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## Beyond Respect for Autonomy

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In this issue of *The Journal of Clinical Ethics*, in "Supporting Pregnant Women through Difficult Decisions: A Case of Prenatal Diagnosis of Osteogenesis Imperfecta," Marilyn E. Coors and Susan F. Townsend discuss the ethics of a pregnant woman's right to put her own interests at risk for the sake of her fetus by choosing to have a cesarean section.<sup>1</sup> They assert that, under these conditions, it is essential that careproviders grant mothers absolute autonomy. The authors address whether or not these careproviders should be paternalistic, in an attempt to prevent the mothers from being harmed, in only this one situation. In principle, such conflicts may be more widespread. Parents may be harmed when they feel emotional pain virtually any time they must make decisions involving their child. I think of a recent study that explored the experience of parents who cared for children who were dependent on ventilators. Based on their findings, the authors concluded these families should be fully informed of the demands and hardships that await them, which may encourage parents to change their minds about initiating treatment.<sup>2</sup>

Coors and Townsend, in considering only the more limited question, implicitly ask whether careproviders should always, absolutely respect parents' autonomy, or, if not, when should they? (Throughout the remainder of this discussion, "parents" will be used to refer to either parents or a single parent.)

It may seem odd to even consider when, if ever, careproviders should not respect parents' autonomy — aside from obvious exceptional contexts, such as when parents make certain choices that violate the law.<sup>3</sup> Aren't Coors and Townsend's arguments for absolute autonomy all that need reasonably be said? I suggest that the answer is no, for two reasons that may not be self-evident. The first reason is normative. It is not clear to all careproviders, everywhere, that they should respect parents' autonomy in any way that is close to this degree; the leading example of this is neonatologists in France. Kristina Orfali reports that many neonatologists in France oppose giving parents of severely ill neonates ultimate decision-making authority, and may consider U.S. laws that require this a perversion of the American legal system.<sup>4</sup> Rather than responding to these conflicts by respecting parents' autonomy, French neonatologists use *certainty* or *uncertainty* "as a tool to manage difficult situations and families."<sup>5</sup> They give parents information in terms of medical certainty, in telling them that it is *medically certain* that their child will die, rather than revealing that they are uncertain.<sup>6</sup> Decisions regarding these children remain within the framework of medicine, and not ethics, and parents then have no reason to challenge these decisions.<sup>7</sup> As this is the case, treatment can be withdrawn without clearly informing parents that an alternative exists.<sup>8</sup>

Part of the rationale is to reassure parents that everything is being done,<sup>9</sup> and "to keep parents under control," and to protect them from "harsh realities."<sup>10</sup> France is hardly a developing country, and the description of this practice is contemporary. This raises the obvious question: Should careproviders treat parents the same way in every country? Or should treatments differ and be more or less paternalistic, based on the values

and sensibilities of those in each culture or country? This question, of *cultural relativism*, will be examined later.

The second rationale is that there are some relatively recent empirical findings that suggest that emotion, rather than reason, often dictates what we choose.<sup>11</sup> Some philosophers have asserted this for centuries.<sup>12</sup>

"Split-brain studies," or research on patients whose two brain hemispheres have been disconnected to treat them for intractable seizures, provide the first source of empirical data.<sup>13</sup> These studies report, in a nutshell, that persons may not always be as capable of exercising true autonomy. It appears that we sometimes make decisions, particularly when we are uncertain, for reasons that are mostly emotionally driven. Most importantly, for the purpose of this discussion, these emotionally driven decisions may go totally against what we genuinely want, in many instances.

Neuro-imaging studies provide the second source of empirical data.<sup>14</sup> The studies suggest that parts of our brains may make decisions and begin to act on those decisions before we realize it. If this is accurate, there may be more justification for careproviders to be paternalistic, as this may be the only way they are able to protect parents from emotionally driven decisions. As a much more radical alternative, they might state that they are medically certain that a child will die, as French neonatologists are reported to do.<sup>15</sup> The possibility that parents' unconscious emotions may determine their decisions — and determine them wrongly — is exceedingly important, as parents can determine a child's outcome. In this country, obviously, there are absolute legal limits to what careproviders can decide, but even if there weren't, parents in the U.S. would demand more autonomy than parents in France.<sup>16</sup> As this is the case, the most appropriate ethical question may be not *whether* — or even *when* — careproviders should respect parents' autonomy, but, in light of the normative and empirical findings presented above, *how* should they respect parents' autonomy? Are there ways that careproviders can help parents be more truly autonomous, and so less vulnerable to being harmed? The answers are the focus of this commentary.

## LEARNING FROM FRENCH NEONATOLOGISTS

Parents who are in a state of uncertainty are especially vulnerable to positive or negative suggestion, and so careproviders are at inordinate risk of doing enormous and permanent — although inadvertent — harm. Due to their medical authority, what careproviders convey, even if only by suggestion, is much more likely to "take" in parents. In light of the exceptional potential for negative effects, the perspectives and rationales of the French neonatologists mentioned above may suggest better insight. What they do may suggest ways that we can be of greater benefit to parents, while respecting their autonomy.

## MEDICAL CERTAINTY AS A TOOL

Orfali and Gordon report that French neonatologists use *certainty* or *uncertainty* as a tool to manage difficult situations and families.<sup>17</sup> They don't convey their uncertainty to parents. In France, decision making regarding neonates is viewed, by both careproviders and parents, as a purely medical exercise.<sup>18</sup> In one neonatal unit, for instance, physicians either adjust the information they give to parents about a baby's clinical status to diminish the parents' hope for the baby's survival, or they present to them that the baby is dying naturally, despite the fact that the doctor has withdrawn certain treatments.

The team does this for many reasons. Chief are that the doctors wish to reassure the parents that everything is being done.<sup>19</sup> They also want to protect them from feeling any guilt.<sup>20</sup> The withdrawal of ventilators, for example, is presented to parents as a test that will allow nature to take its course. If a baby can breathe without a machine, the baby will go home. If not, the baby will die.<sup>21</sup> What are the results of this practice? French mothers of infants in one neonatal intensive care unit (NICU) were compared with U.S. mothers in the same situation. The French mothers "showed the highest level of satisfaction. . . . They also had fewer, if any, residual problems such as anger, depression, guilt, or regrets."<sup>22</sup> A large majority of mothers in the U.S. unit expressed guilt.<sup>23</sup> Parents in this unit were informed about their baby's condition in either optimistic or

highly uncertain terms. If the information was conveyed as uncertain, it increased the mother's anxiety.<sup>24</sup> Orfali and Gordon, who conducted the study, reached this conclusion: "The autonomy model does not seem to respond to the specific needs of being a mother of a critically ill baby in an NICU."<sup>25</sup> They continue: "Theoretical preferences for autonomy do not match the lived experiences of mothers in the NICU."<sup>26</sup> They add: "In the U.S., individuals bear . . . the psychological costs of their choices . . . it seems prudent [therefore] to reconsider the practice of autonomy in particularly stressful situations."<sup>27</sup>

### **CULTURAL RELATIVITY AS A TOOL**

Comparing careproviders' responses to parents of children in the NICU may raise some new questions. Should careproviders' response to parents be culturally relative? Should the response to parents be the same everywhere, whether it is to protect parents, as in France, or respect their autonomy absolutely, as Coors and Townsend might seem to suggest? Many may find this discussion offensive, particularly those who believe that parents' closeness to a child is far too important for careproviders not to respect their autonomy absolutely. Some may criticize using cultural relativity in this context, as it might be seen as too generously concluding that what parents want is right, merely because they want it.

A deeper analysis might consider additional empirical data. Some recent findings suggest, for example, that individuals may differ from each other, often quite fundamentally, in ways that are likely hidden. These differences may warrant considerable, even dispositive, moral weight. Nisbett and colleagues have found, for instance, that Koreans and Americans may respond in totally different ways when their beliefs are challenged. When presented with weak arguments against their beliefs, Koreans are more likely to view their beliefs less favorably. Americans tend to respond in the opposite way. Americans tend to favor the beliefs they initially had. The implications of this finding for careproviders who counsel parents — and for cultural relativity — may be considerable. If careproviders contradict what Korean parents believe, it may prove helpful. If they contradict what American parents believe, it may entrench the parents' views. This may suggest that neonatologists should tailor what they say to parents, depending on the parents.

Beyond this initial (and necessary) question regarding cultural relativity, neonatal practice in France clearly suggests that parents may be exceptionally vulnerable. This might suggest that careproviders in the U.S. should reconsider how they can best respond to parents. What can we do differently here, under our laws, as they now apply? Careproviders have tremendous authority due to their unparalleled expertise in medicine, and the psychological effect this may have on parents is great. It may be underestimated by careproviders and parents. The emotional impact of careproviders' statements is manifested by what has been called "the white coat syndrome." The mere presence of a careprovider can instantly penetrate patients' emotional defenses. Patients (and parents) may react with an autonomic stress response when a careprovider merely enters the room.<sup>28</sup>

This potentially dangerous effect on parents is exacerbated by a well-studied and acknowledged tendency in careproviders to be unduly pessimistic regarding the outcomes of parents and children when children have special needs. Careproviders tend to underestimate how much meaning and joy parents and children may achieve in their lives later.<sup>29</sup> Careproviders may need to have this exceptional and unrealistic pessimism to continue to function emotionally. They see suffering and tragedy on a daily basis. Like parents, their emotions may cause them to have inaccurate beliefs. They may need to experience more emotional distance, perhaps as a defense against becoming too close.

This distancing has been noted universally and over time. This distancing, although emotionally necessary, may have a price when careproviders counsel parents. Careproviders cannot help but have their own view of what parents should do when they must make a decision such as whether to try to keep a child alive. Careproviders may be affected unduly by the distance they feel; they may respond in various ways. One response is for a careprovider to try to be persuasive. The doctors I quoted earlier, who reviewed the experience of parents caring for a child on a ventilator, noted: "An immediate interpretation of these findings is that families should be fully informed of the demands and hardships that await them, encouraging parents perhaps to decide otherwise."<sup>30</sup>

Another doctor's recommendation is less paternalistic and more representative of U.S. physicians: he suggests that physicians first acknowledge that they cannot predict with certainty what they would do. They might say, for instance, he suggests, "I can only imagine what this must be like for you." Having said this, careproviders, if asked, should share their views.<sup>31</sup>

I suggest that there may be a serious problem with this second approach. Suppose, for example, that a doctor, whether earlier or later, recommends that parents withdraw the child's life-sustaining treatment. Suppose the parents go against this and their child lives. Suppose, also, that the child has the worst possible medical outcome, for example, that the child is so severely impaired that he or she can never come home from the hospital. What the doctor recommended may continue to haunt the parents. Since the careprovider recommended they withdraw treatment, and they then went against the advice, this may add profoundly to parents' regret or guilt. This is especially likely due to doctors' exceptional authority. Regret or guilt may be added due to what a careprovider merely connotes, and this may especially be a problem when careproviders are unduly pessimistic. In this context, let us once again examine the recommendation of the careproviders who studied parents of children on ventilators: their recommendation was much like that of the authors of the studies in France, who said we may need to "rethink approaches that may impose preventable burdens on these children and their families."<sup>32</sup>

We should also consider the harmful result, should a careprovider say, "I think you should continue giving life-sustaining treatment," but the parents choose to let the child die. This may be more painful for parents, particularly because they will always remain uncertain whether the child could have had a good (even if rare) outcome. The possibility I wish primarily to raise is that, to whatever degree careproviders express their views, it may affect parents negatively if parents make a different choice. This is in part due to careproviders' exceptional authority, as I have repeatedly said, but may be due also to a tendency present in us all: parents, as all persons, may have a tendency when things go sub-optimally to ruthlessly second-guess themselves. This may occur whether parents make choices that result in their child living or dying. They may respond with wholly unwarranted guilt and regret. This particularly is the case if their careprovider recommended that they make the opposite choice.

### **SPARING PARENTS HARM**

What can careproviders do to try to prevent this? There are several initiatives they can take. First, they can say, "I have my own views, but they reflect only my own life and values. There is no way that I could ever put myself in your shoes and know what is best for you. *You know better than anyone else, anywhere, what is best for you*, even if this decision seems uncertain now, and remains uncertain later. Our laws give this choice to you and you alone, and, in my opinion, it is right that they give this decision, ultimately, to you."

The content of this statement is common knowledge. What may not be common knowledge, even to careproviders, is how important it is to say this explicitly to parents. It may be uniquely empowering for parents to hear at this time that they have greater expertise in this area *than anyone else in the world*. It is particularly important, due to careproviders' singular authority.

In this context, parents are the wisest persons alive. They and they alone have the best sense of what raising their child would mean to them, for example. As a result, they may know best what may be best for their child.

The conclusions of the doctors who studied parents caring for children on a ventilator have been noted above. The authors noted the parents' burden but also said this: "Yet . . . despite the enormous difficulties described by these families, they also reported deep enrichments and rewarding experiences that *they could not imagine living without*."<sup>33</sup> Only the parents will know this about themselves. Careproviders can soften the somewhat frightening message that parents have absolute responsibility to decide, by informing parents that they must attempt to make the best decision that they can, even if later they question whether their decision was the right one.

The careprovider can say, "No one — not me or anyone else — can possibly tell you what you should do

in this instance. It is of the utmost importance, now and always, that you realize and accept your human limitations. Whatever you decide, you can only decide what you believe is best for you and your child now. Whatever you decide now is the right decision, even if, later, you see things differently. It also is true, no matter what anyone else says — even other careproviders — now, or later.”

For some parents, to hear a careprovider say this may be life-altering, as it may prevent feelings such as lifelong guilt, if they later change their mind or their decision is criticized by others. Careproviders who say this may help “immunize” parents from later “stigma,” and the effects may be immense.

Why might careproviders be able to assist parents to this degree? First, because of careproviders’ authority. Second, the support of just one other person may be all that parents need. It is well-acknowledged psychologically that most of us need the support of only one other person to be able to withstand even the most extreme stress. Thus, with the support of only one careprovider, parents may be able to cope with stigma not only then, but thereafter, and cope far better than they would have “on their own.”

Careproviders may be able to assist parents still more if they are willing to share their own views, but with one condition: careproviders and parents must discuss the pros and cons together first. Careproviders can say, “I’ll share my views with you if you want, if you feel this would be helpful, but only if we first discuss together the possible harm of my doing this. I must insist on our discussing the pros and cons first, because this may not be a good idea. My fear is that if I share my views and it turns out that they differ from yours, what I say may make it harder for you to decide what to do. Further, if you decide to go against my views, your decision may trouble you more later. This might occur, even if you feel you are as certain as you possibly could be about what you want, and that you should make this decision wholly on your own. What do you think?”

For careproviders to share their views only under these conditions, rather than respect parents’ autonomy, is paternalistic. It may enable some parents to escape any guilt they might experience should they choose not to follow their careprovider’s advice. Careproviders may soften this further by pointing out to parents that there is a difference between a careprovider’s medical and moral expertise: their medical views are scientifically based, but their ethical views aren’t. Careproviders should know this, but parents may not. Parents may feel merely that they want all the help and advice they can get.

Careproviders should add that they are willing to make decisions with parents — whatever this might mean — if this is what the parents prefer. Then careproviders must point out a potentially important risk. “What if, years from now, you change your mind and believe that you decided as you did because of me? That could be exceedingly hard to live with. You might want to make your decision now, wholly on your own, and I will give you only as much medical information as I can, but not my own personal, non-medically based views. The most important thing now could be that *you* make this decision in a way that you can still say, after 20 years, ‘We feel good about what we decided, because we, and we alone, made the best decision we could at the time.’ ”

Careproviders should say this explicitly because it is important that parents not feel regret to any unnecessary degree. It is important to reduce the possibility that parents will regret having deferred, even in part, their decisions to anyone else. Discussing this beforehand may decrease parents’ feelings of regret, because they may be able to choose with a clearer conscience. They will know that they carefully considered the various risks beforehand. The main loss to many careproviders is that parents may choose not to hear their careproviders’ views, and this may, in turn, alter the child’s ultimate outcome.

This is based partly on a presupposition that has been previously questioned: that careproviders’ personal views warrant moral weight. This should be questioned because equally expert and experienced careproviders may have diametrically different ethical views on what should be done for a child, even when they totally agree on all medical considerations. Given this, children in the same medical situation may end up with far different outcomes when the moral views of different careproviders are given moral weight. As a result, outcomes may be arbitrary when they depend on which careprovider with which moral view happens to be the child’s careprovider.

## LESSONS FROM EMPIRICAL RESEARCH

As indicated above, recent empirical data suggests strongly that we often respond emotionally to events and then use our reason to come up with rationales after the fact to justify what we decided emotionally. In this way, we convince ourselves that what we have chosen, based on factors that are outside our awareness, is, in fact, what we really most want, but the opposite may, however, be the case. This speculation is supported by several kinds of research, as mentioned above: studies of patients whose brain hemispheres have been surgically disconnected to treat them for seizures that couldn't be controlled in any other way, and studies involving brain imaging.

### EMOTIONS MAY DRIVE DECISIONS

In most patients whose brain hemispheres have been disconnected, only the left hemisphere can read and speak, and the right hemisphere can only read. Thus, a written request can be given to the right hemisphere, but only the left hemisphere can explain why the person is doing what he or she is doing. For example, when one such person's right hemisphere was presented the word "wave," he waved. When asked why he was waving, he rationalized this behavior by claiming that he had just seen someone that he knew.<sup>34</sup> This research indicates that when a researcher makes a request to a patient's right hemisphere by a written message, and then asks the patient why the patient did what he or she did, the patient's left hemisphere didn't receive the message, but nonetheless responds. The left hemisphere that speaks has no idea why the right hemisphere acted, nor, for that matter, that the right, nonspeaking hemisphere exists. Regardless, the left hemisphere comes up with a reason.

Researchers, based on these findings, conclude that one of the "main jobs of consciousness . . . is to confabulate . . ."<sup>35</sup> The brain-imaging studies mentioned earlier support a similar possibility, that we make decisions "emotionally," and rationalize them shortly thereafter. Libet, the leading researcher in this area, states, "mental awareness can be delayed up to . . . 0.5 s [seconds]." He concludes, on this basis: "The initiation of the freely voluntary act appears to begin in the brain unconsciously, well before the person consciously knows he wants to act."<sup>36</sup> He adds in another piece, summarizing his research to date, "If one extrapolates [from] this situation (admittedly without direct evidence), then all mental events are initiated and developed *unconsciously*. Indeed most mental events are probably completely *unconscious*."<sup>37</sup> The possibilities that these studies suggest are of the utmost importance to careproviders who seek to maximize parents' autonomy: they suggest that in some, if not all instances, we may make choices that we view as expressing our autonomy when, in reality, the choices do not. We are, put simply, much like persons whose brains have been split, as it is as if some other part of our brain, outside our awareness, makes decisions for us. This possibility, assuming that this takes place, is especially likely to occur when we face uncertainty, because uncertainty can create powerful, different feelings than we normally would be likely to have. Here is the core point: our feelings may provide rare insights into what we really want; on the other hand, they may be wholly misleading.

### GAINING INDEPENDENCE FROM EMOTIONS

When possible, it is important for careproviders to inform parents that the relationship between the intellect and the emotions is not at all "symmetrical." As W.B. Irvine, a philosopher, states in his recent book, *On Desire*, only emotions have "veto power." The intellect has only the "power of persuasion." The intellect can, in fact, persuade, but it can do so only if it can invoke a stronger emotion than the one it wants to suppress.<sup>38</sup>

With this awareness, parents can more rigorously question what they feel. Parents may be more able to choose what they really want to do, given the understanding that their emotional responses may either enlighten or mislead them. They may be more able to accept what they feel and act on it, regardless of their intellect and reasoning, or they may be more able to ignore their emotional responses, should they contradict what parents rationally think they should do.

Let us consider each of these in turn. When feelings are helpful, parents may suddenly experience a powerful, felt awareness of what they really most want. As Irvine states, "certain aspects of the process of emotion and feeling are indispensable for rationality. At their best, feelings . . . take us to the . . . place in a decision-making space, where we may put . . . logic to good use."<sup>39</sup> We often instantaneously experience what we really want in this way. This was described decades ago by Carl H. Fellner and John R. Marshall, who studied how persons respond when first asked if they would be willing to donate an organ. Many of these potential donors immediately had a feeling that determined their answer. Careproviders subsequently gave them information about the gains and risks of the procedure. To the potential donors who had already made a decision, this information generally made little difference. They had "emotionally" already determined what they would do.<sup>40</sup> As Irvine states, "Emotional commitment has a life of its own: it either happens or it doesn't."<sup>41</sup>

Spontaneous feelings can, however, bring about highly harmful results. Instantaneous emotional reactions may cause parents to think that they should, or even must, make a decision that they really don't want to make. Guilt for taking their child's life may, for example, "make them feel" that they should keep their child alive at all costs. Alternatively, parents may feel shame for making a decision that they fear is "overly selfish." For example, parents may feel compelled to let a child who seems to be very badly off die, when what they want is to raise the child, even if she or he remains in the worst possible clinical state. This latter possibility may seem implausible, but it isn't. The response of the parents of children who are chronically dependent on assisted ventilatory support exemplifies this; parents reported "deep enrichments and rewarding experiences that they could not imagine living without."<sup>42</sup>

Such sudden positive — or negative — feelings may arise at any time; any critical event, may, for instance, "shatter" parents' "coping process."<sup>43</sup> It may be more important for parents to be aware of feelings that prevent them from choosing what they really want, than for parents to give positive feelings equal weight. Feelings may cause parents to make choices that depart radically from what they really want and from what seems reasonable. Such "harmful" feelings may occur not only instantaneously; they may exist from the moment their child is born, or even before.

One example of such a feeling is chronic denial; such denial may help parents cope with a child's very serious medical problems in the short run. It may help parents bear, for example, that their child may be so ill that he or she will never be able to leave the hospital. In the longer run, however, this same denial may blind parents from being able to see realistically what they can expect. For example, when a child is in the neonatal ICU, parents typically limit their hopes to the child's day-by-day experience; they may focus only on their child's survival, for example. As Orfali and Gordon state, "One can . . . interpret this response as denial."<sup>44</sup> They add that this "overall inability of mothers to anticipate future quality of life problems while in the NICU is 'problematic' . . . regarding 'any' medical decisions these parents have to make."<sup>45</sup>

Such an exclusive focus on the child's day-to-day survival may prevent parents from asking themselves more fully what the child's survival will really mean to the child and to them. Further, each day that the child continues to survive, their bonding with him or her will increase, and their denial may increase as well. Their bonding may, in fact, be another feeling that exists early on, and may keep them from being able to more accurately anticipate their and their child's likely future. If parents don't realize this, they may not be able to choose what they really most want for themselves and for their child.

My purpose here is not to suggest, in any way, *what* parents should decide. My purpose is to indicate that careproviders can, in light of what we know, make some exceptional efforts to help parents, and possibly make a difference. By alerting parents to the possibility that their emotions may be either helpful or harmful, and that these emotions may express what they truly want — or just the opposite — they may be freed to more truly decide what they really want to do. As Irvine states, "we can study the way we form desires and learn to distinguish those things that are really desirable, given our life plan, from those [that are not]."<sup>46</sup>

How can careproviders help parents do this? They can encourage parents to ask themselves whether what they *feel* is or isn't what they really *want*. Parents may not know to ask this; they may believe, on the one hand, that it is always wrong to act solely on the basis of what they feel. Perhaps they may feel that their

emotions are wholly unreliable. On the other hand, they may believe that they have no choice but to accept what their emotions dictate; that is, that they can't or shouldn't ever act in a way that "betrays" what they feel. They may believe that if they have an emotion that goes against what they think they should do, they have no choice but to wait for their emotions to change, because they can't do something other than what they feel. Both presuppositions will leave parents helpless.

In just a few sentences, careproviders can strongly influence or "nudge" such erroneous assumptions toward perspectives that enhance parents' autonomy. Again, this is because many parents, consciously or otherwise, give careproviders exceptional authority. Careproviders thus can help parents make choices that they otherwise couldn't make. Careproviders can say, for example, "Your feelings may help you to make decisions, but they also may make it harder for you to know what you really want most. This is because feelings may be the only or best indication of what you really want, on one hand, or they may strongly mislead you, on the other."

A specific example that careproviders may use is the following true clinical case, cited by Irvine: a patient whose connection between her two brain hemispheres had been partially severed. Her left hand moved as if it was that of another person. Her left hand tried repeatedly to strangle her during the night when she fell asleep. It became necessary for her to protect herself by tying this one hand down before she went to sleep every night.<sup>47</sup>

This case is an extreme example of how we can work against our own interests. Careproviders can also explain that some emotions emerge in times of crisis, and having a child's life in jeopardy may be the kind of crisis that triggers one of these different, latent emotional responses for the first time. Careproviders can continue, "You might want to keep close track of your feelings, and ask yourself regularly whether you think each feeling is a guide to what you really want, or is misleading you — or neither. You may not ever know, but by asking yourself repeatedly, you may be able to increase the likelihood of choosing what it is that you really want most."

Careproviders can help parents understand this by using the analogy of falling in or out of love. On occasion, people feel that they have "fallen in love," and, from a rational, objective perspective, the one they love may be the very worst person for them. The person may have, for example, a history of constant physical or emotional abuse.

People can also, in an instant, "fall out of love," and such momentary losses of feeling should not necessarily be an absolute guide to what we should do. We may experience such a loss of love after, for example, years in a "good marriage," and then our feelings of being in love may return. Such sudden changes even occur in persons who are most analytical; an example is the philosopher Bertrand Russell, who reported, "Suddenly the ground seemed to give way beneath me, and I found myself in quite another region."<sup>48</sup> He was with a three-year-old boy, and, previously, had taken no notice of him. Then, Russell took the boy's hand for just a few moments to lead him away from his mother so that he would not trouble her while she was experiencing some pain. Russell reports that, at the end of these five minutes, "I had become a completely different person. For a time, a sort of mystic illumination possessed me."<sup>49</sup>

A careprovider can also say, "I will be most willing to help you with this process, if you feel that you would like me to." These initiatives may be especially helpful when parents are "on-the-fence" or highly torn as to what to do, and their emotions may serve as a tie-breaker. They may be able to acquire greater independence from their emotions.

## LEARNING FROM STUDIES OF PARENTS

Perhaps the greatest preventable loss that commonly occurs when an infant is born with special needs is that parents may lose the positive relationship they had with one another. As one parent stated, "It's your couple relationship that will really suffer . . . 80% of people with a sick child end up separated. . . ."<sup>50</sup> The birth of such a child may cause profound lifelong stress for a family. As another parent said, speaking of genetic conditions, "The diagnosis of an inherited condition can drop a bombshell into family relationships."<sup>51</sup>

There are several reasons that parents may lose their relationship. If, for example, the child dies, parents may find that being with their partner evokes memories of their child that are unbearable. Careproviders should tell parents that, at these times, they can help each other more than anyone else can.

### **HELPING PARENTS**

When making difficult decisions, parents know firsthand what the other has gone through. Accordingly, each partner may find that the other is the most helpful support person they have, followed by their families, friends, and health professionals.<sup>52</sup> As a first step, therefore, careproviders should point out how parents can be the best supports for each other. All too frequently, partners seek primary support from others. In one study of several NICUs, for example, a larger proportion of parents took into account their physicians' opinions than those of their partner.<sup>53</sup> Careproviders may be able to benefit parents by asking them to consider this, and by telling them there is one reason that they should seek support from each other above all else: it may be the only way they will stay together, and ultimately most benefit their child.

Careproviders can point out that partners sometimes discover this during a crisis. For example, Will Jimeno, a policeman, was trapped for 13 hours under the wreckage of the south building of the World Trade Center on 9/11. While he was trapped, he talked with his wife on the phone. Previously they had argued over what to name their daughter, but at this time each agreed to go along with what the other preferred.<sup>54</sup> This is a paradigm for what each parent should try to do. Each should strive to say to the other, "I don't want what you prefer but I can accept it, because this is what *you* want, and it's so important to *you*." Careproviders can also point out that after such a decision is made, one partner mustn't ever blame the other later for the decision. Further, there can be no place for one partner to feel that he or she is "owed" a "payback" for sacrificing his or her view.

Careproviders can point out that the decisions parents will make may result in their having a wholly different style of life, and thus, even if they now agree on a decision, this may later change. I think of parents who initially chose to keep and raise a child who had most profound emotional and intellectual deficits. One stayed up to watch the child at night. Their child became an adolescent, and then was physically violent and could cause serious harm. One parent couldn't accept the risk of being hurt, especially when careproviders said their son would do better in an institution. The other parent remained committed to continuing to care for the child at home. The parents couldn't agree.

The importance of careproviders using this example is twofold: first, it helps parents anticipate possible outcomes, so they can then make a better choice. Second, it gives careproviders one more priceless opportunity to emphasize that we can only make the best decision that we can. The memory of these discussions may stay with parents.

### **HELPING PARENTS AS A COUPLE**

Careproviders can help parents to seek help, which may enable parents to have a richer relationship. The primary gain we can have in a relationship is to be able to escape and transcend our emotional isolation. Parents often lack the capacity to recognize and share their vulnerability with a partner. If they can learn how to do this better, it may enhance their relationship during — and after — this most stressful, early decision making involving their child.

### **HELPING SINGLE PARENTS**

Sometimes no other parent is available, or the other parent is unknown or long gone. In these instances, careproviders can explore with the single parent if there is anyone else who might want to help out. This initiative is surprisingly effective, probably because often there are such persons, but single parents assume they either wouldn't want to help, or would help only from a feeling of obligation or pity. Careproviders can point out that asking for help may actually be doing the other person a great favor: How many of us, careproviders can ask, normally feel — after our children are grown, if we've had them — that we can make a really significant difference in someone else's life?<sup>55</sup>

If the parent can suggest someone, a careprovider can offer to contact this person on the parent's behalf. The key here is to start wherever the other person is. "Would you be able," the careprovider can ask, "to meet for just a minute, talk on the phone, or even only send and receive a message using the internet to help this parent?"

## CONCLUSION

In this introduction, I have explored some of the questions Coors and Townsend raise in this issue of *The Journal of Clinical Ethics* regarding careproviders and parents. While careproviders can and should respect parents' autonomy, in the traditional sense, as Coors and Townsend assert, they can also enhance parents' autonomy.

The most difficult thing may be for careproviders to give up sharing their own personal views. One of the key thoughts careproviders should consider is the many ways that this may cause harm. I think in this regard of Kim, a child who was dying. She was offered many opportunities to participate in numerous research trials. Kim participated in many trials until her parents learned, in the last trial, that no child before had ever continued to survive. Kimberly's mother reports that several weeks passed until she and her husband told the researchers, "No." These days were, she says, "the longest days of our lives."<sup>56</sup> What made this time seem the longest, in part, was that many doctors mostly shared one and only one view: they did not tell Kim's parents that one medically reasonable and ethically justifiable choice was for them to not give Kim further experimental treatments. "Why do they not say there is another choice?" Kim's mother asks. "Why will they not say, 'Take Kimberly home, love her, and give her the most normal life you can?'"<sup>57</sup>

## NOTES

1. The consequential arguments for doing or not doing a cesarean section may vary according to the fetus's medical condition. See, e.g., R. Wadhawan et al., "Does Labor Influence Neonatal and Neurodevelopmental Outcomes of Extremely-Low-Birth-Weight Infants Who are Born by Cesarean Delivery?" *American Journal of Obstetrics and Gynecology* 189, no. 2 (August 2003): 501-6.

2. F.A. Carnevale et al., "Daily Living with Distress and Enrichment: the Moral Experience of Families with Ventilator-Assisted Children at Home," *Pediatrics* 117, no. 1 (January 2006): e48-60, p. e49.

3. See, i.e., J.A. Robertson, "Extreme Prematurity and Parental Rights After *Baby Doe*," *Hastings Center Report* 34, no. 4 (July-August 2004): 32-9.

4. K. Orfali, "Parental Role in Medical Decision-Making: Fact or Fiction? A Comparative Study of Ethical Dilemmas in French and American Neonatal Intensive Care Units," *Social Science and Medicine* 58, no. 10 (May 2004): 2009-22, [sciencedirect.com/science?\\_ob=ArticleURL&\\_udi=B6VBF-4B2CFXC-1&\\_cov](http://sciencedirect.com/science?_ob=ArticleURL&_udi=B6VBF-4B2CFXC-1&_cov).

5. *Ibid.*, 10.

6. *Ibid.*, 12.

7. K. Orfali and E.J. Gordon, "Autonomy Gone Awry: A Cross-Cultural Study of Parents' Experiences in Neonatal Intensive Care Units," *Theoretical Medicine and Bioethics* 25, no. 4 (2004): 329-65, p. 352.

8. Orfali, see note 4 above, p. 11.

9. Orfali and Gordon, see note 7 above, p. 345.

10. *Ibid.*, p. 346. A recurrent argument also used by French neonatologists is that their own medical interventions have brought these critical situations. Therefore it is their professional duty to correct them. Orfali, see note 4 above, p. 15.

11. W.B. Irvine, *On Desire* (New York: Oxford University Press, 2006).

12. Chief among these are St. Augustine, Hume, Schopenhauer, and Russell. See, i.e., *ibid.*, 115-9. Russell stated, for example, "the discovery of our own motives can only be made by observing our actions and inferring the desire which could prompt them." *Ibid.*, at 118, citing B. Russell, *The Analysis of Mind* (London: George Allen and Unwin, 1921), 30-1.

13. M.S. Gazzaniga, "Forty-Five Years of Split-Brain Research and Still Going Strong," *Nature Reviews*

*Neuroscience* 6 (2005): 653-9.

14. B. Libet, "Reflections on the Interaction of the Mind and Brain," *Progress in Neurobiology* 78 (2006): 322-26.

15. Orfali, see note 4 above.

16. P. Alderson, J. Hawthorne, and M. Killen, "Parents' Experiences of Sharing Neonatal Information and Decisions: Consent, Cost, and Risk," *Social Science and Medicine* 62 (2006): 1319-29.

17. Orfali, see note 4 above, p. 12.

18. *Ibid.*, 10.

19. Orfali and Gordon, see note 7 above, p. 345.

20. *Ibid.*, 351. One parent states, "what if we had not resuscitated them . . . I am haunted by that," p. 342.

21. *Ibid.*, 352.

22. *Ibid.*, 353.

23. *Ibid.*, 349.

24. *Ibid.*, 347.

25. *Ibid.*, 348.

26. *Ibid.*, 349.

27. *Ibid.*, 356.

28. A.J. Engler, "Maternal Stress and the White Coat Syndrome," *Pediatric Nursing* 31, no. 6 (November-December 2005): 470-3.

29. E.g., "many HCPs [healthcare providers] hold negative prejudgements toward life with disability." Carnevale et al., see note 2 above, p. e58.

30. Carnevale et al., see note 2 above, p. e49.

31. A.A. Kon, "Answering the Question: 'Doctor, If This Were Your Child, What Would You Do?'" *Pediatrics* 118, no. 1 (July 2006): 393-7. Kon states, "It is appropriate to answer the parents' question, because this is a medical judgment," (p. 394).

32. Orfali, see note 4 above.

33. Carnevale et al., see note 2 above, p. e59.

34. Irvine, see note 11 above, p. 97.

35. *Ibid.*

36. *Ibid.*, 93. Libet states: "There is a subjective referral backward in time to coincide with the time of the primary cortical response to the earliest arriving sensory signal," Libet, see note 14 above, p. 322.

37. Libet, see note 14 above, p. 324.

38. Irvine, see note 11 above, p. 76.

39. *Ibid.*, 114.

40. C.H. Fellner and J.R. Marshall, "Kidney Donors — The Myth of Informed Consent," *American Journal of Psychiatry* 126, no. 9 (1970): 1245-51.

41. Irvine, see note 11 above, p. 74.

42. Carnevale et al., see note 2 above, p. e49.

43. Orfali and Gordon, see note 7 above, p. 344.

44. *Ibid.*

45. *Ibid.*, 341.

46. Irvine, see note 11 above, p. 106.

47. *Ibid.*, 95.

48. B. Russell, *The Autobiography of Bertrand Russell* (Boston: Little, Brown and Company, 1967), 220.

49. *Ibid.*

50. Carnevale et al., see note 2 above, p. e54.

51. R. McGowan, "Beyond the Disorder: One Parent's Reflection on Genetic Counselling," *Journal of Medical Ethics* 25 (1999): 195-9, p. 197.

52. S. Lee et al., "Acculturation and Stress in Chinese-American Parents of Infants Cared for in the Intensive Care Unit," *Advances in Neonatal Care* 5, no. 6 (December 2005): 315-28, p. 316.

53. J.C. Partridge et al., "International Comparison of Care for Very Low Birth Weight Infants: Parents'

Perception of Counseling and Decision-Making," *Pediatrics* 116 (2005): 263-71, p. 265.

54. D. Thomson, "Oliver Stone's Trade Center Is Two Stories Short," *Washington Post*, August 9, 2006.

55. A good example is provided by a person who donated a kidney. After donating, the person said, "Criticism is not so painful because you know you did something good." Fellner and Marshall, see note 40 above, p. 575.

56. L. Markell, *Little One Laugh Little One Run* (Bloomington, Ind.: Author House, 2005), 89.

57. *Ibid.*, 77.