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Quality of Life and Elective C-Sections: Defining Limits to Maternal and Family Interests

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ABSTRACT

The author analyzes the lessons for ethics consultants presented by McCrary and colleagues in their case, "Elective Delivery Before 39 Weeks' Gestation: Reconciling Maternal, Fetal, and Family Interests in Challenging Circumstances."[1] Clinical ethics cases that involve different specialists representing the best interests of different parties in a case, such as this case involving neonatologists and perinatologists, are complex and time-consuming. The author concludes that ethics must insure the interests of the fetus and future person are not subsumed to the interests of those with a voice, without deliberate reflection and strong ethical justification.

McCrary, Shah, Combs, and Quirk have been remarkably thorough and fair in their case report. It is truly an exemplary case. This commentary will focus on some of the lessons ethics consultants need to learn from the case, more than on the actual facts of the case.

First, an anecdote for clinical ethics consultants who do not have an MD:

This is reported to have occurred many years ago at a very prestigious hospital in the Northeast that was home to some of the leading neurologists in the nation. New neurology residents on July first were greeted by the chair of the department, author of the leading text in the field at the time, with these words: "Your primary job over the next four years is to protect the central nervous system of your patients from the neurosurgeons."

Of course, this was partially tongue-in-cheek. But there is always some truth that makes a joke funny. The chair really did like to say that, and he was making a point. While one hopes that the harms done by neurosurgery have decreased considerably thanks to surgical advances over the past two or three decades, that is not the point. He was letting his charges know that they had patients to protect, and an area of expertise where they should not be deferential to surgeons with their own (different) area of expertise.

The lesson, from the perspective of a clinical ethicist, is that one cannot analyze a case from only the perspective of the physician calling the consult. One must at the very least consider the opinions of other physicians involved in the case, and perhaps even some physicians not involved in the case. It will be quite com-

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mon to have two clinical disciplines who would see a case differently, whether it is neurology and neurosurgery, or surgery and anesthesiology, or, as in this case, neonatology (a subspecialty of pediatrics) and perinatology (a subspecialty of obstetrics). Ethicists ought to be familiar enough with all of the disciplines of medicine and surgery to be able to anticipate differences, or at least realize the importance of seeking input from clinicians from all the relevant disciplines. Whether it is on the job training, or a fellowship program, this should be one of the competencies for clinical ethics. (This is not to claim that all individuals in one profession will agree, but their training does make a difference in what values and whose interests they represent.)

To many readers this is no doubt obvious. But to many ethicists, survival as an outsider in the medical world can seem treacherous, and one's expertise seems incapable of questioning a physician's expertise, so it can become second nature to think that one must take the word of the consulting physician for granted. If one doubted it, or disagreed with him or her, one might never again be asked for a consult by that physician.

While there might be such expectations of loyalty on the part of the physician calling a consult, it might not be—an increasing number of physicians now are familiar and comfortable enough with ethics consults that they could express an opinion while remaining open to other considerations outweighing their opinion. Merely by requesting an ethics consultation, one hopes they are acknowledging that the decision involves disputed values, and not just facts. An ethicist might conclude that if he or she always agrees with the consulting physician, something is probably askew, and that, in that instance, one is adding little to the discussion.

Ethicists can encourage a more sophisticated understanding of ethics by stating in advance that most consults involve the comparison of two or more good (ethically justifiable) choices, trying to decide which one might be the best of the available options—in contrast to judging that any one of the options (or the proponent of any of the options) is unethical. But, unlike the implication of terms like "mediation" or "facilitation," there isn't always a middle position that "splits the differences." Sometimes, as in this case, there are two defensible but mutually exclusive views.

This case then is a true dilemma of choosing between the best interest of the woman who wishes to be a mother and the person whom she hopes will be her child. Using the common terminology in clinical ethics, it is a case of maternal-fetal conflict. But while that term is mostly used for women earlier in the pregnancy who have behaviors that are likely to be unhealthy for their potential future child (for example, drinking and smoking, or abusing drugs) in this case the woman cannot be accused of being irresponsible. So it is easy for perinatology to be sympathetic, and consider acceding to her wishes. The perinatologist is, and should be, her doctor first and foremost.

On the other hand, the strong opinions voiced by neonatology are well justified. The evidence for longer gestation is strong, and gets stronger with every study. Even since this case occurred there has been more evidence that 39 weeks is better than 37 or 38 weeks.[2] The American College of Obstetrics and Gynecology (ACOG) is right to say that no elective c-sections should be performed before 39 weeks, and if anything, that might be justifiably revised to 40 weeks. While the authors correctly cite the research that people who live with disabilities are often happy with their lives, this should not be taken to mean that we should allow potential parents to make choices that increase the chances of a person having to live with lifelong disabilities, if they can be avoided. It is wonderful that these potential parents say they will love their child even if he or she has to live with lifelong disabilities; however that willingness does not give them the right to impose this risk on their potential child. It is still best to try to prevent those disabilities, especially since they will be lifelong—likely continuing even after the parents are no longer alive and so no longer able to care for their child. (This observation may have interesting ramifications for the enormous recent interest in happiness in popular psychology. Happiness may be greatly exaggerated in

importance. To use a classic quote from Mill's *Utilitarianism,* although it may sound harsh: "Better to be Socrates dissatisfied than a fool satisfied.")

The authors raise profound questions concerning families as units, and whether clinical ethics has separated out the individual interests of family members in an unnatural way. This is worth serious consideration. However, many of these issues about family units were raised in the context of geriatrics ethics, where there is evidence that elders would wish to allow their adult children some latitude in making decisions about their end-of-life care, and not make their own preferences into an absolute value. (Some people phrase this critique as a protest that "autonomy" is taken to be the most important of the four principles. However proponents of the four principles never made that claim, nor supported any effort to axiomatize the principles.)

To extend these concerns to pediatrics, though, would require much greater support. Parental choices that might lead to permanent damage to a child are different, and there is no way for those children to voice their willingness to have their own best interests subsumed to those of their parents. Furthermore, the critique of "autonomy" most likely would push us to the opposite conclusion: holding that ethics tends to make "autonomy" dominant, and seeing that as a mistake, would more likely lead to the conclusion that we ought not to let the "autonomy" of a pregnant woman trump the best interests of her future child.

At the very least, everyone in the neonatal intensive care unit (NICU) is familiar with "the estimator"[3] that summarizes outcomes data for preterm babies. While the outcome for this baby was fortunately very good, some big risks were taken. Let me share another anecdote:

NICUs are unique units in many ways. One has kind nurses, often with powerful maternal instincts at work. One has kind doctors, also often with powerful maternal instincts at work. (And paternal instincts are just as powerful in nurses and doctors.) Outsiders may find it comforting to state that there are "miracles" happening every day. But the NICU in many hospitals is also where there are more deaths than any other unit. And, often, in private, neonatologists have to face the fear that the deaths in the unit are not the worst thing about their job. When they see some of their severely handicapped survivors, they can be led to doubt if they are doing the right thing.

I recall one neonatologist telling me about seeing a former patient years later in the grocery store with her mother, the child now in a wheelchair, spastic and contracted in all four limbs, blind and breathing with a tracheostomy. This is the outcome, not death, that I would want to weigh against the mother's powerful wish to have a c-section and be relieved of her fears of another placental abruption. Loss of pregnancy is a tragic outcome, especially this late term and for a couple who see their options dimming, so this would not be an easy choice. Given that Mrs. S has lost three pregnancies, I can understand the support she was given by the ethicists and perinatologists.[4]

Nevertheless, one must also imagine how the parents might feel if their child had a bad outcome after an elective c-section. The burden of responsibility for that outcome might also be devastating. Hence I would have added my support to the neonatologist's offer to keep the patient in the hospital and closely monitored for another three to four weeks, and tried to persuade the parents that this was a risk worth taking for the welfare of their child. Every extra day *in utero* should be appreciated as a valuable milestone. What is impossible to predict, unless one was there, is whether I would have, in the end, suggested that the team refuse to comply with the parents' request.

Perhaps the most important observation in this case study is that "the practice of medicine is not a science." The same is true, of course, for the practice of clinical ethics. No ethics consultant can be up to date in every medical specialty, not even physician ethicists. One will often hear an internist on the ethics service express hesitation at being involved in a consult in pediatrics, or vice versa. Every consultant must begin a consult with the presumption that the physicians involved in the case know more of the relevant clinical facts than the ethics con-

sultant. But the sophisticated consultant also realizes that two physicians will often be of two opinions on the best ethical approach to the patient. And often the consultant must talk to both physicians one-on-one to get the entire story. Only then would one be at all prepared to start to make an evaluation of the available options.

One also often has to do some independent research to get further data. One can ask the attending questions, but one cannot expect the attending to do your research for you. So for example, in the case at hand, one ought to find out the recommendations of both ACOG and the March of Dimes concerning elective c-sections. Putting equal focus on the best interest of the future child, who cannot speak for him- or herself, but whose welfare is most at stake, is very important. This tension with the pregnant woman is what is being reflected in the differences between the neonatologist (representing the interests of the future child) and the perinatologist (representing the interests of the pregnant woman).

Many readers may be thinking to themselves that they do not always do all of this, perhaps because they don't have time. That leads to a very important observation about clinical ethics consultation: doing ethics consults properly can take quite a bit of time. I have doubts about whether any consult can be adequately handled in an hour or two, although many are. If one is completed that quickly, it is at least a warning sign that corners may have been cut, trusting opinions without fact-checking research and hence without asking important follow-up questions, or merely listening to only the opinions of one attending rather than all involved physicians. Furthermore, non-physician members of the team may have critical information to share. Ignoring nursing and social work, for example, can lead to ethical errors in judgment. The time used for consults, however, can be hard to measure, especially in surveys that don't distinguish (to take one example) between informal consults (for example, "information requests" in the hallway or over the phone) from formal consults with written notes in the chart. The latter should not be done without thorough research and investigation.

Having watched or been involved in hundreds of consults at a half-dozen hospitals, here is my unscientific data: a "normal" formal consult takes about five hours of work for an individual consultant. It usually takes at least one hour poring over the chart before talking to the patient, family, and members of the healthcare team. Those discussions and meetings take at least two more hours. The research and writing of the note takes at least another hour, even if it is a familiar topic, and two (or more) if it raises issues that are new to you. If a team is involved, then it will obviously involve yet more person-hours.

A complex case can easily take 10 or more hours. If the principals expect a quick process, or the medical circumstances demand it, then one must to be able to commit five to 10 hours to a consult in the 72 hours (three work days) after the request comes in. That is why there must be protected time in the contract of the person who is designated as the primary clinical ethics consultant and/or the director of the ethics consult service of any hospital with a significant number of ICU beds. I would expand that claim to require a full-time person (or two half-time positions) if it is a teaching hospital, in order to cover regular teaching rounds for residents.

NOTES

1. S.V. McCrary et al., "Elective Delivery Before 39 Weeks' Gestation: Reconciling Maternal, Fetal, and Family Interests in Challenging Circumstances," in this issue of *JCE.*

2. E.M. Boyle et al., "Research Effects of gestational age at birth on health outcomes at 3 and 5 years of age: population based cohort study," *British Medical Journal* 344 (1 March 2012): e896.

3. This widely used "calculator" is the result of a large and influential study for the National Institute of Child Health and Human Development Neonatal Research Network. J.E. Tyson et al., "Intensive Care for Extreme Prematurity—Moving beyond Gestational Age," *New England Journal of Medicine* 358 (17 April 2008): 1672-81; *http://www.nichd.nih.gov/about/org/cdbpm/pp/prog_epbo/epbo_case.cfm.*

4. J.P. Spike, "Ethical Issues in Pregnancy Loss," in *Loss in Pregnancy and the Neonatal Period,* ed. J.R. Woods and J.E. Woods (Pittman, N.J.: Jannetti, 1997), 331-46.