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At the Bedside

An Ethical Priority Greater than Life Itself

Edmund G. Howe

There was even a beauty in it, if only because Harold was doing something he believed in for once, and against all the odds.

—Rachel Joyce, *The Unlikely Pilgrimage of Harold Fry*

ABSTRACT

This article discusses a case in this issue of *The Journal of Clinical Ethics* by McCrary and colleagues, "Elective Delivery Before 39 Weeks' Gestation Reconciling Maternal, Fetal, and Family Circumstances," in which parents asked the medical team to deliver their fetus "early."¹ The author discusses (1) the importance that parents have to a child when they are able to love the child, and how important it is for decision makers to consider this; (2) exceptional approaches that may enable parents to "change their minds"; and (3) substantive and procedural innovations that may help to prevent clinicians' views from playing too big a role and/or being arbitrary. The author concludes by describing how he felt when reading the case and uses this to illustrate how clinicians may benefit by assessing their feelings.

In this issue of *The Journal of Clinical Ethics*, S. Van McCrary, Shetal I. Shah, Adriann Combs, and J. Gerald Quirk report on a case that was as emotionally gripping for me as any that

has appeared in *JCE*. In the case, Mr. and Mrs. S asked that their 34-week-old fetus be delivered early, to give the fetus the best chance of being born alive. Mr. and Mrs. S say they cannot bear the fear that their baby will not be born alive: "we can live with a damaged baby, but cannot live with the uncertainty of not having a baby." They have lost three fetuses, and, during her last pregnancy, Mrs. S had a complication called placental abruption and nearly died with the fetus. Her symptoms suggest this complication may be recurring. As the case report notes, "Mrs. S now finds herself in the early twilight of her reproductive lifetime. . . . That twilight now becomes acutely darker with the news that a friend has delivered stillborn baby twins as a result of a placental abruption at 34 weeks of gestation." The authors relate what decision was made in this difficult case, and why.

The case raises far-reaching ethical questions that range from what the clinicians should have done to what weight (if any) parents' views and/or feelings should have whenever they go against the best interests of their fetus. These questions may extend to the best interests of children, and even to the best interests of other loved ones. Still deeper are questions on how

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the person who is making the decisions should weigh an increased risk that a fetus may be born with special needs due to an earlier birth—and who should make these decisions. I will address these questions below. I will also consider how our own feelings may be important in our clinical work, and so I will note now that you may want to read the case by McCrary and colleagues first to see how you respond emotionally to it, and then return to my article and my comments on the case.

CHILDREN WITH SPECIAL NEEDS AND THE IMPORTANCE OF PARENTS TO THEM

One of the most critical value conflicts in this case is the fetus's best interests against the parents' best interests—a traditional moral framework involving values and principles. A second moral framework that could also be used is what I shall call the care perspective, which could result in an altogether different outcome.² In all ethical deliberations, regardless of the framework, those who make the decisions should have all of the most morally relevant considerations on their "table." Given this, I will first present a consideration that those making decisions may want to consider: the unique benefits that wholly committed parents may be able to offer their child, especially when their child has special needs. For this group of children, these relationships may be more important than anything else. I will consider the needs of these children, and then consider the needs of their parents.

Children with Special Needs

Some hold that, ethically, the interests of children may warrant absolute (or at least nearly absolute) priority in most (or all) contexts, because children are exceptionally dependent and thus vulnerable, and so need such protection. The interests of fetuses—children-to-be—may warrant, in some contexts, comparable protection for the same reasons. For example, in the case of Mr. and Mrs. S by McCrary and colleagues, the neonatologist on the team reports that there are no conflicting interests, because no child, given an option, would choose to be

born "with 35 percent less brain size and risk the long-term neurologic sequelae of this elective late-preterm birth." These children may have special needs of all kinds and degrees. I will consider their physical and cognitive needs separately, for the greatest clarity.

Children with special physical needs. People's special needs may differ most profoundly. Still, most may be strongly affected by their relationships with others (as is also the case for those without special needs). Karen Metzler is a woman who had spina bifida, who died last spring at about age 60. She said, "Though there are commonalities among persons who are handicapped, there are differences, because we are all individuals."³ Notwithstanding these differences, she placed great importance on relationships with others for herself and for people with needs like hers. She believed that what she had learned about interacting with others might be worth her passing on, and she thus shared what she tried to do when someone rejected her because she was—using her word—"handicapped." "I strive," she wrote, "to accept even those who reject me. For I have realized that in essence I reject others when I do not accept their rejection of me."⁴ She gives her reason: "He is a member of a society in which handicappedness is not a universal, but a uniqueness—a stigmatized one."⁵ Metzler found, as this passage may connote, that her relationships with others were a key factor in her experiencing great quality of life, so much so that she was a passionate advocate for the interests and equal treatment of all those who have special needs.

The most important of her relationships was the one she had with her parents. She spoke often about them, saying again and again how lucky she'd been that they'd been who they were. That there is a good possibility Mr. and Mrs. S would be like Metzler's parents is the core consideration that should be on a decision maker's table. Mr. and Mrs. S may, like Metzler's parents, be as dedicated to their child as they could possibly be. The case report indicates that Mr. and Mrs. S feel an exceptional degree of commitment—whether their judgment is extremely enlightened or not. This degree of

commitment (so important to all children), if not there from the beginning (for whatever reason), may be something that others can't "create"; some child psychotherapists say that, even with therapy, they can't create *energy* within children who lack it.⁶ Likewise, the degree of commitment that Mr. and Mrs. S display may be a quality that adult therapists can't create within people who choose to be parents. However this quality might be inferred, those making decisions should particularly consider it. In this instance of Mr. and Mrs. S, their commitment may be implicit because of what they are doing and what they are saying. They *want* this child, they say, whether or not he or she will have special needs. With Mr. and Mrs. S, this quality may be less in doubt.

Children with special cognitive needs. It is possible that no special need in a child is so severe that it could not be overcome by a dedicated parent. A paradigmatic example may be pain so unbearable that it could prevent a child from being able to reap the kind of quality of life that Karen Meltzer achieved with the help of her parents. Pain can be emotional as well as physical, and the emotional pain caused by special cognitive needs is the second core issue that I will consider. This pain is felt by children who aren't able to understand *why* they are undergoing painful and/or frightening procedures and feel additional panic. Like unbearable physical pain, it can blot out a child's capacity to enjoy, even with a parent's help, a rich and/or meaningful quality of life, howsoever it is defined.

How children's special cognitive needs affect them may be critical. It may be that not understanding certain things, such as that they are dying, could spare them pain. The concern I will focus on, however, is the increased emotional pain brought on by not understanding. In some cases, even parents as committed as Mr. and Mrs. S may not be able to offset it.

In this regard, I think of my experience as an ethics consultant with the family of a child who had Werdnig Hoffman disease, a genetically acquired illness that, in one variety, brings about progressive, ascending muscular paralysis, usually beginning in infancy and bringing about death by age two. The young girl's pa-

ralysis had gone from her toes to her chest, weakening her respiratory muscles so that she acquired pneumonia. On this particular admission to the hospital, her pneumonia had been successfully treated with antibiotics, but her medical team feared that, as her paralysis worsened, she would soon get pneumonia again, and on this next admission, it would be necessary to start artificial ventilation if she was to survive. Thus the medical team called for an ethics committee consultation, asking whether an artificial ventilator should or should not be started on her next admission. Pediatric respiratory experts were consulted, and all thought that artificial respiration should *not* be begun, because they thought that if the machine was begun, the child would not be able to understand why. Also, they said (although this was not part of their primary reasoning), if on a machine, she would no longer be able to benefit from her parents' hugs, which would "add insult to injury." But they agreed if there was some other pediatrician who could be found who would treat her with artificial respiration under these conditions, with the necessary medical expertise, they, ethically, wouldn't object.

After the ethics committee decided this and departed, I went to the child's hospital bed. As I stopped outside her door, I heard sounds coming from her room that I could not have imagined. The members of the ethics committee had imagined that the family was significantly stressed. After all, this little girl was dying, and soon would be dead. But at that moment, she and her parents were obviously *euphoric*—as if they felt they had nothing to feel sad about. It was as if they were having a nonstop party! Her parents laughed; she shrieked with laughter. In all that was joyful, she was the leader.

I considered, on this basis, trying to reconvene the ethics committee. Perhaps I should have, but I didn't. Might this little girl, with *these* parents and with *her* spirit, have emotionally withstood artificial respiration well enough that she would have continued to have a life worth living—one that, if she could speak, she would have said that she wanted? It is now impossible to know. Based on the recommendation of the specialists, the girl's pediatrician had

“called around” to find someone to take over her care, but found no “takers.” The parents had wanted the medical team to do all that could be done, and, despairing, they took their daughter home and never returned. I don’t know what happened later. The attempts to find another pediatrician who was willing to treat the child might have been of critical importance, and I shall discuss the decision in some detail, below. Still, this example illustrates that parents’ commitment to their child may have a beneficial effect and may warrant decision makers’ consideration in these cases.

Mrs. and Mr. S, and Similar Parents

If Mrs. and Mr. S’s interests are considered to be separate and mutually exclusive from the fetus’s, there would be competing interests. If it is assumed that the child would do better if delivered later, the best outcome would be for Mr. and Mrs. S to change their minds. Then the best interests of the parents and their fetus would be the same, and the fetus would not be delivered early. The medical team in this case tried to bring this about. They tried to get the parents to agree to psychotherapy, for example, but didn’t succeed. Their effort raises questions for the future: How, in general, might clinicians best try to bring about the best outcome? I will discuss this and suggest a way that clinicians may go farther than they usually do.

Persuading by not persuading. It may be that members of the medical team cannot convince Mrs. and Mr. S by providing accurate information. If the team can find a way to enable the parents to feel sufficiently safe, however, the team may have the best chance to enable the parents to change their minds. If the team can do this, it may allow the parents’ brains to open up new brain circuits. These newly opened circuits may allow the parents to consider another option, such as waiting longer. There may be optimal ways to do this. A team member could say to the parents in private, “You should know, first, that *I, personally*, in regard to your request, see both pros and cons either way, and so if I were you, I don’t know what I would want.”

Why do this? If the team member says that he or she morally disagrees with the parents,

this, in and of itself, may emotionally threaten the parents to the extent that the opposite view becomes more deeply entrenched. One problem is that if a team member does say this, he or she should actually have this belief. What could team members who do not have this as a genuine view possibly do? They could try to find a way to establish a feeling of safety for the parents, which might take even more effort. They could, for example, try to find another clinician who *does* genuinely have this view who works inside their hospital—or even outside it. It might be possible to do this, and, if they do, it may be the quickest and surest route to helping the parents feel safe.

For example, such a “neutral” clinician could, genuinely, say something like this: “Your desire for an earlier delivery may be the best one. Looking at this together may suggest this is the case—or it may not. You have been, to me, unimaginably traumatized by what you have experienced. You have lost three children during previous pregnancies and lost your last child, dreadfully, under the same circumstances you are experiencing now. Maybe you know about what psychologists call ‘one-time learning,’ which means that after even just one terrible thing happens, like losing a child, parents are profoundly afraid it will happen again.

“You have lost three children and I can’t imagine these terrible losses are not affecting you. But *how* they are affecting you is a different question. I hope you would be willing for us to discuss what you want to do now.

“Is what you experienced before affecting what you want now? Maybe. Maybe not. If we discuss this, we might see. We have nothing to lose. We all want what is best for your child. This is why you want your child delivered now. It could be that discussing this together will end up greatly benefiting your baby. Again, what have we got to lose? I know what you most want is what is best for your child.”

Before saying these things, this neutral clinician should explain that the medical team sought and found him or her for this reason: “They found me at another hospital,” he or she might say; “they wanted me to come here and talk with you, because they hoped that since I

see the logic in your request, you might be more willing to discuss this with me.” Informing the parents about this exceptional effort may indicate to them, more effectively than anything the medical team could say directly, how important it is to them to do what is best for the fetus, and also to do what the parents want, if this is at all possible. Often individuals will strongly reject others’ statements that threaten them, but will remain open to indirect suggestion.

This degree of effort is exceptional and may even be without precedent. Should we ever go this far? It might depend on whether parents like Mrs. and Mr. S need this kind of effort to feel safe enough to be able to change their minds. Susan Johnson, a leading eminent therapist, explains this best:⁷ strong emotions, she says, tend to restrict our “range of attention.” A “negative emotion,” like the fear experienced by Mr. and Mrs. S can result in their having “irrational beliefs.”⁸ Negative emotions such as fear can, Johnson says, “fool us,” even to the extent that we can no longer “think straight.”⁹ She says that areas of the brain that specialize in cognitive tasks, like the prefrontal cortex, “get starved.”¹⁰ How could this be reversed? Johnson says, “Nearly all therapy models now agree on the necessity of creating safety . . . if for no other reason than to facilitate our clients’ open exploration of their problems.”¹¹ This is the same kind of “safety” that I urged above, which may be necessary to “free” parents to be able to consider their other option—waiting longer. Johnson goes on to say, however, most importantly, “Often this means that therapists need to resist the pressure to fix problems instantly and find the inherent logic in how their client is feeling and acting.”¹² Elaborating on this, Johnson says that, in general, therapists must go slowly; in her words go “slowly, softly and simply—to create a fourth S—emotional safety.”

Yet, as McCrary and colleagues point out, both the fetus and the parents have limited time—not sufficient time to go slowly and hope for a change. But change can still occur, especially with this approach, all at once. Johnson states, “In one stroke, a tuned-in reflection can calm clients and build safety . . . so that grasping a [previously missed] key elements is pos-

sible.”¹³ She states after only one meeting that parents could evoke an immediate change in each other, through this same kind of safe, emotional “mechanism,” because “holding the hand of a loved and dependable partner is a safety cue that changes how the brain perceives and encodes threats.”

Members of the medical team may try this, although they may be less likely to succeed. If a member of the medical team tries this, she or he should point out to the parents that regardless of what decision is implemented, they should, to the degree possible, not feel regret at a later time. The team member should add that this is critically important, regardless of the decision made. This is so important because parents are so exceptionally vulnerable.

Harms to which parents are particularly vulnerable. It is not widely recognized how strongly parents may be affected by the death of a fetus. The sense of loss may be as great as after a child dies. Society’s lack of support for parents can result in “disenfranchised grief,” a kind of grief I discussed in other contexts in the last issue of *JCE*.¹⁴ This grief occurs after a loved one dies and it can’t be “openly acknowledged, publicly mourned, or socially supported.” The lack of support may be due to cultural practice, which may not be rational or humane.

Parents often experience disenfranchised grief after a fetus dies, but their grief may be so generally unappreciated that clinicians may miss it. In one study, clinicians were often perceived by couples as minimizing their loss because the clinicians treated it as a medical event, not as the loss of a baby-to-be.¹⁵ An example is when a staff member referred to a would-be mother’s delivery of a dead fetus as an “abortion,” when the would-be mother did not perceive it this way at all.¹⁶ This clinician wasn’t intentionally unkind, but might have used a different word if more aware of how profound these losses are to a patient who would have been a mother. Unfortunately, as clinicians know all too well and fear, “Words and actions from staff at and around critical times of loss are not forgotten.”¹⁷

In the case of Mr. and Mrs. S, if attempts to resolve the perceived conflict between their request and the best interest of the fetus fail,

should the effect of their grief be considered as a morally relevant factor? If yes, how much moral weight should it be accorded? How might Mr. and Mrs. S respond if the medical team won't deliver the fetus early, and, as the parents most fear, the fetus dies as a result? It could be anticipated that, in addition to grief, these parents would feel rage, and it could be imagined that this feeling may darken the rest of their lives. Should that risk also be factored in?

It may be that "ethics" can't be used to determine what (if any) moral factors involving the parents should be factored in. "Ethics" can't be used to determine, in a valid way, or a way that is soundly determinative, whether the members of the medical team who wholly opposed the parents' request—or the members of the team who favored earlier delivery—were right or wrong in this case. I am not seeking to answer this question here. It may be among those questions that ethical analysis is least able to "validly" resolve. But another ethical framework, the care perspective, may suggest more strongly which tack the medical team might take when they feel "stuck" between two reasonable, competing courses. We shall turn to this now.

ETHICAL AND CLINICAL IMPLICATIONS

No doubt, the core question regarding this case, within a traditional moral framework, is whether the parents' wishes and/or interests should have any moral weight, and, if they should, how much weight they should have. The interests of both the fetus and parents may, however, be understood as being aligned, or even as more aligned than competing. Analysis that uses such a framework, such as the care perspective, may result in clinicians assessing a fetus's best interests differently. Starting from this perspective, I will now consider the substantive question of what clinicians, or whoever it is that will make this decision in this kind of case, should consider. I will then go on to discuss how clinicians may best proceed.

Substantive Implications

I discussed above the influence that parents can have on their children, and that this rela-

tionship may be the single most important factor in determining whether a child, especially a child with special needs, will have an overall positive quality of life. Enabling this to happen is a principal focus of the care perspective.

Nel Noddings unequivocally urges the importance of clinicians' giving greater moral weight to the relationship between parents and their children in her book, *Caring*.¹⁸ To illustrate, she relates how she was willing to lie about her son's absences from school, saying he was ill when he wasn't: "The school . . . prefers to hear that my son was ill. I prefer to say that he was [ill] because not saying it will cause my son to be punished. So I may choose to lie regularly in order to meet my son as one-caring rather than as one conforming to principle."¹⁹ This illustrates the occasional contrast between the framework she favors and more traditional ethical analysis based on more abstract moral values and principles. To elaborate, she explains how people are (unfortunately, in her view) all too prone to having their underlying feelings dictate their beliefs, without their knowing this: "in arguing from principles, one often suppresses the basic feeling that prompts the justification."²⁰ As I suggest above, this has been documented by brain imaging studies, and may have been what occurred in the minds of Mr. and Mrs. S. Noddings also implies how she would love her child unconditionally, and adds, more specifically, quoting Uric Bronenbrenner, that children need the enduring irrational involvement of one or more adults: "Somebody has to be crazy about that kid."²¹

Such a degree of caring may be present initially in parents—or may not, even with therapy, be forthcoming. It is said by some child psychotherapists that the one quality that child psychotherapy can't create or bring about in children is *energy*, and it may be that, similarly, *committed, unconditional caring* for a child is the one quality in parents that even the best therapy can't bring about. Research indicates the many ways, and extent to which, exceptional caring generally benefits children; as Johnson states, for example, "Countless studies on infant and adult attachment suggest that our close encounters with loved ones are where most of

us attain and learn to hold onto our emotional balance.”²² This view echoes what leading child psychotherapists now are doing in this field. At a recent major international meeting, three such edge-of-the-field approaches were presented. One eminent internationally recognized therapist, for example, does not do therapy with children; rather, she teaches the child’s main caregiver how he or she can be the child’s “best therapist,” because this caregiver, not she, will be the one who will be with the child 24 hours each day. To use her therapeutic skills in front of a child, in the presence of the main caregiver, could undermine the child’s trust and conviction that the caregiver, instead of the therapist, can give the child what he or she needs.²³ Another therapist seeks to help children who are too violent to be able to stay long in one place by first finding a person who is willing and available to be the child’s primary, full-time caregiver after the child’s discharge. This therapist tries, more than anything else, to teach the caregiver how to “tune in” to what the child is, “underneath it all,” experiencing. The therapist may ask a child to express what he or she feels to the caregiver not in words, but through music, on a xylophone.²⁴

This emphasis on a child’s relationship with another—in these examples, a caregiver—is mirrored in therapy with adults. An example is therapy intended to help adult patients who are too stressed by past trauma to respond to “anything else.” Therapists try to teach these patients how to use previously acquired positive images of past relationships with loved ones to dispel and replace the negative images that recur so painfully that they “sap” the patients’ capacity to respond to conventional therapies.²⁵ But what if the patients don’t have past, positive memories? I imagine that clinicians might be able to give patients new positive memories and images, by making the patients feel safe enough.

Many parents put their child—and their relationship with their child—this much ahead of the “usual” moral principles. For example, as I reported in *JCE* previously, during a natural disaster such as a flood, people may choose to stay with loved ones—or even a pet—even when their choice may result in loss of life. In the case

above, Mr. and Mrs. S may be this committed to their child, and if they can offer the child this kind of relationship, it may be ideal; if the child later has special needs, it will be what the child will need most.

A paradigmatic example of a clinical instance in which the care perspective differs from an ethics based in moral principles is maternal-fetal surgery. Chervenak, McCullough, and Brent provide a moral framework based on principles for clinicians to use when deciding what to do in these cases. They affirm that clinicians have ethical obligations to both the “pregnant and fetal patient. The fallacy of rights-based models, here, that see both these patients as competing and mutually exclusive,” they argue, “only appear to be easy to apply clinically and to be universally applicable. Their apparent robustness creates a veneer of certainty that, when subject to clinical scrutiny, collapses.”²⁶ Liaschenko, Debruin, and Marshall also assert that, as opposed to regarding the fetus and parents as separate entities who each have separate rights, the parties’ interests should be regarded as aligned.²⁷ They state, “The two-patient obstetric model is ethically controversial and does not represent an established norm in the field of bioethics or perinatal medicine,” and that to regard the pregnant woman as an adversary of the fetus in this instance, is as if the mother and fetus lived in “some alternate universe.”²⁸ Their view emphasizes what they see as the overriding importance of the relationship between the mother and her fetus. The core reality they see in this context is a fetus’s and his or her mother’s interdependence.

Adding the moral weight of aligned relationships shifts ethical analysis beyond a consideration of principles such as competing interests or competing rights. For example, should a fetus have spina bifida, an analysis based on an aligned relationship may suggest that the mother should have greater discretion regarding whether to have maternal-fetal surgery, rather than leaving this more up to clinicians, who will rely primarily on research indicating that the benefits of the surgery justify the risks.

In the case of Mr. and Mrs. S, such an alternative view might suggest that, if the arguments

for delivering the fetus earlier would be at best inconclusive, clinicians might, out of respect for the fetal/parental relationship, consider the parents' request, at least when some "tie-breaker" must be used "by default."

Procedural Implications

The most troubling aspect of this case—whether or not the actual outcome was "right"—is the possibility that if different clinicians had been involved, the outcome may have been different. For example, what if all but one of the medical team had opposed an early delivery, rather than only one member of the team? There are reasons that members of the medical team should be making this decision (at least in theory) and reasons that they should not be involved, wholly or even partially. A key reason for their making the decision is that they may know best what is best for the fetus and parents, based on their knowledge and past experience. Another reason is that many parents may want clinicians to make these decisions.

There are several reasons, on the other hand, that clinicians should not be this involved—or involved at all. First, it has been found that clinicians as a group, empirically, tend to underestimate how well children with special needs and their parents will do. McCrary and colleagues note this. This finding might be valid for many reasons, and may be, in net effect, for the good. That is, clinicians may feel extreme emotional pain in response to a loss such as losing a fetus,²⁹ and such losses may take place repeatedly, over time. Overly pessimistic expectations may provide clinicians some protection, which may be necessary to allow them to continue practicing for the public's good.

Another argument against the involvement of clinicians is that they, when in doubt, may opt for the more conservative of their professional medical standards, which may leave them more reluctant to make ethical exceptions when they should. An example of this may be the plight of the child I described above who had Werdnig Hoffman disease. She may have benefitted more from staying alive longer even though other children with the same illness may not have. Also, clinicians may err by doing what

they believe is safest for them under the law. For example, in one study, 85 percent of clinicians working with a group of patients who were particularly prone to suicide reported that they had responded in ways that would relieve their own anxiety about legal and other negative risks, rather than in their patients' best interests.³⁰ This proclivity is understandable, in that clinicians, too, must feel safe, but it may add to the risk that, in ethically marginal cases, clinicians will not make an exception when they perhaps should. Some decisions of this kind should be made by the "greater society" (and I will consider an example of this shortly). All laws can't possibly bear in all situations, and, in some individual cases, relying on the law cannot help but be ethically suboptimal.

It should be noted that the clinicians in the case of Mrs. and Mr. S took this kind of risk and granted the parents' request, although they may have felt that this was the less safe route, and their courage in doing this should be recognized. What, though, in the light of these conflicting considerations, should clinicians who are confronted by such a dilemma do?

First, they could try approaching the parents as an "ethically neutral clinician," as described above, even when they are not ethically neutral. That is, they could acknowledge their own non-neutrality as honestly as possible, and say to parents, for example, "This may 'come out' the way that you are requesting. Or, maybe not. But by discussing this together, in case you change your minds, what have we to lose?"

If this doesn't succeed, there are additional, unusual procedural initiatives that clinicians might want to consider. They might consider a "solution" like the one that the expert consultants and ethics committee arrived at in response to the child with Werdnig Hoffman disease. They decided that the girl's parents could have what they wanted if a clinician with sufficient expertise was willing to give the child the treatment the parents requested. This solution could be seen as representing a substantive change from other resolutions that the clinicians would consider. The question posed, should this option be strongly considered, might be less what the *clinicians* should do; the question may be

whether *reasonable persons* might reasonably, ethically, disagree? Thus, the question to be considered might not be so much what the clinicians believe is right, or whether some or all happen to agree with the decision, as, even if they are all of one mind-set, there might be others who hold a different view.

This is what happened in the case of Mrs. and Mr. S. The members of the medical team were of one mind: the parents should wait. Yet they still recognized that there might be a sufficiently valid alternate view—namely the view of the parents. This approach, when applicable, does not depend on the moral views of whatever clinicians just happen to be there. Criteria for not doing this still exist. For example, there might be certain decisions that should be made only—if at all—by the “greater society,” and then perhaps only through legislation, rather than through the courts. Such a situation occurred when most, if not all, of the medical team involved (or at least the doctors and nurses, who were the most outspoken) believed strongly that a baby born with anencephaly in Fairfax, Virginia, should be allowed to go without full life-supporting measures, and, therefore, die. In this instance, the court refused to let this happen; the decision to go against the wishes of the parent, in this context, the court reasoned, should be made only by the greater society.³¹

Ethically, this decision may be seen as shifting who has what “burden” in these situations. This may be a change for those who are making decisions (with or without the parents): from having the burden to make the case that going along with the parents *is* reasonable, to having the burden to make the case that going along with the parents *is not* reasonable.

Practically, clinicians might also look at the “substantive change” that this would require as shifting the “burden.” That is, rather than those wishing to support a parents’ request having the burden of showing why this *should* happen, those who oppose the parents’ request might instead have the burden of showing why this *should not* happen.

With this shift, there would still be—in the United States at least—some safeguards. First, as in the case of Mrs. and Mr. S, and in case

involving the girl with Werdnig Hoffman disease, several members of the care team would be needed to grant the parents’ requests; that is, more than one member of the case team would, ethically, in theory at least, have to agree to do this. Second, there is, in other countries as well as in the U.S. (as mentioned earlier), a strong and realistic fear in clinicians of professional, civil, and even criminal repercussions. This fear played a role in the case of Mr. and Mrs. S, as noted above.

If clinicians accept this risk, there are additional possible ethical implications that involve the efforts that members of the care team (or someone) should expend before and after this kind of decision might need to be made. First, before such situations arise, the staff could try to identify those clinicians who would be the best to meet with parents in these situations, and also to identify who might be willing to treat a fetus—or another patient—in such situations. Then, should such a case arise, the hospital already knows which clinicians (if any) could best take on these roles.

A paradigmatic example for nearly all hospitals is that of Jehovah’s Witness patients who come in needing surgery, but refusing blood. Before this occurs, it is possible to ask all surgeons whether they would be willing, under these conditions, to operate without using blood. Thus, this could be known in advance. It may also improve treatment, and, by allowing “bloodless” surgery to occur earlier, could possibly save some of these patients’ lives.

As for the girl with Werdnig Hoffman disease, when no clinician in a hospital will agree to a request from parents, and members of the team agree to try to find an “outside” clinician to treat, hospitals can try to arrange, in advance, who would try to find an outside clinician. This same liaison might also try to engage with parents, such as the parents of the girl with Werdnig Hoffman disease or Mr. and Mrs. S, in the hope that the parents might change their minds.³²

Should members of the care team at a hospital go this far? This answer, ethically, should depend on the answer to the question I asked at the beginning of this article: How great is the value of reducing the likelihood that a child,

due to being delivered earlier, will acquire special needs? In some cases it might be absolutely critical that the person who has the responsibility to make calls to find an outside clinician does not have a bias going “the other way.” If the person making the calls has no bias, making the calls may be warranted. But if the caller is not without bias, the phone calls might be no more than perfunctory: the caller would go through the right motions, but his or her bias might determine what occurs. Outsiders might be much more likely to reject a request. The caller’s negative bias would become a “self-fulfilling prophecy.” Perhaps this is what occurred when calls were made to find an outside pediatrician to treat the child who had Werdnig Hoffman disease. Perhaps the clinician who opposed starting the respirator may have conveyed this to those he or she called. I don’t know.

THE NEED FOR CLINICIANS TO ASSESS THEIR FEELINGS

Discerning our emotional responses to a case, even when just reading it, may be revealing in several clinically significant ways. For example, it suggest insights we have missed or core realities that we too readily have dismissed or denied.³³ When I first read the case of Mrs. and Mr. S, I was singularly moved and engaged. First, I feared for the child-to-be. But then I became somewhat less invested, even bored. I thought that I felt bored because I anticipated—wrongly, it turned out—that after the authors discussed this agonizing, all-absorbing dilemma, they would present ethical analysis that would be pat, even if right. I expected that they would explain why they should give absolute priority to the best interest of the fetus, soon-to-be-child. But as I read on and found that the authors had mostly gone a different way, I felt relieved. I didn’t feel relief because this was a decision with which I necessarily agreed, but because it wasn’t pat, and had taken the parents’ heartfelt feelings, rightly, into account—whether or not this should have swayed the decision. Finally, I read of the child’s actual outcome. I took a deep breath. This was followed by a feeling that I can best call sharp regret.

Why? I thought: “But what if this baby had been born with profound special needs and what if this outcome had resulted from this same decision?” What can be gained from reflecting on feelings such as these?

First, we can wonder, why, overall, we are singularly engaged (if and when we are). For me, in this case, it was due to this being a fetus and one at such high risk. Perhaps all of us tend to respond most intensely to the plight of a child. Clinically, such exceptional intensity may tend to bamboozle our thinking. It may alert us to the singular and quite appropriate commitment that others, such as the parents, felt—although the parents may have felt that it would be impossible to feel as strongly as they did in this case. In this regard, it may be worth noting that, in the last issue of *JCE*, I wrote about the possible special importance of clinicians’ giving due moral weight to what patients find especially meaningful. I suggested two categories: (1) donating an organ, such as a kidney, to a stranger, and (2) undergoing cosmetic surgery for a loved one. Parents’ requests for a fetus or child may be in this same exceptionally meaningful category—perhaps even more so.

Second, we can seek to glean the possible meanings of each feeling we experience. I will do this now in regard to each of the emotions I listed above, to exemplify what kind of hidden insights I have in mind.

I listed four feelings: fear, boredom, relief, and regret. My fear may have blocked me from using the moral reasoning I otherwise might use. This blocking isn’t uncommon, as I’ve already said. This awareness, in turn, might alert us to a similar type of blocking that the parents may be undergoing, although without their knowing this. This experience may help us to think more clearly, and to understand and relate better to parents. This may give us a better felt sense of how important it is for us, above all else, to try to help parents who are in these situations to feel safe.

My boredom may have been as boredom often is: an emotional defense to protect me from feeling some emotion that would be much worse. The worse feeling might have been, I expect, a general anguish at not knowing what

would happen next in the case. This feeling might mirror those of the parents and those of the care team, on both “sides.”

My relief that the authors were not being pat, but were taking into account the parents’ feelings, may have been the clue to a more invidious, subtle risk. I may have felt relieved because, in placing what I consider “due” moral weight to the parents’ feelings, the members of the care team/authors happened to agree with me. This is worth stressing, because this risk is so common and the harm it causes can be so great. We all may often have a hidden agenda, to want to affirm within ourselves what we already think. Our brains may “short circuit” themselves, without our knowing this, in this quest. The risk here for ethicists is that they may, without knowing this, rationalize and justify what they’d already felt beforehand was right. Knowing this, we should regularly reconsider what we think we are best doing.

The regret that I felt, I suspect, is a human propensity that is particularly tragic. After a bad thing happens, we ask, “What else could we have done?” For example, this compelling proclivity is emphasized sometimes after a loved one has taken his or her life. We may torture ourselves wondering, “If I’d only called earlier?”

This lack of being fair to ourselves in acknowledging accurately what we have done, and what we can’t, spreads to not knowing the good we do. I am reminded here of the following, from my own experience. A girl just graduating from high school chose to care for another girl her age who had profound physical, but not cognitive, special needs. The teenaged caregiver took the girl with her everywhere, even to the mall and to meet with her friends. After a year or so, she felt profoundly burnt out, and she quit. Her guilt at this plagued her, hounding her every day, until the girl she cared for died, and the girl’s parents asked her former caregiver to come to their daughter’s memorial service. At the service, the parents went on and on, before everyone, at how lucky their daughter had been to have the young caregiver for this time in her life. They related how their daughter had often said, before dying, how that year was by far the best she had ever had in her life.

Clinicians may learn, then, how prone to unwarranted regret they and parents can be. This may suggest to clinicians that we can forewarn parents that, even though they may now have achieved what they want, a terrible end may occur, and, if it does, they should not feel that they made, in any way, a wrong choice.

In the case of Mrs. and Mr. S, however, a still greater risk, and the deepest concern, is that they may “wake up,” as it were, and agonizingly recognize and regret the evidence-based “mistake” that they may have made. That is, if their fetus has complications, it may, indeed, be most harrowing. Thus, clinicians who weigh their own feelings and reflect on what they mean may get in touch with the greatest threat that these parents face: we may say to them, in anticipation, that they must commit themselves, beforehand, to forgiving themselves if they later come to believe that they made a grave mistake in requesting that their fetus be delivered early. Saying this to the parents may put on a light at the end of the tunnel, even if there is a worst result. As our “words and actions at and around critical times of loss are not forgotten, words of kindness and touching have the potential to have long-lasting healing effects.”³⁴

The member of the care team who most opposed Mr. and Mrs. S may have been the best one to say these things. Saying this to them, when he most opposed their choice, may have strongly emphasized the importance of their making this choice, and so may have brightened the light at the end of the tunnel to the greatest extent, should that have ever been needed.

CONCLUSION

The cardinal point in this article is that parents’ and clinicians’ relationships with each other may be of the greatest importance when a fetus’s interests are at stake. This may mean taking extraordinary, unprecedented measures, which alone may be enough to enable parents like Mr. and Mrs. S to feel “sufficiently safe” to be able to change their minds. Martin Buber, as much as anyone, perhaps, recognized the importance of people’s relationships. He wrote how this is ever foremost, since birth: “The pri-

mal nature of the effort to establish relation is . . . seen in the earliest . . . stage . . . timid glances move out into indistinct space . . . hands sketch delicately and dimly in the empty air, aimlessly seeking and reaching out . . . this very movement of the hands will [try to] win . . . a woolly Teddy Bear . . . the instinct to make contact . . . (first by touching and then by 'visually touching' another being) . . . is inborn."³⁵

NOTES

The quotation at the beginning of this article is from R. Joyce, *The Unlikely Pilgrimage of Harold Fry* (New York: Random House, 2012), 115.

1. S.V. McCrary, S.I. Shah, A. Combs, and J.G. Quirk, "Elective Delivery Before 39 Week's Gestation: Reconciling Maternal, Fetal, and Family Interests in Challenging Circumstances," in this issue of *JCE*.

2. N. Noddings, *Caring* (Berkeley, CA: University of California Press, 1984), 42.

3. K.M. Metzler, "Human and Handicapped," in *Moral Problems in Medicine* (Englewood Cliffs, N.J.: Prentice-Hall, 1976), 358-63, 359.

4. *Ibid.*, 362-3.

5. *Ibid.*, 363.

6. Noddings, see note 2 above, p. 37.

7. S. Johnson, "The Great Motivator/ Power of Emotion in Therapy," *Psychotherapy Networker* 36, no. 3 (May/June 2012): 27-57, 28.

8. *Ibid.*, 31.

9. *Ibid.*

10. Johnson, note 7, p. 31.

11. *Ibid.*, 32.

12. *Ibid.*, 33.

13. *Idid.*

14. E.G. Howe, "How Should Careproviders Respond to Patients' Requests that May Be Refused?" *The Journal of Clinical Ethics* 23, no. 2 (Summer 2012): 99-109, 107.

15. A. Lang et al., "Perinatal Loss and Parental Grief: The Challenge of Ambiguity and Disenfranchised Grief," *Omega* 63, no. 2 (2011):183-96.

16. *Ibid.*, 191.

17. *Ibid.*, 185.

18. Noddings, see note 2 above.

19. *Ibid.*, 57.

20. *Ibid.*

21. *Ibid.*, 61.

22. Johnson, see note 7 above, p. 32.

23. C.M.G. Ippen, "Restoring the Protective Shield: Core Concepts from Child-Parent Psychotherapy," presentation at the International Society

for Traumatic Stress Studies, 27th Annual Meeting, Baltimore, 3-5 November 2011.

24. R. Kagan, "Real-Life Heroes: A Developmental, Attachment-Centered Intervention for Children with Complex Trauma," workshop at the International Society for Traumatic Stress Studies, 27th Annual Meeting.

25. D. Lee, "Using Compassion-Focused Therapy to Work with Shame-Based Flashbacks in PTSD," presentation at the International Society for Traumatic Stress Studies, 27th Annual Meeting. See P. Gilbert, "Introducing Compassion-Focused Therapy," *Advances in Psychiatric Treatment* 15 (2009): 199-208. See M. Mikulincer and P.R. Shaver, "An Attachment Perspective on Psychopathology," *World Psychiatry* 11, no. 1 (February 2012): 11-15.

26. F.A. Chervenak, L.B. McCullough, and R.L. Brent, "The Professional Responsibility Model of Obstetrical Ethics: Avoiding the Perils of Clashing Rights," *American Journal of Obstetrics and Gynecology* 205, no. 4 (October 2011): 315.e1-5, 315.e4. See also, B.A. Brody, L.B. McCullough, and P.P. Sharp, "Consensus and Controversy in Research Ethics," *Journal of the American Medical Association* 294 (2005): 1411-4; B.M. Dickens and R.J. Cook, "Legal and Ethical Issues in Fetal Surgery," *International Journal of Gynecology and Obstetrics* 115 (2011): 80-3; N.S. Adzick, "Fetal Surgery for Myelomeningocele: Trials and Tribulations," *Journal of Pediatric Surgery* 47 (2012): 273-81.

27. J. Liaschenko, D. DeBruin, and M.F. Marshall, "The Two-Patient Framework for Research During Pregnancy: A Critique and a Better Way Forward," *American Journal of Bioethics* 11, no. 5 (May 2011): 66-8.

28. *Ibid.*, 66.

29. R.A. Sansone and L.A. Sansone, "Physician Grief with Patient Death," *Innovations in Clinical Neuroscience* 9, no. 4 (April 2012): 22-6.

30. R. Krawitz and M. Batcheler, "Borderline Personality Disorder: A Pilot Survey about Clinician Views on Defensive Practice," *Australia's Psychiatry* 14 (2006): 320-2.

31. See, e.g., *In re Baby K*, Federal Report 10 (February 1994) 590-0 (U.S. Court of Appeals, Fourth Circuit): "The court noted that until Congress recognizes exceptions legislatively, hospitals will be required to provide similar care in analogous situations."

32. Noddings, see note 2 above, p. 103.

33. *Ibid.*, 57.

34. Lang et al., see note 15 above, p. 185.

35. M. Buber, *I and Thou* (New York: Scribner Classics, 2000), 38-9.