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## *At the Bedside*

# Professionalism: One Size Does Not Fit All

*Edmund G. Howe*

### ABSTRACT

When a child is born with or acquires special needs, the parents may find some parental tasks more difficult. They may not know how to make their tasks easier, or that some parents find it exceptionally rewarding and meaningful to raise their children with special needs. This piece explores how clinicians might share this potentially life-altering information. It also explores when and why clinicians might want to make one-of-a-kind exceptions to their usual professional practices.

In this issue of *The Journal of Clinical Ethics (JCE)*, several authors discuss what may be the most difficult decision parents and clinicians will ever make: whether to allow their child to die. In "A Quality of Life Quandary: A Framework for Navigating Parental Refusal of Treatment for Co-Morbidities in Infants with Underlying Medical Conditions," Sarah N. Kunz, Ryan M. McAdams, Douglas S. Diekema, and Douglas J. Opel give guidelines for clinicians when parents decide that it is best for their child to die.<sup>1</sup> Kunz and her colleagues consider situ-

ations such as when diagnostic surgery is needed to help parents make life-or-death decisions. In "Witnesses to Mute Suffering: Quality of Life, Intellectual Disability, and the Harm Standard," Lisa Freitag further considers these questions,<sup>2</sup> and comments particularly on infants who have severe cognitive deficits and on infants who probably will live only a short while.

In "Home Birth of Infants with Anticipated Congenital Anomalies: A Case Study and Ethical Analysis of Careproviders' Obligations," Jane Jankowski and Paul Burcher address an ethical question that arose before a child with special needs was born.<sup>3</sup> His parents continued to plan to deliver him at home, although they knew this would pose greater risks. The authors ask whether, under these conditions, a midwife should assist in the birth and whether a pediatrician should attend the birth. Melissa Cheney, in her commentary, "Of Missing Voices and the Obstetric Imaginary: Commentary on Jankowski and Burcher," adds her experience as a midwife and her perspective as an anthropologist.<sup>4</sup> For instance, Cheney wonders what the mother in this case heard, and what she missed, when she was told of her baby's absent corpus callosum and asymmetric cardiac ventricles. She offers how patients have described receiving "dreaded news": " 'The earth fell away under my feet.' 'My ears started ringing, and my heart was pounding.' 'I couldn't hear what anyone was saying.' 'My vision went away, even though my eyes were open.' "

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In this introduction I discuss these questions, as they occur not only in the context of infants who have severe defects and/or who soon may die, but also in children who have less serious problems and in older children. The feelings of parents, in situations similar to the examples above, are likely to be among the most intense that can be experienced. Given this, I will discuss some exceptional measures that clinicians may wish to take into account. The impetus for making these suggestions is the numerous experiences of unparalleled joy, and the good times and the bad times that parents of children with special needs have shared with me.<sup>5</sup>

I have had the uncommon good fortune, for nearly 40 years, to teach with these parents. Where I teach, students begin their ethics studies each year by meeting with these parents in very small groups, and the parents tell their stories.<sup>6</sup> (This program was initiated by developmental psychologist Janice L. Hanson and pediatrician Virginia F. Randall.) One parent, Coleen O'Brien, said, "During the ethics course session, the students always get personal and ask if we were afraid of our child dying, what the child knew, and how siblings were affected."<sup>7</sup> For the most part, these parents choose to teach because they have cherished raising their child. They may not be a representative group, but they do show that parents can find raising a child with special needs as meaningful and rewarding as parenting a child who does not have special needs—or more so. This may be most important for some parents to know.

In addition, parents may want to know what, practically, they can do, and others in similar situations may be able to offer then a great deal—as is the case in so many other clinical contexts. One parent states, "I will tell my story to educate, to inspire, to enhance understanding, and to heal myself."<sup>8</sup>

Because parents may feel depressed and stressed when they first learn that their child has special needs, they may want to know about other approaches that may also help. Thus, I will include some examples of these approaches too.

## ISSUES FROM "A QUALITY OF LIFE QUANDARY"

### Stopping Treatment for a Child

Surely clinicians should draw a line when parents treat, or seek to influence the treatment of, a child in a way that appears to be ethically unjustifiable. This is part of what Kunz and colleagues suggest. Here are a few structural examples from my experience. I think of an infant who was dying on a

respirator who seemed to be in great pain. His parents refused to consent to giving him pain-relieving meds. They believed God didn't want that. The child's medical team called me when I was at a conference. I was on this hospital's ethics committee and they knew I teach ethics. They felt highly stressed and asked me what I thought they should do. Even though I was far away and responding over the phone, I said they should give the baby pain meds immediately. I added that they should also immediately inform the appropriate authorities, and, if they had trouble getting through to the authorities, they should relieve the child's pain at once, no matter what. I said this because, to me, ethically, leaving this child in pain even for just an unnecessary moment was comparable to child abuse. They did, and the baby died shortly afterwards, free of pain. The parents accepted this, although they may have seemed resigned to it.

In the next case, the best decision for the child was less clear. As noted above, it is possible for parents to find exceptional meaning and feel exceptional joy in having and raising a child with special needs. Learning about this might make a difference when parents must make a life or death decision. This is such an example. A teenaged boy had profound physical limitations from the time of his birth, and couldn't walk. He was severely cognitively impaired. He went to a special day care center during the day and seemed to enjoy it. Then he was found to have a brain tumor. His surgeons said they could remove the tumor, but they expected that after surgery the boy would be more cognitively impaired, but they couldn't say how much more. His parents already felt overwhelmed caring for him. They refused to consent to the surgery. The surgeons accepted their decision, and the boy died.

How might we think about this outcome? If they were in this situation, Kunz and colleagues may have overruled the boy's parents. Would they have been right to do so? Perhaps another outcome was possible. What if the parents were able to acquire *different* feelings for their son? Some parents report they at first felt overwhelmed, but were able to come to feel immense joy in raising their severely ill child, even when they never expected they could. Some parents report they initially felt disappointed, but later came to feel great joy, feeling very differently from how they initially imagined they would.

When parents initially or later report such joy and meaningfulness, it could be, of course, profound "after-the-fact" rationalizing. But the passion with which they express this exhilaration, both when their child is alive and even years after their child

has died, and the extensive number of parents who report these extremely positive feelings, make this possibility less plausible. Remarkably, and possibly counter-intuitively, parents report that they change, even when their child's condition didn't, in ways they never imagined possible. We might ask, in parallel, what do physicians owe to parents when their decision to treat seems unrealistically optimistic? We might assume that when the child may do poorly, and especially when the child may die, physicians rarely choose not to share this information. Most of the time, physicians want parents to be prepared for the worst outcome.

It may be helpful to parents of a child with special needs to learn that other parents were able to come to find joy and meaning in raising their child. It would be optimal to alert parents to this possibility before a life-or-death decision arises, allowing parents time to explore this possibility, if they want. Whenever a child's health worsens, it is very difficult for parents. How much foreknowledge is possible or practical will vary among parents, so it may be optimal for physicians to regularly assess this with parents. A severely ill child may do better when her or his parents change, because the parents may be able to increase the ways that they express their love for their child—for example, by increased touching.

### Why Is Such Change Possible?

We may be able to change in ways we can't well predict, and may be able to change more than we can even imagine. This is common knowledge, in that it happens every time we believe we can't cope—and then can. This possibility is supported by recent studies that report that physically, to an extent, our brains are and always remain “plastic,” that is, they remain able to change.<sup>9</sup>

This plasticity of the brain has limits, but these limits may lie well outside what we envision, and thus can predict. What might this mean for clinicians, and for parents? Ethically, this poses a most important question: Should clinicians inform parents who feel overwhelmed by caring for a child with special needs about the possibility that their experience could change, or should clinicians say nothing? Should clinicians allow parents to be “where they are” and not risk harming them by telling them about the possibility they could change?

The answer depends on the range and depth of the change that is contemplated. It may also depend on the clinician's capacity to gauge the pluses and minuses of presenting this option, and to share the pluses and minuses with parents, to reduce the pos-

sible significant risks to parents. The kind of change we are considering, which may take the parents from deep despair to what psychologist Barbara Fredrickson characterizes as “exhilaration,” is not uncommon in other contexts.<sup>10</sup> For instance, the family members and loved ones who care for patients with dementia often report experiencing this kind of change, especially with the right kind of help.

Caregivers who have been able to gain meaning and happiness in their life can help others who have not. Contact with others who are caring for a loved one with dementia is now routinely recommended. Support and guidance from others who have experienced similar stress and found ways to transcend it often can make an enormous difference—moving the caregiver's life from being darkly clouded to again living under the sun.

Those who provide care to a loved one with dementia often gain help due to the urging and effort of the patient's clinician, and this is what I am suggesting that clinicians do to help the parents of severely ill children. The changes in those who are for patients with dementia are noteworthy here, for two reasons. First, the caregivers report they experience profound joy *as* they care for their loved one, as well as when they look backward. They report that this occurs even though the patient *continues to get worse*. Those who care for a patient with dementia may feel overwhelmed. When they can meet with others who felt the same way but were able to come to cherish the person with dementia—and their own life—the careproviders who feel overwhelmed may find they too can accomplish this change.

Ethically, for clinicians, the problem is this: If clinicians say to parents that some other parents have changed, the parents may feel rage and/or guilt, and may feel it forever. Yet, if clinicians don't mention this possibility, parents may never know that this change can happen. Parents, like some loved ones who care for a patient with dementia, may feel overwhelmed and not know that they could feel anything else. Parents may want, more than anything else, to be able to change from feeling overwhelmed to cherishing every moment with their child. Even when parents know they want this kind of change, or have seen it, they might not know, at all, how to best proceed. And what would be the best way for clinicians to tell parents all of these things?

Such an initiative may seem most intrusive. But despite its intrusiveness, some clinicians may feel that, morally, they can't refuse a possibility to be of help. Some may feel obligated. Still, they should ask themselves, “Does *ought* imply *can*?” This may be an instance in which this intervention may be only

praiseworthy, not obligatory. It may be “right” only for those clinicians who can do this satisfactorily.

### Giving Parents a Choice

Raising a child can be extremely demanding, especially when a child has special needs. One child, since birth, had great difficulty swallowing. If she ate in too-large bites, she could aspirate food into her lungs, which could be fatal. Her parents had to feed her small amounts of food every two hours, around the clock. Another child was so emotionally disturbed that his parents had to lock every door and window in the house at night, to keep him in. The question arose whether they should consider implanting a microchip in him so they might better find him if he ran away again. (They did not.)

These two cases illustrate two cardinal rules for clinicians who decide to talk with parents about the possibility of change. First, clinicians should take the parents literally when they share stories about their experiences with their child. They must hear what parents say when they describe their pain.

As with the parents who fed their daughter around the clock, and the parents who considered micro-chipping their son, some accounts may seem too extreme to be true, and, at least initially, clinicians may try to second-guess parents and tell them they just need to try harder. Clinicians may respond this way for many reasons, for instance, because they feel unbearably helpless, and, as a defense, engage in denial. Clinicians may feel so sorry for parents—and their child—and think they can do more than they can. For parents, thought, such responses sting.

The second rule is for clinicians to explicitly affirm the pain that parents report. A clinician could say that, because of what the parents are going through, the clinician could not see how the parents could *not* feel overwhelmed. After saying this, the clinician could ask the parents if, together, they could explore some means by which it might be possible for the parents to gain greater external support.<sup>11</sup> For example, few parents of a child with special needs (or, for that matter, caregivers of a loved one with dementia) haven't felt, at some time, that they had to “battle the system.” If a clinician offers to do what she or he can, the parents may better succeed, and at least they will not feel so alone.

Parents of a child with a condition that is especially uncommon frequently have more severe problems obtaining the help that they need from social agencies. This may be because it is easier for an agency to know how to respond when it sees a child who has medical problems it has seen before.

Similar to those who care for a loved one with dementia, parents of a child with severe illness require external support to do well. They need time for rest, sleep, and respite. Ideally, they should be able to look forward to having some time on their own. To provide this kind of support, a clinician may not need to do more than make needed referrals or write a few letters. A clinician may need to be persistent in these efforts.

When a clinician offers to help parents get the external support they need, the parents' trust may increase “disproportionately,” and this greater trust may enable a clinician to effectively say to parents what parents might otherwise reject outright. A clinician may need to repeat advice, to be sure that parents hear what is said: that with external support, they might not feel overwhelmed.

A clinician also could offer the following information, something that parents may not have considered or imagined: they may feel as overwhelmed as they do in large part *because they have an exceptional capacity to love*. Loving their child, but not being able to relieve the child's pain, may leave them feeling unbearably helpless. This pain may be much too much for them to overcome.<sup>12</sup> When people have an exceptional capacity for compassion, it often leaves them more vulnerable. This is especially likely when the one who is hurting is their child.

A clinician might begin a discussion with parents by saying that he or she faces a clinical dilemma. To best resolve the dilemma, the clinician would like to ask the parents what they would want the clinician to do. The clinician can explain that she or he knows parents who, like them, have or had a child with profound special needs who once felt overwhelmed like they do, but who now thrive. If the parents want, the clinician could discuss with them how they might pursue this possibility. Yet, the clinician should add—quickly—that sharing this could cause the parents harm, and that the parents could, wholly justifiably, not want at all to pursue this. The clinician can add, finally, that he or she feels very sorry, in case saying this has already caused the parents any harm.<sup>13</sup> The clinicians may then ask the parents what they want to do.

### The Possibility of Change

What can parents do if they want to see if they can change? For many people, it might seem that saying they will try is the only acceptable answer. For this reason, clinicians must go to great lengths to spell out why *not* wanting to try would be okay. For example, attempting this may be futile, and par-

ents may sense this in advance. They might be wrong in thinking this, but later the worry that they may have failed—whether that is rational or not—may live within them and haunt them thereafter.

If parents do say they want to try to change, there are several possibilities. Antidepressant psychotherapy and/or medication may help. When parents first learn that their child has or will have special needs, they may feel depressed. That feeling may harm not only them, but their child. Parents' depression may result in an infant later lacking "emotional scaffolding," that may help a child cope much better with stress, or be more "resilient."<sup>14</sup>

Parents' maladaptive beliefs may be unremittingly painful. Some parents feel guilty when their genetics may have affected their child. For example, a woman had a son with severe physical problems, and learned that some of his problems may have been from the genes she passed on to him. Her mother had had emotional problems that caused her to be a less than optimal parent, which were totally unrelated to the genetic problems of the boy. But the boy's mother felt she was a bad mother, as her mother had been a bad mother to her.

In cases like this, therapy may give parents relief from such thoughts and enable them to enjoy parenting. Here, there was a strong reason to believe that cognitive therapy would be extremely helpful, because the woman's reasoning was irrational. She equated being bad—making a bad choice—with being "bad" when there was no choice—due to one's genes. Cognitive therapy seeks to help a patient recognize such irrational thoughts on her or his own.

Clinicians' interventions may help parents who want to feel more positively toward their child. Parents may gain from pursuing "self-help" strategies. Parents can learn not only new and better strategies for coping, they can come to feel greater empathy and compassion for their child, over time. Barbara Fredrickson, mentioned above, is a psychologist who has spent her life seeking to help people change from feeling overwhelmed to finding joy in what they can't change. She reports that the first "bedrock" for doing this is for people to feel safe.<sup>15</sup> This is a reason that clinicians might, before doing anything else, work to gain more external support for parents. The second "bedrock" is to *connect*.<sup>16</sup> Connecting is the key to all of the techniques that Fredrickson has studied and teaches. This connecting, she says, is not through words; rather, this "syncing up" with another involves people connecting in the moment, in every way they can: eye contact, touching, and gesture.<sup>17</sup> These ways of connecting are usually possible with a child. This process of connecting, she

asserts, changes people "within"—"It is not the words that count, but rather the feelings these words evoke."<sup>18</sup> This kind of day-to-day shift in one's conscious attention and focus is now being clinically explored in other medical contexts. The more one purposefully does this, the more effectively it may work over time.

Clinicians who want to do this may look for nonverbal signs, "however small," of others' suffering. In adults this may be a grimace, a furrowed brow, a heavy sigh, a slumped posture, or any clue that the other person "is carrying some burden on his or her shoulders or in his or her heart. . . ."<sup>19</sup> Fredrickson advises, "See if you can feel in your own body and heart the heavy load that this person endures."<sup>20</sup> This kind of suffering is also possible to detect in a child, and is a far cry from the all-too-common response of parents who may, with good intentions, tell a child, angrily, to "just cheer up." Fredrickson cautions that when using these techniques, people shouldn't try to connect too much with another person, all at once.<sup>21</sup> This caveat is important for clinicians who are thinking of referring parents to Fredrickson's work. Parents must be prepared for change within themselves—if it occurs—to take place over time. But, if and when this connecting occurs, Fredrickson says, even when it happens slowly, it raises "the ratios of positivity to negativity" for all who are involved.<sup>22</sup>

A more likely source of change, from negative to positive feelings, is to pair up parents who feel overwhelmed with one or more parents who have a child with special needs who have felt like this, but who successfully made a transition from negative to positive. It is said by some in mental health that what people most need to successfully cope with stress is knowing people who are struggling as they are, so they aren't so alone; people who have struggled but have successfully overcome the same problem; and people who are knowledgeable. Other parents who felt negatively toward their severely ill child and who now wholly cherish their child most likely offer all three. There are many of these parents, and clinicians may do the most to help parents who feel overwhelmed by helping them to get in touch with other parents.

This is a well-known way to help loved ones who are caring for a patient with dementia to return to again loving life, when they have previously felt overwhelmed. While still being caregivers, they can regain their prior zest for living, even though the patient's *dementia will continue to get worse*.

While there are innumerable people who care for patients with dementia who have regained their

joy for life, it may be more difficult for parents with a severely ill child to find other parents in the same situation. Clinicians may have to make more of an effort to help bring these connections about. In the interim, or while working on making connections, clinicians may, themselves, provide a sufficient bridge and hope to parents to enable them to be open and eager to change, when they can.

An example is a parent whose child had a rare debilitating disease. At first no one could figure out what it was, and even after the medical team figured out what it was, there was no known treatment. Before the diagnosis, the head of the care team told the child's mother that his team *would do everything possible* to figure out what was wrong and to treat it. Although the team treated the boy in a way that was "the first of its kind," the treatment didn't succeed, and the boy died. The mother later said that although her son's dying had been terrible, the head of the team had taught her that she still could feel immense joy when being with her son, and thus, she not only felt no regrets, she chose to have a second child, *knowing that the child could have the same disease*. As it happened, the second child, a daughter, did have the same disease. This child, though, received a new treatment that had been developed since the first child's death, and the child survived and did well.<sup>23</sup>

### Preparing Parents for Ominous Diagnostic Findings

In their article, Kunz and colleagues describe how surgery was needed to determine an infant's prognosis. Surgery may show that a condition, such as abdominal cancer, has spread. If it has spread, the argument may become stronger for the parents to let their child die sooner, even possibly during the surgery, after a diagnosis has been made. Parents who are waiting for such diagnostic information during surgery may find the waiting unbearable. Once they receive this diagnostic information, they may find that making a decision whether to let their child die becomes even worse. For example, they may have decided before the surgery what they will do, depending on what the surgeon finds. When they actually have more information, though, what they decided previously and what they feel "on the spot," after hearing the diagnosis, may differ, and this may cause great stress.

Even when such stress is a onetime experience, its effect may be long term. It may dampen the parents' capacity for joy, forever. They may, due to this onetime profound stress, acquire a posttraumatic

stress disorder that persists. We might ask, can clinicians help prepare parents for this? Can they help reduce this possibility? The answer may be "yes."

*Stress inoculation* is an approach to anticipating and reducing stress pioneered by Don Meichenbaim. He reports this approach has been effective in helping patients cope with their own serious illness, or to better prepare for the death of those they love most.<sup>24</sup> This approach involves people trying to anticipate what they will later say to themselves, so they can seek to alter their thoughts if they are maladaptive. People can also "practice," in at least their mind's eye, what they will experience later, in ever more difficult and challenging ways. For example, I might imagine that I will say in my mind, based on what I have said to myself previously, "I can't cope with this situation." If this is what I imagine, I might next practice saying, as I repeatedly imagine a dreaded situation, more vividly each time, "I can cope with this situation."

Whether this approach (or any other) is at all sufficient to reduce parents' fears for a child is open to doubt—parents' feelings may be just too strong. They might be able to design rational beliefs for themselves, but the fear they feel may be far more than they can shake. Fredrickson suggests that even this may be possible, however. She describes an instance in which Laura, an adult friend of hers, was with her mother, who was dying of breast cancer. "Toward the end, her mother's pain, confusion and frailty intensified to the point where she'd wake up terrified, hallucinating and unsure whether she was dead or alive."<sup>25</sup> In response, Laura seeks to accept what she can't fix: she seeks to be *fully present with her mother* every moment that she can. This was, it seems from what Laura felt and said, the key. She sought to connect with her mother in every way she could, so that, as her mother was dying, she would not feel so alone. At the end, Laura slept by her mother's side, holding her hand as she died.<sup>26</sup> Fredrickson comments, "When suffering subsides, as it always does, if people can learn to be fully present with the other, moment by moment, the ensuing shared sense of calm 'can be 'beautiful,' even 'exhilarating.'"<sup>27</sup> For Laura, touch and eye contact were "huge" resources.<sup>28</sup> In the same way, parents of a severely ill child can touch and have eye contact with their child.

### Parents Who Felt Exhilarated Even When their Child Was Dying

A young girl came to the hospital with Werdnig-Hoffman disease, a genetic disorder that usually pre-

sents at less than six months and results in progressive, ascending muscular paralysis, much like amyotrophic lateral sclerosis, a disease Lou Gehrig, the Yankee baseball player, had, and Stephen Hawking, the physicist, has now. The girl was 27 months old, with pneumonia caused by lung muscle weakness from the disease. She was expected to die by 30 months. Although antibiotics treated the pneumonia successfully, members of her care team anticipated that, as her paralysis continued to ascend, she would have pneumonia again and would most likely need to be placed on a respirator. At the request of the care team, the ethics committee convened, proactively, to consider what the team should do at her next expected admission. The committee consulted with pediatric respiratory experts, and all involved thought that the burdens from being placed on a respirator would by far outweigh the gains for this little girl. The committee reasoned that, if placed on a respirator, the young girl would not understand what was happening, would frequently experience discomfort from the suctioning of her airway that would be required, and, still worse, her parents would not be able to comfort her by giving her hugs. The committee advised against a respirator in the future.

As a member of the committee, I felt not so sure, and after the meeting I went to see the girl in her room at the hospital. Members of the ethics committee had not seen her. Approaching her room, I was surprised. I did not hear the relative silence I expected. Rather, shrieks of joyous laughter pealed from her room into the hallway. The ethics committee had imagined that her family would be bereft, but they were not. As Fredrickson noted, some people in this situation can still feel exhilarated by being together—and this family did.

### Preparing Parents for Deciding Life or Death

When surgeons report the results of diagnostic surgery to parents, and the parents then must decide what to do, they are especially vulnerable to believing that they have made the wrong choice—regardless of what their choice is.<sup>29</sup> Clinicians may be able to help parents prepare for making these kinds of choices by discussing with parents, in advance, what may occur and, as Meichenbaum urges, what the parents might or might not think. Clinicians may discuss with parents that, regardless of what the parents may have already decided in advance, later, on the spot, they may change their mind.

Clinicians might suggest that if this occurs, it might be best for parents to try to *welcome* this different impulse, because it provides them with new

information that they didn't have before. Should this occur, it may make the parents' decision making more difficult. Yet, if parents can welcome the new impulse, as opposed to feeling more disturbed, having this new information may make decision making less painful. Clinicians can add that there may be no way that parents can ever be sure what they should do, even though they still have to make a decision, and that whatever the parents decide, they should not have regrets. Neither should they second-guess themselves.

Finally, clinicians should indicate that they will help the parents and decide *with* them—if this is what the parents want, to the extent that the parents want to do this. Doing all this with parents may be critical to their faring well at the time, and in the future. What is most important if clinicians do this, however, is that they not convey their personal views unless the parents ask.<sup>30</sup>

Clinicians may (or may not) feel that they have the capacity to do all this, and even if they believe that they can, they may not be right. This may be best regarded as an ideal, pointing the way to what clinicians may best seek to do, more and more, singly or in groups, over time.

It may be devastating to parents if a clinician allows her or his own biases to show, because if the parents go against what their clinician conveys—for example, the parents “choose life” and their child does poorly—the parents may feel painfully guilty if they did not “listen” to their clinician. Contrariwise, if a clinician recommends that a child not be treated, and the parents choose to go along and “choose death,” the parents may thereafter blame themselves for capitulating to the advice of another. Therefore, clinicians should state explicitly that parents should, at all times, including just after diagnostic surgery, feel totally free to choose what feels right for them, regardless of any leaning a clinician knowingly or inadvertently may have implied. That parents have complete discretion in deciding what to do in these situations is a precondition that must be understood by all.

It may be more difficult to fulfill these recognitions than it may seem. Clinicians sometimes experience great difficulty in not letting their underlying biases show through. This is especially the case when a child has more serious special needs. In some cases, parents have felt hurt, even after decades. An example, and one of the worst I have heard, is that of a clinician who was trying to persuade a mother to abort her fetus, and argued that if she gave birth to the infant, it would not look human; it would look like a little eel.

It is common to hear that some clinicians “slight” babies with special needs, perhaps inadvertently. There are reports from some new mothers that when their child with special needs was born, their clinician had a perhaps involuntary response of revulsion and would not look at the baby. Other clinicians, probably as inadvertently, change their language when they see a newborn with special needs. For instance, they refer to the newborn not as “him” or “her” but as “it.”

These responses may be mostly or wholly outside a clinician’s conscious control. Clinicians may, though, at least seek to attend to this risk, beforehand, by scrutinizing their views and then paying attention to what they do and say.<sup>31</sup> It may not be possible for clinicians to *always* be optimally supportive, because parents may differ in ways that clinicians can’t know. For example, one clinician, seeking to be empathic, said to a parent after such a birth, “I’m sorry.” “Why?” the mother growled. “My child is a beautiful child.” The mother, a decade later, still feels enraged.

It is tempting to imagine that there is a response that will suffice in every case. Perhaps there is. But another report of a clinician’s pain is also worth considering. A pediatric resident wasn’t sure whether a girl just born had Down syndrome. The resident opted to say, “Congratulations—enjoy your beautiful baby girl.” A week later, the resident called the baby’s pediatrician “to see how things had worked out.” The pediatrician responded, “‘How could you . . . let the parents leave the hospital thinking they had a healthy baby?’ ”<sup>32</sup>

Clearly, under today’s standards, the resident should have told the mother that her child had Down syndrome. This anecdote illustrates, nonetheless, how difficult it may be for clinicians to tell the truth in a way that, if possible, is supportive, and at the least, doesn’t offend.

#### **CHILDREN WHO HAVE SEVERE COGNITIVE DEFICITS OR WHO MOST LIKELY WILL DIE**

In “Suffering: Quality of Life, Intellectual Disability, and the Harm Standard,” Lisa Freitag says what may be especially critical on a child’s “quality of life axis” is not the number of surgeries nor the current level of suffering, but the child’s eventual intellectual ability and long-term survival. While intellectual ability and survival are crucially important, some parents greatly value their child as the child is, and this has profound implications for clinicians. Such parents may be regarded as exceptional in that they can look beyond—or at least seem

to look beyond—their child’s condition. All parents may not have this capacity. The capacity of some parents to do this may reflect their being able to positively use denial. It may enable them to overcompensate for feelings that otherwise might differ, so that, even unconsciously, they can set a course against more common, less positive responses. After all, parents in the delivery room, reactively, look for two arms and two legs, five fingers and five toes.

The interventions I’m suggesting may benefit all parents who have children with special needs, regardless of their initial responses. Parents of children with severe illness report, even years after their child has died, that their time with their child was, and remains, by far, the emotionally richest and most joyous time in their life. Many parents document this through numerous pictures that depict their unambiguous joy. This raises the question of the degree to which the capacity of these parents to cherish their children as they do is “fixed,” or is obtainable by others. Open discussion of this uncertainty may help some parents who feel, inappropriately, that they have somehow “failed” in this regard—even when their physicians have stated just the opposite.

With these concerns in mind, should clinicians tell parents that it is possible that they and their child might thrive? Whether clinicians do or don’t do this may make the difference in what the parents decide regarding treatment for their child. Here are some examples.

#### **Children Who Cannot, at All, Respond Verbally**

Parents, over and over again, describe the joy and meaning they have had raising a child who can’t verbally respond. Some of these children have siblings, and they, too, express unparalleled joy in having a nonverbal child as a sibling. One boy had older siblings who would go upstairs and then come down dressed as characters they’d seen on TV. He’d roar with laughter with them, every time. They would enjoy bringing their friends home, and the boy would try to tap them with his fingers as they’d purposefully swoop by. Both parties would roar with laughter as they played. The boy died as a young teen. One of his siblings, now grown, says that if she could have him be born all over again, without his many problems, she wouldn’t. She says she wouldn’t because of how much joy and inspiration he’d given to everyone he’d met. His parents feel likewise.

Perhaps it can’t be expected, much less be possible, that siblings—or most parents—could express other than positive view. Some parents, however,

support and encourage their other children to freely express how they feel and have felt, especially when their feelings are negative. For example, some siblings wholly disagree about bringing home friends. In some instances, the “proof” that what sibs say is really what they feel, is in what they do. Some seek professions helping such children. It is possible that this may unconsciously be an overcompensation against negative feelings they harbor but “their mind” can’t accept.

This same boy offers an additional lesson for clinicians. When he went for medical appointments, which were many, his clinicians often spoke only to his parents. He couldn’t express himself in words, but, nonverbally, it was clear at these times that he felt enraged. This response is common among patients who can’t express themselves verbally. Patients who are nonverbal—for example, patients who have dementia—who come to appointments with their caregivers experience this all the time. When clinicians are with such patients, clinicians should routinely first speak to the patient. I ask the patient initially, always, whether it is all right for me to talk with his or her caregiver. If there is no response, I say to the patient that I will speak with the caregiver, but to please feel free to interrupt me at any time. This same approach is warranted with children who can’t express themselves, but like this boy, still can attend to what is said.

### **Children Who Probably Won’t Live Long**

Parents may gain lifelong meaning from being with their infant for only a few minutes. One mother gave birth, for instance, to an infant who lived just 10 minutes. Clinicians had predicted this and had urged her to have an abortion. She refused. She wanted to see her baby, even if he lived for only the shortest time. She arranged to have him baptized. Years later, she still deemed these minutes by far the best in her life.

A last word is warranted. After the mother said she would deliver her baby, her clinician said he had never delivered a baby like hers before. They could, he said, both learn, together. The mother’s experience was much more powerful and profound than the clinician’s, but in this way they were “hand in hand.”

### **Clinicians’ Options**

What might clinicians take from this? They could, as discussed, seek to insure that they tell parents that some parents can and do have incredible

joy and meaning from raising a child who has severe illnesses, even when the child may soon die. As noted above, doing this may enable parents to seek changes and make decisions that they otherwise wouldn’t make. Clinicians can express, in advance, that they fear there may be a potential downside of disclosing this option for change. Should a clinician make this intervention, she or he must try to insure that, if parents *try* to acquire positive feelings, and can’t, *they do not feel that they have failed*. The stakes are very high. Yet, the alternative is to *not* let parents know that there may be a better avenue to pursue. Since there is evidence that caregivers’ lives improve when a clinician encourages them seek guidance and support from other caregivers, the choice to inform parents about an analogous route may be justifiable, and perhaps even preferable.

Clinicians could also strongly support parents in agreeing to most elective procedures for their child, if that would enhance the child’s and/or the parents’ quality of life—if the parents want this support. *Because a child can’t communicate or will soon die should never be an argument against doing an elective procedure*. The ethical basis for such “equality” when making decisions about treatments isn’t so much justice or utility, although both may warrant some moral weight. Some might argue that if a child is going to die soon, performing an elective procedure to enhance the baby’s or the parents’ quality of life does not make sense (that is, it would be dis-utilitarian). My arguments are based more on compassion. Elective interventions can mean a great deal—perhaps everything—to parents and their child, whether or not the interventions can be rationally justified. For the most part, that is what this introduction is about.

### **MEETING THE NEEDS OF THOSE WHO ARE WORST-OFF AND ALONE**

In “Home Birth of Infants with Anticipated Congenital Anomalies: A Case Study and Ethical Analysis of Providers’ Obligation,” Jankowski and Burcher suggest it would not be appropriate for a palliative care pediatrician to attend the home birth of an infant with known, possibly life-threatening, congenital anomalies. The authors give many reasons, for instance that the pediatrician is a specialist in palliative rather than neonatal care. Their reasons, individually and especially when combined, ethically, may convincingly support their argument that the pediatrician shouldn’t come to the parents’ home. But their various arguments against the presence of

the pediatrician are not fully self-evident, nor are they absolute contradictions, and thus are less strong than if they were absolute arguments. As Bernard Williams wrote, in a different context, “These people would certainly not make the same point if they merely said that this action was, by a long way, the one that they most favoured.”<sup>33</sup>

Williams posits there are two different kinds of arguments. In the first, there is an overwhelming reason to decide one way, or close to overwhelming. In the second kind, there is no one overwhelming reason, but instead there are a number of different reasons that may point toward the same decision. It is easier to offer a counter argument to the second kind of argument. In their article, Jankowski and Burcher do not offer one “clinching” argument; they offer many arguments added together. This makes the possibility of a plausible counter argument stronger.

A further, unstated, possible ethical issue that should be recognized in this case is that some clinicians may view parents who insist on home birth for an infant with known, possibly life-threatening congenital anomalies as ethical wrongdoers. Given this, any participation by a clinician, to any extent, would make the clinician guilty of complicity. But, in this case, whether participation in a home birth would be wrong is highly open to question.

I noted previously that parents who feel overwhelmed in response to raising a child with severe special needs may feel this way because they are exceptionally loving.<sup>34</sup> The parents in this case may have acted as they did, and may have even hoped that their child would die, for the same reason. They might have feared that their infant would suffer unacceptably (whether or not such fears were accurate). Even if the parents’ actions were ethically wrong, it is open to question whether that determination should “count” in regard to whether a pediatrician should have attended the birth.

In many cases, especially when people act badly, perhaps a clinician should try to meet their underlying needs to a greater extent, rather than to a lesser extent. This point is primarily deontological. As David Hume wrote, “Treating vice with the greatest possible candour . . . we must acknowledge that there is not . . . the smallest pretext for giving it the preference above virtue . . . ; except in the case of justice, where a man, taking things in a certain light, may often seem to be a loser by his integrity. . . . Perhaps . . . [morality] must appeal to the Heart. . . .”<sup>35</sup>

This appeal to feelings raises the possibility that the pediatrician’s decision of what to do might have involved not only different views of what values should have been accorded the highest priority, but

what moral framework (or frameworks) should have been used, as well. If, for example, the moral weight of feelings should “count,” then an assessment of the weight of feelings, and their weight relative to abstract principles, may become murkier.

Still, it may be that, optimally, in some instances, we need to resort to both. As Thomas Beauchamp and James Childress state, citing Alisa Carse, “in a defensible ethical theory, action . . . is not necessarily always governed by or derived from principles. . . . An ethic that emphasizes the virtues of caring . . . liberates health professionals from narrow conceptions of role responsibilities often found in professional codes of ethics.”<sup>36</sup>

These preliminary considerations may open up the question about what might serve as adequate or even overriding reasons for the pediatrician to have gone “the other way” and to have gone to the parents’ home. It would seem that there are three reasons this may be so. First, to benefit the newborn child. The “fatal anomaly” the child might have had might have been, the authors tell us, repairable. (The parents refused additional tests that might have helped determine this, so no more is known.)

A second reason would be to better meet the needs of the parents, especially because their decision to not come to the hospital, to an extent, estranged them from the medical system. This made them, in addition to being worse-off, alone. Because the parents chose to birth at home, the infant and mother would not have been able to receive the optimal medical care they needed, and could have received, at the hospital. As a result—whether this is rational or not—the parents felt estranged. If the pediatrician had come to the house before the birth, the parents might have seen this as a sign of respect, and, consequentially, it could have created greater trust. This possibility, especially at that time, more than anything else, might have helped the parents.

The pediatrician could have come to the home and indicated openly that, due to many factors, she might have had little or nothing “medically” to offer, other than palliative care for the infant, if it were needed. The pediatrician could have pointed out that, as the parents knew, the high-tech equipment present at the hospital that could help their infant might not have been available at their home (although the pediatrician could have indicated she would inquire about that). More crucially, the pediatrician could have indicated that, no matter what, she would be there with them. This offer of support is the same kind of support offered by the clinician to the mother whose child had a disease that no one could identify, mentioned above.<sup>37</sup>

Such a show of respect might have been warranted, based on the parents' need, but it might also have been warranted because of its possible beneficial effect for the parents and their child. In response to the pediatrician's doing this, the parents might have come to the hospital for delivery after all. A third reason would be to benefit the midwife.

### Helping the Parents and, Especially, the Mother

Jankowski and Burcher raise important issues. The palliative care pediatrician might have lacked optimal skills for the care of a newborn who needed assistance but was not dying. The high-tech machines available at the hospital probably could not have been set up in the parents' home. Ethically, on a wider scale, it might have been that the pediatrician's coming could have done many other children and parents great harm. It might set a precedent. Other mothers might, as a result, might choose to deliver at home, in spite of the fact that their child would then be at higher risk. Other mothers might then *expect* a pediatrician to come to their home, and when a pediatrician wouldn't come, these mothers might choose to deliver at home regardless.

But would these things actually occur? It may be that the parents in this case were unique—an anomaly. It may be, at present, that there is insufficient proof that such horrific effects would actually occur, although this could be later assessed and, if found to not be true, future policies could be established, and, after this “*n* of 1,” be “redetermined.”

Said differently, the parents' position seems to have been close to (if not entirely) unprecedented. Since the problems created for others that theoretically could result from the precedent of this pediatrician coming to the parents' house under these conditions are no more than speculative, this may make the argument stronger that, in this one instance, at least now, there might have been a reasonable ground for the pediatrician to come to the house.<sup>38</sup>

The greatest argument for this may be compassion.<sup>39</sup> These parents were hurting. They faced giving birth to a baby who was quite likely to die, or, if not likely to die, to have some serious problems. After all, the mother and father explored funeral arrangements. This might not have been a *bad* thing, in the sense of being heartless toward their child. Jankowski and Burcher say that the parents feared going to the hospital because the hospital might have denied them the choice to let their baby die by giving less-than-maximal treatment, out of compassion.

It might be that this, indeed, would have occurred. Kunz and colleagues' analysis would seem

to support this possibility. In their decision to deliver their baby at home, these parents were acting within the law. It is open to question whether clinicians should help children, and people in general, to the degree that they can, if the patients and parents are acting within the law, or whether clinicians should do less than this, based on what they view as their professional ethics.

### Helping the Midwife

If the palliative care pediatrician had visited the parents at their home before delivery, it might have been most supportive for the midwife. The midwife must have felt highly stressed. And most alone. Her predicament is clear. If she attended the birth and the baby had a complication resulting from the birth, the midwife might have felt partially responsible. If the midwife refused to attend the birth under these circumstances, it might have moved the parents to come to the hospital, and their child may have done better. But, on the other hand, if the midwife chose not to assist, the baby may have been born with complications due to difficulty in delivery that the midwife may have been able to prevent. Thus, the midwife could contribute to the child's harm, no less the mother's, regardless of what she chose. Thus, she was *hurting*.

The palliative care pediatrician might have been able to reduce the midwife's plight, and coming to her aid might have been justified by the professional allegiance that the two clinicians shared. From within the moral framework of the ethics of care, Nel Noddings notes,

This commitment to care and to define oneself in terms of the capacity to care represents a feminine alternative to Kohlberg's 'stage six' morality. At stage six, the moral thinker transcends particular moral principles by appealing to a higher principle—one that allows a rearrangement of the hierarchy in order to give proper place-value to human love, loyalty, and the relief of suffering.<sup>40</sup>

The pediatrician's moral (or at least professional) “obligation” to this child and his parents, relative to her “obligation” to the midwife, under this framework, might have been less. Relative to the midwife, the child and parents might have been, to a greater extent, strangers to the pediatrician. Thus, the pediatrician's duty to the child and parents, who were strangers, might not have been “triggered” to the extent it would have been by the plight of the midwife.

For example, ethically, if not legally, the pediatrician might not have seen herself as yet involved in a patient/physician relationship. (Legally, of course, there would have been additional duties once a relationship had been established.) Here we might wish to consider Noddings again, who wrote, “But what of the stranger . . . ? . . . If either [the stray cat or the stray teenager] presents himself, he must be received not by formula but as individual.”<sup>41</sup> Or perhaps Peter Singer, who pointed out what we all know: that it is much harder to love the children of strangers than to love your own children.<sup>42</sup>

The question posed by Noddings and Singer relative to this case is whether there are contexts in which clinicians should have the same ethical obligations to strangers that they have to their patients. I suggest that, in rare instances such as this, there might be. There are also views in favor of caring for all of these persons as individuals, not as strangers, from outside Western medical professional ethics. In their article in this issue of *JCE*, “Medical Professionalism in China and the United States: A Trans-cultural Interpretation,” Jing-Bao Nie, Kirk L. Smith, Yali Cong, Linyin Hu, and Joseph D. Tucker write that Chinese physicians have an oath they view much as we view the Hippocratic oath.<sup>43</sup> In this oath, Chinese physicians aspire to treat even strangers like family, and, in regard to treating some patients as individuals and not treating other individuals at all, *physicians are free to use their discretion*. Perhaps these traditional Chinese aspirations have application in this case.

### CONCLUSION

In response to the articles by Kunz and colleagues and by Jankowski and Burcher, I have discussed four questions: What should clinicians do before they decide whether to comply with parents’ decision to stop treatment for their child? What should clinicians do before diagnostic surgery is performed on a child? What should clinicians do when a child has exceptional cognitive needs? And what should clinicians do when a child may live for only a short time?

In response to Jankowski and Burcher, I have explored ethically plausible reasons that a pediatrician might have come to the parents’ home. The considerations I raise here may or may not be relevant to the outcomes of these particular cases, but they may be most relevant in others.

The points I have made are based primarily on the feelings of parents. I am suggesting—whether this is wholly rational or not—that there is a place

for clinicians to do for these patients, as individuals, what clinicians might not usually do. Ethically this approach may involve applying not only abstract ethical principles but also (or instead) an ethics of care. In the cases discussed in this issue of *JCE*, those who might be helped by clinicians are hurting in the extreme.

I am suggesting that clinicians might consider making exceptions to their usual professional practices when their patients (or colleagues) are most hurting and most alone. This call may have a place for clinicians who wish to give others truly optimal care, although, as Cheney points out, this may involve risks: “I have had the opportunity to review a small number of cases where what started as ‘going out on a limb’ for a well-informed and well-loved client turned into life-altering grief for all involved,” she relates.<sup>44</sup>

This approach could be called “*sui generis* professionalism,” if you will pardon the pun, in that clinicians who want to follow this approach would regard every clinical encounter as a potentially unique instance, in which giving a patient the best care possible requires clinicians to make an exception to what they would usually do. I suggest further that such inclination and openness may represent an ethical perspective that transcends—goes above and beyond—other views of professionalism that are less open to making such exceptions.

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### NOTES

1. S.N. Kunz, R.M. McAdams, D.S. Diekema, and D.J. Opel, “A Quality of Life Quandary: A Framework for Navigating Parental Refusal of Treatment for Co-Morbidities in Infants with Underlying Medical Conditions,” in this issue of *JCE*.

2. L. Freitag, “Witnesses to Mute Suffering: Quality of Life, Intellectual Disability, and the Harm Standard,” in this issue of *JCE*.

3. J. Jankowski and P. Burcher, “Home Birth of Infants with Congenital Anomalies: A Case Study and Ethical Analysis of Careproviders’ Obligations,” in this issue of *JCE*.

4. M. Cheney, “Of Missing Voices and the Obstetric

Imaginary: Commentary on Jankowski and Burcher," in this issue of *JCE*.

5. The bad times experienced by parents may also involve a partner. For example, one patient I saw had been blind since birth because he had received too much oxygen. At that time, the safest amount of oxygen wasn't known. His injury contributed to his parents' divorce.

6. J.L. Hanson and V.F. Randall, "Medical Ethics with Parent Collaborators," in *Patients as Advisors: Enhancing Medical Education Curricula* (Bethesda, Md.: Uniformed Services of the Health Sciences, 2006), 101-5.

7. This quotation of parent Coleen O'Brien is from Hanson and Randall, "Medical Ethics with Parent Collaborators," *ibid*.

8. See, e.g., E.S. Jeppson, J. Thomas, *Essential Allies/Families as Advisors* (Bethesda, Md.: Institute for Family Centered Care, 1995), and J. Thomas, E.S. Jeppson, *Words of Advice/ A Guidebook for Families Serving as Advisors* (Bethesda, Md.: Institute for Family Centered Care, 1995.) Quote is from page 54.

9. "Training and functional demand are likely to play crucial roles in the facilitation of these plastic processes." A. Pascual-leone et al., "Neuroplasticity in the Adjustment to Blindness," in *Neuronal Plasticity: Building a Bridge from the Laboratory to the Clinic*, ed. J. Grafman and Y. Christen (New York: Springer, 1999), 93-108, 94.

10. B.L. Fredrickson, *Love 2.0: Creating Happiness and Health in Moments of Connection* (New York: Penguin Group, 2014) 148. Fredrickson is a Professor of Psychology at the University of North Carolina at Chapel Hill. See [www.PositivtyResonance.com](http://www.PositivtyResonance.com), accessed 31 December 2014.

11. An example for parents of a child with Down syndrome, living in Maryland, is: <http://specialneeds.dhmh.maryland.gov/>, accessed 23 January 2015.

12. T. Shakti, "Violence for Goodness Sake," *New Scientist* 224, no. 2997 (29 November 2014): 30-1.

13. "Even informing patients of a right to decide may cause harm." T.L. Beachamp and J. F. Childress, *Principles of Biomedical Ethics*, 7th ed. (New York: Oxford University Press, 2013), 110.

14. A. Stein et al., "Effects of Perinatal Mental Disorder on the Fetus and Child," *Lancet* 384, no. 9956 (14 November 2014): 1800-19. See, generally, S.M. Southwick and D.S. Charney, *Resilience* (New York: Cambridge University Press, 2013).

15. Fredrickson, *Love 2.0*, see note 10 above.

16. *Ibid.*, 20.

17. *Ibid.* 20-1.

18. *Ibid.*, 152.

19. *Ibid.*

20. *Ibid.*

21. *Ibid.*, 146.

22. *Ibid.*

23. The mother's choice to have another child despite this same risk may, of course, have had many other motivations. Thus it is wholly unclear, over all, whether her physician's support helped.

24. D. Meichenbaum, "Stress Inoculation Training: A Preventative and Treatment Approach," 491-516, in *Principles and Practice of Stress Management*, 3rd ed., ed. P.M.

Lehrer, R.L. Woolfolk, and W.S. Sime (New York: Guilford Press, 2007).

25. Fredrickson, *Love 2.0*, see note 10 above, pp. 148-9.

26. *Ibid.*, 148.

27. *Ibid.*

28. *Ibid.*

29. K.H. Abbott et al., "Families looking Back: One Year After Discussion of Withdrawal or Withholding of Life-Sustaining Support," *Critical Care Medicine* 29, no. 1 (January 2001): 197-201.

30. R.M. Veatch, "Generalization of Expertise," *Hastings Center Report* 6, no. 2 (1973): 29-40.

31. For an example of how such measures can reduce one's personal bias, see J. Johnson and B.L. Fredrickson, "We All Look the Same to Me: Positive Emotions Eliminate the Own-Race Bias in Face Recognition," *Psychological Science* 16, no. 1 (2005): 875-81.

32. D. Ofri, *What Doctors Feel: How Emotions Affect the Practice of Medicine* (Boston, Mass.: Beacon Press, 2013), 113.

33. B. Williams, *Moral Luck: Philosophical Papers 1973-1980* (New York: Cambridge University Press, 1981), 18, 126.

34. See the discussion of this in the text and in Shakti, "Violence for Goodness Sake," see note 12 above.

35. D. Hume, "Conclusion, Section II," in *An Enquiry Concerning the Principles of Morals* (Oxford, U.K.: Clarendon Press, 1975), cited in D. Parfit, *Reasons and Persons* (New York: Oxford University Press, 1984), 529-30.

36. Emphasis added. T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics*, 7th ed. (New York: Oxford University Press, 2013), 37.

37. This second case is discussed in S. Calahan, *Brain on Fire* (New York: Simon & Schuster, 2012), 134.

38. "We may define the nature of the mental attitude which underlies all philosophical thinking as: a love-determined movement of the inmost personal Self. . . ." M. Scheleron, *The Eternal in Man* (New Brunswick, N.J.: Transaction, 2010), 74. "Now it is evident that the doctrine established differs sharply from all doctrines of a primacy of will or of intellect in our minds, since it asserts a primacy of love and hate not only over all forms of volition but over all forms of 'representation' and judgment." *Ibid.*, 88-9.

39. N. Noddings, *A Relational Approach to Ethics and Moral Education* (Berkeley, Cal.: University of California Press, 2013), 42.

40. *Ibid.*, 47.

41. *Ibid.*

42. P. Singer, *The Life You Can Save* (New York: Random House, 2010), 139. See, e.g., N.A. Fox, "Attachment of Kibbutz Infants to Mother and Metapelet," *Child Development* 48 (1977): 1228-39.

43. J.-B. Nie, K.L. Smith, Y. Cong, L. Hu, and J.D. Tucker, "Medical Professionalism in China and the United States: A Transcultural Interpretation," in this issue of *JCE*.

44. M. Cheney, "Of Missing Voices and the Obstetric Imaginary: Commentary on Jankowski and Burcher," see note 4 above.