

When a Mother Changes Her Mind About a DNR

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Generally, wide latitude is granted to parents when making decisions for their child on the basis of the wide acceptance of the special relationship between parent and child and the important role played by parents in the lives of children. However, when high-risk decisions are made, health care teams serve as an important societal safeguard that questions whether a parent is an appropriate decision-maker for their child. Child advocacy is an essential function of the pediatric health care team. In this ethics rounds, we examine a case of an infant with a complex medical condition requiring prolonged hospitalization that results in a clash of understanding between a mother and medical team when the mother abruptly requests removal of life-sustaining treatment. We present an ethical decision-making framework for such cases and examine the impact of barriers and unconscious bias that can exclude parents from their rightful role in directing care for their child.

Some infants are in the NICU for a long time. Often, they experience many medical ups and downs. These take an emotional toll on parents. Parents respond in different ways. Some get angry. Some get depressed. Marriages break up. Some parents stop visiting the NICU. If the infant eventually recovers, many of the problems go away. If the infant remains chronically ill, the emotional problems can be exacerbated by worries about the future. They can also be made worse if the parents and health professionals don't trust each other. In this ethics rounds, we present a case in which parents and doctors seem unsure of each other's values and motives.

THE CASE

SW was a 7-month-old complex former 23-week preterm infant with numerous medical problems, including necrotizing enterocolitis with subsequent short gut, intraventricular hemorrhage with posthemorrhagic hydrocephalus and a ventricular

reservoir, and chronic lung disease requiring tracheostomy and ventilator dependence. At numerous points, NICU staff members discussed the option of redirecting care toward palliation. SW's mother consistently and adamantly rejected the team's analysis and requested continued aggressive treatment.

SW's mother was seldom present in the NICU. Many doctors and nurses felt that SW's mother was not interested in SW's well-being.

By the time she was 7 months old, SW's medical situation had stabilized. She remained ventilator dependent. She could take adequate nutrition enterally. She demonstrated appropriate social interactions for a 7-month-old such as smiling and visually engaging with caregivers. However, she had significant spasticity in all extremities, and neuroimaging revealed significant white matter changes, cystic lesions, and overall brain volume loss. Therefore, discussions regarding her long-term

abstract

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Drs Higginson, Ransom, Ledoux, Parker, Hester, Lantos, and Ms Lang contributed to the design of this manuscript, the drafting of the manuscript, and the review of the manuscript; and all authors approved the final manuscript as submitted.

DOI: <https://doi.org/10.1542/peds.2017-2946>

Accepted for publication Aug 31, 2017

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: No external funding.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

To cite: Higginson J, Lang KR, Ransom H, et al. When a Mother Changes Her Mind About a DNR. *Pediatrics*. 2018;142(2):e20172946

neurocognitive outcome were overall guarded given the high probability of severe impairment.

Staff began preparing for discharge, including training the mother in home care for this fragile, technology-dependent child.

SW's mother did not participate in training. She stated that she would be unable to care for SW at home and requested placement in medical foster care or a long-term care facility. After diligent searching, no such placement could be found. At that point, SW's mother changed her mind and requested that life support be withdrawn and SW be allowed to die.

The mother's request for discontinuation of life-sustaining treatment (LST) raised concerns. At this point, SW's quality of life seemed reasonable. Many staff felt the mother's behavior throughout the hospital course disqualified her as the appropriate decision-maker and openly questioned her fitness to make this choice for SW.

JASON HIGGINSON, MD, MA, HELLEN RANSOM, DHCE, MATTHEW LEDOUX, MD, AND CLINT PARKER, MD, PHD COMMENT

At its core, this case is an examination of surrogate decision-making. What distinguished this case was the difficulty the medical team faced when a parent troublingly changes course on the basis of factors the medical team was reluctant to accept or not able to readily comprehend. Parental decisions are often followed and respected with little protest. However, the medical team is obligated to analyze parental decisions for any red flags that may invalidate them. In this case, the basic ethical question was whether it is permissible to honor the request to withdraw LST from SW. To make an informed decision, the range of likely outcomes needed to be assessed: what was SW's likely prognosis

(survival, cognitive functioning, development, etc) in a "best case" scenario (maximal resources, time, parental involvement, etc) and in a "likely case" scenario (institutionalized with minimal parental involvement).¹ The possible consequences of withdrawal included death but also possible survival despite removal of the ventilator, continued hospitalization, and likely long-term institutional care. The consequences of continued treatment included likely continued short-term survival requiring invasive interventions with the possibility of dying despite such interventions. If SW survived long enough, she may transfer to a long-term care facility; however, the likelihood of discharge to her mother's care was low. SW's long-term prognosis was poor given the "likely scenario" and would preclude her from living at home; she would likely require permanent institutional care.

SW's mother is the appropriate surrogate decision-maker due to a lack of paternal involvement. The appropriate decision-making standard is the best interest standard.² For ethical evaluation, we can distinguish 2 important questions. First, what are the reasons that support or forbid a decision to withdraw LST from SW? Second, what are the reasons that SW's mother used when making her decision? The answer to the first question is an attempt to decide whether withdrawal of LST is clearly in SW's interest, clearly not in her interest, or simply indeterminate on the basis of the available facts. The answer to the second question is an attempt to decide whether SW's mother's decision was a "good" decision. One might judge a decision to be good on the basis of both the process one went through and the outcome one reaches. Ideally, the decision regarding LST for SW is based on her best interest and made

with relevant and important factors after careful deliberation.

Reasons supporting withdrawal of LST would be the balance of burdens and benefits. Burdens of continued LST would include diminished cognitive capacity, diminished life opportunities due to severe disability, continued physical suffering, minimal interaction with family, and an increased likelihood of death despite continued intervention. Benefits of continued LST would include continued biological existence in the short-term and the possibility of improvement and long-term survival. On the basis of these considerations, some may conclude that it is clearly in SW's best interest to withdraw LST, and some may conclude the exact opposite. We suspect, however, that many would conclude that either of these decisions would be "reasonable" in the sense that good reasons could be garnered for either one of the decisions. Both decisions are epistemically "justified" in the sense of being reasonable.³ Let's assume that the PICU team believes that it would be reasonable to withdraw LST from SW, and, in addition, suppose they also believe that it would be a better choice than continuing LST given the balance of benefits and burdens. Perhaps if challenged by a parent that did not want to withdraw LST they would also concede that this option is also reasonable, despite their own belief regarding the balance of benefits and burdens, and would defer to the parent's wishes. Why would they defer to the parents? This deferential treatment is grounded in the special relationship between parent and child as well as the important social role played by parents and responsibilities expected of parents.²

What made this case so troubling for staff was not the actual decision SW's mother made but that it was not a good decision. It appears she based her decision on factors that may not be deemed relevant and

important by the PICU staff. The worry is that SW's mother chose to withdraw LST solely because it was best for her and the rest of her family and not necessarily what was best for SW. She cannot take care of SW at home, and SW's continued life in such a diminished state within a hospital or even a long-term facility would create psychological, if not financial, burdens on her and her family. We imagine the reasons and motives in these types of cases are irremediably mixed. The PICU staff likely believe that the process by which the mother makes her decision should be free of self-interested and other concerns that are not directly related to SW's well-being. However, we don't think such a standard is realistic or required.⁴ As a moral agent, SW's mother must consider multiple moral considerations, some of which may not be directly related to SW's well-being. The PICU staff has a more limited moral concern: solely the well-being of SW. This difference may lead to suspicion by the PICU team. Sometimes, this type of suspicion is a good thing. If there is clear consensus that a surrogate's decision-making is overly influenced by self-interested or other considerations and is clearly not in the patient's best interest, then it is the medical team's duty to intervene and disallow the surrogate's choice. However, in this case, the actual decision made by the mother was one that the team concedes is reasonable and had previously advocated for. The medical team's unease does not appear to be about the objective moral permissibility of the decision but centers on the perception of the mother's reasons for the decision. Some moral unease is justified if the mother was overly influenced by self-interested or other concerns; however, some unease may not be justified. As mentioned above, the moral decision-making calculus of the mother may need to legitimately consider moral concerns that the medical team doesn't believe are

appropriate for them as medical professionals.⁵

A further potential source of moral unease may be a perception that SW's fate is simply a matter of bad luck. If SW's parents had been happily married with a large reservoir of financial resources, time, and psychic energy, SW may have gone home and possibly maximized her limited potential for a good life. However, SW's parents are not happily married and have limited financial resources, time, and psychic energy. As a result, SW's already limited life will likely come short of her maximal potential, and withdrawal of LST becomes a more reasonable moral option. And this is no fault of SW. It seems unfair. It is certainly unfortunate. And yet this unease, although real and pointing toward deep philosophical questions regarding the nature of a just society, are not exactly directed at the decision to withdraw LST. This decision must be made within the confines of the actual and not the counterfactual.

In conclusion, the decision to withdraw LST from SW appears to be morally reasonable. Whether it is actually in SW's best interest seems to be a difficult if not impossible question to answer. Given that it is a morally reasonable option and it is the option preferred by the surrogate, we believe it is a morally permissible course of action. The moral unease of the team appears to be based on the perception of how the mother made her decision and the rapid about-face by the mother that seems self-motivated. This represents a conflict of moral decision-making perspectives, each of which, although different, is legitimate. That is, although objectively both the mother and the medical team reached an outcome that is morally justified, there may be unease at the fact that different processes were used to come to this outcome. Some of this unease may

have arisen from the fact that the medical team used a narrow moral paradigm (solely the best interest of SW) and the mother used a broader moral paradigm (other-directed moral concerns). Some of this unease, however, may have also arisen from a perception that SW's fate was a matter of bad luck. However, this unease, although troubling, would not change the fact that withdrawal of LST, given SW's circumstances, is morally reasonable and permissible.

KELLIE R. LANG, JD, RN AND D. MICAH HESTER, PHD COMMENT

The concept of "child advocacy" is deeply woven in the fabric of pediatric health care providers and is manifest in their moral comportment through the principle of protection.⁶ At times, then, they serve as an important societal safeguard when questioning whether a parent is an appropriate decision-maker for their child. However, parents are the traditional, even "natural," advocates for their own children; their role is unique, socially sanctioned, and rightly privilege vis-à-vis their own children. Thus, when health care providers' and parents' perspectives are not allied with regards to decision-making, there is a basic obligation to explore the parental values and interests at play to act appropriately as "societal safeguards." In SW's case, as presented, so little is known about the mother's situation, values, and interests that the primary task at hand should be to explore the situation further before determining what should be done for SW.

As given, the case provides us some, but only little, insight. We know that SW was born prematurely, has spent 7 months in the NICU, and continues to survive despite multiple health challenges. At this time, we are told that the health care team believes that SW's quality of life was reasonable, but we do not know from

whose perspective or what factors were considered.

Meanwhile, SW's mother has been SW's decision-maker. We know of no other family (father, grandparents, loved ones, etc). Early on in her stay, the health care team recommended palliative treatment because of her serious and multiple anomalies. However, SW's mother chose to continue life-prolonging treatment. During SW's time in the NICU, mother was "seldom present," and the health care team interpreted this (and maybe other actions like not participating in training for home care) to mean that she was not interested in SW's well-being.

As the health care team prepared SW for discharge, her mother admitted that she would not be able to care for her fragile, technology-dependent child at her home. Instead, SW's mother requested her daughter be placed in medical foster care or a long-term care facility. Medical foster or long-term care placement could not be secured, at which point SW's mom requested withdrawal of life support for her daughter.

Of course, this leaves many things unsaid in the case. When a parent is not often present with their hospitalized child, it can be the result of a variety of issues and concerns. Sometimes parents openly explain to us why they are not regularly in the hospital, but more often they do not. Associating a parent's presence or absence with their emotional level of care and concern for their child is not uncommon. However, before doing so, providers must assess for potential barriers to parents' presence or engagement with their child's health care team. There are 4 questions that we suggest asking (and answering) to gain insight into what we do not know: Where does the mother live? Does she have convenient transportation available to her? Who are SW's additional family members? Does SW's mother feel that she has support in her community? These are

hardly exhaustive of what we need to learn about SW's family situation, but the questions themselves (and certainly the answers) begin to point toward issues that must be clarified about the context of the mother's situation. These questions highlight several potential barriers to consider, including transportation availability and other competing needs/responsibilities, such as parental emotional well-being. In addition, we recommend exploring whether the "culture" of the hospital nurtures and supports parents who are managing their lives with limited resources with additional vulnerability of having a child with complex medical needs and limited or no resources to care for them.

Lack of efficient transportation can be a huge barrier for parents to visiting their hospitalized child. A parent may simply not be able to get to the hospital. Their reasons may be related to finances, time, safety, or other constraints. These other constraints may include employment, child care, or exhaustion. Questions about transportation easily roll into questions about other competing needs and/or responsibilities: is SW's mother's environment conducive to promoting healthy coping and resiliency? This would include getting adequate rest, nutrition, and having a support person or system. Exploring further, given evidence that prematurity is a risk factor for postpartum depression⁷ and that (at least) nearly one-third of mothers of premature infants experience posttraumatic stress disorder a month after birth,⁸ we wonder whether SW's mother is experiencing depression or posttraumatic stress disorder. Because mothers who are depressed are less responsive and less interactive with their infants⁷ and a parental coping style of avoidance is associated with greater prevalence of anxiety, depression, and other mental health problems,⁸ this assessment

(and treatment if needed) is critical to our ethical analysis.

Finally, hospital culture may be a significant yet less-recognized barrier to parental presence in the hospital. Despite our best efforts, parents may not feel that their contributions and perspectives are heard and respected. Although pediatric providers have expectations of parents (certainly around how often they should visit), these are not communicated up front. In addition, hospital culture may inadvertently promote biases and underlying assumptions as facts. As human beings, we all categorize groups, consciously and unconsciously.⁹ When we have an unconscious bias, we hold an inflexible, implicit belief about a particular category of people.⁹ Our biases, particularly unconscious ones, may damage a therapeutic relationship with parents. Parental behavior, attire, and language or speech patterns may all influence how they are perceived and treated by hospital employees and the health care team. Parents pick up on what we think of them and may experience stereotype threat. Stereotype threat is the stressful psychological state that occurs when a person fears being judged by others on the basis of a negative stereotype.¹⁰ Stereotype threat triggers physiologic and psychological processes, including anxiety, negative emotions, and negative cognitions that result in adverse behavioral effects. In health care, stereotype threat has the potential to not only impair patient (or parent) adherence but also to impair patient communication skills (including fluency and ability to respond to questions), discount feedback from providers, and avoid and disengage from the health care system.¹⁰ These behaviors reinforce stereotypes held by providers.¹⁰

Before coming to any conclusion about SW's mother's decision-making, we should want to know

much more about her life, her reasons, and her values. Asking the right questions allows us to sift and sort through various hypotheses about what is motivating parents. When we see parents differently and recognize their inherent vulnerability in having a hospitalized child, we are more likely to feel compassion and empathy. This can help in restoring our therapeutic relationship with the parent and, in a case like this one, may allow the parent and the health care professionals to create a path forward and decision as to what is best for SW.

All of the cases in Ethics Rounds are based on real events. Some incorporate elements of a number of different cases in order to better highlight a specific ethical dilemma.

ABBREVIATION

LST: life-sustaining treatment

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Pediatrics 2018;142;

DOI: 10.1542/peds.2017-2946 originally published online June 21, 2018;

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