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Yoram Unguru

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# DECISION MAKING FOR CHILDREN WITH LIFE-LIMITING ILLNESSES: A CLINICAL APPROACH

YORAM UNGURU, MD, MS, MA\*

## CASE STUDY<sup>1</sup>

Michael, a fifteen-year-old with metastatic osteosarcoma, has not responded to conventional therapy. For almost one year, he was treated in a therapeutic, randomized clinical trial, which consisted of standard therapy (up-front chemotherapy, limb salvage surgery, and postsurgical chemotherapy). When his cancer responded poorly to up-front therapy, he was randomized to receive additional “experimental” chemotherapy.

Michael has a very close relationship with his mother, and he has been an active participant in every treatment conference. For the most part, Michael tolerated the treatment; however, he struggled both physically and emotionally with the last three months of treatment. Michael’s end-of-therapy scans confirmed that the tumor was still present in both the bone and the lungs.

Michael’s mother wants to proceed with an (unproven) experimental therapy in an effort to prolong his life. Michael, on the other hand, does not desire this intervention. Michael asks the physician not to administer the drug and to allow him to die on his “own terms.” Michael’s mother (emphatically) states that this is her decision to make and not his. She adds that if the physician is not willing to treat him, she will take him to a doctor who will.

This case raises many important questions. For example, as Michael’s physician, are you comfortable with the decision he is asking you to allow him to make? How do you balance Michael’s goals with those of his mother’s and your own? How can you (or should you) find a way to enable Michael’s mother to allow him to transition into control of his own health care management? Who ultimately is responsible for Michael’s care and health? Should the fact that the treatment in question is considered experimental make a difference?

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\* Division of Pediatric Hematology/Oncology, The Herman and Walter Samuleson Children’s Hospital at Sinai; Berman Institute of Bioethics Johns Hopkins University.

1. *Terminal and Chronic Illness Panel Case Studies*, UNIV. OF MD FRANCIS KING CAREY SCHOOL OF LAW, [www.law.umaryland.edu/faculty/conferences/conf108/Terminal\\_Illness\\_Case\\_Studies.pdf](http://www.law.umaryland.edu/faculty/conferences/conf108/Terminal_Illness_Case_Studies.pdf) [hereinafter *Symposium Case Studies*] (last visited Jan. 3, 2012).

## I. INTRODUCTION

Medical decision making involving older children requires the physician to obtain both the patient's assent and parental permission.<sup>2</sup> Pediatricians are ideally positioned to deal with the inevitable conflicts inherent in these situations as exemplified in the case study above.<sup>3</sup> In order to address the questions that this case study presents, this article will first explore the decision making capacity of children<sup>4</sup> and explain the concept of assent as related to a minor's decisions regarding his or her treatment regimen.<sup>5</sup> Next, the article will discuss recent research, which demonstrates the need for direct communication between parents, physicians, and children.<sup>6</sup> Lastly, this article will conclude with recommendations for a practical decision-making model and a discussion of the case study presented above.<sup>7</sup>

## II. DECISION-MAKING CAPACITY AND ASSENT

By definition, "children constitute a vulnerable population."<sup>8</sup> The vulnerability of children relates directly to their limited decision-making capacity (i.e., the ability to make reasonable decisions).<sup>9</sup> Thus, because many children, especially infants and young children, lack decision-making capacity to make informed and voluntary decisions, they are deemed vulnerable and merit special protections.<sup>10</sup> Older children and adolescents, however, often possess the capacity for decision making and therefore may be qualified to make select decisions while unable to make others.<sup>11</sup> It is usually the pediatrician's role to determine if a child

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2. See 45 C.F.R. §§ 46.401–407 (2010) (establishing that a physician must solicit a child's assent and a parent's permission for a child to participate in a clinical research study); see also Comm. on Bioethics, *Informed Consent, Parental Permission, and Assent in Pediatric Practice*, 95 PEDIATRICS 314, 317 (1995) (noting that, in addition to obtaining parental permission, physicians should, in most cases, obtain patient assent as well).

3. See generally *Symposium Case Studies*, supra note 1.

4. See *infra* Part II.

5. See *infra* Part II.A–D.

6. See *infra* Part III.

7. See *infra* Part IV.

8. Wilma C. Rossi et al., *Child Assent and Parental Permission in Pediatric Research*, 24 THEORETICAL MED. & BIOETHICS 131, 131 (2003).

9. See *id.* at 135–36 (noting that children less than seven-years-old are considered incapable of providing assent, and among children aged seven to fourteen, assent can be easily compromised by the power relationship between parents and children).

10. See Lawrence Schlam & Joseph P. Wood, *Informed Consent to the Medical Treatment of Minors: Law and Practice*, 10 HEALTH MATRIX 141, 149–50 (2000) (noting the belief that children lack the "maturity, experience, and capacity" necessary to make difficult decisions and are therefore incapable of making medical decisions and need to be protected from themselves).

11. See CHILDREN'S ONCOLOGY GRP., ASSENT TASK FORCE, GUIDELINES FOR INVOLVING CHILDREN IN DECISION-MAKING ABOUT RESEARCH PARTICIPATION 1, 4, 7, available at [http://www.pediatricethics.com/documents/policies/Decisions\\_Oncology.pdf](http://www.pediatricethics.com/documents/policies/Decisions_Oncology.pdf) [hereinafter COG TASK FORCE GUIDELINES] (last visited Jan. 7, 2012) (explaining that for decisions related to research

or adolescent has the ability to make a given decision.<sup>12</sup> Thus, it is appropriate and ethically justifiable to solicit assent from children who are unable to make autonomous choices.<sup>13</sup>

Assent refers to the active agreement of a minor to participate in a diagnostic or treatment regimen.<sup>14</sup> The ethical principle of pediatric assent recognizes that children (especially adolescents) are capable of participating at some level in decision making related to their care.<sup>15</sup> The assent requirement seeks to respect children as individuals with emerging autonomy.<sup>16</sup> Above all else, assent is about respecting a child's "developing capacity,"<sup>17</sup> assisting the child in understanding his condition and treatment at a developmentally appropriate level,<sup>18</sup> and involving him in appropriate decision-making tasks.<sup>19</sup>

Meaningful assent requires an appreciation of the child's developmental stage *and* recognition of his basic preferences.<sup>20</sup> A child should be included in medical decisions to the extent that he or she is able to and wants to be involved.<sup>21</sup> Parents and physicians need to encourage children to communicate openly so that children may be active participants in the assent process.<sup>22</sup> Shared decision making empowers children to the extent of their capacity.<sup>23</sup>

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participation, children fourteen years of age and older may potentially reach the decision-making capacity of many adults).

12. See Tara L. Kuther, *Medical Decision-Making and Minors: Issues of Consent and Assent*, 38 ADOLESCENCE 343, 345 (2003) (noting that physicians are largely responsible for determining whether a minor has the capacity to consent to specific treatment based partly on the minor's comprehension of the procedure and the possible outcomes).

13. *Id.* at 351 (describing that minors may not be capable of autonomous decision making in all circumstances, but that it is still appropriate to involve them in the decision-making process).

14. *Id.*

15. *Id.*

16. NAT'L COMM'N FOR THE PROT. OF HUMAN SUBJECTS OF BIOMEDICAL & BEHAVIORAL RESEARCH, DEP'T OF HEALTH, EDUC. & WELFARE, No. (OS) 77-0004, REPORT AND RECOMMENDATIONS: RESEARCH INVOLVING CHILDREN 71, 72 (1977) [hereinafter NAT'L COMM'N REPORT AND RECOMMENDATIONS].

17. William G. Bartholome, *Ethical Issues in Pediatric Research*, in THE ETHICS OF RESEARCH INVOLVING HUMAN SUBJECTS: FACING THE 21<sup>ST</sup> CENTURY 339, 358 (Harold Y. Vanderpool ed., 1996).

18. *Id.* at 360.

19. *Id.* at 360-61.

20. See *id.* (noting that the multiple elements of assent recognize the child's developmental maturity and inclinations).

21. Yoram Unguru et al., *Rethinking Pediatric Assent: From Requirement to Ideal*, 55 PEDIATRIC CLINICS N. AM. 211, 217 (2008).

22. *Id.* at 217-18.

23. See Gail Geller et al., *Informed Consent for Enrolling Minors in Genetic Susceptibility Research: A Qualitative Study of At-risk Children's and Parents' Views About Children's Role in Decision-Making*, 32 J. ADOLESCENT HEALTH 260, 269 (2003) (noting the positive impact that shared decision making had on children).

Like other areas of child development, capacity for decision making occurs along a spectrum and evolves with time and experience.<sup>24</sup> Factors influencing this process include a child's maturity level, ability to reason and consider the impact of their decision, including relevant alternatives and consequences, and prior decision-making experience.<sup>25</sup> With regard to the latter, one might imagine two children of the same age, Jane and Joe. Consistently throughout her life, Jane's parents have allowed her to participate in and to make decisions. As Jane has demonstrated an appreciation for and gained experience with the decision-making process, her parents have gradually allowed her to participate in and make more substantive decisions. Joe's parents have adopted a different approach. They have allowed him to make routine choices but have not given him the chance to participate in making significant life-decisions, preferring instead to make such decisions on his behalf. As one might surmise, Jane is seemingly better prepared to appreciate *and* to understand the nuances of medical decision making than Joe, who has been insulated from making life-decisions and who may be less equipped to participate meaningfully in and to assent to medical (and research) decisions.<sup>26</sup> Accordingly, no two children attain decision-making capacity similarly.<sup>27</sup>

As recognized in common law, minors possess varying degrees of decision-making capacity.<sup>28</sup> The rule of capacity, also known as the Rule of Sevens, is strictly an age-based criterion.<sup>29</sup> Accordingly, minors under seven years of age have no such capacity; minors "between seven and fourteen have a rebuttable presumption of no capacity"; and minors "between fourteen and twenty-one, have a rebuttable presumption of capacity."<sup>30</sup> Evidence from the social sciences supports the notion that, in general, children fourteen and older appear to be as competent as adults in making informed treatment decisions.<sup>31</sup> As the example of Jane and Joe illustrates, age alone, however, is not an adequate indicator of a child's ability to understand.<sup>32</sup>

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24. Mary Ann McCabe, *Involving Children and Adolescents in Medical Decision Making: Developmental and Clinical Considerations*, 21 J. PEDIATRIC PSYCHOL. 505, 508 (1996).

25. *Id.* at 509–10, 513.

26. *Id.* at 511 (explaining that family factors may determine a child's level of involvement in the decision-making process).

27. *Id.* at 509.

28. *Cardwell v. Bechtol*, 724 S.W.2d 739, 744–45 (Tenn. 1987) (noting the common law recognition of varying degrees of decision-making capacity in minors).

29. *Id.* at 745.

30. *Id.*

31. Lois A. Weithorn & Susan B. Campbell, *The Competency of Children and Adolescents to Make Informed Treatment Decisions*, 53 CHILD DEV. 1589, 1595 (1982).

32. See Rossi et al., *supra* note 8, at 132 (noting that age, maturity, and psychological state are all factors that should be considered when determining a minor's capacity); see also Robert Bennett, *Allocation of Child Medical Care Decision-Making Authority: A Suggested Interest Analysis*, 62 VA. L. REV. 285, 309 (1976) (noting that experience will change a child's decision-making capacity).

### A. Limits of Assent

In pediatric medicine, shared decision making is a worthy and valuable standard. Shared decision making strives to respect both parents' and children's preferences and values while meeting the goals of medicine.<sup>33</sup> Typically, parents and children share similar ideals and more often than not, in medical situations, the two align with one another.<sup>34</sup> However, disagreements do occasionally occur and this has clear implications for assent.<sup>35</sup> Every effort should be made to secure a child's readiness to accept treatment, but as recognized in the law, it is the parents, not the child, who are the ultimate arbiters of decision making.<sup>36</sup> Accordingly, parents may compel their child to accept a treatment, so long as that treatment is in a child's best interest.<sup>37</sup> In other words, parental permission may trump a child's assent.<sup>38</sup> The principle of respecting a child as a developing person requires that physicians inform the child that while they value his or her opinion, in specific instances his opinion may be overridden.<sup>39</sup> Failure to do so has the potential for damaging the child's developing self as well as the trusting relationship between the child, his parents, and the physician.<sup>40</sup>

### B. Determining the Validity of a Child's Decision

For a medical decision to be valid, it must be voluntary and informed.<sup>41</sup> Decisional capacity matures along a continuum dependent on time and experience;<sup>42</sup> as such, children possess varying degrees of decision-making capacity, which is determined primarily by the *type* of decision and the *risks and benefits* involved.<sup>43</sup> The threshold level of capacity is a useful model to assist in determining if a particular child may make a given decision.<sup>44</sup> For high-risk

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33. See Geller et al., *supra* note 23, at 269 (noting that both children and parents value shared medical decision making).

34. See COG TASK FORCE GUIDELINES, *supra* note 11, at 7 (recognizing that fundamental disagreements between parents and children, with regard to research participation, are rare).

35. See Kuther, *supra* note 12, at 354–55 (describing the ways in which disagreements occur and how to proceed despite the disagreement of the parties).

36. *Id.* at 344, 356.

37. *Id.* at 344.

38. *Id.* at 344, 355–56.

39. *Id.* at 352–53 (noting that physicians should always be up-front with minor patients about how the patient's values and preferences will be incorporated into the decision-making process).

40. See Francoise Baylis et al., *Children and Decisionmaking in Health Research*, 21 IRB, July–Aug. 1999, at 5, 8 (stating that children may be “seriously harmed by having something done to them without their knowledge or understanding”).

41. Kuther, *supra* note 12, at 344.

42. McCabe, *supra* note 24, at 507–10.

43. *Id.* at 509–10 (describing the varying levels of situations and factors that influence a minor's capacity to make competent decisions).

44. See Alex Buchanan, *Mental Capacity, Legal Competence and Consent to Treatment*, 97 J. ROYAL SOC'Y MED. 415, 416, 418 (2004) (defining a threshold level of capacity).

decisions (e.g., refusal of a life-saving intervention), a higher threshold of decision-making capacity is necessary; for low-risk decisions (e.g., choosing between two equally efficacious medications), a lower threshold is appropriate.<sup>45</sup>

Historically, assessment of decision-making capacity has focused on understanding, an important component of decision-making capacity.<sup>46</sup> Yet, in practice, evaluating understanding is a difficult task.<sup>47</sup> Part of the problem relates to the definition of understanding, which is multidimensional (i.e., elements of understanding include, but are not limited to, comprehension, knowledge, and awareness).<sup>48</sup> Additionally, few validated tools exist for assessing understanding, and most are designed for adults, not children.<sup>49</sup> What is clear is that three factors must exist for a child to possess decision-making capacity: (1) a child's choice must be voluntary; (2) his or her choice must be both reasonable and rational; and (3) the child must understand information that is relevant to his choice.<sup>50</sup> Although evaluating a child's understanding remains an essential element of assent, it alone is insufficient in assuring that assent is significant and meaningful.<sup>51</sup> As appreciated by the American Academy of Pediatrics (AAP), the process of obtaining a child's assent requires several steps:<sup>52</sup> the physician must (1) help the patient achieve awareness of his or her condition; (2) tell the patient what he or she can expect regarding diagnosis and treatment; (3) assess the patient's understanding; (4) assess factors influencing patient responses (i.e., undue pressure); and (5) solicit the patient's willingness to accept care.<sup>53</sup>

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45. Cf. Kuther, *supra* note 12, at 354 (opining that a physician should respect a minor's decision with regard to elective treatments but "probe further" where a minor is refusing treatment with benefits that outweigh the risks).

46. See, e.g., Protection of Human Subjects, Research Involving Children: Report and Recommendations of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 43 Fed. Reg. 2084, 2098 (Jan. 13, 1978) (emphasizing that pediatric researchers should make sure minors of a certain age have the requisite understanding about their involvement).

47. See Kuther, *supra* note 12, at 346 (noting that there is a lack of clear guidelines in determining a minor's maturity or decision-making capacity).

48. WEBSTER'S II: NEW COLLEGE DICTIONARY 1202 (2001).

49. Cf. Buchanan, *supra* note 44, at 415–16 (applying the threshold level of capacity theory to adult patients); Cathy Charles et al., *Shared Decision-Making in the Medical Encounter: What Does It Mean? (or It Takes at Least Two to Tango)*, 44 SOC. SCI. & MED. 681, 682 (1997) (applying shared decision-making theory to adult decision making with regard to medical treatment).

50. See Kuther, *supra* note 12, at 344.

51. See Comm. on Bioethics, *supra* note 2, at 315–16 (outlining the multiple elements required for obtaining assent, including understanding).

52. *Id.*

53. *Id.*

*C. Societal and Legal Attitudes Towards Assent*

Sufficient evidence supports a role for children's involvement in decisions related to their care and research involvement.<sup>54</sup> In addition to promoting a child's developing sense of autonomy and personal responsibility, participation in decision making may in fact improve a child's response to treatment.<sup>55</sup> Nevertheless, there is reluctance on the part of legal institutions and the public at large to include children in certain treatment- and research-related decisions.<sup>56</sup>

Part of this reluctance concerns the potential for child-parent conflict as it relates to the appropriate moral weight to assign to children's assent or dissent.<sup>57</sup> As appreciated by Baylis and colleagues,<sup>58</sup> this is particularly germane to children's involvement in research settings,<sup>59</sup> yet it is relevant in the clinical arena as well.<sup>60</sup> If a child's decisions carry the same power as the decisions of his parents, then from a moral and ethical perspective the child may veto the parents' decision if and when he disagrees about research involvement or a particular clinical decision.<sup>61</sup> Purely from an enforcement perspective, the difficulty with this scenario is primarily a legal one.<sup>62</sup> While morally a child's decisions may be no different from those of his parents, the difficult question that arises in such a situation is: should the decisions of a child who lacks legal standing be as authoritative as those of his parents?<sup>63</sup> Baylis et al. argue that concepts of assent (for research), which rely on decisional authority, are too narrow and instead need to be expanded in its focus and consider to what extent a child may participate as "assenter or dissenter."<sup>64</sup> Thus, a child

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54. See Kuther, *supra* note 12, at 348–50 (showing that adolescents and adults have similar decision-making capacities for certain types of decisions).

55. Cf. Rochelle T. Bastien & Howard S. Adelman, *Noncompulsory Versus Legally Mandated Placement, Perceived Choice, and Response to Treatment Among Adolescents*, 52 J. CONSULTING & CLINICAL PSYCHOL. 171, 172 (1984) (citing a study on an elderly population which demonstrated that those seniors who had control over their decisions were happier and healthier than those who did not have any control).

56. Baylis et al., *supra* note 40, at 6.

57. *Id.*

58. *Id.* at 5.

59. See generally *id.* (discussing the involvement of children in the research decision-making process).

60. Christine A. Zawistowski & Joel E. Frader, *Ethical Problems in Pediatric Critical Care: Consent*, 31 CRITICAL CARE MED. S407, S408 (2003) (applying assent requirements to pediatric clinical care).

61. See Baylis et al., *supra* note 40, at 6 (noting the difficulty in determining the amount of decision-making power that children should have in the medical setting).

62. *Id.* at 9 (discussing that parents are entrusted with the responsibility of making decisions on behalf of their children because it is believed that they will act in the child's best interests, and if not, can sometimes suffer legal repercussions).

63. See *id.* at 8 (establishing the difficulty in determining when children have the necessary capacity to make decisions for themselves).

64. *Id.* at 8.



may still have a valuable contribution even if he lacks decisional authority.<sup>65</sup> Baylis et al. describe this as a “receptive role” rather than a “decisional role.”<sup>66</sup>

#### *D. Assent to Research as Compared to Clinical Care*

Assent for research differs from assent for clinical care.<sup>67</sup> For assent to be truly meaningful, an understanding of the difference between the two is imperative. Clinical care (i.e., treatment) focuses on an *individual* patient.<sup>68</sup> It employs recommended treatments—the benefits of which are assumed to outweigh the risks.<sup>69</sup> Clinical research, on the other hand, seeks to provide generalizable knowledge with the potential for benefiting *future* patients (and may not offer benefit to the participant at all).<sup>70</sup> Therefore, while clinical care is grounded in promoting a patient’s best interests, clinical research does not share this goal; instead, it employs subjects as a means to an end.<sup>71</sup> Appreciating this difference in the purposes of clinical care and research is extremely important.<sup>72</sup> Thus, before a child (or adult) assents to research participation, he must understand the underlying purpose of the research protocol and that it may hold no direct benefit to him, or may even harm him.<sup>73</sup> Hence, assent or consent to research demands a more nuanced and refined decisional capacity than assent and consent to clinical treatment.<sup>74</sup>

65. See *id.* (referencing a child’s ability to participate without actually having the final decision-making authority).

66. *Id.*

67. Compare 45 C.F.R. § 46.402(b) (2010) (“Assent means a child’s affirmative agreement to participate in research. Mere failure to object should not, absent affirmative agreement, be construed as assent.”), and § 46.408(a) (“[T]he IRB shall determine that adequate provisions are made for soliciting the assent of the children, when in the judgment of the IRB the children are capable of providing assent.”), with Kuther, *supra* note 12, at 351 (describing assent as it pertains to the medical treatment of minors as “an interactive process between a minor and a physician that involves developmentally appropriate disclosure about the illness and solicitation of the minor’s willingness and preferences regarding treatment”).

68. Paul Litton & Franklin G. Miller, *A Normative Justification for Distinguishing the Ethics of Clinical Research from the Ethics of Medical Care*, 33 J.L. MED. & ETHICS 566, 566 (2005).

69. *Id.*

70. Charles W. Lidz et al., *Competing Commitments in Clinical Trials*, 31 IRB, Sept.–Oct. 2009, at 1, 1.

71. Gail E. Henderson et al., *Clinical Trials and Medical Care: Defining the Therapeutic Misconception*, 4 PLOS MED. 1735, 1736 (2007) (“[I]t is a misconception to believe that the purpose of clinical trials is to administer treatment rather than to conduct research”).

72. *Id.*

73. Sanford Leikin, *Minors’ Assent, Consent, or Dissent to Medical Research*, 15 IRB, Mar.–Apr. 1993, at 1, 5; Lauren K. Collogan & Alan R. Fleischman, *Adolescent Research and Parental Permission*, in ETHICS & RESEARCH WITH CHILDREN: A CASE-BASED APPROACH 77, 87 (Eric Kodish ed., 2005).

74. Collogan & Fleischman, *supra* note 73, at 87 (noting that informed consent is different for clinical treatment situations and clinical research).

## III. FINDING A BALANCE

The need for direct communication between parents, physicians, and children with life-limiting illnesses is increasingly apparent.<sup>75</sup> This communication includes discussions relating to prognosis and even death.<sup>76</sup> Hinds and colleagues found that children with life-limiting cancer between ages ten and twenty were capable of participating in end-of-life decision making.<sup>77</sup> Children typically want to be involved in decisions that concern their bodies and health.<sup>78</sup> They also generally recognize their role in decision-making as intertwined with that of their parents and appreciate and respect their parents' input,<sup>79</sup> particularly when they perceive a situation to be more risky.<sup>80</sup> Most children do not expect to make decisions on their own but wish to be involved in the process and have their opinions respected.<sup>81</sup> Shared decision making enables children to clarify their own values and preferences.<sup>82</sup> Assent should not be viewed as a challenge to parental authority and parental decision making.<sup>83</sup> Assent and parental permission are not mutually exclusive; instead, the two complement one another and result in a more collaborative and substantive shared decision-making model.<sup>84</sup> As appreciated by the AAP, meaningful assent is best viewed as a process wherein children, parents, and physicians participate in *joint decision making*.<sup>85</sup> Importantly, this process is individualized based on the unique capabilities of the child.<sup>86</sup>

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75. CTR. FOR BIOETHICS, UNIV. OF MINN., END OF LIFE CARE: AN ETHICAL OVERVIEW 48 (2005) (discussing the importance of involving a dying child in treatment and health care discussions).

76. Comm. on Bioethics & Comm. on Hosp. Care, Am. Acad. of Pediatrics, *Palliative Care for Children*, 106 PEDIATRICS 351, 353 (2000); Bruce P. Himmelstein et al., *Pediatric Palliative Care*, 350 NEW ENG. J. MED. 1752, 1753, 1756 tbl.3 (2004) (discussing how to communicate with children facing life-threatening illnesses); see generally Javier R. Kane et al., *Understanding the Illness Experience and Providing Anticipatory Guidance*, in TEXTBOOK OF INTERDISCIPLINARY PEDIATRIC PALLIATIVE CARE 30, 30 (Joanne Wolfe et al. eds., 2011) (noting the importance of communication between a physician and the family members of a child with a life-threatening illness).

77. Pamela S. Hinds et al., *End-of-Life Care Preferences of Pediatric Patients with Cancer*, 23 J. CLINICAL ONCOLOGY 9146, 9153 (2005).

78. See, e.g., Geller et al., *supra* note 23, at 264 (noting that children generally felt it was their decision of whether to participate in genetic research).

79. Rossi et al., *supra* note 8, at 139; see also Geller et al., *supra* note 23, at 264; Yoram Unguru et al., *The Experiences of Children Enrolled in Pediatric Oncology Research: Implications for Assent*, 125 PEDIATRICS e876, e880 (2010).

80. Geller et al., *supra* note 23, at 265–66.

81. *Id.*

82. *Id.* at 270.

83. Cf. Comm. on Bioethics, *supra* note 2, at 315 (noting that while advocating the solicitation of assent from a child, practitioners still need the “informed permission” from the parents for medical interventions).

84. See Geller et al., *supra* note 23, at 269 (arguing that a shared-decision process, which includes both children and parents, can enhance cooperation).

85. Comm. on Bioethics, *supra* note 2, at 315.

86. Baylis et al., *supra* note 40, at 7 (describing the four criteria for making an individualized assessment of a child's decision-making capacity in research participation).

Mack and colleagues surveyed parents of children with cancer and found that parents rated the quality of care provided by physicians more favorably when physicians communicated directly with their children (when appropriate).<sup>87</sup> Similarly, in a survey of over 400 Swedish parents of children who died of cancer, Kreicbergs et al. found that none of the parents who spoke with their child about death regretted doing so, whereas more than one quarter of parents who did not speak with their child regretted not doing so.<sup>88</sup> The latter parent group had higher levels of anxiety and depression than parents who spoke to their children.<sup>89</sup>

Parents are not alone in valuing the importance of direct communication between children and physicians.<sup>90</sup> Recent research has shown that children with cancer consider direct communication between doctors and children more important than any other aspect of improving adolescent decision making.<sup>91</sup> Nearly forty years ago, following parental approval, Nitschke et al., began including children with cancer, ages five and older, who were near death, in end-of-life discussions.<sup>92</sup> They found that the majority of children and parents found the child's inclusion a positive experience.<sup>93</sup> They also reported that some children from whom information was withheld experienced fear and isolation prior to dying.<sup>94</sup>

Pediatricians are in a unique position to help children and parents with appreciating and developing their own practical approach to shared decision making. When a child is ill, parents seek to protect and to isolate their child from harms. Many parents perceive decision making itself as burdensome and in an effort to shield their child, assume full decision-making responsibility.<sup>95</sup> Clinicians need to be aware of this phenomenon. As a trusted caretaker, pediatricians can, and

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87. Jennifer W. Mack et al., *Parent and Physician Perspectives on Quality of Care at the End of Life in Children with Cancer*, 23 J. CLINICAL ONCOLOGY 9155, 9159 (2005).

88. Ulrika Kreicbergs et al., *Talking About Death with Children Who Have Severe Malignant Disease*, 351 NEW ENG. J. MED. 1175, 1177 (2004).

89. *Id.* at 1184.

90. CTR. FOR BIOETHICS, UNIV. OF MINN., *supra* note 75, at 48.

91. See Unguru et al., *supra* note 79, at e880 (advancing a study on children with cancer about their understanding of research and treatment, which demonstrated that 39% of those children surveyed wanted more discussions directly with doctors); see also Mack et al., *supra* note 87, at 9160 (noting the importance of communication with children, especially near the end of their life).

92. Ruprecht Nitschke et al., *Perspective: Care of Terminally Ill Children with Cancer*, 34 MED. & PEDIATRIC ONCOLOGY 268, 268 (2000).

93. See *id.* at 269 (stating that regardless of the child's therapeutic choice, fewer than one-third of the children reacted with sadness, anxiety and anger when included in the final stage conference to discuss their unresponsiveness to further therapy).

94. *Id.*

95. See McCabe, *supra* note 24, at 511–12 (explaining how a decision-making situation may be difficult and burdensome for a child); Alan Meisel, *The "Exceptions" to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decisionmaking*, 1979 WIS. L. REV. 413, 423 (1979) (stating that, in general, family and friends are interested in a loved one's medical decision because of the desire to relieve the patient's pain and suffering).

should, help parents develop the skills to allow their children to think independently.<sup>96</sup> Children, especially ill children, need to know that they can depend on their parents to support them as they learn to make appropriate decisions.<sup>97</sup> Including children in decision making empowers children. It provides them with a sense of purpose and control and promotes improved future choices.<sup>98</sup>

Collaborative decision making does not require that children's, parents', and physician's decisions carry equal weight.<sup>99</sup> Rather, all parties should be able to respectfully state their desires and concerns.<sup>100</sup> Thus, parents should allow children to speak freely; they must honestly and thoughtfully listen to and acknowledge what their child has to say.<sup>101</sup> Children need to know that while their preferences will be heard and considered, decision making is a joint endeavor, and ultimately, their decision may be overturned.<sup>102</sup> As the child's advocate, pediatricians are ideally situated to serve as a bridge between the child and his parents, easing some of the burden, mediating disagreements, and assisting both sides in reaching a reasonable decision—one that is acceptable to all stakeholders.

#### IV. RECOMMENDATIONS FOR A PRACTICAL DECISION-MAKING MODEL

As appreciated by others, a tangible model of assent gives choices to children of all ages.<sup>103</sup> The type and extent of acceptable choices are unique to each child and contingent upon the child's maturity level, history of decision making, and

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96. Cf. COMM. ON PALLIATIVE & END-OF-LIFE CARE FOR CHILDREN & THEIR FAMILIES, INST. OF MED., WHEN CHILDREN DIE: IMPROVING PALLIATIVE AND END-OF-LIFE CARE FOR CHILDREN AND THEIR FAMILIES 129 (Marilyn J. Field & Richard E. Behrman eds., 2003) (describing that the entire palliative care team, including, doctors, nurses, consultants and chaplains, can help families reach their goals).

97. See Bartholome, *supra* note 17, at 358 (noting the general fragility of children and the need for encouragement and reinforcement by parents in the context of giving medical consent).

98. See Comm. on Bioethics, *supra* note 2, at 315 (stating that including children in medical decision making empowers the child and can "improve long-term health outcomes").

99. See McCabe, *supra* note 24, at 508–09 (noting the varying levels of child, parent and caregiver involvement in medical decision making).

100. See Geller et al., *supra* note 23, at 269 (discussing the importance of shared decision making between parents and children which inherently involves both parties voicing their opinions); see also Myra Bluebond-Langer et al., "I Want to Live, Until I don't Want to Live Anymore": Involving Children with Life-Threatening and Life-Shortening Illnesses in Decision Making About Care and Treatment, 45 NURSING CLINICS N. AM. 329, 336–40 (2010) (discussing the issues that must be considered when involving children in medical decision making as well as suggesting an approach for involving children).

101. See Kuther, *supra* note 12, at 351–52 (noting the importance of including minors in discussions about their medical treatment).

102. Comm. on Bioethics, *supra* note 2, at 315–16.

103. Nancy M. P. King & Alan W. Cross, *Children as Decision Makers: Guidelines for Pediatricians*, 115 J. PEDIATRICS 10, 11, 15 (1989) (arguing that children of all ages can participate at some level of the decision-making process).

familial values.<sup>104</sup> As children gain an appreciation for and awareness of the decision-making process, they should be granted greater responsibility and allowed a higher threshold for decision making.<sup>105</sup>

Applying this model to the case study presented at the beginning of this article, Michael, as a fifteen-year-old, is sufficiently mature to understand the issues related to his treatment and to participate in decision making. His experience with his disease and past treatment regimens has also resulted in a level of maturity that exceeds his age. Michael understands the nature of the proposed treatment, including its risks and expected benefits. He has voiced the opinion that he does not wish to proceed with an experimental regimen, an opinion not shared by his mother. Given his level of maturity, failure to respect his wishes, especially regarding an experimental treatment regimen that is unlikely to significantly alter the course of his illness, would be profoundly disrespectful and potentially harmful. Ignoring his wishes may also lead to feelings of isolation and distress.<sup>106</sup>

Situations like Michael's do not lend themselves to easy solutions. By helping to facilitate, clarify, and resolve areas of contention, pediatricians can be extremely helpful.<sup>107</sup> The challenge for pediatricians is to do so in a way that is both sensitive and respectful of the conflicting needs of the child, parents, and providers.<sup>108</sup> In many cases, simply providing a space where Michael and his mother can speak freely about their choices and the reasons for those choices will lead to a solution that is acceptable to both. Michael needs his mother to hear what he is saying, and the physician's role in this case is not simply to override his desires but to facilitate the opportunity for his mother to understand what he needs in this difficult situation.

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104. *See id.* at 12, 13 (stating that when determining a child's capacity to make decisions, physicians and parents should examine several factors, including age, intellect, past decisions, and familial values).

105. *Comm. on Bioethics, supra* note 2, at 316.

106. *Bartholome, supra* note 17, at 358.

107. *See Kuther, supra* note 12, at 343 ("The information provided by physicians about illness and treatment options is vital to patients' decision making and influences their psychological well-being.")

108. *See King & Cross, supra* note 103, at 16 (arguing that it is important for physicians to recognize and balance the conflicting needs of the child-patient and parents).