

# Should Neonatologists Give Opinions Withdrawing Life-sustaining Treatment?

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An infant has a massive intracranial hemorrhage. She is neurologically devastated and ventilator-dependent. The prognosis for pulmonary or neurologic recovery is bleak. The physicians and parents face a choice: withdraw the ventilator and allow her to die or perform a tracheotomy? The parents cling to hope for recovery. The physician must decide how blunt to be in communicating his own opinions and recommendations. Should the physician try to give just the facts? Or should he also make a recommendation based on his own values? In this article, experts in neonatology, decision-making, and bioethics discuss this situation and the choice that the physician faces.

Neonatologists often meet with parents to discuss an infant's diagnosis and prognosis. When the diagnosis includes severe neurocognitive impairment and the prognosis for recovery is bleak, neonatologists may wonder how directive to be in counseling parents about the appropriateness of continuing life-prolonging interventions. Conversely, physicians may feel that they know more and understand the implications of continuing treatment better than most parents do. However, parents are the ones whose values should be the primary consideration and who have to live with the long-term consequences of any decision. In this *Ethics Rounds*, we present a case in which a physician decides to be bluntly honest about his own opinions and recommendations. We then ask a number of physicians and bioethicists to discuss the pros and cons of this approach to shared decision-making (SDM).

## THE CASE

The physician sits down to counsel the parents of a child who had

been born at 23 weeks. The infant has had a difficult hospital course. She had a massive intracranial hemorrhage, seizures, and very bad lung disease. Currently, when the child is 3 months of age, the physician knows that the next step is either to pursue a tracheostomy or to withdraw ventilatory support. However, he has concerns about tracheostomy placement in this patient. He has seen families fall apart under the strain of home care for neurologically devastated children with tracheostomies. When the physician was younger, he tried to be nondirective in his counseling. He no longer follows this approach; he now stresses the bleak prognosis. He tells the parents bluntly that their child will never walk, talk, go to school, or interact with friends. He talks about how difficult it will be for the parents to leave the house, even to run errands such as go to the grocery store or get a haircut, and how it will disrupt the family and other children, potentially leading to divorce or job loss. He often uses stories of other families who have experienced this situation to illustrate

## abstract

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his points. The physician always gives his own opinion and always paints a harsh picture. For example, he will say, "I am a doctor, and I don't think I could take care of a child like this at home. My recommendation is not to do the trach. It is up to you, but my recommendation is not to do this."

Is the physician's approach to counseling ethically acceptable?

**Comments by Drs Blumenthal-Barby, Lemmon, and Ubel and Ms Rao**

Sometimes medical decisions primarily rely on medical facts. In such cases, it is appropriate for physicians to engage in directive counseling. For example, when a patient comes in with a fractured bone seeking help, a physician ought to tell the patient that he needs to get the bone set and casted immediately. This kind of directive counseling does not threaten patient autonomy because the patient's goals are obvious. Physicians are simply telling patients how to meet those goals.

The question, however, is whether directive counseling is appropriate when a medical choice depends on important value judgments. In the present case, there is no obvious medical recommendation. The best approach requires a weighing of both child and parental interests and values. Some ethicists argue that directive counseling is never appropriate in such circumstances because it undermines autonomy. Others have argued that directive counseling can promote autonomy by helping people avoid choices that do not reflect their values or interests.

Such directive counseling can be dangerous. It is only appropriate if physicians consider the answers to 4 important questions. If the answers to these questions are affirmative, then persuasion and directive counseling might be justified. If not, then such counseling may be unjustifiably undermining family autonomy.

*Question 1: How certain is the child's poor prognosis?*

Prognostication is particularly difficult in this population of patients. Even more concerning, clinicians frequently overestimate poor outcomes. This child's prognosis will depend critically on the location of the hemorrhage, the presence of brainstem involvement, and the presence of additional brain abnormalities. Over time, the child's prognosis will become clearer as neurologic findings evolve. However, the need for prognostic accuracy must be balanced with the risk of delayed decision-making. Before physicians engage in directive counseling, they should consider whether their judgments regarding poor prognosis are based on objective and accurate evidence and not on a biased sample (eg, the physician seeing only bad cases that require readmission and not patients who do well) or upon the physician selectively remembering the worst cases and overestimating poor outcomes.

*Question 2: How certain is the negative impact on the child and family's quality of life if the family proceeds with the tracheostomy?*

The intention of the physician in this case is clearly to help the parents make a decision that is in the family's best interest. Similar to the issue of certainty regarding prognosis about clinical outcomes, the prognosis with respect to psychosocial impact and quality of life of a significantly impaired and technology-dependent child should also be evidence-based. Physicians should be aware of their own personal and occupational biases.

Caring for a technology-dependent and/or profoundly neurologically impaired child is a demanding, all-consuming experience. It carries financial, emotional, and physical burdens.<sup>1-3</sup> But that is not the whole story. Raising such children can

also bring families joy in their roles as parents and advocates. Even severely impaired children can have meaningful interactions with loved ones. Furthermore, the death of a child can also have profound and negative effects on parents and siblings.

Despite the possibility of such joy, many families foresee negative rather than positive impacts on the family. The physician has perhaps seen families torn apart by their efforts to care for such children. These experiences may motivate him to emphasize the negative aspects of the tracheostomy. This family could be one of the exceptions, however. They may experience more positive than negative outcomes. The physician should cautiously assess whether there are characteristics of this family that might make that the case. He should use his best judgment, but there is no neutral course; he has to say something. Physicians must always act, decide, and counsel in the face of some uncertainty. It makes sense to err on the side of the most likely outcome, barring evidence to the contrary.

*Question 3: Are the parents adequately informed about their options and still free to choose among those options?*

The central question is whether, after such directive counseling, the parents are adequately informed without certain options being taken off the table. In other words, does directive counseling undermine their freedom of choice? When engaging in directive counseling in a case such as this one, physicians should make sure that the parents have been informed of all the options and the consequences of each. In this case, the physician emphasizes the likely negative consequences of proceeding with a tracheostomy and does not discuss positive consequences. Thus, he is not lying, but he is giving only part of the truth. Such information does not guarantee that autonomy

has been maximized. The physician must make sure that the parents feel as if they still have a voice to decide in favor of the tracheostomy if that is their preference. A concern would arise if the physician's more directive approach makes the parents feel as if they cannot speak up and choose the tracheostomy. This question is ultimately an empirical one that each physician must consider as he or she uses more persuasive counseling techniques. We do know that stories from other families in similar situations (which the physician in this case employs) are particularly powerful.<sup>4</sup> Whether the family still feels able to "go their own way" will depend on the personality characteristics of the family and the power dynamics at play.

The key question is this: is the only way to protect parental autonomy to frame the options as neutrally as possible and then require the family to make an "active choice" between proceeding with the tracheostomy or not? We believe that there is no such thing as a truly neutral frame because the order, tone, and framing must be presented in some way, and each way influences decision-making. Autonomous choices are shaped by such framing, but they still exist.<sup>5</sup> This scenario is especially the case if the decision makers themselves (in this case, the parents) would not resist or repudiate the influences on their decision-making process. They may welcome the physician's guidance as a means of relieving decisional burden and guilt.

*Question 4: Will the physician's directive approach damage the physician-family relationship?*

In deciding when directive counseling is morally justifiable, physicians should consider whether such counseling would be viewed as reasonable in the context of the expectations, roles, and boundaries of the relationship. They should consider whether that counseling

approach will be viewed as too strong of a push, as disrespectful to parental decision-making, or as the physician crossing role-specific boundaries. Some might argue that the physician has "gone outside of his role" in the physician-patient relationship, which is to be a neutral provider of medical facts. We appreciate the need to be sensitive to the differences between medical facts and value judgments.<sup>6</sup> We also believe, however, that there is a difference between informed and uninformed value judgments and that the physician's experience and expertise contribute to his ability to assist the parents in this difficult decision and exercise his beneficence-based obligations toward the family and the child.

The case, as presented, does not provide enough information to make a judgment about Dr X's approach. Instead, we suggest key normative questions that can guide thinking and reflection about what sort of "choice architecture" to create when interacting with families in pediatric critical care.

#### **Comments by Drs Loftis and McCullough**

In cases such as the present one, wherein there is no reasonable possibility of neurologic development for the infant but technology exists to continue life-sustaining therapies indefinitely, the parents must participate in complex decision-making. We are asked to consider if this physician's very directive approach to counseling is ethically justified.

Over the last decades, the pendulum of medical decision-making has swung from paternalism to autonomy and now seems to have returned to somewhere in the middle. SDM is hailed as the way to uphold autonomy yet not deprive the patient of the expertise of the physician. SDM is endorsed by the American College of Critical Care and the American Academy of Pediatrics (AAP).<sup>7-9</sup> In

this model, the physician and the patient (or surrogate) agree up front on how they would like to make decisions together. The power of this model is that it upholds a patient's autonomy in deciding who makes the decisions. This model also allows for some flexibility. A patient may choose to postpone a recommended outpatient procedure but to defer to the physician about choice of medication.<sup>10</sup>

The SDM model does not specifically address how decisions should be made for infants and children who legally have no voice and whose life experiences (often) cannot help inform the decision-making process. The best interest of the child standard (BIS) is currently recommended as the standard by which parents and physicians should make decisions for children. However, the AAP acknowledges that this standard of decision-making does not always prove easy to define, although it is usually held that parental permission articulates what most agree represents the "best interests of the child."<sup>7</sup> Article 3 of the UN Convention on the Rights of the Child<sup>11</sup> states that "in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration." Assessing the best interests of a child generates the professional responsibility to evaluate and balance "all the elements necessary to make a decision in a specific situation for a specific individual child or group of children."

These definitions are so broad that they are generally felt to be unhelpful, and some have called for BIS to be replaced with a "do no harm" principle.<sup>12</sup> In 2009, Malek<sup>13</sup> sought to bring increased clarity to the definition of BIS by comparing various documents that tried to

operationalize the concept. She found that BIS covered 12 domains that were considered universal: life; health and health care; basic needs; protection from neglect and abuse; emotional development; play and pleasure; education and cognitive development; expression and communication; parental relationship; identity; sense of self; and autonomy. This biopsychosocial approach<sup>14</sup> to BIS requires clinicians to take a comprehensive view of a child's well-being, limits overemphasizing physical well-being and survival, and puts appropriate weight on the effects of a condition or treatment(s) on a child's other interests and how they might be positively or adversely affected by short- and long-term functional status and other outcomes. Malek noted that the lack of any one of the interests can severely compromise a child's overall best interest and that there is a diminishing marginal utility in furthering a single component of BIS to the detriment of others. Of particular note is the assertion that interests are not interchangeable; the promotion of one interest is unlikely to compensate for a deficit in another.

The BIS thus understood helps to clarify the ethical obligations of both clinicians and parents. As a consequence, parental autonomy is subject to an ethically justified limit: physicians should not offer and parents are not permitted to authorize clinical management that is not compatible with the BIS. To distinguish decision-making under this constraint from the autonomy of adult patients, the AAP has taken the view that "parental permission" rather than consent is the guiding ethical concept for decision-making with parents.

This biopsychosocial approach to BIS and the concept of parental permission provide ethically justified, clinically applicable guidance for how

Dr X and other pediatric critical care team members should engage the parents in their preferred decision-making process. The child in this scenario is likely to never "walk, talk, go to school, or interact with friends," which would then mean that of the domains listed earlier, more than one-half of them would never be achievable. The physician, through his clinical experience, does not believe that there is the possibility of emotional development, play and pleasure, education and cognitive development, expression and communication, identity, sense of self, or autonomy. The child will always be chronically ill, making a deficit in the domain of health as well that results from both disease-related and iatrogenic burden. Is it reasonable to expect that parents would be able to tease out from among those technologically possible supports the creation of a complex plan that is in the best interests of their child, without significant input from their physician? We think not. If the experienced physician decides it is not in the best interest of his patient to be supported by these life-sustaining technologies, he should not offer them. But that would be at odds with the principles of SDM.

The physician in this scenario clearly feels caught between 2 conceptual frameworks, that of BIS and that of SDM, so that the exercise of parental permission is compatible with BIS. In offering directive counseling, Dr X is being honest, explaining that his opinions are based on his clinical experience about the outcomes of patients such as this child. He is not being coercive because he is not exerting controlling influence accompanied by a threat, but perhaps he is being too blunt. As a consequence, he missed the opportunity to create a supportive approach to deliberative exercise of parental permission. To achieve this goal, the physician should ask parents about their

possible earlier experiences with critically/chronically ill friends or family members or see if they have an understanding of a life filled with technological supports, before he gives his recommendation. At the end of the day, however, the physician needs to assure himself that the parents fully comprehend the ramifications of their decision so that the physician can be confident that he has discharged his duties consistently with BIS and that the parents have done the same, resulting in an ethically justified exercise of parental permission. He should participate in SDM but should share his clinical experiences about outcomes and explain fully his concerns about how using all available technologies may not be in their child's best interest.

#### Comments by Dr Meadow

There are several possible ways to discuss this interesting case. One would be to condemn Dr X for failing to follow the current recommendations promulgating nondirective counseling as the most appropriate approach. That approach would be wrong. Nondirectiveness is appropriate in some situations but not in others. This situation may be one where it is inappropriate.

A second issue that needs to be raised is how accurate Dr X's intuition is regarding this child's likely future outcome. Remarkably, for a field that has developed so much antenatal predictive data, neonatology has a paucity of publications about cases such as this one; that is, an infant with a large brain bleed who is ventilator-dependent. We have far better predictors that rely on antenatal information (gestational age, birth weight, corticosteroid use, sex) than we do from postnatal information; that is a failure of our field's collective insight. It is particularly true for data available while a child still requires mechanical ventilation (as with the infant in this case) when ethical alternatives, such



as extubation and compassionate care, are still available. We should do better at this.

Let us assume for the moment, however, that Dr X's intuitions about this child's likely future function are correct. Now what? Well, he can either remain silent or share his views. We all, I think, agree that he cannot unilaterally extubate the infant without the parents' consent. But how directive should he be when seeking that consent? When does he cross the line between informing them and browbeating them?

If the parents have made their preferences clear during previous conversations (eg, if they have said we will accept and love whatever infant we have), then I think Dr X should probably swallow his advice and support their expressed wishes. His best choice is less clear if the parents themselves are uncertain or conflicted. The argument for nondirective counseling in those cases is an attempt to preclude "cultural imperialism" or to avoid "anti-impairmentism." I'm not persuaded by that argument. Dr X has considerable experience in this area and sharing it with the parents seems reasonable to me. The real ethical argument against Dr X giving directive advice is that in another scenario, a different attending might give these same parents different counseling and the same infant might end up dead in one scenario and alive in the other. Is that fair to the child?

I would say 2 things. First, it is not necessarily fair that the same infant would live under the care of one attending neonatologist and die under the care of a different attending physician. But we know that such practice variation happens all the time. Similar patients get different advice and have different outcomes. As long as his advice is not unreasonable, Dr X has to call it the way that he sees it, and do and

say what he thinks is right and most helpful. In situations such as this one, nondirective counseling is not the best way to care for suffering parents.

### Comments by Dr Cummings

Decision-making in western medicine has evolved significantly over time, swinging from physician paternalism to patient autonomy, settling most recently on SDM. Many other approaches to medical decision-making have been described, including the informative, interpretive, and deliberative or collaborative models.<sup>15</sup> The SDM model now widely favored in pediatrics emphasizes mutual participation by physicians and parents, trust, open communication, and collaboration.<sup>16-19</sup> Such a deliberative approach allows for discussion of medical facts, as well as of values held by the patient or the patient's family, and incorporation of these factors into the decision-making process.<sup>17-20</sup>

This case highlights several important issues relevant to SDM. This physician has returned to the paternalistic model, regardless of whether he realizes it. He appears frustrated and dissatisfied with his own previous counseling attempts. He suggests that if parents were simply told the "truth" they would be convinced to choose the "right decision," the one he clearly prefers, which is to decline tracheostomy for their neurologically devastated child. Based on his own personal values and prior experiences, this physician thus assumes that he knows what is in this patient's best interest. Although this approach may be well intentioned, it is an ethically unacceptable counseling approach.

With what seems to be limited understanding of parental values and limited parental participation, this physician presents only selected information to the parents to

encourage them to assent to what he considers the best decision. By this approach, he is imposing his own values and recommendations based on anecdotal and past experiences, without incorporating relevant data or elucidating values central to the family.<sup>16</sup>

The decision not to pursue a tracheostomy may be best for some families. But it should only be made after discussing and understanding their individual values, preferences, and circumstances. This decision-making process is different for every family. Some families know what they want for their child right from the start, while other families do not always have a clear understanding of preferences at first or they change their minds. This scenario is acceptable, and families should be supported.

So what should Dr X do? As with many ethical dilemmas, the crisis is preceded by many, many decisions that have been made in the past. As presented, it seems that this family is hearing about the 2 options—to pursue tracheostomy or withdraw life-sustaining interventions—for the first time when the child is 3 months of age. These choices should have been anticipated and gradually introduced to this family earlier, to allow sufficient time for ongoing discussion.

Although it is admittedly challenging at times to ensure that parents are as fully informed as possible when faced with such difficult decisions, we have to do our best. Doing our best includes discussing possible negative and positive consequences for all ethically acceptable options.<sup>20</sup> It also includes discussing uncertainty regarding prognosis, when appropriate. Families do not want medical information or prognoses sugarcoated. They want the truth. But they want it explained to them with compassion. It would be a disservice to omit the realities that some families struggle with when caring for neurologically devastated

children with tracheostomies at home. It would also be a disservice to fail to inform parents that some families who do choose to pursue tracheostomy are able to adapt and thrive amid such challenges, showing remarkable resilience. A balanced discussion of both realities should occur, accurately and evenly painted. Families faced with the difficult decision to either have a tracheostomy placed for their child or withdraw life-sustaining interventions should also have the opportunity, if feasible and if they are interested, to connect and talk with families who have chosen these paths.

A return to either total physician paternalism or total patient autonomy would be unfortunate. An exhaustive list of information and options provided to parents by a detached physician, devoid of interpretation or personalization, would be as problematic as Dr X's approach. Families want physicians to give their recommendation. This request should be viewed as an opportunity to delve further into parental values and preferences, and move past the informative or patient autonomy model. Generic recommendations, however, such as in this case, which fail to incorporate intimate knowledge of the parents' unique perspectives and preferences, should be avoided. Instead, thoughtful recommendations carefully tailored to each family's specific medical and social situation may be helpful.

SDM may be limited or even prevented by inherent power imbalances in medicine and unconscious biases.<sup>21,22</sup> Some families with preferences and values differing from the physician or medical team may be reluctant to speak up. Such power imbalances may be amplified in the inpatient or intensive care setting, as in this case, where high acuity and complex technology are combined with intense emotional reactions.

To attempt to overcome such barriers, physicians should inform families about SDM, explaining that parental input is expected and valued. Physicians should emphasize that there are no right or wrong decisions, only the best decision for their child and family.<sup>22</sup> In nonurgent cases such as this one, it is important to allow time for parents to think and discuss, and offer the opportunity for subsequent follow-up conversations.<sup>22</sup>

Both physician and parental input remain critical in the SDM process in pediatrics.

### Comments by Dr Lantos

SDM sounds wonderful in theory. According to one idealized view, shared decisions involve a clear division of labor. Physicians bring the facts, and parents bring their values. Parents are thus informed and empowered to make decisions that best reflect their own values. It is never so easy in practice. Physicians also have values. Parents are not always clear about their own beliefs. The emotional cauldron of the ICU changes people's own understandings of what is most important in life. Physicians and parents have to talk together, each making a series of micro-ethical calculations about what or what not to say, to both respect one another and to maintain self-respect. The present excellent discussions highlight some of the considerations that will enable physicians to do a better job of helping parents make agonizing decisions during these difficult times.

### ABBREVIATIONS

AAP: American Academy of Pediatrics  
BIS: best interest standard  
SDM: shared decision-making

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