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In Whose Best Interests? Critiquing the “Family-as-Unit” Myth in Pediatric Ethics

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Additional information is available at the end of the chapter

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Abstract

In pediatrics, parents are the presumed surrogate decision-makers for their children. Parents are generally obligated to make decisions in the child's *best interest*. When assessing what is in the child's best interests, parents should consider the child's experience of illness, potential for suffering (physical or psychological), and ability to understand and tolerate treatment. Yet, parents may consider a variety of factors other than best interest when making treatment decisions for their children. Moreover, parents may equate the child's best interest with their own (or their family's) and make decisions that, in some situations, will place children at significant risk of serious harm. Clinicians may be reluctant to challenge parents due to a perception that their obligations require treating the family “as a unit.” After detailing a case from the author's own practice in clinical ethics, this essay will challenge the view that “family-centered” (as opposed to “patient-centered”) care is an appropriate ethical model for pediatric decision-making. Specifically, the physician-patient relationship—or, in this context, the *pediatrician-child relationship*—ought not to be reconceptualized into the *pediatrician-parent-child relationship*, since the latter perspective potentially misidentifies who the patient is and may inadvertently suggest there is warrant for “treating” the family's suffering at the expense of the child's welfare.

Keywords: pediatric bioethics, family-centered care, best interest standard, surrogate decision-making, pediatrician-child relationship

1. Introduction

In the absence of clear direction from the patient at a prior time of capacity, and when the patient's treatment preferences cannot be inferred from knowledge of his or her values,

surrogate decision-making will be based on the *best interest standard*. The pediatric setting¹ is no different, where parents are the presumed decision-makers for their children.² According to this standard, parents are obligated to make decisions based on factors such as the child's apparent experience of illness, potential for suffering (physical or psychological), and ability to understand and tolerate treatment [1]. Yet, in the clinical setting, parents may be influenced by a variety of factors other than best interest when making treatment decisions for their children [2]. From my own experience, parents may equate the child's best interest with their own (or their family's) and make decisions that, in some situations, will place children at significant risk of serious harm. Clinicians, for their part, may be reluctant to challenge parents due to a perception that their medical obligations in this setting require treating the family "as a unit."

After detailing a case from my own practice in clinical ethics, this essay will challenge the view, held by some bioethicists and clinicians, that "family-centered" (as opposed to "patient-centered") care is an appropriate ethical model for pediatric decision-making. I will argue that the moral basis of pediatric ethics is not qualitatively different than the ethics of medicine in the adult setting. Specifically, the physician-patient relationship—or, in this context, the *pediatrician-child relationship*—ought not to be re-conceptualized into the *pediatrician-parent-child relationship*, since the latter perspective potentially misidentifies who the patient is and may inadvertently suggest there is warrant for "treating" the family's suffering at the expense of the child's welfare. This thesis will be sustained from a reflection on the moral responsibility incumbent on surrogate decision-makers. Concluding remarks will offer practical suggestions for improving decision-making at the bedside.

2. Case³

Mrs. Rusin was 30 weeks pregnant with her second child. During a routine obstetric visit, she was found to have placental insufficiency, causing an abnormal fetal heart rate; Mrs. Rusin was rushed to the hospital for emergency delivery. The infant was named Konstantin, after Mrs. Rusin's own father who was still living overseas. Immediately after birth, Konstantin was transferred to the hospital's neonatal intensive care unit (NICU) for prematurity, sepsis,⁴ and further heart monitoring. Mrs. Rusin was moved from Labor and Delivery to a regular hospital bed for recovery, where she remained for 2 days. During this time, medical decisions for Konstantin were being authorized by his father in the NICU.

¹ Pediatrics is the branch of medicine that focuses on infants, children, and adolescents. Neonatology is a subspecialty of pediatrics that focuses on the medical care of newborn infants.

² This presumption could be rebutted if, for example, the parents themselves were incapable of medical decision-making or had conflict of interests.

³ This is a composite case; the names and details contained within have been de-identified.

⁴ Neonatal sepsis refers to "invasive infection, usually bacterial, occurring during the neonatal period." Indications of sepsis include "diminished spontaneous activity, less vigorous sucking, apnea, bradycardia, temperature instability, respiratory distress, vomiting, diarrhea, abdominal distension, jitteriness, seizures, and jaundice" [3].

"Everything possible should be done," Mr. Rusin instructed the clinicians. Consequently, when Konstantin's medical condition deteriorated further, cardiopulmonary resuscitation and multiple life-sustaining supports (mechanical ventilation, vasopressors, and artificial nutrition and hydration) were initiated. On day three, Mrs. Rusin was discharged from the hospital; she joined her husband at bedside and agreed that all treatments should be provided. At this early stage in his hospitalization, the cause of Konstantin's ailments and chances for recovery were uncertain; for this reason, the medical team did not think Mr. and Mrs. Rusin's requests were unreasonable.

Several days later, despite maximal ventilatory support, Konstantin did not show any signs of improvement. He could not be weaned from the ventilator and he remained dependent on artificial tube feeds. By day seven, he developed uncontrollable seizures, believed to be due to intracranial hemorrhage. There was concern for significant neurological impairment. Despite efforts to control his seizures, the episodes continued, sometimes multiple times each day.

During one of these acute deteriorations, the bedside nurse could perceive that Konstantin was in significant distress. She related her concern to the parents, but they dismissed it outright: "We only need more time before Konstantin will finally be well enough to come home and meet his brother." The nurse gently responded: "In my experience, infants like Konstantin may be too sick to leave the hospital. He has already suffered some cognitive impairment. If his seizures don't resolve soon, he is at risk for global neurological damage. If that happens, I believe we should not pursue aggressive measures to sustain his life. He will only continue to suffer." Mrs. Rusin and her husband were indignant, indicating that they would never consent to such treatment limitations, especially those that would result in Konstantin's death. In Mrs. Rusin's words, "We are the decision-makers; we have the right to decide what we do and don't want!"

Another week passed with no clinical improvement. The NICU team recommended to the parents to agree to a "do-not-resuscitate" (DNR) order and not escalate treatment further; Mr. and Mrs. Rusin remained unwilling. At this point, the medical team requested an Ethics Consult. A multidisciplinary team and family meeting were held the next day. In attendance were the attending physician, medical resident, bedside nurse, palliative care team, social worker, chaplain, ethicist, and Mr. and Mrs. Rusin. The purpose of the meeting was to discuss Konstantin's poor prognosis, likelihood for recovery, and to better understand the parents' perspectives regarding goals of care. The attending physician related that, despite numerous efforts, the team remained unable to control Konstantin's seizures; in his opinion, Konstantin had suffered and would continue to be at risk for suffering, significant, irreversible neurological damage. His anticipated prognosis was believed to be 1 year, although a more realistic estimate was 6 months. The ethics consultant explained how, in such cases, the parents are required generally to make decisions in Konstantin's best interests. Mr. and Mrs. Rusin took a moment to digest this new information; they then asked whether it would be possible to take Konstantin home, even if it were anticipated that he would eventually die in that setting. The attending related that Konstantin is permanently ventilator dependent and feeding tube dependent and that it is very unlikely that he would be able to go home. "In such unfortunate circumstances, I would

recommend that we simply make Konstantin comfortable. We can remove aggressive life supports and allow him to die with optimal palliative care. This is called *comfort care*."

There was a long, drawn-out pause. Mr. Rusin took a deep breath. He then spoke.

"My wife and I, we ... we simply *need* more time. This is all happening too quickly. Konstantin might turn around. How could we live with ourselves if we give up before giving him a chance? Unless you tell us there is no opportunity for improvement, we want to continue therapy for the next couple of weeks." Although they thought it unlikely that Konstantin would improve to be discharged home, the team reluctantly agreed to continue aggressive efforts for a 2-week trial period. The team did manage to persuade Mr. and Mrs. Rusin to agree to a DNR order.

Konstantin did not improve during the interim—his seizures only intensified further. The nursing staff became increasingly distressed. The attending physician confirmed—after receiving a senior second medical opinion and seeking the guidance from expert consultants—that Konstantin's condition was too fragile for him to be discharged home, even on home hospice. With this updated information, Mr. and Mrs. Rusin better appreciated the magnitude of the situation. Since the option of returning home was definitively closed, the parents were again asked if they would consent to transition Konstantin to full comfort care and allow him to die.

Mrs. Rusin sat down and started crying. In between sobs she related: "My father ... he has always been present during my most difficult decisions, and—and—he's not here." There was a brief pause. "Konstantin's life support can't be turned off without Daddy by my side. I ... I wouldn't be able to cope." Mr. Rusin put his arms around his wife and addressed the team: "This has been a whirlwind for us. In a couple of days, our first son celebrates his fourth birthday. As parents, we also need to protect him, too. I can't allow him to be scarred for years because his birthday coincided with his younger brother's death." To this, the attending responded: "I clearly recognize your profound need for support during this difficult time. How about we wait several days until after your son's birthday? That should give enough time for Mrs. Rusin's father to arrive."

What the attending did not realize, however, is that Mrs. Rusin's father lived abroad and did not have a visa for entry to the United States. Obtaining an "emergency" visa could take upwards of 2 weeks. Mrs. Rusin clarified this. She stated, "As soon as he's here with us, I will allow the supports to be turned off. Until then, I cannot do it."

All involved and agreed that the best course of action would be to transition Konstantin to comfort care as soon as possible. However, the Rusin family was also in a time of great emotional need. As one team member put it, "We always strive to provide family-centered care. This means we treat the whole family. Their needs must be considered, too." Although the NICU team was deeply disturbed with the prospect of waiting 2 weeks before transitioning Konstantin to comfort care, the attending physician eventually acceded to the parents' request.

Konstantin continued to seize. Two weeks later, once Mrs. Rusin's father arrived, life supports were discontinued. Konstantin died soon thereafter.

3. Case reflections

Deciding for others in any medical context is complex. The pediatric setting is no different. Below, we discuss a number of complexities that emerged during this case.

Clinicians are entrusted with significant responsibility for their patients' well-being. Yet, clinical judgment is inherently probabilistic and practiced amidst uncertainty. Prognostication, therefore, presents unique challenges to the treating team. Clarifying those treatment modalities that may offer some realistic potential for benefitting Konstantin will be directly related to his anticipated prognosis. However, because his survival and anticipated quality of survival are initially difficult to characterize, ascertaining what would be in his best interests is not immediately clear. Should he remain in the NICU for another 2 weeks, in order to gain more certainty about his clinical trajectory? Or, would it be better to withdraw aggressive treatment, since his condition has not improved and his clinicians do not suppose this is likely to change? When communicating such options to Konstantin's parents—a process which presents its own obstacles—Mr. and Mrs. Rusin may be skeptical: "How can we be sure that he will *not* improve? Is it not the case that physicians are sometimes mistaken?" Assessments of probability and risk are value-laden evaluations; it should not surprise us when parents and clinicians disagree regarding how to weigh each variable. Are parents to blame when, in the absence of clinical certainty, they insist that "everything possible" be done to try to save their child?

Families experience significant stress, fear, and uncertainty during their child's stay in the NICU. It is a foreign setting [4]. There are new sounds—beeping monitors, infants in distress, and the constant (albeit brief) encounters with the large clinical team (attending physician, medical fellow and resident, nurses, consulting specialists, palliative care experts, social workers, chaplains, and ethicist). Parents are often unprepared, overwhelmed, shocked, and may experience hopelessness and despair [5]. In one study, some of the highest reported stressors identified by parents included "feeling helpless about how to help my baby during this time"; "seeing my baby stop breathing"; and noticing that "my baby seems to be in pain" [5]. The subjective experience of parents may be likened to an "emotional roller-coaster" [6]. It is common for parents to find the experience stressful and disruptive [7] to their everyday routine, and the routines of their children at home. This may be the first time that parents are asked to make "life-or-death" decisions under significant pressure. Deciding between a "certain" death of a child—by placing limitations on the aggressiveness of interventions—versus continuing treatment in the hope that it "may eventually work"—is terrifying for families. Strong emotions come into play, including "the belief that the death of a child violates the natural life cycle, parental guilt, crushed familial expectations, and the sudden nature of the illness or injury" [2]. Parents (and their families) will live with the consequences of their decision for months, even years. For example, Jones and colleagues note that "Bereaved parents are at risk for anxiety, depression, suicidal ideation, prolonged grief, decreased quality of life, relationship struggles, and social decline" [8]. In addition to the vulnerability inherent in being a patient, the vulnerability of parents, too, is significant and should be addressed.

Their vulnerability in this case manifested itself on multiple levels. Initially, Mrs. Rusin was a patient, undergoing emergency surgery; she later became separated from her child at

a crucial moment.⁵ Mr. and Mrs. Rusin also were separated during their first 2 days following the delivery of Konstantin; Mr. Rusin may have felt significant stress by making critical decisions in his wife's absence, and Mrs. Rusin probably felt to some extent abandoned and sequestered from her family. Several days later, Mr. and Mrs. Rusin were told that their child was not improving clinically. Yet, this fact may not have been readily apparent to them. Clinical information between the team and family is asymmetrical. Nonclinicians may see matters differently: Konstantin remains in the NICU, he had been tolerating his tube feeds (regardless of whether or not they are "artificial"), and the ventilator was allowing him to breathe; without these supports, Mr. and Mrs. Rusin's child would certainly die. Is there any alternative in these circumstances? Furthermore, although Konstantin was reported to be seizing, the seizures may have been subclinical and reported only by the bedside nurses. Mr. and Mrs. Rusin may not have registered Konstantin's pain and discomfort and assumed that the doctors were simply "going along" with the nurses. Thus, a disconnect may occur between teams and parents regarding whether or not the infant is in pain [10].

As we have stated, adjusting to the NICU takes time for parents. Yet, during this process, the parents are told by the team about a request for an Ethics Consultation. One of the first questions Mr. and Mrs. Rusin probably had asked themselves is, "Are we (or someone else) acting unethically?" Many clinicians have never heard of "Ethics" as a consulting service; it should not surprise us if families have not either. The family is then requested to participate in yet another interdisciplinary team meeting—only this time, Ethics will be present. "The 'Ethics Police' is coming to set the record straight," I can imagine the parents saying to themselves. Upon arriving at the meeting, a simple fact becomes obvious: Mr. and Mrs. Rusin are outnumbered. Given the multiple members of the primary team (the attending physician, resident, and bedside nurse), consultants (palliative physician), and others (social worker, chaplain, and ethicist), a not entirely unreasonable interpretation would be: "They are all ganging up on us."

During the meeting, Ethics explains that decisions must be made in the infant's "best interest." This would appear to be relatively straightforward, until one wishes to attempt to define what it means to choose in the infant's best interest. Is it better to live with the assistance of life-sustaining treatment or die? This question is challenging enough in the adult setting when the patient in question had expressed some treatment preferences in the past or at least had written them down in an enduring advance directive. Consider, by contrast, the situation in which an adult patient had never expressed his wishes regarding medical treatment, but we know reasonably well what he was like, based on reports from the family regarding his values; in this situation, we can try to "reconstruct" what his wishes are likely to be in the current situation. Of course, there are important epistemological questions that could arise about how we truly know what we think the patient would want now. In contrast to all of this, we have the current situation, in which Mr. and Mrs. Rusin must decide in Konstantin's best interest. And, here, we must acknowledge significant disagreement among members of the team, as well as the family. Let us now move to consider the best interest standard.

⁵ For the importance of maternal bonding, see [9].

4. Departing from the best interest standard

The *best interest standard* applies when a patient had never expressed capable preferences with regard to medical treatment and his or her preferences cannot be inferred from the surrogate's knowledge of the patient. For neonates such as Konstantin, this is the default decision-making standard.⁶ In assessing what will be in their child's best interests, Mr. and Mrs. Rusin will need to choose in a way that will "promote maximally the good (i.e., well-being)" [11] of Konstantin. More specifically, this standard directs Mr. and Mrs. Rusin "to determine the net benefit for the patient of each option, assigning different weights to the options to reflect the relative importance of the various interests they further or thwart, then subtracting costs of 'disbenefits' from the benefits of each option" [11]. Important considerations when deciding in this context include "the relief of suffering, the preservation or restoration of functioning, and the quality as well as the extent of life sustained" [12].

The best interest standard has both defenders [13, 14] as well as critics [15–18]. The standard has been criticized for being vague, subjective, and incoherent, and some commentators have proposed alternative criteria for decision-making—for example, the "harm principle" [16], the "not unreasonable" standard [18], and the "basic interests" standard [19]. Rather than entering into this specific debate, I wish here to reflect more closely on Konstantin's case, and ask why, although his best interests were initially appealed to, decisions were ultimately made that were not congruent with those interests. Mrs. Rusin's emotional distress and her older son's anticipated distress were considered (either implicitly or explicitly) by the team to be morally relevant factors in the decision. Such "family interests" would appear to have been validated by the team (however reluctantly) to the detriment of Konstantin's own well-being. Konstantin, who continued to seize, had a protracted and intensified dying process. Why was this allowed to occur?

The reasons, I would submit, are subtle. Mr. and Mrs. Rusin were directed to base their decisions on Konstantin's best interest; neither they, nor the team, were in vocal opposition with that standard. Moreover, neither the team nor the family went so far as to argue that the family's interests, *independent* of Konstantin's, were ethically relevant (a view sometimes advanced in the bioethics literature). Instead, the family based their decision on Konstantin's best interest; only later did they request that the clinicians delay the implementation of that plan of care. Thus, once the decision had been made, its practical implementation had to be agreed upon by all parties. And it is here that the team was in a tough position: either accept the parents' request or risk that the parents will demand that full aggressive treatments continue indefinitely. From an ethical perspective, however, the overall plan of care and the therapeutic means to achieve that plan are not the only relevant aspects; the practical implementation of that plan must also pass ethical muster. It is not uncommon for families to ask for brief extensions of life-sustaining treatment so that a geographically distant loved-one may be able to say final good-byes. Rarer still would be those requests by a family to continue aggressive life-sustaining treatments for a week for the same reasons. Why, then, were

⁶ This standard will also be the default decision-making standard in emergency settings for all patients.

Konstantin's treatments permitted to continue for 2 weeks? What made the parents' request appear reasonable?

My suspicion is threefold. First, the team wanted to support the parents during this devastating time, while also ensuring that an appropriate plan of care would eventually take place. Decision-making is a process, and these decisions take time for families to feel comfortable in arriving at a mutually agreed upon plan of care. Second, it is quite natural (and human) to wish to avoid conflict. Disagreement, itself, is time-consuming, stressful, and unpleasant. When an alliance between family and team is most needed, putting pressure on the family would create significant tension. Seeking to avoid conflict in the clinical setting is common. One study found that physicians may acquiesce with families "in order to eliminate a disagreement" [20]. Walking the fine line with Mr. and Mrs. Rusin left the team in a compromise position. Third, and most significantly from my perspective, the parents' request went unchallenged due to a prevalent, albeit misguided, interpretation of what it means to provide *family-centered care*. We will focus on this aspect in the remainder of this article. I will argue that an invalid inference was made in assuming that the provision of family-centered care entails giving ethical deference to the family's interests (as somehow independent of the infant's best interests). This does not follow. As I detail below, an *approach* to providing care is not a *standard of decision-making*. This is not to say, however, that teasing these apart in an actual case is never without its challenges.

5. From *family-centered care* to the *family's interest in care*

In the past, hospitalized children were cared for almost exclusively by health care professionals; parental visitation was significantly (if not completely) restricted [21]. The standard of decision-making was clearly paternalistic: doctors decided what was in the child's best interest. This began to change once research began to document the serious consequences that occur to the child—emotional, psychological, and developmental—if separated from the mother for a significant period of time [21]. The rise of family-centered care, I would suggest, should be understood against this backdrop. It is not insignificant that the early stages in the development of family-centered care generally took place amidst other major rights movements (e.g., civil rights, patients' rights, women's rights)—movements that in many ways challenged the traditional paradigm in which medicine had hitherto been practiced. Instead of a standard that gave deference to the physician's perspective, family-centered care placed primacy on the parents' determination of what is in the child's best interest. Who was in authority to decide in these cases changed, whereas the decision-making standard remained the same. Families, notably parents, became the default surrogate decision-makers for their children.

As simple as this shift was, it would appear to have changed yet again. Whereas family-centered care originally meant that the family's interpretation of what would be in the child's best interests was decisive, advocates of a family-centered approach would appear to be arguing for something different: the family-centered approach means that the family's interests should be factored in treatment decisions. The family's interests, some might hold, necessarily include the child's interests. What does a commitment to family-centered care really mean?

Family-centered care is the dominant approach in pediatrics today.⁷ Family-centered care starts from the premise that families have many important roles—for example, safeguarding the well-being of its members—and translates that idea to the medical setting. Partnerships and collaboration among families, patients, and healthcare providers are sought, and various kinds of support (emotional, social, and developmental) are considered “integral components of health care” [24]. Such a partnership, according to the Institute for Patient- and Family-Centered Care, “redefines the relationships in health care” [24]. One might be tempted to speak here of the “patient-parent-pediatrician relationship,” to borrow a term from Lantos [25], as though the parents, too, were patients.

Family-centered care, as articulated by a multidisciplinary task force and summarized by Harrison [21], recognizes the following. Whereas medical teams change continually, the child’s family remains. Families’ diversity (e.g., cultural, ethnic, racial, spiritual, social, economic, and educational) should be recognized and honored. Families have different ways of coping, which means various targeted supports (e.g., developmental, educational, emotional, and financial) should be provided to assist them. And, finally, families and their children “possess a wide range of strengths, concerns, emotions, and aspirations beyond their need for specialized health and developmental services in support” [21].

In my clinical experience, a commitment to family-centered care means in practice that families are given more opportunities to participate actively in their child’s care while admitted to hospital. For example, parents may be allowed to sleep in the same room with their child overnight; they participate on daily multidisciplinary rounds; and clinicians seek their input at the bedside. If a child is to be discharged home, teams may teach families how to deliver care in that setting. Families, too, may have medical needs. If a child were to die, bereavement support is available to families.

Family-team partnership makes a lot of sense. Seriously ill children may be admitted frequently to the hospital, and parents and families are the “continuity” caregivers for their child. Young children are literally voiceless; their families must be their advocates, safeguarding the child’s interests. Instilling firm partnerships with clinicians makes it more likely that the child will be provided excellent care within and beyond the hospital. As related by the American Academy of Pediatrics, this approach has been shown to “improve the patient’s and family’s experience, increase patient and family satisfaction, build on child and family strengths, increase professional satisfaction, decrease health care costs, and lead to more effective use of health care resources” [23].

Finally, we must bear in mind that families have a number of important functions, such as preserving the child’s life, forging a child’s identity, socializing children, nurturing children, and nursing children when they are ill [26]. Furthermore, families also have inherent value; they are “places of love”; “where lives are shared”; where “family members encumber their children with ‘thick’ conceptions of the good” [26]. In light of the functions and inherent value of families, one might argue that the family’s interests (medical or nonmedical) should be taken into account when making treatment decisions for their kin. That is,

⁷ It has been endorsed by the American Academy of Pediatrics [22, 23], for example.

one might argue that family-centered care requires that clinicians take into consideration the legitimate interests of families in addition to the medical interests of patients (who happen to be family members). We will consider, and ultimately reject, this suggestion in the next section.

6. The “family-as-unit” myth in pediatrics

In the bioethics literature, many authors—see, for example, [26–29]—contend that the family’s interests ought to be given serious consideration when treatment decisions are being made for their sick children. This is for a variety of reasons. First, a family is a “unit.” Individual members of that unit will be affected by whatever decisions (medical or otherwise) are made. As Lindemann Nelson has written, “The care of an acutely ill child requires the family to channel many of its resources toward a single member: an arrangement that can usually be sustained for a while but that cannot continue indefinitely while the other members do without. Illness disrupts ordinary familial functions and, if it is serious enough, threatens to break the family altogether” [26]. Second, the lives of family members are intertwined with one another. What happens to one person matters to the others. “There is no way to detach the lives of patients from the lives of those who are close to them,” writes Hardwig. “Indeed, the intertwining of lives is part of the very meaning of closeness” [27]. Put differently, family members are “stuck with each other” [30]. Third, families encompass an assortment of interests, both individual and collective. Each family member has unique projects, desires and hopes; families also promote shared aims. At times, the interests of some members will be more relevant to decision-making than others: “the interests of some members sometimes give way to the interests of others, or to the interests of the family as a whole” [28]. Fourth, to be a member of a family means that you are not entirely free to choose as you please [27]; being a member of a family creates responsibilities and obligations. The family may limit the autonomy of its members. Finally, many health care professionals—ethicists included—sometimes act as though the *medical interests* of patients were the only aspect that mattered for the purposes of decision-making. But for families, this is not always true. As Hardwig has argued, “Even life or death is not always the most important consideration. [...] We must beware of the power of the medical context to subordinate all other interests to medical interests. Sometimes non-medical interests of nonpatients morally ought to take precedence over medical interests of patients” [31].

In light of these points, one of two alternative conclusions is plausible: either (a) the family’s interests ought to be given consideration when parents make decisions for their child; or, alternatively, (b) parents should choose the option that will promote the family’s overall interest, since the child’s best interest is intimately connected with the family’s interest. I will argue that although consideration should be given to the family’s interests, pediatricians are morally obligated to factor only the child’s best interests in decision-making. Family interests, I will argue, are generally *secondary* to the medical interests of the patient. I therefore reject (b).

A myth is “a widely held but false belief or idea” (OED). All myths contain elements of truth. Neonates like Konstantin are part of a family; the Rusin family is a group of individuals that

forms a unit; and the life of each of its members matters to the group. Moreover, Mr. and Mrs. Rusin likely have shared communal goals and a vision of the good of family life. One would expect Konstantin and his brother to be inculcated in this ethos. But why should the family's interests matter? What is it about the family's interests that are morally relevant? Is it the fact that long hospitalizations will drain the family's emotional and financial reserves, such that Mr. and Mrs. Rusin would not be able to provide adequately for Konstantin's brother and for each other? These concerns are not insignificant, and clinicians should explore with the family these sources of stress. Nevertheless, what is it about the family's interests that are morally relevant for the pediatrician? Perhaps the family's interests are important when considering general ethics; how might these interests apply to medical ethics? We must remember, although family-centered care is the dominant approach in pediatrics, family-centered care is not a standard of decision-making. It is a myth to think otherwise.

Although being a part of a family generally creates responsibility, the extent of this responsibility will depend on one's *role* within the family. Mr. and Mrs. Rusin have primary responsibilities toward each other, and to their children; very young children do not (at least not initially). Children gradually will acquire such obligations commensurate with their level of maturity. Being a family member at times will require sacrifices of one's interests to the good of the family. Yet, whereas Mr. and Mrs. Rusin may decide to sacrifice their individual interests to the greater good of their family, this expectation cannot be made of Konstantin and his brother (although, presumably, it could in the future). And since Konstantin is currently incompetent, Mr. and Mrs. Rusin may not decide to sacrifice his interests for the greater good of the family: parents may not use their progeny to further their own (or their family's) ends.

Family members have responsibilities to one another. Yet even this is a matter of degree. For example, before making a major career change or relocating his family across country, Mr. Rusin should consult with his family—primarily, his wife.⁸ He would be a bad parent as well as a bad husband if he did otherwise. After speaking with his wife, Mr. Rusin may decide that the additional salary he could make at a new job across country would not be the right decision for his family at this time, taking everyone's interest into account. In deciding not to uproot and relocate his family, Mr. Rusin would be sacrificing some of his personal interests—namely, his career-furthering interests—to the greater family good. We expect families to do this since they generally aim to further the collective interests of their members; the life they create is a life shared together. But this does not apply to Konstantin and his brother; they do not have duties analogous to their parents at this time—although they will one day. And yet, whereas very young children cannot be made martyrs for their parents' causes, adult patients may choose to sacrifice themselves in this way for their families as a final gesture of love.⁹

⁸ This example is modified from Hardwig [27].

⁹ A not infrequent example concerns the adult patient who retains decision-making capacity. He may experience significant symptom burden and yet refuse standard of care medical management—for example, pain medications—in order to remain awake and lucid during family visits. Such an arrangement would be ethically acceptable because the patient capably authorized it. By contrast, it would be wrong to force similarly situated incapable patients to suffer, simply because the family requests it.

Although family interests should be taken seriously by clinicians, such interests are generally *secondary* to the medical interests of the patient, which ought to remain primary. This is for several reasons. First, everyone has interests—families, patients, and clinicians—but not all interests are ethically relevant. Patients have an interest in returning to a state of health, and clinicians have an ethical obligation to focus on the health-related interests of the patient. Thus, in the medical setting, it is the medical interests that matter. This is not to deny or diminish the relevant interests of families. However, the primary obligation of the physician is to this patient, in these circumstances, at this moment in time. It does not really matter that the patient happens to be a child. A patient is still a patient. Physicians have primary obligations to their patients based on their role as healers, and only secondary obligations to patients' families.¹⁰ Second, although the lives of family members are interconnected, we must bear in mind that this state of affairs in the Rusin family is unidirectional—from parent to child, not the other way around. It is not a *relationship* until the child can be an active participant in family life. Until that time, Konstantin remains wholly dependent on his family. The parents are in relation to the child, but the child is not actually in relation to his parents in any meaningful sense. Finally, children may not be sacrificed for their family's causes. We routinely override parents when their idiosyncratic beliefs place the child at significant risk of imminent, irreversible harm. Because very young children are incompetent, they cannot consent to sacrifice themselves. This could shift, of course, as the child matures. A 10-year-old child might be able to make some small sacrifices for his family's overall good. But the physician and family should ask for his permission. We cannot expect this of neonates like Konstantin or small children like his brother.

The obvious objection is that, in at least some cases, families will be greatly affected by the treatment decisions they are required to make according to the best interest of their children. The family's communal interests will be at stake. To this, my response is that, in clinical ethics, there may be exceptions to the general rule. All relevant stakeholders will have to consider the exact point of conflict. Imagine that there were two available treatments for Konstantin's seizures. Option A is invasive, causes discomfort, but otherwise is safe, effective, and covered by his parents' insurance. Option B, by contrast, is not invasive, causes no discomfort, and is otherwise safe and effective, but *not* covered by his parents' insurance. All things being equal, Konstantin's best interest is better served by Option B; however, it is not covered by his parents' insurance. If the cost is high, the treatment may not be in his family's overall interest, relative to other ends it could achieve (e.g., education for Konstantin's brother) with the same money. But notice that this is only a nominal difference between Option A and Option B. Both are safe and effective, so it is really a question of how much discomfort the family would be willing for Konstantin to endure and how much money the treatment will take away from the other valid interests of the Rusin family. By contrast, if Option A were known to be ineffective and Option B effective, the Rusin family might need to make further sacrifices. And if Option B were almost prohibitively expensive, but the only treatment known to reverse Konstantin's seizures and prevent significant neurological

¹⁰ However, compare with Jones et al. [8]: "because the family is the greatest influence in the life of the child, and the well-being of the child and family are intrinsically linked, care for the child must include care for the family. Physicians are ethically bound to care for the family along with the child." The basis for this assertion is unclear, as well as its limits.

devastation, the Rusins might have to sacrifice their collective interests in order to obtain it. Thus, families should have some freedom to balance and weigh the competing interests of its family members in coming to a decision. This does not mean, however, that families should be allowed to make decisions that maximize their interests to the detriment of the medical interests of the child. Families should be overruled in such cases.

7. Concluding thoughts and practical considerations

Although often claimed to be a "right" or "entitlement," decision-making for others is primarily a responsibility to be discharged according to widely recognized legal and ethical standards that have been elaborated over the past several decades. When surrogates do not have clear direction from the patient at a prior moment of capacity, and when the patient's treatment preferences cannot be inferred from knowledge of his or her values, surrogate decision-making will be based on the best interest standard. For adults who have been permanently incompetent, this will be the default standard. For very young children who are currently incompetent, this will be the default standard. It is not clear why that standard should change in pediatrics. "Mini adults" are still human beings; patients with different disease types are still patients; and medicine for children and medicine for elderly adults remain, in essence, the same. The moral basis of pediatric medicine is not qualitatively different than the ethics of medicine in the adult setting. For this reason, I would suggest that the *physician-child relationship* in pediatrics should not be re-conceptualized into the *physician-parent-child relationship*. The latter perspective misidentifies who the patient is and may inadvertently suggest there is warrant for treating the family's suffering at the expense of the child's welfare, as happened in the case of Konstantin.

In light of this analysis, I offer the following three general rules for helping clinical teams to decide how to approach the question of family-centered care in medicine in general.

1. If the patient retains capacity, when making decisions she should be encouraged to take into consideration how this treatment will affect her family. Responsibilities are inherent in family life. She may be convinced that the less-than-optimal treatment should be pursued, so as to maximize the family's interests. Indeed, the capable patient may decide to sacrifice herself to the collective good of the family. This is her right to decide.
2. If the patient is currently incapable of medical decision-making, but there was strong evidence that she would want her family's interests to be primary and her own secondary, clinical teams would have an obligation to follow that previously expressed capable wish. I am thinking here of the patient who might write into an advance directive: "If my continued treatment is so financially expensive, emotionally burdensome, or would require such sacrifices on the part of my family so as to eclipse any real benefit to them or to me, I direct my physicians to refrain from starting life-sustaining treatments and, if such treatment has already been initiated, I direct that it be promptly withdrawn."
3. If a patient had never been capable, one may not infer that she would consent to being sacrificed to the collective good of the family. Incapable patients are not responsible to

their families in the same way that families are to them. Physicians should remind surrogates that decisions in this third category require determining what are in the current best interests of the patient. Surrogates who demand or refuse treatments based on the overall interests of the family (not the patient's best interest) should be overridden.

Based on these general rules, the more compassionate solution in cases such as Konstantin's would be to retain a family-centered paradigm with a patient-focused standard of decision-making.

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