics committee at the hospital where Emanuel was born to respond expeditiously and effectively to the conflicts surrounding Emanuel’s care.\textsuperscript{529}

Emanuel’s parents reported in a 1999 article about their son’s birth and neonatal care that they “learned on [their] own that an ethics committee existed at [the] hospital.”\textsuperscript{530} They requested a consultation with the committee but were told that that was not possible because the person who headed the committee was on vacation.\textsuperscript{531} A month later, a meeting was arranged for the parents with the committee.\textsuperscript{532} Montalvo and Vila described that meeting as a “farce, a mere formality to rubber stamp the course of action the neonatologists were already determined to take.”\textsuperscript{533} Then, about a week before Emanuel was discharged from the hospital, representatives from Child Protective Services arrived at the parents’ apartment.\textsuperscript{534} The

\begin{itemize}
  \item \textsuperscript{525} Id. at 526.
  \item \textsuperscript{526} Infant Case I20124, supra note 27.
  \item \textsuperscript{527} See id.
  \item \textsuperscript{528} See Lang et al., supra note 497, at 266–68.
  \item \textsuperscript{529} See Montalvo & Vila, supra note 510, at 525–26.
  \item \textsuperscript{530} Id. at 525.
  \item \textsuperscript{531} Id. Ethics committee chairs are entitled to vacations. However, a substitute should be nominated for the time that the chair is unavailable. Far more worrisome is Montalvo and Vila’s description of the proceedings once an ethics committee convened. Id. at 525–26.
  \item \textsuperscript{532} Id. at 525.
  \item \textsuperscript{533} Id. at 525–26.
  \item \textsuperscript{534} Id. at 526 (emphasis added).
\end{itemize}
parents' description of that encounter and its sequelae is disheartening:

It was like a scene from an undercover drug bust... They interrogated our neighbors in a search for any incriminating information they could use against us... We have learned through our contacts with other parents on the Internet that such retaliations against dissenting parents in the NICU are common.\(^{535}\)

iv. Miller v. HCA

Miller v. HCA\(^ {536}\) similarly involved a baby born near the twenty-fourth week of gestation.\(^ {537}\) The child survived but did not flourish.\(^ {538}\) Her parents initiated legal action against the hospital where their child was born.\(^ {539}\) They sought compensation for the enormous expenses they faced caring for their daughter.\(^ {540}\) Many years passed between the initiation of suit and a decision by Texas's highest court, holding against the parents.\(^ {541}\) After a Texas appellate court ruled against the Millers, but before the state supreme court rendered its decision affirming the court below, Mark Miller expressed his frustration to a journalist:

We don't need anyone's pity... This isn't about feeling sorry for Sidney or for us. This is about parents being able to make a choice [about their child's medical care]... But [the hospital] forced it on us... They decided. Then they took all my money. Then they washed their hands and said, 'You go home and live with the consequences.'\(^ {542}\)

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535. Id.
536. Miller v. HCA, 118 S.W.3d 758, 761 (Tex. 2003) [hereinafter Miller].
537. Id. at 761.
539. Miller, 118 S.W.3d at 764. The Millers sued the hospital in which their infant was born and its parent company. Id. They did not sue any of the clinicians involved in caring for the mother or the baby. See id.
540. Id.
541. Duggan, supra note 538, at F.
542. Id. at F3.
Just before Sidney's birth at the start of the twenty-fourth week of gestation,\textsuperscript{543} two physicians informed her parents that her prognosis was dismal.\textsuperscript{544} The parents decided not to attempt resuscitation at birth.\textsuperscript{545} However, a hospital administrator who had learned about the decision stated that an unwritten hospital policy provided for resuscitating any baby weighing more than 500 grams and who was born alive.\textsuperscript{546} Just before the baby's birth, treating physicians admitted to significant uncertainty about the appropriate response to a neonate born as prematurely as Sidney.\textsuperscript{547} In light of the treating doctors' original grim prognosis, the parents refused to consent to "heroic measures" for the fetus at birth.\textsuperscript{548} Their wishes were recorded in the mother's hospital chart.\textsuperscript{549}

Sidney weighted 615 grams at birth.\textsuperscript{550} She was resuscitated.\textsuperscript{551} She survived, and she grew.\textsuperscript{552} But over time, her condition did not improve.\textsuperscript{553} As she entered adolescence, Sidney had the cognitive capacity of the average six-month old.\textsuperscript{554} She had diminished eyesight, limb paralysis, and cerebral palsy.\textsuperscript{555} Fluid leaked from her brain.\textsuperscript{556} In 1992, Sidney's parents sued the hospital in which she had been born and HCA, its parent company, contending that the hospital and HCA were vicariously liable for violating informed consent obligations in treating Sidney

\begin{footnotesize}
\begin{enumerate}
\item \textsuperscript{543} Miller, 118 S.W.3d at 763.
\item \textsuperscript{544} Id. at 761–62.
\item \textsuperscript{545} Id. at 762.
\item \textsuperscript{546} Id.
\item \textsuperscript{547} Id. (noting that neonatologist present at baby's birth asserted that he "needed to actually see Sidney before deciding what treatment, if any, would be appropriate").
\item \textsuperscript{548} Id. at 762.
\item \textsuperscript{549} Id. at 763.
\item \textsuperscript{550} Id.
\item \textsuperscript{551} Id. at 761.
\item \textsuperscript{552} Id. at 764.
\item \textsuperscript{553} Id.
\item \textsuperscript{554} Holly O'Neal Rumbaugh, Note, Miller v. HCA, Inc.: Disempowering Parents from Making Medical Treatment Decisions for Severely Premature Babies, 41 HOUS. L. REV. 675, 696 (2004). Sidney also had seizures and spastic quadriparesis. Id. At age 13, Sidney was cared for at home by her mother, was in diapers, and was unable to feed herself or walk. Id. at 696–97.
\item \textsuperscript{555} Id. at 696.
\item \textsuperscript{556} Id.
\end{enumerate}
\end{footnotesize}
RESOLVING HEALTH CARE CONFLICTS

Despite her parent’s refusal to consent to that care. The parents did not sue any of the doctors involved in Sidney’s neonatal care. The Millers’ claims against HCA were tried before their claims against the hospital.

In 1998, a Texas trial court awarded the Millers over $60,000,000. At the time, Sidney Miller was seven years old. A Texas appellate court reversed the jury’s verdict for the Millers. The appellate court concluded that parents had a right under Texas law to refuse life-sustaining care for a child only under very limited circumstances. That court opined that Texas clinicians were not obligated to “follow a parent’s instruction to withhold urgently-needed life-sustaining medical treatment from their child” unless the “child’s condition [had] been certified as terminal.” One justice dissented from the appellate court decision. In the view of dissenting Justice Maurice Amidei, only a court order would have allowed the hospital to treat Sidney despite the refusal of her parents to consent to care.

The state supreme court, affirming the decision of the court of appeals, framed its task as deciding whether the child’s parents or her clinicians had authority to make major medical decisions for her. The state’s highest court, relying on an

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557. HCA v. Miller, 36 S.W.3d 187, 190 (Tex. Ct. App. 2000) [hereinafter HCA, Inc.]. Additionally, the suit alleged that the hospital was liable for failing to have had a policy “to prevent such treatment without consent.” Id.

558. Miller, 118 S.W.3d at 764.

559. HCA, Inc., 36 S.W.3d at 190.

560. See Miller, 118 S.W.3d at 764. The jury had awarded the parents of Sidney Miller $29,400,000 (medical expenses), $13,500,000 (punitive damages), and $17,503,066 (prejudgment interest). Id.

561. Id.

562. HCA, Inc., 36 S.W.3d at 187.

563. Id. at 193–94.

564. Id. at 195.

565. Id. at 197 (Amidei, J., dissenting).

566. Id.

567. Miller v. HCA, Inc., 118 S.W.3d. 758, 766. (Tex. 2003) (“The case requires us to determine the respective roles that parents and healthcare providers play in deciding whether to treat an infant who is born alive but in distress and is so premature that, despite advancements in neonatal intensive care, has a largely uncertain prognosis. Although the parties have cited numerous constitutional provisions, statutes, and cases, we conclude that neither the Texas Legislature nor our case law has addressed this specific situation.”).
implicit message in a 1920 case, concluded that a physician is permitted to provide life-sustaining care to a minor, even in the absence of parental consent, “under emergent circumstances.”

This conclusion is peculiar because even before the child’s birth, her parents had explicitly opposed providing life-sustaining care to her. The court justified the physicians’ caring for Sidney despite knowing that the baby’s parents had refused to consent because consent became a non-issue in an emergency.

The Millers seemed to have had the authority, under the state supreme court’s reading of the claims brought against HCA, to have withdrawn life-sustaining care from Sidney once the emergent condition that existed at her birth had receded. However, they did not do that. That may reflect the difficulty surrogates face in withdrawing care in comparison to the somewhat less disturbing request to withhold care.

John Paris and co-authors consider this phenomenon:

Stopping a treatment that is sustaining the life of their child is, for many parents, psychologically or morally impossible. Even if assured that the cause of death would be the underlying disease and not the withdrawal, these parents continue to believe that turning off the respirator would “cause” their child’s death. They could never agree to such an action.

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568. Moss v. Rishworth, 222 S.W. 225, 226 (Tex. Comm’n App. 1920). The case involved an operation performed on a child without parental consent. The Texas court in Moss held against the physician, because the child’s situation was not an emergency, even though the surgery in question was needed. Id.

569. Miller, 118 S.W.3d at 767. The court defined “emergent circumstances” to involve a situation in which “death is likely to result immediately upon the failure” to provide needed care. Id.

570. Id. at 762.

571. Id. at 768.

572. But see id. at 768.

573. Id.


575. Id.
Parents who may find it impossible to consent to the withdrawal of care from their child may be relieved when responsibility for that decision is taken from them:

When, despite our best efforts, medical interventions on the extremely premature infant do not succeed in reversing disease processes, we need not compound the grief of parents by asking their permission to withdraw the failed therapies. It is enough for the parents to agree that in light of their baby's condition, the focus should be on keeping the child's final moments as comfortable as possible. Then the most the physician can do is to support the parents as they keep company with their baby in the last stages of its brief life.576

Mark Miller’s response to his daughter, eleven years after her birth, echoed the perspective described by Paris:

I want people to understand that not once have I ever wished that Sidney was dead... I donated six pints of blood in nine weeks for that baby. We never did anything after she was born that would compromise her. We signed every consent form for every treatment after the damage was done—anything to alleviate her pain.577

v. Miller v. HCA: What Might Have Been

Like the parents in Montalvo, and unlike AB’s mother, Sidney Miller’s parents578 were angry and bitter toward the hospital in which their baby was born and toward the clinicians who treated their child.579 In all likelihood some part of the bitterness and frustration felt by Sidney’s parents resulted from

576. Id. at 151.
577. Duggan, supra note 538, at F3.
578. Miller, 118 S.W.3d. 758.
579. Compare supra note 525 and accompanying text (discussing the feelings of the parents in Montalvo, with supra note 526 and accompanying text (discussing the feelings of AB’s parents), with Duggan, supra note 538, at F3 (discussing the feelings of the parents in Miller).
Sidney's compromised condition. The Millers sought respect and some control over their child's care. Their anger, frustration, and bitterness were grounded in their perception that they lacked control over their child's care and were paid no respect by those who made health care decisions for Sidney.

The Millers did not claim that Sidney's medical care was negligent. Her poor outcome may have been unavoidable. They claimed, instead, that they had the right to authorize withholding care from the infant at birth. That right was denied to them, both in the hospital and in court. Had a hospital ethicist or ethics committee been involved in mediating disagreements among those involved in medical decision-making for the Millers' infant—especially disagreements between the Millers and the baby's clinicians—Karla and Mark Miller might have felt less isolated and might not have felt that they had been denied the right to participate in decision-making regarding the treatment their child received; instead, they felt that their very personhood had been displaced by presumptive experts who took almost exclusive control over Sidney's medical decisions.

Especially after Sidney's resuscitation immediately after her birth, an ethics consultant might have spoken with Sidney's parents about withdrawing life-sustaining care. Although surrogates, and especially parents, are often far more reluctant to withdraw life-sustaining care than to have it withheld initially, Sidney's parents might have decided to withdraw care with the support of an ethics consultant and, perhaps, even with the support of clinicians. Alternatively, the Millers, recognizing that they were expressly presented with a choice, might have decided not to withdraw life-sustaining care. Whatever their choice, they would probably have felt less frustrated and less angry had they

580. See supra sections IV.A.iv, IV.A.v (discussing Sidney's condition).
581. See Duggan, supra note 580, at F3.
582. See id.
583. Miller, 118 S.W.3d at 764.
584. Id. at 762.
585. Id. at 764.
586. Id. at 767–68.
588. See supra note 585 and accompanying text.
had the opportunity openly to ponder Sidney’s medical choices with supportive ethics consultants and clinicians.

**B. Parents Asking that “Everything” Be Done for Ill Newborns**

Parents of seriously ill newborns respond in different ways to recommended medical treatments for their infants. Karla and Mark Miller did not want their premature infant resuscitated at birth. In other cases, parents’ responses to similar challenges have differed from the responses of the parents whose babies’ care is examined in Section A of this Part. In the two cases examined in this Section—one considered by the Brookside ethics consult service and the other by a court—the parents of seriously ill newborns asked that “everything” be done for their infants. In each case, the child’s clinicians had concluded that the infants could not survive, and thus recommended against life-sustaining care.

i. The Case of Baby Female “DS”

DS’s mother (“RS”) and the baby’s clinicians knew before the child’s birth that she would be born with multiple medical challenges. Those challenges involved serious cardiac, renal, and gastrointestinal abnormalities. After DS’s doctors consulted with each other, it became clear that the success of proposed repairs to any of these systems depended on

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589. Kathryn L. Weise et al., *Guidance on Forgoing Life-Sustaining Medical Treatment*, 140 Pediatrics 1, 4 (2017), http://pediatrics.aappublications.org/content/early/2017/08/24/peds.2017-1905. (“Family decision-makers may disagree with medical recommendations . . . because of different perceptions and expectations about the child’s current and future quality of life, different interpretations of the prognosis, or religious and culturally based beliefs that influence their sense of what is in the child’s best interests.”).

590. Miller, 118 S.W.3d at 762.


592. See Infant Case I20124, supra note 27; see also Hudson, 177 S.W.3d 232.

593. See Infant Case I20124, supra note 27; see also Hudson, 177 S.W.3d 232.

594. Infant Case I20124, supra note 27.

595. See id. at 1.

596. Id.
improvements in the functioning of the other organ systems.\textsuperscript{597} Each of those repairs was deemed to have been medically improbable or impossible.\textsuperscript{598}

Surgery was performed on the infant soon after her birth, but a series of medical events resulted in significant deterioration of the infant's already-compromised medical status.\textsuperscript{599} The baby's clinicians explained the child's dim prognosis to her parents and suggested that the infant be treated only with palliative measures to keep her comfortable.\textsuperscript{600} The parents disagreed with that course of care and asked that everything be done to keep DS alive.\textsuperscript{601} One of the baby's doctors sought participation from the hospital's ethics consult service.\textsuperscript{602} At that point, the infant's doctors estimated that DS would not live for more than days (at the most weeks), with or without invasive care.\textsuperscript{603}

The ethics consultants identified the central ethical challenge to involve a conflict between the infant's surrogates' autonomy—the parents' right to make medical decisions for their child—and the clinicians' obligation of non-maleficence—the obligation to refrain from providing treatment that might create a burden outweighing the benefits.\textsuperscript{604} The ethics team referred to an article published in the \textit{Journal of the American Medical Society} asserting that physicians need not implement patients' requests for care that the physicians deem extremely unlikely to benefit the patient.\textsuperscript{605} In the view of DS's clinicians, that was DS's medical situation and, in consequence, only palliative care to mitigate end-of-life suffering would benefit DS.\textsuperscript{606}

\textsuperscript{597} Id. DS's cardiac problems required surgery, but that surgery could not be performed unless the infant's kidney function improved. \textit{Id}. That would have required dialysis—deemed extremely unlikely to prove successful given the infant's size and age. Other recommendations for the baby's care similarly depended on improving the function of other organ systems which in turn were considered unlikely to respond favorably to treatment. \textit{Id}.

\textsuperscript{598} Id.

\textsuperscript{599} Id.

\textsuperscript{600} Id.

\textsuperscript{601} Id. at 1, 4.

\textsuperscript{602} Id. at 1.

\textsuperscript{603} Id.

\textsuperscript{604} Id. at 2.

\textsuperscript{605} Id. at 2, 4 (referring to A.S. Brett & L.B. McCullough, \textit{Addressing Requests by Patients for Nonbeneficial Interventions}, 307 \textit{J. AM. MED. ASS'N} 149, 149–50 (2012)).

\textsuperscript{606} Id. at 1.
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Rather than expressly denying the parents' preference for more aggressive care, the ethics team recommended "nudging" DS's parents toward acceptance of the clinicians' determination. As a tool for effecting this nudging, the ethics service invoked the suggestion that clinicians rely on a "do-not-escalate-treatment" (DNET) order. The consult service expected a DNET order might serve the "best interests of the child," a standard described as incumbent on all decision makers in the context of a desperately ill child. More particularly, the team opined that the baby's clinicians were not required to provide cardio-pulmonary resuscitation ("CPR") to DS, despite DS's parents asking that everything be done for their daughter. In explaining that conclusion, the ethics report refers to the harm that CPR would impose on this very ill and fragile neonate, with almost no likelihood that the procedure would be successful.

Finally, the ethics team recognized its obligation, as well as that of the medical staff, not to exclude the parents from discussions about their child's care. Thus, the team recommended adhering to the physicians' conclusion that palliative care alone would serve DS, but modulating that recommendation within the context of a DNET order and at the same time, focusing on the profound needs of the child's grieving parents. In this, the parents were assisted by a hospital chaplain and by the involvement of Child Life.


608. Infant Case 120124, supra note 27.

609. Id. at 2 (citing Juliet Jacobson & Andrew Billings, Easing the Burden of Surrogate Decision Making: The Role of a Do-Not-Escalate-Order, 18 J. PALLIATIVE MED. 303, 306 (2015)).

610. Id. at 2.

611. Id. at 3-4.

612. Id. The report noted that CPR could not be withheld without the concurrence of two physicians. Id. at 3. Further, the child's parents would have to be informed of the decision to withhold CPR. Id.

613. Id. at 3-4.

614. Id.

615. See id. at 4. Child Life specialists work with ill children in hospitals and with their families to help people cope with "the stress and uncertainty of acute and chronic illness, injury, trauma, disability, loss and bereavement." What Is a Certified Child Life Specialist?
ii. Sun Hudson

Sun Hudson’s case and his mother’s responses to the care recommended for her infant reflect the limitations of a hospital ethics committee that, apparently in good faith, attempted but failed to create a context for harmonious decision-making. Sun’s story resembles that of DS. However, Sun’s mother (the only parent involved in the infant’s new life) may have lacked capacity to make decisions for her infant son. Still, the course of Sun’s case offers an important comparison to the course of DS’s case insofar as Sun’s mother, like DS’s parents, sought continued treatment for her son, whose clinicians had recommended that care be withdrawn. The infant’s clinicians had concluded that Sun would die soon in any event and that continuing life-sustaining care served primarily to prolong the baby’s suffering. Finally, Sun’s case offers a rare comparison between the work of an ethics committee and a court of law, both of which responded to Sun’s case. There is a record both of the work of the ethics committee that failed to resolve the dispute with Sun’s mother and the judicial responses.

Sun was born in 2004 with a serious genetic condition called thanatophoric dysplasia. The condition is fatal. Wanda Hudson, Sun’s mother, had a different explanation of Sun’s situation. She told the clinicians at St. Luke’s Episcopal Hospital that Sun had no earthly father, that he was the “son of the sun in


616. Hudson v. Tex. Children’s Hosp., 177 S.W.3d 232 (Tex. App. 2005). This decision focused on Sun’s mother’s request that the trial court judge recuse himself. See id. at 233.

617. See id.

618. Compare id., with Infant Case 120124, supra note 27.


620. Id.

621. Conway, supra note 425, at 1125.

622. See Lightfoot, supra note 619 at 852–55.

623. Id.


626. Conway, supra note 425, at 1125.
the sky,” and that he would live. In Sun’s early weeks of life, Wanda Hudson was committed involuntarily to St. Luke’s Episcopal Hospital, a psychiatric facility, but was released when found not to pose a threat to herself or to others.

Clinicians, ethicists, social workers, and members of the clergy spoke with Hudson about her baby’s medical condition and impending death. She countered their conclusions with her own, claiming that Sun was normal and simply needed time to develop. Under the Texas Advance Directives Act, Sun’s care could be terminated despite his mother’s refusal to consent to the withdrawal of life-sustaining care. Among other things, that step required review by the hospital ethics committee. Hudson, as the child’s surrogate decision-maker, was invited (as directed by law) to participate in the ethics committee’s deliberation. Moreover, the committee’s agreement with the clinicians about the withdrawal of care gave the patient (here the patient’s mother) the right to ask for an alternative health care facility. Despite the efforts of Texas Children’s Hospital to identify a hospital willing to admit Sun, dozens of hospitals refused to accept him as a patient.

Texas Children’s Hospital then took an unusual step by helping Hudson find and pay for an attorney. She sued Texas Children’s Hospital in November 2004. Several months later, a Texas probate court judge sided with the hospital against Hudson and authorized the withdrawal of life-sustaining care for Sun. In

627. Lightfoot, supra note 619, at 852.
628. See id.
629. Id.
630. Id.
631. Id.
632. Id.
633. Id.
634. Id. at 852–53.
635. Id. at 853.
636. Halevy, supra note 625, at 283 (reporting that forty hospitals declined to accept Sun as a patient).
637. Lightfoot, supra note 619, at 854.
638. Halevy, supra note 625, at 282.
639. Id. at 283.
March 2005, Sun’s respiratory tube was removed. The failure of the ethics committee at Texas Children’s Hospital to mediate among the parties’ conflicting perspectives was atypical for that committee. Sun’s story was also unusual; it must be viewed as an outlier among cases involving seriously ill neonates in that Sun’s mother may well not have been capable of making medical decisions for her infant. That notwithstanding, Sun’s story does suggest that some bioethical conflicts can elude even the most attentive ethics committees.

V. CONTRASTS BETWEEN COURT RESPONSES AND ETHICS CONSULT RESPONSES TO HEALTH CARE CONFLICTS

The process of resolving health care conflicts can be daunting for judges, who do not often handle cases involving health care conflicts, and for bioethicists, who do it daily. Each forum has advantages and disadvantages.

This Part, summarizing and further analyzing materials presented in previous Parts of the article, focuses explicitly on the comparative advantages of engaging ethics consultants versus engaging courts in the review of health care conflicts. Comparative disadvantages of each mode of review are noted as well, though often implicitly, by way of comparing each forum’s advantages.
with those offered by the other. The comparisons suggested in this Part are grounded on analysis of qualitative data presented in earlier Sections of the article.

Relying on discussion of matching ethics consultations and court cases in earlier Sections of the article, Section A of this Part discerns the comparative benefits brought to the resolution of health care conflicts by ethics consultants in hospitals, on the one hand, and those brought by the judicial process, on the other. Then, Section B considers institutional shifts that might enhance the benefits of each mode of responding to health care conflicts for patients, their clinicians, their family members, and their surrogate decision-makers.

A. Comparing Modes of Reviewing and Resolving Clinical Bioethics Conflicts

Each of the stories described in this article, some told by judges and some by ethics consultants, is challenging. Most reflect strong emotional responses from stakeholders—emotions ranging from hope to despair, from anger to complacency, from confusion to acknowledgment. Many of the stories retold here are troubling, not only because they involve illness and sometimes death, but also because the challenges the participants faced often involved significant medical uncertainty that can exacerbate conflicting relationships among stakeholders.647

The responses of the stakeholders were often colored by the successes or failures of the medical treatments offered, but that is only part of the story.648 Even stories with undesired endings can leave stakeholders with a sense that their views matter—with a sense of having been witnessed within the process that surrounds their or their loved ones’ medical care.649 This is also the case for clinicians.650 The moral distress that clinicians experience in caring for ill patients, especially in the presence of patient-clinician conflict, can be severe.651

Many bioethicists and others have delineated the benefits and drawbacks of involving hospital ethics consultants in health

647. See, e.g., supra Parts II and III.
648. See supra Parts II and III.
649. See Scott, supra note 5, at 381.
650. Id. at 370.
651. Id.
care conflicts. This article joins that set, but with a specific focus, a product of the scope of research on which its analysis has depended. The ethics consult reports that are compared with matching legal cases in this article suggest that ethics consultation can benefit stakeholders as courts generally do not and cannot, but that court decisions—especially those resulting from appellate review—can be invaluable to society’s attempts to meet bioethical challenges.

Court cases, decided by judges and sometimes reported on in public media, offer society a context within which to reconsider its assumptions and reshape its preferences. Ethics consult services, mediating health care conflicts through careful focus on the beliefs and values of stakeholders, can empower patients and family members with the realization that they have been witnessed; their voices have been heard. That alone can alleviate the stress of a health care conflict. It is not a reflection of or a substitute for respect for patient autonomy, often heralded as a central principle of clinical ethics. But it may be of equal significance insofar as ethics consultations can empower patients or their family members even though their preferences are not implemented. That happened, for instance,

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652. See, e.g., ASBH, CORE COMPETENCIES, supra note 33 (listing goals of healthcare ethics consultation); Sally E. Bliss et al., Measuring Quality in Ethics Consultation, 27 J. CLINICAL ETHICS 163 (2016) (using post-consultation satisfaction surveys to measure the quality of ethics consultation); Scott, supra note 5, at 377 (noting role of ethics consultants may include, among other things, “individualized coaching”); Amy T. Campbell et al., How Bioethics Can Enrich Medical-Legal Collaborations, 38 J.L., MED. & ETHICS 847, 853 (2010) (ethics committees or consultants may “offer a different perspective on a vexing case” and may “reorient parties to common goals”). But see Robin Fretwell Wilson, Hospital Ethics Committees as the Forum of Last Resort: An Idea Whose Time Has Not Come, 76 N.C. L. REV. 353 (1998) (noting comparative disadvantages of ethics consults as compared with court review).

653. See supra note 27 and accompanying text (noting source of ethics consult reports reviewed in this article).

654. See supra Parts II and III.

655. See, e.g., supra Parts II and III.

656. Scott, supra note 5, at 381 (citing Nancy M. King, Who Ate the Apple? A Commentary on the Core Competencies Report, 11 HEC FORUM 170, 174 (1999)).

657. Scott, supra note 5, at 399.

658. See, e.g., ALBERT R. JONSEN, MARK SIEGLER & WILLIAM WINSLADE, CLINICAL ETHICS: A PRACTICAL APPROACH TO ETHICAL DECISIONS IN CLINICAL MEDICINE 47-48 (7th ed. 2010).

659. See supra Parts II and III.
for BB whose child, AB, was given a blood transfusion despite BB’s refusal to consent. 660

Correlatively, ethics consultants encourage relationships among stakeholders. 661 Although Brookside’s ethics consult service’s written reports sometimes denote the central ethical challenge in a case in terms of conflicts among autonomy, beneficence and, non-maleficence—principles that have become foundational in American bioethics 662—the ethics team at Brookside often enables parties to surmount conflicts among autonomy, beneficence, and/or non-maleficence by encouraging the development of relationships. 663 That encouragement and its successful consequences were significant for CO and the clinicians involved in CO’s pregnancy care. 664 A conflict between CO and her clinicians about the advisability of an immediate cesarean (with CO opposing that option) was transformed into an accommodation that favored CO’s preference for continuing her pregnancy while, at the same time, she agreed to reconsider her medical choices with her clinicians if her medical status or that of the fetus deteriorated. 665 This accommodation respected CO’s personhood and acknowledged her capacity to make a medical choice for herself and her fetus that differed from the choice recommended by her clinicians. 666 Moreover, the accommodation made sense to CO’s clinicians. 667

CO’s case illustrates the significance of nuance and process to the success of ethics consultations. 668 Skill at discerning nuance and attending to process can be essential to the satisfaction of stakeholders. 669 Those skills may produce results ultimately as important to stakeholders as final determinations.

660. Id.
661. See Scott, supra note 5, at 382.
662. See generally Pregnancy Case P20123, supra note 27; Infant Case I20171, supra note 27; Infant Case I20138, supra note 27; Infant Case I20124, supra note 27.
663. Id.
664. Pregnancy Case P20122, supra note 27.
665. See id.
666. See id.
667. See id.
668. See id.
669. Cynthia M.A. Geppert & Wayne Shelton, Health Care Ethics Committees as Mediators of Social Values and the Culture of Medicine, 18 AMA J. ETHICS 534 (2016); James A. Tulsky & Bernard Lo, Ethics Consultation: Time to Focus on Patients, 92 AM. J. MED. 343, 344 (1992) (noting increase in “everyone’s satisfaction” when physicians are encouraged to “engage
Other advantages of ethics consultations reflected among these cases follow from the ethics team's construction and operation within hospitals. These include the team's accessibility, timeliness, and familiarity with medical care. For instance, the ethics consult service that responded to JT and her clinicians was at work almost immediately after JT arrived at the hospital in active labor in her twenty-fourth week of pregnancy. The service's accessibility and early involvement in JT’s care enhanced the ability of the ethics consult service to respond with significant success to the conflict about care between JT and her clinicians.

The ethicist who managed this case was herself a physician. But even non-clinician ethicists in hospital settings have greater experience with and expertise in understanding the facts and nuances of medical stories than do most judges. Ethics consultants also have the flexibility to reshape and restore conversation should a patient or patient's surrogate dismiss implications of the conversation.

If an ethics consultant fails to resolve a health care conflict, the patient and the hospital can seek redress in court. The emotional and financial costs of a decision to seek a legal resolution can be high, but the opportunity for court review is essential. An ethics consult may be unsuccessful for a variety of reasons. The case of Sun Hudson illustrates that possibility despite a committed ethics committee. Parties to an ethics consultation may be distressed by the lack of clear rules about fair process. At least in theory, judicial proceedings are governed by rules aimed at establishing fair process. Further, judges may be more objective than ethics consultants at least insofar as they are institutionally

in dialogues” with patients); John Tuohey, Ethics Consultation in Portland, 87 HEALTH PROGRESS (2006) (noting the importance of facilitating “respect for both patient choices in the absence of decision-making capacity and patient decisions made when such capacity is present.”).

670. See, e.g., supra Parts II and III.
671. See Pregnancy Case P20123, supra note 27.
672. See id.
673. See id.
676. See supra Part III.B.2.
distinct from those working within the hospital. Justice Liacos, in *Superintendent of Belchertown State School v. Saikewicz* opined that judges are more "detached but passionate" than "any other group purporting to represent the 'morality and conscience of our society,' no matter how highly motivated or impressively constituted." Moreover, court decisions, after exhaustion of the right to appeal, are enforceable. That limits uncertainty, and judges' decisions, at least those issued by appellate courts, are available to the public and serve as legal precedent or as models for future cases raising similar issues. Sometimes appellate decisions responding to health care conflicts reshape society's options and perspectives. A string of court cases dealing with questions about the right to withhold or withdraw life-sustaining care from patients without capacity served this function at the turn of the twenty-first century. This set of cases, which began with *In re Quinlan* in New Jersey in 1976 and included *Cruzan v. Director* and *Schindler v. decision-making meetings.  

677. Ethicists may exhibit biases that favor clinicians or hospitals over patients. Awareness of this potential for bias can go far toward ameliorating it. Further, procedures can be put in place that preclude egregious instances of bias. These might include inviting the patient (or his or her surrogate) to attend decision-making meetings.  


680. *Court Records and Proceedings: What is Public and Why?, CONNOR REPORTING*, https://connorreporting.com/court-records-proceedings-public (last visited Oct. 18, 2018). However, many of the trial court decisions of relevance to this article were not, in fact, made public. Information about those judges' reviews was garnered from the decisions of high courts, scholarly commentary, and media reports.  


683. See, e.g., infra notes 684–86 and accompanying text.  

Schiavo,685 encouraged society and thus legislators to reexamine responses to end-of-life options.686

Court proceedings and judges' decisions in cases such as these have stimulated social discourse.687 That discourse provides grist for the public mill and thus enables society to reconsider and reshape its responses to illness and health. Public interest may also coalesce around a case being considered by a hospital ethics consult service rather than by a court, but this is less common, in part because hospitals are obliged to protect patient privacy and because in-hospital resolution of such conflicts has no value as precedent and may thus be of less interest to a wider community.688

At the same time, the law can too easily level a challenge presented by a moral dilemma with the presumptive certainty of a legal rule.689 Judith Hendrick has suggested that, for this reason, the law may emerge as "more a menace than a friend and certainly a poor substitute for moral consensus."690 Additionally, she states:

[L]egal intervention almost inevitably leads to "legalism"—a process Callahan describes as the translation of moral problems into legal problems; the inhibition of moral debate for fear that it will be so translated, and the elevation of the moral judgments of the courts as the moral standards of the land.691

She cautions that the difference between "what should be done morally" and "what needs to be done legally" should be attended to and preserved for, if the two merge, clinical ethics

685. See Schindler v. Schiavo, 403 F.3d 1223 (11th Cir. 2005) ( siding with husband, against parents, of incapable patient in a persistent vegetative state; husband wanted life-sustaining care terminated).


687. See id.

688. See, e.g., Hendrick, supra note 32, at i52.

689. Id. at i50.

690. Id.

691. Id. (citation omitted).
committees “become little more than legal watchdogs whose only
function is to promote adherence to law.”692

B. The Future

Ethics consult services693 and courts serve different
functions in responding to bioethical conflicts.694 Moreover, each
forum sometimes assists with the functions of the other.695 Courts
called upon to resolve bioethical conflicts have sometimes
suggested that such cases would better be handled by ethics
committees than by courts or have depended on the findings of
hospital bioethicists.696 Bioethicists and others engaged in
responding to such conflicts through ethics consult services have
sometimes sought resolutions in court or even supported a
patient’s seeking a resolution in court.697

Ethics consult services are better equipped to respond to
such cases than are courts and offer a more appropriate setting for
responding to stakeholders’ needs and values than do courts.698
They are able to mediate among stakeholders’ disparate
preferences, while acknowledging the personhood of patients,
family members, and clinicians.699 Courts, on the other hand, can
define moral limits for the parties to a health care conflict and for
society far more broadly than can in-hospital ethics consult
services.700 In this, court decisions in cases addressing issues that
occasion significant conflict within society (such as those relating
to birth, pregnancy, and end-of-life questions) can encourage
society to examine its deepest assumptions.701 At their best, the
distinct functions of ethics consult services and of courts can, and
should, complement each other.

692. Id. at i51.

693. Use of this phrase in the remainder of this Part should be read to include ethics
committees.

694. See generally Annas & Grodin, supra note 10.

695. See generally id.

696. See, e.g., In re A.C., 573 A.2d 1235, 1246 (D.C. 1990) (en banc) (noting
limitations of court review); In re Quinlan, 355 A.2d 647, 668 (N.J. 1976).

697. See Lightfoot, supra note 619, at 854.

698. See Thaddeus Mason Pope, Multi-Institutional Healthcare Ethics Committees: The
Procedurally Fair Internal Dispute Resolution Mechanism, 31 Campbell L. Rev. 257, 271–72
(2009) [hereinafter Multi-Institutional Healthcare].

699. See, e.g., supra Parts II and III.

700. See Wilson, supra note 652, at 397–98.

701. See id. at 396–97.
That complementation could be furthered through the institutionalization of a method for ethics consult services and courts, especially, in cases involving both, to communicate with each other. Courts should be able to benefit from prior work done by ethics consultants who attempted to respond to a conflict that ultimately made its way to court. Court review of ethics consult reports in cases that were entertained by a consult service before a party sought legal redress should be encouraged and facilitated. This would provide courts with valuable information about the stakeholders involved in a health care conflict, their needs, beliefs, and preferences, and about the framework (practical or theoretical) within which the conflict at issue developed.

Additionally, creating specialty or problem-solving courts to respond to health care conflicts in hospitals and other health care facilities has some merit as such courts would gain experience dealing with health care conflicts. However, even specialized problem-solving courts are unlikely to provide an adequate substitute for the work done by ethics consultants.

Problem-solving courts have achieved some success responding to the needs of substance abusers, people with mental illnesses, people who are homeless, and veterans who have been accused of minor crimes. The legal system has also supported the development of a few specialty courts that entertain civil disputes. In theory, problem-solving specialty courts could be

702. Jeffrey P. Spike, When Ethics Consultation and Courts Collide: A Case of Compelled Treatment of a Mature Minor, 1 NARRATIVE INQUIRY BIOETHICS 123, 130 (2011) (recommending that a court hearing a case involving a health care conflict after review by an ethics consultation should “include a review of the ethics consultation” in the court’s proceedings).

703. In most cases, court review of hospital ethics consult reports would require permission from the patient or the patient’s surrogate. See Nicholas P. Terry, What’s Wrong With Health Privacy?, 5 J. HEALTH & BIOMED. L. 1, 15 (2009).

704. See, e.g., Jayanth K. Krishnan et al., Grappling at the Grassroots: Access to Justice in India’s Lower Tier, 27 HARV. HUM. RTS. J. 151, 180 (2014) (noting that civil specialty court judges may become experts in issues addressed by such courts).

705. See Multi-Institutional Healthcare, supra note 698, at 265–68 (discussing the multiple roles played by ethics consultation services in healthcare organizations).


707. A few states and municipalities have created civil specialty courts; they have focused on business issues, tax issues, and commercial litigation. See Laurie Kratky Doré, If You Build It, Will They Come? Designing Iowa’s New Expedited Civil Action Rule and Related Civil Justice Reforms, 63 DRAKE L. REV. 401, 406, n.13 (2015); Tamar M. Meekins, “Specialized Justice:” The Over-Emergence of Specialty Courts and the Threat of a New Criminal Defense Paradigm, 40 SUFFOLK U. L. REV. 1, 3 n. 7 (2006).
constructed to respond to health care conflicts. That development, however, would contain significant risks. It might displace the most impressive components of the ethics consultant’s work that entails a focus on personhood and relationship and the ability to devote many hours to achieving the promises of that focus.

Courts, even specialized courts, are not likely to have the resources to sustain that focus and may flatten moral challenges by shaping them to fit a legal mold. Moreover, development of specialized courts to handle cases occasioned by health care conflicts could lead to the diminution of appellate review in such cases. That risk is significant in this domain of cases insofar as appellate court opinions have opened windows for debate through which society has been encouraged to reconsider fundamental values and reshape bioethic challenges. Appellate courts can review problem-solving court's procedures. However, the majority of people who appear before judges in problem-solving courts waive the right to appeal. In practice, that limits the capacity of the court system to construct appellate decisions that can lead to re-shaping legal and communal visions of far-reaching social challenges.

Continuing to rely on two parallel—largely separate—systems for resolving health care conflicts involves some waste and uncertainty, but the benefits of preserving both contexts for dispute resolution are significant. When done well, ethics...
consult services offer patients, their families, clinicians, and other hospital staff an opportunity to resolve conflicts through a process that depends on respect for the value and dignity of each stakeholder.\textsuperscript{715} Few courts, if any, even among problem-solving courts, have the resources or institutional capacity to do comparable work.\textsuperscript{716} Yet, court review of health care conflicts is an essential component of shaping a wiser health care system—one attuned to fair process and constitutional rights in responding to bioethical challenges.\textsuperscript{717}

VI. CONCLUSION

Only in the last three or four decades have ethics consult services been widely available in hospitals and other health care facilities.\textsuperscript{718} The ASBH Task Force delineated “core competencies” that aim to ensure “quality improvement in ethics consultation.”\textsuperscript{719} These competencies were intended to serve as voluntary guidelines.\textsuperscript{720}

Commentators questioned the status and value of a presumptive profession without professional status, without mandatory rules, and without accreditation demands.\textsuperscript{721} Giles Scofield suggests:

[I]t makes eminent sense to heed Paul Starr’s advice, which is that we should not simply take the field’s claims at face value, but that we should instead be skeptical of, question, and even challenge both the claims and the denials that the field’s practitioners make, both in terms of what they say about themselves and in terms of what they insinuate about the rest of us.\textsuperscript{722}

\textsuperscript{715} See, e.g., supra Parts II and III.
\textsuperscript{716} See generally James A. Dator, Futures and Trial Courts, 18 WIDENER L.J. 517, 521 (2009) (discussing the limitations of trial courts).
\textsuperscript{718} Scott, supra note 5, at 365.
\textsuperscript{719} ASBH, CORE COMPETENCIES, supra note 33, at 11.
\textsuperscript{720} Id. at 31. Until recently, the Task Force did not “wish certifying or accreditating bodies to mandate any portion of its report.” Id.
\textsuperscript{721} Scofield, supra note 34, at 96–97.
\textsuperscript{722} Id. at 99.
Recently, the American Society for Bioethics and Humanities (ASBH) has developed and recommended use of a "healthcare ethics certification examination." The exam tests five areas of skill development: "assessment, analysis, process, evaluation, and quality improvement" as well as "foundational knowledge," deemed important to the work of clinical ethicists.

Work toward this article commenced with the sort of skepticism that Scofield recommends. However, careful attention to the Brookside ethics consult reports, only a small percent of which are expressly considered in this article, dissipated most of that skepticism. That said, no claims are made here about the work of ethics consult services in general. It is noted only that one consult service, developed along guidelines in harmony with those recommended by the ASBH Task Force, has performed impressively, serving a useful function. The service's work is labor intensive and can be expensive. However, the benefits for each of the stakeholders in cases occasioned by health care conflicts in hospitals and other health care settings are significant. Simply avoiding litigation, one outcome of a successful ethics consultation, can balance the costs of sustaining a consult service. Litigation is expensive, public, and time-consuming.

Thus, ethics consult services and courts of law offer complementary modes of responding to health care conflicts in hospitals and other health care facilities. Each approach serves a set of essential functions not served by the other. Neither should be displaced by the other. Deliberation among those internal to

723. ASBH, Healthcare Ethics Consultation Certification (HECC) Examination Content Outline, http://asbh.org/certification/content-outline (last visited June 11, 2018) (noting that "[t]he 2017 ASBH Role Delineation Study and needs assessment are the key documents used to create the HECC examination content outline").

724. Id.

725. See ASBH, CORE COMPETENCIES, supra note 33.

726. As a general matter, patients only indirectly bear the costs of ethics consults. It has proven difficult to assess the "value" of ethics consults. But see Mark Repenshek, Assessing ROI for Clinical Ethics Consultation Services, HEALTH CARE ETHICS USA 12, 18 (2017) (measuring effects of ethics consultations on "established quality metrics").

727. See supra Parts II and III.

728. See Spike, supra note 702, at 130.

729. Id.
each of these approaches should include constant reference to and self-adjustments in light of the results of the other approach.